Current Practice in the Prevention and Treatment of HIV/AIDS in Children

At the 1997 National Abandoned Infants Assistance Grantees' Conference, James M. Oleske, M.D. shared his knowledge and experience in the treatment of children with HIV/AIDS. Dr. Oleske, one of the nation’s foremost pediatric immunologists and infectious disease specialists, is Francois-Xavier Bagnoud Professor of Pediatrics at the University of Medicine and Dentistry of New Jersey (UMDNJ). He is also Medical Director of the Francois-Xavier Bagnoud Center for Children (formerly known as CHAP), one of the nation’s largest treatment centers for childhood HIV/AIDS, and the New Jersey AIDS Education and Training Center at the UMDNJ. In addition to his clinical, administrative, and research responsibilities, Dr. Oleske publicly advocates for women, children, and adolescents with HIV/AIDS. In his presentation, Dr. Oleske provided an overview of a model for effective interventions with children and families affected by HIV/AIDS. He also shared current information on the perinatal transmission of HIV and recommendations for the treatment of children. The following article summarizes the main points of his presentation.

Model for Managing HIV/AIDS

Given the nature of AIDS, a chronic disease model must be used to effectively treat children with HIV. Within this framework, comprehensive services should be delivered by a multidisciplinary team through prevention-oriented programs, which identify and intervene with populations that are at risk of transmitting or being infected by the virus, and intervention services provided through all stages of the disease. Specific services include: monitoring infants born to HIV-infected women; HIV testing and counseling; psychosocial support and care; clinical/immunological monitoring; anticipatory management; nutritional support; preventive therapy; treatment and management of cancer and of organs affected by HIV; specific antiretroviral treatment; and pain management. Also, in order to be accessible to families affected by HIV, these services should be culturally relevant and focused upon the family and the community.

Perinatal Transmission of HIV

Drawing from this framework, Dr. Oleske believes that the early identification of HIV in pregnant women is critical in order to optimize outcomes. A woman is more likely to transmit HIV to her fetus during the early or late stages of the disease which are characterized by high levels of HIV replication and of viral loads. At early stages of the disease, however, a woman is most likely to benefit from antiretroviral medications, such as AZT, which can reduce the viral load, and, therefore, the risk of perinatal transmission.

In 1994, the ACTG 076 study found that, when pregnant women with HIV were given AZT, perinatal transmission of HIV was greatly reduced. While these results provided hope for women with HIV, they also raised questions about the long-term adverse effects on the fetus and the mother. Specific concerns include the development of an AZT-resistant virus and the effect of AZT on the progression of HIV in the mother and its long-term effects on children. In response to these concerns, a 2-year post-partum follow-up study of women who received AZT during pregnancy was conducted. Although there were no significant findings, Dr. Oleske believes more follow-up needs to be done. Additionally, a 4-year follow up study (PACTG 076/219) is being conducted to assess the late outcomes for children whose mothers were given AZT during pregnancy. So far, the findings suggest that AZT does not increase their rates of
cancer or death; yet these children need to be monitored for a longer period before any conclusions can be made.

While appropriate medications should be available to pregnant women with HIV, good nutrition and a healthy lifestyle also are important in preventing the perinatal transmission of HIV. These factors are critical in maintaining lower levels of viral activity and in preventing the development of HIV-related symptoms. Consequently, early identification provides HIV-infected pregnant women with options for interventions which reduce the risk of perinatal transmission, and it can lead to the early detection of infants with HIV.

**Treatment of Children**

As with adults, the treatment of children with HIV has been shifting away from monotherapy, the use of one medication, to combination therapy, the use of multiple medications. With combination therapy, patients are often prescribed antiretroviral treatments along with protease inhibitors, a relatively new type of drug. Because combination therapy acts upon HIV in different ways, its benefit is the reduction of a person’s viral load without the development of resistance to the medication.

However, there is a lack of information about the effects of HIV medications, including antiretroviral treatment and protease inhibitors, on children. Compared with research on adults, few clinical trials have been conducted for children. Additionally, federal regulations do not require pharmaceutical companies to test drugs for use in children. As a result, the Federal Drug Administration (FDA) has only approved 5 antiretroviral medications for use in children, compared to 11 for adults. To encourage the approval of more drugs for use with children, Dr. Oleske advocates for the FDA to mandate pharmaceutical companies to test their medications with children, and for the development of more clinical trials for children. At the same time, Dr. Oleske advised that the treatment of children with these medications must not be delayed due to a lack of clinical trials and that research must be integrated with the treatment of children in a manner which ensures that care is not contingent upon participation in trials.

Dr. Oleske also cautions that, while combination therapy appears to be the most promising treatment of HIV/AIDS, it poses unique challenges to children with HIV and their families. Specifically, because this therapy requires strict adherence to dosing schedules and storage requirements in order to be effective, families may have difficulty complying. In fact, a family’s ability to comply with a child’s treatment regime is significantly influenced by the quantity of medications, storage needs, and palatability of medications, as well as family issues (e.g., whether or not a child is in foster care) and cooperation from schools or day care providers. In addition, this treatment can significantly affect children’s quality of life. For this reason, Dr. Oleske stressed the importance of using treatment regimes of the lowest possible toxicity in order to enhance these children’s quality of life.

Nutrition also is important in managing HIV in children. HIV places additional nutritional requirements on children, yet children with HIV often have diminished appetites as a result of their illness and medication. Therefore, it is important that children’s nutritional needs are addressed and monitored through treatment. Dr. Oleske suggested one way to monitor these needs is through regular assessments of viral loads which, he maintains, should be covered by third party payments.

Dr. Oleske also emphasized the importance of pain management in the treatment of pediatric HIV. He outlined common myths about children and pain, including the belief that children do not feel pain as much as adults and that pain medication should not be given to children. When his patients have pain due to the disease and treatment procedures (e.g., blood drawing, injections), Dr. Oleske identifies the pathologies which cause pain and uses non-pharmaceutical interventions, such as distraction and imagery, to enhance these children’s quality of life. Consequently, Dr. Oleske’s knowledge, commitment, and compassion offer guidance and hope.

— Amy Marlo, MURP
Research Assistant
National AIA Resource Center
The Children's AIDS Network Designed for Interfaith Involvement (CANDII) is an independent, not-for-profit, community-based organization providing comprehensive services to children affected by HIV/AIDS and their families. In 1992, the U.S. Department of Health and Human Services, Administration for Children and Families awarded CANDII an Abandoned Infants Assistance (AIA) grant for its Child and Family Support Project. After a successful four-year project, CANDII was recently awarded a second AIA grant.

