

FAMILY OPTIONS PROJECT PRACTICE GUIDE

A Comprehensive Permanency Planning Project for HIV-Affected Families

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INTRODUCTION

The Family Options Project is a collaboration between the Illinois Department of Children and Family Services, the AIDS Legal Counsel, and LSC and Associates, which provides legal, and policy direction for the Project. The Family Options Project also works with HIV case managers, community HIV programs, hospitals, clinics, and Title IV projects. Funded by the U. S. Department of Health and Human Services Abandoned Infants Assistance initiative and the Illinois Department of Children and Family Services, the Family Options Project has provided legal and social work permanency planning and other supportive services to families in which at least one parent has HIV or AIDS since 1996. The mission of the Family Options Project is to demonstrate that families with HIV, who face a multitude of demands and decisions, can make and carry out their own permanency plans with the assistance of a multidisciplinary collaboration of social work and legal services.

The purpose of this Practice Guide is to facilitate the adoption of the Family Options Project model by interested, multidisciplinary agencies. Since its inception, several lessons have been learned which may be useful to providers using the Family Options Project as a model for permanency planning projects in their communities. These lessons have been the primary basis for additional development and improvement to the Family Options Project over the years. This Guide describes the administration, staffing, and client recruitment of the Family Options Project Model (Chapter 1); concerns regarding family and service issues involved in implementing the Project (Chapter 2); and common issues found in multidisciplinary collaboration between attorneys and social workers, and suggestions on how these issues may be handled (Chapter 3).

CHAPTER 1. DESCRIPTION OF THE FAMILY OPTIONS PROJECT MODEL

The goals of the Family Options Project are to engage parents in the program in making and carrying out future care and custody plans for their children, in addition to providing access to a broad range of counseling and other supportive services. The program supports families by helping parents develop a legal plan for their children while retaining care and custody of their children for as long as possible. The Project also helps divert children who might otherwise be at risk of child welfare and foster care placement to voluntary legal permanency plans and safe, stable care giving arrangements. A team of social work and legal staff ensure that services are comprehensive and offer a continuity of care. A model of comprehensive legal and social work

services helps families stabilize and facilitates the family's work on its own permanency plan.

The Family Options Project model is based on stages of service provision, involving multi-disciplinary staffing and selective client recruitment. This chapter describes these components and additional aspects of the Project including legal and policy enhancements for permanency planning and peer support.

I. PERSONNEL

The necessary personnel for this project include:

- Project Director
- Legal and Policy Director
- Clinical Coordinator
- Social Workers
- Attorneys
- Policy Associate
- Paralegal
- Evaluator
- Evaluator Associate

The Project Director is responsible for the overall direction and achievement of the project goals. The Legal and Policy Director is responsible for overall administration and supervision of legal services delivered by the Project, as well as policy initiatives, and client advocacy on legal and benefit issues. The Clinical Coordinator, who has an MSW, is responsible for administration of the program including case assignment, reports, and clinical supervision.

Three part-time social workers, all with MSWs, provide clinical services. Staff with this level of education and experience is necessary to meet the psychological and social needs of these families. Some of the more difficult issues addressed by social workers include grief and loss, disclosure of HIV status, broken connections between family members, and a lack of resources. Families served by the project are frequently isolated. Frequently family members experience illness or must provide care for another family member and find travel difficult. Thus most of the services are provided in the home and range from counseling or therapeutic interventions to service linkage and coordination.

Attorneys and a policy associate who each are assigned part-time to the Project provide legal and policy services. All attorneys are experienced in providing permanency planning and other supportive legal services to HIV-affected parents and caregivers. A part-time policy associate monitors project policies and procedures, assists with training and education programs, and develops new policy initiatives. A part-time administrative assistant/paralegal also assists with the Project.

The Evaluator is responsible for the overall design, implementation and analysis of the project evaluation. The evaluation associate collects data from the team and consumers, maintains the database, and participates in data analysis.

II. ELIGIBILITY FOR SERVICES

In order to receive services, a family must meet the following criteria:

- the family must be HIV-affected (a member must have HIV or have had HIV);
- the family must have a minor child or children; and
- the family must be in need of assistance in developing a plan for the future care of a child or children.

Both birth parents and caregivers may access services to plan for the future care and custody of HIV-affected children. HIV-infected birth parents may obtain a range of services that facilitate: 1) stabilizing and preserving the family; 2) securing a legal permanency plan for the future care of the children; and 3) implementing of the plan at the parent's death, including the transition for the children into the new caregiver's home. Caregivers who are already caring informally for HIV-affected children may obtain services that formalize legal plans and stabilize or maintain the new family care configuration.

III. SERVICE PROVISION

Services use a stage framework developed in the first year of the program and refined from practice experience. While presented as a linear process, Project experience has been that there is no "typical" length of time in each stage; each family moves at its own pace. In addition, parents may encounter obstacles at any point in the process that require returning to an earlier stage. The stages (described below) include: 1) Outreach and education, 2) Developing a permanency plan, 3) Securing a legal permanency plan, and 4) Aftercare.

Social work services are provided primarily in the home on a weekly or biweekly basis with telephone contact as needed. Legal services are provided primarily in the attorney's office, client's home, or at outreach sites, with telephone contacts made as needed. Clients are considered "active" as long as they have had a contact with a staff person within the last 90 days. If clients become inactive because of 90 days without contact, they can reactivate services simply by contacting the social worker and/or attorney. In other words, client cases are rarely "closed" but considered a part of the project as long as they need services.

A. STAGE 1: OUTREACH AND EDUCATION

Legal and social work staff spend time weekly on site at area clinics and residential facilities where they have opportunities to introduce themselves to potential clients and to service

providers. As part of outreach and education, social work staff explain to HIV-affected parents and caregivers the value and process of planning as well as information about the project's services. Legal staff educates consumers on the legal aspects of planning, including available options, and the responsibilities and rights of guardians, adoptive parents, and biological parents under each of these options. Education on potential ways to support permanency, including benefits, short-term guardianships, wills, and powers of attorney are also provided.

B. STAGE 2: DEVELOPING A PERMANENCY PLAN

1. Assessment Phase

The purpose of the assessment is: 1) to determine what assistance the family needs in order to complete a plan; and 2) to assess what assistance the family needs to prevent disruption, i.e. to improve or maintain their healthy functioning. The second purpose has taken on new significance as people with HIV are living longer and may be caring for their children for years before a plan is implemented.

If the client is not going immediately to legal services, a social worker begins the process by doing an assessment of the family's needs and readiness for planning. The assessment includes family demographics, medical history of parent/caregiver and children, family's past and current living situation, previous child welfare and legal involvement, adult's employment history, and a genogram. The clients are asked to identify family strengths and weaknesses as well as difficulties that the family is currently encountering and to identify how, if at all, those difficulties might influence planning. With the client's consent, outside sources may be contacted to complete some of the assessment. Throughout this process the client also gains an understanding of their strengths, and resources that may be available, which helps them become invested in the process.

2. Family Support Services

In order to improve healthy functioning, social workers and attorneys provide an array of services. Social workers and clients identify family problems that may deter planning or areas of concern that can be addressed concurrently with planning. For example, parenting children with behavioral problems and handling conflict with extended family are repeated themes for these families, both birth parents and new caregivers. Therapeutic interventions that include problem-solving, education, and skill development are supplemented with advocacy and referrals to outside services as needed, e.g. mental health services, respite care, and housing.

Legal services also support family stability by assisting clients in accessing and maintaining public benefits, housing, and addressing discrimination issues. Linkage to legal services that address domestic violence issues is also in place. Family supportive services are provided throughout the planning process with problems and goals reviewed every six months to ensure that families are safe and healthy as they plan for the future.

Typical support issues that occur include disclosure of HIV status and identification of potential future caregivers. While project social workers do not disclose on behalf of a family member, they may facilitate discussions that lead to disclosure and be available to answer questions and provide support to family members, including children. Although the Family Options Project staff encourages parents to disclose their HIV status to their children and to potential caregivers, disclosure is not required per se. The social worker and birth parent may also work together to reconcile family differences so that another family member may eventually be identified as the potential caregiver.

When a caregiver has been identified and has agreed to provide care, the next steps include meetings with the attorney, social worker, birth parent, and potential caregiver to: 1) make sure that the potential caregiver understands how assuming responsibility for the children will change their family; 2) address any concerns that the caregiver might have; 3) explain some of the effects that a parent's death might have on a child; and 4) make sure the potential caregiver is physically and financially able to care for the children. The social worker and/or attorney explore with the family whether or not family members, friends, the children, and the non-custodial parent will agree to the proposed permanency plan. If family members or others who have cared for the children in the past indicate that they will oppose the plan in Court, project legal staff should be made aware of this information so that they can anticipate this potential problem with the plan.

The social worker, with the permission of the family and the potential caregiver, investigates whether or not the potential caregiver has a history of child abuse or neglect, prior criminal convictions, or pending criminal charges. For "legal services only"¹ cases, the attorney assigned to the family completes this step. The Project makes sure that the family, as well as the potential caregiver, is informed of the results of the background check. If the chosen caregiver has felony convictions and/or indicated reports of child abuse and neglect, the Project works with the family to help assess next steps, which may include reforming the plan or attempting to move forward with the plan if the family chooses and offenses revealed through the background check would not preclude court approval of the plan.

Current caregivers of HIV-affected children may approach the Family Options Project for assistance in developing a care plan after a parent has died. In these cases, where there is no parent remaining to assess the plan, a social worker will conduct a family assessment of the current or intended caregiver, including the household composition, family medical history, the children's history in the caregiver home, family strengths and weaknesses, a genogram, and family difficulties. As with the birth parents, the caregiver's needs will suggest what services need to be implemented to facilitate the legal plan and to ensure that the care giving family is stable.

¹ "Legal services only" cases are cases in which the client does not wish to work with a social worker, and is seeking only legal services to support the permanency plan.

3. Legal Screening and Assessment

In all cases, the attorney consults with the family to ensure that the plan is legally viable and that the family is in agreement as to the permanency plan. The attorney, using “best interests of the child (ren)” standards that are defined by law, also assesses the proposed plan. This step is especially critical if opposition to the family’s plan is anticipated. If a court ordered permanency plan is desired, the attorney also assesses whether the proposed caregiver meets statutory and court requirements for appointment as a guardian, standby guardian, foster parent, or adoptive parent.

If, after completing the screening process, the attorney finds that the plan is ready to move forward, the case is accepted for legal services and a more thorough legal assessment is begun.

Although the screening process is essentially a preliminary assessment, a more comprehensive legal assessment is begun as soon as the project team (attorney and social worker) and the family determine that the case is ready for legal services. During this assessment process, previously gathered information is verified, and additional information is gathered including:

- verification of the legal needs of the family with respect to permanency planning;
- working with the family to identify the appropriate legal client for purposes of representation (primarily the parent, although if the parent is deceased or incapacitated this step becomes more complex);
- completing the required fact finding and investigation;
- verifying who may have legal standing and be entitled to notice of the proceeding;
- continuing to evaluate the legal risk (or vulnerability to legal challenge) of potential plans; and
- determining appropriate legal strategy.

If, after completing the legal assessment, the attorney finds that the plan is ready to be legalized, the attorney begins the process for securing a legal permanency plan for the children.

C. STAGE 3: SECURING A LEGAL PERMANENCY PLAN

1. Securing a Court Ordered Plan

Every effort is made to develop a plan that meets the agreement of all parties with legal standing in the case. Parents are asked to obtain consent to their plan from those who might present a potential legal challenge. Attorneys also contact others with legal standing, such as a non-custodial father or mother (with the client’s permission) to discuss the feasibility of obtaining their consent to the parent’s legal plan. In general, because of limited staff time and resources, few cases are accepted in which a trial is anticipated. However, possible cases for trial are evaluated on an individual basis, and may be accepted.

Attorneys follow the case appearing in court on subsequent dates, if necessary, to represent the client. Once the Court approves the plan and issues an Order, attorneys obtain certified copies for the family.

Social workers work with the family and the attorneys during this stage, intervening if family problems arise and supporting the family through the process. Concurrent interventions are commonly carried out during this stage in order to monitor a family's confidence in their plan, and help maintain momentum towards the court proceeding(s) and beyond.

2. Other Legal Permanency Planning Arrangements and Supports are also available to Family Options clients.

These arrangements and supports may be chosen by families to supplement a court ordered plan or to assist the family when a court ordered plan could not be legally secured. Private legal arrangements include short-term guardianship (private arrangements valid for up to 60 days and renewable) and testamentary guardianship (designation of a guardian in a will).

Legal documents that support a parent's efforts to plan also include powers of attorney for health care and property and assistance with establishing parentage. Other legal services to support a permanency plan include: assistance with Supplemental Security Income; Social Security Disability Benefits; Survivor's Benefits; Dependent's Benefits; Children's Supplemental Security Income; Social Security overpayments and waivers; Social Security deeming and in-kind support and maintenance; Medicaid; Medicare; Food Stamps; Aid to the Aged, Blind and Disabled (AABD); Qualified Medicare Beneficiary Program (QMB); Supplemental Low Income Beneficiary Program (SLIB); TANF and other cash assistance; the child health insurance program; and Circuit Breaker program for older caregivers.

D. STAGE 4: AFTERCARE

1. New caregivers

When a plan has been implemented, new caregivers are supported by social work and legal services through a transition period of approximately 6 months. Social workers assess the new family's need for services in order to support the new placement. Issues that commonly arise include grief and bereavement, financial strain, parenting concerns and child adjustment, and family adjustment to new roles and members. Social workers, as with birth families, intervene with problem-solving, parenting skill development, and family counseling as needed. They may also refer to outside agencies for mental health or respite. Legal support, such as access to public benefits, is also provided as needed to support the new home.

Standby guardianship cases require specific legal assistance. In those instances, the Court appoints a standby guardian who, in effect, "stands by" until needed which is usually at the

parent's death or incapacity. Once the duties are activated, the standby guardian may act for up to 60 days without court supervision. Within those 60 days, the standby guardian must file a petition to be appointed "regular" or long-term guardian of the minor. Full guardianship is generally granted, unless the Court finds that it is no longer in the minor's best interest.

Family Options Project attorneys work with the family and Project social workers to evaluate the situation at the time of the parent's death or incapacity. If the standby guardian is still willing and able to assume full guardianship, the Project represents the standby guardian in the full guardianship proceeding. If the standby guardian is no longer willing or able to serve, or would otherwise not be approved by the Court, the Project works to develop a new plan with the family. In cases where children are orphaned with no responsible relative or friend willing or able to take custody, the Project will work with the Illinois Department of Children and Family Services to arrange foster care or other appropriate placement.

2. Birth Parents

Birth parents may complete a plan, which does not take effect until their death or incapacity (standby guardianship or standby adoption). In those instances, after the plan is secured but before it is implemented, birth parents and their family may continue to receive aftercare services for approximately 6 months, including social work and legal services that support their family's stability. When the plan is activated, project staff will again become active with the family facilitating the transition as described above with new caregivers.

Sometimes a court ordered plan becomes unworkable in a given family situation. For example, caregivers become ill or cannot support the children financially. In those situations, legal staff, social workers, and family begin the process again to design a new permanency plan for the child.

E. CASE EXAMPLES

As noted earlier, while the Family Options Project model is linear, experience has shown that there is no "typical" length of time spent by a family in moving through the process; each family moves at its own pace. In addition, parents may encounter obstacles at any point in the process that require returning to an earlier stage. First, consider a fairly complex case that required multiple permanency plans:

Case Example 1

Mr. and Mrs. King were homeless substance abusers for most of their adult lives. Mrs. King had three daughters ages 10, 14, and 19, who were raised by relatives. Seven years ago, Mr. and Mrs. King got into and met at a treatment program, were married to one another and brought the children together to make a home. They were very proud of their legitimate relationship. They

had their first child together. Sadly, the baby girl was diagnosed with AIDS. This led to the HIV diagnosis of both parents as well. Mrs. King had many symptoms but refused medications. Although infected, Mr. King was healthy and took care of himself. Their baby girl was six years old and was diagnosed with autism when the Kings contacted the Family Options Project to make a permanency plan. Mrs. King wanted Mr. King to adopt her daughters. The Family Options Project provided legal services for the adoption and subsequently helped the Kings obtain a court appointment for Mr. King's brother as the children's standby guardian.

This family is resilient but made many adaptations to function, often in crisis and at risk for abuse and disruption. Mrs. King had never parented her children. Her 14-year old daughter had primary responsibility for the autistic child who required constant supervision. The teenager resented this responsibility and threatened to run away. Mrs. King had unrealistic expectations and disciplined her daughter with physical punishment. Both this daughter and her mother had been sexually abused by the same uncle as young girls, but mother refused to talk about it. Mr. King was a strong male figure, but backed up his wife. The Family Options Project social worker facilitated parenting skills that permitted the 14-year old daughter some personal expression and brought her into support group of other affected young adolescent girls.

Less than one year after making a legal plan, Mrs. King became critically ill and died. Mr. King was there to care for the children, but the autistic child with AIDS might need to come into group home placement. However, with the Family Options Project aftercare services, the social worker helped this father develop parenting skills to preserve his family.

Less than six months later, Mr. King died suddenly. The standby guardian, Mr. King's uncle, had become involved in gambling, lost his home, and could not provide care for the Kings' children. Yet he did not want to give up guardianship of the girls because of their monthly cash benefits. The adult daughter, now 26, came home to live with her sisters. The Project social workers conducted family sessions that helped the family decide that continuing to live together under the supervision of the adult daughter was the best plan. The Project attorney met with the family, then worked with her uncle who decided to resign as standby guardian. The attorney then represented the daughter in successful petition to become guardian of the younger children. With continued aftercare services, and at a recent family retreat, these daughters are beginning to address their many losses in a supportive peer environment.

Case Example 2

The second case is a fairly straightforward but also time-consuming case in which a family could not achieve legal permanency until after the parent's death. Mary was a Family Options Project client for two years. She was diagnosed with AIDS in 1996, and was in and out of the hospital frequently. She knew she needed a guardianship plan for her only son Leo. Leo was 10, but acted like an old man and he was depressed about his sick mother who was barely able to function. His father used drugs and was in jail. Mary stated that her parents were willing to take care of Leo, but they rarely visited or helped Mary. Neither Mary nor the grandparents would contact the attorney to establish a standby guardian. Mary believed that "God will provide," but if Grandma got more involved, God would think that Mary wanted to die.

Depression immobilized the family. Family therapy focused on the barriers to planning. Mary was able to disclose to her son the nature of her illness. This brought Leo closer to his mother, and he discussed the secrets and feelings that gave him anxiety. Shortly after his mother's next hospitalization, Leo's behavior deteriorated. As a result, a family meeting was held, at which the grandparents revealed that they were not sure they could handle Leo.

Mary's condition deteriorated and the Family Options Project attorney was called to her deathbed. At that time, the grandparents agreed to accept responsibility for Leo. Unfortunately, Mary ultimately passed on. Through the Family Options Project, a social worker was available to Leo over the next year as he grieved the loss of his mother and adjusted to living with his grandparents. Leo's grandparents were able to rely on the attorney and social workers to help them better understand their new rights and responsibilities.

The social work preparation was a critical stage in making this permanency plan work. The Project attorney is currently representing the grandparents in their petition for guardianship of Leo, and helping them access benefits for Leo.

F. ADDITIONAL ASPECTS OF THE PROJECT

1. Legal and Policy Enhancements for Permanency Planning

New legislative solutions were developed to help expand legal permanency options based on case experience: Illinois is one of the states with the comparatively "new" options of standby and short term guardianship, and current Project staff were involved in drafting and coordinating the legislation that helped make these options law.

Standby guardianship enables parents to designate someone of their choosing as a standby guardian, who will effectively "stand by" until needed. The court-ordered future guardianship becomes active upon the parent's death, or when the parent is no longer able to make and carry out day-to-day childcare decisions. A legal presumption that appointment of the standby guardian as permanent guardian of the minor is also created. Standby guardianship enables parents to provide care for their children for as long as possible, while giving the parent and future caregiver the assurance of a court appointment for future guardianship.

Short-term guardianship is a private, short-term appointment by a parent of a "short term guardian" for a child for up to 60 days. The appointment takes place without any court involvement. This option has been frequently used by clients of the Family Options Project during periods of a parent's hospitalization. It provides the security of a private guardianship arrangement for a child who might otherwise be without a caregiver while a parent is incapacitated.

Effective since 1998, amendments to the Illinois Probate Act, allow a guardian of a minor to designate a standby guardian (the designation must be followed by court appointment), and to also appoint a short-term guardian for the child (755 ILCS 5/11 et seq.). Previously, only parents

could make such designations.

Prior to January 1, 2000, adoptions could not be finalized if an adoptive parent died during the pendency of the proceeding. The Family Options Project legal staff developed an amendment to the Illinois Adoption Act that provided for finalization if the parent dies while the adoption is pending in court (750 ILCS 50/14b). For example, in one Family Options Project case, a stepparent who had parented two children for 12 years petitioned to adopt the children. He died in 1998, after waiting for over 6 months for a home study to be conducted by county social services. Without this amendment to the law, the adoption could not have been finalized. Yet it was very important to the family that the children have the legal recognition that he was, in fact, their parent. Because of this amendment, the adoption was finalized.

The Family Options Project legal staff developed a new option for parents called standby adoption. Illinois is the first state with a standby adoption law (750 ILCS 50/1 et seq, effective January 1, 2000). Standby adoption provides that a terminally ill parent² may petition the court for appointment of a standby adoptive parent, who will “stand by” until needed - either at the parent’s death or when the parent directs that the adoption should be completed. The parent executes a specific consent and, if the court appoints the standby adoptive parent, a legal presumption - that it is in the child’s best interest for the adoption to be finalized when needed - is created in favor of the standby adoptive parent. This new option has the potential to give even greater permanency to some families than standby guardianship.

2. Peer support

Birth parents, caregivers and their families are offered quarterly recreational and social activities such as retreats, cultural activities, and educational sessions. Support groups are implemented when a core group and need is identified. These activities provide additional peer and social support to the HIV-affected families. HIV-affected families are often isolated and lack the opportunity to converse with other parents and children in similar situations. Two types of activities developed by the Project were family retreats and an adolescent girls group.

Family retreat events give birth families who have made plans, as well as new caregiver families, an opportunity for conversation and recreation with one another. While there is little direct discussion about HIV/AIDS, everyone at the retreat knows that everyone else is somehow affected. A second identified need was for pre-adolescent girls to experience age appropriate emphatic friendships outside of their families. These girls were somewhat isolated as caregivers for their HIV infected parents and siblings. They had already experienced a good deal of loss and subsequent responsibilities. These girls were at risk for depression and acting out behaviors such as experimentation with sex and drugs. The development of a “Girls Group” offered girls an

²As of January 1, 2005, “terminal illness” will no longer be a requirement in a standby adoption in Illinois.

adolescent experience. As social workers continue to identify other sub-groups, other closed, time-limited groups can be developed to meet the needs of these affected families and children.

3. Team consultation with experts in family issues of loss and disclosure

To assist with work on loss and disclosure, the team consulted with two outside professionals. Social workers (and attorneys) integrated the knowledge and skills obtained through this consultation into practice work with families and children. The project also included this important information in many of the training events and conference presentations regarding working with HIV affected families. The two experts also made presentations to families and caregivers at project family events and forums.

CHAPTER 2: FAMILY AND SERVICE DELIVERY ISSUES IN PERMANENCY PLANNING

The Service Delivery goals of the Family Options Project include providing a coordinated program of comprehensive, accessible permanency planning services to HIV-affected families, particularly those at risk of state child welfare system involvement; preventing disruption of HIV-affected families through social work services that support legal permanency planning and healthy family functioning; and providing legal permanency planning services to HIV-affected families and caregivers, which will promote family stability and ensure future legal permanency.

I. LESSONS LEARNED

Following are several lessons that have been learned throughout the development and implementation of the Family Options Project. These lessons provide insight into various issues that must be addressed in the development of a permanency planning project.

A. THE PROCESS OF COMPLETING A PERMANENCY PLAN CAN BE LENGTHY

Permanency planning is more time intensive than many service providers originally anticipate. Even with the support and services provided by permanency planning projects, parents with HIV/AIDS face extraordinary burdens and challenges as they plan for the future care of their children. Legal and psychosocial issues that HIV-affected families face when making a plan can include:

- reluctance on the part of the parent to disclose his or her illness, which may pose a threat to family and other relationships, employment, religious and community status, and personal safety;
- the prospect of facing a legal dispute with the children's other parent(s) or another person with legal standing, who may oppose the custodial parent's wishes;

- the presence of substance abuse and mental health problems;
- a family's current or past child welfare system involvement, which may impede planning for families who lack the authority to make their own plans (because the child welfare system has custody of the children);
- a mistrust of the legal system, which family members may perceive as having treated them unfairly in the past;
- the challenge of securing a legal plan that is responsive to the child's and the family's needs for permanency and supportive benefits;
- acceptance or denial of the infected family member's HIV/AIDS status; and the challenge of identifying a willing and able substitute caregiver.

