The challenges that families face in caring for a child with a disability or a chronic illness are reviewed in this report on respite care. A parent's narrative describes the difficulties in providing around-the-clock care to a child with a chronic illness. The benefits of respite care are outlined as follows: gives the family peace of mind, allows the family to enjoy favorite pastimes, improves the family's ability to cope with daily responsibilities, helps preserve the family unit, allows the family to become involved in community activities, allows the family to take a needed vacation, and makes it possible for family members to establish individual identities. The federal legislation impacting on respite care is reviewed and the funding problems are addressed. Suggestions are provided for parents on determining whether the family could benefit from respite care, locating respite care services, and asking the right questions to obtain essential information from service agencies. Contains a resource list of 9 references, 6 additional resources, and 18 organizations. (CR)
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.” It discusses the emergence and diversity of respite care services, with particular emphasis on the benefits of respite care for families of children with disabilities or special health care needs. Tips and advice for parents who are seeking respite care are also presented. This issue concludes with a current listing of readings and organizations that can provide parents and others with additional information on the subject of respite care.

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).

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 our son’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 nurses 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.

\[Ω\]

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.

“Parents...are clearly the experts about the need and importance of respite care.”

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. xii).

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 “burn-out” 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 indi-
vidual with his or her own personal-
ity 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 mem-
bers, friends, 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 neces-
sity for respite care. Basically,
however, all families require some
relaxation, diversion, and the secu-
ritv 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 cer-
tainly I can’t relax if I’m not confi-
dent about the reliability of the

person watch-
ing my chil-
dren. I think
many profes-
sionals 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.”

**Benefits of Respite Care**

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 pre-
sure the family unit and lessens
the pressures that might lead to
institutionalization, divorce,
eglect and child abuse;

**Involvement.** Respite allows fami-
lies 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.

Often, we hear the question,
“Who takes care of the caretakers?”
Caretakers can include not only
parents, but also brothers and sisters,
grandparents, and extended family
and friends. Respite gives caretak-
ers the opportunity to have a rest, to
take care of personal matters, to
enjoy some leisure time, and occa-
sionally to be relieved of the con-
stant need to care for a child with a
disability or chronic illness.

The child or youth with disabili-
ties also benefits from respite care,
gaining the opportunity to build
new relationships and to move toward
independence. In many families, it
is common for children to attend day
care or after-school care, interact
with peers and adults outside the
family, and stay with a child care
provider while their parents enjoy an
evening out. Respite provides these
same opportunities for children with
special needs.

For older individuals with a
disability, respite can assist in
building skills needed for indepen-
dent living. Since the most appro-
priate living situation for many
adults with a disability is in a group
home or other supported environ-
ment, out-of-home respite care can
enable families to test this option, explore community resources and prepare themselves and their family member with a disability for this change.

States and communities are recognizing that respite care also benefits them. On average, the costs for respite services are 65 to 70 percent less than the costs of maintaining people in institutions (Salisbury and Intagliata, 1986). The cost-effectiveness of respite services allows scarce tax dollars to be used for additional community-based services. During the previous decade, over 30 states passed legislation for in-home family support services, including respite care, using either direct services or voucher systems (Agosta and Bradley, 1985).

With the 1986 passage of the Children's Justice Act (Public Law 99-401) and its amendment, the Children's with Disabilities Temporary Care Reauthorization Act (P.L. 101-127), respite care has gained support at the Federal level. This legislation authorized funding to states to develop and implement affordable respite care programs and crisis nurseries. Unfortunately, while this Federal funding provides relief for some families, access and affordability continue to be issues for many families in need. As Brill (1994) observes:

Families soon discovered that the law fell short of providing national guidelines for respite care. Every state dispensed different versions of the services, and individual agencies devised their own criteria for length of time and funding allotments. (p. 49)

Thus, in spite of the availability of government funding in some areas, many respite care programs must charge for their services. This practice reduces expenses for providers and makes it possible to serve more families. However, charging for respite services can limit their availability to those families who can afford the fees (Cohen and Warren, 1985).

