



The Technical Assistance Center for Lifespan Respite Fact Sheet Number 11, August 2014

Respite for Families Caring for Children Who Are Medically Fragile

Introduction

Children with special health care needs (CSHCN) are at an increased risk for physical, developmental, behavioral, and/or emotional conditions, and generally require health care services of a type or amount beyond that of a general pediatric population. Medically complex or medically fragile infants and children comprise a subgroup of the CSHCN population who have numerous medical needs resulting from multiple chronic conditions, technology dependence, and/or complex medication treatments. Over the last thirty years, children who have medically complex needs are experiencing higher survival rates due to advances in neonatal and pediatric critical care as well as improvements in general medical and nutritional care (Peterson-Carmichael, S & Cheifetz, I, 2012).

Until the 1980s, 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, especially respite services, for these families has increased immensely. Respite is especially important for families to help support their ability to continue to provide care at home.

This ARCA Fact Sheet is intended to provide a basic overview of useful information for respite providers who work with individuals and families with children who are medically fragile. It is also

meant to assist Lifespan Respite grantees and their collaborators by increasing their understanding of the unique needs of this population and their family caregivers. Such insight and direction will help State Lifespan Respite programs and others develop strategies to increase respite quality, access, and capacity for this population through partnerships with community-based services and enhanced provider recruitment and training efforts. Information is also included to help families find, select and pay for respite.

Definition and Prevalence

The U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB) defines children with special health care needs (CSHCN) as: "...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." According to the most recent National Survey of Children with Special Health care Needs, 15.1 percent of children under 18 years of age in the United States, or approximately 11.2 million children, are estimated to have special health care needs. Overall, 23 percent of U.S. households with children have at least one child with special health care needs (U.S. Department of Health and Human Services, 2013). The leading conditions associated with activity limitations have been and continue to be largely developmental, emotional, and behavioral in nature rather than physical (Halfon, et al, 2012).

Children who are medically fragile or medically complex represent a subset of children with special health care needs. There is no single definition of medically fragile or medically complex children, so estimating prevalence is somewhat subjective. Although there is no standard definition of medical complexity, children with complex medical needs may be characterized as having 1) chronic, severe health conditions; 2) substantial health service needs; 3) major functional limitations; and 4) high health resource utilization with an overall prevalence of less than 1% of all children (Berry, J., et al, 2013). The Children's Hospital Association estimates that approximately 3 million of the nation's 76 million children have medical complexity (Children's Hospital Association, nd).

Taking a closer look at the most recent data from the National Survey of Children with Special Health Care Needs can help to further understand the number of children who may be considered medically complex. Using these data, the reported number of children who have 1) multiple functional limitations, 2) breathing or respiratory problems, or 3) use durable medical equipment can be estimated. Children with special health care needs who have functional limitations experience the most adverse child and family level impacts. The population estimate of children qualified on the CSHCN screener criteria for functional limitations due to health conditions lasting 12 months or longer was approximately 2.6 million or about 3.5 percent of all US Children. While there may be overlap of children in these three categories, it is instructive to also examine the number of children who use durable medical equipment or have breathing or respiratory problems. In the National Survey of Children with Special Health care Needs, it was reported that over 1.2 million children (11.3 percent of all CHSHCN) relied on durable medical equipment in the past twelve months and over 1 million (9.5 percent of all CHSHCN) experienced a lot of difficulty with breathing or other respiratory problems (Data Resource Center for Child & Adolescent Health, 2013).

Relative to the number of children with special health care needs overall, the numbers of children who are medically fragile or have complex medical conditions is relatively small and most individual conditions do not seem to be significantly increasing in incidence. Yet, the prevalence of medically complex children in hospitals in the US today has been increasing due primarily to the increased medical complexities of the cases. The increase may be explained by "a combination of increased survival rates, resulting from lowering mortality rates of preterm infants and children born with congenital defects, and shorter hospitalizations with increased use of home therapies" (Burns, K.H. et al., 2010).

Challenges Facing Family Caregivers/Parents

Parents of CSHCN often forgo their own medical appointments, nutrition, exercise, and stress reduction activities as care for a medically fragile child can be all-consuming. There is tremendous financial strain on families of CSHCN regardless of income or insurance status. Furthermore, parents or other family caregivers often do not have sufficient time to foster family relationships, maintain friendships or hobbies, or to spend time with other children.

Parents of CSHCNs overall report poorer general health, more physical health problems, and increased depressive symptoms compared to parents of typically developing children (McBean, A. and Schlosnagle, L, 2013). Effects may be exacerbated for family caregivers of medically complex children. With many children who are medically fragile now being cared for at home, parents must assume responsibility for demanding and complex care that previously had been provided by skilled nurses in a hospital environment. The physical demands and psychosocial stress that this may impose, coupled with social isolation and increased financial issues associated with caring for a medically fragile child at home, may take a toll on the physical and emotional health of the parents (Kuster, P. and

Merkle, C., 2004). Children who are medically fragile may also have intellectual disabilities that may raise additional care issues and challenges for families.

