



Respite in Community-Based Grants for the Prevention of Child Abuse and Neglect (CBCAP)

What is Respite/Crisis Care and How Does it Fit Into the Array of Child Abuse and Neglect Prevention Services?

Respite and crisis care provide a continuum of services, from planned temporary relief for the primary caregiver of children with disabilities or chronic illness, to emergency care for children at risk of abuse or neglect. Such emergency respite provides a temporary safe haven for the child while the parent or guardian seeks assistance with an emergent problem, such as substance abuse, domestic violence, or a housing, personal health, or job crisis.

CBCAP captures this definition as "short term care services provided in the temporary absence of the regular caregiver...to children who are in danger of abuse or neglect, who have experienced child abuse or neglect, and/or who have disabilities, chronic or terminal illnesses. Such short term care is provided within or outside the child's home...and is intended to enable the family to stay together and to keep the children living at home and in the community."

Respite and Crisis Care programs (often referred to as "crisis nurseries" or "Crisis Respite") rarely operate in isolation, but rather as a key component of comprehensive family support services or child abuse prevention strategies. Intended to alleviate social, emotional, and other stresses on caregivers, the programs may offer an array of support services, including individual, family and support group counseling, substance abuse prevention and treatment, sibling care, case management, parenting classes, and information and referral.

The definition of "Community-Based and Prevention-Focused Programs and Activities to Prevent Child Abuse and Neglect" in Title II of the Child Abuse Prevention and Treatment Act includes respite among programs designed to strengthen and support families to prevent child abuse and neglect.

New CBCAP Retains State Authority to Use Funds to Start-up New Respite Services

The "Temporary Child Care for Children with Disabilities and Crisis Nurseries Act" (TCCA) provided the only federal start-up dollars for respite.¹ In 1996, TCCA was consolidated into the former "Community-Based Family Resource and Support Program," (CAPTA, Title II) in which States retained the ability to use funds for development of new respite programs.

The most recent reauthorization changed the name of the program to the Community-Based Grants for the Prevention of Child Abuse and Neglect (CBCAP). The intent to protect the integrity of the former respite care programs was retained in the new CBCAP language. CAPTA Title II still provides the only source of federal start-up or capacity building funds for planned and crisis respite services for children.

A CBCAP performance measure requires States to demonstrate in their annual report to the U.S. Secretary of Health and Human Services that they are addressing documented unmet needs identified by the inventory of current services that the State must conduct. Since states must provide or arrange for respite as a core service as practicable, the need to build capacity of existing respite services is critical.

Dramatic needs for new respite services still exist. Many respite programs report waiting lists of 400 to 500 families. An ARCH annual survey of its National Respite Network found that 63% of surveyed crisis respite programs and 48% of surveyed planned respite programs had to turn families away in a given year. Nationally, this represents an extremely conservative estimate of 258,000 families who were on waiting lists for planned respite care in 2000 alone, and 840,000 families who were turned away.²

Local Community-Based Child Abuse and Neglect Prevention Programs Required to Provide or Arrange for Respite as a Core Service through Contract or Agreement

Respite is a vital component of family support and child abuse and neglect prevention strategies. Respite is often the most frequently requested support service by families.

Respite services are not costly, especially in light of the cost savings inherent in avoided foster care or other out-of-home placements. The annual cost estimate for planned respite for one family based on the average annual number of hours of respite used is \$1,442.88. Annual crisis care cost estimates per family are probably even lower since crisis respite is used only in extreme emergencies when the family is at imminent risk of abuse or neglect and no other supports are identified. In contrast, the Child Welfare League of America reports that the average monthly cost of foster care for children up to age 16 with special needs is \$11,651 per year.³

Respite is an investment that can reduce family stress and the abuse that may result. Many communities where these programs are located have reported significant reductions in costly out-of-home placements, decreased likelihood of abuse or neglect, and enhanced family well-being.⁴ New preliminary data from the ARCH outcome-based evaluation pilot study show that respite may also reduce the likelihood of divorce and help sustain marriages.⁵

Emerging Practices in the Prevention of Child Abuse and Neglect, a report prepared for the Office of Child Abuse and Neglect, Dept. of Health and Human Services, presented outcomes from a 2-year project to identify programs and initiatives for the prevention of child maltreatment. Of the twenty-two community-based programs chosen to be highlighted, three are respite/crisis nursery programs, and several others rely on respite as one of the key program components.⁶

