



Respite Care for Children with Serious Emotional Disorders and Their Families: A Way to Enrich Family Life

In surveys of the needs of families of children with serious emotional disorders, respite care is frequently identified as one of the most needed and least available services for families. While some families who have relatives and friends to provide care are able to get a break, respite care is not available in many communities. In contrast, caregivers who access respite care report that they are able to gain relief from care-giving responsibilities, take care of important needs, and have time for relaxation. Families have a variety of interests, activities, needs, and preferences for respite care, resulting in the need for an array of respite care options to be available to families. This article provides a review of the benefits of respite care for families who have a child with a serious emotional disorder and examples of the range of respite care strategies that communities have developed to respond to the different needs and preferences of families.

From time to time, all families experience stress related to financial difficulties, work, family relationships, or the challenge of balancing work, family, and other responsibilities. Stress may be particularly severe for parents of children with serious emotional and behavioral disorders. Relationships with relatives, friends and neighbors may be strained due to misunderstanding of the child's behavioral disorder, work opportunities may be limited, and there are extra demands on time for mental health treatment and meetings with service providers. Stress associated with the continuing responsibilities and demands of care-giving may result in tiredness, depression, and health problems for parents. In addition, the presence of a child with a serious emotional disorder in the family may limit the time parents can spend with their other children and may constrain families' leisure activities. When families have access to respite care, they are able to take time to relax, re-energize, and enjoy a break from care-giving.

Support for the benefits of respite care has come primarily from research with families of children with

developmental disabilities and chronic illnesses and from families caring for a relative with Alzheimer's disease. Respite care has been recognized as an important service for families of children with developmental disabilities since the 1970s, although respite services for these families continue to be fragmented (Singer & Irvin, 1991). For families of children with serious emotional disorders, respite services have been slow to develop. Families around the country who do not have relatives or friends to provide informal respite care have had difficulty finding respite services in their community. Since the advent of the Child and Adolescent Service System Program (CASSP), respite care has increasingly been seen as an element of the array of community-based services in the system of care in children's mental health, and featured in a small number of model programs.

Respite care is seen as providing benefits to all members of the family: Parents receive a break from care-giving, siblings of the child with a disability may have opportunities for more activities and interactions with parents, and the child with a disability receives a positive social experience. Respite care is also conceptualized as a strategy to support families who are experiencing distress, thereby preventing the placement of children in out-of-home care, and avoiding family breakdown (Webb, 1990). Emergency respite care, provided through respite care centers and crisis nurseries, is designed to support parents through a crisis by reducing family stress and giving parents time to deal with concrete problems (Webb & Aldgate, 1991).

In a recent study of respite care services, families' reasons for using respite included a family emergency, the child was having a difficult time, the caregiver needed a break, and relaxation was needed for the caregiver (Boothroyd, Kuppinger, Evans, Armstrong, & Radigan, 1998). The families who used respite care services were found to have fewer relatives or friends available to provide respite compared to similar families who did not use respite services. The researchers

concluded that respite care promotes wellness in parents, enables parents to better care for their children, and also provides opportunities for respite providers to model behaviors and teach children new skills (Boothroyd et al., 1998, p. 373).

When respite services are offered as a component of System of Care services in children's mental health, the diversity of families' needs requires a range of options from which families may choose. Within the two broad categories of respite services (in-home care and out-of-home care) there are variations depending on: the respite care setting (provider's home, foster home, group home, camp, or community recreational facility); whether respite is regular, planned, or provided on an emergency basis; and whether respite care is overnight or only during the day. There are also variations depending on the type and level of training of respite providers, the kinds of activities planned for the child, and the payment system. Multiple types of respite care services are necessary to meet the range of children's and families' needs. The age and developmental needs of the child with a serious emotional disorder are considerations in decisions about whether the ideal type of respite care will be at home, in the respite provider's home, or at a group care facility or camp.