Sleep deprivation resulting from provision of continuous care may also negatively affect a caregiver's overall health and well-being. In a recent study, parents of CSHCNs reported overall worse sleep quality than parents of typically developing children. As a result, parents of CSHCNs reported worse general health and memory than parents of children with no disabilities. Poorer parental health has been associated with recurrent hospitalizations for their children with disabilities (McBean, A. & Schlosnagle, L., 2013).

Moreover, as children with complex needs and multiple chronic conditions are living longer, parents of medically fragile children can face caregiving responsibilities throughout the child's lifetime (Kuster, P. & Merkle, C., 2004).

Barriers to Respite Facing Family Caregivers of Children Who are Medically Fragile

A wide array of support services are needed by families to maintain their child with disabilities and complex medical conditions at home. Families caring for children who are medically fragile may have an especially critical need for respite since the demands of having to provide continuous hands-on care, including medical treatment, interventions, and support, for longer periods of time during the day are undoubtedly significant.

Unmet Need

Eighty-one percent of family caregivers of children with special health care needs do not use respite (NAC and AARP, 2009). According to the most recent National Survey of Children with Special Health Care Needs, the parents of nearly one in five of the 11.2 million children with special health care needs (CSHCN) reported needing at least one family support service. The service most often needed was family counseling (11.9 percent), followed by

respite care (6.7 percent) and genetic counseling (6.5 percent). In this survey, half of children whose families reported a need for respite care did not receive it. Families whose children were more seriously affected were among those more likely to report an unmet need for family support services. Of children whose daily activities are consistently affected, the families of 18.1 percent did not receive all of the family support services they needed (U.S. Department of Health and Human Services, 2013).

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; 2) respite providers are not adequately trained to meet the intense needs of their child; 3) if respite options are available for families of children who are medically fragile, they are usually too expensive for families; and 4) families may be reluctant to leave their child in someone else's care or they may simply not know how or where to seek respite. The absence of emergency, overnight or extended respite for families is in especially short supply.

Financial Burden

Out-of-pocket costs such as therapies, home health care, prescription drugs, mental health care, medical equipment, and dental services, combined with a greater chance that one parent had to forego employment, can result in significant financial burdens for families that leave little disposable income for support services, such as respite. Financial difficulties are especially burdensome for many families of CSHCN whose conditions more dramatically affect their daily lives. More than one-third (38.5 percent) of children whose conditions usually or always affect their abilities live in families who report experiencing financial problems, compared to only 9.4 percent of children whose conditions never affect their abilities (U.S. Department of Health and Human Services, 2013).

If a child with a complex medical condition is eligible for state or federal funding, but also has an additional diagnosis of intellectual or developmental disability or mental illness,

disagreements or confusion may ensue regarding the state agency responsible for covering respite expenses and other family supports.

Too Few Qualified or Consistent Providers

As for many other populations, even when families may have the resources to pay for respite, such services for this population may be difficult to find. Respite may not be available at times families need it the most – evenings, weekends or for other extended stays – or providers may not have the training to qualify them to handle the special pediatric medical needs of these children, such as gastrostomy tube feedings, tracheostomy care or other complex medical interventions. Respite for ventilator-dependent children may be especially difficult to find. A child who is medically fragile who also has intellectual or developmental disabilities (ID/DD), serious behavioral issues, or other challenging non-medical needs, require respite providers who have had training to deal with these unique needs. With high turnover, finding consistent and reliable providers who will be available for families over the long-term is another challenge, especially if the family has invested time and energy in training in complex medical tasks.

Transportation

Transportation barriers are also significant for this population if out-of-home respite is required. Transporting a child with complex medical needs and their specialized equipment can pose considerable challenges. For example, children who are ventilator dependent require specialized transportation and help from a medical professional. Almost Home Kids (AHK) in Illinois received private foundation funding to establish a Transportation Respite Program to transport children safely from

27 communities in the western suburbs of Chicago to the AHK facility. A member of the AHK nursing team accompanies the child, both to and from their home in a specialized medivan (Almost Home Kids, 2013).

Other transportation barriers may affect the respite experience. In some states, home health agency employees are not permitted to drive the family vehicle, regardless of family permission. This may limit the recipient's ability to enjoy their break from their parent/caregivers and the ability to go somewhere without their parent.

Lack of Information

Many families lack information about how to find, choose and pay for respite. Some may not even know such a service exists. For others, a reluctance to leave their child in someone else's care can be a significant barrier.