Considering the barriers faced by these families, it is no surprise that it can take months, even years, for some families to make permanency plans. For example, families participating in the Family Options Project take an average of eight months to complete a legal plan for their children.³ Some families begin the planning process, have that process interrupted by other, more pressing issues within the family, and then re-engage in planning when they are able to focus on the issue of permanency planning once again.

B. NOT EVERYONE WILL MAKE A LEGAL PLAN, BUT PARENTS CAN MAKE IMPORTANT PROGRESS TOWARD PLANNING

Parents may not complete plans for a variety of reasons, e.g. the onset of sudden illness, a mistrust of the legal system, or the emotional difficulty of facing death. Kin caregivers may not want to formalize a plan that will change family relationships and intrude on parents' rights. However, with the assistance of a permanency planning project, parents may decide on someone that they would like to care for their children, such as an aunt, and talk with the potential caregiver about doing so. In these cases, the progress made towards planning, including informal care plans, is significant, even though these permanency plans are not legally recognized.

C. HIV-AFFECTED FAMILIES WHO ENGAGE IN PLANNING OFTEN REQUIRE A RANGE OF THERAPEUTIC AND LEGAL SERVICES

HIV-affected families who engage in planning often require a range of therapeutic and legal services to address their multiple issues and support family stability, safety, and permanency. It is only when these needs are addressed that families are able to focus on making care plans for their children.

³A completed legal plan usually includes either a court ordered permanency plan (such as a standby guardianship), or another legal plan secured by legal documents to support the parents' plan for future care and custody of the child (such as short-term guardianship or similar temporary caregiver designation device, and/or a will).

Social work services are needed not only to engage families in legal planning, but also to support healthy family functioning by addressing families' multiple needs. As noted earlier, permanency planning can be a lengthy process and demand a range of services and skills from social work practitioners. In many cases, social workers associated with permanency planning projects address a variety of clinical issues in order to facilitate planning and to promote healthy family functioning. Some of the issues that permanency planning project staff must address include: parents' and children's fears about health and death; parents' difficulties disclosing HIV and AIDS as well as antiretroviral regimens; the tension and conflict that often arises when family members and birth fathers become involved; and parents' spiritual beliefs that planning betrays faith in God's plan for themselves and their families. Some of the barriers addressed by project clinical staff include parents who, for a variety of reasons, cannot identify an appropriate future caregiver; children's behavior problems, as identified by parents and caregivers; issues about parenting and a lack of parenting skills; closure that some parents feel is negative closure; and the financial strain that characterizes many of the families.

The provision of supportive legal services to stabilize a family's situation can help engage families in permanency planning. Frequently, parents or caregivers approach permanency planning projects with requests for assistance on matters that are not of a direct permanency planning nature, such as legal assistance to address problems with access to cash, medical, disability, housing benefits, or legal assistance to address discrimination and employment issues. By offering legal services to assist with more short-term needs and by forming relationships with the families, projects can sometimes engage more families in the long-term task of permanency planning.

D. ASSISTANCE WITH PUBLIC BENEFITS CAN BE CRITICAL TO A PERMANENCY PLAN

Permanency planning projects often focus significant amounts of time and energy on public benefits, which are critical to low income HIV-affected families. In many permanency planning project, including the Family Options Project, families are first assessed for public benefits eligibility, with the goal of improving their overall financial stability and ensuring their access to health care. In addition, the project staff helps the families determine whether their preferred future caregiver will have access to the resources necessary to provide care for their children. Ensuring that caregivers, both current and future, optimize available benefits for the family helps to secure a permanency plan and prevent high-risk families from becoming involved with the child welfare system. The Family Options Project considers assistance with public benefits to be a critical part of their permanency planning program.

E. ADDITIONAL LEGAL SERVICES ARE OFTEN PROVIDED TO SUPPORT THE FAMILY'S PERMANENCY PLAN

Additional legal services are often provided to support a family's permanency plan. Such

services might include assistance with powers of attorney for health care and property, living wills, advanced directives and wills. Power of attorney designations can help parents designate agents with the authority to make health care or financial decisions on their behalf when they are unable to do so. These designations will have an impact on the children's well-being during the periods when the parent(s) are unable to act for themselves. Living wills and other advance directives are also used in some states to indicate a person's wishes regarding treatment in specific circumstances.

By executing a will, parents can provide for the disposition of property that will take effect after death, potentially ensuring that available resources go to their children. A will may also be used to express the parents' intentions concerning guardians for their children although, as noted earlier, a court may decide that the parents' intentions are not in the best interests of the children.

F. SOME FAMILIES NEED MORE THAN ONE PERMANENCY PLAN

Many families develop more than one plan to ensure permanency for their children. For example, a mother may want to have her current husband adopt her children so that the children will remain with him if she dies. This family may also be encouraged to develop a standby guardianship arrangement so that a future caregiver of both parents' choosing will step in to care for the children if something happens to both of them. Alternatively, the children in the family may have more than one father, which may affect the choice of future caregiver and the type of legal plan selected for each child.

G. SOME PERMANENCY PLANS WILL NEED TO BE REWORKED

Permanency plans often have to be re-worked, most often because a prospective new caregiver becomes ill or is otherwise unable to assume care for the children. Permanency planning project staff work diligently to ensure that parents have made solid decisions that are appropriate and feasible before the plan is legalized to prevent having to rework a plan at a later date because the parent changed his or her mind.

H. AFTERCARE SERVICES ARE CRITICAL COMPONENTS OF PERMANENCY PLANNING PROJECTS

Aftercare services, services that are provided to the children and new care giving family after the permanency plan has been implemented due to the death or incapacity of the parent, are a critical part of the permanency planning process. The Family Options Project continues to provide social work and legal services at this crucial time to the new caregiver to support their needs and preserve the placement. Issues that commonly arise for newly reconfigured families include grief and bereavement on the part of the children and the caregiver; concern about having to support the additional children; parenting concerns; the children's adjustment to their new home; and the family's adjustment to their new roles and family members.

To address these issues, social workers may assist families with problem-solving, parenting skills development, and family counseling. Attorneys may assist new caregivers in accessing benefits on behalf of the children now in their care. Depending on the state law, project attorneys may need to help standby guardians obtain guardianship of the children after the parent has died or become incapacitated. Additionally, attorneys may provide services to families interested in successor planning or reworking a permanency plan.

I. PROVIDER AND CLIENT EDUCATION ARE ALSO CRITICAL TO THE SUCCESS OF PERMANENCY PLANNING PROJECTS

Health care and case management providers need a basic understanding of the legal options available to families related to permanency planning, and of the legal services available in the community. This type of education can help the providers become more comfortable in addressing permanency planning issues with their clients. Education and outreach to clients is also important to the success of permanency planning project. As clients become more aware of the options available to them and more knowledgeable about the legal process, their mistrust of the legal system may decrease and they may feel more empowered to seek legal assistance in securing permanency plans for children.

J. THE OLDER POPULATION OF NEW CAREGIVERS CAN BENEFIT FROM MAKING PERMANENCY PLANS

Frequently, it is the grandparents, aunts, and uncles of children who are orphaned by HIV who become their caregivers. This population of relatively older caregivers can benefit from planning for children in their care so that, if needed, a successor caregiver can step in and assume responsibility. "Successor permanency planning" may also be beneficial for any caregiver, regardless of age or health. Permanency planning staff should routinely work with families to explore the need for successor care giving plans.

K. INVOLVING DIFFERENT FAMILY MEMBERS IN A PERMANENCY PLAN CAN HELP THE FAMILY REACH AN AGREEMENT

A number of permanency planning projects, including the Family Options Project, use family meetings to help families reach an agreement concerning a permanency plan. Family meetings, generally facilitated by clinical staff, are often used to resolve conflicts within families related to proposed permanency plan. If these meetings are held earlier in the planning process, they may help parents better understand the various placement options and/or provide them opportunities to express special wishes for their children or their child rearing preferences.

L. EXISTING PERMANENCY PLANNING OPTIONS FOR FAMILIES NEED EXPANSION AND REFINEMENT

Families need expanded and refined permanency planning options. This is especially true in states where planning options are severely limited due to a lack of standby guardianship legislation. Even in states with standby guardianship laws, permanency planning staff often finds that the options available to the families do not always provide the flexibility and security needed by the families.

Standby adoption is an example of an innovative legal mechanism developed in response to the needs of families affected by HIV, including families served by the Family Options Project. Standby adoption provides that a terminally ill parent⁴ may petition the court for appointment of a standby adoptive parent, who will “stand by” until needed - either at the parent’s death or when the parent directs that the adoption should be completed. Permanency planning projects, like the Family Options Project, can play an important role in identifying and providing education about the legal needs of HIV affected families.

II. ADDITIONAL ASPECTS OF PERMANENCY PLANNING

Evaluation findings from the Family Options Project suggest that permanency planning with HIV-affected families is a vital service, which involves a lengthy and time intensive process. This process requires program flexibility and staff with a wide range of skills to attend to the family’s psychological, social, and legal needs.

In addition to the “Lessons Learned,” as outlined above, when developing a permanency planning program in another community, it will be important to keep in mind the following additional aspects learned from the Family Options Project.

- HIV-infected parents value HIV-specific permanency planning services.
- Outreach in clinics and facilities is crucial to engaging clients in services.
- Staff must be flexible and committed to the long-term while remaining focused on the goal of planning.
- Families are best served by social work services that support and promote healthy family functioning in tandem with permanency planning.
- Families are best served by legal services that support and promote family stability concurrently with permanency planning.
- Peer support and social interaction are valued and necessary to support family stability and permanency planning.
- New caregivers, as well as birth parents, need services that promote permanency planning and family stability.

⁴As of January 1, 2005, “terminal illness” will no longer be a requirement in a standby adoption in Illinois.

CHAPTER 3. PRACTICAL ISSUES IN MULTIDISCIPLINARY COLLABORATION

Attorney-social worker collaborations have been developed in response to the complex and diverse needs of HIV-affected families. Since the mid-1990's, programs like the Family Options Project, the Family Center in New York City, and Family Ties in Washington, D.C. have offered social work, legal and other services to support HIV-affected families in making future care and custody plans. In each of these programs, attorneys and social workers have collaborated to address client needs that are made more complicated by HIV/AIDS.

The Family Options Project has had great success in addressing these needs. By training attorneys and social workers together and meeting frequently to staff cases and discuss the project's development, the project has experienced positive growth and for the most part prevented conflicts. But new cases, new laws, and new family situations and fact patterns have brought new issues for the team to address. Potential new conflicts for any program in which social workers and lawyers collaborate should be an ongoing concern – one that needs tending to prevent outcomes for clients, service providers, and programs.

I. THE ROLES AND RESPONSIBILITIES OF PROJECT ATTORNEYS AND SOCIAL WORKERS

The Family Options Project team includes both social workers and attorneys who come to the Project with different professional and personal experiences. Social workers are bound by their Code of Ethics, as well as mandatory child abuse and neglect reporting laws in Illinois. Attorneys are bound by the Code of Professional Responsibility and the Attorney/Client Privilege⁵. While the entire team is working towards to same goal - the safety and best interests of the child - conflicts sometimes arise between the social work and legal aspects of a particular case. These conflicts, and suggestions of ways to resolve them will be discussed in more detail below. However, it is important for any group attempting to establish a multidisciplinary, permanency planning project like the Family Options Project, to have a good understanding of the different roles of each of these professions in the project. It is also essential for all team members - especially social workers and attorneys - to believe that the advantages of working together as a

⁵ The attorney-client privilege is a rule of evidence protecting communications between an attorney and a client from compelled disclosure in court or in the course of governmental investigation. It differs somewhat from the broader overall ethical duty of attorneys to maintain client information as confidential. If an attorney needs to reveal confidential information to social workers or other professionals, the client must consent and be fully informed of all the possible consequences, including waiver of attorney-client privilege.

team to help their clients outweigh any limitations.⁶

The entire Family Options Project team has the best interests of the client and his/her family at heart, yet each team member may take a different approach towards getting the desired results. It is essential, therefore, for each team member to understand and respect the nature of the other members' professional training and approach to problem solving. Social workers collaborating in this type of multi-disciplinary approach to permanency planning need to have an understanding of the legal options available to the client, but should not attempt to resolve these legal issues. Attorneys must have an understanding of the psychosocial aspects of the legal issues, and usually need access to information concerning interpersonal and family issues to formulate an effective legal plan.⁷ Attorneys should not try to resolve the client's psychosocial issues without the assistance of the social workers on their team. "The optimum approach integrates the knowledge and skills of both disciplines through service collaborations and referrals and encouraging professionals to maximize their expertise within the parameters of their legal and ethical responsibilities."⁸

A. THE SOCIAL WORKER'S ROLE AND RESPONSIBILITIES IN A PERMANENCY PLANNING PROJECT

The Family Options Project utilizes social workers to provide a broad range of social services, including social work services that support development of legal plans, which may include: problem-solving; assistance in identification of a potential caregiver; family conflict resolution; coordination of family meetings, including meetings regarding disclosure of HIV/AIDS status; and linkage to legal services and to other social services.

Supportive therapeutic interventions are also offered to help stabilize families as they work toward developing a permanency plan. Supportive therapeutic interventions designed to support healthy family functioning are offered by many permanency planning projects because many HIV-affected families have a history of involvement with the child welfare system. For example, nearly half of the families served by the Family Options Project have been involved with the state's child welfare agency. Many of these families have regained custody of their children and are working toward making their own future plans. After learning that many of the project's clients were either young mothers, mothers who have only recently begun parenting their children, parents who lacked sufficient parenting skills, or older caregivers who have, out of necessity, begun to care for young children, the Project learned that development of parenting skills is an important component of the Family Options Project. Supportive therapeutic interventions also include individual and family counseling, grief counseling, HIV/AIDS education (especially the

⁶Retkin, Stein and Draimin, "Attorneys and Social Workers Collaborating in HIV Care: Breaking New Ground," *Fordham Urban Law Journal* (Vol. XXIV, 1997), p. 565.

⁷*Id.*, p. 546.

⁸*Id.*, p. 565.

impact of HIV/AIDS on families) and peer support. Further, referrals for additional HIV/AIDS services, mental health and substance abuse services, and advocacy for public benefits are provided.

Social work services are also provided to new caregivers to support the transition of the children into the home and to create a stable family environment for the children and the new family. These services can include grief counseling, conflict resolution, development of parenting skills, education on the impact of HIV/AIDS on families, and referral to and advocacy for public benefits and mental health services. Social Workers also work to provide opportunities for peer support, such as retreats, social activities, support groups, and special events.

B. THE ATTORNEY'S ROLE AND RESPONSIBILITIES IN A PERMANENCY PLANNING PROJECT

Legal services are provided to families served by the project so that, optimally, a court-ordered permanency plan for the children can be secured. Permanency plans are designed to meet the needs of individual families and the children. Legal permanency plans have primarily involved guardianships, standby guardianships, short-term guardianships, adoption, and standby adoption. Flexible permanency plans, such as standby and short-term guardianships, are sought for families so that the parent(s) can retain custody of their children for as long as the parent(s) is able to provide care, yet have the assurance that the caregiver of their choice will assume responsibility for the children when needed. Guardianship and adoption services are also provided for families in which the parent(s) may have died or become incapacitated prior to Family Options involvement.

Other legal services are provided to help stabilize a family and support its legal plan. These services include assistance with medical, disability, and/or housing benefits and employment issues. By offering legal services to assist families with their more immediate needs and by forming relationships with the families, attorneys can often engage more families in the long-term task of permanency planning.

Additional legal services are often provided to support the family's permanency plan. These may include assistance with powers of attorney for health care and property as well as wills. Power of attorney designations can have an impact on the children's well being during period of time when parents are unable to act for themselves. Will designations also can be used to express parents' intentions concerning guardians for their children, although in Illinois, standby guardianship designation and court appointment help to provide a more secure legal plan.

Legal "aftercare" services include helping a standby guardian obtain guardianship of the children after the parent has died or become incapacitated. Attorneys also help new caregivers access benefits on behalf of the children now in their care. Assistance is also provided to new caregivers who wish to make their own permanency plans for the new children in their care. In

addition, attorneys provide services to families interested in successor planning or reworking a permanency plan.

II. IDENTIFYING AND RESOLVING ETHICAL AND LEGAL CONFLICTS IN MULTIDISCIPLINARY COLLABORATION

In any multi-disciplinary permanency planning project conflicts may arise and programs should work to minimize such conflicts before they occur. The Family Options Project trains their attorneys and social workers together. While this does not prevent all conflicts, it does provide the attorneys and social workers a better understanding of each others roles in the process and assists them in better handling the conflicts that do arise.

Conflict between social workers and attorneys in a permanency planning project may arise in a variety of settings. One of the primary conflicts may develop around the identification of the client for the project. For an attorney, the client is an individual who comes to the project seeking help. Due to potential conflicts of interest, the attorney cannot also represent the client's spouse, partner or family; however, the work done by the attorney on behalf of the client may ultimately benefit all of these people. Social workers, on the other hand, are not limited to representing only one person. Social workers often treat entire families, and in the context of the Family Options Project, this is usually the case. Since social workers normally have the first contact with the Family Options Project clients, conflicts may arise when the time comes to formally "legalize" the permanency plan developed by the family.

This conflict in the identification of the client can lead to larger problems. For example, the attorney's client identifies the person she would like to take guardianship of her child, while other family members have determined that the person may not be a suitable choice. The social worker helps the parent examine her choice in the context of best interests for her children. The attorney is then in the unenviable position of advocating for the client while the social worker has to deal with the family conflicts. If the relatives have any legal standing, this could result in a contested hearing where members of the team may take a position to support different family members.

For example, the attorney may be representing the mother, Mary, who has chosen her sister Joan as the potential caregiver for her child, Gregory, in the event of her death. After working with the family and social worker and developing the appropriate documents, Mary may change her mind and decide that the child should go with the birth father, James, who has never legally established paternity of the child. The team in the project may believe that James, who has a history of substance abuse and has never supported or lived with Gregory, may not be the best choice as potential caregiver. Still Mary may believe that the James is now a good choice, and may ask the attorney to help establish paternity for Gregory.

In this type of situation, the project team must meet to discuss each available option, and

the social worker may help to identify why the proposed caregiver would not be in the children or family's best interests. The team will apply best interests standards to the parent's choice and assists the parent in evaluating their choice. In general, during these discussions there is agreement among the team, however as additional information is gathered situations may change. The attorney, however, bound by the attorney-client privilege and the duty to maintain client confidentiality, may not be able to freely participate in these discussions. This could lead to issues of mistrust and concern among the project team members. In order to handle this type of situation, it is imperative that the social workers and attorneys have a good understanding of and respect for each other's roles in the project, and keep in mind that the safety and best interests of the child are of paramount concern at all times. With time and experience as a team, the Family Options Project has been able to develop ways to resolve most of these issues.

Identification of the client may also be made easier if the team did an initial projection on each case to determine who the likely caregiver would be in one year. For example, initial discussions should include identification of what might go wrong with the family's plan over the next year, and who the new caregiver might be if the proposed caregiver could not assume his/her responsibilities.

According to the Social Workers Code of Ethics,

[w]hen social workers provide services to two or more people who have a relationship with each other (for example, couples or family members), social workers should clarify with all parties which individuals will be considered clients and the nature of social workers' professional obligations to the various individuals who are receiving services. Social workers who anticipate a conflict of interest among the individuals receiving services or who anticipate having to perform in potentially conflicting roles . . . should clarify their role with the parties involved and take appropriate action to minimize any conflict of interest.⁹

In addition to client identification issues, conflicts in this type of multi-disciplinary practice may also arise in the sharing of information. The Family Options Project model is a team approach with all members of the team working together to assist the permanency planning needs of the client. Every client signs a consent during intake that allows the team social workers and attorneys to consult and share information on their case. However, there may be times when the social workers or attorneys feel they cannot share all of the information in their possession with the other members of the team. For example, due to the mandatory child abuse and neglect reporting obligations of the social workers, and the attorney's ethical duty to maintain client

⁹See National Association of Social Workers, Code of Ethics, §1.06(d)(1977), as cited in Retkin, Stein, and Draimin, "Attorneys and Social Workers Collaborating in HIV Care: Breaking New Ground," *Fordham Urban Law Journal* (Vol. XXIV, 1997).

confidentiality, the attorneys may not be able to disclose information to the social worker that might result in a triggering of the mandatory reporting rules.

In addition, there are times when the attorney cannot disclose information due to the attorney-client confidentiality. For example, the client, Mary, may request that the attorney not disclose a potential caregiver's (Joan) past conviction for an misdemeanor offense (for example, prostitution or misdemeanor drug possession) that involved nonviolent behavior, even though that type of offense might not legally disqualify the caregiver from becoming the child's standby guardian. Mary may feel as though she is protecting the confidentiality of the caregiver, Joan. The social workers may believe that information about caregiver history is necessary to assist the family in developing a permanency plan. It is the nature of social workers to look at the situation as a whole and as a result, they may resent the non-disclosure of information by the attorneys. These feelings may cause damage to the relationships of the team members and hamper the ability of the team to work together to help the family.

In this type of situation, it is essential that the team members discuss why the information will not be disclosed. It would be important for team members to know that the information withheld from the team by the attorney was not relevant to the safety and well being of the children. Good communication between the team members is essential and can help lessen the negative effects of the non-disclosure. Talking through different decisions and motives would help to build respect and trust for the different professional values and roles. It is important for the team to develop and have the clients sign appropriate release and consent forms, allow for the disclosure of information among the team.

In order to assist with resolving these conflicts, it is essential that the social workers on the team receive training on the attorney-client privilege and attorney duty to maintain client confidentiality, and that the attorneys on the team receive training related to the social workers' Code of Ethics, obligations of confidentiality, and mandatory reporting. Without this training, members of the team may view the non-disclosure of information as arbitrary, which may lead to distrust among the team. Since the benefits of the multi-disciplinary approach to permanency planning are well documented, it is important to address these issues and potential conflicts at the inception of the project with specific models for conflict resolution determined by the team as a whole. Specific models should be devised by each individual project since problems can be very case-specific and depend, in some part, on the background and experience levels of the individual team members.

CONCLUSION

As the Family Options Project has developed over the past eight years, it has been a tremendous success in assisting families touched by HIV and AIDS. Other communities attempting to develop a similar multidisciplinary collaborative project may use this Practice Guide as one of the multiple potential models for this type of permanency planning project. All programs

in which lawyers and social workers collaborate must be mindful of potential conflicts in client situations, and consistently tend to those conflicts as much as possible to prevent negative outcomes for clients, service providers and programs. Doing so will help foster more growth and development of these valuable interdisciplinary efforts for families.

FAMILY OPTIONS

Phase II

**A Comprehensive Permanency Planning Project for HIV-Affected Families
Illinois Department of Children and Family Services**

FINAL REPORT

2004

Grant Number 90CB0071

Project Period: September 30, 2000 – September 29, 2004

Abandoned Infants Assistance Act

United States Department of Health & Human Services

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Acknowledgments

The Illinois Department of Children and Family Services extends sincere appreciation to the United States Department of Health and Human Services, Administration for Children, Youth and Families, and the Children's Bureau for all of their support through the Abandoned Infants Assistance Act for the opportunity to develop and refine the Family Options Project through Phases I and II.

Family Options is grateful to the community of HIV and child welfare service providers who learned to become aware of the need to plan for children and referred families to this program.

Finally, thank you to the families who opened their minds, their homes, and their hearts to the difficult process of making plans for their children. We have learned a great deal from these families. They have provided the inspiration to continue the work of Family Options.

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INTRODUCTION

Beginning in 1996, the Family Options Project was designed to demonstrate that families with HIV, who face a multitude of demands and decisions, can make and carry out their own permanency plans with the assistance of an interdisciplinary collaboration of social work and legal services. A model of comprehensive legal and social work services helped families stabilize and facilitated the family's work on its own permanency plan. The Project also helped divert children who might otherwise be at risk of child welfare and foster care placement to voluntary legal permanency plans and safe, stable caregiving arrangements.

