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ABSTRACT

This collection of five factsheets provides basic information about the need for and provision of respite care services for particular populations. Each factsheet is presented in a format which provides some background information on the population, a brief discussion of the purpose of respite care programs for this group, a discussion of the characteristics of the population and/or program considerations, and a conclusion. A list of several suggested references and organizational resources completes each factsheet. Factsheets are titled: "Respite Care for Children Who Are Medically Fragile"; "Crisis Nursery Care for Infants and Children Who Are Medically Fragile"; "Respite Care for Children with Developmental and/or Physical Disabilities: A Parent's Perspective"; "Respite Care for Children with Autism"; and "Respite Care for Children with HIV-Related Conditions." (DB)

[Respite Care for Children.]

ARCH Factsheet Number 11, May, 1992

ARCH

Access to Respite Care and Help
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Respite Care for
Children Who Are Medically Fragile

Background

Over the past twenty years, the proliferation of medical technology has presented new challenges in the field of social services and community-based care for infants and children who are medically fragile. In addition to the increased sophistication of medical technology, the rate of premature delivery continues to rise along with childhood trauma which increases the need for more complex dependence on various technologies and medical intervention services. The aggregate number of children who are medically fragile is steadily growing and the aggregate burden on support systems, both familial and societal, is also growing (Hochstadt & Yost, 1991).

It is estimated that 10 to 15% of children within the United States have a chronic health condition, with about 1 million of these children having costly and disabling conditions (General Accounting Office, 1989). In addition, it is estimated that approximately 17,000 to 100,000 children are technology-dependent (Office of Technology Assessment, 1987). For years, these children, dependent on technoloy and medical intervention services, lived in hospital settings for the duration of their lives. Because of concerns for high hospital costs on a continued basis or long-term care costs for institutional settings and the humane interest for returning children to the nurturing environment of their families, these children are now living at home in communities all across the country. Thus, the need for community-based support services for these families has increased immensely.

A wide array of support services are needed by families to maintain their child with disabilities at home. In 1980, respite care was the most requested service of families caring for children with disabilities at home (Cohen & Warren, 1985). Families caring for children who are medically fragile also have this same need for respite care, which at times, may be critical for the long-term stability of the family and child at home.

Purpose

Many existing respite care programs have been reluctant to care for children who are medically fragile due to the tenuous nature of the medical conditions of these children. However, in recent years, a limited number of respite care services, specifically designed to care for children with medical needs, have emerged as a support option for families. These services have proved to be beneficial from the families' perspective and also from a cost containment perspective as compared to continuous hospital stays or long-term institutional care. Governmental entities, community programs, hospitals, and private insurance companies are realizing the importance of community-based respite options for families as more and more children survive due to their dependency on medical technologies. It is with this movement, that many states and communities are looking towards establishing respite options for families of children who are medically fragile.

Respite Program Options: General Partnerships & Resources

Two of the primary barriers from parental report of respite options for children who are medically fragile are: 1) respite services for families of children with severe medical conditions are unavailable; and 2) if respite options are available for families of children who are medically fragile, they are usually too expensive for families and many times, the respite providers are not adequately trained to meet the intense needs of the child. Because of these barriers, many states, governmental agencies, and community providers have developed various options for respite support services for families of children who are medically fragile through partnership programs. These may include the following:

1. Many states have developed family support legislation which includes appropriations at the state level for support options. This may include an entitlement program in which a family is entitled to a certain amount of respite care services per year sponsored by the state or a voucher method in which families receive funds to purchase respite services from community providers or through informal support networks. These community providers may include home health care agencies, respite programs equipped to handle children with medical needs, or family friends and neighbors who have been trained by the family. This allows families' choice in their providers and strengthens informal networks for families when more established programs are not available. The partnership between the family, state and community has proven to be very effective in maintaining children with medical needs in the community.