Respite Options

Governmental entities, community programs, and hospitals are increasingly realizing the importance

The Center for Medically Fragile Children at Providence Child Center, Portland, Oregon

This center provides 24-hour nursing care for children with complex medical needs in a home-like environment. Respite care for medically fragile children is available for families in Oregon and Southwest Washington who need help for a variety of reasons. Team-based care involves pediatric-skilled nurses, therapists and outside specialty physicians to manage symptoms, treat post-surgical pain, monitor medications, conduct physical therapy and provide specialized feeding. Respite care is typically paid privately or by Medicaid. Transitional care is also available for new caregivers—or those whose roles have changed due to a child's illness, accident, surgery or diagnosis. These caregivers may stay in a special apartment on site while receiving care training. End-of-life care is also provided. <http://oregon.providence.org/patients/healthconditionscare/respite-care-for-medically-fragile-children/Pages/default.aspx>

of in-home or community-based respite options for families as more and more children survive due to their dependency on medical technologies. More states and communities are looking towards establishing respite options for families of children who are medically fragile.

Hospital-Affiliated Respite

Some community hospitals have realized the importance of support services and respite care for families of children who are medically fragile or may have additional medical needs 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. Families can contact local children's hospitals to see if a program exists in

their community. For contact information, visit the National Association of Children's Hospitals and Related Institutions found at <http://www.childrenshospitals.net>.

Community-Based Respite

Increasingly, community-based 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, permanency planning in adoption services, medical respite houses, and care coordination services. In some communities, faith-based organizations have sponsored respite services or supported programs through their missions. Some may even utilize well-trained volunteers working under close supervision with medically-trained staff.

These community-based services cost less than in-patient hospital stays based on a daily per diem rate. Decreases in re-admissions of children to hospitals and decreases in family stress levels may be seen due to the availability of community-based support and respite services. In addition to medical supervision, out-of-home respite may even be able to offer therapeutic, developmental, recreational and educational activities for the child. Like hospitals, community agencies have become creative in funding these services through private foundations and donations, and community, state and federal funds.

Prescribed Pediatric Extended Care Centers (PPECs) are care models that provide specialized child care and out-of-home medical non-residential day treatment for children who require constant medical attention. They typically deliver skilled nursing care for up to 12 hours a day, five days a week for children who are medically

Almost Home Chicago and Naperville, Illinois

Almost Home Kids (AHK) exists in two locations in Illinois – Chicago and Naperville. Both locations provide transitional care in a home-like setting to children with complicated health needs, training for their families and respite care. Almost Home Kids is a short-term community based pediatric healthcare facility that brings together medical professionals, recreational volunteers, community providers, and private and corporate donors. AHK is licensed by the state Department of Public Health. Almost Home Kids has served over 1,000 children who are medically fragile and their families. The program was made possible and funded through 2003 state legislation that revised the Alternative Health Care Delivery Act making possible "Children's Community-Based Health Care Centers". AHK offers respite care, transitional care (120 day hospital to home program) and transportation for respite care. The respite component of AHK provides care ranging from a 24 hours to 14 days. <http://almosthomekids.org>

Friday NITE Friends Plano, Texas

Friday NITE Friends is a medical respite program based in Plano, Texas. This non-profit was founded in 1992 by Custer Road United Methodist Church to provide respite for medically fragile and special needs children. Medical staff work on-site, along with church and community volunteers to provide the respite experience. Care is offered every Friday evening at no charge to families. Siblings 12 years old and younger are also invited to attend to offer an additional break to parents. <http://www.fridaynitefriends.org>

fragile and are most frequently used by parents or guardians who work or attend school. Some may provide respite services and families should seek out a PPEC in their community to see if it does so. Funding is usually provided by Medicaid or private insurers. Not every state has a PPEC, although increasingly states are beginning to develop and license them. Some examples include the PPEC at the Broward Children's Center in Broward County, FL (<http://bcckids.org/programs/ppec>), Your Child's Place in Washington, PA (<http://www.yourchildspplace.org>), and Sproutlings Pediatric Day Care & Preschool in Louisville, KY (<http://sproutlingsdaycare.com/medically-prescribed-day-care>).

In-Home Respite

In-home respite using home health agency aides, family and friends, and even volunteers are another option for families, provided they feel that the individual is competent and adequately trained to deal with the needs of their child. When transportation poses significant challenges, in-home respite may be the only option.

Family caregivers may have concerns about the competence, and even willingness of certain providers to deal with medical complexities,

equipment or medical emergencies. Consumer or participant-directed respite, where families hire and train their own providers, is supported in some states using public and/or private funding sources, and may provide an option for in-home respite. While many families may prefer participant-directed respite because of the control it allows over the respite situation, state regulations that limit the ability and/or the availability of individuals to administer medication or undertake medical tasks may pose limitations to this option.

To find in-home respite, contact local nursing or home-health agencies. *Rewarding Work* provides online registries of independent providers or personal care assistants who may be available to provide respite in Arizona, Connecticut, Massachusetts, New Jersey, New Hampshire, Rhode Island, and Vermont (<http://www.rewardingwork.org>). Many states also have online respite locators or registries through their State Lifespan Respite program, State Respite Coalition or other state disability agency. You can link to all of these from the ARCH state resources map at <http://archrespite.org/respitelocator/respite-locator-service-state-information-map>.

