Respite Care -- Part I
Overview of Respite Care

Introduction

Over the years, there has been a growing awareness that adjustment to the special needs of a child influences all family members. This awareness has generated interest and has led to the development of support services for families to assist them throughout the lifelong adjustment process. Within the diversity of family support services, respite care consistently has been identified by families as a priority need (Cohen & Warren, 1985).

The following was written by a parent of a child with a chronic illness.
"Of the first six months of my child's life, three and a half months were spent in the hospital. We lived in a world of intensive care, with cardiac monitors, oxygen tents, tubes in every orifice and IV's in every extremity of my daughter's body.

"The weeks my daughter was home were completely taken up with her care: two hours to get a meal in her, so for six hours a day I was feeding her; up many nights holding her so she could sleep on my shoulder so that she could breathe if she had a respiratory infection. Respiratory infections were frequent because of her disabilities, and many nights my husband and I would have to get our older child up, take him to our neighbor's house and take my daughter to the hospital where she could have oxygen if her breathing got too labored. After getting her admitted, we would go back home, and get up again the next morning to get our son off to school and to return to the hospital. This after being awakened in the middle of the night with a phone call from the hospital saying that they were transferring her to intensive care so she could be watched more closely.

"Did we need respite? You bet we did! This was important particularly with a disabled and medically fragile child who needed expert care.

"During that time, either my husband or I always had to be with our daughter while the other ran to the grocery, the bank, the pediatrician for the individual's health care needs, or just to sleep for a few hours. Our friends disappeared from our lives, and our relatives lived far away. The world of normal family life in which family members live, work, and play together and take joy in each other's accomplishments, activities, and outings vanished.

"Our daughter had major surgery scheduled at six months and she would be hospitalized for at least 10 days. I approached my daughter's doctors with our family's need for a rest. Would they and the nurse's care for her for seven days while our family went away? We wouldn't leave for three days after surgery to make sure she was on the road to recovery. We felt safe leaving her in their hands, and we could truly relax.

"The week that our family stayed at the beach was the most wonderful gift during those six months. It was truly a blessing, not only for us but for our daughter, for it gave us the opportunity to stand outside the situation and view it from a distance. It enabled us to review what had gone on before, to put things into perspective, to think and plan. We were also physically restored, and we were able to go on with much more strength for the next 12 months caring for our daughter. Respite care was unavailable 11 years ago when we needed to cope with the challenges my daughter presented to our family. I had to make it happen."

All parents need a break now and then, to have time for themselves away from the responsibilities of caring for their children. This is true for families of children with disabilities or chronic health care needs too, only for these families it may be more difficult to arrange.

While respite may be a new word for some people, it is not a new phenomenon; it emerged in the late 1960's with the deinstitutionalization movement. One of the most important principles of this movement was the belief that the best place to care for a child with special needs is in the child's home and community. Families with a child who has a disability or chronic illness know the commitment and intensity of care necessary for their children. The level of dedication and care becomes part of daily life, part of the family routine, but this same commitment can make stress routine too. Parents can become accustomed to having no time for themselves. According to Salisbury and Intagliata (1986), "the need of families for support in general and for respite care in particular has emerged as one of the most important issues to be addressed in the 1980's by policymakers, service providers, and researchers in the field of developmental disabilities," (p. xiii).

Respite care is an essential part of the overall support that families may need to keep their child with a disability or chronic illness at home. United Cerebral Palsy Associations, Inc. (UCPA) defines respite care as "a system of temporary supports for families of developmentally disabled individuals which provides the family with relief. "Temporary" may mean anything from an hour to three months. It may also mean "periodically or on a regular basis." It can be provided in the client's home or in a variety of out-of-home settings," (Warren and Dickman, 1981, p. 3). Respite services are intended to provide assistance to the family, and to prevent "burnout" and family disintegration. Since not all families have the same needs, respite care should always be geared to individual family needs by identifying the type of respite needed and matching the need to the services currently available, or using this information to develop services where none exist. Once identified, it is also important for families to have ready access to that type of respite, in an affordable form.

Regardless of the type of respite program utilized, the emphasis should be on orienting services toward the entire family. The birth of a child with a disability or the discovery that a child has a disability or chronic illness is obviously a difficult time for the entire family, including siblings, grandparents and other relatives. Families need to adjust to major changes in their daily lifestyles and in their dreams. Extended family and friends will also need to adjust to these changes. These changes will take planning and time. We are accustomed to typical family life; a child with a significant disability or chronic illness is not typical. Therefore, plans for an untypical lifestyle call for creativity and flexibility. It is also important to bear in mind that the child will change as he or she grows and develops into an individual with his or her own personality and ideas.

Many families will find these changes difficult to handle. Many communities may be limited in their resources or in their interest in meeting the special needs such families present. These combined factors can leave the immediate family with the full-time care of their child and can lead to feelings of isolation from other family members, friends, and community activities, religious and social functions. Even performing the basic necessities of daily life, such as grocery shopping or carpooling, can become difficult to impossible.

It is obvious to anyone who has lived this life that respite care becomes a vital service—a necessity, not a luxury. Parents, of course, are clearly the experts about the need and importance of respite care. Just as families differ, so will the necessity for respite care. Basically, however, all families require some relaxation, diversion, and the security of knowing that their children are safe and happy. The most difficult problem for the family with a child who has a disability is finding the quality of care and expertise the child needs.

As one parent put it, "Families need an uncomplicated, easily accessible means of arranging respite care to suit their wants and needs. When a potential pleasure becomes more trouble than it's worth, then I give it up. I always measure the event against the complications involved in making it happen. Time off is no relaxation if I spend the entire time worrying if the kids are OK. I can't enjoy myself if I think they are unhappy, and certainly I can't relax if I'm not confident about the reliability of the person watching my children. I think many professionals are under the misconception that time away from the cares of rearing a child with a disability is what I need to maintain my sanity. I need much more than time—I need the security that comes from knowing that the person I've left my son with is as capable as I am of providing for his needs. You simply can't relax and enjoy yourself and worry at the same time. It's peace of mind I need—not just time."