Family Options has been in the forefront in creating innovative and flexible legal options for families who wish to make legal permanency plans for their children. These have included standby and short-term guardianship, post death adoption judgment, and standby adoption laws. These new legal options have been developed to address the obstacles to voluntary permanency planning encountered by Project clients.

Phase II funding for years 2000-2004 permitted the Project to further refine the model of interdisciplinary services and legal options establishing a program that effectively supports permanency planning for children at risk.

EXECUTIVE SUMMARY

STATEMENT OF THE ISSUE

1. HIV affects a significant number of people with children in Metropolitan Chicago. The Chicago Department of Public Health estimates that there are approximately 6,000 women with HIV/AIDS living in Chicago. Assuming that 80% of these women are mothers, we can estimate that there are 12,000 affected children in the Chicago.

2. HIV affected children and youth have special needs. While most of these children are not themselves infected with HIV, they experience a range of behavioral and emotional problems related to: the potential loss of a parent; the uncertainty about their future; family conflicts about care and custody decisions; the secrecy, stigma, and isolation often associated with HIV/AIDS; and the pressures associated with transitioning to a new caregiver.

3. Families need assistance to cope with the multiple stressors of living with HIV/AIDS to maintain stability. HIV affected families need education and assistance to plan for the future care of their children and to support the new care configuration after a parent dies.

PROGRAM GOALS

1. To *provide a coordinated program of permanency planning services to HIV-affected families living in the Chicago metropolitan area*, a population at risk of becoming involved with the state child welfare system.
2. To *prevent disruption of HIV-affected families by providing social work services* that support legal permanency planning and healthy family functioning.
3. To *provide legal permanency planning services to HIV-affected families and caregivers* which will allow parents to provide safe and stable homes for their children and will also ensure a smooth transition to a secondary caregiver when and if the parents become unable to care for their children due to illness and death.

PROGRAM METHODOLOGY AND APPROACH

The Family Options Project provided social work and legal permanency planning services to Chicago area HIV affected families who chose to develop a future plan for the care and custody of their children in the event of critical illness or death. The program was conceptualized using a stage framework developed in the first year of the program and refined from practice experience. While presented as a linear process, there was no “typical” length of time in the stages; each family moved at its own pace. Some parents encountered obstacles at different points in the process that required returning to an earlier stage.

Stage 1: Outreach and education: Legal and social work staff visited HIV clinics and residential facilities on a regular basis where they had opportunities to introduce themselves to potential clients and service providers educating them on the need for future care planning of HIV affected children.

Stage 2: Developing a permanency plan: Social workers conducted an assessment and provided counseling services to parents about their choice of a future caregiver, their fears, hopes, and wishes for their children including any special needs, and any family conflicts they anticipated with their plan. This was followed by joint meetings between the parent and potential caregiver and may have included an attorney to consult on legal options and public benefits. The social worker continued to support the family by counseling on disclosure of HIV status, resolution of family conflicts, parenting advice, or family sessions with the children.

Stage 3: Securing a Legal Plan: The identified client signed a retainer with a Project attorney that specified the legal services provided. Their custody options included short-term guardianship, standby guardianship, private guardianship, standby adoption, or adoption. Other legal services included powers of attorney, wills, establishing parentage, and assistance with public benefits.

Stage 4: Aftercare: After the parent’s plan was secured but before it was implemented, they may have continued to receive social work and legal services that supported their family’s stability. When the plan was activated, Project staff again became involved with the family, facilitating the transition to the new caregiver.

Standby guardianship cases required specific legal assistance to petition appointment of the long-term guardianship of the children. The new family commonly required assistance with public benefits and counseling sessions as they adjusted to new roles and as children experienced loss and difficult behaviors. Social workers intervened to help stabilize and maintain the family.

RESULTS, BARRIERS, and SOLUTIONS

Objective #1 Results: One hundred eighty-nine (189) families and 368 children accessed Family Options services during the four year Phase II. These numbers were lower than expected because the use and success of highly active antiretroviral therapy (HAART) continued to have an impact as parents are living longer and planning seems less urgent. Social service staff at HIV/AIDS service organization were busy addressing the day-to-day issues faced by families, e.g. housing, substance abuse, so planning was not a high priority. Addressing planning also required talking about death and dying which was beyond the comfort and skill level of referral sources. When the intake numbers were low, Project staff focused their time on stabilizing and supporting families before and after a plan was completed, rather than emphasizing planning.

Objective #2 Results: One hundred forty-one (141) HIV-infected parents and caregivers and 275 of their children received social work services including 1,659 in-person contacts, 197 attempted contacts, and at least 200 phone contacts. To enhance social services, the staff and evaluation team developed a program logic model along with a planning barriers and facilitators checklist (see Appendices) as a clinical tool to be used in conjunction with the assessment form. Treatment plans were implemented and reviewed quarterly to assess how the family was progressing and if appropriate services were being provided.

Objective #2a Results: Ninety-three families or 49% of families who were actively planning during Phase II put at least an informal plan in place; these families represented 177 children. For 38% or 67 of those children, an informal plan was the farthest step completed in the planning process; these children did not go on to have legal plans secured by the end of Phase II.

Objective #2b Results: 113 HIV-infected birth parents and their families received social services.

Objective #2c Results: Thirty-nine (39) caregivers of children whose parent has had HIV/AIDS received social work services from the Project. This population is difficult to target as they are not accessing HIV services; there is no longer an infected member in the family so they are not attached to HIV/AIDS service organizations. Caregivers also often do not recognize the impact of HIV/AIDS on the family and children so they do not request HIV specific services. In-depth services were provided to those requesting services, integrating interventions for grief and loss into social work practice (see Appendices). Two forums on disclosure and grief were offered exclusively to caregivers.

Objective #2d. Results: The Project facilitated family retreats (22); HIV-positive parent groups (8 sessions); and affected youth support groups (11 sessions). Lower numbers of women and youth than anticipated attended the group because of illness or other commitments. The logistics of getting people to the meeting, setting up, ordering food, getting people home, and de-briefing was left to the clinical social work staff in addition to facilitating the meetings. It was difficult to staff appropriate event planners for this kind of project.

Objective #3 Results: 132 families and 255 children received legal services, including guardianship, adoption, stand-by guardianship, wills, power of attorney, benefits advocacy, and assistance with discrimination and confidentiality issues. The Project attorneys participated in retreats and trainings in order to engage families in services and overcome people's distrust of the legal system.

Objective #3a Results: 63 families and 110 children completed at least one legal plan. The legal plans included: 40 guardianships, 23 stand-by guardianships, 6 custody, 5 successor guardianships, 5 paternity established, 4 adoption, and 1 adult guardianship. Twenty-nine families also completed wills designating guardians for 47 children. Numbers were lower than projected because families face more immediate psychosocial and legal issues than planning. However, comprehensive legal services were provided, in addition to planning, to

assist families in gaining stability and managing more immediate concerns thus eventually freeing up time and energy to plan. Both short-term guardianships and informal plans were indications of critical steps towards a formal plan and stability for the children.

Objective #4a Results: Sixty (60) training sessions were provided reaching 1,383 service providers and consumers. The majority of the sessions were conducted with HIV/AIDS services organizations. Training topics included: disclosure, grief and loss, best practices, mental health and HIV, public benefits, legal options, and planning.

Objective #4b Results: The Family Options Staff consulted with child welfare, public health case managers, and attorneys across the state. Few permanency-planning resources are available outside of Chicago and Family Options social workers and attorneys did not have the capacity to counsel or represent clients in Illinois outside of Cook County. Additional funding was sought from the Illinois Department of Public Health for the purpose of facilitating permanency-planning training in three downstate regions. The Family Options team presented both clinical social work and legal issues, including aspects of coordinating the multi-disciplinary aspects of the work, reaching nearly 100 providers across the state.

Objective #4c : Results: 45 outreach presentations and 925 service providers and consumers received information through outreach.

Objective #4d: Results: Attorneys and paralegals, partially funded by Family Options, were available at the HIV CORE Center Clinic three days per week and a Project social worker was available one day a week. Many clients were already aware of the Project's services. Others were not comfortable approaching the staff, especially in a public place such as a hallway or waiting room. Staff found an office in which to meet confidentially with people who were referred and participated in staffings which raised visibility of the Project and increased accessibility to service providers.

Objective #5 Results: The Family Options Project, in conjunction with the Families and Children's AIDS Network (FCAN), continued to implement and refine each of Illinois' permanency planning legal innovative reforms – standby guardianship, standby adoption, and short-term guardianship. *Standby adoption amendment:* successfully supported the removal of the terminal illness identification requirement from standby adoption law.

Guardianship amendment: While difficult for some legislators to support, modifying the felony guardianship ban to consider best interests of children had strong support from lawyers and judges who work with this law. The bill will be introduced again in the 2005 legislative session.

Objective #6 Results: Virtually every outreach and training event conducted by Project staff included both a social worker and an attorney to increase knowledge on the model of interdisciplinary practice. Participants learned the benefits of this model through case coordination, technical assistance, and training. Social workers and case managers primarily attended these events, with few attorneys attending. The team attested to the fact that legal plans were more likely to be completed when social workers and attorneys worked together with the families. A practice guide for lawyers and social workers regarding joint permanency planning work was developed.

Objective #7 Results: Knowledge of HIV-affected families and permanency planning was enhanced through evaluation research, including completion of a longitudinal study of family and plan stability. Two peer-reviewed articles have been accepted for publication and are in press in social work journals. The evaluation team took primary responsibility for 8 conference presentations. The data on post-completion stability of plans has been collected and entered into a database. Preliminary findings are presented in the Evaluation Section. A manuscript will be submitted, in conjunction with the Family Center, by June 2005.

Case studies from Phase I were followed-up at the end of Phase II with one additional interview. A manuscript focusing on the case studies will be submitted to a peer-reviewed social work journal by July 1, 2005.

Through a collaboration with the Family Center, a sister program in New York City, Dr. Warren Reich introduced the evaluation team to a type of data analysis – Hierarchical Classes or HICLAS -- which can yield useful results without a large sample. The evaluation team is also working with Dr. Warren Reich from the Family Center to combine data so that we will have larger data sets and also opportunities to look at trends across sites.

EVALUATION FINDINGS

The Family Options Project served primarily African-American women. This population is representative of women with HIV in the target area of Cook County and of the relative caregivers who often take on the care of the children. Most of the birth parents were also low-income. More than one-third of the birth parents had been involved with the state child welfare system during the last 20 years suggesting that these are families at risk for abuse and neglect.

Caregivers who sought Project services already had care of the HIV-affected children and were seeking help to formalize their care situation. Caregivers generally had more income than birth parents and encompassed a broader range of ages than birth parents, from older adolescents to the elderly.

The clients came to the Project with a variety of legal goals, some being permanency options and some that supported family stability or facilitated planning. Stand-by guardianship was the permanency goal that the largest percentage of birth parents selected at intake. When a plan was completed, the average time to completion was one year. Some clients, however, took years or had still not completed at the end of Phase II.

The majority of social work contacts included the provision of supportive counseling to the birth parent, children, and/or caregiver. Adult and child mental health, medical issues, and family conflict were the most discussed topics. Similarly, a percentage of birth parents and caregivers made legal plans but also needed legal assistance that promoted the family's stability such as public benefits or housing or laid a foundation for legal planning such as paternity.

The clients identified ensuring a smooth transition for their children and having a choice in their future as the main benefits of the services. Although not necessarily lacking family networks, clients often reported having "someone to listen to them" and to talk with them about difficult issues as a valued service that they received. Clients enjoyed the opportunities to meet with their peers during social occasions but also looked for more formal opportunities, such as groups, to talk with others about planning and family issues.

The Project did not reach its objectives of number of people served or number who secured goals (see Results section for more detail). Fewer people were served in Phase II than expected. A new component of the program –informal caregiver plans – documented an important step for families, especially those who did not secure a legal plan.

Staff provided intensive services to the active clients and were challenged to remain focused on Project goals, considering the families' multiple needs, such as mental health, family issues, and medical concerns. The post-completion study suggests that even when legal goals were secured, a year or two later a substantial percentage of plans were not being implemented as originally conceived. While all the participants were still the legal guardian of the children, and most families reported positive situations with the children in their care, these needs were noted in the past year: 42% had been contacted about a problem behavior in school; 32% experienced a decrease in their income; 31% had a hospitalization; 29% were considering changing their legal plans for the children.

Lessons Learned

- Ongoing and aggressive outreach and development of the client base is key to program success.
- Focused treatment plans and ongoing assessment of progress towards family goals are essential to the planning process. As people with HIV live longer, plans may not be implemented for years, but they face constant challenges to family preservation and stability.
- Custody planning services may be more effective provided in the context of an HIV family centered program where it fits into a continuum of other supportive services.
- Children's grief and loss issues deserve more attention. Whether before or after mother's death, the children served by the Project had multiple losses that put them at risk for poor mental health and conduct problems.
- Adult mental health, especially depression, must be addressed with birth parents and caregivers.

FAMILY OPTIONS -- PHASE II
FINAL REPORT 2004

I. STATEMENT OF THE ISSUE

HIV affects a significant number of people with children in Metropolitan Chicago.

The Illinois Department of Public Health reports nearly 40,000 people with HIV/AIDS in the state. Approximately 33,000 or 83% of them reside in the metropolitan Chicago area. The proportion of AIDS cases among women in the city has more than doubled to 24% with heterosexual transmission now becoming the leading mode of infection among women of color. Chicago Department of Public Health estimates that there are approximately 6,000 women with HIV/AIDS living in Chicago. Based on needs assessments, 80% of these women are mothers and have an average of 2.5 children each. Thus, we can estimate that there are 12,000 affected children in the city. These families need comprehensive, family-centered services to cope with their parent's illness and potential loss.

HIV affected children and youth have special needs. A conservative estimate of 3,500 Chicago youth have been left motherless because of HIV/AIDS. This includes young children through adolescents. While most of these children are not themselves infected with the HIV virus, they experience a range of behavioral and emotional problems relating to: the potential loss of a parent; the uncertainty about where they will live if mother can't take care of them; family conflicts about care and custody decisions; the secrecy, stigma, and isolation often associated with HIV/AIDS; and the pressures associated with transitioning to a new caregiver. Studies have shown that children whose mothers are living with HIV/AIDS present more problem behaviors than children whose parents are not infected; these children have been found to be less social, more withdrawn, had attention problems, and report more depression.

HIV-affected families are at risk of becoming involved with the child welfare system. Histories of drug abuse, domestic violence, mental illness, and chronic illness affect the stability of families with children. Nearly half of the women with HIV were infected through drug use. The Illinois Department of Children and Family Services (DCFS) estimates that alcohol and/or other drug use continues to be a documented issue for at least 74% of the child abuse and neglect caseload, placing these clients at risk for HIV. As of September 2004, the DCFS AIDS Project had documented a cumulative total of 1351 women known to be HIV positive and their 3332 children (317 are HIV-infected). DCFS estimates that approximately

22% of the HIV positive women in the state have a history of involvement with the child welfare system.

Families are at risk of child welfare involvement because they lack the resources and support needed to keep their families stable and intact. Children of parents without care plans are taken by police to the DCFS Emergency Resource Centers when their parents become too sick to care for them or die. The crises for these children are compounded when there is no plan in place for them.

Families need assistance to cope with the multiple stressors of living with HIV/AIDS and planning for the future care of their children. Further development of parenting skills is important since many HIV positive people are living longer and parenting children experiencing behaviors problems associated with family histories of drug abuse, domestic violence, mental illness, and child abuse and neglect. Individual and family counseling, along with peer support can help to address social isolation and the careful disclosure of their HIV status, how this illness affects their family, and potential family conflicts in considering future care plans for their children.

Many parents have not made plans to ensure the future care of their children. While most parents have thought about what might happen to their children if they became too sick or died, few have taken steps to formalize plans to care for them. Parents often find it too painful to discuss these future events with potential caregivers or they are hoping to remain healthy. Some parents cannot identify a potential caregiver or would like to avoid old family conflicts in their families of origin or with the families of their partners. They may not be aware of legal child custody options now available or are reluctant to become involved with the legal system because of past experiences in juvenile or criminal courts.

Families need assistance when a parent or caregiver dies of AIDS. Surviving children have unique needs, as do their new caregivers. All of the family members are dealing with the loss of the parent because she has been mother, sister, and daughter. Tension and family conflict may become problematic as children are integrated into a newly reconstituted family. The children may exhibit behavior and emotional problems, and the new caregivers need help learning how to parent these children. Even after the death of a parent, families still deal with the stigma and isolation associated with HIV/AIDS. Older caregivers such as grandparents may feel particularly isolated and less able to care for children with unique and special needs. Home-based, therapeutic interventions help the families through this transition period to develop stability.

HIV-affected families and service providers need education about permanency planning. Permanency planning is an intense and often lengthy process that many providers may be unprepared to address or may neglect to address due to the more pressing client priorities including medical care, compliance with antiretroviral therapies, substance abuse, and housing. Education can make people aware of the many psycho-social issues involved, the barriers for some families and the range of legal custody options available in Illinois.

II. PROGRAM GOALS

1. To provide a coordinated program of comprehensive, accessible permanency planning services to HIV-affected families living in the Chicago metropolitan area, a population at risk of becoming involved with the state child welfare system.
2. To prevent disruption of HIV-affected families by providing social work services that support legal permanency planning and healthy family functioning.
3. To provide legal permanency planning services to HIV-affected families and caregivers which will allow parents to provide safe and stable homes for their children and will also ensure a smooth transition to a secondary caregiver when and if the parents become unable to care for their children due to illness and death.

III. PROGRAM METHODOLOGY AND APPROACH

A. Target Population

The Family Options Project served Chicago area families affected by HIV/AIDS that included:

- Parents who wanted to develop a plan for the future care and custody of their children;
- Parents who needed assistance in implementing a legal permanency plan;
- Caregivers of orphaned children who wanted legal guardianship and stability.

B. Eligibility for services

In order to receive services, a family met the following criteria:

- the family was HIV-affected (a member had HIV/AIDS or died of HIV/AIDS);
- the family had minor children;
- the family needed assistance in developing a plan for the future care of a child.

C. Personnel and Meetings

Family Options was staffed by a multi-disciplinary team of social workers and attorneys. The Project made its home at the Illinois Department of Children and Family Services through the AIDS Project in the Clinical Services Division. The Team was comprised of twelve professionals working out of four offices in the social work, legal and evaluation fields. None of the positions were dedicated to work full-time on the Project except for the Evaluation Associate. The rest of the team worked from 8-32 hours a week on the Project.

The Project Director was responsible for the overall direction and achievement of the Project goals. The Coordinator was responsible for the day-to-day operations of the program including educational outreach, intake, bi-weekly team meetings, reports, organizing Family Events, and the coordination of social work and legal services. The Project Director, Coordinator, and two social workers had Master Degrees in Social Work. This level of education and experience was necessary to meet the clinical psycho-social needs of these families. Two social workers carried caseloads of 15-20 HIV-affected families. In the last year of the Project, unspent resources were used to fund a bi-lingual case manager to provide social services to a caseload of 5 Spanish speaking clients. This particular case manager was a former Family Options client who adopted an HIV infected child when his mother died, bringing personal experience to the work.

Legal and policy services were provided by three attorneys and a policy associate. The Legal and Policy Director was responsible for overall administration of legal services delivered by the Project and advocacy for progressive policy initiatives. Two additional attorneys worked through the AIDS Legal Council of Chicago and were experienced in providing permanency planning and other supportive legal services to HIV-affected parents and caregivers; one attorney was bi-lingual. A policy associate monitored Project policies and procedures and assisted with training and education programs. An administrative assistant/paralegal assisted the legal and policy work.

The Evaluator worked from the Institute for Juvenile Research at the University of Illinois at Chicago and was responsible for the overall design, implementation and analysis of the Project evaluation. The Evaluation Associate collected data from the Family Options team and consumers, maintained the data base, co-facilitated case studies, and participated in data analysis. Both people held advanced social work degrees. The Evaluation Associate attended bi-weekly team meetings to maintain regular data collection. The Evaluator provided semi-annual reports

of findings to determine implementation and outcome objective trends. A Logic Model process grew out of these findings under the direction of the Evaluator.

D. Overview of Project Services

The Family Options Project provided social work and legal permanency planning services to Chicago area families affected by HIV who chose to develop a future care plan for the care and custody of their children in the event of critical illness or death. Parents with HIV obtained a range of services that facilitated: 1) securing a legal permanency plan for the future care of the children; 2) stabilizing and preserving the family; and 3) implementation of the plan at the parent's death, including the transition for the children into the new caregiver's home. Caregivers who were already caring for HIV-affected children obtained services that formalized legal plans and stabilized or maintained the new family care configuration.

E. The Family Options Permanency Planning Model

The program was conceptualized using a stage framework developed in the first year of the program and refined from practice experience. While presented as a linear process, there is no "typical" length of time in the stages; each family moved at its own pace. Some parents may have encountered obstacles at different points in the process that require returning to an earlier stage. The stages included: 1) Outreach and Education, 2) Developing a Permanency Plan, 3) Securing a Legal Permanency Plan, and 4) Aftercare.

Social work services were provided primarily in the home on a weekly or biweekly basis. Legal services were provided in the attorney's office, client's home, or an outreach site. Clients were considered "active" as long as they have had a contact with a staff person within the last 90 days. They could have reactivated services by contacting the social worker and/or attorney. Client cases were rarely "closed" but considered a part of the Project as long as they needed services.

Stage 1: Outreach and education

Social work and legal staff visited HIV clinics and residential facilities on a regular basis where they had opportunities to introduce themselves to potential clients and service providers. Staff also selected programs for special presentations. As part of outreach and education, social work staff explained to HIV-affected parents and caregivers the value and process of planning and information about the Project services. Legal staff educated consumers on the legal aspects of planning, including available options, and the responsibilities and rights of guardians,

adoptive parents, and biological parents under each of these options. Staff also provided information on benefits, short-term guardianships, wills, and powers of attorney.

Clients were self referred or referred by a service provider. The social worker or attorney who received the referral determined the appropriateness of the family for Family Options services using the eligibility criteria and completed Intake forms. The Clinical Coordinator made case assignments to a social worker or, if the client requested legal services only, the Legal and Policy Director assigned the case to a staff attorney. Consideration was made for client history, required expertise, and current caseload size.

The initial meeting was scheduled with the identified client and other family members as were determined to be appropriate. The purpose and range of the Project services were summarized. After careful explanation, clients were asked to sign two forms: 1) Consent to receive services and participate in evaluation; and 2) Authorization to Communicate with Agencies, Service Providers, and Institutions.

Stage 2: Developing a permanency plan

2a. Assessment: The team member began the process of planning by doing an assessment of the family's needs and readiness for planning. The assessment included family demographics, medical history of parent/caregiver and children, family's past and current living situation, previous child welfare and legal involvement, adult's employment history, and a genogram. Social workers helped the parents to consider potential caregivers while keeping in mind the children's needs and best interests.

The clients were also asked to identify the family strengths and challenges which might impact planning and helped social worker determine what steps needed to be taken to complete a plan. Social workers also assessed what issues needed to be addressed to improve or maintain healthy family functioning. This aspect of treatment took on new significance as people with HIV are living longer and may be caring for their children for years before a plan needs to be implemented.

2b. Family Support Services: Once parents identified a relative or friend they would like to care for their children, the social worker facilitated discussions between the two to determine if the caregiver was willing and able to take on this role, sometimes for the first time. The parents described their children's special needs and expressed their hopes and wishes for the children. The social worker also explored whether or not family members and the non-custodial parent agreed to the proposed plan. This process often included working together to reconcile family

differences to eventually choose the best caregiver. When the potential caregiver finally agreed to take the children, an informal plan was documented by the social worker.

In the course of developing the permanency plan, social workers and attorneys provided an array of other supportive services to maintain family stability. Parenting children with behavioral problems and handling conflict with extended family were repeated themes for these families. Therapeutic interventions included supportive counseling, problem-solving, education, and skill development.

Most clients had an HIV case manager who handled referrals for immediate care needs. Legal services supported family stability by assisting clients in accessing and maintaining public benefits, housing, and addressing discrimination issues. Supportive services were provided throughout the planning process with problems and goals reviewed quarterly to ensure that families are safe and healthy as they plan for the future.

Although Family Options staff encouraged parents to disclose their HIV status to their children and potential caregivers, disclosure was not required. Social workers often facilitated discussions that led to disclosure and were available to answer questions and provide support to family members, including the children.