Other Respite Options

The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act require that reasonable accommodations required by a child or adult with a disability be made in already available services in the community. As a result, child care, after-school care, day camps and recreation programs are increasingly serving children with a range of disabilities and chronic conditions. Increasingly, volunteer opportunities may be available through faith-based and volunteer community organizations.

To Search for Respite

To find respite options, families can contact condition-specific organizations, such as Easter Seals, The Arc or United Cerebral Palsy. (See Resources at the end of this fact sheet for contact information.)

For more information on respite providers and funding sources by state, visit the ARCH National Respite Locator Service at <http://archrespite.org/respitelocator> and the ARCH State Resources Map at <http://archrespite.org/respitelocator/respite-locator-service-state-information-map>.

Federal Funding

Federal funding opportunities exist to support respite for families of children who are medically complex. For more information on each program, see *Federal Funding and Support Opportunities for Respite* at http://www.lifespanrespite.memberlodge.org/Federal_Funding_Guide.

Children with Special Health Care Needs under the Maternal and Child Health Block Grant (Title V of the Social Security Act)

The purpose of the Title V MCH Block Grant is to promote and improve the health of pregnant women, mothers, infants, children, and children with special health care needs (CSHCN). States must use at least 30% of their funding for services for CSHCN. States have wide latitude to focus on direct services for CSHCN; population-based services, such as newborn screening or immunization; infrastructure-building services; and enabling services. In program governance, respite is specifically identified as an “enabling service” (Dougherty and Kagan, 2012). However, only a few states such as AR, CT, MS, NH, OK, TX, and VT have used or currently use Title V funds for respite, although it is an allowable use of funds (ARCH, 2013).

- The **Oklahoma CSHCN** program contracts with a respite facility to provide respite to medically fragile children. Children can stay at the center for a total of 7 days one time per year. Children do not attend school or receive therapy while there, but they do participate in recreational activities.
- **Children with Special Health Needs Clinics** within the **Vermont Department of Health** supports the Respite Care Program for Families,

which provides limited funds to families to offer a rest from their caregiving experience. Eligibility for Respite Care funding is based on a family's income and the specific needs of individual children.

To see if your state Title V program provides respite, see ARCH's *State Funding Streams for Respite across the Lifespan: 2013 Update* (see References). To contact a state's maternal and child health agency's CSHCN program, see <http://www.amchp.org/Policy-advocacy/MCHAdvocacy/Pages/StateProfiles.aspx>.

Medicaid (Title XIX of the Social Security Act)

Medicaid pays for medical services for individuals who are financially and medically needy. Several options currently exist for states to fund or support respite services.

In most states, long term services and supports (LTSS), including respite, are largely provided under **Medicaid Home and Community-Based Services (HCBS) 1915(c) Waivers**, which allow states considerable flexibility in the type of HCBS services offered on a statewide level. Sixteen states (CA, CO, FL, IL, KS, MN, NM, NY, NC, ND, OK, OR, SC, TX, UT, and VA) have waivers that pay for respite and other home and community-based services for children who are medically fragile, medically complex, technology dependent or technology assisted who would reside in a hospital setting or long-term care setting if such waiver services were not available (Perrin, 2012). Unlike Medicaid medical assistance, waivers are not an entitlement program and may have long waiting lists so it is very important for families to get information as soon as possible following a diagnosis. For information on home and community-based Medicaid Waivers by state and how to access them, visit the ARCH State Resources Map at <http://archrespite.org/respitelocator/respite-locator-service-state-information-map> and click on a state or see *ARCH's Compendium of Home and Community-Based Medicaid Waivers that Pay for Respite* (see References).

Increasingly, states are moving to **Medicaid managed care for LTSS** and respite will have to be reconsidered as a benefit under Medicaid managed care plans included as a benefit. At least half the states are expected to employ managed care for long term services and supports by the end of 2014 (Caldwell, 2013). In addition, recent federal legislation now allows states to elect to fund home and community-based services as a state plan option, specifically under **HCBS State Plan Option 1915(i)**. Under this scenario, covered individuals would not have to meet an institutional level of care need and there would be no waiting lists or caps on services (Caldwell, 2013; Dougherty and Kagan, 2012).

The **Early and Periodic Screening Diagnosis and Treatment Program (EPSDT)** is an entitlement under the Medicaid program. Covered services include Nursing Care and Personal Assistance Services (NCPAS). As a result, EPSDT allows states to offer 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 may allow the families to receive respite when children are receiving these covered benefits.

Social Services Block Grant (SSBG – Title XX of the Social Security Act)

The SSBG may be used by some states to pay for support services to families of children who meet income and disability eligibility criteria. 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.

