



Respite and Crisis Care

What is Respite?

Respite provides a temporary safe haven and meaningful experience for a child that allows short-term relief for parents or primary family caregivers to attend to their own and other family members' health, social or emotional needs. It is a preventive strategy that strengthens families, protects their health and well-being, and allows them to continue providing care at home. Respite is an important component of a continuum of comprehensive family support and long-term services that are available to caregivers not only on a planned basis, but also in the event of a crisis or emergency situation.

According to "Community Based Child Abuse and Neglect Prevention Grants" (CBCAP), Title II of the Child Abuse Prevention and Treatment Act (CAPTA), the term "respite care services" specifically means:

"short term care services provided in the temporary absence of the regular caregiver (parent, other relative, foster parent, adoptive parent, or guardian) to children who— (A) are in danger of abuse or neglect; (B) have experienced abuse or neglect; or (C) have disabilities, chronic, or terminal illnesses. Such services shall be provided within or outside the home of the child, be short-term care (ranging from a few hours to a few weeks of time, per year), and be intended to enable the family to stay together and to keep the child living in the home and community of the child."

Respite Models

Many models of planned respite exist, ideally to be able to meet the particular needs and preferences of the family. Various respite models are provided through state or local disability organizations such as Easter Seals, United Cerebral Palsy, or The Arc, or are privately owned and operated by profit or non-profit entities or individuals. Many public entities, such as schools or community mental health centers, may also be used

to support or provide respite services. Models include, but are not limited to:

- In home respite with trained professionals or volunteer providers
- Out-of-home (child care centers or schools, family day care homes, foster care homes, hospital, or specific respite facility), also using trained or volunteer providers
- Periodic respite (churches, community centers or other community-based organizations that support periodic respite events)
- Summer camps, recreational or after-school programs

Each model has its benefits and each may be utilized by families at different times depending on their needs and circumstances. However, a full array of available respite options in a particular community may frequently be limited by too few state or local resources, including a lack of qualified respite providers, volunteers or agencies which provide respite services. Often weekend, evening and overnight options are extremely limited.

Increasingly, through Medicaid waivers, state or federally supported family support or respite programs, and even CBCAP funded efforts, respite is available through vouchers, which encourage and support consumer direction. Families are considered the employers and are provided funds to purchase their own respite, often selecting, hiring and training their own providers, who may be neighbors, friends, other family members or church or civic group volunteers. Families may also purchase respite from existing agencies or providers.

Crisis respite is defined as temporary emergency care for children, available any time of the day or night, when families are facing a crisis and no other safe child care options are available. Crisis respite services are often also referred to as "crisis nurseries." Crisis nurseries were first developed in the early 1970's, primarily for children ages 0-5, though many crisis

respite programs now accept children of any age. Crisis nursery and crisis respite programs were also designed to offer an array of support services to the families and caregivers of these children. In addition to dedicated center-based crisis respite facilities, crisis respite can be offered in conjunction with homeless or domestic violence shelter services, or in foster or family day care homes. Crisis respite programs were first highlighted as “innovative programs” in *Emerging Practices in the Prevention of Child Abuse and Neglect* presented by the Children’s Bureau’s Office on Child Abuse and Neglect in 2003 (Caliber Associates, 2003).

Who Needs Respite and are These Families Being Served?

As a primary prevention service, it could be argued that all families with children face stress and/or hardship that place them in need of respite at some time in their lives. However, planned and emergency respite services are most often requested and utilized by families of children with physical or emotional disabilities or chronic conditions; families at risk of abuse or neglect who are in or out of the Child Protective Services System (CPS); grandparents and other kinship care providers; foster and adoptive families; and families in domestic violence situations or in temporary crisis resulting from homelessness, illness, job loss or other emergency situations.

In 2001, the last year federal data were collected, 9.4 million children under age 18 were identified with chronic or disabling conditions (US Health Resources and Services Administration, 2001). Without adequate family supports, children with disabilities are almost four times more likely to be victims of neglect, physical abuse, or emotional abuse, and almost 3 times more likely to be victims of sexual abuse than children without disabilities (Sullivan & Knutson, 2000). About 30% of children in foster care have severe emotional, behavioral, or developmental problems, requiring foster families to look to respite for support and a necessary break from caregiving. (American Academy of Child and Adolescent Psychiatry, 2005). In addition, approximately 150,000 children ages 5-17 with at least one disability are adopted, increasing the pool of families who could benefit from respite, but may not know how or where to find or pay for the supportive service (Kreider, 2003).

