Respite Care for Children Who are Medically Fragile

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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 technology 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 services 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.

   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 in-patient 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
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**

(Available from Pro-Ed, Inc., 8700 Shoal Creek Blvd., Austin, TX 78758).


Resources

SKIP of New York (SICK Kids Need Involved People)
213 West 35th Street, 11th Floor
New York, NY 10001
(212) 268-5999

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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