Lifespan Respite Care Program (Title XXIX of the Public Health Service Act)

The Lifespan Respite Care Program provides competitive grants to states in order to develop coordinated systems of accessible, community-based respite services for all family caregivers regardless of the age or special need of the care recipient. These efforts are geared to maximizing

RidgeLine Specialized Pediatric Day Health and Respite Care Services Inc. Grass Valley, California

RidgeLine Pediatric Day Health & Respite Services is a fully licensed day health facility for medically fragile children from birth to 21 years of age. A no cost nursing assessment is required to determine the child's eligibility. Services include full-time day care as well as respite. RidgeLine is staffed by Registered Nurses, personal care assistants and occupational and art therapists. There is limited overnight respite for those children enrolled in RidgeLine. Care is provided in a child-friendly, accessible facility. Appropriate federal and state programs are billed for services and private pay is an option. <http://www.ridgelinepediatric.com>

use of existing funds and leveraging new dollars for respite. As of early 2014, 31 states and the District of Columbia received Lifespan Respite grants. States conduct needs assessments and, if they are providing direct services with their Lifespan Respite grant funds, have the option to serve identified unserved or underserved populations. One example of maximizing existing funds to serve CSHCN is illustrated by the recent agreement entered into between the AZ Lifespan Respite program and the state's Title V CSHCN program to provide respite vouchers for this population.

For more information on State Lifespan Respite grantee activities, see http://archrespite.org/images/2013_Master_GraneeTable_Activities_March.pdf.

State Funding in Adoption Assistance

Limited state funding exists for select groups of children who are medically fragile. For example, the **Georgia Division of Family and Children Services (DFCS)** will fund respite for children who currently receive ongoing adoption assistance benefits and

are deemed medically fragile by a licensed medical provider. This service is available for children who were placed on adoptive status while in the permanent custody of DFCS or transferred to a relative/individual for the purpose of adoption from DFCS custody. Services are available statewide. For more information, visit the state website at <http://dfcs.dhs.georgia.gov/respite-care> or the Georgia Center for Resources and Support which helps administer the program at <http://www.gacrs.org>. Check with your state office on Adoption Assistance to see if respite for children who are medically fragile is supported through federal or state funds for post-adoption support services by visiting the Child Welfare Information Gateway at https://www.childwelfare.gov/adoption/adopt_assistance/questions.cfm?quest_id=7.

Considerations for Family Caregivers

Most parents and family caregivers choose to provide care at home and derive great emotional and spiritual rewards from providing this care. However, caring for a child with special needs can take a toll on a family caregiver's health and well-being and may even affect family relationships and marriages (Harper, et al, 2013).

Respite can be helpful in providing relief from ongoing caregiving. We now know that for respite to be most effective it should be delivered as early in the caregiving experience as possible and should allow the caregiver relief from the caregiving experience (Lund, D., et al, 2010). It is important for family caregivers to recognize when they need a break in order to continue providing care to their child and how important it is to seek help before a crisis arises. Help in finding the resources and support to gain access to respite services and funding streams is critical to this process.

Considerations about the type of care most preferred may depend on the immediate needs of the family caregiver. If transportation poses significant challenges, especially if transporting critical medical equipment is necessary, then a caregiver might want to consider in-home respite, where a

trained provider comes into the home. However, if the family caregiver's greatest need is catching up on sleep for example, than out-of-home respite may be the preferred option so that the family caregiver has sufficient privacy for rest at home. Hospital-based or community agency programs that have trained medical staff may provide reassurance for families if medical emergencies should arise. Some families, however, may prefer more relaxed homelike community-based respite programs. Respite providers and even volunteers can be trained to administer medications, if permitted by state law, or to undertake necessary medical tasks, with supervision, especially if families are involved in and provide the training to meet the unique needs of their children.

Respite is very important for children with complex medical needs as well. Extended hospital stays or bouts of serious illness that result in increased isolation, may affect their ability to maintain friendships and engage in normal childhood

St Jude's Children's Hospital Helping Hands Program

Even when the child may be in the hospital, parents can feel the stress of remaining by the bedside for days at a time. Parents, particularly those without extended family close by, often find themselves unable to leave their child's room or bedside for things as basic as running an errand, eating a meal, taking a mental break, or talking with the medical team. Volunteers were enlisted and trained to provide in-hospital respite for parents of children undergoing extensive treatment for cancer. After a four month pilot program, the hospital expanded the initiative to a 7-day a week service. While this particular service was limited to oncology patients, it is a model that could be replicated for other children with complex medical needs while receiving treatment in the hospital (Carter KB and Mandrell BN, 2013).

activities. Respite situations that provide social or therapeutic interaction can be important for these children.

For guidance on how to find and select respite providers, see ARCHs ABCs of Respite <http://archrespite.org/consumer-information>, or contact your state's Family Voices or Family to Family Health Information Center (see Resources at the end of this fact sheet for contact information).

Considerations for Respite Providers/Administrators

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 residential care.

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 and 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.