2c. Current Caregiver Services: Current caregivers, relatives or friends, of HIV-affected children were referred to the Family Options Project for assistance in developing a care plan after a parent has died. In these cases, where there was no parent to assess the plan, a social worker would conduct a family assessment of the current or intended caregiver, including the household composition, family medical history, the children's history in the caregiver home, family strengths and weaknesses, a genogram, and family difficulties. As with the birth parents, the caregivers' and children's needs determined what services were implemented to facilitate the legal plan and worked to improve or maintain the stability of this family.

2d. Legal Screening and Assessment: Social workers referred cases for legal services through a screening process with the attorneys to determine the family's readiness for legal service applying the "best interests of the child" standards that are defined in Illinois statute to the proposed plan. The attorney then consulted with the family to ensure that the plan was legally viable and that their family was in agreement. This step was especially critical if opposition to the family's plan was anticipated. The attorney also assessed the appropriateness of the proposed caregiver, ensuring that this person met statutory and court requirements for guardianship, standby guardianship, foster parent, or adoptive parent.

With the permission of the family and potential caregiver, the Project conducted a background check to determine if the caregiver had a history of child abuse or neglect, prior criminal convictions, or pending criminal charges and they were informed of the results. If the chosen caregiver had felony convictions and/or indicated reports of child abuse and neglect, the Project worked with the family to determine the next steps, which included reforming the plan or attempting to move forward with the plan if the family chooses.

Although the screening process was a preliminary assessment, a more comprehensive legal assessment began as soon as the Project team and the family determined that the case was ready for legal services. During this assessment process, previously gathered information was verified, and additional information was gathered including:

- verification of the legal needs of the family with respect to permanency planning;
- working with the family to identify the appropriate legal client for purposes of representation (primarily the parent, although if the parent is deceased or incapacitated this step becomes more complex);
- completing the required fact finding and investigation;
- verifying who may have legal standing and be entitled to notice of the proceeding;
- continuing to evaluate the legal risk (or vulnerability to legal challenge) of potential plans; and determining appropriate legal strategy.

If, after completing the legal assessment, the attorney found that the plan was ready to be legalized, the attorney began the process for securing a legal permanency plan for the children.

Stage 3 : Securing a Legal Permanency Plan

3a. Securing a Court Ordered Plan: When the client was ready to proceed, s/he and the attorney signed a retainer agreement that specified the legal services that would be provided by the attorney. Clients were apprised of the rights and responsibilities of birth parents and new caregivers, which varied by the legal option chosen.

Every effort was made to develop a plan to which all of the parties with legal standing in the case could agree. Parents were asked to obtain consent to their plan from those who might present a potential legal challenge. With the client's permission, attorneys contacted others with legal standing, such as a non-custodial father or mother to discuss the feasibility of obtaining their consent to the parent's legal plan. In general, because of limited staff time and resources, few cases were accepted in which a trial is anticipated. However, possible cases for trial were evaluated on an individual basis, and could be accepted.

Depending upon the plan developed by the client, appropriate documents were developed and reviewed with the client. Notice is provided to all persons entitled under the relevant statute. The proceedings and potential outcomes were again reviewed with the family.

Attorneys followed the case appearing in court on subsequent dates, if necessary, to represent the client. Once the Court approved the plan and issued an Order, attorneys provided follow-up legal services as needed.

Social workers continued to work with the family during this stage, intervening if family problems arise, supporting the family through the process, monitoring a family's confidence in their plan, and helping to maintain momentum towards the court proceeding and beyond.

3.b. Other Legal and Benefit Services were available to Family Options clients. These services supplemented a court ordered permanency plan or assisted the family when a court ordered plan could not be legally secured due to disagreement or problematic background checks. Legal documents that supported a parent's plan included powers of attorney for health care and property. Private legal arrangements included short term guardianship (private arrangements valid for up to 60 days and renewable), testamentary guardianship (designation of a guardian in a will), or establishing parentage.

Attorneys also assisted clients with benefits to support a permanency plan including: Supplemental Security Income; Social Security Disability Benefits; Survivor's Benefits; Dependent's Benefits; Children's Supplemental Security Income; Social Security overpayments and waivers; Social Security deeming and in-kind support and maintenance; Medicaid; Medicare; Food Stamps; Aid to the Aged, Blind and Disabled (AABD); Qualified Medicare Beneficiary Program (QMB); Supplemental Low Income Beneficiary Program (SLIB); TANF and other cash assistance; the child health insurance program; and Circuit Breaker program for older caregivers.

Stage 4: Aftercare

4a. Birth parents: Birth parents may have completed a plan which did not take effect until their death or incapacity (standby guardianship). After that plan was secured but before it was implemented, birth parents and their family may have continued to receive social work and legal services that supported their family's stability. When the plan was activated, Project staff again became involved with the family, facilitating the transition with the new caregivers for the children.

Sometimes a court ordered plan became unworkable in a given family situation. For example, caregivers became ill or unable to support the children financially. In those situations, legal staff, social workers, and family designed a new permanency plan for the child.

Follow-up contacts were made with families in aftercare through a Family Options event, at community programs, or through an evaluation survey. Additional services were provided as needed to stabilize the family or to reexamine the permanency plan and its viability. These contacts contributed to preservation of families and enhanced our knowledge about the long-term stability of planning with HIV-affected families.

4b. New caregivers: When a plan was implemented at the death or debilitation of the parent, new caregivers were supported by social work and legal services through a transition period ranging from several months to several years. Social workers assessed the new family's need for services to support their stability. The issues that commonly arose included family adjustment to new roles and members, financial strains, grief and loss, children's emotional stress and behaviors, and parenting concerns. Social workers intervened with problem-solving, parenting skill development, and family counseling as needed. Access to public benefits, was provided maintain the stability of the new home.

Standby guardianship cases required specific legal assistance. In those instances, the Court appointed a standby guardian who, in effect, "stands by" until needed which is usually at the parent's death or incapacity. Once the plan is activated, the standby guardian acts for up to 60 days without court supervision. Within those 60 days the standby guardian filed a petition to be appointed "regular" or long-term guardian of the minor. Full guardianship was generally granted, unless the Court finds that it is no longer in the minor's best interest.

Family Options attorneys worked with the family and Project social workers to evaluate the situation at the time of the parent's death or incapacity. If the standby guardian was still willing and able to assume full guardianship, the Project represented the standby guardian in the full guardianship proceeding. If the standby guardian was no longer willing or able to serve, or would otherwise not be approved by the Court, the Project worked with the family to develop a new plan. If cases arise where children were orphaned with no responsible relative or friend willing or able to take custody, the Project worked with the Illinois Department of Children and Family Services to arrange foster care or other appropriate placement.

F. Additional Program Features

Legal and policy enhancements for permanency planning: Family Options continued its practice of monitoring Illinois laws and policies that impact voluntary permanency planning and developed enhancements, including new permanency planning mechanisms, as needed.

Education and implementation of these enhancements were provided to Family Options clients and in other relevant child welfare programs.

Peer Support and Family Retreats: Birth parents, caregivers and their families were invited to regular events or retreats that offered education, therapeutic support, recreation, and celebration. Retreats and support groups were developed as needs were identified. HIV affected families were often isolated and lacked the opportunity to converse with other parents and kids in similar situations. These events gave birth families as well as new caregiver families an opportunity for conversation and recreation with one another. While there was not always direct discussion about AIDS, there was safety in the fact that everyone there knew that everyone else was somehow affected.

Affected youth were also isolated as caretakers for their HIV infected parents and siblings. They experienced a good deal of loss and subsequent responsibilities. They were at risk for depression and acting out behaviors such as experimentation with sex and drugs. Group events offered affected youth an opportunity to have fun, to share their fears and concerns, to experience empathic friendships outside of their families, and to normalize their adolescent experience.

Family Option Forums: The Family Options Team learned that the community of HIV and child welfare providers, attorneys, and consumers wanted education on the psycho-social and legal aspects of permanency planning. Quarterly forums meetings were organized to provide education and consultation on relevant issues by team members or local experts in the field.

Consultation: Family Options sought out special consultants for the team who provided in-service workshops and on-going consultation. One was an experienced Grief Counselor who specialized in children and loss. The other was a psychologist who specialized in the disclosure of HIV/AIDS to children. The materials and skills gained were integrated into the practice of the Family Options team and often included in training and conference events.

Network Member: The DCFS AIDS Project has strong linkages with the HIV women and children programs in Chicago and Illinois. Because Family Options resides within this child welfare program, it became a member of the HIV community network and the recognized provider of permanency planning services to HIV affected families in the continuum of care.

This network included the valuable linkage between the state child welfare services and community-based service system for people with HIV coordinated through the HIV/AIDS Case Management Cooperative. That system involved 55 local agencies ensuring access to medical care, housing, food services, emergency financial assistance, transportation, and other needed services for HIV affected clients. This linkage also included the Illinois Department of Public Health AIDS Services who managed the Ryan White Care Act service coordination throughout the state.

IV. RESULTS, BARRIERS, AND SOLUTIONS

Objective #1 300 HIV-affected families and 750 children in Chicago will access Family Options services.

Results: One hundred eighty-nine (189) families and 368 children accessed Family Options services during the four year Phase II. Those services included either social work or legal or a combination of the two. Some families from Phase I did not actively use social work or legal services but participated in other project services, e.g. retreats or support groups

Barriers: The objectives were set higher in Phase II for two reasons. First, the trends in HIV-infection indicated that there would be increasing numbers of women in the Chicago area with HIV/AIDS and thus more parents needing services. Second, since this was a continuation grant, there was no time needed for start up. Services were provided seamlessly across Phase I and Phase II thus allowing more months for intake and service provision. Despite these assumptions, the numbers of families in the program did not increase. Additionally, the numbers of children being planned for per household in the program was less than in Phase I. The numbers were based on an average of 2.5 children per parent as seen in Phase I. In Phase II, the average number of children being planned for per parent was 1.9 children. The Project staff are not sure how to explain this trend but speculate that one reason might be the decreased need for plans for older children as parents are living longer.

The use and success of highly active antiretroviral therapy (HAART) continued to have an impact as parents are living longer and planning seems less urgent. As always, the more immediate challenges that these parents face in day-to-day living, such as mental health problems, housing, and health can take precedence over thinking about the future and planning for death or illness, a subject which is difficult to think about in the best of circumstances.

Social service staff at HIV/AIDS service organization were busy addressing the day-to-day issues faced by families, e.g. housing, substance abuse, so planning was not a high priority.

Addressing planning also required talking about death and dying which was beyond the comfort and skill level of some staff. Staff turnover at agencies in general was high requiring ongoing education and engagement of service providers on Family Options services and the need for permanency planning.

As staff reached out to agencies outside the HIV/AIDS service organizations, stigma made outreach more difficult. For example, substance abuse treatment centers were likely sources of referral for the program. However, by becoming involved with Family Options, clients were automatically disclosing their HIV status to staff and clients at the treatment center. Solutions: During the first 18 months years of Phase II, an aggressive outreach plan was developed and implemented including weekly presentations to service providers and consumers. Attorneys and social workers made weekly visits to the Core Center, the primary care center for people with HIV/AIDS in the Chicago area and to the Sister of Sobriety House (SOS), a residential facility for homeless women with substance abuse problems that serves many women with HIV/AIDS. The program would have benefited from ongoing and more aggressive, targeted outreach geared to consumers rather than providers.

When the intake numbers were low, staff focused their time on stabilizing and supporting families before and after a plan was completed, rather than emphasizing planning. Legal services were expanded in Phase II to engage families and to meet their stability needs. Services for Spanish-speaking families were also expanded in the last year. Legal services were available to Spanish-speaking clients throughout Phase II. In the last year of the Project, social work services were extended to Spanish-speaking clients with the hiring of a bi-lingual, bi-cultural social worker.

Objective #2 240 HIV-affected families and 600 of their children will receive social work services.

Results: One hundred forty-one (141) HIV-infected parents and caregivers and 275 of their children received social work services including 1,659 in-person contacts, 197 attempted contacts, and at least 200 phone contacts. The average contact was 94 minutes in length with the largest number of contacts (799) lasting 2 hours. Ninety percent (90%) of the contacts involved supportive counseling; education was provided in approximately one-quarter of the contacts.

Other services (advocacy, assessment, crisis intervention, problem-solving, and conflict mediation) were provided in a small proportion of contacts (1% - 8%). Adult mental health was a topic in two-thirds (67%) of the contacts; child behavior and mental health was discussed in over half (58%). Other topics discussed were medical/medication (30% of contacts), family conflict (21%), planning options (17%), death/loss/grief (16%), and future caregivers (13%).

Barriers: The barriers encountered here were similar to those encountered with Objective #1.

The numbers served were set high for this objective based on past trends. The multiple challenges faced by these families and the success of anti-retroviral therapy combine to deter parents from planning for the future. As noted in the topics, mental health was a major issue in these families. Many parents could have benefited from mental health services but most families were already working with multiple providers so one more provider or appointment was not feasible. The stigma associated with mental health also prevented parents from seeking or using traditional mental health services. Often clients did not perceive a need for mental health services or were reluctant to develop a relationship with another service provider. As they had an established relationship with the Family Options social worker, they relied on the Project social worker for support and counseling. Social workers spent much of their time addressing mental health issues prior to or in conjunction with making a plan. This focus on long-term work

subsequently shifted the focus from active outreach to potential clients to maintenance of present clients,

Solutions: Halfway through Phase II, based on an annual review of the progress towards objectives, the staff and evaluation team began a series of meetings to examine service use and subsequently took steps to focus the service provision. As the annual review, staff noted that 40% of clients were receiving aftercare services or services post-completion of a legal plan. The staff and evaluation team reviewed data on those clients to determine if there were any trends apparent for those who received long-term services. Based on that meeting, treatment plans were implemented. The treatment plans were reviewed quarterly to assess how the family was progressing and if appropriate services were being provided.

In the last year of Phase II, the staff and evaluation team developed a program logic model (see Appendix) and a planning barriers and facilitators checklist as a clinical tool to be used in conjunction with the assessment form. This form was implemented for nine months of the program and with 14 clients. Since the form was implemented late in the Project's tenure, the aggregate results were not used to inform service implementation but did inform individual practice.

Objective #2a At least 2/3 (66%) of families served will have an informal plan in case of death or hospitalization.

Results: Ninety-three families or 49% of families who were actively planning during Phase II put at least an informal plan in place; these families represented 177 children. For 38% or 67 of those children, an informal plan was the farthest step completed in the planning process; these children did not go on to have legal plans secured by the end of Phase II. An informal plan was defined as a parent expressing their wishes to a potential caregiver regarding the children's future care and the potential caregiver verbally agreeing to provide that care. When a social worker

determined that the parent and potential caregiver were in agreement, the social worker filled out the required section on the service delivery form completed for each social work contact. The documentation of this informal plan was not legally binding but might have been helpful in court if the parent died before legalizing the plan. The agreement between caregiver and parent also marked the farthest that many parents would go in the process but, nonetheless, an important step that was not documented in Phase I.

Barriers: An initial challenge was agreeing upon a definition that was clear and could be routinely applied and then documenting the informal plan on a consistent basis. The staff and evaluation team struggled to identify a form of documentation that was not threatening to the parents, e.g. signing a form. Some parents did not reach this step because they did not have an appropriate potential caregiver or because they were reluctant to disclose their HIV status to their friend or family member.

Solutions: The Evaluation Associate requested documentation on a regular basis from the social workers and provided clarification about the definition as needed.

Objective #2b Provide social work services to 160 HIV-infected parents and their families

Results: 113 HIV-infected parents and their families received services.

Barriers: The barriers for this objective were similar to those for Objective #1.

Solutions: Same as #1

Objective #2c Provide social work services to 80 caregivers

Results: Thirty-nine (39) caregivers of children whose parent has had HIV/AIDS received social work services from the Project. Social workers supported the caregiver and children in grieving a parent's death and adjusting to new roles and living arrangements.

Barriers: This objective was set based on the large and unexpected number of caregivers who requested and received Project services in Phase I. This population is difficult to target as they are not accessing HIV services; there is no longer an infected member in the family so they are not attached to HIV/AIDS service organizations. Caregivers also often do not recognize the impact of HIV/AIDS on the family and children so they do not request HIV specific services.

Solutions: In-depth services were provided to those requesting services. Approximately two years into Phase II, the team consulted with Cathy Blanford, an expert in grief and loss, and, as a result, integrated interventions for grief and loss into their practice (see Appendices). In addition, two forums on disclosure and grief were offered exclusively to caregivers. The staff and a caregiver also did a presentation on loss experienced by caregivers and their children at the AIA Kinship Conference.

Objective #2d. 160 parents and caregivers will participate in peer support through retreats, social activities, and support groups.

Results: *Retreats/social activities* -- Twenty-two (22) retreats and social activities were offered during Phase II. Ten were offered to parents and caregivers only and 12 included adults and children for a total of 648 units of service provided¹. The retreats included activities and topics such as: memory and scrap books; dance; taking care of your inside self; pamper yourself; family picnic; family zoo trip; and crafts.

HIV-positive parent group -- A group for HIV-positive mothers was held from February through June 2002. Two groups of 10 sessions (20 sessions total) were offered; each session lasted 90 minutes. Three to four women attended each session. The goals for the group were to:
1) build a support network for HIV positive women and 2) educate and encourage discussion

¹ This number does not represent 629 different individuals but rather the sum of the number of people who attended all of the retreats/activities. Some individuals attended several events.

around issues determined as important by the group members. The Project social workers identified common themes in their work with the women – dealing with HIV, drug and alcohol recovery, parenting, and relationships; these themes were the basis for group development. In the group, the women were given the opportunity to express themselves and share their experiences through activities, information, and discussion.

Affected youth support groups – In response to the deaths of several parents at a residential facility for families with HIV/AIDS, the social workers recognized a service need for the youth. The goals of the group were to: 1) provide the youth living there a place to process multiple losses; 2) teach them healthy coping skills to deal with the issues of grief and loss; and 3) prepare the youth for the upcoming holidays. The group met weekly for four weeks; each session was two hours in length. The group met during October, November, and December of 2000. The youth ranged in age from 11 to 17 years old. Eight children attended the first two sessions and five attended the last two. The groups incorporated artwork, writing, and discussion.

Another support group was implemented in Spring 2003 for adolescent girls whose mothers had died of AIDS. Four girls, ages 15-18, attended the group for six weeks held at the Family Options Project Office. Through journaling and discussion, the girls shared memories of their mothers with each other and processed their feelings of sadness, fear, and anger about her loss and their current living circumstances. Interventions were offered to empower and build the self-esteem of these young people. Once the girls were at the group session, they participated well. It was difficult, however, to maintain their attendance.

Barriers: Retreats/social activities -- An event/retreat coordinator who was appropriate for the services, i.e. developed good activities within the Project budget, was difficult to identify and retain. Many more clients committed to attending than actually attended making it difficult to plan for food and supplies. Transportation for clients is always a challenge with the cab system

cumbersome and unreliable. As with any chronically ill population, ill health sometimes precluded attendance. Ill health or lack of child care precluded some clients from attending. Additionally, groups are a much used modality for people with HIV/AIDS and in substance abuse recovery, so clients can be inundated with group opportunities.

Support Groups – Lower numbers of women and youth than anticipated attended the group. Though meetings were scheduled at their convenience, there were usually good reasons people could not attend. The logistics of getting people to the meeting, setting up, ordering food, getting people home, and de-briefing was left to the clinical social work staff and led to exhaustion on top of facilitating the meetings. Holding meetings at the residential facility was more accessible, but the downside was privacy.

Confidentiality was a ground rule, but most challenging for the youth who lived in the same facility where the group met. They expressed a lack of trust in general with the facility staff and occasionally with each other – “everyone knew everybody’s business”. Facility staff and residents occasionally walked into the room where the group was being held. These factors hindered openness in some instances. A couple of the adolescents also posed a behavior problem that was disruptive to the group.

Solutions: *Retreats/social activities* -- Staff were flexible and creative in identifying retreat coordinators. One of the staff attorneys proved most successful as she was dedicated, knew the population, and could plan useful, inexpensive activities. In order to improve attendance, staff made reminder calls before each event and, if necessary, made transportation arrangements in advanced for clients.

Support groups – In order to increase attendance numbers, participants were called a day ahead, given bus cards and gas money for transportation. The facilitators and group members laid down ground rules around confidentiality. At the residential facility meetings, the social workers prevented disruptions by putting a ‘do not disturb’ sign on the door. When disrupted

they immediately but politely asked the staff or resident to leave the room. They also tried to offer the adolescents a forum where they could talk about problems and solutions that they had with the residential staff. Behavior problems were addressed during the group through redirection. When a group member behavior became too disruptive, she was asked to leave that session.

The social workers developed the Project-based Adolescent Girl's Group in response to the lack of privacy at the residential facility and provided the transportation for them to ensure attendance. The Project Director took on the responsibility for the logistics so that the social worker could focus on the youth.

Objective #3 Provide comprehensive legal services to 150 families and 376 children, including permanency planning, benefits advocacy, and other assistance that supports family stability.

Results: 132 families and 255 children received legal services, including guardianship, adoption, stand-by guardianship, wills, power of attorney, benefits advocacy, and assistance with discrimination and confidentiality issues. Legal counseling was the service provided the most with team consultation, documentation preparation, non-client consultation, and investigation or research as services also emphasized in legal service provision. In addition to Family Options clients, legal only services were provided to clients of another permanency planning program that provided social services only.

Barriers: As noted before, fewer clients were intaked in Phase II than expected and the number of children per household was lower in Phase II than in Phase I.

Solutions: The Project attorneys participated in retreats in order to engage families in services and overcome people's distrust of the legal system. The attorneys at AIDS Legal Council, a subcontractor with the Project, provided information to clients who accessed their services about

the legal services available through the Family Option Project. The Family Options attorneys were also heavily involved in outreach and training to providers.

Objective #3a 100 families with 250 children completing legal permanency plans

Results: 63 families and 110 children completed at least one legal plan. The legal plans included: 40 guardianships, 23 stand-by guardianships, 6 custody, 5 successor guardianships, 5 paternity established, 4 adoption, and 1 adult guardianship. Twenty-nine families also completed wills designating guardians for 47 children.

Barriers: As noted before, families face more immediate psychosocial and legal issues than planning. Some parents expressed the belief that planning was giving up on the future. Also as noted, the numbers served in Phase II were lower than expected. As fewer numbers were served and more attention was paid in-depth to families, permanency became less of a goal for families and staff and day-to-day concerns took focus.

Felony convictions have always been a barrier for some families but not if a grandparent was chosen as the potential caregiver. During Phase II, the appellate court decision required that the law be applied to everyone considering guardianship or adoption, including relatives. As many of the Project's clients choose their parents, i.e. the children's grandparents, as potential caregivers, the application of these laws made formalizing plans a challenge.

Since the Project's beginning, the legal director worked closely with judges to educate them about HIV family issues and the available legal options. During Phase II, changes in judges required a concerted re-education efforts by the attorneys. Due to a change in judge, out-of-state guardianship became more difficult in Phase II which created roadblocks for a few families receiving Project services.

Solutions: Comprehensive legal services were provided, in addition to planning, to assist families in gaining stability and managing more immediate concerns thus eventually freeing up time and energy to plan. Through the provision of these services, parents also developed trust

with staff and were not as threatened with discussions about making plans. Short-term guardianships were completed with 52 children and informal caregiver plans for 95 children were documented in Phase II. Both short-term guardianships and informal plans were indications of critical steps towards a formal plan and stability for the children. Attorneys with the Project drafted legislation that would change the law about felony convictions to reflect the best interests of children, which should facilitate the formalization of plans.

Attorney worked closely with judges to facilitate the legal process with families. For example, if children were working closely with a Project social worker, judges rarely appointed a guardian ad litem (GAL). This procedure streamlined the legal process for families.

Objective #4 Increase awareness of the importance of permanency planning, planning needs of families, barriers and options available.

Objective #4a 24 training sessions reaching 1200 service providers and consumers

Results: Sixty (60) training sessions were provided reaching 1,383 service providers and consumers. The majority of the sessions were conducted with HIV/AIDS services organizations. Legal and social work staff and evaluation team members also made at least two presentations per year at conferences. Ten (10) forums were offered for providers and consumers in Chicago, Peoria, Belleville, and Rockford. Training topics included: disclosure, grief and loss, best practices, mental health and HIV, public benefits, legal options, and planning.

Barriers: There were no barriers to reaching this objective.

Solutions: Because service provider turnover in agencies was high, Family Options staff offered and provided multiple trainings to some agencies.

