

DEPARTMENT OF CHILD & FAMILY STUDIES
LOUIS DE LA PARTE FLORIDA MENTAL HEALTH INSTITUTE

A SYSTEM OF CARE FOR PERMANENCY PLANNING: CHILDREN AFFECTED BY HIV/AIDS

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EXECUTIVE SUMMARY

THE PERMANENCY PLANNING COMMITTEE

The Permanency Planning Committee, which formulated the initial idea for this critical issues analysis, is a sub-committee of the Banyan Adoption Consortium. The Consortium, developed by the Banyan Family Center at the Louis de la Parte Florida Mental Health Institute, is composed of professionals with an interest in special needs adoption. An off-shoot of that interest, shared by several Consortium members, was the plight of children whose parents or caregivers are afflicted with HIV/AIDS. The fate of these children, themselves not infected, but affected, is often in doubt, as their caregivers are reluctant to reveal their illness, or to make permanent plans for their children prior to death.

The Permanency Planning Committee studied the issue for nearly a year. In the spring of 1997, they decided to examine in greater depth the situations and needs of this often overlooked group of children. They concluded that a preliminary step to developing any proposal for effecting change in the lives of these children was to obtain more information about these children and answer the following questions: Who are they? What are their needs? What are their families' needs? How is the community meeting those needs? Are their caregivers making permanent plans for them; and, if not, why not? In order to be able to conduct a study of these issues, the group decided to seek a critical issues analysis grant from the Children's Board of Hillsborough County.

THE STUDY

The design of the study depended largely on primary sources: the infected caregivers of affected children. The analysis was composed of focus groups, one-on-one interviews, and surveys. With the exception of two focus groups of professionals familiar with HIV/AIDS, all of these methodologies relied on the caregivers and their children. This design seemed consonant with the purpose of the study: to analyze the permanency and support needs of children at risk of parental loss due to HIV/AIDS.

Recruitment of participants for the study required careful planning on the part of research staff, as well as extensive collaboration with community partners who work with HIV/AIDS victims. Due to the sensitivity of the subject, special effort was made to protect the confidentiality of those who agreed to be part of the study. Interviews and focus groups were scheduled at times and in locations convenient to participants, including in their homes. The study was also sensitive to culture and arranged interviews in Spanish for monolingual caregivers.

RESULTS OF THE STUDY

Results of the study indicated that there are a number of agencies and programs available to families dealing with HIV/AIDS. Primary among them are: Tampa AIDS Network (TAN), Francis House, Mercy House (a program of Catholic Charities), and Bay Area Legal Services. Other resources were mentioned as well. Caregivers seemed generally satisfied with the services they received. Some, however, did not seek outside help, either because they did not know what services were available, or because they feared discovery of their illness if they were to be seen at an agency. The stigma associated with HIV/AIDS creates

fear and distrust among the afflicted, which inhibits their ability to reach out for help, from formal or informal sources.

When participants did express dissatisfaction with community services, they often blamed reduction in funding for the loss of programs, such as counseling for children or group sessions for adolescents. They also commented on difficulties accessing services due to transportation and childcare needs.

Results of the analysis further indicated that participants were about evenly divided between caregivers who had disclosed their illness to their children and those who had not done so. Reasons given for not telling included: young age of child, fear of rejection, desire not to burden child, and lack of knowledge of how or if to inform the child.

Data on permanency planning revealed that overall the caregivers in the study had not made legal, formal, written plans for their children's care following their deaths. For example, only five of 25, or 20%, of interviewees had made legal plans. Some had made informal, verbal arrangements with friends or relatives; very few had made no plan of any kind. Caregivers were often unaware of the importance of permanency plans, or hoped they would never need one. If they did recognize the need, they often did not know how to make those arrangements.

ACTION PLAN

The foundation piece for the Action Plan which has resulted from this analysis is a Coalition of stakeholders that will be responsible for implementing major portions of the Plan. The research team from the Louis de la Parte Institute will take the lead in convening the Coalition, which will include family members affected and infected by HIV/AIDS, as well as agencies: Tampa AIDS Network, Francis House, Mercy House, Family Enrichment Center, Bay Area Legal Services, and other community partners. The Coalition's mission will be to create, initiate, organize and oversee a system of care to address the needs of affected children and their infected caregivers. This responsibility may include identifying funding opportunities.

The system of care which has emerged from this analysis includes four service areas: Education, Legal, Mental Health, and Social Supports. In each area the plan utilizes a culturally competent, strength-based, family-centered, and community-based approach. The areas and action steps are summarized as follows:

EDUCATION

Results: There is a need for comprehensive education about HIV/AIDS for the general public, pre-adolescents and teens, and extended family members who are affected by the disease.

Action Steps: *Members of the Coalition will develop a comprehensive training and education plan that will include: a county-wide AIDS Awareness campaign for the general public; development of mechanisms to disseminate HIV/AIDS information in schools as well as other community sites where adolescents congregate; provision of in-home and community-based education for extended family members; and organization of a conference for affected and infected family members. Caregivers will be utilized as speakers and for peer training of family members.*

Results: There is a need for agencies to demonstrate greater sensitivity with regard to culture, gender, and ethnicity.

Action Steps: *The Coalition of Stakeholders will generate a plan to increase cultural sensitivity among agency personnel by: utilizing the expertise of the Louis de la Parte Institute and TAN in conducting training; facilitating focus groups with family members to identify relevant*

cultural, gender and ethnic issues; and encouraging efforts to increase diverse representation among service providers.

Results: There is a need for more consistent dissemination of information regarding issues related to HIV/AIDS.

Action Plan: *The Coalition along with community partners will facilitate efforts to improve dissemination of information that is uniform and consistent to individuals who have HIV/AIDS; and will encourage providers to train staff to provide complete information in a timely manner.*

LEGAL SERVICES

Results: Overall caregivers in this study did not have legal, formal, written permanency plans for their children.

Action Steps: *The Coalition will develop strategies to increase availability of legal services to caregivers infected by HIV/AIDS.* These strategies may require identifying funding opportunities, and/or organizing volunteers. The Coalition will promote: the increase in the number of legal professionals who can assist caregivers in permanency planning; more in-home and community-based legal assistance; parent training on the facts about permanency planning, conducted by legal experts, at various sites in the area; design and circulation of a family-friendly brochure regarding permanency planning, which will include a list of resources; and funding for legal expenses for permanency planning for low-income caregivers.

MENTAL HEALTH SERVICES

Results: There is a need for more consistent counseling, therapeutic and mental health services for primary caregivers, affected children/adolescents, extended family members, and others affected by HIV/AIDS

Action Steps: *Members of the Coalition will collaborate with other community providers to offer enhanced mental health services:* providing a variety of in-home and community-based, family-centered and culturally sensitive mental health services for caregivers, utilizing peer support and interventions that will guide them in dealing with their children's responses to the illness; offering interventions appropriate to the developmental needs of children and adolescents; and developing forums where extended family members may share feelings and experiences and gain information.

SUPPORT SERVICES

Results: There is a need for more informal support that addresses the needs of infected caregivers and their affected children.

Action Steps: *The Coalition will develop a comprehensive plan to increase informal supports:* involving churches in the Coalition and encouraging them to offer supportive services and activities for these families; recruiting community volunteers to provide support for families; developing a "time-dollar" program for affected families to exchange volunteer time for services; and establishing a peer support group for primary caregivers who are infected with HIV/AIDS.

Results: Group and social activities are needed that will promote a sense of wellbeing among caregivers and their children.

Action Steps: *The Coalition will develop a plan and proactively seek opportunities for families to engage in activities unrelated to HIV/AIDS:* to arrange excursions to

museums, festivals, and other entertainment centers; to promote participation in recreational activities, such as teams and clubs; to recruit and train mentors to work with affected children; and to recruit volunteers from the peer support group and churches who will offer respite for caregivers.

Results: Lack of transportation is a barrier to accessing services for caregivers and children affected by HIV/AIDS.

Action Steps: *The Coalition will develop a program, which will require innovative planning as well as additional funding, to increase transportation options for families affected by HIV/AIDS.* The program may include: organizing carpools utilizing support group members; arranging “time-dollar” plans wherein caregivers may receive transportation in exchange for providing some type of service; soliciting donated taxi rides from local companies; and exploring the possibility of partial funding for vehicles for qualified caregivers.

Results: There is a need for childcare to be available outside of usual working hours (on weekends and during the night) to meet the needs of infected caregivers.

Action Steps: *The Coalition will consult with community providers to develop a list of adult caregivers who will be available to care for children during times of crisis or medical emergency; and will explore other avenues to provide caregivers with access to 24 hour childcare to accommodate nontraditional employment schedules and emergencies.*

ORGANIZATIONAL DEVELOPMENT

The Coalition of Stakeholders will be a new entity composed of organizations which have collaborated in the past, and which have been involved in this analysis. The cornerstone of the group will be the presence of infected caregivers who have affected children among the membership. The Coalition will determine its own procedures, and will ultimately identify a lead agency. The group will oversee the implementation of this Action Plan, and will respond to the concerns of the affected children and their families.

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We especially want to express our gratitude to those caregivers who have HIV/AIDS, and to the children who are affected by the disease, who were willing to share with us their experiences, their knowledge, their fears, and their hopes. Without their remarkable contributions, this study would not have been possible.

I. INTRODUCTION

PERMANENCY PLANNING FOR CHILDREN AFFECTED BY HIV/AIDS

BACKGROUND

The basic idea for this critical issues analysis originated in a subcommittee of the Banyan Adoption Consortium. The Consortium is a project of the Banyan Family Center in the Department of Child and Family Studies at the Louis de la Parte Florida Mental Health Institute. Organized in the summer of 1996, the Consortium is made up of private clinicians and other mental health providers whose practice involves children with special needs and their adoptive families (Appendix 1). The purpose of the Consortium is to provide these practitioners with opportunities for networking, sharing information, enhancing their skills through training, and collaborating on special projects.

One such project soon emerged among Consortium members: A shared concern regarding the plight of children whose parents or caregivers have HIV or AIDS, and whose futures are in doubt. A community therapist, Kathy Cahill, described the situation of one of her clients who had AIDS and was attempting to raise children; and then told of a children's group she worked with at Francis House, and of their mothers' reluctance to divulge their illness to their children. Several Consortium members formed a subcommittee to further study the problem and the community's response.

The group, initially the AIDS Adoption Committee, began meeting monthly in the fall of 1996. However, it became the Permanency Planning Committee as the focus of discussion became the needs of affected children for permanency as their parents' deaths approached. Members of the Permanency Planning Committee included Sue Street, Department of Counseling Education at USF; Lo Berry, Northside Community Mental Health Center; Kathy Cahill, private practice; Art O'Hara, Children's Home Society; Giovanna Welch, Family Enrichment Center; Marilyn Merida, Tampa Bay Pediatric/Family AIDS Program; and Judy Moore, John Mayo, Sabrina Brinson, and Marcelle Maylott of the Banyan Family Center. The group invited the Department of Children and Families to send a representative as well as an attorney to attend.

By spring 1997 the group began looking into ways to secure funding to support further assessment of this situation, and to propose some interventions and supports to address the permanency needs of these children.

PROBLEM VALIDATION

The national, state and local statistics of the AIDS pandemic are staggering. The total reported number of AIDS cases in the United States as of June 30, 1997 was 612,078; 62% of them have died. In Florida 65,016 cases had been reported as of December 31, 1997; 57% had died (Florida Department of Health, 1998).

Florida is one of five states that account for more than half of the AIDS cases in the US. It is the second leading state in the number of pediatric AIDS cases (New York is first); and is the leader for the number of heterosexual AIDS cases. In Hillsborough County, 3,679 cases had been reported by December 31, 1997 (Florida Department of Health, 1998).

These numbers, however, fail to convey the human toll, especially to the least documented victims of this disease: the children whose parents or caregivers are ill with HIV/AIDS. Since the beginning of the pandemic, thousands of children have been orphaned, losing one or both parents and sometimes other caregiving relatives as well. By 1996, the number of such orphans increased to 45,600, and it is predicted to reach between 82,000 and 125,000 orphans by the year 2000 (Dansky, 1997). These children, three-fourths of whom are not infected, will require care.

When awareness of the AIDS epidemic began, the focus of concern was on individuals, primarily males, who were the most frequent victims of the disease. However, during the 1990s, the demographics of the disease have changed. Women became the fastest growing segment of the population with HIV/AIDS; it is now one of the four leading causes of death in women of between the ages of 15-44, and the leading cause of death in women of color in the same age group (US. Department of Health & Human Services, 1996). Although it is not recorded how many of these infected women have children who are not infected, it is known that most of them are of childbearing age, that approximately 50% have contracted the disease through heterosexual contact, and 30% through intravenous drug use. (Men who have HIV/AIDS sometimes care for their children as well; often after the mother has died of the disease.)

STATEMENT OF NEED

In Hillsborough County there are presently 632 women who have been diagnosed with AIDS; 58% of them are African American. Fifty-six percent contracted the disease through heterosexual contact. (Data on the number diagnosed with HIV is not available). Increased services and supports have not, however, accompanied this increase in the proportion of women infected with HIV/AIDS. In fact, in general support for AIDS related programs has dwindled; as one provider remarked in one of this project's focus groups "people are tired of hearing about AIDS." In addition some of the data reported in the newspapers and other publications indicates that the number of people diagnosed with AIDS has decreased, as has the number of deaths. Pediatric AIDS has also been reduced from 25% to about 8% of newborns whose infected mothers have taken AZT during pregnancy.

As AIDS has always been a fearful and repugnant thought to most of the public, this news has generally been received with relief and a false sense that the epidemic has been conquered. Such optimism is not warranted, particularly when one considers infected caregivers and children. Nonetheless, funding for AIDS programs has been more difficult to come by, and, when priorities have to be set, life and health sustaining programs of course come before psychosocial supports and interventions. In addition, some of the newer medications, such as the protease inhibitors, are very expensive. With only so much funding available, these medical interventions take precedence over mental health or other social supports.

Programs such as the Tampa AIDS Network (TAN), for example, which has been the lead agency in this area in helping victims of the disease, has experienced significant cuts in funding. That agency has, therefore, had to make adjustments in services; those largely targeted for reduction or elimination were the social and mental health components of their service; those programs of help to families of victims. Many of those programs had been available to affected children. In addition, counseling services are known to be important in helping infected caregivers cope with their situation and make thoughtful decisions regarding their children's future.

The Permanency Planning Committee studied the data about HIV/AIDS, as well as the services available to victims and their children in this county. They were especially concerned

about those affected children about whom little has been known, statistics are mainly estimates, and who seem not to be eligible for many services. What information emerged indicated that these children often end up in foster care or substitute care, as their infected parents or caregivers frequently fail to make permanent plans for them. Various reasons were posited for this reluctance on the part of the caregiver; but the plight of these “invisible children” has become recognized as a significant social problem.

Members of the committee then joined with research staff from the Louis de la Parte Florida Mental Health Institute to design a study of these affected children and their infected caregivers. The central issue was the children’s need for permanency. However, the design of the analysis linked the permanency planning issue with the service needs of the families. The underlying premise was that a system of supports would be an essential factor in a caregiver’s being able to contemplate the reality of their situation, and to make permanent plans for their children.

PLAN FOR ANALYSIS

The general **research question** of this analysis was, what are the permanency and support needs of children at risk of parental loss due to HIV/AIDS?

The **target group** for analysis was the primary caregivers who were infected with HIV/AIDS and their minor children who were not infected, but were affected by the disease. The study was limited to Hillsborough County.

There were three primary areas to be examined in the analysis:

1) How these families cope with the impending death of the primary caregiver.

- The extent to which the infected caregivers make plans for the care of their children after their death.
- The factors which affect their making informal or formal, legal plans for their children.
- The extent to which the caregivers have divulged their illness to their affected children.
- The emotional, social, environmental and other factors that affect caregivers’ decisions to divulge their illness.

2) The needs of these children and families, and the extent to which the formal system of agencies and services respond to those needs.

- What services/resources are available to these families?
- Consumers’ experiences with services.
- Gaps in and barriers to service delivery.

3) The informal system available to these families, and the extent to which informal supports meet the needs of the infected caregivers and their children.

The method of analysis consisted of three primary tools:

1) Focus groups: two groups of primary caregivers, two of providers familiar with

the issues confronting families dealing with HIV/AIDS, and one of children/adolescents affected by the disease.

2) Semi-structured interviews: 25 one-on-one interviews with infected primary caregivers.

3) Surveys: 20 surveys to be completed by infected caregivers.

These methodologies were selected to best capture the experiences and views of the caregivers and the children themselves, as they are the experts in telling us what they need and what their problems and concerns are. The intent was to develop an analysis that accurately conveyed their opinions, expressed in a “safe,” confidential, supportive setting.