Services to Children and Families

The mission of CANDII is to improve the quality of life for children affected by HIV/AIDS. The purpose of the Child and Family Support Project (CFSP) is to prevent the abandonment, neglect, and/or abuse of children affected by HIV and substance abuse by providing support to their families. All of the families served by the project have at least one member (and most often 2-3) with HIV infection, and approximately 75% of the families served have at least one member with a substance abuse problem. For those families who are not actively facing substance abuse, it is most often in their family history.

To support the children and their families, project staff and volunteers provide a number of services which include: day and respite care, preschool play groups, transportation, support groups for caregivers and children, individual and family counseling, and service coordination. In addition, by collaborating with CANDII's other projects, staff can offer crisis care, volunteer buddies, and housing support to eligible families.

The child care programs (day and respite care and preschool play groups) are designed to offer safe, nurturing, developmentally appropriate play activities to children, birth through age 5, while offering needed respite to their families. CANDII has two child care centers where child development specialists (one at each site) are assisted by paraprofessionals and trained volunteers to care for a total of about 30 children. Through this program, staff also monitor child development and assist families in nurturing that development. Referrals for early intervention and special education services are made where appropriate.

The needs of older, school-aged siblings are addressed through CANDII's Children's Support and Activities Groups. Children aged 6-16 are placed in developmentally appropriate groups which meet after school and throughout the summer. These groups are facilitated by project staff and are designed to help children cope with the impact of HIV and substance abuse in their lives. Often the 6-7 year-olds are just beginning to understand what HIV is all about and disclosure is an important issue for discussion. Some of the older children have been living with substance abusing parents and in violent families, and may be seeing parents and siblings die from complications of AIDS. Group discussion and activities often facilitate improved coping skills and enhance children's overall mental health.

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Mental health needs are also addressed through individual and family counseling. Issues related to illness and death, substance abuse, relationships, self-esteem, and permanency planning are among a multitude of issues CANDII families are facing. A licensed clinical social worker, on contract with the project, offers counseling in families’ homes, at one of CANDII’s program sites, or in “neutral” locations.

Support groups for caregivers have offered women facing HIV and substance abuse the opportunity to meet with peers and share information, resources, concerns, and support. Educational opportunities have occasionally been integrated into the support groups, but participants most often determine the topics and the direction of the discussion. Issues related to child care and development, relationships, and managing health care and other systems are frequent topics addressed in the groups.

Finally, this system of services is monitored and linked through service coordination—helping families to identify their needs and gain access to necessary resources. Service coordinators visit families at home at regular intervals and help them to develop, implement, and monitor their individualized family service plans.

Permanency Planning

Helping mothers with HIV to plan for the permanent care of their surviving children is another component of the CFSP. Most of the families served by CANDII are headed by single women with HIV. Many of these women are also chemically dependent. Some of them have family and other support to provide permanent care for their children when they are no longer able to. They may, however, need assistance in making these arrangements formal and in facilitating a smooth transition for the children. Other mothers who have no one to care for their children, or who find their support unreliable, may need assistance in making alternative plans. Such planning involves a wide range of physical, emotional, financial, spiritual, and social issues.

Until 1996, CANDII was part of a collaborative permanency planning project called My Sister’s Children. This project, funded through the Adoption Opportunities Program, was designed to assist families with this planning by providing counseling, placement, and adoption services. With the end of this program, CFSP and other CANDII staff have assumed responsibility for the counseling and planning components, with referral for legal and placement support when necessary.

Assessing a parent’s readiness to begin this planning, and facilitating the planning process during the frequent times when parents vacillate between readiness and unreadiness, present many challenges to project staff. Often, mothers with HIV will identify permanency planning as a priority during periods of illness, but when that period passes, the issue is no longer a priority. Also, project staff have found that chemically dependent women are less likely than their peers to address this issue, even when it is presented to them. They are so caught up in their addiction, facing great inner turmoil, and perhaps recognizing that they have not been the kind of parent they have wanted to be, that they are unable to plan for the reality that they may leave their children before they are “ready.” Helping these women understand the importance of planning for their children’s future requires diligence and caring support on the part of the service coordinator. Bringing up the issue at regular intervals, taking advantage of every opportunity to partner this issue with another in discussion, and respecting parents’ rights to plan at their own pace are important considerations.

Another frequent challenge involves the rights of absent fathers. Often, mothers have strong feelings against the fathers of their children and do not want them to parent their children. Fathers may have been abusive, may be substance abusers and/or HIV-infected themselves, or may simply have been uninvolved in the lives of their children. Unless their parental rights have been terminated, however, they must be given the opportunity to express their interests. This causes great stress for many mothers.

Another issue involves the choice of a permanent caregiver. Some mothers assume that a family member will care for their children when they are no longer able to. When the situation presents itself, however, this family member may not have the resources or the interest to take on this responsibility, or they may be willing to take one of the children, but not the whole family, despite the mother’s wishes for her children to stay together.

My Sister’s Children, the collaborative project mentioned earlier, recruited and trained potential adoptive families for children who lost their parents to AIDS and for whom no other options were available. The goal was to facilitate as smooth a transition as possible by encouraging the families to spend time together, get to know each other, build a trusting relationship, and become comfortable with differences in caregiving styles. All this would occur before the mother entered the end stage of her disease. However, only a very small number of families considered this option. One mother who entered into a relationship with a potential adoptive family, and for whom the experience appeared very positive, eventually decided she could not resolve the differences in religious practices and terminated the relationship. She now plans to leave her children with her sister.

Stand-by guardianship has been regarded in many areas as a critical mechanism for supporting parents with HIV/AIDS and other life-threatening illnesses. Indeed, it is one way to assist parents in making decisions and having those decisions recognized by the courts. Stand-by guardianship legislation was introduced into the Virginia General Assembly last year and was referred for further study. Project staff are working on this study and providing information to legislators. Although stand-by guardianship is not the answer to all of the questions surrounding permanency planning, it is one valuable tool.

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What Should They Know of Death? 
Supporting Children Affected by AIDS

A simple child
That lightly draws its breath
And feels its life in every limb
What should it know of death?

—Wordsworth (1928, pp. 74-75)

The notion of childhood innocence as revealed by the poet suggests that a child’s personal awareness of death should be avoided or postponed. Unfortunately, for children affected by AIDS, this fantasy is lost amidst the chaos and confusion that the child and family must confront—sometimes preceding—the diagnosis.