Illustrating Congressional intent to consider respite and crisis care as core services, Rep. George Miller (D-CA), Ranking Member of the House Education and Workforce Committee, in a Congressional

Record Statement in support of the legislation authorizing CBCAP cited this evidence. He urged the Department of Health and Human Services, as well as State and local community-based programs, to consider the data on respite and crisis care effectiveness and cost-savings when implementing child abuse and neglect prevention strategies.⁷ Congressional intent was reiterated in the final conference report to accompany the legislation: "...the conferees want to recognize the importance of respite care and other services as positive, cost-effective, community-based child abuse and neglect prevention programs. As evidence shows, respite and crises care programs are effective prevention strategies associated with avoiding more costly and traumatic out-of-home placements, including foster care. By retaining current law for local program criteria, the conferees have not intended to discourage or limit the ability of the lead entity or local program to provide or arrange for respite."⁸

CBCAP Intends Full Inclusion of Families of Children with Disabilities and Parents with Disabilities

Throughout Title II, and especially in the eligibility section, the ability of the lead entity, local programs, and networks to include families of children with disabilities, parents with disabilities and organizations who work with such families is strongly emphasized. The law is clear that in planning for or in providing services to families, the additional needs of families of children with disabilities and parents with disabilities may not be ignored, and in fact must be funded.

In many states, families of children with disabilities and parents with disabilities are populations which have been overlooked in the provision of comprehensive child abuse and neglect prevention and family support services, despite the fact that an estimated 9-15% of all children have some type of disability.⁹ Individuals and organizations which work with families of children with disabilities, as well as families themselves, have a wealth of experience in the family support area. They have much to contribute as vital partners in any new collaboration.

Respite is especially valuable to this population, since the need is so outstanding. Estimates are that children with disabilities are 3.76 times more likely to be victims of neglect, 3.79 times more likely to be physically abused, and 3.88 times more likely to experience emotional abuse than children without disabilities.¹⁰

There are nearly 9 million parents with disabilities in the U.S. — 15% of all American parents. Yet, the needs and capabilities of these parents are exceedingly misunderstood. 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.¹¹ A comprehensive approach to prevention necessitates that these families' special needs are taken into account.

Footnotes

¹ ARCH National Resource Center on Respite and Crisis Care (January 1994), *Understanding the TCCA*, Fact Sheet Number 31.

² ARCH National Resource Center on Respite and Crisis Care (2000), *National Respite Network Survey Report*

³ Dougherty, Susan, and Elisabeth Yu, Maggie Edgar, Pamela Day, and Casandra Wade (2002), *Planned and Crisis Respite for Families with Children: Results of a Collaborative Study: A Monograph prepared by the Child Welfare League of America and the ARCH National Respite Network and Resource Center.*

⁴ ARCH National Respite Network and Resource Center (2002). *Annotated Bibliography of Respite and Crisis Care Studies: Second Edition.* Chapel Hill, NC: ARCH National Respite Network and Resource Center.

⁵ Wade, C., Kirk, R., Edgar, M., & Baker, L. (2003). *Outcome Evaluation: Phase II Results.* Chapel Hill, NC: ARCH National Resource Center for Respite and Crisis Care.

⁶ Caliber Associates (2003), *Emerging Practices in the Prevention of Child Abuse and Neglect*, Washington, DC: Office on Child Abuse and Neglect, U.S. Dept. of Health and Human Services.

⁷ Hon. George Miller, “Keeping Children and Families Safe Act of 2002,” *Congressional Record*, October 17, 2002, E1923-24.

⁸ House Senate Conference Committee, “Keeping Children and Families Safe Act of 2003,” June 12, 2003, Report 108-150, p. 37.

⁹ National Clearinghouse on Child Abuse and Neglect Information (2001). *IN FOCUS: The Risk and Prevention of Maltreatment of Children with Disabilities.* <http://nccanch.acf.hhs.gov/pubs/prevenres/focus.cfm>.

¹⁰ Sullivan, Patricia M. and Knutson, John F. (Oct. 2000), “Maltreatment and Disabilities: A Population-based Epidemiological Study,” *Child Abuse and Neglect*, Volume 24, Issue 10.

¹¹ Barker, Linda Toms and Vida Maralani, *Challenges and Strategies of Disabled Parents: Findings from a National Survey of Parents with Disabilities*, Through the Looking Glass: 1997.

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FRIENDS has existed since 1995 and is a collaborative effort of organizations with many years of experience in delivering training and technical assistance. For more information, please visit the FRIENDS website, www.friendsnrc.org

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