2. Many governmental programs have developed funding streams to encourage a partnership between federal and state governments to provide support services to families. These include the following:

a. Title V: Services to Children with Special Health Needs under the Maternal and Child Health Block Grant (Part 2 of the Social Security Act), formerly known as state Crippled Children's Services, offers in many states in-home nursing care, home care, and respite care for families of children with chronic illnesses and medical needs;

b. Title XIX: Medicaid - Traditionally Medicaid (federal dollars are provided as a match to state dollars) services have included the payment for medical services for individuals who are financially and medically needy. With recent changes at the federal level, states have been given considerable flexibility in the type of services offered on a statewide level. The Early and Periodic Screening Diagnosis and Treatment Program (EPSDT) of Medicaid allows states to offer up to 32 additional services including home care or in-home nursing care for children with complex medical needs and home respiratory care for children who are ventilator-dependent. These generic support services allow the families to receive respite. In addition, Medicaid allows waiver options at the state level for home and community-based services. For example, the Medicaid 2176 Home and Community-Based Waivers, available to states for the funding of a variety of home and community support services, is one program that is capable of bringing relief to many families of children with complex medical needs by paying for respite services. Medicaid also offers Model Waivers to states to provide in-home nursing care and out-of-home respite care to families of children with complex medical needs who would reside in a hospital setting or long-term care setting if such waiver services were not available; and

c. Title XX: Social Services Block Grants has many programs available based on income and disability eligibility of families and children. Services offered under this federal program are state specific and can often provide short-term in-home support services for families of children who are medically fragile.

3. Many community hospitals have realized the importance of support services and respite care for families of children who are medically fragile and have developed community-based programs through a partnership with community, state, federal, and private funds. These community-based programs may include hospital-based respite programs, home care for children who are ventilator-dependent, out-patient and care coordination services for home care, medical respite houses, and transitional hospitals in which programs and staff are focused on the long-term needs of the child and family rather than on traditional acute-care hospital services. Hospitals have become very creative in funding these services through private insurance (cost containment factors), private and community support (United Way, fraternal organizations), and state and federal funds through offering a wide array of medical and support services.

4. Many community agencies have also realized the needs of families of children who are medically fragile and have developed such services as medical foster care, medical day care services, foster care programs for children who are HIV infected, permanency planning in adoption services, medical respite houses, and care coordination services. On average, these community-based services cost one-third of the cost of inpatient hospital stays based on a daily per diem rate. Besides the cost factors, community agencies have found decreases in re-admissions to hospitals of children and decreases in family stress levels due to the availability of community-based support and respite services. Like hospitals, community agencies have become creative in funding these services through private insurance, community funds, and state and federal funds.

Program Considerations

Establishing a respite program for families of children who are medically fragile can be a challenging and rewarding experience. Community service agencies interested in starting respite services must learn new skills such as medical terminology, medical management, sharing roles, and developing cooperative relationships with a wide variety of co-collaborators, including family members. In addition, these agencies must develop strategies that will ensure quality services at affordable costs. The following program variables need to be considered in establishing a respite program for families of children who are medically fragile:

Community & Family Needs Assessment

The first step in establishing a respite program for families of children who are medically fragile is to conduct community research regarding the needs of families (i.e., the number of families needing respite services, the type of services families want - in-home or out-of-home, financial structure of families, etc.), current community resources that are available to families, and the feasibility of collaboration and coordination with existing services in the community. For a successful respite program, it is imperative that family input into the design and structure of the program be solicited. For example, many families of children who are medically fragile feel more comfortable using respite services that are available in licensed medical facilities (i.e., hospitals, medical day care centers) where emergency response systems are established. Families have also reported that out-of-home respite allows them to sleep comfortably for short periods of time so that they can regain their stamina to meet the intense medical needs of their child once that child is at home. Having a licensed respite provider come into their home may not allow families the privacy to regain their sleep. A small variable such as this can be a deciding factor for a family to utilize respite services.

Licensing & Standards

Once a program structure is developed, it is critical for the agency or hospital developing the respite service to check state licensing requirements for facility use, staffing, training, health standards, and medical collaboration. Each state varies on the licensing requirements of in-home providers and facility-based services. In some states, only licensed personnel (i.e., nurses) are allowed to administer medications or perform health related tasks whereas, other states have made allowances under their health services code to allow trained, but unlicensed, respite providers to administer on-going medications and perform some basic health related tasks. The involvement of licensed personnel within the respite program structure will depend on the licensing standards of the state and the level of care needs of the child being served in the respite program.