This design also involved collaboration with agencies and providers in obtaining the participants for the analysis. These same professionals (and others) participated in the provider focus groups, which served as a means to learn the professional community’s views of this problem, as well as their assessment of what the system should offer these children and families.

The project team, which were primarily staff of the Department of Child and Family Studies at FMHI, and included two graduate research assistants, collected the data, conducted the focus groups and interviews, and analyzed the findings. As much of the information came directly from the caregivers and children themselves, flexibility on the part of the staff was needed in arranging interviews and groups, at the convenience of the participants, and often in their homes or agreed upon neutral site.

DESIRED OUTCOME OF ANALYSIS

The study was designed to provide a “snapshot” of these affected children and their primary caregivers; to include a descriptive analysis of the demographics of the group included in the study, their needs, the services they have received and their experiences with those services, as well as their other, informal sources of support, and how effective those are. However, this analysis was not designed to be only descriptive and quantitative, but affective and qualitative as well. The analysis elicited participants’ feelings about their situations, their children and families, the stresses and pressures they confront, and how they deal with the enormity of their problems. The analysis accessed those areas in order to be able to address ways to approach those personal, and familial issues in a meaningful way.

Finally, the analysis developed a number of recommendations for assisting these children and families, based on the input of the caregivers and children themselves, and of the providers who participated in the study. From these recommendations, the team has developed an action plan to address the gaps in services, and then designed a system of care that will support these families, and will allow the infected caregivers to respond to the permanency needs of their affected children.

ORGANIZATION OF THE ANALYSIS REPORT

This document is comprised of four main sections. The Introduction has presented the development and rationale for the project, as well as the initial plan for carrying out the analysis. Section 2, the Methodology, describes the research design, data collection, and analysis. In Section 3, the Results, the major findings are analyzed and discussed. Lessons Learned and Recommendations for Future Research are reviewed in Section 4. In Section 5, the final section of the report, the Action Plan is detailed, highlighting the strategies which have been developed from the findings of the analysis. This section also identifies a plan for implementing these strategies.

II. METHODOLOGY

This section describes the methodology including: Study Participants, Design and Implementation Process, Data Collection, Recruitment Strategies, and Analysis.

STUDY PARTICIPANTS

A total of 77 participants were successfully recruited for the five focus groups, 25 individual/semi-structured interviews, and 20 surveys. The breakdown of this total number of participants comprised the following:

- 63 HIV/AIDS infected primary caregivers with one or more dependent children,
- 4 HIV/AIDS affected adolescents aged 10-14 years who have a primary caregiver infected with the virus and
- 10 professional service providers or private practitioners who have knowledge of, or work with, HIV/AIDS affected/infected families (Table 1).

TABLE 1: CATEGORIES OF STUDY PARTICIPANTS

PARTICIPANT CATEGORY	NUMBER RECRUITED
Primary Caregivers	63
Adolescents	4
Service Providers	10
Total Participants	77

There were a total of 32 participants involved in the focus groups, 18 of whom were primary caregivers infected with HIV/AIDS, four adolescents, and ten professional/private service providers. All participants were only permitted to take part in one of the research methodologies and there were no duplications of any participants in the study. The 63 primary caregivers and four adolescents in the study represented 65 different families in Hillsborough County.

TABLE 2: BREAKDOWN OF PARTICIPANTS BY RESEARCH METHOD

RESEARCH METHOD	NUMBER OF PARTICIPANTS
Focus Groups (Primary Caregivers)	18
Focus Groups (Adolescents)	4
Focus Groups (Providers)	10
Interviews (Primary Caregivers)	25
Surveys (Primary Caregivers)	20
Total Participants	77

GENDER DISTRIBUTION

Gender distribution heavily favored females across all three data collection methods, though this was not a design feature of the methodology. Fifteen of 18 participants in the primary caregiver focus groups were female, and three male. Twenty-three out of 25 primary caregivers who participated in the semi-structured interviews were female and two male. Similarly, 18 out of 20 primary caregivers surveyed were female and two male. Eight out of ten provider focus group participants were female, and two male. Three out of four adolescent focus group participants were female and one male. A total of 68 females and nine males were successfully recruited as participants in the study (Table 3).

TABLE 3: BREAKDOWN OF PARTICIPANTS BY GENDER

RESEARCH METHOD	MALE	FEMALE	NUMBER OF PARTICIPANTS
Primary Caregiver Focus Groups	2	16	18
Provider Focus Groups	2	8	10
Child/Adolescent Focus Groups	1	3	4
Primary Caregiver Interviews	2	23	25
Primary Caregiver Surveys	2	18	20
Total Number of Participants	9	68	77

ETHNICITY

The ethnic composition of participants showed marked diversity across three major ethnic groups, typical of the overall Florida demographics: Hispanic/Latinos, African Americans, and Caucasians. A fourth category “other” was created to include those in the study who did not classify themselves as any one of these three groups. The data recorded 35 Hispanic/Latino participants, 27 African Americans, 13 Caucasians, and two persons of “other” ethnic origin. There were no persons of Native American ethnicity or origin reported in the study. (Table 4).

TABLE 4: BREAKDOWN OF PARTICIPANTS BY ETHNICITY

METHOD	HISPANIC/ LATINO	AFRICAN AMERICAN	CAUCASIAN	OTHER ETHNICITY	TOTAL
Primary Caregiver Focus Groups	10	6	2	0	18
Provider Focus Groups	0	2	7	1	10
Child/ Adolescent Focus Groups	3	0	1	0	4
Primary Caregiver Interviews	9	14	2	0	25
Primary Caregiver Surveys	13	5	1	1	20
Total Participants	35	27	13	2	77

STUDY DESIGN AND IMPLEMENTATION

The main purpose of the critical issues analysis study was to examine issues of service availability and accessibility for primary caregivers infected with HIV/AIDS; and assess the degree to which these caregivers had developed permanency plans for their children and adolescents who are affected by HIV/AIDS. The design and implementation process of this study was therefore, carefully chosen and developed based on a family-centered, and culturally sensitive approach. These principles represent two of the System of Care Principles first introduced by Stroul & Friedman (1986) and formed the basis of the approach that was used to assess the service needs of this target population. This study was unique because it focused not only on the infected primary caregivers but also affected children who were often ineligible for most services because they were not infected with HIV/AIDS. The study also examined the relevancy of permanency plans to the participants in the study.

The study design is based on three main research tools: focus groups, interviews and surveys; and used primarily qualitative measures to assess family needs, satisfaction, identify gaps and assess the extent to which permanency plans have been developed by primary

caregivers in the study.

The qualitative methods were chosen because it was felt that these methodologies would be more successful in tapping into the types of issues that the primary caregivers and their families faced. In addition, the focus groups and interviews allowed free flowing participation and seemed more family-friendly. The study design was also based on a family-focused and culturally sensitive approach, and accommodated the participants' unique social, linguistic and cultural backgrounds. Interviews were scheduled at times and locations that were most convenient for family members.

The following phases were involved in the design and implementation of the study: grant-writing, planning, technical assistance/training, orientation, data collection, data analysis, and final report and action plan. Each phase is briefly described below:

- Grant Writing: A grant proposal was written and submitted to the Children's Board during Fall-Spring 1996-97, based on Banyan Center Adoption Consortium subcommittee recommendations to conduct a critical analysis study of Permanency Planning for children affected by HIV-AIDS. Funding was approved in total direct costs for approximately \$20,000 to undertake the study beginning Fall 1997;
- Planning: Project team planning/organizational meetings were held at USF-FMHI Department of Child & Family Studies TREAD Division (e.g. December 11, 1997), to initiate contacts with collaborating service provider agencies such as Tampa AIDS Network (TAN), Francis House, Mercy House (Catholic Charities), County Health Department, Children's Medical Services, Bay Area Legal Services, other local providers. Planning of scheduled interviews, time-lines, project personnel task assignments, and discussion of recruitment strategies also took place.
- Technical Assistance/Training: Training sessions on cultural sensitivity and focus groups were held January 8 and 9, and February 5, 1998. All training and preparation were done through lectures, workshops and seminars. Training was coordinated by USF-FMHI-TAN professionals, Ruby Joseph and Marylin Merida.
- Orientation: In order to facilitate the recruitment process, team member Ruby Joseph presented an overview of the entire study to case managers at TAN, during one of the monthly meetings. Service provider focus group participants were subsequently recruited from various agencies including Tampa Aids Network (TAN), Hillsborough County Public schools, USF/FMHI Center for HIV Education, Bay Area Legal Services, Family Resources.
- Data Collection: Actual data collection involving the different research methodologies including focus groups, individual interviews and surveys occurred from February 5 through July 1998, with all project staff fully involved. Many of the interviews took place at participants' homes to accommodate transportation problems, while others occurred at TAN, Mercy House, Francis House, and Florida Mental Health Institute. All times and locations for interviews were chosen to accommodate family schedules and requests. Data collection was followed by data transcriptions, systematic formatting and documentation of all information.
- Data Analysis: The data analysis process began on April 7 and ended in August 27, 1998. This process which included group discussions and planning of the final report, was strategically moved to an off campus site for better concentration, focus and input into the process. These retreats allowed full participation of project staff, especially enlightening others about their individual interviews, and focus groups.

- **Final Report and Action Plan:** The final report and action plan were completed September 30, 1998. The Action Plan sets out steps that address some of the issues and needs identified in the study. It outlines a System of Care that supports Permanency Planning and comprehensive services for children, adolescents and their families affected by HIV/AIDS.

DATA COLLECTION

The data collection process involved the following three principal qualitative methods that provided rich data for the critical issues analysis of permanency planning for children, adolescents and their families affected by HIV/AIDS in Hillsborough County, Florida:

- Focus groups
- Individual (one on one) / Semi-Structured Interviews
- Surveys.

All questions for the focus groups, interviews, and surveys centered around issues of permanency planning (plans made for children), needs of primary caregivers and children affected by HIV/AIDS, formal/informal supports systems available/unavailable to them. Instruments included three focus group protocols or questioning routes designed for primary caregivers, adolescents, and providers (Appendix 4); a primary caregiver semi-structured interview guide (Appendix 5) that was also translated into Spanish, and a survey (Appendix 6).

FOCUS GROUPS

Five 2-hour focus groups were conducted with the following categories of participants:

- 2 groups of primary caregivers infected with HIV/AIDS,
- 2 groups of professional providers or individuals with knowledge and experience in working with affected or infected families (Appendix 7)
- and 1 group of adolescents aged 10-14 years, who have a primary caregiver infected with the HIV/AIDS virus.

Each primary caregiver was reimbursed \$25, while the four children/adolescents were each paid \$15, with an additional \$10 provided for their respective caregivers. Provider focus group members were offered no monetary compensation for their participation.

The focus group method was chosen as a data collection technique for the critical issues analysis study, because it is a carefully planned discussion or conversation designed to obtain information about participants' perceptions and experiences regarding a defined area or topic of interest. Focus groups take place in a permissive and non-threatening environment, and are carefully designed to ensure that participants have similar characteristics which give them some common reference point. This common reference point allows participants in the group to communicate and discuss in a more open, in-depth manner (Krueger, 1994).

Each focus group was conducted by a lead interviewer or moderator, who led the questioning route designed to elicit information about availability of services, permanency planning issues and needs of families. The lead interviewer was assisted by a co-moderator who was responsible for providing technical supports such as audio tape recording the focus group sessions, taking detailed notes, assisting with order and propriety of the session, and

leading a final 15 minute flip chart review of the taped session recapitulating participants' major points. This final exercise also ensured data reliability and accuracy of participants' responses.

Summaries of each focus group transcript were subsequently formatted using a focus group summary sheet highlighting the two most significant critical issues analysis themes: services and permanency planning (Appendix 8). The formatted summary sheet information was then used as corpus for all project team discussions, writing of the final draft report and Action Plan.

INDIVIDUAL/SEMI-STRUCTURED INTERVIEWS

Twenty-five semi-structured interviews, each lasting approximately an hour and half, were conducted with 25 different primary caregivers diagnosed with HIV/AIDS, who had at least one uninfected/affected dependent child. Each participant was reimbursed \$25 for the interview. The interview protocol was similarly designed to elicit information about availability of services, permanency planning, support issues and needs of families (Appendix 5).

During the one on one interview sessions, participants were allowed unrestricted time and scope to respond to the semi-structured questions. The technical assistance training held in January and February had sensitized interviewers about cultural competence issues regarding HIV/AIDS infected/affected persons. Many of the individual interviews turned out to be voluntary biographies providing in-depth information about the primary caregivers' lives, circle of friends and other acquaintances.

As with the focus groups, each interview was led by one project team member assisted by a co-interviewer. The co-interviewer served as a reliability check, and assisted with transcriptions and case summary write-ups.

SURVEYS

Twenty surveys eliciting similar information about primary caregivers with HIV/AIDS and their affected children and families were administered to a different cohort of primary caregivers. TAN case management team and other collaborating service provider agencies assisted voluntarily with this effort. Fourteen of the primary caregivers surveyed were paid \$5 each. The study team adopted this strategy after several months of frustrating recruitment attempts had failed to secure the 20 survey participants.

RECRUITMENT STRATEGIES

The project team learned early that the target population of this critical issues analysis was one faced with a lot of social stigma and prejudice, because of "folk models" and stereotypes created about HIV/AIDS infection and transmission modes (Agar & Macdonald 1995). Therefore, the study team fully expected that recruiting potential study participants would be a challenge. Consequently, the over all recruitment strategy adopted was comprehensive and consisted of a variety of recruitment methods:

- Broad Outreach to Communities: Flyers directly targeting the study population were sent out. These flyers were put in different locations including neighborhood community centers, laundromats, and provider agencies such as TAN, Francis House, and the County Health Department (Appendix 9).
- Service Provider Recruitment: A service provider agency liaison was identified to link the team with different agencies in order to identify potential participants. clients.

The agencies mentioned above were among the local providers that played an essential role in the recruitment process.

- Word of Mouth: Team leaders met with key service agency staff/personnel and private practitioners who were involved with the study target population through direct services. This group of providers such as program directors, human services coordinators, doctors, clinicians, counselors, therapists, case managers, and others.
- Presentation to Agencies: Another strategy involved giving public presentations to agencies who were involved in providing services to people living with HIV/AIDS. The main purpose of these presentations was to provide agency staff with information about the study design and project implementation emphasizing the importance of the study and the advantages of the study to clients. This strategy included phone calls and meetings between lead FMHI staff members and various agency staff and administrators.

SCREENING PROCESS

This process involved the following steps:

- Screening Questionnaire: A screening tool was developed to carefully select participants who met all the necessary study criteria. The questionnaire elicited primary demographic information such as participants' linguistic and ethnic backgrounds, how they had found out about the study, marital status, number of dependent children, time of first HIV-AIDS diagnosis, decision regarding disclosure, health status, interview appointments and scheduling (Appendix 10).
- Acknowledgment of Consent/Assent: All participants were asked to complete an informed consent form (Appendix 11), which is an official University of South Florida document, designed to authenticate and legitimize their voluntary non-coercive participation in the study. This document was specifically worded to reflect a HIV/AIDS cultural competence-based format that addresses cultural sensitivity issues unique to that population. It also informed participants about what was expected from them in the focus groups, interviews and surveys. Four versions of the Informed Consent document were created to suit the different categories of participants in the study: primary caregivers, adolescents, and providers. In addition, the informed consent forms were prepared in Spanish for the Spanish-speaking participants.

OFFICIAL USF-IRB

An official University of South Florida IRB was issued on February 10, 1998 as legal professional compliance seal to honor with propriety and respect, all institutional regulations and requirements regarding research involving human subjects. This document formally signaled initiation of the study.

DATA ANALYSIS

The data analysis process began immediately following the interviews. Team members first used verbatim transcripts of the recorded focus group and semi-structured interviews as corpus for writing case summaries. Team members then produced the summaries as well as written interpretations of the focus groups, interviews, and survey data. Paired interviewing teams brought diverse perspectives to the summaries and interpretations, which enriched participants' views. Such paired effort was replicated at the larger data processing and analysis

forum of project team meetings, where interviewers discussed their individual cases or interviews. To facilitate this process, all the transcripts were reproduced and distributed among team members, at least a week before scheduled “Retreat” meetings, to help re-acquaint them with the information content of the transcripts and make quality input in the discussions.

Discussions took place at a number of off campus “Retreat” meetings held early July through mid August, in the local Tampa business suite of one the team members. A systematic documentation of participants’ responses to key issues relating to permanency planning (plans made for children), needs of primary caregivers and children affected by HIV/AIDS, and formal/informal support systems available/unavailable to them, was developed. These major themes were highlighted on a flip chart.