For the child who has family members with AIDS, the sense of loss and grief may begin a considerable period of time before the loved one becomes terminally ill or dies. There typically are episodes of acute illness in which the person may be near death but recover following hospitalization. The child is again and again confronted with the threat of death, only to gain a respite until another crisis occurs. This child is facing a high probability of being orphaned, which is truly formidable.

For families and children who witness the progressive mental and physical deterioration of an AIDS patient, the mourning period may begin early, and is often complicated and prolonged. Frequently, the gradual disfigurement and “wasting away” of the individual with AIDS may cause the child to withdraw. As a result, many children experience guilt once their parents’ death has occurred. If this guilt is not expressed, it may result in psychiatric symptoms, such as depression.

Additionally, children of all ages are at risk for feeling that they are in some way responsible for the death of a loved one. They are forced to deal with losses that occur at an unexpected time in their life cycle. If survivor guilt is unattended, it can adversely affect the child’s capacity to grieve. Further, if more than one significant person is affected, a child may not have time to mourn one death and loss before another occurs.

Needs of Bereaved Children Affected by HIV/AIDS

Children experiencing the loss of a loved one have various needs that can be addressed through support and therapeutic intervention.

Understanding
In bereavement, children need to understand what is happening and what has happened to them and to their loved ones. With AIDS, communication may have been suppressed due to the stigma associated with the disease, the shame and guilt, or the chaos experienced by the family as members deal with the multiple challenges associated with the diagnosis. Conversations that are held may be limited to adult family members for fear that including the children may result in revealing information that they might not understand or know how to cope with. This secrecy can increase a child’s anxiety, for typically the child is aware that something is seriously wrong. In such a closed environment, children are likely to create and imagine a range of frightening possibilities and may blame themselves for the mysterious and inexplicable changes that have occurred.

Expression
Children need to express an emotional response in anticipation of a loss, or during and following a loss. The family’s secrecy may restrict the amount of anticipatory grieving experienced by the child. Even when the child is aware of losses in the family, the child’s emotional response may be muted or suppressed to preserve the family’s secret, or repressed as the child assumes increasing responsibility in the family. Also, the adults in the family may be so preoccupied with their own stress and grief that they are unable to acknowledge the needs of grieving children.

Grieving and bereaved children of all ages respond to projective techniques that employ a variety of mediums. Sand tray, clay, paint, crayons and markers, paper and pencil, small, bendable dolls, puppets, musical instruments, and medical-oriented toys are useful in allowing the child to express pent-up emotions. Often children need little or no guidance to project fears related to dying or losing a parent, anguish related to deaths that have already occurred, and anxiety about medical interventions into creative play.

Commemoration
The grieving process often is facilitated by commemorating the loss of the loved person in some formal and informal manner. This can be achieved through ritual. Rituals evolve from primary human need, develop naturally, and are best interpreted as expressive behavior. They are helpful for children because they facilitate the grieving process by allowing the child to let go of the lived experience with the loved one, and to hold on to memory in a more appropriate way.

A ritual can be as simple as lighting a candle in memory of a deceased loved one, or as intricate as weaving many symbols together to convey a more complex message. Rituals that encourage remembering and community support are often expressed in the context of religion. However, many families affected by AIDS may be severed from the support of the religious community due to life style (which may include drug use) and various stressors. Without the religious community, the family may experience a void of rituals to commemorate and acknowledge the death of a significant person.

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If a ritual (such as a funeral) took place without the child's involvement, it will be necessary to recreate a bereavement ritual in which the child participates. In providing the child with an opportunity to engage in ritual, one should first identify the focus and purpose of the ritual with regard to mourning, specify what message is to be conveyed (involving the child in this decision), choose the type and elements of the ritual, create the context, and prepare the child. After implementing the ritual, it will be important to process the experience with the child, to find out how the child feels and what is left to do to achieve some sense of closure. For example, if a child has not said a final good-bye, a message may be composed that states what he or she would like to have said personally. This message may be written and left or buried at the grave, or launched in a helium balloon. Following this ritual, time to acknowledge and discuss the impact on the child should be provided.

**Letting Go/Going On**

The grieving process includes learning how to continue the process of living one's life. Letting go of someone significant is an extremely difficult task for a child. Resistance is normal and should be anticipated. Often the primary fear that the child harbors is that the loved one will be forgotten. Some of this fear may be mitigated by providing opportunities to record memories. A journal may be initiated, including documentation of important dates and events, and narrative that the child may write himself or dictate to someone else to record. A memory box (in the form of a cigar box or shoe box) may be decorated and contain special items belonging to the deceased, or items that trigger memories of the loved one. This personal box allows the child to conceal and access these memories while maintaining privacy.

Additionally, many children who lose a parent to AIDS find the world an unpredictable, even dangerous place in which to live and consider adults in general to be unreliable. In order for the bereaved child to engage in the future, caring adults, some of whom will serve as role models, must be available to the child. Children need assistance in order to construct some sense of meaning to what has transpired, learn to incorporate such experiences into their lives, and identify purpose in life.

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**Children's Conceptions of Death**

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<thead>
<tr>
<th>Age:</th>
<th>Birth to 2 years</th>
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<tbody>
<tr>
<td>Concept of death:</td>
<td>Perceives death as separation or abandonment; feels a sense of loss; realizes that something is different.</td>
</tr>
<tr>
<td>Reaction:</td>
<td>May be anxious.</td>
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<tr>
<td>Intervention:</td>
<td>Provide consistent care in a familiar environment.</td>
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<table>
<thead>
<tr>
<th>Age:</th>
<th>2 to 6 years</th>
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<tbody>
<tr>
<td>Concept of death:</td>
<td>Beginning to understand reality of death, but is confused; realizes that being dead means not being alive; may see death as reversible. May believe that dead person still physically exists. May believe that he or she is responsible for the death (magical, egocentric thinking). Fears punishment, fears that death is contagious.</td>
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<tr>
<td>Reaction:</td>
<td>May be curious, confused; may ask body-oriented questions.</td>
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<tr>
<td>Intervention:</td>
<td>Discuss death concretely and accurately: &quot;Joe is dead. We will never see him again. We are sad.&quot; Provide reassurance that the child is not responsible for the death and that the child will be cared for. Encourage questions; provide honest, simple, direct answers. Stories about dead pets and other animals are helpful.</td>
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<table>
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<tr>
<th>Age:</th>
<th>6 to 12 years</th>
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<tbody>
<tr>
<td>Concept of death:</td>
<td>Learning to think logically and to solve problems. Death is concrete with specific causes. Understands biologic functioning. Death is considered a universal and irreversible event. May have morbid interest in skeletons or, conversely, may have an exaggerated fear of dead things. Begins to deal with possibility of own mortality.</td>
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<tr>
<td>Reaction:</td>
<td>May be angry or curious or may act as if nothing happened.</td>
</tr>
<tr>
<td>Intervention:</td>
<td>It is reasonable to explain that death occurred because the heart stopped beating, etc.</td>
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<table>
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<tr>
<th>Age:</th>
<th>12 and over</th>
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</thead>
<tbody>
<tr>
<td>Reaction:</td>
<td>May exhibit exaggerated risk-taking behavior.</td>
</tr>
<tr>
<td>Intervention:</td>
<td>Be available for questions and discussion of death-related concerns.</td>
</tr>
</tbody>
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The 21st of September, 1997, will be one year since Morgan died. It sounds so final. It is final.