Staffing

Staffing of a respite care program for families of children who are medically fragile will depend on the following conditions: 1) type of respite program structure - in-home or out-of-home. In an in-home program, staffing ratios are usually one to one with trained and/or licensed personnel performing the respite services depending on the standards of the state. In an out-of-home respite program such as a hospital-based service, staffing ratios can range from one to one to one to three. 2) level of care needs of the child who is medically fragile. Some children will require a one to one ratio because of the medical technologies that are required and other children may not require a sole provider. 3) standards of care as outlined in state licensing requirements. Some states require staffing in a respite episode to be one to one for children who are medically fragile.

Training

Training is a critical component of any respite care program and must adhere to the state licensing requirements. In addition, training in a medical respite program must encompass a broader scope of skill levels to accommodate the intense needs of these children. For example, respite providers need to be trained in such areas as administration of medications, medical terminology, medical management, use of medical and specialized equipment, use of cardiopulmonary resuscitation, and universal health and safety standards. Also, respite providers must be trained in addressing sensitivity issues of the family who many times feels guilty. Additional areas of training include collaboration with medical personnel and emergency procedures. Families need to be an integral part of the training process as they understand their child's needs better than anyone. The involvement of families in training also conveys a "sense of security" for families that the provider understands the intense needs of their child and has empathy towards the family situation.

Medical Services and Collaboration

Medical respite programs must also include direct physician and/or nursing collaboration in the care of children who are medically fragile. Some respite programs require direct physician orders for certain health related tasks while other programs require direct contact with the physician before a respite episode will take place. In either situation, respite providers must work in conjunction with medical and/or nursing staff in charting medical services and in performing certain medical tasks. Most medical respite programs require an initial medical exam and assessment before the family receives the service.

Summary

Providing respite care services to families of children who are medically fragile has proven to be a cost effective means of keeping families together and decreasing hospital stays and re-admissions for children. In addition, medical respite services have also been beneficial to communities in supporting families and in untapping valuable resources for the benefit of children in need. The challenges presented by increased use of medical technology are being widely accepted by community agencies in the development of respite options for families of children who are medically fragile.

Innovative Community-Based Respite Support Programs

The Respite Station
Santa Rosa Children's Hospital
P.O. Box 7330/519 W. Houston
San Antonio, Texas 78207-3198

Prescribed Pediatric Extended Care, Inc.
12402 N. 56th Street
Tampa, Florida 33617

Pediatric AIDS Respite Program
New York Hospital/Cornell Medical Center
525 E. 68th Street F134
New York, New York 10021

Cradles & Crayons
Specialized Day Care
1711 Broadway
Kansas City, Missouri 64108

Pediatric Transitional Care Program
La Rabida Children's Hospital and Research Center
East 65th Street at Lake Michigan
Chicago, Illinois 60649

References

Cohen, S., & Warren, R.D. (1985). *Respite Care: Principles, Programs and Policies.* Austin, TX: Pro-Ed, Inc. (Available from Pro-Ed, Inc., 8700 Shoal Creek Blvd., Austin, TX 78758).

General Accounting Office. (1989). *Health care: Home care experiences of families with chronically ill children.* (GAO/HRD-89-73). Washington, D.C.

Hochstadt, N.J., & Yost, D.M. (1991). *The Medically Complex Child.* New York: Harwood Academic Publishers. (Available from Harwood Academic Publishers, P.O. Box 786, Cooper Station, New York, NY 10276).

Office of Technology Assessment, U.S. Congress. (1987). *Technology-Dependent Children: Hospital v. Home Care - A Technical Memorandum.* (Office of Technology Assessment-TM-H-38). Washington, D.C.: U.S. Government Printing Office.