The following categories of service availability and permanency planning related issues formed the corpus of information obtained in this study. These issues formed the basis of the final report and Action Plan:

- Available Resources/Service Agencies and Providers, and participant’s rating of service effectiveness/responsiveness; existence of Formal/Informal Supports; Service barriers/Family needs;
- Permanency Planning (formal written/informal/non-initiated/undecided); explanations of permanency plans made/not made; disclosure of disease; cultural interpretations of the above;
- Other important issues/information related to services, permanency planning and family needs not directly elicited by focus group/individual interview protocols.

Each category of issues was also measured quantitatively, to determine the most critical issues with respect to permanency planning and the perceived service needs of the affected children, adolescents and their families.

In order to adequately describe study participants, the analysis also included a compilation of demographic information on family member participants (Appendices 2 and 3) (i.e. primary caregivers and children/adolescents). This data also included information on the following areas:

- Referral source, or how participants found out about the study (a self evaluation mechanism of how well we did/didn’t do with recruitment)
- Participants’ preferred language
- Age
- Gender
- Marital status
- Ethnicity
- Number of children being cared for including their ages
- Date of Primary Caregiver diagnosis
- Disclosure status (have primary caregivers told /not told children and why)
- Primary caregiver’s general state of health.

At the end of the data analysis process, an outline of the final draft report including clearly specified deadlines and assigned portions of the narrative, was distributed to the five members of the Report writing team. The full draft report and Action Plan were completed after peer editing and external review of the draft documents.

III. RESULTS

Several major findings emerged in two major areas relating to: **Services and Permanency Planning**. Other significant findings that emerged which did not relate specifically to these two areas are also discussed in this section under **Additional Observations**.

SERVICES

Data on services is discussed in relation to Service Availability and Service Effectiveness. With respect to the area of Service Availability, information relates specifically to available resources, barriers to accessing resources, service and needed services were gleaned. This data collectively provide a picture of the current service system and highlight the areas that need to be improved and other new services that are needed but not currently place. Service Effectiveness addresses the issue of the usefulness of these available resources to the families in the study.

SERVICE AVAILABILITY

AVAILABLE RESOURCES—FORMAL

The interviews and focus groups highlighted several important formal and informal services, which providers and primary caregivers regarded as being useful support systems. A comprehensive list of these supports and services are listed alphabetically in the Appendix 12.

Although the list of available resources is comprehensive, some of the identified agencies deserve particular attention because they were mentioned consistently in the surveys, interviews and focus groups and reportedly provide a wide range of services to many of the study participants. These providers include Tampa Aids Network (TAN), Francis House, Mercy House, Bay Area Legal Services and various medical services facilities including the Hillsborough County Health Department, Children's Medical Clinic, and the University of South Florida Medical Clinics. Other important resources identified in the study include the Department of Children and Services, which was responsible for providing food stamps and financial aid benefits which some of the study participants received. Other less mentioned but also important service agencies included United Cerebral Palsy, Great Day, Big Brothers Big Sisters, Tampa Hillsborough Action Plan (THAP), Metropolitan Life Ministries, Salvation Army and Tampa Crossroads. Some participants identified a few churches such as St. Vincent DePaul and St. Peter Claver. Data also revealed that many participants were also utilizing various support groups including Alcoholics Anonymous (AA), Narcotics and Anonymous (NA), and agencies such as DACCO for detoxing and rehabilitation.

The most frequently mentioned agencies and the services that participants described as being most helpful include the following:

TAN

- Food Bank - this service provides food, medical supplies, household detergents, and other supplies to families.
- Assistance with bills - participants reported that they had received assistance with utilities and rent.
- Emergency transportation - to take clients to the hospital in case of medical

emergencies.

- Housing - limited housing available for people with HIV/AIDS.
- Advocacy - includes supporting families and assisting them with paperwork, linking them with other services, providing and giving them general guidance and support to families to enable them deal more effectively with larger public bureau cracies.
- Case Management - provides clients with a case manager responsible for providing services and overseeing the overall delivering of services for the client.
- Group counseling - provides support group meetings for clients and their families and some general counseling services. Also includes “Miral,” a Spanish speaking group for females.
- Activities and Entertainment - provide some activities for children affected or infected with HIV/AIDS by giving tickets for theme parks such as Disney World, Adventure Island and Busch Gardens. Also provide summer camps for children.
- Christmas Gifts - provide gifts for children at Christmas.
- Conference organization - arranged for some parents with HIV/AIDS to attend conferences on Health Issues related to living with AIDS.

Analysis of the data confirmed that TAN is the primary agency that serves people who have HIV/AIDS. This agency reportedly provides a broad variety of services for its clients. In addition, many participants acknowledged that severe cuts in this agency’s funding had reduced the availability of some of these services that had previously been provided. Participants especially complained that counseling and group sessions were not as readily available as they had been in the past.

Francis House

- Day care for younger children
- Individual and group counseling
- Support groups for children, adolescents and men
- Christmas gifts and parties
- Clothing
- After school program

Mercy House

- Housing
- Food
- Recreational activities for children
- Tutoring for children
- Informal client support of each other

Bay Area Legal Services

This agency was mentioned particularly among participants who had made some sort of legal plans and arrangements for their children.

- Establish legal plans and arrangements regarding the custody and general welfare of the children of parents infected with HIV/AIDS.

Medical services were reported to be available through different agencies with the Health Department, Children Medical Services, University of South Florida Medical Services (USF Medical School) being the health care facilities that participants seemed to use the most.

Health Department

- General medical services
- Medication
- Dental Care
- Eye Care
- Services of a social worker
- Services of the specialty care clinic for HIV/AIDS
- Pharmacy services
- Psychiatric services

Children's Medical Services/USF Medical School

- Medical services
- Psychiatric services
- Medications
- Case management
- Services of a social worker
- Transportation services
- Counseling

AVAILABLE RESOURCES—INFORMAL

With respect to informal sources of support, participants reported that overall there were not many available that provided assistance that directly related to their HIV/AIDS status. While some participants in the surveys, interviews and focus groups suggested that neighbors and the church were sources of strength or support, very few indicated that any of these types of support helped them directly to deal with their illness. Instead, many primary caregivers reported that they have no informal support from their family, neighborhood or local churches. Many described feeling isolated by their illness. Providers in the focus groups echoed similar sentiments regarding a lack of informal sources for people with HIV/AIDS. One such participant explained, "There are people with no informal support whatsoever."

Data from the study suggest several factors account for the general inadequacy of informal supports. These contributing factors include the stigma attached to HIV/AIDS, widespread ignorance regarding AIDS among the general population and a deep fear that people with HIV/AIDS have of being ostracized and rejected by others. According to participants, all of these factors made them unwilling to disclose their condition to other informal sources such as local churches and immediate and extended family members who could be potential sources of emotional, financial and spiritual support.

Participants described their fear of disclosing that they had HIV/AIDS in numerous ways. One interviewee reported that instead of receiving help and support she was rejected and humiliated by neighbors as well as family members. A few caregivers had actually moved away from their families to prevent them from finding out about their HIV/AIDS status and/or to prevent possible rejection by their families.

BARRIERS TO ACCESSING RESOURCES

As one can observe, many services were listed as being available to participants. However, data suggest that the availability of these services and programs did not necessarily mean utilization of services. Participants reported that several factors hindered access to these services. Some of these barriers were a direct result of the socio-economic status of the primary caregivers in the study, others were a result of agency practices, and other factors related more specifically to the HIV/AIDS disease.

Some of the factors affecting utilization of both formal and informal services included the following:

- Transportation
- Day care
- Criteria for qualifying for services
- Negative perception of bureaucratic agencies
- Lack of information about available resources
- Stigma attached to AIDS
- Confidentiality

TRANSPORTATION

Comments and observations made by participants in the surveys, focus groups and interviews clearly indicate that lack of transportation serves as a major barrier to services. Many of the primary caregivers in the study were in the low-income bracket and some of them did not have their own transportation and therefore, getting to services often posed problems.

DAY CARE

of the participants in the entire study were female primary caregivers with children and day care for their young children was an issue. A participant speculated that a reason for the drop in attendance in some of group sessions at TAN was primarily due to transportation and day care problems that primary caregivers were experiencing.

CRITERIA FOR QUALIFYING SERVICES

The study suggests that many services are strictly for adults and children with HIV/AIDS, and because of this affected children often do not qualify to receive services. Participants in the provider focus groups gave examples of how strict qualifying criteria prohibit service use. One such participant explained: “Kids have to meet medical requirements to get mental health counseling service.” Another provider claimed: “T-cell must reach a certain level which is so low the infected person must be almost dead to get Medicaid. Affected children don’t get Medicaid.”

NEGATIVE PERCEPTION ABOUT FORMAL SERVICE SYSTEMS

Some participants in the provider focus group identified the negative perception that family members sometimes have towards the service system as another barrier to service utilization. Primary caregivers who have had other negative experiences with other human service system are reluctant to go to these other agencies for help because they feel that they will go through a similar negative experience. One provider reported: “It (service system) is not a user-friendly area ... social services ... forms to fill out ... I wouldn’t want to go through what they have to go through.”

LACK OF INFORMATION ABOUT AVAILABLE RESOURCES

Problems relating to lack of information were twofold. There was a general lack of knowledge about existing services among study participants and the general public as well as inconsistencies in dissemination about resources. Many caregivers did not have any knowledge about resources and services that were available to them. Several participants in the focus group commented that they had not known that certain services existed. One particular caregiver stated that after the doctor had diagnosed her with HIV/AIDS she was not given any information and did not know where to go. Participants in the study also reflected that many people just don't know where to go and some even commented that most of the general public is unaware of TAN's presence in the community and are similarly unaware of what TAN offers to people with HIV/AIDS.

In addition, the study revealed that even when information is available the actual dissemination of this information is often inconsistent. For instance, some participants reported that their case managers at TAN kept them abreast of the different resources that were available to them while others complained that their caseworkers did not give them much information about resources. It appears that the quality and quantity of information that primary caregivers have access to depend to some extent on their caseworker.

STIGMA ATTACHED TO AIDS

In both the interviews and focus groups participants gave illustrations of how family, neighbors and others had treated them once they found out they were HIV positive or had AIDS. A comment made by a young mother in the study graphically demonstrates the depth of the stigma that is attached to AIDS:

She [participant's mother] didn't want me around her. She told everybody I know. People would talk about me, spit at me. They would snatch their kids away if I said something to one of them. Nobody wanted anything to do with me. People treated me like trash. And for a long time nobody wanted anything to do with me in the neighborhood. And I was called names like 'bitch, whore, slut.' I was spit at and spit on by people. Nobody would help me with anything. I mean nobody would let me sleep on their couch. I would ask people for glasses of water I couldn't get it. They wouldn't let me drink out of their water hose.

Another mother spoke candidly about her experience when her family discovered that she had AIDS:

You tell your family you have AIDS, they don't want you around. And my sister's like that. Even though she came to Miami and picked me up and brought me to her house, she was very ignorant! She got me plastic forks and plastic spoons ...

Such stigma makes it difficult for people with HIV/AIDS to come forward and seek help from other individuals who are not relatives but are part of a formal service system.

CONFIDENTIALITY

Participants in focus groups and interviews felt that the issue of confidentiality was a major

obstacle that prevents people with HIV/AIDS from seeking services. As one participant explained: “I’ve thought about TAN, but I think of running into someone I know and I get petrified.” The reluctance and feelings towards their privacy and confidentiality were also demonstrated by one primary caregiver who made this comment:

When you go to the gynecologist on 30th street, they already know where you’re coming from TAN ... they want you to tell them all over again what you’re being treated for ... they can do some asking about your problem but they don’t have to go into graphic details of how did you get it and stuff like that.

Others spoke of being afraid that coming for services could lead to their diagnosis being found out by others. This breach in confidentiality did not necessarily mean a breach by agency staff but rather a breach by other clients. A participant in one of the family focus groups described how another client had met her at TAN and has subsequently informed her family about her status.

SERVICE GAPS AND NEEDED SERVICES

As already demonstrated in the section on available resources, people with HIV/AIDS have several resources, programs and services available to them. However, there are still some gaps in the service delivery system that were identified by providers and primary caregivers. The study revealed that some of the services that are provided to people with HIV/AIDS are inadequate in terms of their quality and/or quantity and therefore, need to be improved. Other services are greatly needed but are not even in existence.

Results show that while certain service needs were identified by a specific group of participants, e.g. just providers, others appeared to be more broadly recognized across all data collection sources. Consequently, data from the different research sources i.e. surveys, family and provider focus groups, and interviews with primary caregivers demonstrated that there is a big gap in some areas. The following discussion reviews these service areas some of which will be discussed in further detail in the section on Implications.

It is important to note that some of the identified gaps were more a function of the socio-economic status of the participants in the study who were generally low-income families rather than HIV/AIDS status. As such some of the gaps would apply to families in similar economic situations. Nonetheless, these deficiencies are made more acute by the fact that participants in this study have HIV/AIDS.

BETTER TRANSPORTATION

Study participants indicated a need to provide HIV/AIDS primary caregivers with more transportation. Many primary caregivers reported that transportation was a very urgent need and providers confirmed that transportation presents a significant challenge to many families affected by HIV/AIDS.

Although TAN provides transportation for medical emergencies and for some medical appointments, many participants stated that they often experience difficulty in getting transportation to attend other appointments and activities.

CHILD CARE

Participants reflected on the child care need in general and some pointed out that this was particularly necessary in case of hospitalizations of primary caregivers. Providers also com-

mented on the need to provide more day care for the children affected by HIV/AIDS, especially younger children. Information from the study seems to indicate that Francis House and Great Day are the main agencies that provide child care. This does not appear to sufficiently meet the demands of primary caregivers and some participants suggest that a 24-hour child care service is needed.

HOUSING

Some providers and primary caregivers identified the need for more low-income housing to help address the housing problems, which some participants felt was a very important issue. One primary caregiver complained: “TAN has apartments but you have to be full blown AIDS to get in them. They shouldn’t have to wait until we’re dying to help us.” Another primary caregiver expressed a slightly different view stating that the inadequate provision of housing specifically for people with HIV/AIDS was a result of the funding cuts which TAN has had to absorb. Regardless of what reason was given, it is clear that housing remains a need for some families.

MORE SUPPORT SERVICES FOR CHILDREN AFFECTED BY HIV/AIDS

As previously discussed there appears to be the need to provide more support services for children who are not infected with HIV/AIDS but are affected by the disease. As one provider participant reported, “They [affected children] are the forgotten group. But they act out and get into trouble.” Other primary caregivers felt that children affected by HIV/AIDS needed more activities and programs that were not necessarily connected to the disease.

MORE THERAPEUTIC SERVICES FOR FAMILIES AFFECTED BY HIV/AIDS

Time and time again primary caregivers indicated a need to provide therapeutic support for their children to help them better deal with and cope with the effects of the primary caregiver’s illness. In particular, participants made a special emphasis about providing activities and support services for adolescents and teenagers.

This need was expressed by a provider who stated simply, “I don’t think counseling should take place after death occurs! It should be before that!” Primary caregivers alike commented on the need to have counseling for their children and several mothers were concerned about how their children were coping. One mother expressed this urgent need concretely in these words:

They need to make some improvements ...do a little bit more though...like maybe children like my daughter [the 9-year-old] maybe she can like have counseling. They don’t have no counseling for at neither one of the programs...they need somebody to talk to her [i.e., daughter] and explain to her like a counselor, because she’s taking it real hard because me and the baby have it. They need some support for her, she need support...TAN, Mercy House, Francis House, all three of ‘em need to do it!

The children in the study confirmed this need with one child explaining that “it helps kids to know somebody is there.”

The cutbacks affecting TAN, which is clearly the largest local agency that serves people with HIV/AIDS in Hillsborough County, have negatively affected the number of services that participants can now receive. Many participants in the interviews and focus groups commented that recently there has been a reduction in the number of support group sessions available for

them to attend.

Some participants also reported that therapeutic services were also needed for other extended family members and significant others who were also being affected by the HIV/AIDS status of the primary caregivers.

BETTER DISSEMINATION OF INFORMATION

As already indicated in the section on barriers to access of services, dissemination of information is a problem. Consequently, some providers and primary caregivers identified the need for better advertisement of available resources, services and programs stating that improvements were necessary around this issue. At least one provider spoke of the difficulties of advertising their services referring to the situation as a “Catch 22” because that agency would be viewed as an “AIDS agency” which would in turn lead HIV/AIDS clientele to fear that their confidentiality might be compromised.

Also as indicated in the discussion on barriers, some participants did not feel that they have the information they need. Therefore, the availability of consistent processes and procedures for distributing information to and among individuals with HIV/AIDS was reported as an identified gap.