For children and youth with normal and real concerns or fears can in fact cause parents to believe that respite is just not worth it. It is important that as a parent you become comfortable with your decision and develop the trust critical to maintaining the peace of mind necessary for relaxation and enjoyment. One way to accomplish this goal is to begin now to think about respite care and whether you, your family, and your child with special needs would benefit from it. The following suggestions may help.

How can you tell if your family could benefit from respite care?

Ask yourself the following questions:
1. Is finding temporary care for your child a problem?
2. Is it important that you and your spouse enjoy an evening alone together, or with friends, without the children?
3. If you had appropriate care for your child with special needs, would you use the time for a special activity with your other children?
4. Do you think that you would be a better parent if you had a break now and then?
5. Are you concerned that in the event of a family emergency there is no one with whom you would feel secure about leaving your child?
6. Would you be comfortable going to a trained and reputable respite provider to arrange for care for your child?

If you have answered “Yes” to several of these questions, you and your family could benefit from respite care and should investigate the resources in your community.

"In spite of the availability of government funding in some areas, many respite care programs must charge for their services. This practice reduces expenses for providers and makes it possible to serve more families."
Many agencies and organizations have information on respite care services. (For a referral, contact the National Respite Locator Service, operated by the ARCH National Resource Center: 1-800-773-5433). In general, seek out groups or professionals who work with children your child’s age. For example, if your child is in preschool, contact the staff at his or her school and discuss the need for respite care with the staff. If there is a parent group associated with your school, or if there is a local parent group concerned with children who have needs similar to your child’s, ask them. If your child is an adolescent, talk to the staff at his or her school or, again, identify parent groups in your area with needs similar to yours.

The following list presents some of the types of groups you may want to contact in seeking services. Many will be listed in your telephone book. If you experience difficulty locating the organization in your community, often a state contact can be made. For further information and assistance, contact NICHCY, and be sure to ask for a NICHCY State Resource Sheet for your state. Additional resources are listed at the end of this Briefing Paper.

### State and Local Disability or Support Groups
- The Arc
- United Cerebral Palsy Associations, Inc.
- Autism Society of America
- Brain Injury Association
- Mental Health Association and CASPP
- Spina Bifida Association
- National Easter Seal Society
- Parent Training and Information Center
- Parent-to-Parent
- University Affiliated Program(s)
- Community Services Board
- YMCA/YWCA
- Churches
- Recreation Centers

### What should you know when seeking respite care services in your community?

Ask yourself the following questions. The information will be helpful to you when contacting agencies in your local community about respite care (Bradley, 1988).

1. **What kind of services do I need?** (Long-term, short-term, or both? Why?)
2. **Do I prefer services in my home, or at a school or community setting?** (This will depend on the type of service you need.)
3. **Can I donate my time to a cooperative, or in an outside setting?** (This will depend on the type of service you need.)
4. **Does this agency provide the types of service I need?**
5. **Is there a cost for the service?**
6. **Am I able to afford this service?**
7. **If I can’t afford the service, are there funds available to assist me?**
8. **Who is responsible for the direct payment to the provider?**
9. **How are respite providers selected?**
10. **Are the providers trained?**
11. **How many hours of training have they had?**
12. **Do these providers have training in First Aid and CPR?**
13. **What other areas are covered in their training?**
14. **For out-of-home care, does anyone monitor the facility for safety and health measures?**
15. **Will I be able to have a prior meeting with the care provider?**
16. **Will I have an opportunity to provide written care instructions to the provider?**
17. **Will I have an opportunity to assist in training the provider with reference to my son’s/daughter’s needs?**
18. **What is the policy that covers emergency situations?**
19. **Will I have to carry additional insurance to cover the provider while he/she is in my home?**
20. **Is there a policy which deals with mismatches between providers and the family?**
21. **Can I request a specific care provider and have the same person with my child each time?**
22. **Will the respite care provider care for my other children too?**