Compound this picture with the growing number of grandparent or kinship caregivers. In the US, 6.7 million children, with and without disabilities, are in the primary custody of an aging grandparent or other relative other than their parents. Parental substance abuse, HIV/AIDS, incarceration, poverty, death, or military deployment are the reasons more children are now in kinship care. Moreover, the children are likely to exhibit difficult behaviors or have disabilities themselves (Generations United, 2004). Significant percentages of these grandparent caregivers are poor and have access to few resources or supports (Ehrle, J, et al, 2001).

CAPTA legislation also requires that CBCAP leads take into account the special needs of parents with disabilities. An estimated 10 million families in the U.S., about 15% of all US families, include at least one parent who has a disability. In a national survey, 42% of parents with disabilities reported facing attitudinal barriers including discrimination, and 15% of parents with disabilities reported attempts to have their children taken away from them (Barker and Marlani, 1997). A comprehensive approach to prevention necessitates that these families’ special needs for respite and other supports are taken into account.

State and local surveys have shown respite to be the most frequently requested service of parents and other family caregivers (Brazil, K, et al, 2005; ongoing personal communications with State Respite Coalitions). Yet respite is unused, in short supply, inaccessible, or unaffordable to many of the nation’s family caregivers. In a study of a nationally representative profile of noninstitutionalized children ages 0-17 year of age who were receiving support from the Supplemental Security Income (SSI) program because of a disability, only 8% reported using respite care, but three quarters of families had unmet respite needs (Rupp, K, et al, 2005-2006). This study suggests a myriad of barriers that prevent families from accessing the respite they need.

A variety of federal, state, and private sources provide some assistance with respite, but the degree of respite and crisis care support varies widely by state and even county (Day, 1999). Most respite programs impose restrictive disability, age, and income eligibility criteria that exclude many families, especially families of children with emotional or mental health conditions

or physical disabilities, or children with disabilities over age 18 who are still living at home.

In addition, a lack of family resources to pay for care and a reluctance to ask for help, are significant barriers to respite access. Moreover, a critically short supply of qualified or trained respite providers, too few respite options available on weekends or evenings, a lack of state and community fiscal resources to sustain or expand programs, and limited information on how and where to find and pay for respite result in long waiting lists for services, or in the case of crisis care, families turned away in the midst of a crisis.

In 2006, Congress enacted the Lifespan Respite Care Act to assist states in coordinating state and federal funding streams and approve access to respite for all families regardless of age or disability. As coordination systems, Lifespan Respite programs, when fully funded, will help overcome many of these barriers, but the dependence on CBCAP's funding stream to ensure that there are sufficient respite options for families at risk of abuse or neglect will be ongoing as well as expanding.

Presenting the Evidence about Respite

While most families take great joy in helping their children with disabling or chronic conditions to live at home, it has been well documented that family caregivers experience physical and emotional problems and undue levels of stress directly related to their caregiving responsibilities. Respite has been shown to help alleviate the stress resulting from caring for a child with a disabling or chronic condition – the very stress that is often a precursor to abuse or neglect (ARCH, 2002).

State Lifespan Respite Programs are statewide systems up and running in Oklahoma, Oregon, Nebraska and Wisconsin to improve respite coordination and delivery for families regardless of age or disability. These Lifespan Respite Programs have been able to demonstrate that with increased access to respite, families have demonstrated lower levels of stress and isolation, the precursors to abuse or neglect.

- In a survey of NE's family caregivers, respite was shown to reduce feelings of stress and isolation. The survey found that one out of four families with children under 21 reported that they were less likely to place their

child in out-of-home care once respite services were available. In addition, 79% of the respondents reported decreased stress and 58% reported decreased isolation (Jackson, Barbara, Munroe-Meyer Institute, University of NE Medical Center, January 2001).