MORE COORDINATION AND COLLABORATION BETWEEN AGENCIES

Closely related to the issues of inconsistency in the dissemination of information is the problem of inadequate coordination and collaboration among providers who serve people with HIV/AIDS. There appears to be a need for better coordination and collaboration among the agencies that were identified in the study in order to facilitate more effective service delivery to families affected by HIV/AIDS. Some study participants felt that communication between agencies needs to be improved.

EDUCATION AND OUTREACH

The need for better education was evidenced on three levels. One focused on the broad outreach and awareness to the general population at large, another level was to the youth and a more specific level of education related directly to those who are more directly affected by this disease.

Many individuals who completed the surveys and participated in the focus groups and interviews acknowledged that there is a need to inform and educate the general public. Participants felt that a lack of knowledge and awareness of the disease contributes to the wrong information about AIDS and fear and stigma that many people attach to AIDS. All participants expressed the need for this type of education but primary caregivers and providers seemed to be most anxious about this lack of education.

Other participants were more focused on trying to educate the younger population primarily pre-teenagers and teenagers stating that AIDS Awareness and Sex Education must be included in the school curriculum. Others felt more outreach into local communities is essential in order to reach younger children and adolescents. The children’s focus group validated the concerns and needs regarding education with one child pointing out just how ignorant people were when it comes to AIDS. She pointed out that “you can’t get AIDS from a chair and you can’t give a chair AIDS.”

Yet other participants expressed the need to educate and inform their family members and children who were most immediately affected by this disease. This study revealed that this target population needs a more fundamental type of education that may differ in scope than the education that the general public and younger population need to receive.

CULTURALLY COMPETENT PROVIDERS

Some participants identified the need for providers to be more culturally and linguistically competent. This need was identified not only by some primary caregivers but also by a few providers. In one of the provider focus groups the principles of being culturally sensitive and family-centered in service delivery to families affected by HIV/AIDS were mentioned as being critical to effective service delivery. While this was not a widespread area of concern some participants did contend these issues needed to be emphasized and suggested that these areas should be more adequately addressed by service providers.

LEGAL SERVICES

Primary caregivers who completed surveys highlighted the need for more legal assistance in establishing plans for their children. Providers also acknowledged that this was an area that needed to be improved. This study showed that Bay Area Legal Services is the only available resource for family members to utilize for assistance in drawing up written permanency plans. One provider commented that Bay Area Legal Services “is the only game in town.” Since many of the family members identified this as an area of need, it appears that there should be more of these types of services accessible to families affected by HIV/AIDS.

Whereas all study participants generally identified these previously discussed needs certain issues were more specific to particular groups. The gaps/service needs listed below include services that need to be improved or modified that were identified by specific participant categories.

TABLE 5: GAPS/NEEDED SERVICES AS IDENTIFIED BY SPECIFIC STUDY GROUP PARTICIPANTS

ADOLESCENTS	PRIMARY CAREGIVER
Have more caring providers	Dental services Better medication from the Health Department
	Food Bank - need fresh fruit and more appropriate food for HIV positive and AIDS clients.
	Living facilities for men with AIDS

EFFECTIVENESS OF SERVICES

The other major aspect reported under Services relates to the effectiveness and usefulness of these services. Participants were generally positive in their feedback regarding the services provided by the main service agencies such as TAN, Francis House, Mercy House, health services provided through Children’s Medical Services/Health Department and University of South Florida Medical Clinic and Bay Area Legal Services. Surveys, interviews and focus group data revealed that participants feel positive about staff employed in these agencies. They are also generally pleased with the effectiveness of the services provided and many applauded the usefulness of the services to them and their families.

Specific reaction with regard to the services of agencies mentioned above are discussed in the preceding sections.

TAN

Many of the study participants had received or were currently receiving some service provided through TAN. Participants consistently mentioned the Food Bank, which provides food, medical supplies and other household items to clients and this service received positive ratings among primary caregivers. One study participant explained, "To have the food bank is a blessing because I can go there and get groceries or whatever I need to help me make it through the month" Some participants were very impressed and pleased with the general services obtained through TAN and consequently rated their effectiveness very highly. The following comments made by three different primary caregivers depict these observations.

*... the services at TAN are very good. Excellent ...
...the services are great. Everybody there is helpful ...
... it's like they're reaching so you won't be alone ...*

Other participants appeared most impressed by the overall dedication of the staff at TAN. One of these participants reported on this type of staff dedication and helpfulness:

The services at TAN are very good. They are courteous; they call me to remind me of my appointments, since at times I forget about them because I have so much in my head. They call me to know how I am doing ...

Others were more simple in their descriptions about the effectiveness of TAN services with one participant claiming "I think TAN is doing a wonderful job on services" and another stating "They've (TAN) been a blessing." Others were less enthusiastic about the effectiveness of the services offered but nonetheless, stated that the services met their needs. For instance, one participant responded: "I really don't have anything negative to say about TAN. They've been there when I needed them and we have a good relationship I guess." Another reported, "I'm satisfied with TAN and they've helped me a lot." Many others focused more specifically on the usefulness of other financial assistance that TAN offers towards the payment of their rent, electricity and other utilities.

Notwithstanding these results, as previously noted many participants also remarked that perhaps the quantity and in a few instances the quality of services had diminished in recent times. Many candidly attributed these shortcomings to cutbacks in funding. This sentiment is expressed by one mother who stated that "TAN services used to be better TAN services used to be great, lots of things for children but no more."

Participants clearly recognized that TAN bears the responsibility of providing most of the services to families infected and affected by AIDS. In spite of a decrease in funding which according to participants has resulted in a reduction or elimination of some of the programs that TAN provides, many still acknowledged the usefulness and effectiveness of those services that are still available. A few participants admitted that TAN has a huge role to fulfill.

FRANCIS HOUSE

Services received through Francis House, like TAN were also rated positively. Participants who had received services from Francis House particularly highlighted children's services including day care and afterschool programs. One mother proudly reported on how much her

children are benefiting from attending the day care program at Francis House: “They learn Spanish, French, English. They learn how to spell their name at the age of three. They also love going there.” Other parents were impressed by the art classes for younger children and other participants found the support group session helpful. In addition, this agency was also commended for its group counseling session for children, adolescents and even men.

The only criticism voiced by a couple of participants regarding Francis House was that in order for a person with HIV/AIDS to be able to utilize the child care services they were required to attend the support group sessions. Also, as already indicated in the section on gaps, some participants also felt that there needed to be more activities for the teenagers and not just younger children.

MERCY HOUSE

Mercy House was also rated positively for providing much needed services such as transitional living accommodations and food for young HIV/AIDS infected mothers and their children. Not surprisingly participants are appreciative of the services since this agency provides them with essentials (i.e. room and food). The support offered by other clients living at this facility was noted as another indirect benefit. The deficiencies reported include the fact that there is no formal counseling provided at this facility.

HEALTH DEPARTMENT / CHILDREN’S MEDICAL SERVICES / USF MEDICAL SCHOOL

Medical support services received through the Health Department, Children’s Medical Services and University of South Florida Medical School were viewed favorably. Several participants mentioned that Dr. Nelson is particularly helpful and it appears that the general medical needs of participants are being met. Dental services, however, still appear to be a problem for people with HIV/AIDS.

BAY AREA LEGAL SERVICES

Legal assistance provided through Bay Area Legal Services by Larry Goodwin also received very favorable reports. Primary caregivers reported that these services had helped them to prepare permanency plans and wills for their families. In addition, the efforts of Larry Goodwin were noted in the provider focus group where one participant reported on his hard work and dedication to primary caregivers who had used Bay Area Legal Services to establish permanency plans and living wills. In re-emphasizing the usefulness and need for the type of services rendered by Larry Goodwin, this participant remarked, “Larry needs to be cloned.”

PERMANENCY PLANNING

With respect to permanency planning for children affected by HIV/AIDS, the analysis centered around two major areas relating to Disclosing HIV/AIDS Status and Establishing Permanency Plans. These two areas are discussed in detail in the subsequent sections.

DISCLOSING HIV/AIDS STATUS

The study suggests that the issue of how and why primary caregivers’ disclose their HIV/AIDS diagnosis is complex. Data indicate that disclosing one’s HIV/AIDS status is dependent on several factors. Consequently, the decision whether or not to tell one’s children appears to be an individualized decision that varies with the dynamics of each family, status of the primary

caregiver's health and other factors such as the primary caregiver's feelings as to what the repercussions of such disclosure might be.

Data from the study provide very detailed information on disclosure to immediate family, particularly, biological children. The study further provides some information regarding disclosure to other extended family members, neighbors and friends. This analysis further suggests that the decision of whether or not to tell one's children may not necessarily rest solely with the individual who has HIV/AIDS. Indeed, in some instances, other extended family members revealed the primary caregiver's condition without their permission and in one instance another client revealed the primary caregiver's condition to her family.

The analysis also shows that among the study participants, there was a mix of individuals who had disclosed their HIV/AIDS status and those who had chosen not to do so. Although no specific polling of the primary caregiver focus groups was done, it appeared that distribution among these two contrasting actions was fairly even. Similarly, the analysis of the 25 interviews showed that parents were divided almost evenly between the two decisions however, a fair proportion of interview participants had told some but not all of their children. Survey participants also were split between the two decisions. Table 6 provides a specific breakdown of how primary caregivers who participated in the interviews and surveys handled the issue of disclosure to their children.

TABLE 6: PRIMARY CAREGIVERS' DISCLOSURE OF HIV/AIDS TO CHILDREN

RESEARCH METHOD	TOLD CHILDREN	NOT TOLD CHILDREN	TOLD SOME CHILDREN BUT NOT OTHERS
Interviews	9	9	7
Surveys	7	11	2

REASONS FOR NOT DISCLOSING

As previously mentioned, the reasons why primary caregivers had not disclosed their condition to their children varied. One of the most frequently stated reasons for not disclosing this information to the children given by primary caregivers who completed the surveys and participated in the focus groups and interviews was that the children were too young. Many of the primary caregivers had very young children, toddlers and infants.

Interestingly, even when the children themselves were infected, a few parents in the focus groups indicated that they had not told these children that they (i.e. the children) were infected because they thought the children were too young. They also stated that as parents they wanted to spare their children the rejection that often occurs when children inadvertently disclose that they have HIV/AIDS.

Many participants with older children [i.e. over 7 years] had decided not to reveal this information to them. Some reported that they simply did not want to burden their children with

their problems. This concern was validated in the children's focus group where the children (who had been told about their parent's HIV/AIDS status) expressed their concern for their parents' general well-being: "I worry about how long my mom will be here. I don't have a dad, I still need my mom."

Other primary caregivers stated that they feared they would be rejected and/or disrespected by their children. Others were more fearful of the possible negative repercussions that disclosure could have on their children's school behavior and grades. A few parents believed that although their child(ren) were a little older they were not mature enough to handle the knowledge of their parent's HIV/AIDS diagnosis.

Some other participants did not believe in telling their children because they were not sick and could function and live as normally as they had prior to their diagnosis. They argued that there was no need to disclose the information about their HIV/AIDS status and shatter their children's sense of security.

Other participants also said that they did not quite know how to tell their children and a few primary caregivers reported that in order to disclose their illness to their children they had taken their children to TAN under the guise that they were there to receive information. This response seems to indicate that there is a need for support in this area of disclosure because some parents might want to tell their children but cannot find the words to do so.

A few parents reported that they had not disclosed their condition to their children because they were simply respecting their spouse's/significant other's wishes and remaining silent.

In summary the factors listed below were presented as the major reasons why participants had not revealed their HIV/AIDS condition to their children.

Reasons for Non-disclosure

- Child was too young
- Unwillingness to burden child with parent's problems
- Fear that child would reject them
- Negative repercussion on child's behavior
- Fear that child would tell others
- Unwillingness to change child's perception and sense of security
- Denial/general unpreparedness
- Other spouse request that child not be told

It should be noted that although many primary caregivers had not informed their children about their condition, some were willing to admit that their children did know that they were sick. Consequently, non-disclosure did not mean that children were ignorant about their parents' condition/illness.

DISCLOSURE TO OTHERS

The issue of primary caregiver disclosure of their HIV/AIDS status was not limited to just their immediate children. Study participants had also revealed their condition to other immediate and extended family members, their significant others including ex-spouses and boyfriends/girlfriends. A handful of the participants had told their neighbors and one or two stated that their church pastor was aware of their condition.

The primary reason for non-disclosure to extended family members, and other friends and neighbors was primarily a fear of rejection. However, many participants also stated that they did not think it was anybody's business and therefore, saw no need to divulge this information.

REPERCUSSIONS OF DISCLOSURE

An interesting finding related to disclosure about their HIV/AIDS was the issue of the repercussions of such disclosure. This included the ultimate effects that disclosure had on primary caregivers, family members and other individuals.

Participants in the study indicated that once their HIV/AIDS status had been revealed there were often repercussions that they had to deal with. These repercussions and consequences were both positive and negative. Some participants reported that family members have supported them. However, while some primary caregivers received immediate support from their family, others received family support gradually over time. One primary caregiver reported on the gradual nature of the acceptance and support he received from his family stating, "In the beginning it was hard, now it's better." This analysis also revealed that although many of the participants reported having supportive families to assist them, some of these same participants also acknowledged that their families were unaware of their illness.

To a large extent family members' reactions to primary caregivers' disclosure also seemed to be very subjective, varying not only from one family to another but also varying among family members. One mother describes the different effects her disclosure had on her three sons: "My 12-year-old is like my father. Always looking after me, telling what I need to do. My 9-year-old avoids the subject but is more upset about it. The 7-year-old is not really interested. He has a short attention span."

Additional adverse reactions to disclosure of primary caregivers' HIV/AIDS statuses included rejection and lack of support for primary caregivers, isolation of primary caregivers, increase in responsibilities of affected children and an increase in negative behaviors of affected children.

Rejection and Lack of Support

Some study participants had experienced negative reactions from immediate family members as was revealed by one primary caregiver who reported on her mother's reaction: "If you get sick, I'll have to put you in a nursing home—you can't never live here!" One survey participant indicated that since her disclosure, her 14-year-old daughter has kept away from her. Another survey participant wrote: "He [my father] don't want me in the house."

Isolation of Primary Caregivers

Another consequence of disclosure was the sense of isolation expressed by some participants who felt that they were either not understood and/or not getting what they needed. For example, one primary caregiver in her interview explained that people needed to "sympathize and not pity people with HIV." Another parent who was living at Mercy House and receiving transitional living accommodation and food made this statement about the support that she was receiving from staff: "But I don't need somebody to tell me what to do or to judge me." Comments like these suggest that although many of these participants had divulged the information to family members and professionals they still end up feeling isolated and misunderstood.

Increase in Responsibilities of Affected Children

A consistent finding was that participants felt that their children, in a sense, lost their childhood innocence when they knew about their parents illness and assumed the caregiving responsibilities of an adult parent. Data revealed that while primary caregivers are grateful for their children's concern and interest, they also feel that it interferes with their being a "normal" child. Consequently, they feel saddened by the fact that their illness has caused these children to

have to grow up too fast. This concern was another reason why parents felt that their children needed more counseling services.

Yet other participants acknowledged that they were uncertain about how their children were coping with the knowledge of their parents' HIV/AIDS status. This concern was reflected in the many requests that primary caregivers made regarding the need for more counseling and support services for their children. Although the need to support and counsel family members was mentioned as important, counseling for children and adolescents was the most frequently mentioned of all service needs.

Negative Behavior of Children

Some participants reported that their disclosure had negatively affected their children's behavior which included their acting out in school. One survey participant reflected on how her disclosure had changed her son: "It's changed my son's attitude for the worst."

ESTABLISHING PERMANENCY PLANS

The development of permanency plans among primary caregivers with HIV/AIDS was a critical aspect of this study. This aspect related to what steps and actions primary caregivers were taking to prepare for their children's future in the event of their death or their inability to physically care for their children. Data revealed that there are four basic scenarios of how parents respond to the issue of permanency planning. These scenarios are represented by four basic categories:

- Legal, formal, written plans (written and legally binding arrangements),
- Informal plans (verbal agreements that are not written),
- Undecided (primary caregivers are unsure about who should be the legal guardians for the children), and
- No plan (no thoughts or arrangements verbal or written about who should be the legal guardian).

Legal, formal, written plans were considered to be the most significant and effective type of permanency plans in this study. Such plans are legal document(s) that clearly designate who should have legal custody of the children in the event of the primary caregiver's death or inability to take care of their children. All significant parties named in the plan were aware of the plan and legal guardians who had been identified had accepted this responsibility. Such plans may also have included a will that divided the caregivers' assets and identified the purposes for which these assets should be used. The primary emphasis however, is the assignment of a legal guardian who would be responsible for the care, safety and well being of the minor children. These plans were legally binding.