A national survey of parents' preferences in respite care showed that parents clearly preferred informal, individual relationships with family, friends, and neighbors that have been trained as providers (Knoll & Bedford, 1989). Respite centers and day care providers ranked as the next most preferred option, followed by private homes, and finally respite services in institutional settings. Parents emphasized their desire to be active partners in the planning and implementation of programs and services. In another study, families with children with serious emotional disorders expressed a preference for in-home respite care (Evans, Armstrong, Dollard, Kuppinger, Huz, & Wood, 1993).

For respite care services to be most effective in supporting families, they are ideally conceptualized as a part of the system of care array of services. While respite care may provide relief to families, families are likely to gain more benefits when respite is offered as part of a family-centered service plan that addresses the family's needs. Further, families may need financial support to pay for respite services.

The FUN Program in Ventura County, California is an example of an innovative respite care program for children with serious emotional disorders and their

families (Linder, Luick, Stitch, & Stitch, 1999). This program offers families up to twenty hours per month of planned respite care paid for according to a sliding scale. Respite care provided by trained workers focuses on strengthening community child care systems and providing family-to-family support. Through connections with community programs, children and youth gain opportunities to participate in social and recreational activities such as Boys and Girls Club and YMCA activities, overnight campouts, and visits to local attractions of interest to kids.

There have been few well-designed studies of the outcomes of respite care for the families of children with serious emotional disorders. In one of the few controlled studies of the effectiveness of respite care for families with children with emotional and behavioral disorders, families who received an average of twenty-three hours per month of preplanned respite care reported fewer out-of-home placements, greater optimism about caring for their child at home, and reduced care-giving stress compared with similar families who were on a waiting list (Bruns & Burchard, 2000). In addition, the families reported that their children displayed fewer negative behaviors in the community. Greater use of respite services was associated with more positive outcomes, pointing to the need to increase the intensity of respite services to impact some outcomes.

Recruitment, training, and payment for respite services are challenges to be faced in developing respite services. The Oklahoma Respite Resource Network is based on the philosophy that families are the experts on the care needs of their children and that parents and family members are the best trainers of their own respite providers (Percival, Kovach, Selvidge, & Bentley, 2001). By providing vouchers to pay for respite care, Oklahoma's Lifespan Respite program has enhanced the capacity of families to recruit their own respite providers in the community and to negotiate their own arrangements. Each family of a child (or adult) with a disability receives vouchers for \$300 or \$400, depending on family income, every three months to pay for respite care. In Tennessee, families of children with a serious emotional disorder who qualify for the state's Medicaid Waiver Program receive \$500 allowance per year to cover respite care expenses (www.trn.org).

For families unable to identify their own respite providers, Oklahoma and Tennessee each have a centralized database of respite providers who have completed the state's respite care training through a toll free telephone line or website (oasis@ouhsc.edu;

www.trn.org). While Oklahoma's respite training is offered through several state level departments, Tennessee has a 40-hour respite care training program focused specifically on respite care for children with serious emotional disorders. Respite providers who wish to receive funding through the Tennessee Medicaid Waiver program must provide references, agree to undergo a criminal background check, and complete the training program. These states also invite recreational professionals, such as staff at Boys and Girls clubs and the YMCA, to participate in their training activities. The training provides a way for staff to increase their knowledge and skills for working with children and youth with serious emotional and behavioral disorders. The result is an increase in opportunities for youth with emotional disabilities to participate in community activities, thus gaining enrichment for the youth and respite for parents.

With the leadership of the National Respite Coalition and support of the ARCH National Respite Network and Resource Center, the concept of Lifespan Respite has emerged recently as a key concept in respite care advocacy efforts both at the state level and nationally (Kagan, 2001; www.archrespite.org). Lifespan Respite is "a coordinated system of accessible, community-based respite care services for caregivers and individuals regardless of age, race, ethnicity, special need or situation." As of September 2001, three states (Oregon, Nebraska, and Wisconsin) had passed Lifespan Respite Acts. Under this legislation, states are developing infrastructures for planning, providing, coordinating, and improving access for Lifespan Respite for families and individuals with disabilities (National Respite Coalition, 2000). Several other states are considering similar legislation or programs or have pilot programs. The 2000 National Family Caregiver Support Act establishes a family caregiver support system for individuals caring for older adults, and older caregivers caring for grandchildren or adult children with disabilities. At the national level, the National Family Caregiver Support Act justifies the need for a system of respite for caregiver support, and the National Respite Coalition is advocating for a single, coordinated federal program to support the development of Lifespan Respite Services nationwide (National Respite Coalition, 2000).