Resources

SKIP (Sick Kids Need Involved People)
990 Second Avenue, 2nd & 3rd Floors
New York, NY 10022

Association for the Care of Children's Health (ACCH)
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814

Children's Defense Fund
122 C Street, N.W., Suite 400
Washington, D.C. 20001

Federation for Children with Special Needs
95 Berkeley, Suite 104
Boston, MA 02116

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Crisis Nursery Care for
Infants and Children Who Are Medically Fragile

Background

During the last ten years, local crisis nurseries have experienced the need to serve increasing numbers of children who are "medically fragile." Contributing factors include increased drug and alcohol usage, the cutback of funding sources for family medical care, and limited availability of foster homes for children. In addition, traditional placement resources and funding for children's programs have also declined, or were simply inappropriate for children with more serious physical and emotional problems. Crisis nurseries traditionally have accepted referrals for children who have experienced or been at risk of physical and/or sexual abuse, neglect, or abandonment (which frequently included a medical condition). Children who have been at higher risk of abuse because of their medical condition have been added to the population served in crisis nurseries. In either case, this new classification of infants and children who are medically fragile has necessitated specialized forms of childcare, staffing, training, and medical services.

Purpose

The purpose of offering crisis nursery care for infants and children who are medically fragile is to provide a supportive, nurturing environment for children who have special medical problems which require 24-hour observation or treatment. Crisis nursery care for children who are medically fragile is medically supervised child care offered to families in collaboration with a medical facility. This usually occurs when health care needs are 1) beyond the normal care of other children in the same age group (which results in the child's requiring a significant amount of individualized care apart from the group setting); or 2) so specialized that special health care plans directed by physicians and/or nurses are required to provide daily care for the child.

Examples of children who meet the criteria of being identified as medically fragile:

- Infants on an apnea monitor
- Infants born prenatally exposed to alcohol or drugs (e.g., infants with Fetal Alcohol Syndrome or Crack/Cocaine exposure)
- Children who are admitted directly from a hospital where they have received care for a significant injury or illness
- Children with special breathing problems requiring significant care or ongoing alteration in the daily routine due to the medical condition
- Children in Spica Casts (body casts from waist to feet)
- Children with specialized feeding problems (e.g., feeding tubes, cleft lip and palate)
- Children with infectious or contagious diseases (e.g., hepatitis, sexually transmitted diseases, HIV–related conditions)
- Children with chronic health problems such as diabetes, asthma, or seizure disorders

Program Considerations

Child Care

Routine child care functions for children who are medically fragile require the ability to develop individualized child care plans to accommodate the child's specific physical problem. Types of medication (and their effects on the child's waking and sleeping patterns), the child's physical mobility, the age and size of the child, and specific medical issues, must be considered in organizing the child's day. Child care plans must be discussed and understood by all child care staff. Toddlers or elementary age children may require shorter school schedules. Frequently, infants who are medically fragile will require extended feeding schedules because of their inability to retain food, or due to physical abnormalities such as a cleft palate or lack of sucking reflexes. A daily schedule should be developed, and case records should reflect the child's progress toward the established child care plan.

Staffing

Infants who are medically fragile usually require a lower staff-child ratio. This depends on the level of care required. A one-to-three staff ratio is a rule of thumb, but infants or children who are medically fragile (in body casts, etc.) may need one-on-one care during key hours of the day. Nursing staff and the availability of medical consultation are a necessity. Medical care plans must be developed in conjunction with a physician and/or nurse, depending on the severity of the medical problem. Medical staff must supervise the implementation of the crisis nursery care.

Training

Key to the provision of services to children who are medically fragile is the training program for the child care staff. Training must adhere to state licensing requirements. The training program needs to be flexible and ongoing in order to incorporate special topics as well as to offer training in specific areas. It must include discussion of the types of physical problems to be encountered; the use of cardiopulmonary resuscitation; the use of specialized medical equipment, such as inhalers or apnea monitors, feeding tubes, etc.; the administration of medication; charting of medication and physical symptoms; and emergency procedures. When caring for children who are medically fragile, and, indeed, for all children in crisis care, some universal medical precautions should be observed. These precautions include training on the use of plastic gloves, proper handling of diapers, bedding, and of any blood stained clothing or items. Thorough training and education of staff, as well as practice in using various pieces of equipment and various procedures, will ensure a staff "comfort level" when caring for children who are medically fragile. However, no amount of training can take the place of selecting staff who have empathy, a willingness to acquire the needed skills, competent childcare practices, and the patience to work with children who have medical problems.

