

Module Seven

HIV & FAMILIES

What is a Family?

- Families infected and affected by multigenerational AIDS face many unique and tragic circumstances that greatly impact each member. In discussing survivors of primarily natural disasters and other “overlooked victims of overwhelming stress”, Anthony (1986) includes in his description “families who had to cope with loss an bereavement with often little or no help; communities where the “tissues of social life” and the “prevailing sense of commonality” had been damaged by the collective trauma,” (pg. 301), an apt description of families impacted by multigenerational AIDS.
- “HIV involves some of the most vulnerable members of our society and results in a devastation as severe as what has been seen in war zones, yet much more subtle,” Appel & Telingator (1995), pg. 121. The National Commission on AIDS (1992) found evidence that ethnically diverse families who are oppressed by race and socioeconomic status are less likely to seek early treatment, and tend to die sooner. Communities of color are disproportionately impacted by HIV/AIDS because of economic, political and social inequalities.
- Families infected and affected by HIV/AIDS can represent many different constellations. A traditional, intact nuclear family system may prove to be the exception rather than the rule with multigenerational AIDS. Therapists need to monitor their assumptions about who constitutes their clients’ family systems, and help their clients clearly articulate the definition and parameters of their unique immediate support system.
- “Family” may need to be defined in its broadest possible context. Nord (1996) suggests two definitions of family:
 1. Traditional families – Traditional family systems may be thought of in terms of families of origin, defined through relatives, connected by blood, marriage or adoption. (Note: Even though a client may come from a structurally intact traditional family system, it is important not to assume traditional roles within that system i.e. not assuming who is the breadwinner, who is the caregiver, etc.) Many traditional family systems have been greatly impacted by HIV/AIDS. One family system may contain multiple generations infected or affected by HIV/AIDS-related issues.
 2. Nontraditional families – Nord (1996) states that “The impact of AIDS and especially AIDS-related loss, has highlighted the importance, value and

function of families of choice.” Families of choice refers specifically to the network of friends that gay and lesbian people can create to serve in similar functional ways as families of origin when families of origin may reject the gay or lesbian child, and/or the person with HIV. Such gay families can be a part of a multigenerational AIDS family system, and the concept of families of choice is useful in examining other nontraditional family structures that are also frequently seen. Families of choice might also include families of necessity – support systems created as families of origin disintegrate due to AIDS losses or lack of support. Such families can include extended members of the family of origin, grandparents, aunts, uncles, cousins, and may also include non-blood members such as godparents, friends of the family, neighbors, or other members of the client’s community(ies.) Many non-White urban families may fall within this definition, frequently having several generations of family members living within the same household, infected with HIV disease. Many immigrant families may also share similar extended family systems, with multiple family members infected. Many Native American tribes consider even very distant tribal relatives as family. Gay couples may include an infected partner with children. Gay men and lesbians may have adopted a child or children infected/affected by HIV. Pequegnat and Bray (1997) state that social networks (e.g. injection drug users who share syringes in “shooting galleries,” surviving affected family members who combine with other survivors from different families,) may perform familial roles, even when one is close to one’s biological family. One safe assumption is that if one family member is infected with HIV disease, the entire family system, traditional or not, is affected. These extended families become critically important for considerations around disclosure, and the issue of permanency planning arises if parents or guardians become ill and die.

3. People with HIV/AIDS also often create communities of support for one another. Fear of disclosure in one’s ethnic or racial community, in one’s neighborhood or a child’s school may force families to seek support outside of where they would typically turn. HIV support groups, children’s camps, people who volunteer at agencies, case managers, etc. may become part of an extended family and community of support and caregivers for families with multigenerational AIDS concerns.
- Reidy and Taggart (1995) suggest defining family through the parameters of mutual obligation based on devotion, rather than the law.
 - An exercise that might help illuminate non-traditional family structures would be for HOPE training participants to take a few minutes to list/discuss the extended family systems in their own lives...i.e. to ask them who they would be able to count on for emotional, physical, financial and spiritual support and/or caregiving if they became

infected with HIV, and their families of origin were unavailable, for whatever reason.

Epidemiology

- Among women, children, and families, HIV infection is a multigenerational disease. Most children with HIV infection acquired it perinatally. Indeed, it was often the case that illness in a child and subsequent diagnosis of pediatric HIV infection signaled family HIV infection. This was often the impetus for testing of parents and siblings and often revealed HIV infection in mother, father and perhaps several family members.
- In response to the data from ACTG 076 which revealed AZT monotherapy can reduce perinatal transmission of HIV, many states legislated mandatory counseling and voluntary HIV testing for pregnant. Thus, many women learn about their HIV status during pregnancy and face the fact that their other children and their partner need to be tested as well.
- When several members of a family are living with a chronic illness, the family faces some unique challenges. Whether one or more members are living with HIV, HIV affects all family members. In addition to the psychosocial sequelae associated with any chronic illness, families affected by HIV confront stigma, isolation, secrecy, multigenerational illness and loss, and interaction with previous family problems such as poverty and substance abuse.

Key Psychosocial Issues

Illness in multiple family members requires that parents coordinate their own care as well as the care of their children. This includes not only medical appointments but medical regimens that are sometimes complex. It is likely that families will face significant challenges with medical adherence.

- **Affected children** may be “forgotten” (Burr & Lewis, 2000, Geballe, Gruendel, & Andiman, 1995). Parents sometimes become so involved in the care of infected children that the needs of affected children to

unmet. Affected children have health and mental health (Forehand colleagues, 1998) care needs that must be addressed.

Possible group activity: Tic tac exercise. Highlight adherence issues faced by families. Include affected (non-infected) children in the family constellation and have “parents” manage their inquiries about why they don’t get any medication.

- **Children with HIV infection growing into teenagers** present a new challenge in parenting and childrearing. Medical advances have made HIV a chronic illness and

this means that children are living much longer healthier lives. However, the developmental needs of a 16 year-old living with HIV are very different from those of an 8 year-old living with HIV (Lewis, in review, Lewis, Haiken, & Hoyt, 1994). Parents may also face a confusion of sorts because they had not prepared themselves for this challenge. They may have been preparing themselves for the child's death or deterioration and now have to re-orient. It can be emotionally and psychologically challenging for parents to plan for their child's future at the same time they are coping with the uncertainty of disease manifestations associated with HIV infection.