Informal plans include some type of verbal plans or informally understood arrangements between the primary caregiver and the identified family member(s) who would be responsible for the children in the event of the primary caregiver's death. This type of plan ranged from participants who described having detailed specific conversations with other family members to others who reported more casual understandings between them and their families. For instance, one participant mentioned "if anything happens to me my mom gets my kids."

In the *undecided* category, participants have thought about making a verbal or written plan but are as yet, undecided as to who would be their children's legal guardian. As such, the caregiver still has to execute the plan by first making a decision on who the guardian, informing others of the arrangements and putting the plan in writing.

Participants who are in the *no plan* category have not made any arrangements for their

children. The analysis shows that these primary caregivers have not any done thinking about this particular issue.

The findings varied regarding whether or not caregivers had made any type of permanency plans for their children and what specific type of arrangements had been established.

For analytical purposes these four categories were given symbolic value where a *legal, formal, written plan* was considered the best possible strategy that primary caregivers could use to prepare and plan for their children’s future. *Undecided* and *no plan* categories had very little or no real value in terms of effective permanency planning.

Data indicate that it is reasonable to assume that primary caregivers may approach the issue of permanency planning somewhat gradually. It appears that primary caregivers move from having no arrangements and considerations about the future of their children (*no plan*) to becoming ambivalent about who should take care of the children (*undecided*). In the next phase primary caregivers become more specific about who should become the legal guardian of their children and verbalize these wishes to those individuals involved in the arrangements (*informal plan*). In the final phase of planning the primary caregiver puts the verbal arrangements into a legal document (*legal, formal, written plan*).

Data reveal that overall primary caregivers in the study did not have *legal, formal plans* for their children. Although the eighteen focus group participants in the study were not specifically polled, data indicate that primary caregivers in the focus groups like those who participated in the interviews (Table 7) and surveys (Table 8) did not have any *legal, formal, written plans*.

Data further suggest however, that many focus group participants like interview participants had made some informal, verbal arrangements with family members. About 56% (14 of 25) interview participants had *informal plans* (Table 7). In contrast, survey participants seemed to have less *informal plans* with only 25% (5 of 20) of those participants indicating that they had an *informal plan*.

Although the reasons for the difference was not known, results further showed that very few of the interview participants had *no plan* 12% (3 of 25), while almost half of the survey participants 46% (8 of 20) reported that they had *no plan*.

TABLE 7: TYPES OF PLANS MADE BY INTERVIEWEES

TYPE OF PLAN	NUMBER OF INTERVIEWEES
Legal, formal, written plans	5
Informal plans (verbal)	14
Undecided	3*
No plan	3
Total	25

*Primary caregivers who had not decided whom they wanted their children to live with.

TABLE 8: TYPES OF PLANS MADE BY SURVEY PARTICIPANTS

TYPE OF PLAN	NUMBER OF RESPONDENTS
Legal, formal, written plans	7
Informal plans (verbal)	5
No plan	8
Total	20

Another significant finding of the study is that although some primary caregivers had not made formal, written plans, a few of these individuals were very clear and emphatic that they did not want their children being raised by their biological fathers who were no longer living with them. This is particularly disturbing when one considers that the rights of these biological parents have not been terminated and therefore, without the legal documentation, regardless of the primary caregiver's wishes, custody/guardianship of these children could be granted to their biological fathers.

Data also revealed that almost all of the study participants who had made legal permanency plans for their children had used the services of Larry Goodwin through the Bay Area Legal Services. Generally, those participants who had decided to make formal plans were satisfied with the arrangements and the services offered through Bay Area Legal Services.

REASONS FOR NOT ESTABLISHING PERMANENCY PLANS

Participants for the most part gave four basic reasons for not making permanency plans for their children. These include:

- Avoidance/Procrastination/Denial
- Lack of information about Legal Services
- Personal Beliefs about Mortality
- Healthy Spouse/Other parent

Avoidance/Procrastination/Denial

Some of the participants felt a general sense of well being and health despite their diagnosis and were therefore, more inclined to dismiss the need to make formal arrangements for their children. Others had a false sense of security and were of the mindset that "maybe nothing will happen." Some other participants had lived so long with the disease (eight years and beyond) they honestly did not feel an urgent concern about the future. Consequently, these individuals did not embark on establishing any legal arrangements for their children and at very best made less concrete, verbal agreements with family members. Others were just very reluctant to address mortality issues, which would inevitably arise if permanency plans were established. As one caregiver remarked she is taking "One day at a time...if I keep thinking about the future I'm gonna run insane."

Personal Beliefs About Mortality

Some of the primary caregivers were unwilling to make any type of formal arrangements for their children because they believed that when plans were finalized they would die. This belief made them reluctant to solidify plans regarding the welfare of their children. A caregiver explained these sentiments stating, "I don't believe in being jinxed or anything. . . I feel if I was to go ahead and write a paper out [i.e. permanency plan], it would jinx me to be sick."

Lack of Information About Legal Services

Some of the study participants were ignorant about legal issues involved with permanency planning, and admitted that they did not know how to go about establishing a plan for their children. Others had not given the whole subject much thought and believed sometimes very simplistically that their siblings or parents would take their children. In addition, there were those participants who had vague ideas of how to go about making their plans legal and binding, while others were genuinely uninformed about these matters but expressed interest in finding out about their options.

Healthy Spouse / Significant Other (Parent)

In quite a few instances participants indicated that permanency plans had not been made because affected children had another healthy, capable parent who would take care of them in the event of the participant's death. With no real need pending, these caregivers did not want to invest in a legal process that they felt was unnecessary for their particular situation.

OTHER ISSUES RELATED TO PERMANENCY PLANNING

In reviewing and analyzing the findings of the study, participants reported on other emotional issues surrounding their mortality. They also reported on the types of keepsake items they would like to leave behind for their children and loved ones.

An area of concern to some of the primary caregivers related to the financial welfare of their children. Since many of the primary caregivers in the study were low-income it is not surprising that some of them stated that they wished they could leave some financial resources for their children. Only a few were currently financially able to set aside some money each month for this benefit, while a few others had some type of insurance policy available for their children in the event of their death. Others appeared to see the need for financial resources for their children but clearly did not have any means of making this a reality.

Other caregivers were more concerned about how their children would cope after they (primary caregiver) died. Many of the participants reported that they were talking with their children about AIDS and other sexually transmitted diseases in an effort to educate, inform and protect them. Such informal talks were being done proactively to assist their children in planning and protecting themselves for the future.

On a more emotional and personal view, participants reflected on the items, articles and things that they would like to leave behind for their children in the event of their death. The most frequently mentioned items included pictures, video recordings, written poems and stuffed toys. The children in the study also reported that they would like similar items to be left for them as keepsake items. In addition, the children in the study like some primary caregivers expressed a desire to keep their siblings together as a family even if their parent died. They also seemed to be interested in holding on to and cherishing the special times that they were spending with their parents while they were alive. Reflecting on just what she would like her mother to leave her one youth reported: "a whole week of just the family doing what my mom likes with pictures and a video camera so you can hear their voice and hear them laughing."

ADDITIONAL OBSERVATIONS

The participants in this analysis were a group that was largely unfamiliar to the team conducting the study' most of whom had little, if any, direct contact or involvement with individuals who are infected with HIV/AIDS or with their children. Some of what was learned, therefore, was unanticipated. This section discusses a number of these observations.

During the planning process of the analysis, the team was concerned that the infected caregivers would be difficult to access, and once contacted, would be reluctant to discuss their situations. However, although it was challenging to recruit participants, the projected number for the focus groups and interviews were successfully secured.

In addition, those caregivers who participated in the analysis were far from reluctant to share their experiences. Instead they were extremely open, and seemed to derive considerable satisfaction from being able to talk about their situations and share concerns about their children. It seemed a relief to some to be able to talk freely about a subject that they perhaps had not previously been able to discuss openly. Focus groups participants also were able to learn of valuable resources previously unknown to them. Several remarked how pleased they were to have been a part of the study, and volunteered to do so again or to assist in any way possible. They seemed to feel empowered by having their experiences and opinions valued by the interviewers.

Perhaps not surprisingly, the lives of these caregivers are filled with stress, not only from their illness, but also from other socio-economic, social and personal sources. Virtually all participants had very limited financial resources. The majority received little if any financial aid. Some participants reported great difficulty in qualifying for SSI; many stated that their Food Stamps had been drastically reduced. Several participants had found Medicaid benefits unavailable. Families in the study also often had to deal with problems associated with living in low-income neighborhoods. One caregiver described the area where she and her children live as a primary concern: "a high crime area, prostitution, drugs, crime ... isolated, without patrolling, very troubling as a parent." She was more worried about the environment than her health.

Most of these caregivers have struggled with drug addiction or alcoholism; some have been prostitutes or incarcerated. They continue to work hard to maintain sobriety and to remain "clean." In addition, these families often lived death-filled existences, in which friends and relatives die, not only of AIDS, but also often from violence. One participant's sister and nephew died of AIDS; two other nephews were killed. Another participant's brother died of AIDS (he committed suicide), and the father of her two sons also died of the disease. The twelve-year-old daughter of one of the caregivers hung herself; the anguished woman wondered if knowledge of the mother's AIDS condition drove the child to kill herself.

There was a pervasive sense of isolation among these caregivers. As one interviewee exclaimed, "this secret is killing me." She was referring to her inability to share the fact of her illness with even the individual she felt closest to: her mother. Fearing the result of such a revelation, she had in fact moved away from her family to avoid discovery, but had concluded she must tell her mother and was concocting an elaborate plan to do so.

Therefore, the sense of isolation, of stigma, prevented some afflicted caregivers from reaching out to the friends, relatives and others in their lives that could support them. The profound feeling of aloneness appeared to be an internalized sense of separateness brought about by confronting one's own mortality.

In spite of all their heavy burdens—the financial pressures, addictions, loneliness, sadness, shame, fear, as well as the pain and suffering caused by the disease itself—these caregivers showed remarkable resilience and ability to survive and to take care of their families. Several spoke positively about their recovery from drugs or alcohol. “I don’t do drugs no more, I don’t drink, and I feel good about me!” Primary caregivers showed great commitment to maintaining their families, were caring for at least some of their children and tending to their needs.

A number of the caregivers in this analysis were employed either full or part-time, in spite of frequent bouts with pain. One mother, despite exhaustion and leg pain as her illness intensified, supported four children mainly on the \$610 a month she earned as a housekeeper at the Ice Palace. Whatever their employment status, these individuals were able to assemble some type of support system, largely on their own, which allowed them to provide for their children. When asked about how they dealt with their condition, many of them referred to spiritual beliefs, even though they might not belong to a formal religious institution.

Virtually all of the participants in this study concluded their remarks with urgent pleas for dissemination of information or education regarding HIV/AIDS, not as a remedy for their own condition, but as a way to improve the situation for future generations. Although they certainly felt that they and their children would have suffered less stigma and rejection had society had a better understanding of AIDS, they also exposed the need for education about risk-behavior to reduce the incidence of AIDS among young people. This externalization of their concerns, the ability to look beyond their personal tragedies, was found to be a powerful strength in this group of caregivers.

IV. LESSONS LEARNED AND RECOMMENDATIONS FOR FUTURE RESEARCH

LESSONS LEARNED

- 1) Recruitment of participants is a lengthy, demanding process, which requires planning, coordination, and patience.
- 2) Recruitment strategies should be varied, including referral by agency staff, word of mouth, and posting of flyers at strategic locations.
- 3) Successful recruitment requires the ability to establish rapport with potential interviewees, usually during a brief telephone contact, so that they will share information needed for them to become part of the study group: name, address, HIV/AIDS status, number of children, etc.
- 4) Collaboration with community professionals who have contact with potential study participants is essential to successful recruitment, as they are the source of potential interviewees.
- 5) Flexibility and sensitivity to the needs of families must be part of the recruiting process and interviews and focus groups should be scheduled at the participants' convenience.
- 6) In studies which rely on small samples, recruited from agencies which serve the same population, care should be taken to avoid duplication of participants in the study.
- 7) According to ethical and professional practice, participants must be informed about the study, its auspices, purposes, and procedures, at the beginning of interviews and focus groups. The informed consent should be discussed prior to a participant's signing it, and the remuneration procedure described at that time as well. These initial procedures will also help to create a safe and comfortable environment for the participant.
- 8) Researchers must respect each family's home, culture, and life style when conducting interviews.
- 9) Instruments and research methodologies must be adapted to families' culture and language; e.g., monolingual participants were interviewed in Spanish.
- 10) Whenever possible interviews should be conducted in dyads, with one researcher the primary interviewer while the second records the session and takes notes. This method allows the interviewer to pay total attention to the participant's responses. In addition, the two researchers can share and compare their observations, for enhanced validation.
- 11) Involving participants in the research process can be an empowering, therapeutic experience for them.
- 12) Monetary compensation may be vital to obtaining participation of family members in the analysis. This remuneration also serves to signify for the participants the importance of their role in the research process.
- 13) Data analysis is a slow, iterative process that relies on raw data, transcripts and personal observation.
- 14) In projects that depend on qualitative data, brainstorming sessions are useful in teasing out observations, implications, and controlling for subjectivity.
- 15) During research studies that involve sensitive, emotional material, obtained during one-

on-one interactions between researchers and participants, it is helpful for staff to have opportunities to ventilate and “debrief.”

RECOMMENDATIONS FOR FUTURE RESEARCH

A main limitation of the study is that it provides information on a relatively small sample of participants, future research should be conducted on these issues with a larger, more demographically diverse group from varying socio-economic backgrounds.

The findings of this study indicate a need for further research in the following areas:

- The relevance of the developmental stages of children (e.g. early childhood, and adolescents) affected by AIDS to their service needs.
- Studies focusing on the needs of the social support networks of families affected by HIV/AIDS including spouses, parents, siblings, close relatives and other significant parties.
- Studies relating to the impact of culture and ethnicity on coping strategies, various communication patterns and service delivery issues for families affected by HIV/AIDS.
- Further study on the impact of caregivers’ bereavement process on permanency planning.

V. ACTION PLAN

A SYSTEM OF CARE FOR PERMANENCY PLANNING: CHILDREN AFFECTED BY HIV/AIDS

This system will be developed by a Coalition of Stakeholders which includes family members and the following organizations/agencies: Bay Area Legal Services, Children's Medical Services, Family Enrichment Center, Francis House, the Louis de la Parte Florida Mental Health Institute at the University of South Florida, Mercy House, and the Tampa AIDS Network. The coalition will also include other community partners (See System of Care Chart). This coalition will be responsible for implementing the system of care. The analysis team from Louis de la Parte Institute will play the leadership role in convening and establishing this group.

This system of care will be based on five principles: community-based, cultural-competent, family-centered, strengths-based, and integrated and coordinated. Cultural competency and accessibility to services are central themes that will impact overall implementation of the action plan. The action steps will also involve active participation from caregivers and utilize family strengths.

This system of care that has emerged from the major findings of the analysis includes four service areas: Education, Legal, Mental Health and Social Support. This section highlights these major findings and action steps.

EDUCATION

Results: *There is a need for more comprehensive education about HIV/AIDS for the general public, pre-adolescents, teenagers and extended family members who are affected by the disease.*

ACTION STEPS

Members of the Coalition will develop a comprehensive training and education plan.

- Organize a local county wide AIDS Awareness Campaign for the *general public* that will consist of the following:
 - * a selection of written materials,
 - * discussion groups,
 - * invited lectures, workshops, and
 - * public service announcements.

- Provide AIDS information to *Pre-adolescents and Teenagers*:

- * The coalition representatives will meet with designated education administrators regarding the inclusion or extension of the HIV/AIDS information in school curricula. An educator will be invited to represent the school system at coalition meetings.
- * Community partners such as Boys and Girls Clubs will disseminate information.
- Provide home and/or community-based education to *Extended Family Members*:
 - * Community providers will offer families information on AIDS in their community-based agencies and also in the families' homes.
 - * Utilize infected/affected family members for peer training.
- Organize a conference for infected primary caregivers and their families to learn about health issues and other concerns about living with HIV/AIDS. This conference will feature health care providers, mental health and social service professionals and individuals infected and affected by HIV/AIDS.

Results: *There is a need for agencies to demonstrate more sensitivity with regard to culture, gender and ethnicity.*

ACTION STEPS

The Coalition of Stakeholders will develop guidelines for Coalition members and their community partners to provide cultural competence training to service providers.

- Seek the expertise of local partners such as Louis de la Parte Florida Mental Health Institute and TAN.
- Conduct focus groups with family members to assess the relevant gender, ethnic and cultural considerations.
- Make effort to increase the number of services providers from ethnic minorities.

Results: *There is an inconsistency in information dissemination and a need for providers to establish better dissemination strategies.*

ACTION STEPS

The Coalition along with community partners will facilitate efforts to improve dissemination of information.

- Circulate uniform, written material among all human service agencies which serve individuals with HIV/AIDS.
- Encourage providers to train staff to ensure that information is given to all clients in a timely, uniform manner.