Other recent innovations in the arena of respite care are related to new intergenerational family support models. An example of intergenerational support is the Generations of Hope project in which foster families and senior citizens come together in an intergenerational residential development where there is mutual support

and relief for all participants (Eheart & Power, 2001). Mentorship and family support programs in schools, day care facilities, and recreational programs around the country offer ways for children and youth to participate in enrichment opportunities and community activities (<http://www.ed.gov/pubs/LearnCenters/benefits.html>; www.afterschool.gov/cgi-bin/home.pl). These programs also have the added benefit of providing respite for parents and caregivers. Knowing that their children are safe, well cared for, and engaged in enriching activities, parents and caregivers are free to focus on their work, engage in other activities, or gain rest and relaxation.

Family stories:

(Names and some details have been changed to protect the privacy of families.)

Rachel is a single parent with two adopted children with special needs. The eldest, age 12, is diagnosed with attention deficit hyperactivity disorder and bipolar disorder. Rachel described her involvement with respite care services as follows:

We have tried babysitters in the past—neighborhood teenagers—and it has never worked out. It was overwhelming for them. There are times when he needs very firm limits and consistent limits... I've maybe used a babysitter five times over the last eight years, which isn't much.

After (the respite program coordinator) talked about the needs of my children, she recommended respite providers that had gone through the training. She tries to match caregivers and families based on personality, based on the needs of the child, but also based on what the child likes to do. If the child is very active, she tries to get an active provider... She took them skating. She played outside with them. They tossed a football and watched movies... It was an all-day event with both of them. To have both of them together can be challenging, but she did real well, and they liked her; they did well, too... It let me get out for a whole day.

I can go out to a movie or to dinner with a friend... Most recently, I went to a workshop I wanted to go to for myself. It was Friday night and all day Saturday. I went and I came home and the house was intact and everyone was intact. I felt relaxed. I came back refreshed... Some people might say it's a luxury and say it's not that important, but I

would challenge them to spend 48 hours giving total care to a special needs child, and then they can see whether it's a luxury or a need. It's very important for us to have that time for ourselves. I really do rest. The anxiety level is gone. The stress level is gone. I don't worry if they're OK or whether they're going to have fun. I know they're going to be OK, and I know they're going to have fun.

Tracy and her husband are the parents of two boys: a nine-year-old with autism and a six-year-old with developmental disabilities. In response to her son's extreme anxiety, Tracy rarely left her older son during his first nine years, but recently began to use respite services paid for by her state:

I've been home for nine years, and my kids are used to me being there to do reading and handwriting, so I've spent a lot of time over the years being a therapist and a mother... My child has never stayed in a day care... Any kind of added stress for the one with autism causes more problems with him.

With funds from the respite program in her state, Tracy pays her sister who has completed the required training to be a certified respite provider: "I can trust her. I know she's going to do what I ask her to do when I leave."

Tracy used respite care to visit her grandfather in the hospital and also started a college course:

(Respite) gives me time to go to school and do my homework... When she's there, my husband and I have go have a chat about what's going on at work, or what's happening in the family... If the child needs to stay in the home, the parent needs to feel relaxed about leaving them. If I have to feel upset about leaving them, it's not going to help me to have the respite care... It's helped my family tremendously. It helps the kids, the parents, everybody really.

Conclusion

This review of respite care literature and family perspectives makes it clear that families who are caring for children with a serious emotional disorder experience ongoing care-giving challenges that may be stressful and exhausting over time. All families need relief from daily responsibilities; and families with children with disabilities perhaps have a more intense need for relief. While many families are able to meet their needs for a

break within their network of family, friends, and neighbors, this may not be possible for families who do not have a strong support system in their community. For these families, especially, respite care policies and programs may be of great interest. Families who do not have access to existing respite care programs may be able to come together with other families to trade respite services or to develop their own respite network in collaboration with local family support networks and family organizations.

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