- **Changing needs of HIV-infected children growing into teenagers** require that parents and caregivers address the key developmental issues of adolescence. This includes intimacy and sexual development, reproduction, and planning for the future. As with any adolescent, they need to learn sexual responsibility and make plans for personal and career development. It is useful to teach adolescents about intimacy and emotional closeness as well as safer sex practices.
- **Affected children growing into teenagers** are sometimes overlooked. However, it is well-documented (Dane, 1994 Draimin, 1993, Geballe, Gruendel, & Andiman, 1995) that they face some specific challenges growing up in with family HIV. Depression, failing grades, delinquent acts and risky sexual behavior are among the concerns of HIV-affected children. Dane (1994) discusses survivor guilt among HIV-affected children. Surviving children may feel guilty that they didn't do everything they should have done for their parent or sibling. They may blame themselves for the death. They may be angry that their family members died. As a result they may become depressed or act out in destructive ways. Prevention and preservation of their mental health must be among the concerns addressed with families.
- **Fathers** are another group that is often forgotten. Partially because HIV infection can be perinatally transmitted, much of the education, research, and clinical interventions have been focused on mothers. However, fathers play a crucial role, not only in conception, but in the rearing of their children. In some cases, fathers are the primary caregivers of their children and they have special needs. Some fathers are also living with HIV infection. Even when fathers are not living in the home with mother and children, they can be important in their children's lives and must be consulted during permanency planning.
- **Schools** are an important institution throughout the lives of children and adolescents. Specialized school programs may be necessary for HIV-infected children due to cognitive changes associated with disease progression. HIV-affected children can also benefit from school-based activities that foster personal development, problem-solving, and creativity. School personnel also need

education regarding the needs of HIV-affected children (Geballe & Gruendel, 1998).

Parenting in Families Affected by HIV

Challenges to Parenting

Child Functioning

- Children affected and infected with HIV face a myriad of challenges and frequently experience psychosocial difficulties associated with these challenges. These psychosocial difficulties, along with parent-, family-, and context-related challenges, often result in the parenting of these children being extremely difficult.
- In terms of HIV-infected children, research and clinical work have identified a variety of negative psychological sequelae of the disease. Specifically, HIV-infected children, many of whom are now surviving into adolescence, have unique developmental needs. They typically experience more psychological distress (e.g., anxiety and depression) associated with cognitive delay, isolation from peers, and repeated hospitalizations. Additionally, it is not uncommon for these children to display lethargy, lack of interest in social activities, poor attention, and impulsivity due to the primary and secondary effects of HIV.
- Prenatal exposure to illicit substances, may also contribute to their developmental problems. As they transition into adolescence, HIV-infected children appear to be at greater risk for having problems in school (e.g., truancy), and other acting out behaviors (Draimen), as

well as substance use and suicide attempts (Rotheram). Interestingly, it appears that the psychosocial functioning of children with HIV is more closely tied to contextual parent and family factors than to disease and disability factors (Sherwen & Boland).

- Children who are not HIV-infected but reside with an infected parent also experience more psychological difficulties when compared to their peers. Forehand et al. (1998) found higher rates of externalizing problems (e.g., oppositional behavior) and internalizing problems (e.g., depression), as well as poorer social and cognitive competence among the children of HIV-infected mothers relative to demographically similar peers whose mothers were not HIV-infected. Forsyth et al. (1996) have reported similar findings in terms of emotional and behavioral problems. Burian has hypothesized that the major treatable threat to the well being of HIV-affected children is the loss of the primary attachment figure. In the context of HIV, there are many threats to this attachment.

Parent Functioning

- Parenting can easily constitute an overwhelming demand when experiencing the grief and stress associated with terminal illness. Often HIV-infected parents are physically debilitated by their illness, which results in frequent hospitalizations. Additionally, a number of researchers (e.g., Armistead et al; Havens et al.) have demonstrated that HIV-infected parents are at increased risk for mental health problems, such as depressive disorders. Moreover, some HIV-infected parents have a history of or currently abuse substances, further complicating their ability to parent and, specifically, the parent-child relationship (Brown). Lastly, many parents of HIV-infected children experience significant guilt, shame, and anger in response to be HIV-infected. These negative emotions may result in a more lax approach to parenting or emotional withdrawal from the child.
- Researchers and clinicians have noted a variety of ways in which parenting is compromised by HIV. Specifically, Kotchick et al. found that, compared to demographically similar non-infected mothers, HIV-infected mothers were less well able to monitor their child's behavior and had poorer quality relationships with their child. Additionally, Faithfull posits that the imminence of death decreases a parent's ability to set limits and otherwise discipline appropriately as many parents fear disappointing their child or being remembered by the child as harsh or punitive. She also notes the frequency with which HIV-infected parents prematurely withdraw from their children in an effort to minimize the experience of loss, upon illness or death.

The Family Context

- When a family member is ill, familial roles and responsibilities must be reconfigured. This reconfiguration is often very stressful for the family as a whole and children in particular. It is not uncommon for the needs of well family members to be neglected due to the overwhelming needs of HIV infected family members (Fair, 1995). In this context, one or more children will often take on adult responsibilities, which may include caring for an infected parent or sibling, providing the majority of the parenting for sibling(s), assuming most of the household chores, and/or being required to engage in adult decision-making. These responsibilities compound the normative demands of childhood or adolescence, adding to the child's vulnerability to negative outcomes (Dane).
- HIV-affected families were often troubled prior to discovery of a member's infection and, thus, caregivers have not provided the nurturing and supervision required for optimal child development (Dane). This poorer premorbid family functioning further jeopardizes the adjustment of individual family members.
- Another potential effect of HIV in the family is that communication between family members becomes very restricted, particularly when not all family members are aware of the illness (Dane).