Morgan was born on Thursday, February 24, 1994 at 9:05 a.m. — she was beautiful. I knew from the first moment I saw her and held her next to me that she was (and is) my heart and soul. She was a big girl when she was born and healthy in almost every respect. When she was a couple of months old, I found out for sure that she was HIV+ also. My mother went with me to the hospital where Morgan was being monitored at the time, and that was where we were given the news. Deep down inside me, I knew it but it still hurt and I couldn’t help but feel lost and helpless. The good news was that she was doing great. She started on AZT and DDC to help keep her T-cells up and her health good.

Coordinating Services to Support Morgan’s Development

As Morgan grew, I realized that she was not doing everything that other babies her age were doing. She wasn’t sitting up by herself, and she wasn’t crawling yet. When I spoke with her doctor about this, we agreed to switch her care to a different clinic where a multi-disciplinary team examined Morgan and we discussed starting physical therapy for her. They explained that physical therapy would help Morgan with the muscle tone in her legs and help to strengthen her back muscles so that she would be able to sit up by herself and pull herself up to crawl and eventually walk. It was decided that Morgan would be seen at the clinic approximately once every 4 to 6 weeks, and that she would begin physical therapy around age one. After Morgan was a little over a year old, she began physical therapy with a wonderful lady.

Around the time Morgan was 18 months old, the meds she was taking became ineffective for her. She started losing some of her milestones, which for her was a very big deal, so the doctors changed her meds to 3TC, D4T and Nevarapine. These worked great for her, but she had to work extra hard to get back what she had lost and regain her milestones. To help her to accomplish this, in October of 1995, Morgan started at a school for children with and at risk for developmental disabilities. She was the first child at the school who was HIV+, so I had a nurse go to the school to talk with her teachers and the school directors about HIV and AIDS. This helped tremendously and no one was afraid or embarrassed to ask me questions about Morgan’s or my health. On Morgan’s first day there, I couldn’t bear to leave her. But as she came to know everyone, she loved it and her instructors loved her. She had some wonderful teachers to whom I will be forever grateful.

Morgan was doing extremely well. She was very bright and determined to compensate in other ways for the things that she was not able to do. She learned sign language, or I should say that she taught everyone Morgan’s version of sign language so she could communicate. Her vocabulary was limited; she could say some words, but the sign language was enabling her to communicate much more. She was growing so fast and so tall. I took her to the clinic for her monthly visits and to a pediatrician for her regular “well-baby” visits.

A Turn for the Worse

In March of 1996, shortly after Morgan’s second birthday, she got chicken pox over her right eye—just her eye, nowhere else. She was admitted to the hospital as a precaution for a week, just to make sure there was no permanent damage to her eye.

When she was released after a week, she was doing great. Then about mid-May, I noticed a lesion on her bottom. I took her to her pediatrician, where I was told that it was impetigo. I was given some cream for the lesion and some antibiotics for her to take, but it did not seem to help her at all. The lesion spread all over her body, and I took her back to the doctor six different times before they decided to take an x-ray because, by then, her lungs sounded congested as well. The x-ray showed she had pneumonia, which the pediatrician immediately thought was PCP. The pediatrician called Morgan’s doctor at the clinic. We were transported by ambulance to the clinic where the doctor determined that the lesions on Morgan’s body were chicken pox and that she also had pneumonia from the chicken pox—varicella pneumonia.

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Morgan was admitted to the hospital on June 6, 1996, and I finally got to take her home on June 29, 1996. I was ecstatic, but Morgan was far from being completely well. I brought her home on oxygen and a lot of antibiotics, but she was home. Her meds were switched in the hospital as well because of the antibiotics she was taking. Now she was taking AZT, 3TC and D4T. None of the protease inhibitors were available for children at that time. (It was and is extremely frustrating that protease inhibitors are not available for children as readily as for adults. It is only recently that the protease inhibitors have become available for children at all.)

Another Set-back

Morgan’s recovery was slow, but she was progressing. I was taking her to the doctor weekly because I was afraid of a relapse and I wanted her progress monitored as closely as possible. Gradually, the oxygen was decreasing and she was becoming stronger and smiling more. Then on August 31, 1996, Morgan wasn’t feeling well and she was pulling on her ear (she never got ear infections). My first thought was “great now she gets an ear infection on top of everything else she has to deal with.” When her pediatrician examined her, she wasn’t able to tell anything about Morgan’s ears, but she noticed that her lungs sounded “wet.” The doctor put her on a pulse-ox machine to check her oxygen stats. She was in the 80’s, which was not good, so she was given oxygen. I asked the doctor if we could get an x-ray, which did not reveal anything. But, to be on the safe side, the pediatrician wanted me to take Morgan to the clinic to be examined and have this x-ray compared with her previous ones done in June.

When we arrived at the clinic, Morgan was admitted into the emergency room and then into the hospital as a precaution so tests could be run to see what was going on. I called my family to let them know what was going on, but even as I told my mom not to worry, I was scared. This was entirely out of my hands and I was helpless to do anything about it. The doctor determined that Morgan had become reinfected with chicken pox, so he began treating her very aggressively with several different intravenous antibiotics. The antibiotics seemed to be working, but she wasn’t responding as fast as they had hoped. The doctor wanted to perform some additional tests (e.g., a bronchoscopy) to see what, if anything, was happening in her lungs. The bronchoscopy went very well. Her doctor was pleased, but unfortunately Morgan had another type of pneumonia (pseudomonas), so she was given additional intravenous antibiotics. Morgan began to respond well to all the meds, and she was even beginning to eat and was smiling more and more.