Ryan House Phoenix, AZ

Ryan House is designed to provide short-term overnight respite stays and palliative care to children with life-threatening conditions as well as end-of-life care. Ryan House referrals can be made by families themselves, their friends, by physicians or other medical professionals who know the child. Each child is screened for their unique needs and qualifications for services. Families may be asked to provide a medical history and a physical by the child's primary care physician. Ryan House is supported 100% by charitable contributions from generous donors in the community and services are completely free to families. Art, music, and sensory therapies are offered and a fully accessible playground and hydrotherapy pool are available for the children. <http://ryanhouse.org>

All Saints Pediatric Respite Care Racine, WI

Wheaton Franciscan Healthcare – All Saints offers hospital-based Pediatric Respite Care for parents and caregivers who need short-term care for their medically fragile child. Children (through age 17) who have chronic illness, developmental disabilities, are dependent on medical equipment, or need special medical treatments are eligible for respite. Respite is available 24 hours a day and respite may be reserved for 72 hours at a time. Families are charged a per hour rate. <http://www.mywheaton.org/all-saints-hospital/respite-care-racine-wi>

Licensing and 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 ongoing 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 states require staffing in respite to be one to one for children who are 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.

Training

Training is a critical component of any respite care program and may have to adhere to 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 First Aid and CPR and the handling of all types of medical emergencies, administration of all types of medications, medical terminology, medical management, use of medical and specialized equipment, use of cardiopulmonary resuscitation, and universal health and safety standards. If a child also has ID/DD or behavioral issues, additional training to meet their needs is required. Also, respite providers must be trained in addressing sensitivity issues of the family who may be apprehensive about leaving their child with complex needs in the care of others.

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. In some instances, some children may be so

medically fragile that they would feel comfortable using only a nurse for respite.

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 respite can 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, but a mechanism should be in place which would allow input from the child's current providers who are the most knowledgeable about their care.

Considerations for Lifespan Respite Grantees

Lifespan Respite Care programs bring together Federal, state and local resources and funding streams to help support, expand and streamline the delivery of planned and emergency respite services while also providing for the recruitment and training of respite workers and caregiver training and empowerment. Funding is limited, but at least one-third of the currently funded State Lifespan Respite programs funded by the US Administration for Community Living, Administration on Aging are providing direct services or supporting respite through vouchers or other options, especially for unserved or underserved groups. This may provide another source of limited funding for a population such as children who are medically fragile.

While conducting needs assessments in the grantee state to identify service gaps, questions to determine the specific barriers to respite access for this distinct population can be asked, thus creating strategies toward overcoming those barriers.

In addition, Lifespan Respite Grantees, charged with public education and education of family

caregivers, can take the lead in bringing experts together to develop public awareness and education materials that focus on the special needs of children who are medically fragile. Important collaborators might be the state's Title V Children with Special Health Care Needs program, local pediatric medical societies, federally funded Family to Family Health Information Centers, and parent groups such as Family Voices and Parent to Parent.

When developing training materials to recruit and train respite providers and possibly volunteers, grantee programs can seek expertise also from these expert collaborators. Subsequently, training modules can be developed to train providers and caseworkers to respect the dignity of the child client and their family. It is essential to include family caregivers as part of the training team for professionals.

Lifespan Respite programs should work across state agencies to ensure that funding streams remain as flexible as possible and take into consideration the actual hours needed by the family rather than a fixed budget. Many families of children who are medically complex may incur a higher cost per hour if they have to rely on medical personnel to provide respite and as a result may receive fewer hours of respite than needed. Lastly, respite providers/administrators must consider the provision of culturally and linguistically effective respite, both in terms of access (i.e., if there are providers and information about respite available in languages other than English) and culturally appropriate approaches for diverse populations.

If the grant allows funding direct services, participant-directed respite might allow family caregivers to have greater choice in hiring and training their own providers from their communities of support. Finally, training family caregivers to recognize the warning signs of burnout and how to recognize when their child may be in need of additional care, is very important. Developing training programs for peer mentors to assist other family caregivers can be extremely important to families, as the peer mentors understand what

others coping with a child with special health care needs are experiencing.

Recommended Strategies

Expanding respite options and improving respite access, quality and options for families caring for children who are medically fragile or complex will take the work and expertise of health professionals, government agencies, community providers and many others diligently working in partnership with family caregivers. There are steps that Lifespan Respite Programs, state organizations and respite coalitions, respite providers and even family caregivers can take to improve the situation. See Resources at the end of this fact sheet for contact information for organizations mentioned here.

For Family Caregivers/Parents

- Research respite options and funding sources in your community. Contact your state Lifespan Respite Program, state respite coalition, Medicaid Agency, or State CSHCN Program for a list of possible services, funding possibilities and other resources. Search your state's resources in the ARCH National Respite Locator Service at <http://archrespite.org/respitelocator> and the ARCH State Resources Map at <http://archrespite.org/respitelocator/respite-locator-service-state-information-map>.
- Reach out to state or local affiliates of parent groups such as Family Voices or Parent to Parent or to your state's Family to Family Health Education Center for information, support and guidance.
- Contact a state or local chapter of a national disability organization that may provide services and advocacy for your child's specific illness or condition, such as Easter

Seals, United Cerebral Palsy or a condition-specific organization.