- Data from an Outcomes Evaluation Project conducted by the Respite Care Association of Wisconsin in collaboration with the ARCH National Resource Center for Respite and Crisis Care (ARCH) and the University of North Carolina at Chapel Hill, demonstrated that provision of respite significantly reduced caregiver stress, stress-related health problems and social isolation. Furthermore, respondents reported reduced likelihood of institutionalization of the person with special needs and reduced likelihood of divorce (Respite Care Association of Wisconsin, 2003).

Respite and crisis care have also shown promise in helping to avoid or delay out-of-home placements for children and sustaining marriage. A study of Vermont's well-established respite care program for families with children or adolescents with serious emotional disturbance found that participating families experience fewer out-of-home placements than nonusers and were more optimistic about their future capabilities to take care of their children (Bruns, E, 2000). Data from an ARCH outcome-based evaluation pilot study show that respite may also reduce the likelihood of divorce and help sustain marriages (Wade, C., Kirk, R., Edgar, M., & Baker, L., 2003).

As discussed above, respite as a post-adoption service is essential to support families who have adopted children with special needs, especially medically fragile children and children with physical or emotional disorders. The U.S. Department of Health and Human Services has periodically selected Respite Care Services for Families Who Adopt Children with Special Needs as one of the priority areas for funding in its annual Adoption Opportunities discretionary grants programs. Nineteen respite care projects were funded in this priority area in 1990-1991, and 1994-1995. A 2002 report synthesized the information gained from evaluation reports of 8 of the 19 projects. Five programs assessed the impact of the services on the families served. Although not statistically reliable, results indicated that many families felt some relief from child care responsibilities, that the services had helped to improve family

relationships, and that their family's stress level had been reduced (Child Welfare Information Gateway, 2002).

Even more dramatic results were found in a study of *Parents Who Adopt Children with Special Needs*, many of whom were grandparent caregivers in a respite program in southern California. During the three years of the program, services were provided to substantially more families and children than initially intended, and these services were associated with substantially reduced stress levels among parents providing care to special-needs adopted children; improved family relationships in the adoptive families; increased ability of adoptive parents to participate in social and recreational activities; and reduction of risk factors that increase likelihood of abuse and neglect, specifically, parental stress and strain on family relationships (ARCH, 2005).

In assessing the prevention of child abuse and neglect as an outcome, an evaluation of crisis nursery services for five crisis nurseries in Illinois from 2000 to 2003 based on analysis of administrative data reported to the Illinois Department of Human Services (IDHS) found that caregiver reported perception of risk of maltreatment improved during each of the 3 years studied. In FY 2003, 98% of the 745 caregivers completing evaluations reported a reduced risk of maltreatment, up from 73% of 248 caregivers who completed evaluations in FY 2001. In FY 2003, 90% also reported a decrease in stress (Cole, S., Wehrmann, K., Dewar, G., Swinford, L., 2005). An evaluation of a pilot crisis child care project in a rural midwestern state found that in comparisons of child maltreatment rates, there was a significant decrease in the reported incidence of child maltreatment in rural counties with a crisis child care program compared with counties that did not offer this intervention. (Cowen, PS, 1998).

The most recent study conducted by researchers at the ARCH National Respite Network utilized two groups of families in northern California who were compared using data from Child Protective Services (CPS) administrative records. Families in all groups were matched prior to analysis. The comparison group, Group A, comprised families in counties without crisis respite but who would have been appropriate for services had they been available. The target group comprised families who received crisis respite. This group was further subdivided into two

groups: Group B, families with previous histories with CPS; and Group C, families who received crisis respite and had no prior CPS involvement. The children who received care were at high risk for maltreatment when brought to the crisis respite facilities. The study found that the parents who received crisis respite services had an increased number of CPS referrals. It is hypothesized that this outcome occurred because families utilizing services received an increased level of scrutiny by mandated reporters than families not engaged in services. However, those reports are far less likely to be substantiated than reports on children who did not receive crisis respite, suggesting that the children are less likely to have experienced abuse or neglect than the children in a comparison group. Over a quarter of the families using crisis respite thought it was likely that their children might have been placed in foster care had the nurseries not been available (ARCH National Respite Network, July 2007).