Meanwhile, I was working full-time — commuting to and from the hospital about 30 minutes each way. I would be at work by 9 a.m. and leave at 3 p.m. to get back to the hospital. My mom and sister would bring me clothes and take my other clothes to be washed so that I wouldn’t have to go home.

Planning for the End

I remember going to work on September 9th, 1996. Morgan was up when I left — laughing and watching Sesame Street. I kissed her good-bye feeling that she was getting better and I would be taking her home again soon. I called at lunchtime to see how she was doing, and I learned that she had a bit of a fever, but she had eaten her lunch and was playing. I called again around 3:00 just before I was leaving. Her fever had gone higher and she was no longer responding to any of the antibiotics. I called my mom to let her know what was going on, then I left for the hospital. When I got to the hospital, the doctor met me in our room to let me know that, since Morgan was no longer responding to the antibiotics, they were trying some other antibiotics and they would know within the next several hours if those antibiotics were going to work. If not, then we would have to talk. I just kept praying that the antibiotics would work.

My mom got to the hospital and said that she would stay with me. Around midnight Morgan started having trouble breathing and I had to call the nurse and doctors in several times. I was scared; I thought I was going to lose Morgan right then and there. They were able to give her some valium, which quieted her down and helped her relax so that she was able to breathe more comfortably. At 10:00 a.m. the next morning, I met with the doctor and his team, Morgan’s nurse, and the social worker to discuss options for Morgan’s care — none of which I wanted to hear.

“Morgan isn’t responding to any of the antibiotics,” was the first sentence I heard. I remember sitting there listening to the doctor talk about “options” — what they could do for Morgan as far as additional treatment, but that basically nothing was going to help her. All I would be doing was prolonging her life, but what kind of life would she have? She would never be able to play with other children or go to school again, and she would be bedridden and hooked up to IV’s and oxygen for the remainder of her life. I grilled the doctor and his team: “What if this is done? What if that is done? What will happen if we do this?” I questioned him about every possible thing I could think of. The answer was still the same: I could prolong her life, but is that in Morgan’s best interests?

I finally asked the two questions I had dreaded asking, “What can I do to make her final days comfortable” and “How much longer does she have?” I had to know the answers and I had to know that I could be the one to tell Morgan what was going on. After talking with the doctor and his team and listening to everything that they had to say, and them in return listening to everything I had to say, I decided that I could not keep Morgan “alive” just to keep her with me for as long as possible; that would be unfair to her. She was used to playing with other kids, and it would hurt her more if she was unable to do the things she wanted to. So, instead of being selfish (which I wanted to do more than anything else in the world), I would do what was in Morgan’s best interests and have only comfort care measures given.

I then had to sign all the papers — the “Do Not Resuscitate” orders, hospice care papers, withdrawal of medications.
papers—the list was endless. I don't even remember feeling anything at that point. Next I had to call the rest of my family to let them know what was going on. I couldn't do it; my mom had to.

Finally after all the paperwork was done and my family notified, the doctor asked me if I wanted to stay in hospice care where Morgan had been staying, or if I wanted to be transported to another hospital for hospice care. I chose the latter because it was closer to home and would be easier for family and friends to visit. So, on September 11, 1996, once again and for the final time Morgan and I were transported by ambulance to Kaiser Hayward hospice care. The doctors and nurses were extremely kind and generous with us and gave us every allowance. I was given a hospital bed that I could raise up and put one side of Morgan's crib down so that we could sleep together. I remember one night, I couldn't sleep so I was just watching Morgan sleep when I noticed that she wasn't sleeping either. For the next couple of hours we just laid next to each other, watching each other until she finally fell asleep around 5 a.m. That is one of my favorite memories of our last times together.

The Final Days

I was not going into work by this time—I had taken a leave from my job. My last day of work had been September 9th, and from then on I spent every day and night at the hospital. My family and friends took turns staying at the hospital with me so that I would not be alone. The weaker Morgan got, the more she just slept, which the doctors said was normal, and they allowed me to adjust her morphine drip if I felt she was in any pain.

On September 21st, my mom and sister were going to get something for us to eat for dinner, so my father and I stayed with Morgan. When they got back we had dinner. Then my sister and dad went downstairs to get some air and my mom and I were in the room with Morgan when she started having trouble breathing. I looked at my mom and said, "She's really going to leave me isn't she?" I remember my mom's response, "She will always be with you, she will never leave your heart." My mom left to get my dad and my sister and we gathered around Morgan and told her how much we loved her, told her all of our favorite memories with her, touched her, held her hands, and legs, and kept repeating how much we loved her. My sister asked if I wanted to be alone with her and I said yes. So I sat in the rocking chair and my sister picked Morgan up and handed her to me. Then they all kissed her and went out of the room.

I told Morgan how much I loved her and that it was okay to stop, that she was too little to have to work so hard. Morgan opened up her eyes and looked at me and I told her again how much I would always love her. I promised her that I would stay with her as long as I could and that she would always be proud of her mama. Then she closed her eyes, smiled and was gone.

I held her in my arms for a long time. When the doctor came in to check her vitals, she asked if I wanted to put Morgan back in her bed—there was no way I was going to let her go—I wanted her with me for as long as possible. The doctor then checked for vitals and found none so she shook her head and said she was very sorry and turned from me with tears in her eyes and left the room. I held Morgan for as long as they let me, until the funeral home came for her. We said our last "I love you's" and kissed her good bye. I am always grateful that I had that time with her.

Morgan's service was beautiful, like her, and her teachers, nurses and doctors and others who knew her well said many wonderful things about her. Morgan was a wonderful inspiration and teacher to the many people whose lives she touched.

A Look Back

A year and many tears later, I still feel so incredibly lost and alone. But I was very fortunate in many ways. I have an extremely supportive family and network of friends. I am able to voice my opinions and not afraid to do so, especially when it came to Morgan's care and well-being. I was and still am working, and I was able to provide for Morgan and had the resources to get help from various agencies to allow me to take the best possible care of Morgan. Some agencies, however, were not able to help me because of my income. In some cases it seemed as though I would do better to quit working than to keep banging my head against a brick wall trying to get services for Morgan that I was not able to provide for her myself. Yet, since I also do a lot of volunteer work for various agencies, getting those agencies as well as others to help was made a little less difficult, but it still was not easy. This is not the case for all people who are HIV+ or have AIDS and have children who are also infected.