- Prepare a list of questions for potential providers. Find out whether a potential provider is familiar with the technology your child uses and whether they feel comfortable working with it. Inquire about their credentials and work experience, especially as it relates to the complex medical tasks or medications your child may need in your absence. Even though respite providers may be very knowledgeable about caring for an individual who is medically fragile, family caregivers are responsible for ensuring that providers have all the necessary information about the unique needs of their child.
- If your child also has an intellectual disability, inquire about training the providers receive and if it includes working with children who have and ID/DD.
- Consider developing a Care Notebook to more easily share information with providers about all of your children's medical and other special needs. For guidance in developing a Care Notebook, visit http://www.medicalhomeinfo.org/for_families.

Daystar for Medically Fragile Children Rochester, New York

Daystar for Medically Fragile Children is a pediatric day-respite center designed specifically to serve medically fragile infants and young children. Founded by the Sisters of Saint Joseph in 1988 as a foster care provider for medically fragile infants, Daystar now provides nursing supervised respite care for infants and children with multiple serious, and often life-threatening medical and developmental complexities. Daystar's model has been recognized as a Best Practices Program and Environment from New York State's Office of Children and Families (OCFS). Daystar is a certified Medicaid provider and offers pediatric nursing, therapeutic and educational support programming, and parent support and family engagement services to medically fragile children up to age five. <http://www.daystarkids.org>

- Seek support and use respite early and as often as appropriate!

For Respite Providers and Administrators

- Conduct a community-needs assessment to determine the need for daily, emergency, overnight and extended respite services for this population in your local area. Be sure to include input from families and support groups, especially to determine the preferred type, location, and availability of respite options.
- Provide specialized training for current and new respite providers to ensure core competencies in quality complex care delivery. Since many children with complex medical needs may also have intellectual or developmental disabilities, develop and provide training for potential respite providers to deal with a broad range of care needs. Involve parents and family caregivers in curriculum development and in conducting the training.
- Research and become knowledgeable about state and/or local licensing and Department of Labor standards that might impose limitations on the medical care tasks a respite provider can offer, the necessary staffing ratios and training requirements, and the need for medical staff oversight or pre-screening.
- Develop and engage in appropriate responses to specific medical emergencies by having adequate planning in place.
- Include family caregivers as a member of the child's support team and encourage their input in the development of individual service plans.

For Lifespan Respite Grantees and State Respite Coalition

- Grantees, charged with public education and education of family caregivers, can take the lead in bringing experts and

families together to develop public awareness and education materials that focus on the special needs of children who are medically fragile and their caregivers.

- Conduct and use statewide environmental scans or needs assessments to determine the level of unmet need for services for this population and to identify the current respite capacity in the state to serve children with complex medical needs.
- Approach your state's Title V Children with Special Health Care Needs Program to determine avenues of collaboration that might help make a range of respite options available and more affordable for families – from in-home to community or hospital-based programs. Do the same with state Medicaid and other state health, disability and social services agencies that may serve this population.
- Seek out support for training, education, and referral opportunities from important collaborators with medical care expertise such as local community-based hospitals, state pediatric medical societies, nursing and medical social work organizations, and disease-specific organizations, such as United Cerebral Palsy, as well as parent groups such as Family Voices and Parent to Parent and engage families in the process.

Megan's House Albany, Valdosta and Waycross, Georgia

Megan's House, a project of Easter Seals of Southern Georgia, is a respite home for children ages 0-17 who have developmental disabilities, autism, or are medically fragile. Direct care is provided by qualified, experienced direct support professionals and individualized care plans are developed by the Registered Nurse on staff. Megan's House is available for a minimum of 24 hours to a maximum of two weeks per visit and may serve up to two children at one time. Services are provided in three locations, Albany, Valdosta and Waycross, GA. The cost to the family is determined by a sliding fee scale and scholarships are available. http://southerngeorgia.easterseals.com/site/PageServer?pagename=GADR03_respitemplination

- Working with your identified collaborators, support the urgent need for trainee and continuing education in complex care for children by compiling or helping develop training for respite providers in core competencies for complex care.
- Offer participant-directed respite so that family caregivers have greater choice in hiring and training their own providers from their trusted communities of support.
- Explore and support alternative respite options that offer greater socialization and recreational opportunities for children, allow siblings and/or the entire family to take a break together, and rely on informal or natural supports for families in the community.