Medical Services

Collaboration with a medical service (e.g., hospital, clinic, private physicians) which has a basic program of medical care must be in place in order to serve children who are medically fragile. The medical program is developed by trained professionals (doctors, nurses, etc.). Components include:

- Initial medical exam and assessment
- Medical history and prescribed treatment from referring entity. Infants referred from hospitals are more likely to have this information available
- A weekly clinic where children who are medically fragile may be examined by a physician, treatment revised, and any staff concerns addressed
- The availability of emergency consultation with a physician during evening and weekend hours.
- Separate medical exam room where children may be seen by the nurse or physician, sick children may be monitored, medications stored in locked cabinets or locked refrigerator, and medical supplies and equipment stored. This room may also store special foods or formulas required by children
- Procedures for when, how, and where to refer children requiring urgent medical treatment
- Medical staff capability to teach older children aged 6–11 how to care for their own medical conditions

Summary

Crisis nurseries provide temporary child care, and access to support services, for families experiencing extreme stress. Crisis nursery care can be provided for infants and children who are medically fragile. It is critical when establishing services to this group of children that issues of adequate program, staffing, training, and medical protocol be addressed. Children who are medically fragile can be mainstreamed along with healthy children. The types of crisis nursery services, and populations served, may be specified according to the nursery's capability and funding. In this way, valuable untapped placement opportunities can be realized for this very special group of children.

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Respite Care for Children with Developmental and/or Physical Disabilities

A Parent's Perspective

Background

Over the past fifteen years, parents have increasingly made the choice to keep their families together. Children with developmental or physical disabilities are no longer routinely placed in institutional care. As a result, the need for respite care (temporary child care) services has increased. Until recently, respite care has been either unavailable or unaffordable in many states. Personal care through the Title XIX Medicaid program and grants through the "Temporary Child Care for Children with Disabilities and Crisis Nurseries Act of 1986" (as amended), have enabled families to receive respite care for free, or at a reduced, reasonable cost. Forty-six states have some form of respite programs for children with disabilities (Knoli, et al., 1990). States and/or agencies that administer respite care projects have realized the need to provide other supports to families which are flexible and meet the need of the whole family, not just the person with a disability. Respite care services form the basis for many state family support programs.

Purpose

For years families caring for a child with medical or physical involvements have been reluctant to allow others to provide care for their child in their own home. The two most common reasons stated by parents are: 1) concerns about the caregiver's training; and 2) feelings that no one can take care of their child as well as they can. Babysitters, in general, do not have the skills needed to provide the kind of support required to care for children with medical or physical disabilities. Respite care programs for families who have children with developmental and/or physical disabilities provide trained respite care providers for in-home or out-of-home "free" time (respite) for families.

Respite Programs

Highlighting the strengths and needs of the entire family, and not just the needs of the individual with a disability, has been a common thread in exemplary programs. Providing respite care for children with developmental or physical disabilities is not unlike providing respite for any other child. The respite provider needs to know the kinds of behaviors the child is likely to exhibit and be prepared to deal with any unusual needs of the child. This is true of any child. The behaviors and needs of children with disabilities may be more acute, but ascertaining them should be done in the same manner.

For the sake of those programs considering starting a respite program for families with children with developmental or physical disabilities, the following outline is designed to give an idea of the kinds of training and attitudes that are required to provide a quality program.

The Keys to a Successful Respite Program

- Help families feel comfortable and build trust. Spend enough time with the family to develop a level of trust that will allow a free flow of information.
- Provide a flexible structure. The agency should provide as many options as possible to meet the needs of the family, rather than fitting the family into the service available.
- Be family-focused. Empower families to make decisions for themselves. Discuss the strengths and needs of the whole family.
- Provide support. The administering agency and respite care providers must be available to field questions and concerns of parents that may be outside the realm of respite care. This might include linkage and referrals to other agencies or services.
- Allow families to train providers. Be sure to include families in the process of designing the child-specific portion of the provider's training.

Training

Because of the concern that families have about the specialized needs of their children, respite providers should be trained in first aid, CPR, disability awareness issues, specific medical conditions, behavior management, and individual "hands-on" training with the child for whom they will provide care. Many states and local programs have developed respite training manuals which are available to train local providers. (The ARCH Information Center has copies of many of these manuals.)