LEGAL SERVICES

Results: *Overall caregivers did not have legal, formal, written permanency plans for their children who are affected by HIV/AIDS.*

ACTION STEPS

Coalition will compile strategies to increase availability of legal services to families affected by HIV/AIDS. These strategies will include coordinating funding opportunities, seeking volunteers and disseminating information.

- Increase the number of professionals who provide legal services for caregivers who want permanency planning for their children (e.g., consultation, technical assistance).
- Provide more in-home and community-based legal assistance.
- Provide parent training on how to develop a permanency plan.
- Design a family-friendly brochure that outlines the reasons, benefits and procedures involved in formalizing permanency plans for children affected by HIV/AIDS. This brochure will also include a list of available resources and will be disseminated at various human service agencies.
- Seek funding for legal costs associated with finalizing permanency plans for low-income caregivers.

MENTAL HEALTH SERVICES

Results: *Budget cuts experienced by some providers have resulted in a decrease in available mental health services. There is a need for more consistent counseling, therapeutic and mental health services for primary caregivers, affected children, extended family members and other individuals affected by HIV/AIDS.*

ACTION STEPS

The Coalition will collaborate with other community partners to offer enhanced mental health services to primary caregivers with HIV/AIDS, children affected by HIV/AIDS and extended family members and significant others.

For Primary Caregiver with HIV/AIDS:

- Increase in-home, community-based, therapeutic interventions that are culturally-competent and family-centered.
- Provide different types of therapeutic intervention such as group, individual and family therapy.
- Use a strength-based approach in providing peer support and facilitation to help caregivers deal with clinical issues that may interfere with establishing a permanency plan (e.g., peers utilizing experiences to assist others).
- Provide interventions for primary caregivers that assist them in dealing with their affected

children around the following issues:

- * How to increase positive interactions with their children.
- * How to talk with their children about HIV/AIDS, mortality, and the prospect of living with someone else.
- * How to give their children a lasting sense of family identity and connection (e.g., keepsakes such as videos and life books).

For Children Affected by HIV/AIDS:

- Increase on-going individual and group therapy sessions based on the developmental needs of the children (e.g. play therapy group for younger children). This service will be provided through an agency such as the Life Center, which has expertise in responding to grief issues in children.
- Develop more appropriate mental health intervention strategies for teenagers and adolescents (e.g. support groups and expressive activities such as drama and music).

For Extended Family Members and Significant Others:

- Develop forums for spouses, grandparents and other relatives affected by HIV/AIDS to share their experiences and feelings and receive information on coping strategies. Collaborate with existing groups such as the local Tampa Bay “grandparents group” to obtain support for extended family members.

SUPPORT SERVICES

Results: *The findings indicated that overall informal support for caregivers ranged on a continuum from little or no support to satisfactory support. However, there is a need for more informal supports that are tailored to HIV/AIDS related issues.*

ACTION STEPS

The Coalition will develop a comprehensive plan to increase informal supports and resources.

- Invite local churches to participate in coalition meetings.
- Identify churches that are interested in hosting activities, providing counseling and spiritual guidance for families affected by AIDS.
- Recruit volunteers from the community to provide support services for affected families.
- Develop a time dollar program where families affected by HIV/AIDS can volunteer their time or provide some service in exchange for services such as babysitting, transportation, etc.
- Establish a peer support group of primary caregivers infected by HIV/AIDS that provide a forum for caregivers to offer emotional support and advice, and respite for each other.

Results: *Caregivers and children stated that group and social activities were needed to help families and provide an enhanced sense of well-being.*

ACTION STEPS

The Coalition will develop a plan that will outline activities to stimulate affected children and enrich their lives, as well as provide respite opportunities to primary caregivers. Members of the Coalition will be proactive in identifying these opportunities.

- Increase the number of extra-curricular activities for caregivers and their children through trips and visits to museums, art festivals, and entertainment centers.
- Engage infected and affected family members in activities and groups that are not related to HIV/AIDS.
- Recruit and train mentors to assist in nurturing and facilitating the overall development of affected children.
- Provide respite opportunities for primary caregivers and their children by using volunteers from the community, peer support group and churches.

Results: *A lack of transportation was identified as a barrier that prevented caregivers from using formal and informal services.*

ACTION STEPS

The Coalition will seek funding avenues to provide more transportation options (other than bus tokens) for caregivers and implement a transportation plan that specifically addresses the transportation needs of families affected by HIV/AIDS.

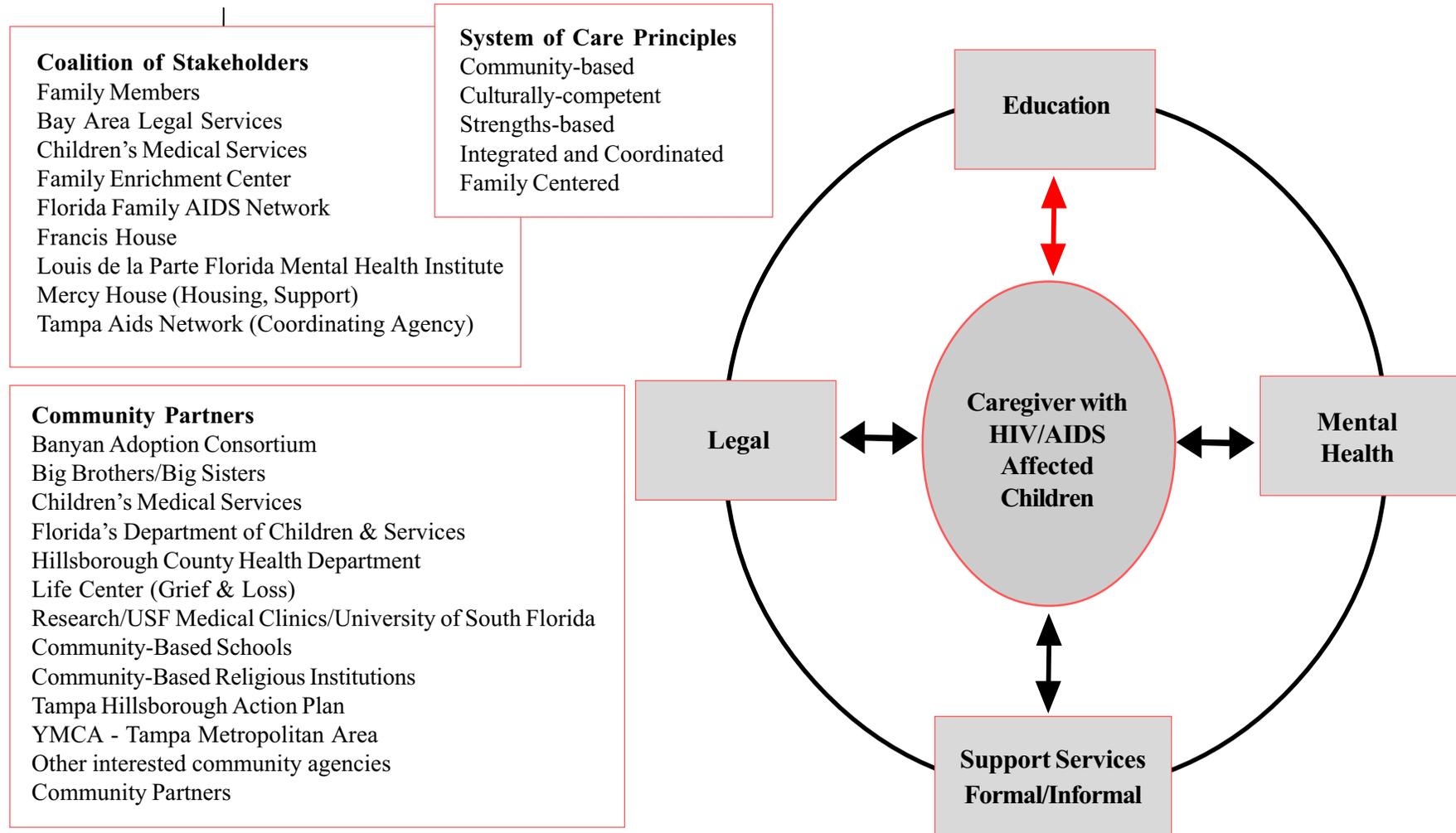
- Develop a transportation program that will include the following components:
 - * Organize car pools among support group members.
 - * Time dollar program where in return for volunteering their services infected caregivers would receive transportation services as payment for their service.
 - * Donations from local companies to pay for cabs for infected caregivers.
 - * Assisting with down payments for vehicles for primary caregivers who meet certain criteria that are set by the coalition and community partners involved.

Results: *There was an expressed concern for service providers to extend child care hours of operation.*

ACTION STEPS

- Develop a list of adult caregivers outside and within the community who will be willing to babysit for affected children when there is a crisis and the primary caregiver is unable to care for the children.
- Explore avenues to create a system where affected families have access to 24-hour child care to accommodate nontraditional employment schedules and times of crisis (e.g., caregiver works evenings, caregiver goes to emergency room and has to remain overnight).

A System of Care for Permanency Planning: Children Affected By HIV/AIDS



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APPENDICES

Appendix 1

BANYAN ADOPTION CONSORTIUM

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John Talone
FMHI. - PDC
Law and Mental Health - MHC 1633
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Appendix 2a

DEMOGRAPHIC SUMMARY OF PRIMARY CAREGIVERS FOCUS GROUPS

Two primary caregiver focus groups consisted of 18 participants total. Sixteen Pre-Screening Questionnaires were filled out for these participants. One of the remaining participants was a spouse of another who arrived at the focus group session. The following demographic information is taken from the pre-screening forms.

HOW DID PARTICIPANTS FIND OUT ABOUT THE FOCUS GROUP?

- 14 found out through their TAN case manager
- 1 found out through the flyer
- 1 found out through another participant

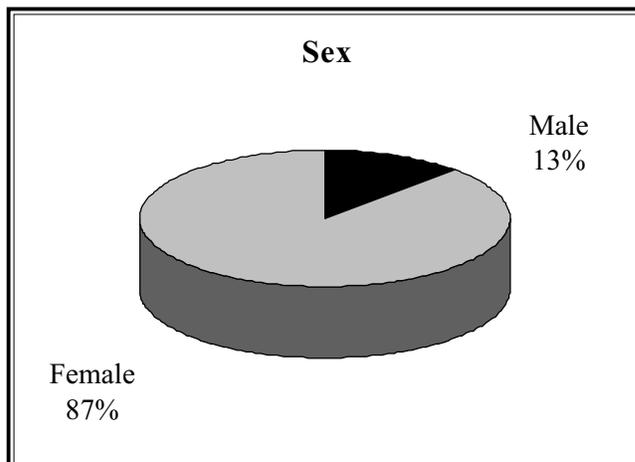
ALL FOCUS GROUP PARTICIPANTS' PREFERRED LANGUAGE IS ENGLISH

AGE OF PARTICIPANTS (Note: One participant did not include her age)

- The **average** age of participants is 32.8
- The **range** of ages is 18 to 44
- Note: One participant is 18 and one other is 20. The next oldest participant is 27.

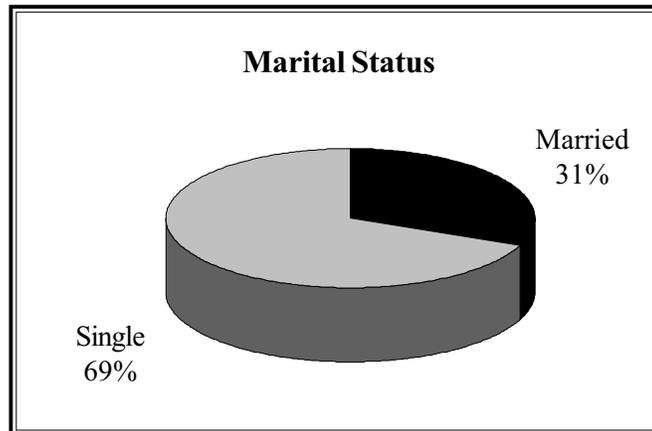
SEX

- 14, or 87%, are female
- 2, or 13%, are male



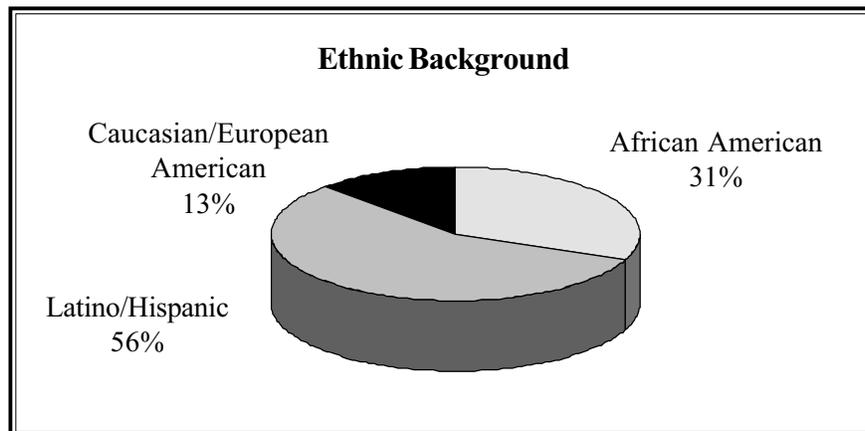
MARITAL STATUS

- 11, or 69%, of participants are single
- 5, or 31%, of participants are married



ETHNIC BACKGROUND OF PARTICIPANTS

- 9, or 56%, of participants are Latino/Hispanic
- 5, or 31%, of participants are African American
- 2, or 13%, of participants are Caucasian/European-American



HOW MANY CHILDREN ARE BEING CARED FOR BY THE PARTICIPANT?

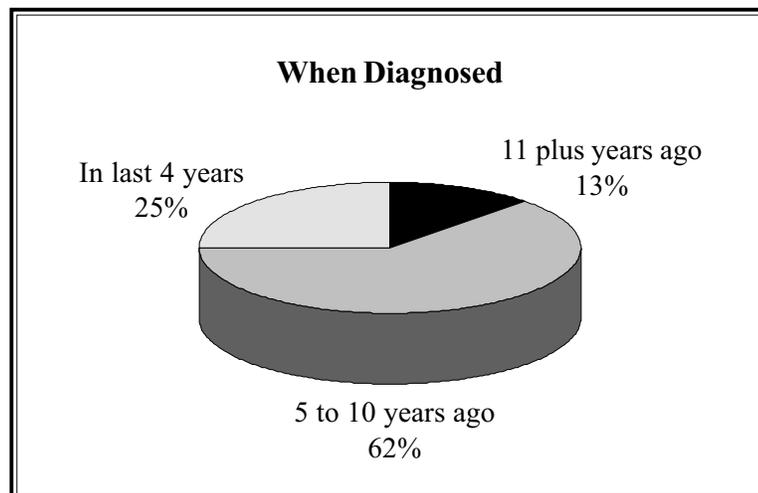
- 9 participants, or 56%, are taking care of 1 or 2 children
- 7 participants, or 44%, are taking care of 3 or more children
- 5 are caring for 1 child
- 4 are caring for 2 children
- 3 are caring for 3 children
- 4 are caring for 4 or more children

CHILDREN'S AGES

- The **average** age of the children being cared for is 7.18
- The **range** is 2 months to 16 years old

WHEN WERE THE PARTICIPANTS FIRST DIAGNOSED?

- 2 diagnosed in 1988
- 3 diagnosed in 1990
- 1 diagnosed in 1991
- 1 diagnosed in 1992
- 1 diagnosed in 1993
- 4 diagnosed in 1994
- 2 diagnosed in 1995
- 1 diagnosed in 1996
- 1 diagnosed in 1997



PARTICIPANTS GENERAL STATE OF HEALTH

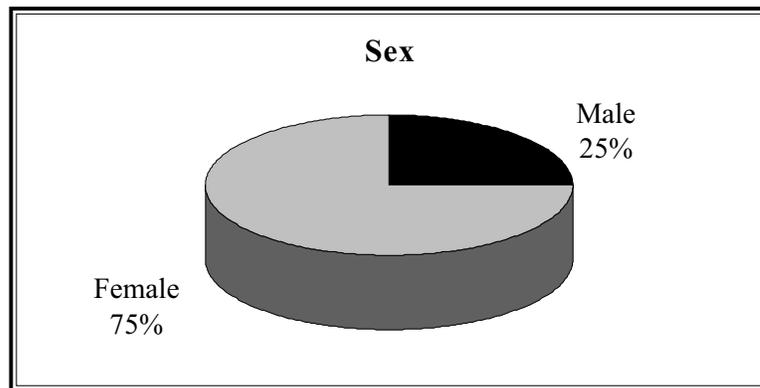
- 1, or 6%, said poor
- 3, or 19%, said fair
- 11, or 69%, said good
- 1, or 6%, said excellent

DEMOGRAPHIC SUMMARY OF ADOLESCENT FOCUS GROUP

Four adolescents participated in the focus group.

