

From: Scott Corcoran [scott@afamilyforeverychild.org]
Sent: Thursday, July 18, 2013 4:01 PM
To: scott@afamilyforeverychild.org
Subject: Respite Care for Children



Dear ,

What is respite care?

Respite care is temporary care for challenging children to give parents some relief.

Raising a child with disability or chronic illness poses many challenges. As families meet these challenges, time off can become a necessity for the caretakers. In recent years, the growth of respite care services—short-term specialized child care—has begun to provide families with some temporary relief.

This Briefing Paper is adapted from a 1989 NICHCY publication called "Respite Care: A Gift of Time."

The birth of a child with a disability or chronic illness, or the discovery that a child has a disability, has profound effects on a family. When parents learn that their child has a disability or special health care need, they begin a process of continuous, lifelong adjustment. Adjustment is characterized by periods of stress, and during this time, family members' individual feelings of loss can be overwhelming, shutting out almost all other feelings. Coping with uncertainty about the child's development may interfere with the parents' ability to provide support to each other and to other family members. Even when the diagnosis is clear, there are still many uncertainties – health, programmatic, and financial.

Social and community support can reduce the stress experienced by families. The support of relatives, friends, service providers, and the community can help families ease the adjustment period.

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).

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 addition to providing direct relief, respite has added benefits for families, including:

Relaxation. Respite gives families peace of mind, helps them relax, and renews their humor and their energy;

Enjoyment. Respite allows families to enjoy favorite pastimes and pursue new activities;

Stability. Respite improves the family's ability to cope with daily responsibilities and maintain stability during crisis;

Preservation. Respite helps preserve the family unit and lessens the pressures that might lead to institutionalization, divorce, neglect and child abuse;

Involvement. Respite allows families to become involved in community activities and to feel less isolated;

Time Off. Respite allows families to take that needed vacation, spend time together and time alone; and

Enrichment. Respite makes it possible for family members to establish individual identities and enrich their own growth and development.

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.

Source: [National Information Center for Children and Youth with Disabilities \(NICHCY\)](#)

Resources

To locate a respite care facility near you, visit [ARCH National Respite Network](#). Click the first link, "Search for Respite Services and Funding".

Become a respite care provider! Learn more [here](#).

Nora Sharp
Matching Assistance Coordinator
A Family for Every Child
nora.sharp@afamilyforeverychild.org