Building *trust* is probably the key ingredient in a successful respite program. Training respite workers is only one step in this process. Establishing close working relationships with the family and ensuring close supervision are other important parts of a successful program.

The Basics — These areas can be taught in a classroom setting using professional staff.

- CPR and First Aid
- Philosophy of family empowerment
- "How to speak DD" — introduction to developmental disability terminology
- "Don't Panic" — introduction to medical and environmental emergencies

The Details — These units should be presented in at least two different forums. The first, as a parent panel with discussion of some personal stories in each of the areas mentioned. The second, as a clinical approach to care, to include a speech therapist, an occupational therapist, and a physical therapist.

- Communication sensitivity — how to communicate with someone who does not talk very well, if at all
- Eating etiquette — good table manners (skills) when working with someone who needs assistance
- The comfort factor, or "how would you feel sitting in the same position all day?"

"Hands On" — This section should take place in the families' homes, and/or, the setting where the respite will actually occur.

- Meet the family and get to know the child
- Trainee asks parents about specific assistance he or she may need to provide
- Parents demonstrate how they assist their child to move, eat, and go to the bathroom
- Trainee works with the child on each of the specific skills parents request until parents are comfortable in how the trainee performs

Conclusion

Successful programs from around the country report that, once these key requirements are met, families will enthusiastically participate in respite services. Programs also report that this process takes some time. The trust that families need does not occur overnight. Allow a considerable amount of time for the program to be fully operational.

This can be one of the most rewarding programs to operate. Families and staff report many heartwarming tales of the benefits that respite has provided.

References

Knoll, J., et al. (1990). *Family Support Services in the United States: An End of Decade Status Report*. Cambridge, MA; Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge, MA 02140.

National Commission on Children (1991). *Beyond Rhetoric: a New American Agenda for Children and Families* (Summary). Washington DC; National Commission on children, 1111 18th Street, N.W., Suite 810, Washington, DC 20036.

Resources

Association for the Care of Children's Health, 3615 Wisconsin Avenue, N.W., Washington, DC 20016. (202) 244-1801. The Association provides information and support on family-centered care for children with special health care needs.

Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge, MA 02140. (617) 876-0426. The Institute has compiled extensive information on respite and other family support services throughout the United States and has numerous documents available.

Family Support Bulletin, produced by United Cerebral Palsy Association, Community Services Division, 1522 K Street, N.W., Suite 1112, Washington, DC 20005. The Bulletin is free of charge and provides excellent information concerning new and upcoming programs nationwide.

Exceptional Parent Magazine, P.O. Box 3000, Dept. EP, Denville, NJ 07834. This is an excellent resource for families and professionals on a wide range of issues concerning children with disabilities.

This fact sheet was developed by Scott Miller, Family Support Services Coordinator for West Virginia. Scott is also the parent of Josh, who has Down's Syndrome.

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Respite Care for Children with Autism

Background

Autism is a lifelong developmental disability, in which individuals may experience difficulty in language/communication, social development, and behavioral responses to their environment.

Autism occurs along a spectrum from mild to severe. Autism in its mildest form may resemble a learning disability. However, the communication and socialization difficulties of autism still result in a need for individualized planning. Of persons with autism, only 2-3% fall at the very severe end of the spectrum, which is often accompanied by severe behavior difficulties, such as intense self-injury and/or aggression. Autism may also be associated with other disabilities due to developmental delays.

Autism is a low incidence disability with a prevalence rate of about 4-5 in 10,000 births. Although there is no known etiology, various theories include a genetic, biochemical, and/or structural component(s). Autism occurs across all socioeconomic levels, races, and regions of the world.

Purpose

Families who have a child with autism often experience ongoing stress. Aspects of the family's life that may be impacted by a family member with autism include family recreation, finances, social relations with friends, relatives, spouses and neighbors, and the emotional, physical, and mental well-being of parents and siblings. Because of the additional care required by a child with autism, families identify respite care as a basic need, with the need increasing as the child gets older. Families who report less stress usually are the recipients of formal support services, such as respite care. Respite care for families who have a child with autism helps maintain family stability and may provide opportunities for the child to participate in special activities.