I miss Morgan incredibly and I will always cherish the time I was allowed to have her in my life. Even though it was for a very short time, she was a dream that came true for me.

— Rhonda L. Hase
Morgan's Mother
Meeting the Needs of Substance Abusing HIV Infected Women with Children: The Wellness Group at Operation PAR

Operation PAR is one of the largest, most comprehensive substance abuse treatment, intervention, prevention and research organizations in the nation. Each year more than 10,000 people access Operation PAR's individualized services designed to meet their needs and circumstances. Since its inception in 1970, Operation PAR has provided treatment services to pregnant and post-partum substance abusing women. These women come to the agency with a host of problems which often include single parenthood, a lack of social support, financial difficulties, legal problems, health issues, a history of abuse, poor housing and a lack of education. Often they feel worthless, powerless, hopeless, fearful and desperate. Typically, one of the first tasks of the program is to help these women address barriers to therapy such as denial, shame and a lack of self esteem.

Operation PAR uses a multi-disciplinary approach to help women overcome these barriers, and to ensure that their therapeutic and support service needs are addressed. The approach encompasses teaching life management skills and parenting skills. Women may also avail themselves of vocational training and job placement services, educational services, medical services, mental health services, child care, transportation and linkage to other area service providers. Staff have learned that, while it is vital to address their substance abuse issues, treating just their substance abuse problem is insufficient to help these women live drug-free lives.

Women with HIV

In recent years, the program has seen a dramatic increase in the number of substance abusing pregnant and parenting women who are HIV infected. The needs of these women vary from the needs of most other program participants in that they are having to deal with their disease in addition to substance abuse and, frequently, mental health issues. Initially, the spiritual component of substance abuse treatment is generally harder for them to grasp because they blame themselves for their disease. Additionally, they must address issues related to the care and well-being of their children. In order to meet the needs of this population, Operation PAR established the Wellness Group which addresses three areas of need: spiritual, emotional and material.

The Wellness Group

Morning hours are spent in an intensive therapeutic group where women can share their feelings. Lunch is provided to the women. Guest speakers from community services such as housing, nutrition, and consumer rights activists are scheduled in the afternoon. The therapeutic services coupled with case management networking have been of great benefit to attendees. Planning for their children's futures, accessing medical care, obtaining money for medications and respite care for children when they are hospitalized are all addressed through the Wellness Group.

Women who attend the group indicate it is the only place where they feel safe to talk about the issues they face. The bonding that occurs and relationships which develop are perhaps the most important benefits the women receive from attendance. It is often the only outlet, the only place, where they can express their emotions freely, obtain the services they need, and feel a part of something that matters.

In addition to the guest speakers and case management service linkage, a rolodex is kept in the group room listing all area service providers and delineating the services offered by each agency. This service has helped some of the women access therapists to help them disclose to their relatives, HIV testing for their children, and transportation to doctors appointments. Women also pass on information regarding services available in the community to other women in the group. This strengthens their linkage to each other and to needed community resources. They get their needs met and usually help someone else in the process.

Women also find strength through the group to talk about the issues they are facing. Common issues such as dealing with shame or depression are addressed in a non-threatening environment. The women realize that there is more stress when one does not communicate. They feel less alone in the group. The women get comfortable with themselves and then with others. Questions such as "Who will take care of my children?" can be asked.

One thing that is missing for women in the Wellness Program are services for their children. They would like for their children to meet each other and have group activities that help the children.
deal with the issues with which they are faced. The women know that their drug use has affected their children. The children have a lot of anger. They have had to take care of themselves, younger siblings and mom. Their mother was not always there when she was needed. The children worry. The women would like a parallel program for their children in order that they may access the counseling services they need and build friendships with youth who have similar experiences.

Nevertheless, the Wellness Group provides resources, support and hope for women who have common needs and a common bond. These women have created something to fulfill their needs that others have not been able to do. When in group with other women who are in a similar situation, they can relate to each other and help each other. They have learned that being clean and sober can be fun, and that others care for them.

Reflections from Women in the Program

Following are comments made by women in the Wellness Program:

"Dealing with the virus was so hard at first. This is the first place I could talk about it. By coming to group over and over I have become at ease with myself and the virus. The fear starts to subside a little over time."

"Bonding seems to come automatically here at the Wellness Program. The tears. The laughs. The hard times. We all can relate and realize we're in the same boat. The real learning comes from the staff. They are always helping us, showing us, making us look at ourselves and how far we have come. When someone new joins the program, we all get to see where we were when we started. Not all of us can be at the same level all the time and this is alright."

"Dying seems to go away really quite fast in this group; it just doesn't hang over your head. Each week we learn more about the virus, ourselves and each other. All these things seem to fall into place a little more each week. The updated information and past experiences of the staff seem to help a lot. No one laughs at one another. Well, maybe if you really did a stupid thing and now you see yourself, we laugh. It feels really good to laugh so much about ourselves. Others may think we are crazy. We're laughing and dying."

"When we get into talking about our kids being taken away or maybe we are just about to get custody back again, this falls real heavy on all of us. We all feel it. There are times when we bring our children to group so they can see where we spend our day getting better. The children get to tell their side if they wish. The real surprise is that they understand more than we thought. Our past was so hard on them. Now we have a better understanding of the problems they have had. It is the same for us. We see all the hurt; the lost time; that we're not dying. We're just starting to love."

"The Wellness Program works because we are able to tell our story and feel so low at times for having done some really bad things. But there's no judgement made of us. That's just where we were at the time. Now we look at ourselves and say let's get building those blocks to keep us off the street and out of jail. Love is the real item here at Wellness. You feel it. You hear it. And the hugs are just the best. We also pray as a group. It's really quite a place, to have come so far and yet you have been here all the time. The truth hurts sometimes, but here we learn to tell it and let it set us free."

— Laura MacDonald
Program Evaluation Coordinator
Operation PAR, Inc.

Call For Articles

The AlA Resource Center is soliciting articles for the Spring 1998 issue of The Source, which will focus on the relationship between substance abuse treatment and child welfare services. The Resource Center invites individuals to submit articles that describe effective practices, innovative programs or current policy in this area. Specifically, we are looking for articles that address: (1) innovative strategies (e.g., through policy, information systems and creative financing) for strengthening systemic links between child welfare services and services for alcohol and other drug problems; (2) best practices in day-to-day collaboration between treatment programs and child welfare agencies; and (3) strategies and curriculum for cross-training treatment providers and child welfare workers. As always, an AlA program will also be featured in this issue. Interested staff from any AlA program are encouraged to submit a proposal for an article that describes an AlA program and its activities related to the integration and coordination of child welfare services and services for alcohol and other drugs.