The Social Context

- The presence of children and the health problems associated with AIDS make it difficult for caregivers to hold a job and, thus, many families affected by HIV live in poverty (Gardener).
- Factors associated with poverty, including residing in dangerous neighborhoods with poorer quality housing and schools and struggling to obtain the resources necessary for survival further exacerbate the negative impact of HIV on families.

Strategies for Intervention

Building on Strengths

- Many families that are affected by HIV hail from cultures where family role flexibility is typical. Specifically, in many communities of color it is not uncommon for their to be at least one adult, other than the biological mother or father, who has a supportive parental relationship with the child. Co-parenting by these individuals,

typically extended family members, is accepted, and children raised by a grandparent, aunt etc. are typically not stigmatized (Dane). Utilizing extended family members for respite care, to better monitor children, and, eventually, as alternative caregivers for a child may be facilitated by the aforementioned cultural strengths.

- Many parents infected with HIV have been parenting their children in far from optimal sociocultural conditions. Even prior to the influence of HIV on the family, parents have often dealt with limited financial resources, concerns about violent neighborhoods, and discrimination. Thus like all parents, parents infected with HIV have considerable knowledge and valuable experience when it comes to parenting under stress. Consequently, parenting interventions might benefit from being interactive, versus didactic, in nature, where parents can share their ideas with one another in an open and accepting environment (Blackwell).

Intervention Targets

- Parenting interventions for families affected by HIV should be designed to help parents experience a sense of control over their life and the life of their child(ren). Parents who feel bonded, responsible, and involved in the care of their child will typically parent better than those who do not (Olson).

- Psychoeducation may also be necessary as some parents have concerns about passing HIV onto their child(ren) through casual contact, even when they have been informed about the routes of infection (Faithfull).
- As with all children, the family characteristics that most contribute to resiliency in children include a consistent nurturing relationship with an adult, consistent parental supervision with predictable rules, and balanced discipline (Kothchick et al.). Additional goals include the presence of open, empathic parent-child communication and cohesiveness among family members (Geballe).

Disclosure

The association between disclosure of HIV infection and child functioning

- There are many relevant clinical assumptions about whether children should be informed about their own or a mother's HIV infection. Most typically, the non-empirical literature tends to emphasize the importance of informing children, in a developmentally appropriate manner, about the illness. However, the majority of the empirical

literature is equivocal at this point. It is unclear whether disclosure of HIV status is a good or bad thing in terms of child functioning, probably because the question is a much more complicated one.

- Conceptual papers or case reports suggest that when a child is told early and repeatedly about their own and/or a family member's HIV status, they have the best chance of adjusting to and effectively coping with the situation. Additionally, there is a prevailing belief that less secrecy around HIV in families helps children feel less shame and may lead to more open relationships among family members.
- Empirical research has resulted in mixed findings regarding the impact of disclosure on child functioning. Some studies have found no relationship, positive or negative, between disclosure and child functioning. Other research has found that it depends upon whom you ask about functioning, mother or child. Children to whom mothers had disclosed their own illness have reported either better psychosocial functioning or no differences in adjustment than those to whom mothers have not disclosed, while mothers have reported observing more problems in their children once they disclose to them.
- Given the discrepancies in the literature around the impact of disclosure on child functioning and the stigmatized nature of this illness, it is important to let a parent set the pace for disclosure and to recognize that it is a parent's right to decide when to tell their child. There are many risks involved with a decision to disclose, as well as a

decision not to disclose. A parent is typically the best judge of when, or if, this process should occur.

The Dynamic Process of Disclosure

- Disclosure of HIV infection is not an either/or phenomenon but a dynamic process. Honest explanations about what is happening around medical procedures or physical symptoms and providing general education about HIV and AIDS may be first steps in the disclosure process and are likely to be just as important as full disclosure of an HIV diagnosis. Moreover, subsequent to a disclosure of an HIV diagnosis, children's informational needs are likely to change as they age and as the illness progresses in either the parent or the child.
- Tasker (1992) identifies four phases leading up to disclosure of a diagnosis to a child:
 1. secrecy phase-parent's initial response to the diagnosis
 2. exploratory phase-secret is still kept from the child and most adults, but the parent guards the secret less intensely
 3. readiness phase-parent becomes more willing to tell the child
 4. disclosure phase-the parent tells the child, in response to a child's question or according to the parent's plan to do so

Factors Influencing Disclosure of HIV Status

- Many factors influence whether a parent chooses to inform a child of HIV in the family, and many women report that this decision is one of the most difficult that they face. Parents tend to tell children who are older and delay telling younger children. In the case where a mother is infected, she is more likely to tell upon experiencing more severe physical symptoms and is more likely to tell daughters versus sons.
- It is important to recognize and be sensitive to cultural and family differences in terms of the kind of information parents choose to share with children. Moreover, because of the stigma that continues to be associated with HIV, a parent may not be able to rely on their typical external resources or support (e.g., church, extended family) when attempting to make or deal with disclosure-related decisions.
- Because disclosure of HIV status is often a "double disclosure", involving the mode of transmission of the illness (i.e., sex or drugs), parents often fear rejection upon disclosure to a child. This may be particularly salient in families where the parent-child relationship(s) is already strained due to current or historical substance use. Interestingly, empirical research has demonstrated that, at least in terms of a child's immediate reaction to disclosure of maternal HIV infection, the likelihood of the child displaying a rejecting or angry response is relatively low.

- Some parents also fear placing too much of a burden on a child by disclosing HIV infection or have concerns that the child cannot keep the secret from others. Not keeping the secret could result in many negative outcomes for families potentially including loss of housing or child custody and other forms of discrimination.

Potential Advantages of Disclosure to Infected or Affected Children

- Literature on other chronic illnesses demonstrates that disclosure of developmentally appropriate facts about parental or child illness improves a child's psychological adaptation to that disease. Despite the unique aspects of HIV as a chronic illness (e.g., stigma, shame), many believe that the advantages to disclosure hold true for this illness as well.
- Children often suspect that something is seriously wrong and, without disclosure, lose the opportunity to dialogue openly about their fears and concerns. Children may also create explanations for the health condition (i.e., "mommy is sick because I am a bad girl") that are worse than disclosure would be.
- Children need to be secure that the information given to them by parents is true and may experience issues around trust and deception if they have been deceived around their own or a parent's illness.
- Children to whom a parent has disclosed may be less likely to experience feelings of loneliness and isolation and may be better able to grieve for their own illness and/or the death of a parent if they can openly discuss the illness and/or death with caring others.