Objective #4b Technical assistance provided to legal and social service providers in downstate Illinois

Results: The Family Options Project Director and Legal & Policy Director consulted with child welfare, public health case managers, and attorneys across the state. Most often the topic concerned the technology of permanency planning options such as standby guardianship and standby adoption. Our attorney also consulted with the Legal Services of Eastern Missouri, a border state to a large southern Illinois city. In addition, a presentation was made at the Illinois Institute on Continuing Legal Education Seminar on Recent Innovations in Adoption for 20 lawyers and social workers from downstate Illinois.

Barriers: While it was not difficult to consult with clients and providers outside of Cook County, Family Options social workers and attorneys did not have the capacity to counsel or represent clients in these downstate areas. There were no legal projects funded to provide these permanency planning services and only a small number of attorneys who were willing and able to learn about these options in order to represent families in downstate Illinois.

Solutions: Additional funding was sought from the Illinois Department of Public Health for the purpose of facilitating permanency planning forums in several downstate regions. During Phase II, programs were held in the south, central and northern regions of the state, in Belleville, Peoria, and in Rockford respectively. Ryan White Case Managers, child welfare case managers, and regional legal programs were invited to the all day program. The Family Options team presented both clinical social work and legal issues, including aspects of coordinating the multi-disciplinary aspects of the work, reaching nearly 100 providers across the state.

Objective #4c : 40 outreach presentations reaching 1000 service providers and consumers

Results: 45 outreach presentations and 925 service providers and consumers received information through outreach.

Barriers: As with the training objective (#4a) service provider turnover was high and providers had busy schedules. Providers were helping clients with issues which were more urgent than planning. Some service providers were protective of clients and services and refused to have Project staff do presentations as their agencies.

Solutions: Staff made multiple and repeated contacts to agencies scheduling informational meetings with services providers and consumers. In addition to outreach, staff took every opportunity, e.g. presentations and policy meetings, to mention the program name and services.

Objective #4d: Weekly outreach will be provided during clinics at CORE Center.

Results: The CORE Center is the primary care center for the majority of people with HIV in the Chicago area providing comprehensive medical and social services. Attorneys and paralegals from AIDS Legal Council of Chicago, partially funded by Family Options, were available at the CORE Center three days per week (approximately 21 hours per week). A Project social worker was available one day. Attorney and social worker presence on a regular basis was intended to increase client's access to Project services through familiarity with and availability of the staff.

Barriers: Many clients were already aware of the Project's services. Others were not comfortable approaching the staff, especially in a public place such as a hallway or waiting room.

Solutions: The attorney found an office in which to meet confidentially with people who were referred to her. This prevented informal contact but allowed for confidential discussions and the attorney could do work in the office when not meeting with clients. Attorneys also participated in staffings at the CORE Center which raised visibility of the Project and increased accessibility to service providers. The Family Options Project Director and staff also worked with the case managers from the parent and child program (First Love) at the CORE Center to facilitate permanency planning.

Objective #5 Monitor the utility and effectiveness of recent Illinois statutory innovations to legal permanency planning options and develop enhancements as needed.

Results: The Family Options Project, in conjunction with the Families and Children's AIDS Network (FCAN), developed and refined each of Illinois' permanency planning legal innovative reforms – standby guardianship, standby adoption, and short-term guardianship – during Phase I . During Phase II, the Project continued to implement these legal options, and further refinements to standby adoption were passed into law. In addition, a major impediment to guardianship emerged during Phase II, and the Family Options and FCAN took a lead role in attempting to correct the law. All efforts in this area were based upon feedback from Project staff and consumers.

Refinements to standby adoption: As initially enacted, Illinois' standby adoption statute provided that only families in which a parent is terminally ill could ask the court to appoint a standby adoptive parent. The Project staff believed that removing the terminal illness requirement would mean that more families could take advantage of this useful legal planning tool. In addition, some legislators believed that the terminal illness identification requirement might be in violation of HIPAA. To correct this situation, a bill to amend the Illinois Adoption Act was drafted and introduced. Ultimately the bill passed both houses of the Illinois General Assembly unanimously.

Guardianship reform: While the Illinois Probate Act provides that no one with a felony conviction can become a guardian, no matter what the circumstances, for approximately 10 years judges were able waive the felony ban and did so in exceptional circumstances, usually when the felony happened long ago and always when the proposed guardian was clearly best person available. An October 2003 appellate court decision, however, held that judges never have the discretion to appoint someone with a felony conviction as guardian, no matter what the

circumstances. This statutory bar created a serious problem for many Project families. Often, the felony conviction was old, or the circumstances of the conviction do not present a risk to the safety of the minor or the disabled person. Moreover, often the child has been in the care of the proposed guardian for a significant period of time and has developed a strong attachment to the proposed guardian.

The Project attorneys provided leadership to a coalition of legal services providers who work with guardianship cases. A bill to amend the Probate Act to specifically permit exceptions to the felony ban was drafted and introduced. It was not passed prior to the end of the Project, but Family Options attorneys will continue to work to educate legislators and others toward its passage.

Barriers: *Standby adoption amendment:* Little resistance to amending the standby adoption statute was encountered. Initially, the Chicago Bar Association Adoption Law Committee expressed reservations to creating more flexibility in Illinois adoption process.

Guardianship amendment: As expected, a great deal of resistance was met in attempting to educate legislators and others regarding the need to modify the felony ban in the Probate Act. Even having the ear of legislators on the issue was difficult, especially in an election year. Securing sponsorship for a bill to modify the felony ban was also problematic.

Solutions: *Standby adoption amendment:* The Project Legal Services Director, as chair of the Committee's legislative subcommittee, ultimately persuaded the Adoption Law Committee to support the removal of the terminal illness identification requirement from standby adoption law. Support was also secured from the CBA Legal Aid, Probate Practice, and Legislative Committees, the AIDS Foundation of Chicago, the AIDS Legal Council, the Chicago Bar Association, Chicago Legal Aid to Incarcerated Mothers (CLAIM), FCAN, the Illinois Department of Children and Family Services, the Illinois State Bar Association.

Guardianship amendment: While difficult for some legislators to support, modifying the felony guardianship ban had strong support from lawyers and judges who work with this law. The Project Director secured the support of the following groups: CBA Probate Practice Committee, CBA Adoption Law Committee, CBA Legal Aid Committee, CBA Legislative Committee, and the Illinois State Bar Association (Family Law Committee and full association), and the Chicago Bar Association. The bill will be introduced again in the 2005 legislative session, and Family Options II staff will continue to provide education on this issue.

Objective #6 Increase knowledge and awareness among legal and social work professionals of the model of interdisciplinary practice.

Results: *Education-* Virtually every outreach and training event conducted by Project staff included both a social worker and an attorney. Information included the roles of social workers and attorneys in delivering Project services and the options and outcomes that clients could pursue, both legal and non-legal. At least three trainings were held specifically on working in the interdisciplinary context including a workshop for the National AIA Grantees Conference on interdisciplinary work with HIV-affected families.

Sharing the model: No other HIV or child welfare program that the Project worked with utilized the interdisciplinary model so each program learned the benefits of this model through case referrals, consultation, and technical assistance. In particular, Family Options attorneys provided all the legal consultation and services for the Second Family Project of Lutheran Social Services of Illinois (LSSI) an early HIV permanency planning project in Chicago.

Practice guide: A practice guide for lawyers and social workers regarding joint permanency planning work was developed. An attorney consultant worked with the team to look at barriers to interdisciplinary practice and solutions that had been worked out by the team. A survey was created and completed by team members followed up by another meeting to discuss

the issues. These issues included client definition, attorney-client privilege, social work responsibilities such as mandatory child abuse and neglect reporting, and team information sharing. The results were compiled to complete a practice guide that provides a project overview and common issues found in multidisciplinary collaboration between attorneys and social workers, with suggestion on how these issues may be handled.

Barriers: Programs working with HIV-affected families often wanted legal information for clients, but felt that they were delivering social services themselves and that families might not need the services of more than one social worker. That model does not provide the quality or expertise of the inter-disciplinary model and it is unknown if permanency plans were completed in that way.

No barriers were experienced to providing training on interdisciplinary practice however, these events were attended primarily by social workers and case managers, with few attorneys attending.

It was not easy to complete the practice guide for several reasons. It was difficult to find an outside party with both clinical and legal experience; the process took much more time than expected, and the staff was still reluctant to openly discuss past disagreements or conflicts about working with clients.

Solutions: *Education:* The team attested to the fact that legal plans were more likely to be completed when social workers and attorneys worked together with the families. Attorneys extended personal invitations to potential attorney participants for training.

Practice guide: It became clear that there must be open communication to express differences in the approach by social workers and attorneys in order to develop the respect and trust that is necessary to serve families successfully. Team training that utilized hypothetical cases where conflicts might be anticipated instead of using past examples of conflict could be a useful and less personal approach to reconciling these differences.

Objective #7 Knowledge of HIV-affected families and permanency planning will be enhanced through evaluation research, including completion of a longitudinal study of family and plan stability.

Results: Two peer-reviewed articles have been accepted for publication and are in press in social work journals. One manuscript is a qualitative analysis of social work progress notes in the Family Options program and delineates the content discussed and strategies used by the social workers. The second is a description of the Family Options practice model.

The evaluation team took primary responsibility for 8 conference presentations. In addition to two grantees' meetings, evaluation findings were presented at conferences sponsored by NIMH Families Preventing and Adapting to HIV/AIDS; HIV/AIDS: The Social Work Response; and the AIDS Alliance for Children and Families.

The data on post-completion stability of plans has been collected and entered into a database. Preliminary findings are presented in the Evaluation Section. A manuscript will be submitted, in conjunction with the Family Center, by June 2005.

Case studies from Phase I were followed-up at the end of Phase II with one additional interview. See the Evaluation Section for case study summaries. A manuscript focusing on the case studies will be submitted to a peer-reviewed social work journal by July 1, 2005.

Barriers: For the long-term stability study, locating consumers from Phase I and following consumers over the course of a year in Phase II were challenges to data collection. The smaller number of intakes and legal completes than expected also affected the sample size.

Solutions: The Evaluation Associate worked with social workers and attorneys to obtain the latest contact information for families that had completed a plan. If her phone calls did not receive a response or if she had not phone number for clients, a letter was sent to the last known address asking the client to call if they were interested in participating.

Through a collaboration with the Family Center, a sister program in New York City, Dr. Warren Reich introduced the evaluation team to a type of data analysis – Hierarchical Classes or HICLAS -- which can yield useful results without a large sample. The evaluation team is also working with Dr. Warren Reich from the Family Center to combine data so that we will have larger data sets and also opportunities to look at trends across sites.

V. EVALUATION METHODS & FINDINGS

A. Evaluation Design and Methods

The evaluation plan included

- 1) implementation objectives;
- 2) outcome objectives;
- 3) examination of the program model

At the beginning of Phase II, the service delivery forms and the assessment form were reviewed and revised to streamline their use and to collect data relevant to the new objectives. The methods for data collection and data analysis for each segment of the evaluation are described below.

1. Implementation Objectives (was the program implemented as planned?).

The implementation objectives were:

1. Who was served by the program?
2. What services were provided?
3. What was the client's perception of those services?

Implementation Objective #1 Client characteristics

Data to evaluate objective #1 were collected for all of Phase II – September 30, 2000 through September 29, 2004. Client characteristics were gathered during the intake phone call or contact and on assessment forms which were completed during the first two meetings with the client by the social worker or attorney assigned to the family. Assessments were completed on one primary client for each family, whether the birth parent or the new caregiver, and on all of the children for whom plans were being made. In twelve families two assessments were completed one for the birth parent client who entered the program and another on the spouse or caregiver when the children transferred to their care.

The Project Research Associate was responsible for overseeing the collection of data and maintaining the project database. Quantitative data were entered into SPSS and analyzed using frequencies and central tendencies. Data on client characteristics was reviewed with staff on an annual basis to assess implementation of the program and make modifications as appropriate.

Implementation Objective #2 Service delivery

Service delivery was monitored through forms completed by the social workers per contact and by attorneys on a monthly basis and through quarterly updates. After each contact with a client or on behalf of a client, social work staff completed a service delivery form describing the length of time, the type of contact, the people involved in the contact, and tasks and/or topics covered, and a brief note describing the contact. Attorneys completed a form monthly regarding services provided for each client with whom they had contact.

Quantitative data were entered into SPSS and analyzed using frequencies and central tendencies. Data on service delivery was reviewed with project staff on an annual basis to assess implementation of the program and progress towards goals.

Objective #3 Client perception of service

Data on client's satisfaction with and perception of services was collected in focus groups and through surveys. Two focus groups were held during November and December 2003 – one with birth parents and one with caregivers. All of the active and inactive clients were mailed a flyer and invited to participate. Clients were reimbursed for their time and refreshments were provided. The evaluator and the research associate facilitated the groups. A list of open-ended questions developed by the evaluation team was used to guide the discussion. The groups were audiotaped with the participants' consent and the tapes were transcribed.

The client satisfaction form developed in Phase I was revised. The research associate attempted to contact all clients, whether active or inactive, at least once during Phase II by

telephone or letter to ask for their response to the survey. Quantitative data from the survey were entered into SPSS and analyzed using frequencies and central tendencies. The focus group transcripts and answers to open-ended questions on the survey were both analyzed in a similar manner. Units of speech, such as a phrase, sentence, or paragraph, that were relevant to the questions were labeled with a descriptive phrase or code such as “keep kids together”. Each of these coded segments was then sorted into a broad category or theme based on the interview questions. The themes were reviewed and refined by the evaluator and the research associate. Both reviewed all categorical decisions and, where differences occurred, they were discussed and clarified until a consensus emerged. Data on client satisfaction were reviewed annually by Project staff.

2. Outcome Objectives (are families moving toward and/or reaching permanency?)

The outcome objectives examined the number of legal permanency plans secured, the number of informal caregiver plans made, and the stability of plans over time.

1. How many families reach permanency?
2. How many families make an informal caregiver plan?
3. How stable are plans over time?

Outcome Objective #1 Completed plans

Data was collected on completed plans beginning September 30, 2000. Quarterly update forms completed by social workers and/or attorneys documented the legal goal completed and the date completed.

Outcome Objective #2 Informal caregiver plans

Social workers documented informal caregiver plans on service delivery forms. An informal caregiver plan was defined as a verbal agreement between the parent and the potential caregiver about the children’s future care. When the social worker confirmed with the parent and caregiver that the agreement had been made, the social worker completed the specified

section of the service delivery form indicating that the plan had been made and the name of the potential caregiver,

Outcome Objective #3 Post-completion stability of plans

This section of the evaluation was designed to answer two questions:

- 1) What is the status of permanency plans at least one year after completion?
- 2) What do the families need in order to maintain those plans?

The evaluation team developed a telephone survey covering four domains –

- Status of the plan – current and future
- Household stability – composition, living situation, financial
- Well-being – child, family, caregiver/birth parent
- Services – currently used and needed

Clients who completed plans in Phase I and in the first year of Phase II were contacted for an interview at least one year after completion. The Evaluation Associate called the parent/caregiver, explained the study, and asked for their verbal consent to participate. If the parent agreed, the survey was usually completed at that time. The parent or caregiver was mailed a grocery store gift certificate as reimbursement for their time.

If the client completed after December 2001, the Evaluation Associate contacted the parent or caregiver one month after completion and asked them to participate in the survey at that point. If the parent/caregiver agreed, the evaluation associate contacted him/her again at six months and 12 months after securing the legal plan to complete a similar survey. Parent and caregivers received a grocery store gift certificate for each interview.

The Evaluation Associate used the last known telephone number for the client. In many instances, clients who completed in Phase I were no longer involved with the Project and had moved or changed telephone numbers. The Evaluation Associate updated telephone numbers through the phone book and through Project staff, made contact with clients through social

events, and sent letters to last known addresses inviting clients to call if they were interested in the study.

3. Program Model (how does the program create change?)

Case studies

A case study methodology was implemented in Phase I. The purpose was to describe the project's services within the client's natural context, including change over a short period of time, and from the client's perspective. In the last three months of Phase II, the four people interviewed for the case studies in the Phase I were re-contacted and asked to participate in a follow-up interview. All four consented. During this interview, participants described any events or changes over the last few years, whether in their household or their permanency plans for the children. They also completed a brief demographic form about themselves and the other members of their household and answered questions about current service use, including use of the Project's services.

Both the evaluator and the research associate conducted the interviews. All of the interviews took place in the participants' home and the participants were reimbursed for their time. The interviews were audiotaped with the participant's permission and the tapes were transcribed. The interview was summarized and added to the previous case studies.

Delineation of social work intervention

Social workers noticed early in the Project's implementation that they were attending to a range of psychosocial issues not apparently related to planning but crucial to moving forward with a legal plan. These issues exemplified the challenges faced by HIV-affected families and the complexities of making a custody plan. In an effort to understand how social workers were intervening, this study was designed to answer two key questions --

- 1) What are the methods used by the social workers with birth parents?
- 2) What is the content of the sessions between the social workers and birth parents?

The Project's social workers completed a brief note for each contact with a birth parent or with a potential caregiver or service provider on behalf of a birth parent. Every third note, in chronological order, was selected for analysis. The findings include an analysis of 89 notes dated April 1, 2001 through March 31, 2002 from social work contacts with or on behalf of 24 birth parents². The clients whose notes were included in the analysis were predominantly female (83 %) and African-American (79%). Their mean age was 36 years old and they were planning for a mean number of 2 children.

The evaluators used thematic analysis to code the progress notes, using the research questions – content and methods – as the major categories for analysis. The two evaluators independently reviewed the first 20 notes and underlined units, such as phrases, sentences, or paragraphs, that had subject matter related to those categories. The phrases or sentence were labeled with a brief descriptive code, which often reflected the language in the phrase or sentence. Each coded segment was then sorted into the categories of “content” and “methods”. These categories were not mutually exclusive; some codes were sorted under both. The researchers met to review and discuss their respective coding; where differences occurred regarding relevant units or descriptive codes, the differences were discussed and clarified until a consensus emerged.

Each researcher then reviewed those descriptive codes and grouped them into subcategories or common themes of content and methods used. Again, the researchers met, discussed the themes and reviewed and refined until an initial framework of themes emerged under each category. As the thematic framework developed, the progress notes were imported into ATLAS.ti, a qualitative analysis computer program, which aided in data coding and retrieval.

² For a complete discussion of the methodology, analysis, and findings, see Mason, S. & Vazquez, D. (in press). *Journal of HIV/AIDS & Social Services*.

This process was used until all of the notes were analyzed, with the researchers meeting after each set of 20-30 notes to review and refine the themes. For the next level of analysis, those themes that included a large number of responses were broken down into subthemes or smaller categories.

The researchers, social workers, and the project director met at two points during the analysis to check the validity of the findings with the social workers' experience. Notes from those meetings were incorporated into the analysis.

B. Findings

1. Implementation Objectives (was the program implemented as planned?)

Implementation Objective #1 Client characteristics

During Phase II, intakes were conducted on 154 families, including 318 children. One hundred twenty-seven new clients continued with the program, signing consents and participating in assessments. A total of 189 families were served during Phase II as some clients from Phase I continued to receive services. Almost half (48%) of all Family Options families were referred by two organizations – a legal service dedicated to serving people with HIV and the primary health care center that serves most of the HIV-infected women in Chicago.

Birth parents

Data was collected on 132 birth parents. A birth parent was defined as any HIV-infected person planning for their children, including biological parents, adoptive parents, and guardians, whether relative or non-relative. The average (mean) age of the birth parents was 35 years with a range of 18 to 58 years. The parents had an average (mean) of three (3) children each but were planning for an average of two (2) children each with a range of one to seven children.

The mean income for the parents was \$ 925 per month with a range of \$0 to \$ 5,100 per month. Nine birth parents or seven percent (7%) had no income. The majority of the birth parents were female (90%) and African-American (73%); twelve percent (12%) were Latino.

The largest percentage (42%) was asymptomatic HIV with the next largest percentage (40%) having a diagnosis of AIDS. Most (79%) had Medicaid as their insurance source. Sixteen percent (16%) were identified as having difficulty reading or writing. Eighty-one percent (81%) were single, separated, widowed, or divorced. Thirty-eight percent reported ever having an open case with the state child welfare system as an adult; eighteen percent had an open case as a child. .

Table 1

Demographics of HIV-infected parents served by the program (N=132)

Mean age	35 years
Gender	
Female	90% (113)
Male	10% (13)
Race	
African-American	73% (92)
Caucasian	7% (9)
Mexican	6% (7)
Puerto Rican	4% (5)
Other Latino	2% (3)
Native American	2% (2)
Other	6% (8)
Mean Monthly Income	\$ 925
Health Status	
Asymptomatic	42% (53)
Symptomatic	16% (20)
AIDS	40% (50)
Number of children	2.9 mean
Number of children planning for	2.0 mean
Education level	
Below high school	8% (10)
Some high school	35% (44)
High school or higher	56% (70)

Children

Data was collected on 318 children whose parent or caregiver was involved with the program. The children being planned for were, like their parents, predominantly African-American (78%). Most (72%) were living with their custodial parent who was the client seeking services; 17% were living with a caregiver, such as a relative, who had no legal status. Twelve percent (12%) of the children were HIV positive. At intake, the children ranged in age from 3 days to 19 years, with a mean age of 8 years old.

Caregiver

Data was collected on 41 caregivers who requested services from the Project. Caregivers were often relatives caring for the children in the parent's absence and seeking the Project's help to legalize and stabilize the placement.

The majority of the caregivers were African-American (77%). Their mean age was 50 years with a median age of 51 and a range of 18 to 75 years. Ninety percent (90%) of the

caregivers were female. Fifty-eight percent (58%) had a high school education or higher. Their income ranged from zero to \$6,477 per month, with an average of \$1,275 per month.

Table 2
Demographics of caregivers served by the program (N=41)

Mean age	50 years
Gender	
Female	90% (35)
Male	10% (4)
Race	
African-American	77% (30)
Caucasian	8% (3)
Puerto Rican	8% (3)
Mexican	5% (2)
Other Latino	3% (1)
Mean Monthly Income	\$1,275
Infected Parent Deceased	55% (21)
Number of children	2.6 mean
Number of children planning for	1.6 mean

Permanency goal

At intake, clients were asked to identify a goal to work for with the program. This information was updated quarterly if the client was using only social work services and monthly if receiving legal services. At the end of Phase II, of those who selected a goal, whether completed or not, half reported stand-by guardianship as their goal.

Table 3
Legal goal as of 9/29/04

Goal	Frequency	Percentage
Stand-by guardianship	93	50 %
Guardianship	50	27 %
Short-term guardianship	7	4 %
Adoption	6	3 %
Paternity	7	4 %
Successorship guardianship	3	2 %
Regain custody	3	2 %
Other	10	8 %
TOTAL	179	100 %

Implementation Objective 2 Service Delivery

The number of intakes was at its highest in year three (44) and lowest in year 4 (21) with an average of 32 intakes per year. Intake was defined as those clients who had an initial contact with a staff person, expressed an interest in planning, had the ability to plan (custody of the children), and gave basic information to complete the intake form. The smaller number of intakes in year 4 can be explained partially by the end of phase two – intake was closed for the last three months of year 4 as the Project terminated its services.

Intakes, however, did not represent the number of people served during a quarter or over the course of a year. Clients received services as long as necessary to complete their plan and often went from active to inactive to active status as their needs for service or their plans changed. On average, 44 families were served per quarter.

Social work services

One hundred forty-one (141) HIV-infected parents and caregivers and 275 of their children received social work services including 1,659 in-person contacts. The average contact was 94 minutes in length with the largest number of contacts (799) lasting 2 hours. Over half (57%) of the social work contacts included a biological parent, mother or father. Current caregivers participated in approximately one-quarter of the contacts; potential caregivers were involved in 7%. At least one child was involved in 42% of the contacts. Collaterals, e.g. case managers, social workers, counselors/therapists, participated in a small proportion (approx. 3%) of contacts.

Table 4
Person included in social work contacts

Contact with	Frequency	Percent
Biological mother	1,056	57 %
Child or children	794	42 %
Current Caregiver	472	25 %
Collateral contact	46	3 %
Potential caregiver	122	7 %
Biological father	175	9 %
Other relative	143	8 %

Note: percentages do not add up to 100% because multiple people could be involved in a contact.

Using a checklist, social workers documented the type(s) of service they provided at each contact and the topics covered in each contact. Supportive counseling was the most provided service with an emphasis on mental health, medical issues or medication, and family conflict.