Respite is not only effective in protecting children, it is low cost. In a joint study conducted by the Child Welfare League of America (CWLA) and ARCH, it was estimated that the costs for CWLA and ARCH agencies to provide planned respite were similar, about \$10 per hour, which is less costly in both financial and social terms than placing children in out-of-home care. The national average (non-specialized) foster care maintenance payment was \$4,832 per year in 1998, while ARCH estimates that providing 12 hours of respite each month costs \$1,422.88 per year (Dougherty, Yu, Edgar, Day, and Wade, 2002). The voucher program is especially cost effective. Oklahoma's Lifespan Respite Program serves approximately 2200 caregivers annually with vouchers. The average cost for the respite vouchers has been between \$5.62 and \$5.87 per hour, compared with \$12.80 to \$26.50 per hour if the caregiver had chosen a provider from a private/public agency (Moss, 2004).

How can CBCAP agencies support respite?

In several sections of the CBCAP legislation, requirements for lead agencies to provide, start up and report on respite as a core service are delineated (FRIENDS, 2004). As the only federal source of funding to actually startup, implement and help sustain respite and crisis care programs, CBCAP dollars are critical to building and ensuring respite availability and affordability as an abuse and neglect prevention program.

CBCAP funds can be used to help existing respite agencies and programs expand services and reduce waiting lists, build new capacity and programming to serve underserved or unserved populations, especially for families in isolated or rural areas or for families who don't meet eligibility criteria for existing programs, and help support agency efforts to recruit and train new providers. CBCAP funds can also be used to support respite vouchers or subsidies to help families pay for respite of their choosing. Working in collaboration with disability organizations, state respite coalitions, other child abuse and neglect prevention programs, family resource centers, community and faith-based organizations, Part C Early Intervention Services, and state and local Developmental Disabilities and Mental Health agencies, CBCAP lead agencies can help improve timely access, availability, and affordability for critical respite and crisis care services.

CBCAP Agencies Take the Lead in Supporting Respite

The Idaho CBCAP program uses part of its allocation to provide respite to underserved populations. Respite care was a special initiative during FY06 with the Idaho Children's Trust Fund funding a multi-year grant to provide respite care in a rural community. In addition, CBCAP funds are used to assist Children's Mental Health and the Idaho Respite Coalition in working to provide respite care to families who are raising children with mental health diagnoses.

In Wisconsin, The Wisconsin Respite Care Association is working with the state Children's Trust Fund to prevent initial occurrences of child abuse and neglect by targeting planned and/or emergency respite care to families exhibiting risk factors. The organization is currently working to: establish regional partnerships to coordinate resources and deliver direct respite care services; establish guidelines/standards for programs and providers; establish evaluation protocol; and provide training and technical assistance.

Nebraska uses its CBCAP funds to support respite in several ways. The Exceptional Family Resource Center in McCook received CBCAP funding to provide respite for families of children with disabilities. CBCAP helped expand respite in an eleven county area in Western Nebraska through *Lifespan Respite*

Subsidies for Families. A new respite program was funded through the YWCA in Lincoln to provide services for children ages six weeks to 12 years, including children with disabilities.

In Alabama, the Children's Trust Fund uses CBCAP funds to contract with United Cerebral Palsy-Huntsville to provide respite vouchers or home health respite in five counties through the Alabama Lifespan Respite Network. Under the voucher program, families of children with disabilities or chronic conditions up to age 19 are eligible for quarterly vouchers and may hire and train anyone of their choosing as long as they are 18 or older and do not reside in the home.

Resources

- Virtual ARCH National Respite Resource Center at www.archrespite.org for numerous respite fact sheets on specialized respite and crisis care, funding, collaboration, etc. and other products such as start up manuals, evaluation guides, survey reports and legislative information.
- State Lifespan Respite Programs: for contact information, see Model State Lifespan Respite Program Fact Sheet at www.archrespite.org/NRC.htm
- State Respite Coalitions: for contact information see www.archrespite.org/NRC.htm
- National Respite Locator Service at www.respitelocator.org

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