Facilitating Disclosure to a Child

- It is important to allow a parent to set the pace for disclosure because if the pace is uncomfortable for the parent, they may disengage from professionals. While following the parent's lead, it may be useful to explore their rationale for not disclosing and the fears they have associated with disclosure.
- It is important to consider the emotional climate in which disclosure to a child would occur. A family must be able to manage this communication in an open and supportive way. Where significant communication problems are present in a family, parents may need assistance with framing their communication to children such that they address the emotional and cognitive needs of the child. Role plays with a parent might prove useful in this regard.

- The information children should be provided regarding their own or another's infection varies greatly depending on the child's developmental stage. Wiener provides guidelines for appropriate disclosure based on developmental stage:
 1. Preschool children – One should provide a general description of the illness and expect that these children will likely need to hear the message repeated a number of times. Very simple explanations around death that are consistent with the family's spiritual beliefs are best.
 2. Children five to eight – These children will need more details about the illness and will likely want to know the name of the disease, what causes it, and whether they or the parent will die. They should be reassured that they did

nothing to cause the disease and, if not ill themselves, will not catch the disease from their caregiver. They should be reassured about who will take care of them in the parent's absence.
 3. Children nine to twelve- These children are likely to ask specific questions about HIV transmission and may want to be involved in permanency planning decisions.
 4. Adolescents – These children need to know the facts about HIV but may not want to hear them. They will have a hard time dealing with information that makes them feel different than others and will fear what others think of them.
- Wiener also provides an action plan for disclosure to a child:
 1. Help the parent identify the place and whom they want present for the disclosure.
 2. Assist parents in determining what the most important message they want to communicate to the child is.
 3. Prepare the parent for the child's potential reaction. Children's reactions may range from fear or anger to support and acceptance. In general, children will react in ways that are characteristic of their personality. For example, if a child expresses pain as anger, the parent might anticipate an angry response from the child.
 4. Provide a supportive individual with whom the parent can process the disclosure discussion after it occurs.

Permanency Planning

Relevant Natural History Data

- Since the early 80's, we have known that HIV can be perinatally transmitted. Natural history studies demonstrated that the rate of transmission from mother to child ranges from 25% to 30% making it likely that 70% to 75% of children born to HIV-positive mothers will be uninfected.
- In 1994, ACTG Study 076 demonstrated that AZT monotherapy could reduce transmission from mother to child to about 8% making it likely that 92% of children born to HIV-positive mothers

would be uninfected. Recent research has demonstrated that this rate can be reduced even further with use of Navirapine during pregnancy.

- Thus, throughout the HIV epidemic, it has been true that children born to HIV-positive women may be uninfected. However, they will still be affected by HIV. They face the possibility that they will lose their mother to HIV disease. In many cases, it is also possible that they will lose their fathers to HIV disease. This places children in a vulnerable position that must be addressed by competent permanency planning with their parents.
- Schuster, et al (2000) studied the characteristics and living situations of children of HIV-infected adults. They found that 28% of HIV-infected adults in care had one or more children under the age of 18. Further, women (60%) were more likely than men (18%) to have children under age 18.

Psychosocial Concerns

- Families living with HIV cope with a variety of psychosocial issues, including stigma, isolation, the multigenerational nature of HIV, access to educational and health resources, disclosure of diagnosis, multiple loss related to not only to death but decreased capacity to participate in daily routines, poverty, and substance abuse.
- Many of these concerns will affect families' permanency planning process. Stigma (Geballe & Gruendel, 1998) may create difficulty for children making a transition from birth family to second family. Dane notes that children may be "strangers within the family, stigmatized by the unacceptable behavior of their parents and the shame of drug addiction and AIDS".
- While extended family members may be willing caregivers, they may be financially stressed and face difficulty incorporate more children into their homes. State laws vary but in many states relatives are not eligible for support when they assume guardianship of children. However, foster parents are eligible for funding.

- Children may have experienced a number of losses related to hospitalization, incapacitating illness, separation from parents and/or siblings during stressful family times or substance abuse. There may be emotional difficulties related to repeated loss.

Possible discussion points: Survey participants asking who has a will? Of those who are parents, how many have a permanency plan for their children? How many are designated as guardians for someone's children? How many think they may be designated as guardians for someone's children, though they have not been formally asked? Review the challenges participants faced in making wills or permanency plans. Explore why some participants believe they are a designated guardian but have no formal plans.

Permanency Planning Process

- The multigenerational impact of HIV infection may mean that children will lose both their parents to HIV infection. Thus, the legal,
- standard which provides for children to be cared for by their surviving parent will not secure care arrangements for many children. Often grandmothers or aunts (Dane, Taylor-Brown) become the primary caregiver for children orphaned by HIV/AIDS.
- In the absence of legal binding arrangements, the future of children is uncertain. Permanency planning is a process that must be approached early in a provider's relationship with a family. The process is filled with legal and emotional complexities. Providers must be prepared that parents may have difficulty approaching the subject. However, without a legal plan, parents' wishes for their children may not be carried out.
- Providers helping parents develop permanency plans must become aware of the legal services available in their area as well as the various types of guardianship arrangements. Taylor-Brown lists several types of arrangements; the availability of these will change from state to state:
 1. Informal arrangements—placing child in the care of a close friend or relative, not legally binding
 2. Power of attorney—person with power to make decisions when parent is unable