Table 5
Type of service provided in social work contacts

Type of service	Frequency	Percent of contacts
Advocacy	16	1 %
Assessment	145	8 %
Crisis Intervention	22	1 %
Education	448	24 %
Problem-solving	97	5 %
Supportive Counseling	1677	90 %
Mediation in Family Conflict	30	2 %

Note: Multiple services were provided in some contacts

Table 6
Topics covered in social work contacts

Topics covered	Frequency	Percent of contacts
Child behavior/mental health	1061	57 %
Planning options	316	17 %
Adult mental health	1865	67 %
Future caregivers	233	13 %
Family conflict	387	21 %
Medical/medication	548	30 %
Parenting skills	218	12 %
Death/loss/grief	306	17 %
Benefits/entitlements	86	5 %
HIV/AIDS	177	10 %
Disclosure	75	4 %
Nutrition/Diet	11	1 %
Substance abuse treatment	112	6 %
Other*	113	6 %

* Other included: child care, respite, education/school, housing, Family Options retreat, rape, return home of children, sexual abuse.

Note: percentages do not add up to 100% because multiple topics could be discussed in a contact.

Legal Services

One hundred thirty-two (132) families and 255 children received legal services. Legal services provided to each family were documented on a monthly basis. If a family received a service during a month, that category was checked on the family form

Table 7

Type of legal service provided

	Average # of families served monthly
Referral	2.1
Legal counseling	9.7
Documentation prepared	6.1
Advocacy/intervention	2.6
Administrative hearing	0.2
Court proceeding	1.8
Investigation/research	4.9
Non-client consultation	5.2
Follow-up	2.1
Other*	1.5

Other included: funeral, gift card, consult with sister program, screening, family conflict/meeting, outreach.

In addition to assistance with permanency plans such as stand-by guardianship, guardianship, adoption, or paternity, attorneys also assisted with wills, power of attorney, benefits advocacy, and discrimination and confidentiality issues.

Implementation Objective 3 Client perception of services

Focus groups

Ten clients participated in two groups – 6 in the parent group and 4 in the caregiver group. All of the participants were women.

The major themes from the group discussions are listed below under each question.

What were your reasons for becoming involved with the Family Options project?

- Want a smooth transition
- Want all of my children to be together under one person's care
- Did not want court involved or fighting over who would get the kids after my death
- Father is unstable and needed to get a family member involved
- A relative died and I took on the care of their children
- Needed a Power of Attorney

How have you and your family benefited from the project?

- Information, “enlightened” on many topics
- Retreats-an opportunity to get away and talk with “like” others
- Social workers supportive and can be counted on in times of crisis
- Social workers come to house, talk and listen
- Lawyers advocate on your behalf
- Lawyer prepared a will
- Ease of mind
- The fact that the program exists

What is least useful about the project?

- Social worker went “over my head” to make changes in services; social worker is “angry with me”

What would you like to see changed?

- Response from worker not always timely
- Did not want to get nudged or persuaded to get a plan in place
- Need more help in facilitating getting signatures
- Legal only clients not getting invited to retreats

What would make planning easier?

- Information about services that are available
- Focus social work services on adolescents
- Have more opportunities for caregivers to get together and talk
- Cab service is not responsive and a different service is needed
- Need housing – more space and more affordable

What topics would you like to know more about or have the opportunity to talk about?

- Affordable housing – section 8 housing
- Difficulties parenting adolescents
- Nutrition/Health
- Medication – side effects
- Medical complications – people who are co-infected
- Drug abuse
- Sexual abuse
- Financial counseling
- Disclosure process
- Mental health information – signs and symptoms

Telephone Survey

Forty-five clients responded to the telephone client satisfaction survey.

Table 8
Client satisfaction survey results

	Strongly Agree (4)	Agree (3)	Disagree (2)	Strongly Disagree (1)	Mean Score
Social Work Services					
I received the kind of services that I wanted (n=38)	29	9	0	0	3.76
The social worker returned my calls in a timely manner (n=38)	32	6	0	0	3.84
Legal Services					
I received the kind of legal services I wanted (n=32)	29	3	0	0	3.91
The attorney returned my call in a timely manner (n=32)	30	2	0	0	3.94
The attorney helped me understand my legal options (n=32)	31	1	0	0	3.97
Services Overall					
The services I received were helpful (n=45)	40	5	0	0	3.89
Program staff were respectful of me and my culture (n=45)	43	2	0	0	3.96
I would recommend this program to a good friend or relative	40	5	0	0	3.89
I feel more comfortable about my family's future since coming to this program (n=45)	40	5	0	0	3.89

Thirty-eight or 84% of the respondents had been visited by the social worker in their home. All of those families (100%) found the visit "very useful" and gave these explanations for how they were useful:

- Someone to talk to
- Gave information and advice
- Caring and concerned

Clients were asked about their satisfaction overall with social work and legal services, depending on what services they had utilized.

Table 9
Overall Satisfaction

	Excellent (4)	Good (3)	Fair (2)	Poor (1)	Mean score
Please rate your overall satisfaction with the services you received from this program (n=45)	42	3	0	0	3.93

The survey also included some open-ended questions or statements for comment.

What has the social worker done that was most helpful to you and your family?

- Problem solving and support
- Education about planning process, rights, and legal options
- Referrals to lawyer
- Concrete assistance including transportation, financial, and counseling for child

What has the social worker done that was least helpful?

Nothing was listed as least helpful

What has the attorney done that was most helpful to you and your family?

- Education regarding legal options and process
- Referrals
- Hope for the future
- Facilitated completion of legal plan

What has the attorney done that was least helpful?

- Felt pressured to complete a legal plan by another program

I feel more comfortable about my family's future since coming to this program.

- Family is more secure with plan in place
- Ease of mind
- Enlightened about legal options

What suggestions do you have to improve the Family Options Program?

- 1) More social activities
- 2) Support groups
- 3) Assistance with Section 8

2. Outcome Objectives (are families moving forward and/or reaching permanency?)

Outcome Objective #1 Plans completed

Sixty-three (63) families and 110 children completed at least one legal plan.

Table 10

Completed goals by child

Goal	Frequency
Adoption	4
Standby guardianship	23
Guardianship	40
Successor guardianship	5
Paternity	5
Wills	47
Adult guardianship	1
TOTAL	125*

* some children had multiple goals completed

Note that having a legal plan in place, in many instances, did not end the family's work with the program. Some families continued to receive aftercare services --- services to support the plan. Other families attained multiple, sequential goals, e.g. stand-by guardianship, guardianship, and successor guardianship.

Of the 24 birth parents who died during Phase II, 17 secured at least one legal plan with the Project. For their initial goal, six birth parents completed stand-by guardianships, three birth parents completed paternity, and eight birth parents completed guardianships with the new caregiver as the birth parent was too ill at intake to care for the children. For four of the six birth parents who completed stand-by guardianships, the Project also completed guardianships for the new caregiver at the parent's death. One of those four continued to plan, with the caregiver eventually completing a successor guardianship.

For the two birth parents who completed a stand-by guardianship and subsequently died, no additional plans were made. In one instance, the child being planned for turned 18 before the mother's death. That child, however, is living with the chosen caregiver. In the other instance, the stand-by guardian could not take on the care of the children at the parent's death; the children are now being cared for by a family friend who may pursue guardianship or adoption in the future.

Of the seven birth parents who died and did not secure a legal plan, two parents put a short-term guardianship in place. Although short-term guardianships are not permanent plans, they are significant steps towards a plan and a good indicator of the birth parent's choice for future caregiver.

Of those families who completed their first plan in Phase II, the mean amount of time involved with the Project was 1 year with the shortest time being 6 days and the longest 7 years.³ Half of the clients took 6 months or less to complete.

Outcome objective #2 Informal caregiver plans

Ninety-three families or 49% of families who were actively planning during Phase II put at least an informal plan in place; these families represented 177 children. For 38% or 67 of those children, an informal plan was the farthest step completed in the planning process; these children did not go on to have legal plans secured by the end of Phase II.

Outcome Objective #3 Post-completion stability of plan

Thirty-nine parents or caregivers were interviewed from 37 families. In two cases a parent died during the course of the study; the parent participated in the first interview and the person who took on the children's care participated in subsequent interviews.

Ninety-five (95) percent of the participants were female. Eighteen were parents and 21 were new caregivers. The average interview length was 20 minutes with the length of the telephone survey ranging from 10 to 30 minutes. The interviewees had completed a plan from 1 to 5.25 years prior to the interview with the mean time since securing a legal plan being 2.1 years.

³ Some clients who completed in Phase II began working with the Project in Phase I.

Table 13.
Race of Participants

African-American	67% (26)
White	28% (11)
Latino	5% (2)

Table 14.
Legal status to child

Custodial Parent	44% (17)
Non-Custodial Parent	3% (1)
Guardian	49% (19)
Adoptive Parent	5% (2)

Table 15.
Relationship to child

Mother	41% (16)
Father	3% (1)
Aunt	13% (5)
Friend	5% (2)
Adult Sibling	5% (2)
Maternal Grandmother	33% (13)

The participant's ages ranged from 24–74 years with a mean of 46 years. Sixty-nine children have been planned for with an average of 1.8 children planned for in each family. The children ranged in age from 2-19 years with a mean age of 11.8 years.

Table 16.
Goal Completed

	N=39
Guardianship	51% (20)
Standby Guardianship	39% (15)
Adoption	5% (2)
Paternity	3% (1)
Adult Guardianship	3% (1)

Most reported positive situations with the children in their care (children getting along with friends, children being funny, children helping around the house). A small percentage, however, reported disruptive behavior including children running away, having physical fights, destroying property, or shoplifting. Forty-two (42) percent of families indicated that someone from school had been in touch with them about their child's problem behavior in the last six (6) months and 35% reported that their child(ren) had temper tantrum during the last six months.

Thirty-two (32%) percent of families indicated that their income had decreased in the last six (6) months while only ten (10%) percent of the families had an increase in their income. Decreases were primarily associated with the loss of public benefits; increases were attributed to a raise in SSI payments.

More than half (60%) of the families indicated a need for financial assistance. The electric/heating bill (33%) and food (20%) were most often reported as the expenses for which parents or caregivers often lacked money. Doctor/medicine bills were of the least concern. Transportation (39%) and a homemaker (27%) were the other services that were most requested.

Thirty-one percent (31%) had been hospitalized in the last year, whether birth parent or caregiver, for medical or psychiatric reasons. Of those who had been hospitalized the number of hospitalizations ranged from one to six times with the average being two hospitalizations in the last year. Sixty-five percent reported health problems that limited what they did.

Slightly over half had felt overwhelmed in the last six months and had no one to help. The vast majority (94%), however, said that they had people to talk to when they needed and a large percentage (87%) used religion as a source of support.

All of the participants were still the legal guardian of the children. However, in six households or 16%, at least one of the children was currently living with someone else. Five of these participants were caregivers who had taken on the care of the children at the parent's death or debilitation but could no longer care for them; one was a parent who became too ill to care for

the child. Nine or 29% of the participants were considering changing their legal plans for the child, whether current caregivers moving the children out of their care or birth parents considering changing their designated stand-by guardian.

The Evaluation team has completed only a preliminary analysis of this data. The team plans to look in-depth at participants who were considering changing their plans to identify patterns that might inform service provision. Additionally, the team will employ Hierarchical Classes or HICLAS data analysis to examine patterns across plan status, household stability, well-being, and services for all participants.

Program Model (how does the program create change?)

Case studies

Three people participated in the case studies -- two birth parents (one male and two female) and 1 female current caregiver; All of the participants were African-American. The following synopses consolidate information from the first two interviews in Phase I, supplemented with data from an additional interview approximately four years later at the end of Phase II.

Ms. Stanton

Ms. Stanton was a 30-year-old African-American mother who lived with her seven children, 5 boys and 2 girls, and extended family members in a Chicago Housing Authority apartment. At the time of Interview 1 her children were ages 12, 9, 8, 7, 6, 5, and 3 years old. She was also caring for two other children, 9 years and 8 years. A friend of hers, who was also HIV positive, left the children behind after living with Ms. Stanton for a few months. Ms. Stanton was not taking any HIV medication, but reported that she felt fine. She made sure her second youngest child, who was HIV positive, visited the doctor routinely and took her medication. The other children in the family were not aware of Ms. Stanton's status and believed their sibling took medication to help her appetite. Ms. Stanton felt the children were too young to handle the information. At the time of Interview 1, Ms. Stanton had recently completed a standby guardianship with the help of a project attorney and social worker. She named her mother as the standby guardian for all seven of her children. Ms. Stanton believed her mother would need financial support and family counseling, but she trusted that her mother would be able to care for the children with the help of her husband, friends and Ms. Stanton's brother. The social worker continued to visit Ms. Stanton on a regular basis to help her work through the sadness and denial that she had about her child's diagnosis.

At the time of Interview 2, Ms. Stanton was 34 years old and her children were 16, 13, 12, 11, 10, 9, and 7 years. She had recently considered getting married but then changed her mind. Her oldest three children, all boys, were living with her brother. Her brother suggested that they live with him because they would "aggravate" her when she was sick. The children she had been caring for when she was first interviewed had gone back to live with their mother. Her sister-in-law and her children had moved out and a god-sister moved in with her two children, 2 and 1 years. Ms. Stanton's 53 year old mother was also living with her after having two heart attacks. The apartment was untidy and did not appear to have been cleaned recently. People walking through the room stepped over a puddle of spilled drink in the middle of the floor. Cockroaches were visible. Ms. Stanton was clearly irritated as family members or friends walked in and out of the apartment and into the room during the interview. By her own admission, Ms. Stanton had spent the previous night drinking and stated that she was "hung over." Ms. Stanton had entered substance abuse treatment earlier in the year and claimed that she no longer did drugs, but admitted that she drank on a weekly basis because it was something she enjoyed.

After her legal plan was complete, Ms. Stanton continued to work with the Project social worker on obtaining substance abuse treatment, returning to school, and keeping herself busy so she did

not go through her “depression stage.” She often felt sick and did not want to get out of bed. Earlier in the year she lost her best friend and this loss was clearly difficult and had a great impact on Ms. Stanton. She felt as if she no longer had anyone to talk to about her status, especially since another good friend of hers was employed and not readily available.

Ms. Stanton believed that her 16 year old son “kinda” knew about her status because he constantly checked up on her and called to make sure his sister took her medication. Ms. Stanton thought he may have found out from her brother but still found it “tough” to have a conversation with him about her status. She felt the other children were still too young to know. Ms. Stanton no longer felt her mother was the best person to care for her children due to her health. Throughout Interview 1 and 2 Ms. Stanton was adamant about all of her children remaining together. She felt her brother and sister-in-law would be the best choice since some of the children were currently living with them. She also thought her oldest son could be a possibility in the future and felt he would do a good job at parenting since he often helps out with the younger children. Ms. Stanton agreed that she would have to be honest with him about her status and the status of his sister if that were to happen. A family meeting was planned for the following month to determine what would be best for the children.

Even though she did not openly discuss her status with her children, Ms. Stanton was currently attending an HIV prevention with her daughters. The class was offered for mothers and daughters in the housing project where she lived. She liked the class because it kept her “mind off stuff.” She taught one class session and received positive feedback but did not reveal her HIV status. Ms. Stanton felt extremely positive about the work she did with the project and did not regret naming her mother as a standby guardian. She felt she was the best person at the time and thought it was helpful to plan for her children. Once a final decision was made regarding a new guardian, Ms. Stanton planned to work with the project attorney to name a new standby guardian for her children.

Mr. Moore

Mr. Moore was a 54-year-old African-American father who lived with his two children in a residential facility for people with HIV. At the time of Interview 1 his daughter was 17 and his son was 15-years-old. Mr. Moore had raised his children on their own since their mother lost custody of them when they were ages two and three. Their mother was also HIV positive and died in the early 90's. At the time of Interview 1, Mr. Moore was thinking about moving because there had been numerous deaths in his residential facility and he was concerned about the impact it had on his children. The lack of privacy and confidentiality was another concern for him and his family. Mr. Moore had been involved with the Family Options project for 3 years and wanted to name his brother as the standby guardian of his two children. He worked with the social worker on this plan but had difficulty following through with the attorney to finalize his plan legally. He felt at ease discussing his feelings with the Project social worker but had difficulty discussing the possibility of death with his children.

At the time of Interview 2, Mr. Moore was 58 years old and his children were 21 and 20 years. They had moved into a home that Mr. Moore had purchased two years prior. The home was on the south side of Chicago and was across the street from his brother. The home was well furnished and extremely neat. He decided to move out of the residential facility because staff turnover was high and there were new rules and regulations that he felt residents did not have a say in. Mr. Moore was visibly ill during the interview and appeared very tired. He stated that he

had numerous medical conditions and had just gotten out of bed before the interview began. His daughter was very attentive to his needs and made sure he had everything he needed during the interview. Mr. Moore explained that she is very concerned about his health and takes care of him all the time. His daughter was attending college and had recently obtained employment. His son was not in school or employed but Mr. Moore had hopes that he would find employment soon. The family had not been involved with the project and since the children were over the ages of 18 Mr. Moore no longer needed to secure a legal plan. He periodically ran in to the project social worker when he lived at the residential facility and was invited to retreats.

Mr. Moore and his family appeared to have a considerable amount of support. Since his brother lived directly across the street, they had frequent contact. Other extended family members visited often, especially for birthday celebrations. The family has been involved with the same church for the past 13 years. Mr. Moore was a deacon and volunteered his time driving members to church and helping out at the food pantry. The family was familiar with the neighborhood and had gotten to know and like many of the neighbors. Mr. Moore also had a personal assistant that provided a tremendous amount of assistance and support to the family. Aside from his personal assistant, his family was the only ones who knew of Mr. Moore's HIV status. Since he has had very few positive reactions when disclosing his status, Mr. Moore felt it was best to keep it a secret from most people. His brother, personal assistant, and doctor were the only people he felt comfortable discussing his health with. He had a hard time talking with his children about his health because "they get too emotional about it." Although his children were over the age of eighteen Mr. Moore still believed they were too young to be on their own should anything happen to him. "They are older but they are not adults by a long shot." Even though the family had difficulty discussing his health and future plans, he stated that his children knew their uncle would be there for them.

Ms. Vance

Mrs. Vance was a mother of eleven and grandmother and great-grandmother of over 35 children. She lived in Chicago Housing Authority subsidized housing with her daughter Angela, her son Charles, 6 grandchildren, and one great-grandson. She had moved into her present household two years prior when her daughter Ramona became ill to care for her four children, ages 16, 13, and 11 (twins). Mrs. Vance provided care for her HIV positive daughter up until the time Ramona died in April of 2000. Her daughter refused to discuss planning options and the future care of her children while she was alive. After her death, an HIV medical treatment center referred her to the project so she could make legal plans for the future care of her grandchildren. Initially, Mrs. Vance had planned on taking guardianship of all four children. There was some discussion about the 13-year-old granddaughter going to live with an aunt before it was eventually decided that she would stay with her grandmother and visit her aunt on the weekends. Not too long after that, her grandson went to live with his father. With the assistance of the project social worker and attorney, Mrs. Vance completed a guardianship for her 3 granddaughters. She continued to receive services from the social worker and participated in retreats offered by the project.

Interview 2 took place four years later. Mrs. Vance had recently celebrated her sixty-fourth birthday with a Wild Wild West theme party thrown by her family. She still lived in the same home and it was filled with pictures of family. Although space was very tight, it was neat and tidy. The grandchildren she had planned for were now 20, 17, and 15 (twins). The oldest

grandchild was still living with his father and had become a father to four children. The oldest grand-daughter that she had guardianship of was now 17 and was no longer living in her home, although she was still her legal guardian. There had been a tremendous amount of conflict between this child and Mrs. Vance. She had a child of her own at age 15 and went to stay with her aunt. Mrs. Vance was not exactly sure what happened but reported that her aunt kept her granddaughter's baby and "put her out." She came back to her grandmother's home before deciding to join a military school. Her son is 2 years old and she plans to regain custody of him when she finishes school and turns 18. The twins are sophomores in high school and Mrs. Vance describes them as very different from each other. One is athletic and likes to play basketball while the other one likes "fixing herself up." Mrs. Vance felt that they got along just like most families and stated that they did not talk about their mother's death or illness at all.

There were several other changes in Mrs. Vance's life since Interview 1 in 2000. Mrs. Vance began caring for two of her great-grandchildren, ages four and three, after a granddaughter that she raised left them with her. She did not have guardianship of them, but had obtained a medical card and food stamps for them. Mrs. Vance wanted to help her granddaughter out but was hoping that she would be able to resume care of her young boys soon. Raising a four and three year old has been difficult at her age. Mrs. Vance also felt that she had raised enough children and was looking forward to enjoying her life.

She had recently joined a group for senior citizens raising grandchildren. The group provided support and education as well as concrete assistance such as vouchers for beds and furniture. There was also a separate group for the children that allowed them to talk about stress they had in their lives. It was obvious that Mrs. Vance found the group to be very helpful. She had a book from the group that she referred to whenever she was feeling stressed out for tips on how to control it.

Mrs. Vance had not been using the project services at the time of Interview Two. She expressed some disappointment about not working with the project social worker anymore and was concerned that the social worker was angry with her. Mrs. Vance did not agree with her granddaughter living with her aunt and felt the social worker went over her head⁴ when she helped this granddaughter move in with her. Mrs. Vance periodically attended project retreats and participated in client satisfaction focus groups.

Delineation of social work intervention

The results of the analysis are presented below under the two major categories: content and methods. The themes under each category are listed in the order of frequency with each item representing a theme stated at least 10 times in the progress notes. The themes are not mutually exclusive; responses could fit under several different themes. The findings are presented in table format and followed by a description and examples.

Content covered

Content was defined as the subject matter or topic for discussion – *what* the social worker and birth parent talked *about* in the session. Earlier in the program’s history, topics discussed in social work contacts were documented on an ongoing basis using a checklist developed by the social workers and the researchers. This study was intended to expand and add depth to the previous findings as the content emerged from descriptions of the actual work, rather than from a pre-selected list.

Table 11
Content covered in contacts

- Physical and mental health
- Relationships with extended family, partners, friends
- Parent/child relationship
- Planning
- Service Use
- Substance abuse
- Loss/adjustment to change

Methods Used

Methods were the procedures or courses of action used by the social worker during the contact with the parent. The themes or categories of methods are presented in Table 2 and followed by a narrative describing the categories and some examples.

⁴ The social worker contacted the state child welfare system to facilitate the granddaughter’s placement with the aunt; the social worker considered this best for the child.

Table 12.

Methods used by the social workers

- Making connections for clients
- Generating and exploring options
- Encouraging action and making recommendations
- Providing information, referral, and advocacy
- Providing emotional and concrete support
- Follow-up and ongoing assessment

The social workers relied heavily on methods that examined the parent's problems and their consequences and looked at the alternatives for resolving the problems. Social workers encouraged parents to think through and explore the different aspects of the problem while making connections between the problem, its causes, and its impact on the client and family. Then they searched with the client for the means to solve it by generating options and exploring the consequences of those various courses of action. While breaking the problem down, the workers were also modeling problem-solving skills and, through the client's active involvement in the process, developing the client's capacity to problem solve. Small steps can have a great impact for families in the present while developing the parent's capacity to solve problems in the future.

The content areas covered by the workers and parents emphasized family, specifically the parent/child relationship and relationships with extended family. Planning for children is done within the context of family. For example, a child who is seen as difficult may complicate planning. Family issues become an additional factor as, in the majority of instances, relatives

become the caregivers for HIV-affected children after the parent's death. Disclosure within the family may exacerbate conflict, further complicating the process. The content described by the social workers was also particular to parents who are challenged by the multiple stressors and stigmas of race, class, gender, substance abuse, death, and HIV/AIDS.

Summary of Findings

The Family Options Project served primarily African-American women. This population is representative of women with HIV in the target area of Cook County and of the relative caregivers who often take on the care of the children. Most of the birth parents were also low-income. More than one-third of the birth parents had been involved with the state child welfare system during the last 20 years suggesting that these are families at risk for abuse and neglect.

Caregivers who sought Project services already had care of the HIV-affected children and were seeking help to formalize their care situation. Caregivers generally had more income than birth parents and encompassed a broader range of ages than birth parents, from older adolescents to the elderly.

The clients came to the Project with a variety of legal goals, some being permanency options and some that supported family stability or facilitated planning. Stand-by guardianship was the permanency goal that the largest percentage of birth parents selected at intake. When a plan was completed, the average time to completion was one year. Some clients, however, took years or had still not completed at the end of Phase II.