Characteristics of Children with Autism

All children who are autistic do not display the same characteristics. The following characteristics are among the most common:

Impairment in Socialization:

- Lack of awareness of others
- Social aloofness
- Lack of cooperative and imaginative play
- Does not imitate
- Does not seek comfort or cuddle as an infant

Language/Communication Deficits:

- Language is not used in a communicative function, instead there may be immediate or delayed echolalia (i.e., what is said to the child is mechanically repeated); perseveration (i.e., the repeating of phrases of speech over and over); pronominal reversal (i.e., The pronouns "I" and "you" are reversed, so that the child may say, "You want a cookie," when s/he desires a cookie)
- Abnormal pitch, rate, rhythm, and/or intonation
- Lack of appropriate nonverbal communication (e.g., eye contact, gestures, pointing, postures)

Abnormal Responses to the Environment:

- Stereotypes or self-stimulatory behaviors (e.g., rocking)
- Resistance to change
- Preoccupation with parts of objects, or an attachment to unusual objects

Behavioral Concerns:

- Self-injurious behavior (e.g., head banging, biting)
- Aggression
- Tantrums

Inconsistent Sensory Responses:

- May appear as if s/he is deaf (e.g. no reaction to very loud noises)
- Stimulus over selectivity (e.g., very sensitive to very soft noises)
- Apparent insensitivity to pain

Program Considerations

Provider Training

Providers who are working with children with autism should be trained about the characteristics of autism. Because of these unique characteristics, children with autism typically require specialized therapeutic and educational services. Respite care providers should be well trained in the basic principles of applied behavior analysis. Training should also include information on communication, behavior management, developmentally appropriate instructional strategies, social skills and incidental teaching.

Child Care Provision

1. Respite care providers should meet with each family before beginning the provision of child care to discuss the child's routines and established patterns. This helps ensure consistency of care for the child and develops a sense of trust between the family, child, and provider. The need for predictability, structure and routine is an important element when providing respite care for children with autism. Children with autism typically insist on sameness. When the environment is altered, they often become anxious. Respite programs should:

   a. *Establish routines:* set specific times for certain activities, such as snacktime, naps, toileting.

   b. *Be consistent:* children with autism experience difficulty in learning. Often, they are unable to generalize what they learn across people, settings, or situations. However, if persons caring for children with autism are consistent, the children do not need to spend as much time testing limits.

2. Respite programs should address the need for behavioral intervention. Behavioral approaches have proven successful in remediating behavioral excesses (e.g., tantrums), as well as behavioral deficits (e.g., lack of self-help skills)

   a. Use redirection: when children with autism are engaging in inappropriate behavior, redirecting the child to another, more appropriate activity may be effective.

   b. Use rewards: choose rewards that are meaningful to the child. The rewards must be individualized, and may require some creativity. For example, some children with autism become attached to specific objects, such as a familiar piece of clothing. Extra time with that object could be a reward.

3. Respite programs should incorporate educational components to assist in completing activities of daily living.

   a. Use clear and simple instructions: due to the attentional problems that children with autism often experience, it is helpful to keep instructions short and concise.

   b. Use prompts and teach in small steps: verbal instructions, gestures, or physical assistance are three prompts that are often used in working with children with autism. Use only as much prompting as is necessary for the child to complete the task, to ensure the child's is active participation. In addition to the use of prompts, it is helpful to divide the task into smaller steps. For example, if the child was being instructed to pull down his/her pants for toileting, the first step may consist of having the child only grasp the waistband; the second step could be pulling the pants over his/her hips, etc. The child is taught one step at a time, and does not move onto the next step until s/he can successfully complete the previous step.

Conclusion

Respite care for families of children with autism provides assistance through the provision of emergency and planned care as well as access to other family support services.

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Resources

Autism Research Institute (formerly Institute for Child Behavior Research), 4182 Adams Ave., San Diego, California 92116

Autism Society of America (ASA), 8601 Georgia Ave., Suite 503, Silver Spring, Maryland 20910, (301) 565-0433.

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ARCH
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Respite Care for
Children With HIV-Related Conditions

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.

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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.

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