3. Designation of a guardian in a will—clearly states the parents wishes but could be change in court after a parent’s death
 4. Adoption—parent terminates parental rights
 5. Voluntary placement in foster care—child placed with relatives or in state approved home; parent retains right to make permanency plans
 6. Involuntary placement in foster care—child removed and placed based upon investigation of abuse or neglect; parent retains right to make permanency plans
 7. Surrendering of parental rights—parent relinquishes ability to make decisions for children
 8. Emergency and respite services—family receives services and parent retains right to make decisions
 9. Standby guardianship—parent retains parental authority and designates a guardian who has authority when the parent is incapacitated
- The advantages and disadvantages of each option must be explored with parents. Because the legal ramifications of any option may change, providers must stay up-to-date on changes in laws. This can be accomplished by establishing networking/collaborative relationships with social workers and attorneys familiar with guardianship procedures.
 - Parents will need emotional support during permanency. It is important to build trust with parents in order to assist them during this process. Some parents may fear that making a permanency plan will speed up their death and as such may resist. It is necessary to be patient and respect a parents wishes while at the same time sharing the possibilities which may occur in the absence of a plan. Providers can begin slowly by assessing who parents count on for babysitting, emergencies, etc.
 - Taylor-Brown offers some key questions that can be asked: Who cares for children when you’re hospitalized? Have you begun to think about an alternative guardian? If so, who? Have you sought legal help? If you are working with only one parent, it is important to know where the other parent is and what their wishes are because they have legal rights which will impact the placement of children.
 - Parents may also be interested in leaving a legacy for their children such as personal items, family photo albums, or videos. Providers will need to explore these desires

with parents. Parents may also need help talking with children about plans for their future. Children need to be a part of the process. Geballe & Gruendel (1998) discuss characteristics

of children and families that support resilience. For children, these include: access to peer and adult support systems, flexible problem solving strategies, active orientation to problem solving, development of a broad range of interests. For families, these include: nurturing relationships between family members, predictability, consistency in parenting, open communication, understanding of children's individual needs.

Transition to Second Family

- Children affected by HIV often have unmet mental health needs (Burr & Lewis, 2000, Geballe & Gurendel, 1998). This may include depression, anxiety, delinquent acts, school failure or risk taking such as unprotected sexual activity. These concerns may or may not have been addressed prior to their parents death and may be exacerbated by the parents death.
- A range of interventions are recommended to help children adjust including: mental health services, school-based interventions, mentoring programs, recreational programs, and creative activities (Burr & Lewis, 2000, Geballe & Gurendel, 1998).
- Second families will need support to help children adjust to loss and family reconfiguration. It can be useful to have birth and second families share child rearing responsibilities prior to a parent's death (Dane). Counseling can also help families transition. Home-based therapy may be a particularly good option to support children's adjustment in their new environment.

Cultural Considerations

- Families have beliefs and values that inform the permanency planning process. There are key cultural values that are likely to arise related to permanency planning (Dane, Taylor-Brown). These include: definition of family, who cares for children, rituals around death and bereavement, and causes of death. Parents may not choose guardians based upon blood relationship. Among African Americans and Latinos, it is common for children to be reared by non-blood kin without benefit of legal arrangement. These "family members" are often "like blood" though not biologically related. In making the choice of a guardian, parents may look to non-blood kin.
- Some parents may fear that talking about death speeds it up. They may be having difficulty making permanency plans because they fear this will cause their death. These experiences may be deeply rooted in cultural belief systems about the power of words and thoughts. It is important to explore and respect parents belief systems.

- In some instances, providers may need to be prepared to help parents make last minute arrangements when a parent becomes very ill or dies.
- Keeping children together will likely be a concern of parents. They may choose guardians based upon the guardian's willingness to keep children together.
- Family rituals around grieving vary greatly. Practices such as funerals, flowers, music, emotional expression, etc. all depend upon the family's cultural belief system and practices. It is important that children and surviving family members receive support during their grief process.

Multiple Loss

- Families facing multigenerational AIDS face a future with multi-dimensional matrices of losses. An adult with HIV/AIDS may face their own intrapersonal multiple losses of their sense of invulnerability or immortality, future, health, control, love, income, status, job, independence, mobility, dignity, role in the world (and in their family,) anonymity, recreation, body image, faculties-capacities, sense of self, as well as interpersonal losses of family and friends (HOPE Training manual 1996).
- The caregiving partner of someone with HIV/AIDS who is also infected her/himself faces the same losses, along with the loss of their caregiving role and the role of spouse/partner/lover, as well as the uncertainty of who will take care of them and/or their children, if the time comes when they, too, become ill.
- Other uninfected caregivers may experience similar devastating and catastrophic losses, i.e. a caregiving grandparent could potentially lose both their child and their grandchildren. Caregiving grandparents also may lose the possibility of a quiet retirement, the loss of privacy when infected family members return home, as well as loss of retirement income in having to pay for infected family member's care.
- An infected child with infected parent(s) may face some of the most tragic losses of all. An infected child who is symptomatic from an early age may never know a healthy, carefree day of childhood. An infected child may experience developmental delays, physically, cognitively, emotionally and socially, as well as the loss of their family of origin.
- An infected and an affected child with infected parents may experience the total loss of his/her family of origin. Both infected and

affected children may then be taken from their physical home and can be separated as they are placed in foster care or different homes following the death of their parents. Both infected and affected children may quickly face the loss of childhood innocence

due to living in the culture of poverty and HIV disease. Uninfected children may become parentified caregivers for younger siblings and/or infected parents, (Levine, pg. 205).