The majority of social work contacts included the provision of supportive counseling to the birth parent, children, and/or caregiver. Adult and child mental health, medical issues, and family conflict were the most discussed topics. Similarly, a percentage of birth parents and caregivers made legal plans but also needed legal assistance that promoted the family's stability such as public benefits or housing or laid a foundation for legal planning such as paternity.

The clients identified ensuring a smooth transition for their children and having a choice in their future as the main benefits of the services. Although not necessarily lacking family networks, clients often reported having “someone to listen to them” and to talk with them about difficult issues as a valued service that they received. Clients enjoyed the opportunities to meet with their peers during social occasions but also looked for more formal opportunities, such as groups, to talk with others about planning and family issues.

The Project did not reach its objectives of number of people served or number who secured goals (see Results section for more detail). Fewer people were served in Phase II than expected. A new component of the program –informal caregiver plans – documented an important step for families, especially those who did not secure a legal plan.

Staff provided intensive services to the active clients and were challenged to remain focused on Project goals, considering the families’ multiple needs, such as mental health, family issues, and medical concerns. The post-completion study suggests that even when legal goals were secured, a year or two later a substantial percentage of plans were not being implemented as originally conceived.

VI. LESSONS LEARNED

1. Ongoing and aggressive outreach and development of the client base is key to program success. For the first two years of Phase II, the Project Coordinator developed and implemented the outreach plan and acted as liaison with HIV/AIDS service organizations. Rather than limiting outreach to the beginning of the program, client outreach should be seen as ongoing and a significant portion of a staff person's time dedicated to this component. An extended and targeted outreach plan should include Project staff availability at key referral agencies and education to consumers and service providers.

2. Focused treatment plans and ongoing assessment of progress towards family goals are essential to the planning process. In Phase I, the Project learned that as people with HIV live longer, a parent may make a plan but not have to implement it for years. Meanwhile families face constant challenges to family preservation and stability. The mental health, family conflict, and practical needs were best addressed before or concurrently with planning, not only to facilitate planning but to support them now. This broader emphasis on stability along with planning could improve children's opportunities for continuity and predictability while living with their parent, as well as after the parent's death.

This approach demanded a great deal of flexibility from staff. In Phase II, staff found that flexibility contributed to a lack of treatment focus, evoking feelings of frustration for clients and staff alike. Due to the long-term in-home supportive counseling, social workers were often perceived as extended family. While this relationship may have been comfortable for families, the process benefited from focused, explicit, and realistic treatment goals with ongoing discussion with clients about progress. Supervision provided feedback and support for addressing lack of progress with clients, making decisions about the disposition of clients if no longer appropriate for services, and supporting staff experiencing burnout.

3. Custody planning services may be more effective provided in the context of an HIV family centered program. These services should incorporate key components of the Family Options model: 1) combined legal and social services; 2) highly trained staff -- clinically and regarding planning issues; and 3) program outcomes that target custody planning. As a part of an HIV/AIDS service organization, planning services could be offered periodically to clients and as part of a continuum of services. Outreach would not be as time-consuming. In addition, families would have relatively seamless access to services that address stability, such as mental health or concrete needs, and service coordination would happen internally, rather than between several service providers.

4. Children's grief and loss issues deserve more attention. Whether before or after mother's death, the children served in the Project had multiple losses, experienced or anticipated, that put them at-risk for poor mental health and conduct problems.

5. Adult mental health, especially depression, was a major concern for birth parents and caregivers. Severe depression, like substance abuse, may be outside the scope of a custody planning and family stability program. Those issues, however, need to be addressed through referral, linkages with agencies, or the development of services that are HIV-sensitive and culturally appropriate.

APPENDICES**Children and Loss****Barriers Checklist****Stages of Planning Chart
Logic Model****Legal Options and Benefits Chart**

CHILDREN AND LOSS

What do children need when they've had a significant loss in their lives?

1. They need information about what happened and why it happened.
2. They need to be able to feel all of their feelings in a safe and protected environment with someone they trust.
3. They need to be able to remember the person or thing that they lost and to be able to celebrate who or what that was in their lives.
4. They need to be able to go on with their lives, to feel safe and whole and loved.

A note of thanks to Cathy Blanford for the attached materials.
She has been our guide and mentor in helping families deal with children's loss.

PATIENTS' CHILDREN HAVE SPECIAL NEEDS

When cancer or any life-threatening illness hits a family, children and teenagers have special problems. Parental debate over when and how much to tell the children, disruption of normal household activity, physical changes in a loved one...all add to the tension of a family already burdened. Parent and Child Guidance Center in Pittsburgh, PA, a group that works with children of chronically ill parents, offers the following helpful suggestions for families:

- ♣ Take time to listen to the child's feelings. Accept them for they are real. Don't try to talk him or her out of them or deny them.
- ♣ Provide honest information at the child's level without frightening him or her. Answer all their questions. Fantasies can be scarier than reality.
- ♣ Understand that the child may need to ask the same questions over and over again many times.
- ♣ Recognize that the child may have worries about abandonment. "Will my other parent get sick, too?" "Who will take care of me?" Reassure the child that the healthy parent can and will provide care.... The best they can.
- ♣ Prepare the child about the effects of different medications on mom or dad.
- ♣ Older children can certainly help with the younger children but care should be taken that they are not given more responsibility than they are ready for or put in the role of a substitute parent.
- ♣ Find time to spend with the children. The ill parent will have some good hours. The healthy parent can set some priorities. Does it matter if the laundry doesn't get done today?
- ♣ Avoid making children feel guilty.
- ♣ Reassure children, younger ones especially, who get sick that they are not in danger of becoming as sick as mom or dad.
- ♣ Recognize the importance of play as a way for a young child to work on his or her feelings. Support it without interference.
- ♣ If the child has a creative and understanding teacher who knows the situation, the teacher may be able to devise some ways in the classroom to enable the child's classmates to understand and make him feel less isolated.

This information is provided by:
 Springfield, MO Make Today Count, Inc.
 National Office
 Make Today Count, Inc.
 P.O. Box 222
 Osage Beach, MO 65065
 Tel: (312) 348-1619

SYMPTOMS AND PSYCHOLOGICAL FIRST AID*

PRESCHOOL THROUGH SECOND GRADE

Response To Trauma	First Aid
<ol style="list-style-type: none"> 1. Helplessness and passivity <li style="padding-left: 40px;">2. Generalized fear 3. Cognitive confusion {e.g. do not understand that the danger is over} 4. Difficulty identifying what is bothering them. 5. Lack of verbalization-selective mutism, repetitive nonverbal traumatic play, unvoiced question 6. Attributing magical qualities to traumatic reminders. <li style="padding-left: 40px;">7. Sleep disturbances {night terrors and nightmares, fear of going to sleep, fear of being alone, especially at night} 8. Anxious attachment {clinging, not wanting to be away from parent, worrying about when parent is coming back, etc.} 9. Regressive symptoms {thumb sucking, enuresis, regressive speech} 10. Anxieties related to incomplete understanding about death: fantasies of "fixing up" the dead: expectations that a dead person will return, e.g., an assailant. 	<ol style="list-style-type: none"> 1. Provide support, rest, comfort, food, opportunity to play or draw. 2. Reestablish adult protected shield 3. Give repeated concrete classification for anticipated confusions. 4. Provide emotional labels for common reactions. 5. Help to verbalize general feelings and complains. {so they will not feel alone with their feelings} 6. Separate what happened from physical reminders. {e.g. a house, monkey-bars, parking lot} 7. Encourage them to let their parents and teachers know. 8. Provide consistent caretaking {e.g. assurance of being picked up from school, knowledge of caretaker's whereabouts} 9. Tolerate regressive symptoms in a time limited manner. 10. Give explanations about the physical reality of death.

*adapted from Pynoos RS, Nader, K: Psychological First Aid and Treatment Approach to children exposed to community violence: Research Implications Journal of Traumatic Stress 1(4) 445-473, 1988

SYMPTOMS AND PSYCHOLOGICAL FIRST AID*

THIRD THROUGH FIFTH GRADE

Response To Trauma	First Aid
<ol style="list-style-type: none"> 1. Preoccupation with their own actions during the event: issues of responsibility and guilt. 2. Specific fears, triggered by traumatic reminders 3. Retelling and replaying of the event {traumatic play} 4. Fear of being overwhelmed by their feelings {of crying, of being angry} 5. Impaired concentration and learning 6. Sleep disturbances {bad dreams, fear of sleeping alone} 7. Concerns about their own and other's safety 8. Altered and inconsistent behavior {e.g. unusually aggressive or reckless behavior, inhibitions} 9. Somatic complaints 10. Hesitation to disturb parent with own anxieties. 11. Concern for other victims and their families 12. Feeling disturbed, confused and frightened by their grief responses, fear of ghosts. 	<ol style="list-style-type: none"> 1. Help to express their secretive imaginings about the event. 2. Help to identify and articulate traumatic reminders and anxieties; encourage them not to generalize. 3. Permit them to talk and act it out; address distortions, and acknowledge normality of feeling and reactions. 4. Encourage expression of fear, anger, sadness, in your supportive presence. 5. Encourage to let teachers know when thoughts and feeling interfere with learning 6. Support them in reporting dreams, provide information about why we have bad dreams. 7. Help to share worries; reassure with realistic information. 8. Help to cope with the challenge to their own impulse control {e.g. acknowledge "It must be hard to feel so angry"} 9. Help identify the physical sensations they felt during the event and link when possible. 10. Offer to meet with children and parents(s) to help children let parents know how they are feeling. 11. Encourage constructive activities on behalf of the injured or deceased. 12. Help to retain positive memories as they work through the more intrusive traumatic memories.

SYMPTOMS AND PSYCHOLOGICAL FIRST AID*

ADOLESCENTS (Sixth Grade and up)

Response To Trauma	First Aid
<ol style="list-style-type: none"> 1. Detachment, shame, and guilt (similar to adult response) 2. Self-consciousness about their fears, sense of vulnerability, and other emotional responses; fear of being labeled abnormal. 3. Post-traumatic acting out behavior, e.g. drug use, delinquent behavior, sexual action out. 4. Life threatening reenactment; self-destructive or accident-prone behavior 5. Abrupt shifts in Interpersonal relationships. 6. Desires and plans to take revenge 7. Radical changes in life attitudes, which influence identity formations 8. Premature entrance into adulthood (e.g. leaving school or getting married), or reluctance to leave home. 	<ol style="list-style-type: none"> 1. Encourage discussion of the event, feelings about it, and realistic expectations of what could have been done. 2. Help them understand the adult nature of these feelings; encourage peer understanding and support. 3. Help to understand the acting out behavior as an effort to numb their responses to, or to voice their anger over, the event. 4. Address the impulse toward reckless behavior in the acute aftermath; link it to the challenge to impulse control associated with violence. 5. Discuss the expectable strain on relationships with family and peers 6. Elicit their actual plans of revenge; address the realistic consequences of these actions; encourage constructive alternatives that lesson the traumatic sense of helplessness 7. Link attitude changes to the event's impact. 8. Encourage postponing radical decisions in order to allow time to work through their responses to the event and to grieve.

Suggestions for Helping Yourself Through Grief *

1. Be gentle with yourself. Your body needs energy for repair.
2. Don't take on new responsibilities right away. Don't overextend. Keep decision making to a minimum for 1-6 months.
3. Accept help and support when offered.
4. Ask for help. It's okay to need comforting.
5. Get plenty of rest.
6. Seek support of others: visit a friend, try to meet new people.
7. Schedule comforting activities during particularly difficult times.
8. Allow yourself to feel the pain. Let the grief/healing process run its course.
9. Be patient with yourself. Healing takes time.
10. Remember that it is okay to feel depressed.
11. It is good to cry. You may feel better afterwards.
12. Read. There are many helpful books on grief. If grief is understood, it can be a little easier balanced.
13. Good nutrition is important to help the healing process. Decrease junk food and try to eat balanced meals.
14. Moderate exercise helps, such as walking, swimming, jogging and exercise classes. They help to work off frustration.
15. Keep a journal. It is a good way to understand what you are feeling and thinking.
16. Develop some new interests or take time for activities you enjoyed in the past.
17. Plan things to look forward to.

18. Do something for someone else. Call a friend and listen, spend time with a lonely person, reach out to a child, volunteer.
19. Remember that you will get better. Hold on to hope. Some days you may just hang on, but better days will be back. You will gradually develop a renewed sense of purpose.
20. It is okay to be angry. Don't push it down. Let it out: go to an open field and yell, hit a pillow, work it off. Talk about your anger with someone you trust.
21. Other ideas: take a hot, relaxing bath; sit in the sun; take time for yourself; go to a movie or watch TV; go out to dinner.
22. Do not have unrealistic expectations of yourself. Grief takes time. It comes and goes.
23. Put balance in your life: read, rest, work, play and get exercise and recreation.
24. Seek the help of a counselor or pastor if grief is unresolved.

* Ideas adapted from and based on Family Life Education, Harrison Diocesan Center, Syracuse, NY, and American Red Cross conference on traumatic stress counseling.

Barriers and Current Issues to Custody Planning.

Social Worker or Attorney _____

Client Type _____

Date _____

Client ID # _____

Instructions: To be completed by the social worker or attorney with the assessment.

Please check off all that apply to the client and client's potential caregiver.

Risks to Stability	Barriers to Planning	Primary Client
<input type="checkbox"/>	<input type="checkbox"/>	No safe or stable housing
<input type="checkbox"/>	<input type="checkbox"/>	Little or no income
<input type="checkbox"/>	<input type="checkbox"/>	No access to medical/ health care
<input type="checkbox"/>	<input type="checkbox"/>	Missing appointments due to poor health
<input type="checkbox"/>	<input type="checkbox"/>	Substance abuse
<input type="checkbox"/>	<input type="checkbox"/>	Child's other parent would not agree with plan
<input type="checkbox"/>	<input type="checkbox"/>	Does not want partner to know about his/her status
<input type="checkbox"/>	<input type="checkbox"/>	Family conflict about potential caregiver
<input type="checkbox"/>	<input type="checkbox"/>	Does not want to disclose status to family (potential caregiver, children etc)
<input type="checkbox"/>	<input type="checkbox"/>	Reluctant to talk to potential caregiver in fear that they will refuse
<input type="checkbox"/>	<input type="checkbox"/>	Does not want any legal involvement
<input type="checkbox"/>	<input type="checkbox"/>	Does not have any personal legal documents
<input type="checkbox"/>	<input type="checkbox"/>	Is undocumented
<input type="checkbox"/>	<input type="checkbox"/>	Does not have custody of children
<input type="checkbox"/>	<input type="checkbox"/>	Unable to consider thoughts of leaving children to another
<input type="checkbox"/>	<input type="checkbox"/>	No suitable/ appropriate potential caregiver was identified.
<input type="checkbox"/>	<input type="checkbox"/>	Chosen potential caregiver may be too old or too young
<input type="checkbox"/>	<input type="checkbox"/>	Cannot find someone to take all the children together Specify: _____
<input type="checkbox"/>	<input type="checkbox"/>	Belief system - (eg. Making plans is like giving up on children)
<input type="checkbox"/>	<input type="checkbox"/>	Just not ready - does not want to
<input type="checkbox"/>	<input type="checkbox"/>	Denial about impending death
<input type="checkbox"/>	<input type="checkbox"/>	Grieving (Family member's death LESS than 1 year ago)
<input type="checkbox"/>	<input type="checkbox"/>	Grieving (Family member's death MORE than 1 year ago)
<input type="checkbox"/>	<input type="checkbox"/>	Other _____

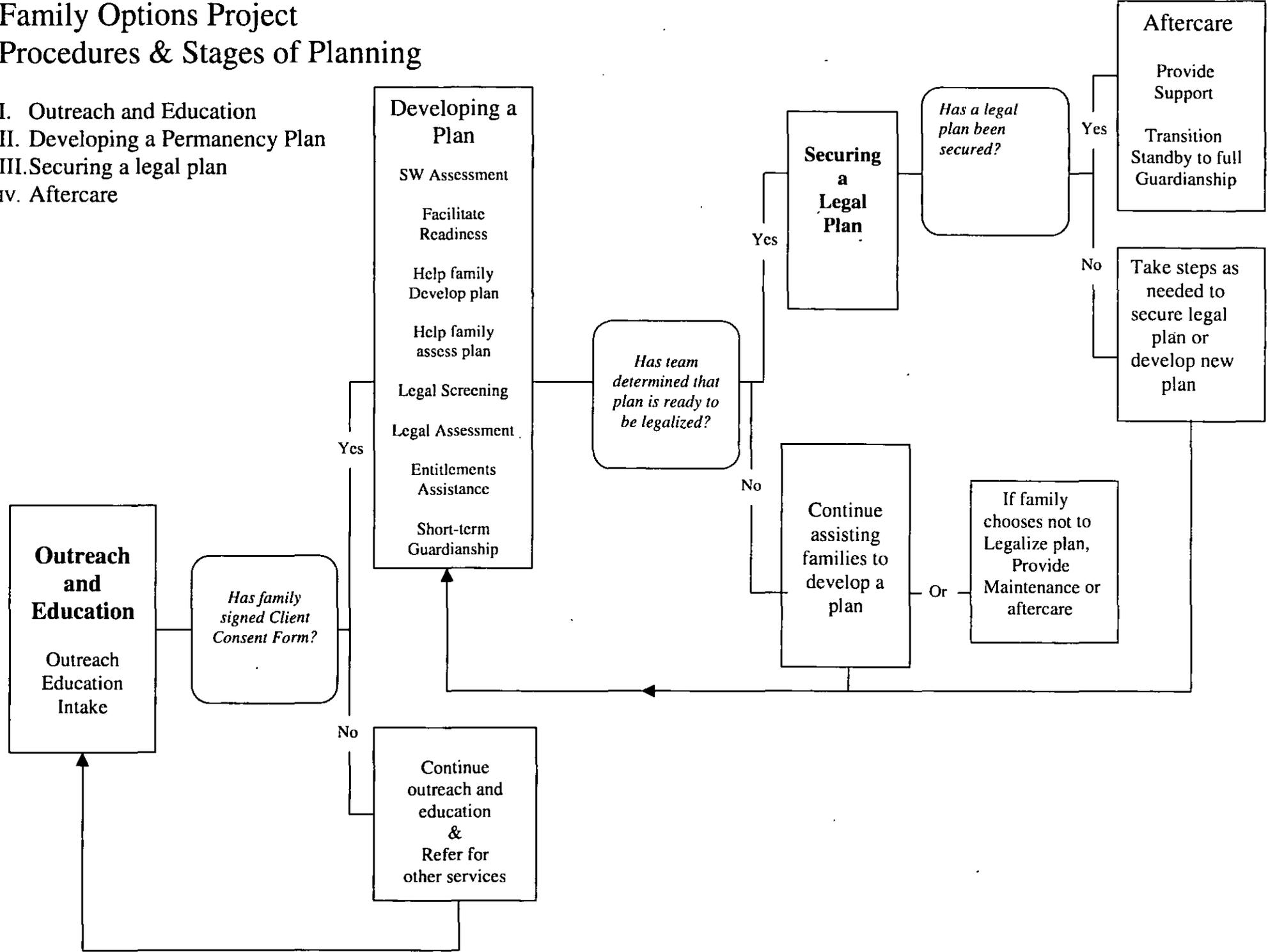
Risks to Stability	Barriers to Planning	Potential Caregiver(s)
<input type="checkbox"/>	<input type="checkbox"/>	No safe or stable housing
<input type="checkbox"/>	<input type="checkbox"/>	Does not have stable source of income
<input type="checkbox"/>	<input type="checkbox"/>	Inadequate / insufficient income
<input type="checkbox"/>	<input type="checkbox"/>	Substance abuse
<input type="checkbox"/>	<input type="checkbox"/>	Involved in past/present criminal justice system
<input type="checkbox"/>	<input type="checkbox"/>	Is undocumented
<input type="checkbox"/>	<input type="checkbox"/>	Grieving

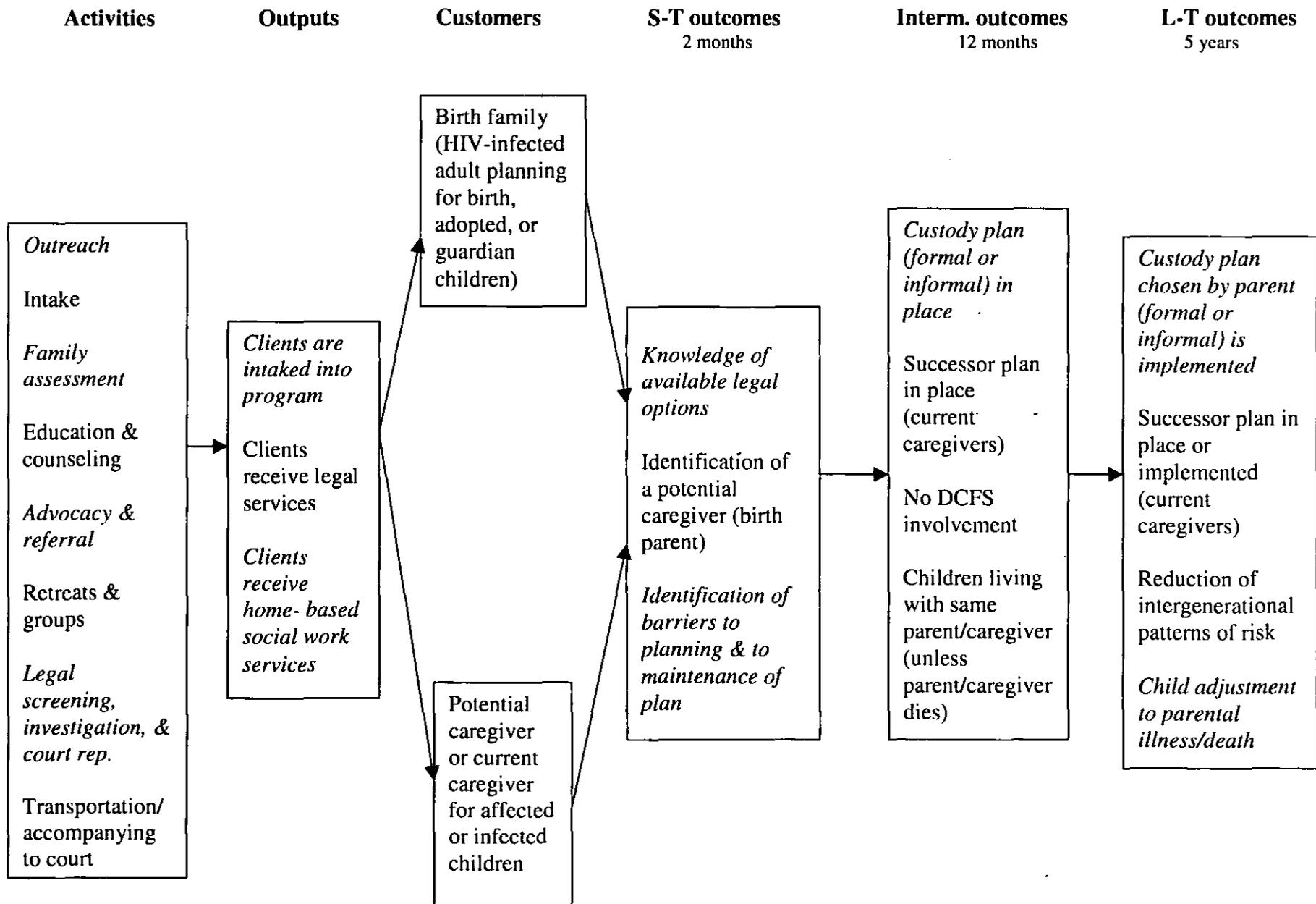
<input type="checkbox"/>	<input type="checkbox"/>	Other
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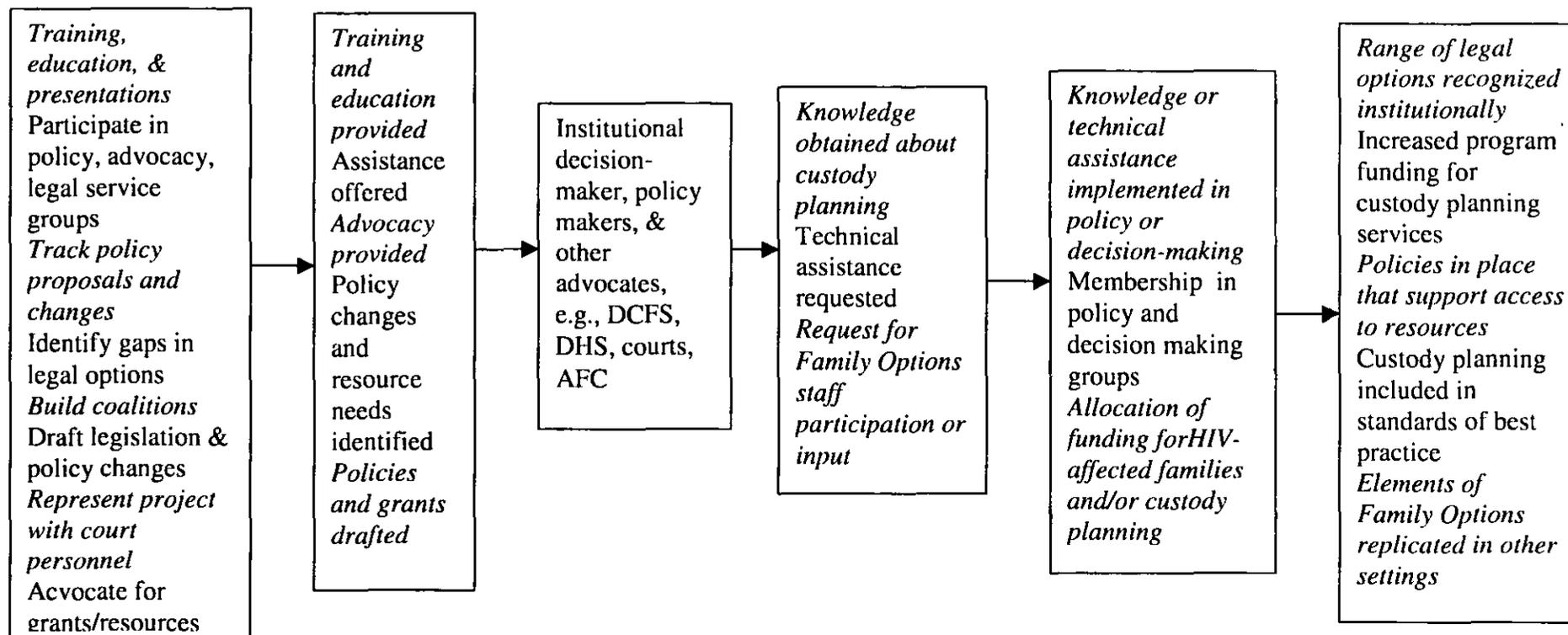
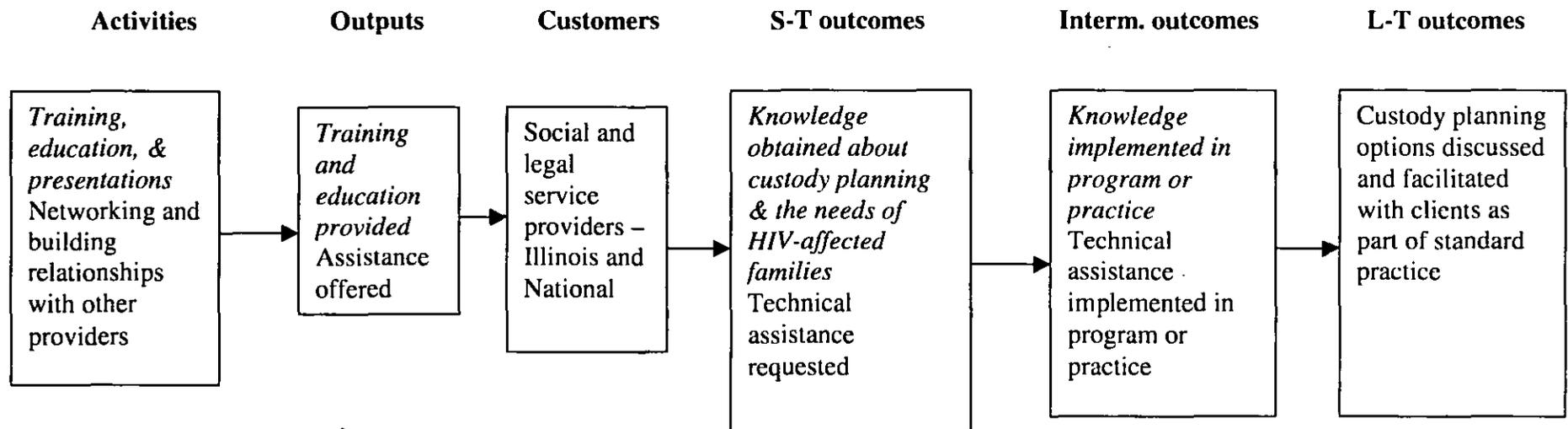
Additional Comments:

Family Options Project Procedures & Stages of Planning

- I. Outreach and Education
- II. Developing a Permanency Plan
- III. Securing a legal plan
- IV. Aftercare







**ILLINOIS LEGAL OPTIONS IN PERMANENCY PLANNING:
RESPONSIBILITIES AND RIGHTS OF GUARDIANS, ADOPTIVE PARENTS AND BIOLOGICAL PARENTS**

	LEGAL STATUS	DECISION MAKING	FINANCIAL RESPONSIBILITY	RELATIONSHIP WITH BIRTH PARENTS	CAREGIVER REQUIREMENTS
SUBSIDIZED PRIVATE GUARDIANSHIP: JUVENILE COURT	<ul style="list-style-type: none"> - Birth parents' rights are not terminated. - Guardian is given all the rights and responsibilities that had belonged to DCFS. - Child's case is closed in juvenile court. 	<ul style="list-style-type: none"> - Most major decisions are made by the guardian, but parents retain rights that include visitation with the child and the right to consent to adoption. 	<ul style="list-style-type: none"> - A subsidy is available which includes a cash payment, a medical card, and payments for nonrecurring expenses related to the transfer of guardianship, and other benefits. - The subsidized guardian may also apply for benefits on behalf of the minor. 	<ul style="list-style-type: none"> - Birth parent(s) has right to visit the child. The guardian will have input into how the visits are structured, but cannot prevent visits from occurring. - If the guardian and the parents cannot work out visitation, the court may order that visits take place on certain days, times, etc. 	<ul style="list-style-type: none"> - Relative or licensed foster parent. The relative or foster parent must have been caring for the child for at least one year, and the child must have been in state custody for at least one year. - The non-related caregiver (foster parent) must be seeking guardianship of a child at least 12 years of age.
STANDBY GUARDIANSHIP: PROBATE COURT	<ul style="list-style-type: none"> - Birth parents' rights are not terminated. - Standby guardian acts only when parent dies or is unable to make and carry out day-to-day child care decisions. (Standby status achieved only after parental designation followed by court appointment). 	<ul style="list-style-type: none"> - Until the standby guardian's duties are activated, parent(s) make all decisions. - Once duties are activated, most major decisions are made by guardian, but parents retain rights that include visitation with the child and the right to consent to adoption. 	<ul style="list-style-type: none"> - The standby guardian is not responsible for the care, custody and support of the minor until his/her duties are activated. - The standby guardian may also apply for benefits on behalf of the minor once duties are activated. 	<ul style="list-style-type: none"> - Standby guardian works in cooperation with the birth parent, and assumes duties only when birth parent dies or is unable to make and carry out day-to-day child care decisions. 	<ul style="list-style-type: none"> - Standby guardian must be at least 18 years of age and a resident of the United States, not adjudged disabled and have no felony convictions. Probate court also will want criminal background and may want child abuse/neglect check.
STANDBY ADOPTION: ADOPTION COURT	<ul style="list-style-type: none"> - Standby adoption is an adoption in which a terminally ill parent consents to custody and termination of parental rights to become effective upon the occurrence of the parent's death, or the parent's request that the adoption be finalized. - Parental rights of terminally ill parent preserved until birth parent dies or wants adoption finalized. Child's other parent may consent to adoption or rights may be otherwise terminated. - Standby adoptive parent acts only when birth parent dies or wants adoption finalized. 	<ul style="list-style-type: none"> - Until standby adoptive parent's duties are activated, birth parents make all the decisions. - Once duties are activated, standby adoptive parents become the legal parents of the child. 	<ul style="list-style-type: none"> - The standby adoptive parent is not responsible for care, custody, or support of the minor until his/her duties are activated. - Once duties are activated and the adoption is finalized, standby adoptive parent becomes completely financially responsible for the child. 	<ul style="list-style-type: none"> - Standby adoptive parent works in cooperation with the birth parent, and assumes duties only when birth parent dies or requests that the adoption be finalized. Once the adoption is finalized, the standby adoptive parent becomes the legal parent of the child. 	<ul style="list-style-type: none"> - Same as adoptive parent.
SHORT TERM GUARDIANSHIP	<ul style="list-style-type: none"> - Private agreement between parent(s) and person who agrees to act as short term guardian. Short term guardian 	<ul style="list-style-type: none"> - Until the short-term guardian's duties are activated, parent(s) make all decisions. - Once duties are activated, 	<ul style="list-style-type: none"> - The short term guardian is not responsible for the care, custody and control of the minor until his/her duties are 	<ul style="list-style-type: none"> - Short term guardian works in cooperation with the birth parent, and assumes duties only as specified by the 	<ul style="list-style-type: none"> - Short term guardian must be at least 18 years of age and a resident of the United States, not adjudged disabled and

	LEGAL STATUS	DECISION MAKING	FINANCIAL RESPONSIBILITY	RELATIONSHIP WITH BIRTH PARENTS	CAREGIVER REQUIREMENTS
	acts as guardian of the person only, not of estate. - Short term guardian acts <i>only as designated by parent, and only for maximum of 60 days</i> . Activation of duties may occur 1) on the date of the written short-term guardian appointment by the parent, or 2) at a specified later date or event as indicated by the parent in the appointment.	most major decisions are made by the short term guardian, but parents retain residual rights. The short term guardian may have the authority to act as guardian for the minor for a period of up to 60 days. Parent(s) may also decide to amend or revoke the appointment at any time.	activated. - The short term guardian may have the authority to act as guardian for the minor for a period of up to 60 days. The short term guardian may also apply for benefits on behalf of the minor once duties are activated.	parent(s) in making the short term guardianship appointment. - Activation of duties may occur 1) on the date of the written short-term guardian appointment by the parent, or 2) at a specified later date or event as indicated by the parent in the appointment. Parent(s) may amend or revoke the agreement at any time.	have no felony convictions.
GUARDIANSHIP: JUVENILE COURT	- If parental rights are not terminated, biological parents retain residual parental rights. If parental rights are terminated, parents have no legal rights. - Guardian (DCFS) has right to custody, educational, medical and other decisions. If parental rights terminated, guardian may consent to child's adoption - Child is a ward of the juvenile court.	- If parental rights are not terminated, most major decisions are made by DCFS, but parents retain rights that include visitation with the child and the right to consent to adoption. - If parental rights have been terminated, then birth parents have no legal rights, including no right to visit and no right to consent to adoption.	- DCFS is responsible for the care and support of the child. Birth parent(s) may be required to contribute. In most cases caregivers (licensed foster parents, relatives) receive some financial payment from DCFS.	- If parental rights are not terminated, birth parent(s) has the right to visit the child. DCFS can regulate how the visits are structured, but cannot prevent visits from occurring. Court may also order visits to be supervised. - If parental rights are terminated, parents have no rights to visitation.	- DCFS is guardian. Substitute caregivers, including foster parents, group homes and institutions, and relatives, must meet various licensing requirements as promulgated by DCFS.
GUARDIANSHIP: PROBATE COURT	- Birth parents' rights are not terminated. - Guardian has right to custody, educational, medical and other decisions.	- Most major decisions are made by guardian, but parents retain rights that include visitation with the child and the right to consent to adoption.	- The guardian is responsible for the care, custody and support of the minor. - The guardian may also apply for benefits on behalf of the minor.	- Birth parent(s) has right to visit the child. The guardian will have input into how the visits are structured, but cannot prevent visits from occurring. - If the guardian and the parents cannot work out visitation, the court may order that visits take place on certain days, times, etc.	- Guardian must be at least 18 years of age and a resident of the United States, not adjudged disabled and have no felony convictions. Probate court also will want criminal background and may want child abuse/neglect check.
ADOPTION: ADOPTION COURT	- Birth parents' rights terminated.. - Adoptive parent(s) has all rights and responsibilities formerly attributed to birth parents. - Adoption is a permanent legal relationship.	- All major decisions are made by the adoptive parent(s) i.e. school, medical treatment, religion, etc.)	- Adoptive parents are responsible for the care, custody and support of the minor. - If parental rights are terminated in Juvenile Court, in many cases adoption assistance is available. Adoption assistance includes a	- Adoptive parents have right to determine the type of relationship that the child will have with birth parent(s).	- Person under no legal disability who has resided in Illinois for continuous 6 month period immediately preceding commencement of the adoption proceeding, or member of the armed forces domiciled in Illinois for 90 days.

	LEGAL STATUS	DECISION MAKING	FINANCIAL RESPONSIBILITY	RELATIONSHIP WITH BIRTH PARENTS	CAREGIVER REQUIREMENTS
			cash payment, a medical card, and payments for nonrecurring expenses related to the adoption.		<ul style="list-style-type: none"> - Residence requirement does not apply to adoption of a related child or adoption of a child placed by an agency. - Must be of legal age and, if married, spouse must be a party to the adoption.

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Permanency Planning & Public Benefits in Illinois

Type of Caregiver	Cash Assistance	Medical Assistance	Food Stamps	Social Security
GENERAL ELIGIBILITY	To qualify for Temporary Assistance for Needy Families (TANF), a child must live with a "caregiver relative" ¹ who may be a parent or other relative. A child who lives with an unrelated adult is not eligible for TANF. If, however, the unrelated adult is the child's legal guardian, the family may be able to receive cash assistance through the General Assistance - Family and Children Assistance (GA-FCA) program. ²	TANF (Temporary Assistance for Needy Families) recipients are also entitled to Medicaid coverage. Children who are not eligible for Medicaid may be eligible for KidCare, which provides free or low cost health services to children whose families earn between 133% and 200% of the federal poverty level. Parents or relative caregivers caring for children may be eligible for low cost health services under FamilyCare if the household income is less than 49% of the federal poverty level.	Eligibility for Food Stamps is based on income standards and household size. A child can be included in the Food Stamp unit of a parent or a caregiver who is "in parental control" of the child. The child does not have to be related to the caregiver in order to be included in the household grant.	A child may be eligible for Supplemental Security Income (SSI) benefits if his or her physical or mental impairment(s) medically or functionally equal the severity of an impairment listed in Social Security's Listing of Impairments and the child is financially eligible. A child may not receive both SSI and TANF; however, an eligible adult whose child receives SSI may be able to receive a TANF adult-only grant. A representative payee can receive Social Security benefits on a child's behalf. An individual responsible for the care of the child may apply for Social Security benefits ³ on a child's behalf.

¹ A caretaker relative refers to an individual related to the child through blood, marriage, or adoption. This definition of "related" will be used throughout this chart.

² General Assistance (GA) is a state program for people who are ineligible for other cash assistance. Some (but not all) townships receive state aid to operate the GA program, as does the city of Chicago.

³ Social Security benefits include SSI benefits, survivor's benefits, and dependent's benefits.

INFORMAL CAREGIVER

An informal caregiver cares for a child but does not have legal responsibility to do so. It may be difficult for an informal caregiver to enroll a child in school or take the child to the doctor without proof of legal guardianship. The ease of obtaining benefits depends on whether the caregiver is related to the child in his/her care.

An informal caregiver who is *related* to the child being cared for may be able to receive Temporary Assistance for Needy Families (TANF) on the child's behalf, either by adding the child to an existing TANF family grant or by applying for a TANF child-only grant.

An informal caregiver who is *not related* to the child being cared for will not be able to obtain cash benefits on the child's behalf without establishing legal guardianship, in which case the caregiver might be eligible to receive GA-FCA on the child's behalf.

An informal caregiver who is *related* to the child can obtain a medical card for a child in his/her care if the child is eligible for Medicaid. The caregiver can apply for medical assistance through KidCare on behalf of a child who is not eligible for Medicaid if the child's income is between 133% and 200% of the federal poverty level. The caregiver may also obtain low cost health services under FamilyCare if the household income is less than 49% of the federal poverty level.

An informal caregiver who is *not related* to the child can also apply for KidCare on the child's behalf.

A child living with an informal caregiver who is "in parental control" of the child can be included in the household's Food Stamp unit as long as the family is otherwise eligible.

An informal caregiver may be able to become a representative payee for a child in his/her care who is already receiving Social Security benefits. An informal caregiver can also apply for disability benefits on behalf of a child who may be eligible.

SHORT-TERM GUARDIAN

A short-term guardian is someone appointed by a parent or legal guardian to act as guardian⁴ of the child. Parents/legal guardians can arrange short-term guardianship through a private, written agreement with the designated short-term guardian. This arrangement does not have to be approved by the court but can be reviewed.

If a child is already receiving cash assistance, a short-term guardian and the parent should decide whether transferring cash benefits to the short-term guardianship is appropriate given the length of time that the child will be cared for by the short-term guardian. If the short-term guardian cares for the child for an extended period of time, this change in the child's placement can be reported to the local public aid office to facilitate the transfer of cash benefits.⁵

If the child has a medical card, the short-term guardian may want access to that card in order to ensure that the child gets appropriate medical care. If the child does not have a medical card, the short-term guardian may be able to apply for medical assistance on the child's behalf. (Please keep in mind footnote 5.)

A short-term guardian may be able to include the child in household's food stamp unit when caring for the child as long as the family is otherwise eligible. Child cannot be included in the parent's food stamp unit, & the families must report changes in the household make-up to the local public aid office. Whether or not to do so is a decision that should be made by both the parent and the short-term guardian.

A short-term guardian who is currently caring for a child may be able to become a representative payee for a child who is currently receiving Social Security benefits with the parent or legal guardian's consent. The short-term guardian may also apply for benefits on a child's behalf if the child is eligible.

⁴ The short-term guardian is able to make decisions for the child that are normally made by the parent for up to 60 days for each short-term guardianship form completed.

⁵ Please keep in mind that some Public Aid local offices will not transfer benefits to a short-term guardian that is not a relative caregiver and require legal guardianship.

<p>STANDBY GUARDIAN</p> <p>A standby guardian is someone who is designated by a parent or legal guardian and appointed by the court to "standby"; in other words, to take care of the child some time in the future. A standby guardian agrees to serve as legal guardian when parents or the legal guardian die or are no longer able to care for the child.</p>	<p>A standby guardian who currently lives with the child and is caring for a child may be able to obtain cash benefits as described in the informal caregiver section above.</p> <p>A standby guardian who does not currently live with the child cannot receive Temporary Assistance for Needy Families (TANF) on a child's behalf until the standby guardianship is activated either by the parent or legal caregiver's death or the parent or legal caregiver's inability to care for the child. Once activated, the standby acts as legal guardian of the child for 60 days after the activating event. The standby guardian will likely be eligible to receive cash benefits on the child's behalf at this time. See Legal Guardian Cash Assistance below.</p>	<p>A standby guardian who currently lives with the child and is caring for a child may be able to obtain medical assistance for a child as described in the informal caregiver section above.</p> <p>A standby guardian who does not currently live with the child cannot access medical assistance on the child's behalf until the standby guardianship is activated and the standby guardian becomes the child's caregiver. See Legal Guardian Cash Assistance below.</p>	<p>A standby guardian who currently lives with the child and is caring for a child may be able to obtain food stamps for a child as described in the informal caregiver section above.</p> <p>A standby guardian cannot receive food stamps on a child's behalf until the standby guardianship is activated and the child is living in the standby's household. The standby can then add the child to an existing food stamp unit or apply for food stamps if the household income (with the child) makes the household eligible.</p>	<p>A standby guardian who currently lives with the child and is caring for a child may be able to become a representative payee for a child who is currently receiving Social Security benefits. A standby guardian who has <i>custody</i> of a child and is caring for a child may also apply for benefits on a child's behalf if the child is eligible.</p> <p>A standby guardian who does <i>not</i> currently live with the child may not apply for benefits on the child's behalf. The standby guardian may act as representative payee for existing benefits if no other adult with custody of the child is able or willing to act.</p>
<p>LEGAL GUARDIAN</p> <p>A legal guardian is a private caregiver who has been approved by the court to act as legal guardian for the child in terms of care, custody, and supervision. Legal guardianship does not expire until the child reaches the age of majority or the guardianship is terminated by the court.</p>	<p>Legal guardians who are <i>related</i> to the child in their care may be able to receive Temporary Assistance for Needy Families (TANF) on behalf of the child, either by adding the child to an existing TANF family grant or by applying for a TANF child-only grant.</p> <p>An <i>unrelated</i> legal guardian cannot receive TANF on the child's behalf; however, this person may qualify to receive General Assistance - Family and Children's Assistance for the child if otherwise eligible.⁶</p>	<p>A legal guardian should be able to obtain medical assistance for the child in his/her care if the child is income eligible for Medicaid or KidCare. A legal guardian can also apply for coverage on the child's behalf.</p>	<p>A child living with a legal guardian can be included in the family's existing food stamp household unit as long as the family remains income eligible. The guardian can apply for food stamps for the household if the household was not previously eligible for benefits but is now eligible with the additional child.</p>	<p>A legal guardian can be named representative payee for a child in his/her care who is already receiving Social Security benefits. A legal guardian can also apply for disability benefits on behalf of a child who may be eligible.</p>

⁶ See footnote 2.

<p>STANDBY ADOPTIVE PARENT</p> <p>A standby adoptive parent is designated by a parent and appointed by the court to "stand by" and adopt the parent's child at some future time, so the adoption is finalized at the parent's death or upon the parent's request that the adoption be finalized.</p>	<p>A standby adoptive parent who currently lives with the child and is caring for a child may be able to obtain cash benefits as described in the informal caregiver section above.</p> <p>A standby adoptive parent who does <i>not</i> live with the child generally cannot receive Temporary Assistance for Needy Families (TANF) on behalf of a child until the adoption of the child is finalized either after the parent's death or when the parent voluntarily surrenders his/her rights. After the adoption is finalized, the adoptive parent becomes the child's legal parent and is entitled to receive TANF for the child if the household is eligible.</p>	<p>A standby adoptive parent who currently lives with the child and is caring for a child may be able to obtain medical assistance for a child as described in the informal caregiver section above.</p> <p>A standby adoptive parent who does <i>not</i> live with the child cannot obtain medical assistance for the child until the adoption of the child is finalized, either after the parent's death or voluntary surrender of parental rights.</p>	<p>A standby adoptive parent who currently lives with the child and is caring for a child may be able to obtain food stamps for a child as described in the informal caregiver section above.</p> <p>A standby adoptive parent who does <i>not</i> live with the child cannot include a child in his/her food stamp unit.</p>	<p>A standby adoptive parent who currently lives with the child and is caring for a child may be able to become a representative payee for a child who is currently receiving Social Security benefits. A standby guardian who has <i>custody</i> of a child and is caring for a child may also apply for benefits on a child's behalf if the child is eligible.</p> <p>A standby adoptive parent who does <i>not</i> currently live with the child cannot apply for Social Security benefits on a child's behalf. The standby adoptive parent may act as representative payee for existing benefits if no other adult with custody of the child is able or willing to act.</p>
<p>ADOPTIVE PARENT</p> <p>Adoption provides a higher degree of legal permanence of a child because it requires the termination of parental rights, or the death of the parents, and it lasts for life. In Illinois, an adoptive parent gains all legal rights and responsibilities for a child and legally becomes that child's parent.</p>	<p>Once an adoption is finalized, an adoptive parent can include an adoptive child in any cash assistance grant the family is receiving just as they would include any biological children in the assistance unit.</p>	<p>Once an adoption is finalized, an adoptive parent can apply for his/her child if the family is income eligible. The adoptive parent's income will be counted when determining eligibility for medical assistance such as Medicaid or KidCare.</p> <p>Once an adoption is finalized, the adoptive parent may also apply for low cost health services under FamilyCare if the household income is less than 49% of the federal poverty level.</p>	<p>Once an adoption is finalized, an adoptive parent can include the child in the family's household food stamp unit as long as the family is income eligible.</p>	<p>Once an adoption is finalized, an adoptive parent can become a representative payee for a child receiving Social Security benefits or can apply for children's Social Security benefits on the child's behalf.</p> <p>If the child is receiving survivor's or dependent's benefits from a natural parent's account before the adoption occurs, the benefits may continue. Depending on when an application for child's benefits is submitted, the child may receive benefits of the account of the natural or adoptive parent.</p>