Background

Among the newest groups of families needing respite care are those who have children with HIV-related conditions. Because of the unique intergenerational nature of the AIDS epidemic, often entire families are infected. The majority of children who have HIV-related conditions acquire the virus through maternal transmission. Frequently, parents learn about their own diagnosis after the birth of a child who tests positive. A positive test may lead to the discovery of a partner’s drug use, infidelity, or bisexuality — issues that by themselves may be sufficient to seriously affect a family’s stability. Relationships may terminate at a time when stability and support are most needed. Parents may be overwhelmed by depression, anxiety and grief. Parents who are HIV positive often have diminished energy and ability to care for their children. Healthy siblings may feel neglected. Children with HIV-related conditions sometimes live with aging grandparents who have their own chronic health problems. Others live with foster parents who may feel overwhelmed by the needs of a sick child.

Although families may recognize the need for childcare assistance, they may not seek it because they are reluctant to disclose the HIV diagnosis. The burden of secrecy may cause chronic and acute discomfort for parents. Parents of children with HIV-related conditions are less likely to leave their children with babysitters or in centers, and frequently will not even use needed medical services in their own neighborhoods.

In addition to the HIV-related conditions, there are multiple other stresses on these families. Often families have experienced substance abuse, poverty, poor nutrition and education, as well as domestic and neighborhood violence. Housing may be overcrowded or substandard; they may even be homeless.

Purpose

Respite care services for families or caregivers who have a child with HIV-related conditions are needed to provide support on both a planned and emergency basis. Respite services provide time for parents to arrange and attend medical appointments; to meet household and family responsibilities; and, to rest.

In-home respite service for families with HIV-related conditions is preferable to center-based service because it is more responsive to the parents’ needs and they are more likely to use it. By sending a respite care provider or trained volunteer to the home, assistance can be offered when the parent lacks the energy to dress and transport the child to a daycare center. Having a respite provider take the child outside the home allows the parent or caregiver to have "free time," and gives the child an opportunity to participate in a special activity.

Program Considerations

One of the greatest needs for families with children who have HIV-related conditions is for professionals to
demonstrate a caring and committed response. For many families, such a response stimulates them to address some of their other needs. In-home respite care can be provided by: 1) a trained, paid staff person from a hospital, home health care, respite care, or foster care agency; 2) a trained volunteer affiliated with an agency; or, 3) an individual, friend, or relative who is willing to provide respite care in exchange for compensation through an informal arrangement with the family.

In-home respite care for families with children who have HIV-related conditions is provided without the benefit of on-site supervision. The work requires initiative, reliability, cultural sensitivity and patience. Since respite care includes visiting a child’s house, the provider/volunteer must be willing to travel in unknown neighborhoods. Providers may be paired for safety purposes. All staff should be required to have a background check against a centralized State registry for a history of child abuse or neglect, a medical exam, and training.

**Training**

Training should include the medical, emotional, and practical issues of working with children who are HIV positive. Training topics should include: epidemiology of pediatric AIDS; infection control; developmentally appropriate childcare; issues related to death and dying; the need for confidentiality; and cross cultural awareness. Providers should expect that the child is frequently unaware of the HIV diagnosis but usually knows "something is wrong." Staff should learn how to answer questions with responses appropriate to the child’s level of development.

**Provider Support and Supervision**

In addition to ongoing telephone contact with the supervisor, respite care staff should participate in a mandatory monthly support group which is professionally led. The support group helps decrease work-related stress, and prevents burn out. For in-home providers, it provides an additional face-to-face meeting between supervisor and provider, and an opportunity for peer supervision and support.

Examples of issues which are raised in staff support group meetings include:

- coping with despair at the magnitude of the families’ present and future problems
- setting appropriate role boundaries with the parent
- answering children’s questions on loss, and the AIDS diagnosis
- dealing with anger at parents who continue to engage in at-risk behavior. Providers must be willing to accept the family on its own terms
- resolving cross cultural issues, such as discipline styles or extended family structures
- discussing workers’ fears of contracting the HIV virus

It should be expected that families in crisis will be apprehensive about strangers entering their homes. Many family members lead unpredictable lives and will miss appointments for respite care services. Efforts should be made to encourage and support participation.

**Use of Trained Volunteers**

Trained volunteers can provide effective respite care. Many people respond to an invitation to work with children who are HIV positive. They enjoy being paired with a child in a "big brother/sister" model of service. Volunteers can be reimbursed for expenses incurred during visits.

**Medical Services**

It should be emphasized that respite care is not a medical service, and providers usually do not have medical training. Children with HIV-related conditions range from asymptomatic to extremely vulnerable or developmentally affected. Often children who are HIV positive (as well as their siblings) are born prenatally exposed to alcohol or drugs, and may be hyperactive or have multiple disabilities. In all cases, it is necessary to
have a complete family assessment which includes a medical history for the child. Children who have HIV-related conditions should be taken for monthly checkups and the results should be reported on an ongoing basis to the respite program. Emergency care procedures need to be clearly established.

**Conclusion**

Families which are affected by the HIV virus are subject to extraordinary stress. Foster families often feel overwhelmed and a child may be transferred from home to home. Respite care for families who have a child with HIV-related conditions provides attention for the child and much needed support for the parent or caregiver.

**References**


**Resources**

Association for the Care of Children's Health (ACCH), 7910 Woodmont Ave., Suite 300, Bethesda, MD 20814; (301) 654-6549.

National AIDS Clearinghouse, P.O. Box 6003, Rockville, MD 20849-6003; (800) 458-5231; FAX: (301) 738-6616.

National Pediatric HIV Resource Center, 15 South Ninth Street, Newark, NJ 07107; (800) 362-0071; FAX: (201) 485-7769.

**About the Author**

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