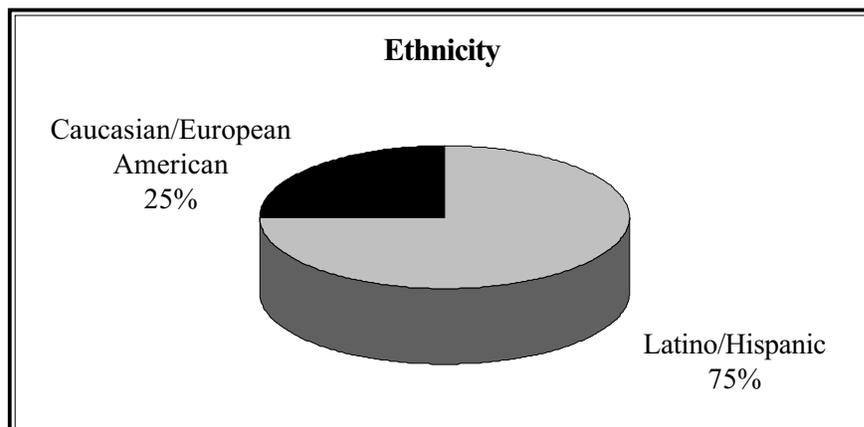
SEX

- 3, or 75%, are female
- 1, or 25%, are male



ETHNICITY

- 3, or 75%, are Latino/Hispanic
- 1, or 25%, is Caucasian/European-American



Appendix 3

DEMOGRAPHIC SUMMARY OF PERMANENCY PLANNING INDIVIDUAL INTERVIEWS

Twenty-five individuals participated in this part of the study. For each participant, a Pre-screening Questionnaire was filled out which covered the following demographic information.

HOW DID PARTICIPANTS FIND OUT ABOUT THE FOCUS GROUP?

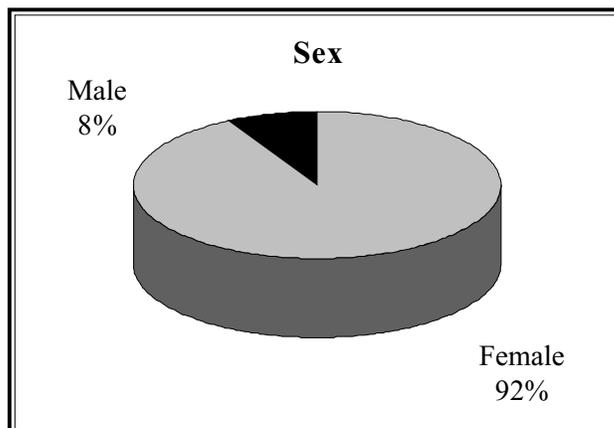
- 9 found out through their TAN case manager
- 7 found out through the flyer
- 4 found out through “other”
- 1 found out through Francis House
- 1 found out through Mercy House
- 1 found out through Great Day
- 1 found out through St. Tims
- 1 found out through Big Brothers/Big Sisters

AGE OF PARTICIPANTS (Note: The age of two participants is unknown)

- The **average** age of participants is 35.7
- The **range** of ages is 18 to 49

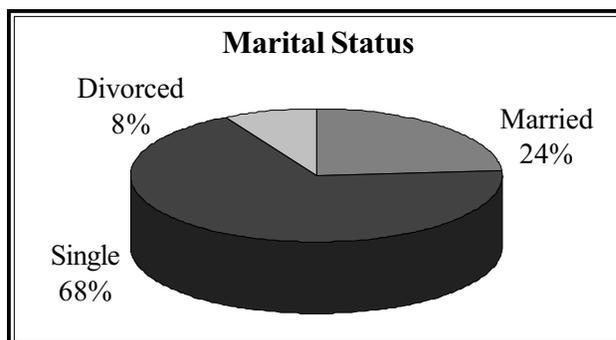
SEX

- 23, or 92%, are female
- 2, or 8%, are male



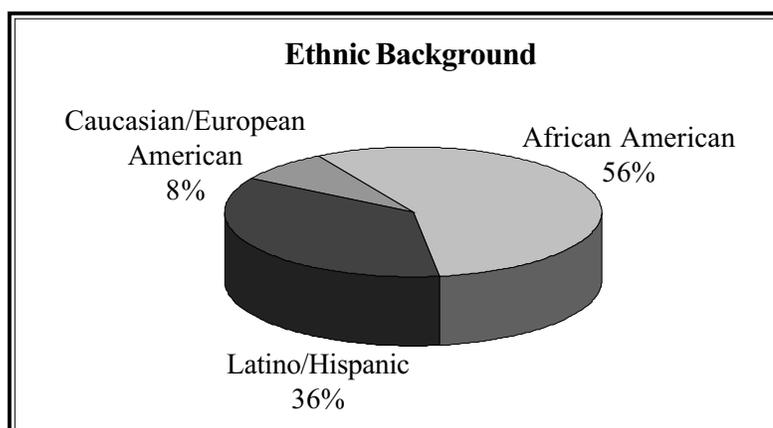
MARITAL STATUS

- 17, or 68%, of participants are single
- 6, or 24%, of participants are married
- 2, or 8%, of participants are divorced



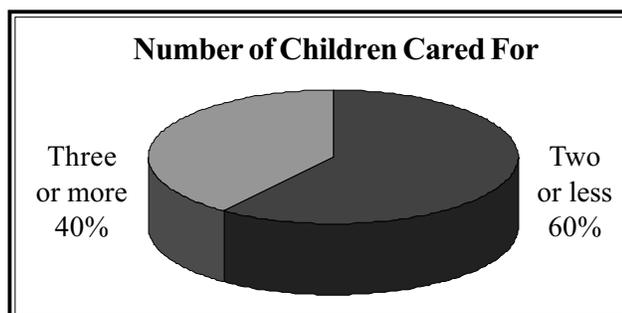
ETHNIC BACKGROUND OF PARTICIPANTS

- 14, or 56%, of participants are African American
- 9, or 36%, of participants are Latino/Hispanic
- 2, or 8%, of participants are Caucasian/European-American



HOW MANY CHILDREN ARE BEING CARED FOR BY THE PARTICIPANT?

- 15 participants, or 60%, are taking care of 1 or 2 children
- 10 participants, or 40%, are taking care of 3 or more children
- 8 are caring for 1 child
- 7 are caring for 2 children
- 6 are caring for 3 children
- 3 are caring for 4 or more children
- 1 is caring for 7 children

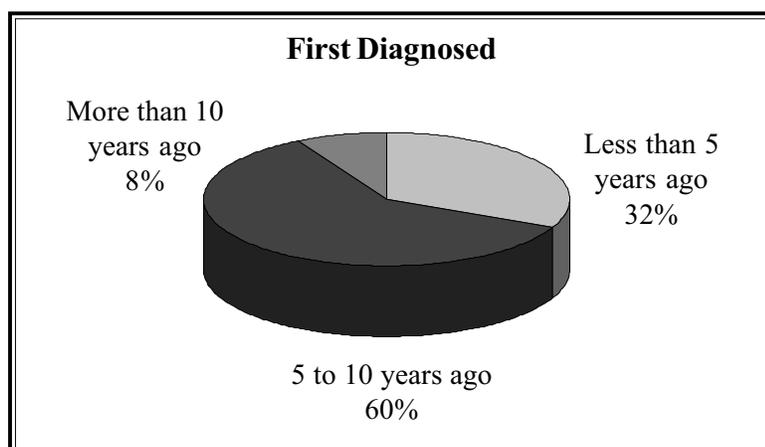


CHILDREN'S AGES

- The **average** age of the children being cared for is 10.1
- The **range** is 1 to 30 years old

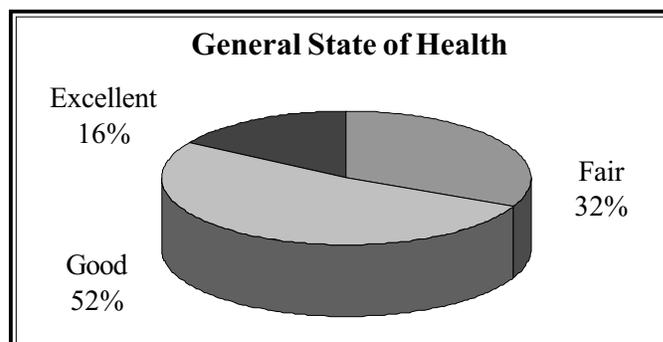
WHEN WERE THE PARTICIPANTS FIRST DIAGNOSED?

- 1 diagnosed in 1985
- 1 diagnosed in 1986
- 1 diagnosed in 1989
- 2 diagnosed in 1990
- 1 diagnosed in 1991
- 3 diagnosed in 1992
- 4 diagnosed in 1993
- 3 diagnosed in 1994
- 4 diagnosed in 1995
- 1 diagnosed in 1996
- 1 diagnosed in 1997
- 2 diagnosed in 1998
- 1 diagnosed 7 to 10 years ago
- 8 diagnosed less than 5 years ago
- 15 diagnosed 5 to 10 years ago
- 2 diagnosed more than 10 years ago



PARTICIPANTS' GENERAL STATE OF HEALTH

- 8, or 32%, said fair
- 13, or 52%, said good
- 4, or 16%, said excellent



PRIMARY CAREGIVER FOCUS GROUP QUESTIONING ROUTE

OBJECTIVE 3: AVAILABLE RESOURCES

Identify Any Existing Family Supports And Programs

1) What are some of the services that you have available to help you and your family?

Probe: What kinds of services are provided for your family?

Effectiveness/Responsiveness

2) Describe the experience you have had with the services?

Probes: What happened (good or bad) when you were getting help?

Have other people you know had similar experiences?

How easy was it for you to contact the people providing the services?

3) Describe how these services have helped/not helped you with your challenges/situation?

Probes: How satisfied are you with the help you have received?

How has this service improved your situation and that of your family

4) What would you like to see done in order to improve the quality of services you are now receiving?

Probes: What would you like to be different?

Informal Supports

5) How do other people such as family members, your church and friends help you and your family with your situation?

Probes: Do you get any help from other sources in your community such as your friends, neighbors or any other individuals?

What other people/supports have been helpful to you?

OBJECTIVE 2: FAMILY NEEDS

OBJECTIVE 3: IDENTIFY GAPS

Needs/Gaps

6) How has the diagnosis of HIV/AIDS affected your family?

Probe: Has your relationship (i.e. attitude, discipline, affection) with your child(ren) changed?

Has your children's attitude towards you changed? (i.e. respect)?

Are there things you can no longer do with your children that you would like to do?

7) What are some of the services that your family needs but is not currently getting?

Probe: Can you explain why you are not able to receive these services?

OBJECTIVE 1: PERMANENCY PLANNING

8) What are some of the concerns, issues that you have regarding the welfare of your children in the future?

Probe: What are some of the issues that have come up since you told your child(ren) about your diagnosis?
What are the reasons that have kept you from telling your children?
What do you think will happen if they never get to know?
Are there any legal issues that you know of that may affect your children's future?
Do you worry that your children might be taken away from you?
What do you think your family needs to help prepare them for the future?

9) Describe any arrangements/plans you have made for taking care of your children in the future?

Probe: Have you thought about adoption, placing them with a family member etc.?
Have you drawn up any legal documents, or made any kind of financial arrangements to help the family in the future?
Are there any special keepsake items that you want to give your children or any special activity you would like to share with your child(ren)?
What supports (formal and informal) have you used to make these plans?

ADOLESCENTS FOCUS GROUP QUESTIONING ROUTE

OBJECTIVE 3: AVAILABLE RESOURCES

Identify Any Existing Family Supports And Programs

1) What are some of the services that are available to help you and your family?

Probe: What sorts of services are provided for your family?

Effectiveness/Responsiveness

2) Describe the experience you or your family had with the services?

Probes: What happened (good or bad) when you were getting help?
Have other people you know had similar experiences?
How easy was it for you or your parent to contact the people providing the services?

3) How have these services helped/not helped you cope with your family situation?

Probes: How satisfied were you with the help you received?
How have these service improved your and your family's ability to cope with this situation?

Informal Supports

4) How do other people such as family members, the church and friends help you and your family with your situation?

Probe: Do you get any help from other sources in your community such as your friends, neighbors or another individuals?
What other people/supports have been helpful to you?

OBJECTIVE 2: FAMILY NEEDS

OBJECTIVE 3: IDENTIFY GAPS

Needs/Gaps

5) How has the diagnosis of HIV/AIDS affected your family?

Probe: Has your relationship with your parent (i.e. attitude, discipline, affection) changed?
Has your attitude towards your parents changed (i.e. respect etc.)?

6) What are some of the services that your family needs but is not currently getting?

Probe: What are some of the services that would be helpful for your family?

Can you explain why you are not able to receive these services?

OBJECTIVE 1: PERMANENCY PLANNING

7) What are some of the concerns and issues that you have about the future of your family?

Probe: Do you worry that you might be taken away from your parent or that your family will be split up in the future?
What do you feel your family needs to help prepare for the future?

8) Describe any arrangements/plans that your family has made for taking care of the children in the future?

Probe: Have any plans been made to place you or your siblings with other family members etc.?
Are you aware of any documents, financial arrangements that that exist to help the family in the future?
Are there any special keepsake items that you would like to receive from your parent or any special activity you would like to share with your parent?

PROVIDER FOCUS GROUP QUESTIONING ROUTE

OBJECTIVE 3: AVAILABLE RESOURCES

Identify Any Existing Family Supports And Programs

- 1) What are some of the services that are available to help parent infected with HIV/AIDS and their families that are affected by HIV/AIDS?

Probe: What sorts of services do you provide to these families?

Effectiveness/Responsiveness

- 2) How would you describe the experience that these families had with the services they used?

Probes: What happened (good or bad) when you were getting help?
Have other people you know had similar experiences?
How easy was it for the family to contact you or the people providing the services?

- 3) Describe how these services have helped/not helped these families cope with problem/situation?

Probes: How satisfied were you with the help you received?
How has this service improved your and your family's ability to cope with their situation?

- 4) What would you like to improve regarding the quality of services you are providing?

Probes: What would you like to be different?

Informal Supports

- 5) How do other people such as family members, the church and family friends help families that are affected by HIV/AIDS?

Probes: What other informal sources of support (i.e. friends, neighbors or other individuals) do families affected by HIV/AIDS receive?
What other people/supports have been helpful to these families?

OBJECTIVE 2: FAMILY NEEDS

OBJECTIVE 3: IDENTIFY GAPS

Needs/Gaps

- 6) What are some of the services that families affected by HIV/AIDS need but are not currently getting?

Probe: Can you explain why you are not able to receive these services?

OBJECTIVE 1: PERMANENCY PLANNING

7) What are some of the reasons that have kept parents from telling their children that they have HIV/AIDS?

8) What are some of the concerns, issues that you (provider) have regarding the welfare of children affected by HIV/AIDS in the future?

Probe: Are there any legal issues that you know of that may affect these children's future?
Are you concerned that children might be taken from their parent because they are unable to care for them in the future?
What do you think these families need to help prepare them for the future?

9) Describe any arrangements/plans that caregivers have made for taking care of their children in the future?

Probe: Have caregivers seriously considered placing their with a family member etc. or putting them up for adoption as permanency planning options?
Has the caregiver drawn up any legal documents, or made any kinds of financial arrangements to help their family in the future?
What supports have you provided to help families plan for the future?

INTERVIEW GUIDE PRIMARY CAREGIVERS

OBJECTIVE 3: AVAILABLE RESOURCES

1) What are some of the services that are available to help you and your family?
(Identify organizations as well as services and programs, if possible).

Probe: What sorts of services are provided for your family?

Effectiveness/Responsiveness

2) How would you describe the experience you had with the services?

Probes: What happened (good or bad) when you were getting help?
Have other people you know had similar experiences?
How easy was it for you to contact the people providing the services?

3) How have these services helped/not helped you with your problem/situation?

Probes: How satisfied were you with the help you received?
How has this service improved your and your family's situation?

4) What would you do to improve the quality of service you (have received) or are now receiving? (Identify specific changes that could improve service/program)

Probes: What would you like to be different?

Informal Supports

5) How do other people such as family members, your church and friends help you and your family with your situation?

(Identify any natural supports different from the more formal agencies that are helpful)

Probes: Do you get any help from other sources in your community such as your friends, neighbors or another individuals?
What other supports have been helpful to you?

OBJECTIVE 2: FAMILY NEEDS

OBJECTIVE 3: IDENTIFY GAPS

Effect Of Diagnosis On Family/Needs/Gaps

6) What are some of the services that your family needs but is not currently getting?
(services that are not available which are needed by caregiver)

Probe: Can you explain why you are not able to receive these services?