To be considered for publication in this issue, please send/fax a brief (150-200 words) abstract of your proposed article to the AlA Resource Center no later than Friday, November 7, 1997. Authors of accepted articles will be notified within two weeks of the deadline. Final manuscripts should be between 1,000 and 2,500 words, and are due Friday, February 13, 1997.

SEND/FAX ABSTRACTS TO:
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Nutritional Guidelines for Women with HIV/AIDS

Women with HIV/AIDS have compromised immune systems which are less able to resist disease and infection. Poor nutrition can further compromise the system, whereas good nutrition can optimize it, help prevent the development of HIV-related symptoms, and improve overall health. Additionally, dietary changes may help control weight loss, a common problem for persons with HIV/AIDS.

For some women, the knowledge of their HIV status initiates their first critical examination of their diet. For this reason, early intervention with HIV infected women should include counseling on basic nutrition (Bell, 1997). However, when counseling or making referrals, service providers should be sensitive to factors which may influence the diets of women with HIV. These factors include: substance abuse, access to adequate and nutritious food (e.g., fresh produce), eating disorders, cultural or ethnic influences, and an individual’s current dietary habits and knowledge of nutrition.

Some general guidelines for HIV positive women are outlined below. However, an individual’s nutritional needs vary depending on one’s food intake, metabolic demands, ability to absorb nutrients, and previous nutritional status. For this reason, it is critical that women with HIV consult with a physician and/or a registered dietitian before making any significant changes in their diet.

Healthy Diet

A well-balanced diet is critical in maintaining the health of women with HIV/AIDS. On a daily basis, women should consume at least 5 servings of fresh fruits and vegetables and at least 6 servings of whole grains, including breads, cereals, brown rice, corn tortillas, and pasta (Wilson, 1994). In addition, 2-3 servings per day of protein, an essential nutrient, are recommended for women with HIV/AIDS (Wilson, 1994). While meat, fish, poultry, dairy, and eggs provide complete proteins, grains, cereals, vegetables, and legumes (e.g., beans, alfalfa, peas, and lentils) provide incomplete proteins, so they should be combined together in meals (e.g., rice and beans; chili and cornbread; and peanut butter sandwiches). Dairy products or calcium-rich alternatives are another important part of a well-balanced diet for women with HIV/AIDS. Nutritionists typically recommend that women consume 2-3 daily servings of these products including milk, yogurt, cheeses, bok choy, broccoli, and soy products (Wilson, 1994). Finally, it is important that women with HIV/AIDS drink plenty of liquids; 6-8 glasses of fluids, such as water, herbal teas, and diluted fruit juices, are recommended each day. However, women with HIV are advised to avoid coffee, tea, and other caffeinated substances (Wilson, 1994).

Substance Abuse Considerations

Cigarettes, alcohol, cocaine, and amphetamines have also been found to negate the positive effects of good nutrition (Wilson, 1994). Yet, many women with HIV/AIDS are currently using these substances or are in recovery. These women tend to have increased nutritional needs in order to detoxify and metabolize drugs and to compensate for the compromised functioning of organs and the immune system (Beckley, 1994). Moreover, certain drugs may inactivate some vitamins and decrease liver and kidney functioning leading to malabsorption and malutilization of nutrients (Beckley, 1994). For example, because alcohol inhibits fat absorption, it impairs the absorption of vitamins A, D, and E which help maintain the eyes, bones, and cells (NIAAA, 1993). In general, it is recommended that women with substance abuse histories consume a low fat diet with nutrient-dense food (Beckley, 1994), similar to the diet outlined above.

Pregnancy Considerations

Women with HIV/AIDS who are pregnant also have specific nutritional needs. On average, women with HIV need approximately 300 additional calories per day and about 10 more grams of protein when they are pregnant. The exact amount, however, should be determined by a doctor and/or dietitian.

Pregnant women who have HIV also require additional vitamins, minerals, and water in order to maintain their health and ensure the healthy development of the fetus (Ploss, in press). For example, pregnant women need more folate and B vitamins which can be found in foods such as dark leafy greens, liver, legumes, and yeast (Wilson, 1994). Moreover, insufficient amounts of Vitamin A (which is found in eggs, dark green leafy vegetables, meat, and dairy products) has been linked to the perinatal transmission of HIV. Studies have shown that women who transmit HIV to their fetuses tend to be deficient in Vitamin A; whereas there were significantly lower transmission rates for women with higher levels of Vitamin A (Meredith and Wolfe, 1995).

Supplements

Although a well-balanced diet is generally considered the best way to improve one’s nutritional intake, many women with HIV/AIDS take multi-vitamin/mineral supplements. These supplements can prevent nutritional deficiencies which develop from unhealthy eating patterns.

References:

and/or decreased nutritional absorption (Wilson, 1994). For this reason, women with HIV/AIDS should consult with their physician or a registered dietitian about enhancing their nutrition through supplements.

Given the potential toxicity of supplements, the importance of professional consultation cannot be overemphasized. For example, while high doses of vitamins and minerals can be used to optimize the immune system, these doses could be particularly toxic to women whose liver functioning has been compromised due to substance abuse (Beckley, 1994). Moreover, while Vitamin A supplements have been recommended for pregnant women with HIV, high levels of Vitamin A can be toxic to the fetus (Ploss, in press). Therefore, particularly when a pregnant woman with HIV has a substance abuse history, supplements should be prescribed based on the estimated liver functioning in order to avoid toxicity to both the woman and the fetus (Beckley, 1994).

Food Safety

Given their increased risk for opportunistic infections, women with HIV should exercise caution in preparing food. All meat, fish, and poultry should be cooked to an internal temperature of 140-145 degrees Fahrenheit, and eggs should be well cooked to avoid salmonella and other bacterial infections (National AIDS Nutrient Bank, 1995). In addition, good hygiene should be used with all food preparation. Specifically, hands should be thoroughly washed, and a 5% bleach solution should be used to clean countertops and cutting boards before preparing foods and especially after preparing raw meat, chicken, or fish (Bell, 1997). Other ways to minimize the risk of opportunistic infections are to carefully wash or peel raw produce, filter drinking water, and thaw meats in the refrigerator or microwave oven, rather than in room air (National AIDS Nutrient Bank, 1995).