- Affected children also may lose social services at a time when they need them the most; when the infected person(s) in the family die. Many HIV/AIDS agencies' missions and/or funding extend only to people with the disease and not those affected by it.
- “Most young people who are orphaned are not HIV infected, but are at high risk of economic deprivation, a range of behavioral and developmental problems, as well as of engaging in high-risk behaviors associated with HIV transmission,” (Levine, pg. 197.) Study after study has shown that the children left in AIDS' wake may turn to drugs, needle sharing, unsafe sexual behavior and/or prostitution as a way of coping with such massive losses, as well as perhaps as a way of identifying with the parent who has died, or as a way of wanting to join their lost family. The profound “invisibility, discountability and interchangeability of the marginalized,” (Hecht, 1994, pg. 133) provide both a self-perpetuating climate of depression and a context within which children and adolescents rapidly lose their idealism, learning to hope for little and expect even less, (Tourigny, 1998).
- Family members also face the loss of members of their extended families, and/or families of choice or their communities of support, which may greatly impact either the individual or the entire family unit. Because of the quality of support and the depth of understanding the people in these communities offer, the community losses can be particularly painful. An example might include a woman may lose a friend in her HIV support group with whom she strongly identified, or her child may lose a friend s/he gained through an AIDS summer camp. “Because of rigidly and narrowly defined definitions of family and support allowed to grieving families of origin, people losing members of their nontraditional family often suffer ‘silent sorrow,’” (Doka, 1994.) Rituals, ceremonies and other societally approved ways of grieving may be denied the person who grieves a non-traditional relationship(s).
- Other unexpected life losses (accidents, other illnesses, other tragic events,) may also visit families with multigenerational AIDS, and may have a greater impact, due to the extreme vulnerability of MGA families.
- Complicated bereavement and bereavement overload are possible for any family member at any time, due to both internal and external losses.
- Losses due to larger socio-cultural circumstances such as poverty, substance abuse, violence, racism and homophobia must also be examined and addressed, (Blackwell, et. al. 1997.) However, clinicians working with families who have lived with such sources of oppression for generations also need to look for the sources of resiliency

that have allowed the family to survive. Such resiliency may often be overlooked by people outside the family's community.

- Blackwell, et. al. (1997), in describing a systems approach to services for HIV infected and affected children and families in New Orleans suggest assessing the micro-system (proximal relationships between the child and his/her caregiver,) the mesosystem (relationships between family members,) the exosystem (features of the family environment/community,) and the macrosystem (larger socio-political structure that encompasses all systems.) This assessment approach is helpful when approaching any issue impacting the family system at any time, especially when examining the issue of multiple losses on all levels, and the interventions that need to occur in that multi-layered system.

Bereavement issues and grieving

- Due to the multiplicity of losses associated with multigenerational AIDS, any and all members of the infected/affected family may need support in their grieving processes at any point across the continuum of their own lives. Due to fears around disclosure and family secrets, children, in particular, may be greatly neglected in their grief. Parents may fear disclosing the HIV in their family, due to their fear of stigma, and being protective of their children, and deny their children the opportunity of expressing their feelings of loss. Parents' denial about their own condition may also prevent the child from being able to do anticipatory grieving. Parents who may also be overwhelmed by the pressures of their multiple roles and losses may not be able to tolerate their children's grief.
- Children also grieve differently than adults, and may have neither the words nor the emotional access and expression that healthy adults do. Children may be intensely grieving, yet appear as though they are back to normal when they are not. Unresolved childhood grief can lead to greater vulnerability and risk-taking in adolescence, and to greater psychological vulnerability throughout life.
- Affected children's grief has been greatly neglected by both service agencies and by research. The affected child who has lost parents and siblings to HIV is at tremendous risk behaviorally and emotionally. The extreme vulnerability of such children may lead to drugs, gang involvement, sexually unsafe behavior, prostitution or violence as a way of trying to manage their complex feelings of loss and grief, and is highlighted in a chilling article by Tourigny (1998), entitled "Some New Dying Trick: African American Youths 'Choosing' HIV/AIDS," which also underscores the violence of the culture of poverty and marginalization. [Tourigny shows that some affected adolescents may crave both the attention and the monetary 'rewards' that can accompany an HIV diagnosis. People with HIV disease may have greater financial and social service support than their uninfected peers living within a culture of poverty. Many of those infected with HIV have been labeled as engaged in a heroic

struggle, and uninfected youth may “choose” HIV/AIDS as a way of also being labeled as a hero. Uninfected adolescents living in a culture of poverty, drugs and violence may also decrease their psychological life expectancy, and a feeling of despair: “Two of my homies gone died last month, from gunshot wounds...I ain’t gonna live no 15 years anyway...” (pg. 155).

- In the gay community, controversy has arisen over ‘bareback sex’ (anal intercourse without condoms,) and affected men ‘choosing’ to become infected after years of having been uninfected, due to many factors, which can include being overwhelmed by multiple losses, and the feeling that HIV infection is both unavoidable and inevitable. This feeling of inevitability may parallel what is occurring for the affected child in a family with HIV, as one young man in Tourigny’s study says “[It]ain’t worth the fight,” pg. 155.] An uninfected child with an infected parent or sibling may “choose” to put themselves at risk for contracting HIV as a way of feeling closer to their infected family member.
- Affected children may lose agency support when they most need it, when a parent or sibling dies, and the agency cuts off support. However, a child’s most basic needs must be attended to before grief work can begin, as Siegal & Gorey (1994) point out, “Meeting the children’s basic physical and emotional needs is a necessary precondition to mourning,” (pg. 68).
- As both infected and affected children move into adolescence, the issue of sexuality emerges as another area of extreme vulnerability and risk for children who have lost parents and family members to AIDS. Direct, honest and explicit education and assessment is crucial in helping these children not continue the legacy of multigenerational AIDS. Abstinence-only education programs have been shown to not be effective for delaying the onset of intercourse, and the National

Institutes of Health's Consensus Panel on AIDS in 1997 said that the abstinence-only approach to sexual education “places policy in direct conflict with science and ignores overwhelming evidence that other programs (are) effective, “ (pg. 13.) Helping parents sexually educate their at-risk children may also help decrease risky behavior, and be more in keeping with a family's values.

- At-risk teens may need greater assistance and support with self-esteem issues, communication skills, and boundary setting, especially with substance use and sexuality issues. Peer education and support groups have been shown to be very effective preventive interventions on such issues as teen suicide, substance abuse, and HIV prevention among adolescent/young adult gay men.
- HIV/AIDS agencies need to continue to provide treatment to the much larger affected population. Grief support groups, permanency planning, caregiver support groups, and economic support, i.e. scholarships for children whose parents have died of AIDS, must be in place for people affected by HIV/AIDS.

- The most effective interventions and programs must be easily accessible, and preferably be located in convenient locations for the families. When possible, “one stop-shopping,” having all services for all members of the family, within the same agency, will be most effective in meeting the needs of the entire family, and increase the likelihood of compliance with meetings and other appointments.