Summary

Providing respite care services to families of children who are medically fragile is a cost effective means of keeping families together, decreasing hospital stays and re-admissions for children, and avoiding out-of-home placement. In addition, medical respite services have also been beneficial to communities in supporting families and in tapping valuable resources for the benefit of children in need. The challenges presented by increased use of medical technology are beginning to be met by community agencies in the development of respite options for families of children who are medically fragile. Lifespan Respite Programs can help bring together federal, state and local resources and funding streams to help support, expand and streamline the delivery of planned and emergency respite services to this population.

Resources

Association of Maternal and Child Health Programs (AMCHP)

2030 M Street, NW, Suite 350
 Washington, DC 20036
 Phone: 202-775-0436
 Fax: 202-775-0061
<http://www.amchp.org>

The Association of Maternal & Child Health Programs is a national resource, partner and advocate for state public health leaders and others working to improve the health of women, children, youth and families, including those with special health care needs.

Children's Hospital Association

401 Wythe Street
 Alexandria, VA 22314
 Phone: 703-684-1355
 Fax: 703-684-1589
<http://www.childrenshospitals.net>

Representing more than 220 children's hospitals, the Association champions public policies that enable hospitals to better serve children and is a resource for pediatric data and analytics.

Easter Seals

www.easterseals.com

Easter Seals programs include a variety of respite services, including adult day services and in-home support and services.

Family-to-Family Health Information Centers

The Family-to-Family Health Information Center (F2F HIC) program is administered by the Health Resource and Services Administration of the US Department of Health and Human Services. Created in 2005, the centers, which are run primarily by nonprofit organizations, are state-wide, family-led entities that provide information, education, training, outreach, and peer support to families of children and youth with special health care needs and the professionals who serve them. To find a state F2F HIC, visit <http://mchb.hrsa.gov/programs/familytofamily/familyhics.pdf> or the Family Voice website at www.familyvoices.org.

Family Voices

3701 San Mateo Blvd. NE
 Suite 103
 Albuquerque, NM 87110
 Phone: 505-872-4774 or (888) 835-5669

Fax: 505-872-4780
<http://www.familyvoices.org>

Family Voices is a national, nonprofit, family-led organization promoting quality health care for all children and youth, particularly those with special health care needs. Family Voices has been working with family leaders and professional partners at the local, state, regional, and national levels since 1992. Search for state affiliates and Family to Family Health Information Center contacts on the Family Voices website. The National Center for Family/ Professional Partnerships for CYSHCN (NCFPP) is a project of Family Voices and can be found on the web at <http://www.fv-ncfpp.org>

Federation for Children with Special Needs

95 Berkeley, Suite 104
Boston, MA 02116
<http://fcsn.org/index.php>

The Federation for Children with Special Needs provides information, support, and assistance to parents of children with disabilities, their professional partners, and their communities. Most Federation staff members are parents or family members of children with disabilities and people with disabilities.

National Center for Medical Home Implementation

American Academy of Pediatrics
141 Northwest Point Blvd
Elk Grove Village, IL 60007
Phone: 847/434-7605
Toll free: 800/433-9016 ext 7605
<http://www.medicalhomeinfo.org>

The National Center for Medical Home Implementation (NCMHI) is a cooperative agreement between the Maternal and Child Health Bureau (MCHB) and the American Academy of Pediatrics (AAP). The NCMHI is housed in the AAP Division of Children with Special Needs. The overarching goal of the NCMHI is to ensure that all children and youth, including children with special needs, have a medical home where health care services are accessible, family-centered, continuous,

comprehensive, coordinated, compassionate, and culturally competent. Resources for families include Building a Care Notebook that can be very useful for families of children with special health care needs to educate their respite provider about the very special needs of their children.

Parent to Parent USA (P2P USA)

<http://www.p2pusa.org/p2pusa/sitepages/p2p-home.aspx>

Parent to Parent programs across the country provide emotional and informational support to families of children who have special needs, most notably by matching parents seeking support with an experienced, trained 'Support Parent'. For local P2P programs, visit <http://www.p2pusa.org/p2pusa/SitePages/p2p-support.aspx>

SKIP of New York (SICK Kids Need Involved People)

213 West 35th Street, 11th Floor
New York, NY 10001
Phone: 212-268-5999
<http://www.skipofny.org>

SKIP OF NY, Sick Kids [Need] Involved People of New York, has been providing service coordination and case management since 1983. SKIP's mission has been to ensure severely sick and/or developmentally disabled individuals/children in New York are able to remain in their home and live with their families. Services SKIP advocates for include but are not limited to home care/nursing services, environmental modifications, Assistive Technology, Family Education and Training, respite, community habilitation, family support services, Early Intervention and pro bono advocacy.

The Arc

<http://www.thearc.org>

The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. The organization encompasses all ages and all spectrums including autism, Down syndrome,

Fragile X and various other developmental disabilities.

United Cerebral Palsy (UCP)

<http://ucp.org>

UCP affiliates provide services and support for people with disabilities on a community-by-community basis.

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About the Authors: This fact sheet was prepared by Jill Kagan, ARCH Director, and Maggie Edgar, ARCH Senior Program Consultant.

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