For Those Individuals Who Have Told Their Children

7a) How has the diagnosis of HIV/AIDS affected your family?

- Probes:** Has your relationship (i.e. attitude, discipline, affection) with your child(ren) changed?
Have your child(ren's) attitude towards you changed (e.g. respect)?

For those Individuals who have not told their children

7b) What are the reasons that have kept you from telling your child(ren)?

OBJECTIVE 1 - PERMANENCY PLANNING

8) What are some of the concerns, issues that you have regarding the welfare of your children in the future? (Family's fears, constraints)

- Probe:** What are some of the issues that have come up since you told your child(ren) about your diagnosis?
Are there any legal issues that you know of that may affect your children's future?
Do you worry that your children might be taken from you?
What do you think your family needs to help prepare them for the future?

9) Describe any arrangements/plans you have made for taking care of your children in the future (Identify actual plans and arrangements).

- Probe:** Have you drawn up any legal documents, or made any kind of financial arrangements to help the family in the future?
What supports have you used to make these plans (informal and formal supports)?
Are there any special keepsake items that you want to give your child(ren)?
Have you thought about adoption, placing them with a family member etc.?

10. Have any particular issues/concerns come up as a result of your disclosing diagnosis?

Yes No

If yes, list these issues/concerns. _____

11. In your opinion are you currently physically and emotionally able

Yes No

If yes, how well do you think you are caring for your children?
(circle the best description)

poor fair good excellent

12. List some of the services that you and your family need but are not currently getting?

13. Do you feel that if these needed services are provided your family life will improve overall?

Yes No

14. List any other concerns, issues that you have regarding the welfare of your children in the future?

15. Do you worry that your children might be taken from you in the future if you become physically unable to take care of them?

Yes No

16. Have you taken any steps to make arrangements for taking care of your children in the future if you become unable to do so?

Yes No

If yes, describe what you have done. (e.g., draw up legal documents, spoken to the children/family members and/or friends about what should happen to the children in the future.

17. Are there any supports or things you need that might make planning children in the future if you become unable to do so?
for the future of your children more effective?

Yes No

If yes, what are these things?

18. Please feel free to share any thoughts regarding this subject matter which you feel are important for us to know.

We appreciate and thank you for your honest responses.

PERMANENCY PLANNING FOCUS GROUP—PROFESSIONALS

MARCH 3, 1998

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Tampa, FL

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3. Francis House
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Tampa, FL 33603

4. Hillsborough County Public Schools
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Tampa, FL 33602

5. Family Enrichment Center/Great Day
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Tampa, FL 33610

MARCH 5, 1998

1. Tampa Aids Network
11215 N. Nebraska
Suite B-3
Tampa, FL 33612

2. Center for HIV Education Research
USF/FMHI
MHC 4-124

3. Family Resources
PO Box 13087
St. Petersburg, FL 33733

4. Bay Area Legal Services
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5. Dept. of Children & Families
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Tampa, FL 33614

Appendix 8a

FOCUS GROUP SUMMARY SHEET

SERVICES

- 1) Identify available resources and give some indication as to participants' assessment of each service's usefulness or effectiveness.
- 2) Describe any issues, barriers or positive, benefits e.g. case manager's attitude, operating hours, confidentiality issues etc.
- 3) Describe any unusual or interesting elements of the services not captured in 2.
- 4) Identify gaps in system (i.e. client needs not addressed)

PERMANENCY PLANNING

- 5) Give some description of the extent to which participants have made plans for their children and indicate what form these plans are in written, verbal, legal etc.
- 6) Give some indication as to whether primary caregivers have told their children and identify reasons why family members have not told their family. (Please discuss biological children separately from siblings and parents).
- 7) Describe other issues that are important to primary caregivers.
- 8) Describe any other findings.

MODERATOR AND CO-MODERATORS COMMENTS

- 9) Please describe any comments/findings pertinent to the study not already mentioned.

INTERVIEW SUMMARY SHEET

SERVICES

- 1) Identify available resources and give some indication as to participants' assessment of each service's usefulness or effectiveness.
- 2) Describe any issues, barriers or positive, benefits e.g. case manager's attitude, operating hours, confidentiality issues etc.
- 3) Describe any unusual or interesting elements of the services mentioned in 2.
- 4) Identify gaps in system (i.e. client needs not addressed)

PERMANENCY PLANNING

- 5) Give some description of the extent to which participants have made plans for their children and indicate what form these plans are in written, verbal, legal etc.

Identify any special keepsake items that primary caregivers want to give to their child(ren).

- 6) Give some indication as to whether primary caregivers have told their children and identify reasons why family members have not told their family. (Please discuss biological children separately from siblings and parents).
- 7) Describe other issues that are important to primary caregivers.
- 8) Describe any other findings.

INTERVIEWERS COMMENTS

- 9) Describe any findings relevant to the study not already mentioned.

Appendix 9

ATTENTION!

WHAT: A discussion group of 12 parents. Strictly Confidential.

WHO: Parents and caregivers who have HIV/AIDS.

WHY: To talk about your needs, available services, plans for taking care of your children, and other issues affecting parents with HIV/AIDS who are caring for their children. We want to know what is working and what could use some change.

WHERE: FRANCIS HOUSE and Tampa AIDS Network (TAN).

WHEN: February 25th and 27th. Afternoon and evening hours.

** You will receive \$25.00 at the end of the group session. **

If you are interested, please call
Meredith Deming at 974-6186
on Thursdays between 12:00 and 5:00 PM.

Appendix 10

The screening questionnaire will be completed after the initial contact has been made with a potential focus group participant.

SCREENING QUESTIONNAIRE FOR FOCUS GROUP PARTICIPANTS

Rap: My name is _____, I work with the Department of Child and Family Studies at the University of South Florida. First, let me explain about the project so you can decide if you're interested in participating in it. This project is being conducted by the Department of Child and Family studies and we are looking at families who are affected by HIV/AIDS in the Hillsborough county area. The goal of this study is to learn about the supports and services that need to be provided to assist these families and develop some possible strategies that will help caregivers with HIV/AIDS adequately support and care for themselves and their children.

Therefore, in addition to obtaining information about family needs and services, this study will look at the different types of arrangements primary caregivers are making in order to ensure that their children will be well taken care of if they become unable to do so in the future. In order to get this information we will be having a small group discussion with about 10 parents who have HIV/AIDS and are taking care of their children. We feel that you can provide us useful information about different services and the kinds of help that families in similar situations might need. We expect that the information you share with us will provide data that is needed to help improve the quality of programs that are currently available for children and families in Hillsborough county.

The group discussion will be tape recorded so that we can better document your comments and experiences but everything you tell us will be confidential and your name will never appear in any documents or reports we produce as a result of this discussion. In addition, your participation will not affect any services you may currently be receiving.

The group discussion will last about 2 hours and your participation is completely voluntary. In other words you can chose to stop participating in the discussion at any time. At the end of the discussion each participant will receive \$25.00 as reimbursement for any babysitting and/or transportation expenses incurred because of the group meeting. Do you think this is something you would be interested in at this time?

If participant says yes, then continue with screening questionnaire.

If no, then ask participant whether they would be interested in doing a one-on-one interview (paid \$25) or completing a survey (not paid).

Interview:

Survey:

Name: _____ **Tel:** _____ **Time to call:** _____

Screening Questionnaire

Complete this form if participant states that he/she is interested in participating in the focus groups.

I'd like to ask you a few questions, is that okay? If yes, then proceed.

1. How did you find out about the focus group?

_____ Flyer

_____ Other (please explain)

_____ TAN case manager

2. What language do you prefer to speak?

_____ English

_____ Spanish

3. Are you Married _____ Single _____ Divorced _____ ?

4. How many children are you currently taking care of? _____

What are their ages

5. What is your ethnic background?

_____ African American

_____ Asian

_____ White

_____ Latino/Hispanic

_____ Other: identify _____

6. When were you first diagnosed HIV positive or AIDS?

Month _____

Year _____

7. Have you told your child(ren) that you are HIV positive or have AIDS?

Yes _____

No _____

8. At this time how would you describe your general state of health?

Excellent _____

Good _____

Fair _____

Poor _____

9. The focus group will take about 2 hours. What is the best time for you to meet with the other parents and us?

	Wednesday Feb. 25, 1998 TAN	Friday Feb. 27, 1998 Francis House
AM (before 11:00 a.m.)		
PM (11:00 a.m. - 1:00 p.m.)		
Evening (after 5:00 p.m.)		

The meeting will probably be held at TAN/Francis House.

10. Would you have a problem with finding a ride? Yes No

11. Can someone take care of your child(ren) while you meet with us?
 Yes No

If no, how many children need babysitting ?
 Indicate their age(s)

12. Name: _____ Age: _____ Sex: _____

Address: _____

Phone: _____ (or phone number to leave messages)

Thank you for your time. We will call you to confirm your attendance.

13. Additional Comments/Observations

Appendix 11a

**CRITICAL ISSUES ANALYSIS
PARTICIPANT'S ACKNOWLEDGMENT OF
INFORMED CONSENT**

PRIMARY CAREGIVER FOCUS GROUPS

I understand that the purpose of this research study is to learn about the permanency and support needs of children, adolescents and families who are affected by HIV/AIDS in Hillsborough County. Specifically, this study will capture the perceptions and experiences of primary caregivers who are infected with HIV/AIDS and their children who are affected by HIV/AIDS.

I am aware that I will be asked to participate in a group discussion and answer questions regarding permanency plans and the needs and services that affect me and my family. If an overflow situation occurs and I cannot participate in the group discussion I will have to complete a brief overflow questionnaire/survey. I understand that this focus group will be tape recorded to ensure that all information is captured more accurately. I understand that the information that is collected will be kept confidential and that I will never be identified by name in any report that is produced as a result of this study. I understand that there are situations which require that this confidentiality be broken. These are: if I am in danger of harming myself or someone else or if child abuse is involved.

I have had the chance to ask questions about the study and I feel that these questions have been answered. I understand that my participation is voluntary. Although I will not be paid for participating, I will receive \$25 as reimbursement for any expenses (i.e. transportation and baby sitting) that I may incur as a result of this study. I am aware that I can discontinue my participation in the group discussion at any time and that any decision I make regarding this study will not affect any other services I may receive.

If you have any questions please contact Judy Moore, Principal Investigator of this study at (813)-974-4463 or Ruby Joseph, Project Manager at (813)-974-9339, Department of Child and Family Studies, Louis de la Parte Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Boulevard, Tampa, Florida 33612-3899.

By signing below, I voluntarily choose to participate in this study.

Participant's Signature

Date

Participant's Name (Please Print)

Witness' Signature

Date

Appendix 11b

**CRITICAL ISSUES ANALYSIS
PARTICIPANT'S ACKNOWLEDGMENT OF ASSENT**

ADOLESCENTS FOCUS GROUP

I understand that the purpose of this research study is to learn about the permanency plans and support needs of children, adolescents and families who are affected by HIV/AIDS in Hillsborough County. Specifically, this study will capture the perceptions and experiences of primary caregivers who are infected with HIV/AIDS and their children who are affected by HIV/AIDS.

I am aware that I will be asked to participate in a group discussion and answer questions about my family's needs and supports. If an overflow situation occurs and I cannot participate in the group discussion I will have to complete a brief overflow questionnaire. I understand that this focus group will be tape recorded to ensure that all information is captured more accurately. I understand that the information that is collected will be kept confidential and that I will never be identified by name in any report that is produced as a result of this study. I understand that there are situations which require that this confidentiality be broken. These are: if I am in danger of harming myself or someone else or if child abuse is involved.

I have had the chance to ask questions about the study and I feel that these questions have been answered. I understand that my participation is voluntary. At the end of the group discussion I will receive \$25 . I am aware that I can discontinue my participation in the group discussion at any time and that any decision I make regarding this study will not affect any other services that me or my family may receive.

If you have any questions please contact Judy Moore, Principal Investigator of this study at (813)-974-4463 or Ruby Joseph, Project Manager at (813)-974-9339, Department of Child and Family Studies, Louis de la Parte Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Boulevard, Tampa, Florida 33612-3899.

Child's Assent

By signing below, I voluntarily choose to participate in this study.

Participant's Signature

Date

Participant's Name (Please Print)

Witness' Signature

Date

Parent's Consent

By Signing below, I agree to have my child participate in this study.

Parent's Signature

Date

Parent's Name (Please Print)

Witness' Signature

Date

Appendix 11c

**CRITICAL ISSUES ANALYSIS
PARTICIPANT'S ACKNOWLEDGMENT OF
INFORMED CONSENT**

PROVIDER FOCUS GROUPS

I understand that the purpose of this research study is to learn about the permanency and support needs of children, adolescents and families who are affected by HIV/AIDS in Hillsborough County. Specifically, this study will capture the perceptions and experiences of primary caregivers who are infected with HIV/AIDS and their children who are affected by HIV/AIDS.

I am aware that I will be asked to participate in a group discussion and answer questions regarding permanency planning and the needs and services for families affected by HIV/AIDS. If an overflow situation occurs and I cannot participate in the group discussion I will have to complete a brief overflow questionnaire/survey. I understand that this focus group will be tape recorded to ensure that all information is captured more accurately. I understand that the information that is collected will be kept confidential and that I will never be identified by name in any report that is produced as a result of this study. I understand that there are situations which require that this confidentiality be broken. These are: if I am in danger of harming myself or someone else or if child abuse is involved.

I have had the chance to ask questions about the study and I feel that these questions have been answered. I am aware that my participation is voluntary and that I can discontinue my participation in the group discussion at any time. I understand that any decision I make regarding this study will not affect any other services I may receive.

If you have any questions please contact Judy Moore, Principal Investigator of this study at (813)-974-4463 or Ruby Joseph, Project Manager at (813)-974-9339,

Department of Child and Family Studies, Louis de la Parte Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Boulevard, Tampa, Florida 33612-3899.

By signing below, I voluntarily choose to participate in this study.

Participant's Signature

Date

Participant's Name (Please Print)

Witness' Signature

Date

Appendix 11d

**CRITICAL ISSUES ANALYSIS
PARTICIPANT'S ACKNOWLEDGMENT OF
INFORMED CONSENT**

PRIMARY CAREGIVER INTERVIEW

I understand that the purpose of this research study is to learn about the permanency plans and support needs of children, adolescents and families who are affected by HIV/AIDS in Hillsborough County. Specifically, this study will capture the perceptions and experiences of primary caregivers who are infected with HIV/AIDS and their children who are affected by HIV/AIDS.

I am aware that I will be asked to participate in a semi-structured interview and answer questions on permanency plans, support needs and services that affect me and my family. I understand that the interview will be tape recorded to ensure that all information is captured more accurately. I understand that the information that is collected will be kept confidential and that I will never be identified by name in any report that is produced as a result of this study. I understand that there are situations which require that this confidentiality be broken. These are: if I am in danger of harming myself or someone else or if child abuse is involved.

I have had the chance to ask questions about the study and I feel that these questions have been answered. I understand that my participation is voluntary. Although I will not be paid for participating, I will receive \$25 as reimbursement for any expenses (i.e. transportation and baby sitting) that I may incur as result of this study.

I am aware that I can discontinue my participation in this interview at any time and that any decision I make regarding this study will not affect any other services I may receive.

If you have any questions please contact Judy Moore, Principal Investigator of this study at (813)-974-4463 or Ruby Joseph, Project Manager at (813)-974-9339,
Department of Child and Family Studies, Louis de la Parte Florida Mental Health Institute,
University of South Florida, 13301 Bruce B. Downs Boulevard, Tampa, Florida 33612-3899.

By signing below, I voluntarily choose to participate in this study.

Participant's Signature

Date

Participant's Name (Please Print)

Witness' Signature

Date

Appendix 12

The following resources provide services addressing the different needs of those individuals participating in this study. The list is compiled in alphabetical order and does not indicate order of importance or any other manner of listing.

Alan Outreach
Alpha House
Bay Area Legal Services
Big Brothers/Big Sisters
The Centre for Women
Children's Medical Services
DACCO
Daystar
Department of Children and Families
Francis House
Family Enrichment Center/Great Day
Hillsborough County Health Department
Life Center
Mercy House
Metropolitan Ministries
MHC Inc./Bay Life
Salvation Army
St. Joseph's Hospital
St. Peter Claver
St. Timothy
St. Vincent de Paul
Tampa Aids Network
Tampa Crossroads
Tampa, Hillsborough Action Plan (THAP)
United Cerebral Palsy
USF Extern Counseling USF Center for HIV/Education
Vision Day Treatment
YMCA

Support Groups:
Alcoholics Anonymous
Narcotics Anonymous
Persons With Aids