Support Groups

- Support groups are an essential need across the spectrum of multigenerational AIDS. Groups should be tailored to each individual's need within the system, (i.e. group for infected children, separate group for infected parents, group for affected pre-teens, group for affected caregivers,) and grief groups need to be integrated into the continuum of services for HIV agencies. Grief groups can help clients break through the isolation, shame and complicated bereavement that can accompany an HIV-related loss. Groups need to take into account the clients' ages, number of losses, disclosure issues, and whether or not to include parents, siblings and spouses in the same groups, etc.

Spirituality and Meaning

- HIV/AIDS has created a crisis of faith for many on all sides of religious communities. People with HIV disease have historically been blamed, condemned and ostracized by religious organizations, cutting off people when they need spiritual support the most. IV drug users,

gay men, people who have had multiple sex partners have all been differentiated from the “innocent victims” of HIV... monogamous heterosexuals who acquired the disease from an infected partner, people who received HIV through blood transfusions, or children infected perinatally. Even “innocent victims” of HIV may have been excluded from their communities of faith, (Shrader, clinical case 1999,) due to ignorance and fear. The acquisition of any life-threatening illness in a family system brings with it the potential for a spiritual crisis. Psychologists and other mental health providers have historically shied away from exploring spiritual/religious concerns, and AIDS research has been relatively neglectful of the topic. However, many, if not most, people with HIV and their survivors will experience some sort of existential crisis in an attempt to try and give meaning to their disease and their lives. Mental health professionals ignoring or discounting this area of concern do a great disservice to people who may have no other outlet to discuss their concerns. In referencing the loss of a parent, Doka (1994) states “The death of a parent is certainly a profound psychological and social crisis for a child, especially when that parent dies of AIDS. It is also a spiritual crisis, where the child, at different points in his or her development, seeks meanings for the event. To ignore that spiritual crisis, and to fail to utilize the strengths of the child's own

spiritual beliefs, rituals, and community, is, at best, less than holistic care, “” (pg. 40 in Dane and Levine.)

- Assessing a client’s spiritual and/or religious concerns and resources is an essential component of HIV counseling and therapy, no matter what the age of the client. Gorsuch and Miller (1999) suggest a guideline in the APA publication Integrating Spirituality Into Treatment, stating, “the term “spirituality” will be used here as the larger construct within which religious involvement is only one aspect...(and) although spirituality may and often does involve institutional religion, it is also meaningfully distinct from religion,” (referencing Shafranske & Gorsuch, 1984, pg. 48.) Spirituality and religious involvement has been found to be often inversely related to physical, mental and substance use disorders. Spiritual assessment can also give a context to a client’s larger worldviews, and treatment can impact spiritual functioning. “Thus, it can be useful to track clients’ spirituality through and after treatment rather than assessing it only at intake,” (Gorsuch & Miller, pg. 50.)
- Gorsuch and Miller, 1999, suggest assessing client’s spirituality in three domains: belief, behavior and experience, (pg. 54). They define beliefs as “consist(ing) of a person’s convictions about the truth or falseness of the content of a statement...which theoretically arise from direct experience and other methods of learning (e.g. modeling,

vicarious learning) and are then used to guide decisions and to interpret new experiences....Beliefs provide the content for one’s reality...” pg. 54.) Spiritual behaviors are defined as “those that involve a distinct spiritual and transcendent component,” (pg. 56,) and give the examples of meditation, prayer and fasting. Spiritual experiences are defined as mystical and profound experiences that may be difficult to communicate, and possessing a transcendent dimension, (Gorsuch & Miller, 1999.) While Gorsuch & Miller recommend using psychometric devices in spiritual assessment, admittedly few exist at this point in time. Consultation with other psychologists and spiritual advisors would be recommended.

- Mental health professionals may be tempted to dismiss spiritual occurrences in clients with AIDS or their survivors, offering scientific explanations for them, or diagnosing and dismissing them as dementia or bereavement when no other evidence supports such a conclusion, closing down their clients quickly. Many people who survive the loss of a loved one often report scientifically unexplainable occurrences involving their loved ones who have died. No matter what the therapist’s belief system, judgment must be suspended in order for a client to feel they can safely explore their spiritual experiences in a non-judgmental atmosphere.
- Helping clients to create and/or discover meaning in the wake of tragedy is a profound intervention, and can help clients heal at deep levels. Yalom (1980) describes meaning as referring to sense or coherence, and states that it is a term for

what is intended to be expressed by something. A search for meaning, therefore, implies a search for coherence. Viktor Frankl (1959,) in his experience as a concentration camp survivor ultimately concludes that only by surviving could he give meaning to the pain he experienced. Farmer and Kleinman (1989) state that a significant component of humane care for people with AIDS, (and their survivors) must include soliciting the stories of the illness(es), listening to their narratives and helping give meaning to their suffering. These searches for meaning frequently may involve spiritual struggles, and challenges to spiritual belief systems.

- Due to the many different systems that clients infected or affected by HIV must interact with, coordination of care is essential. Efforts must be made to include and incorporate spiritual advisors into the treatment team, as they can be tremendous sources of support and strength for the client. However, a careful spiritual assessment is required to determine whether a client's church and/or spiritual system is a source of comfort or an additional source of stress and condemnation.
- AIDS has often demanded that psychologist and other professional caregivers 'break the fourth wall' in terms of taking them into uncharted waters, taking them out of the four walls of the therapy office and into situations unknown. Clients may ask of therapists that they take part in spiritual rituals important to the client. Rituals may include Native American sweat lodge ceremonies, or other cleansing rituals, blessings and prayers from a client's church, etc. As therapists venture further and further outside of their offices and zones of comfort, an ethical guideline to consider is what is in the best interest of my client? Would not participating in an important ritual in the client's life damage the therapeutic relationship, or would participating further blur the lines between client and therapist? Again, consultation is highly recommended.