Diet Therapy

HIV, medications, opportunistic infections, substance abuse, and pregnancy can all lead to conditions such as nausea, vomiting, diarrhea, loss of appetite, and fatigue. Because these symptoms reduce nutrient intake, diet therapy is often a critical component in the treatment of women with HIV (Bell, 1997). Registered dietitians can counsel pregnant women with HIV on their increased calorie and protein requirements and on problems associated with the malabsorption of certain nutrients. With the proper therapeutic diet, women can be well-nourished despite the HIV disease process (Bell, 1997). Therefore, because of the link between nutrition, substance abuse, and the immune system, enhanced nutrition is an important goal for women with HIV/AIDS and should be incorporated into treatment and service plans.

— Amy Marlo, MURP
Research Assistant
National AIA Resource Center

REFERENCES


Did You Know . . . ?

The Federal Drug Administration (FDA) has issued a warning that protease inhibitors, the newest class of AIDS drugs, may contribute to increases in blood sugar and even diabetes in persons with HIV/AIDS. This warning is based on a significant number of reports to the FDA of new or exacerbated cases of diabetes mellitus and hyperglycemia in persons who were taking protease inhibitors. Consequently, the labeling of all four approved protease inhibitors (saquinavir, indinavir, ritonavir, and nelfinavir) will be revised to warn of this potential side effect.

While existing data has not definitively proved that these drugs have caused the elevated blood sugar levels, the FDA does recommend the close monitoring of glucose levels of persons with HIV/AIDS who are taking protease inhibitors. In addition, even though diabetes is a serious condition, the FDA believes that these events occur relatively infrequently, so it does not recommend that treatment with protease inhibitors be suspended. In fact, because diabetes can be controlled through insulin and other more modest agents, the FDA continues to believe that the benefits of protease inhibitors to persons with HIV/AIDS outweigh the risks of taking these drugs.

Nevertheless, person with HIV/AIDS who are on protease inhibitor therapy should know the warning signs of hyperglycemia and diabetes. These signs include: increased thirst and hunger, unexplained weight loss, increased urination, fatigue, and dry, itchy skin.

The FDA encourages all health care professionals to report any cases of hyperglycemia, diabetes, or any other serious toxicity associated with the use of protease inhibitors to the FDA’s MEDWATCH at (800) FDA-0178. For the latest information on diabetes and protease inhibitors, call the FDA’s consumer hotline at (800) 532-4440.
Multiple, Complex, and Dynamic Service Needs

Serving children and families affected by HIV and substance abuse is not easy, and project staff have faced many challenges in doing so. Along with issues around permanency planning, one of the greatest challenges comes from interactions with other systems. Project staff have found that some of these systems are simply not designed to appropriately serve the population. For example, the medications prescribed to one young mother to manage her HIV disease cost approximately $700 per month. Because this woman works and has employer-funded health insurance, she is not eligible for assistance. The insurer, however, requires that she pay for her medicines and then submit claims for reimbursement. This young mother's monthly income (about half of that $700) does not provide her with the cash flow needed to pay for the medicines, even if she does get reimbursed. CANDII's service coordinator continues to work on finding ways the system can be helpful. So far, no one appears willing or able to make procedural revisions necessary to help her meet her needs.

Additional transagency concerns include inadequate programs for substance abuse treatment, particularly for women with children. When mothers finally express readiness to pursue treatment, they often find child care and separation grave obstacles. While CANDII can meet the child care needs through its Crisis Care project, staff believe that many women would be more successful if their children could be included in their recovery efforts. Currently, however, there are no treatment programs in the region which serve chemically dependent women with their children.

Other issues and challenges that project staff have faced include: long waiting lists for treatment programs that are available, gaining access to mental health services through the new Medicaid/HMO system, changes in social security and other benefits programs, and differences in program philosophies and practices. The Children and Families Subcommittee of the Eastern Virginia HIV CARE Consortium, CANDII's transagency advisory board, has been addressing some of these issues and, indeed, transagency collaboration has significantly improved during the last four years. Some of these systemic issues, however, seem to be more difficult and continue to challenge project staff.

Conclusion

CANDII staff are committed to helping women affected by HIV/AIDS and chemical dependencies to care for their children and to meet their needs. Services are designed to be comprehensive, collaborative, and family-centered. While staff realize that they cannot meet all of the complex and changing needs, there has been some progress and successes.

A recent client-satisfaction survey found 95% of the respondents very satisfied with the quality of services, with their ability to gain access to services, and with staff responsiveness to their needs. Thirty percent of the mothers are either working or attending classes, up from ten percent in 1992. When the project began, approximately 30% of the mothers enrolled had been referred to the Child Protective Services (CPS) system. With a great deal of support, all but two of these mothers have been able to keep their children and care for them appropriately. In the last two years, none of the mothers has had children involuntarily removed from her care, and only 3% (less than 2% of the population served) have been referred for CPS intervention.

Permanency planning efforts have also made an impact. Since the beginning of the AIA project in 1992, 21 mothers have died, leaving behind 47 children. Of these 21 families, 16 had permanency plans in place that were actually implemented, and 5 had last-minute family arrangements made for them. None of the children entered the foster care system.

— Judy Cash, MEd
Project Director, CANDII

Spiritual Dimension

The illness and death of a significant person are often accompanied by spiritual issues and concerns for children. Many troubling questions may provoke the child. Confusion often surrounds the child who asks—and often finds no answers—to the questions of why the loved one became ill and died, where he or she has gone, what will happen now to the child, and who will care for the child in the absence of this significant person? Children need to have at least one individual who is comfortable addressing these issues and who can provide reassurance and concrete answers at a time when the world has turned upside down and there seems to be no concrete foundation to stand on—and to count on—for tomorrow.

Whether or not the child and family practice an identified religion, the concept of a higher power or strength beyond oneself can be acknowledged and supported. Troubling euphemisms ("He went to sleep," "God took him because he was good,") can be replaced by less abstract, more comforting statements: "He is dead, but his memory will live on to guide us." Younger children need concrete answers, while adolescents often choose to engage in philosophical discussions and deliberate on the meaning of life. While one may not always be able to provide the answers, a constant, attentive presence will assist in reducing fears and ensuring that the child knows he is not alone in his journey to search for meaning.

How a child grieves will be determined in part by the individual coping level, and by family communication and coping styles. Grouping by age can be helpful in understanding the general characteristics of how children conceptualize death (see box on page 6). However, it is wise to keep in mind that each child is unique, and that children may regress during stressful times.

— Martha Blechar Gibbons, PhD, RN, CPNP, CS

REFERENCE