Multisystems Assessment and Case management

The Myriad Issues

- Many families living with HIV infection are also dealing with a myriad of other health and social problems such as poverty, homelessness or substandard housing, violence, substance abuse, poor access to health care, poor education, poor access to information, and discrimination. Many are interfacing with social service agencies to care for their basic needs such as food, clothing, and housing. Thus, they may be involved with a variety of case managers and other service agents.
- With the diagnosis of HIV infection, we add a new list of care providers including physicians, nurses, social workers, and psychologists. Each provider may serve a different yet crucial role for the family. However, accessing and making the most of a relationship with a provider can be a cumbersome task for a family. While the aim

is to empower the family to make the best use of available resources, families may become overwhelmed and confused about how to best utilize services.

- Boyd-Franklin (1989) offers the multisystems approach as an effective strategy for coordinating care and building collaboration among providers involved with a family. Within this approach, the needs as well as resources of individuals and families are assessed at various system levels.

a. Individual level

1. *Examples of needs include: individual psychotherapy, support groups for parents or children, medical care, access to clinical trials, psychological assessment*

2. Subsystem level—Siblings, Spousal subsystem, Parent-child relationship
 - a. Examples of needs include: support for affected children, negotiation of safer sex, parenting support for HIV-positive parents
 3. Family Household
 - a. Examples of needs may include: permanency planning, housing, basic needs; Family therapy or family interventions may be indicated
 4. Extended Family, Non-blood kin
 - a. *Families may need assistance renewing ties with family to build support systems*
 5. Community, School, Church
 - a. *Parents may need assistance accessing appropriate school placements or services for children such as early intervention services; Community and faith-based organizations may provide support groups, recreational activities, AIDS ministries*
 6. Social Service, Health and Mental Health Providers
 - a. *Families may be involved with a number of various providers but need assistance clarifying their roles and feeling empowered to make to best use of their services*
 7. Legal Systems, Policy Issues
 - a. *Families living with HIV may need legal resources to address issues of guardianship, permanency planning, or living wills; Since many services are linked to someone with HIV infection, affected children may face the loss of services once the family member with HIV disease dies.*
- By assessing these various levels providers can determine individual needs such as individual or group psychotherapy, family or couples therapy, mentoring, parenting support. But equally important a provider can determine family, community, and service resources. This can help facilitate collaboration among providers as well as empowerment of families to identify which providers are best to consult regarding particular concerns.
 - The multisystems approach helps to prevent isolation of families and duplication of efforts among providers. Families become increasingly aware of what services are available and how to access them and providers build networking and collaborative relationships to better serve the families they have in common.
 - Boyd-Franklin and Boland (1995) indicate that multisystems case management helps to clarify the roles of various service providers so they can more effectively manage multiple problems. The value of this approach for families affected by HIV disease cannot be

overestimated. Families affected by HIV disease have many needs and HIV may not be the most pressing need from their viewpoint. The multisystems approach is built upon the idea that empowerment is the ultimate goal of case management and

intervention with families. Providers aim to help families understand and negotiate systems. Families are engaged as active participants in developing a plan most responsive to their needs. The family learns how to network within the various systems and build relationships with providers who can support their access to services.

Another Systems Approach: A Model Program

- The Pediatric AIDS Program in New Orleans utilizes a systems approach based upon Bronfenbrenner's model (Blackwell, Gruber, & vonAlmen, 1997). These authors also note that services must target multiple needs because families confront not only HIV but social issues such as poverty. As in the multisystems approach the child is seen as part of a larger system that includes individual, family, community and political factors.
- In this model the systems levels are divided as follows:
 1. Microsystem—individual child and their relationship with their caregiver
 2. Mesosystem—relationships between family members
 3. Exosystem—features of the environment and community
 4. Macrosystem—larger socio-political structure surrounding all other systems
- Each layer is viewed as having an important impact on the family. Thus, services are constructed to address each of the system levels. Services include case management, child development, and support services. Interventions are designed to impact at each system level. For example, case management is designed to include the following interventions at the various system levels.

1. Microsystem—Reinforce positive parenting
 2. Mesosystem—Family counseling
 3. Exosystem—Identify community resources including housing or childcare. Connect with community-based resources
 4. Macrosystem—Encourage clients to become involved in national policy initiatives related to HIV care.
- Like the multisystems approach, families are active participants in their treatment. Families are helped to learn the impact of various systems levels on their lives as well as how to impact different system levels.

Possible Discussion Point/Activity for providers: Provide a case example and have providers make a multisystems assessment and develop a list of resources, collaborative relationships, and potential interventions across the multisystems levels.

Have providers make a list of other providers/services within their community with whom they can network/collaborate to address the multiple needs of families. If providers are present from several different organizations, ask a member of one organization to describe the services that are offered/available at another organization -- often, there is quite a bit of misunderstanding about what different organizations in a community actually have to offer; allow participant from described organization to "fill in the blanks" and correct misinformation.

DEVELOPMENTAL ASPECTS OF A CHILD'S AWARENESS OF DEATH

<u>AGE</u>	<u>CONCEPT</u>	<u>HELPFUL RESPONSE</u>
0-3	Separation	Much physical presence
<p>NOTE: Impact of separation on infants who have no words (language) to describe it; only emotions. Dying infants, like dying adults who are declining in their intellectual capacities need to be talked to and HELD.</p>		
3-7	Physical life goes on elsewhere. Sense of permanence emerging	Clear "dead" definitions Answer questions specifically Introduce "grief" concept
*6-10	Permanent (but not me).	Practical issues of who

Real life/spiritual
afterlife confusion

will take care of them.
Explore feelings.

*This is a very vulnerable age because cognitive understanding and emotional ability to cope are not coordinated.

10-adol. Death is permanent *and* it
will happen to me later.
Egocentric, ambivalent,
exaggerated sense of
responsibility

Lots of permission to
grieve. Flexibility is
the key. Tease out role
expectations; Really
explore magical thinking,
guilt and shame.

Three questions dying children ask:

- Will it hurt?
- What will happen next?
- Will I be remembered?

Three questions grieving children ask:

- Is it my fault?
- Can I catch it (Will it happen to me, too?)
- Are *you* going to die too?

-- Dottie Ward-Wimmer, RN, MS