### A Final Word...

Caring for a child with disabilities or severe health problems can be a full-time job. It is easy to become overwhelmed with the care needs of a child with a disability or chronic illness. Often, families who would not hesitate to call for relief from the constant care of their typical children hesitate to call for relief from the care of their child with a disability or special health care need. That is why respite, as the word implies, is truly an interval of rest. Respite care can be your answer to renewed energies and a new perspective. If respite care is not available in your community, make it happen. The best advocate for your family and your child is you. One of the most important goals to strive for is family unity and well-being. It is important to remember that you, too, can have the gift of time that respite care represents.
References


Additional Resources


The Center provides a central contact point for the identification and dissemination of relevant materials to crisis nurseries and respite care programs. Numerous fact sheets and general resource sheets (including state contact sheets) are available about respite care and crisis nursery care. ARCH also operates the National Respite Locator Service whose mission is to help parents locate respite care services in their area. Please contact them at 1-800-773-5433.

Organizations

CLEARINGHOUSES AND TECHNICAL ASSISTANCE:

ARCH National Resource Center for Crisis Nurseries and Respite Care Services — Chapel Hill Training-Outreach Project, 800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514. Telephone: (800) 473-1727; (919) 490-5577. The mission of the ARCH National Resource Center is to provide support to service providers through technical assistance, evaluation, and research.
OTHER ORGANIZATIONS:

The Arc (formerly the Association for Retarded Citizens of the United States) — 500 E. Border Street, Suite 300, Arlington, TX 76010. Telephone: (800) 433-5255; (817) 261-6003; (817) 277-0553 (TT).

Association for the Care of Children’s Health (ACCH) — 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814. Telephone: (800) 808-2224; (301) 654-6549.

Association for Persons with Severe Handicaps (TASH) — 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204. Telephone: (410) 828-8274; (410) 828-1306 (TT)

Autism Society of America — 7910 Woodmont Avenue, Suite 650, Bethesda, MD 20814. Telephone: (800) 3-AUTISM; (301) 657-0881.

Brain Injury Association (formerly the National Head Injury Foundation) — 1776 Massachusetts Avenue N.W., Suite 100, Washington, DC 20036. Telephone: (800) 444-6443; (202) 296-6443.

Epilepsy Foundation of America — 4351 Garden City Drive, Landover, MD 20785. Telephone: (800) 332-1000 (outside of MD); (301)459-3700.

National Down Syndrome Congress — 1605 Chantilly Drive, Suite 250, Atlanta, GA 30324. Telephone: (800) 232-6372; (404) 633-1555.

National Down Syndrome Society — 666 Broadway, New York, NY 10012-2317. Telephone: (800) 221-4602; (212) 460-9330.

National Easter Seal Society — 230 West Monroe Street, Suite 1800, Chicago, IL 60606. Telephone: (800) 221-6827; (312) 726-6200; (312) 726-4258 (TT).

Sick Kids (need) Involved People (SKIP) — 545 Madison Avenue, 13th Floor, New York, NY 10022. Telephone: (212) 421-9160.


United Cerebral Palsy Associations, Inc. (UCPA) — 1660 L Street N.W., Suite 700, Washington, DC 20036. Telephone: (800) 872-5827; (202) 842-1266.

Zero to Three/National Center for Clinical Infant Programs — 734 15th Street, NW, Suite 1000, Washington, DC 20005-1013. Telephone: (202)638-1144. (Voice); 1-800-899-4301 (Publications).

FAMILY SUPPORT PROJECTS:

American Association of University Affiliated Programs (AAUAP) — The AAUAP represents the national network of University Affiliated Programs (UAPs) in the United States. The UAPs provide interdisciplinary training for professionals and paraprofessionals and offer programs and services for children with disabilities and their families. Individual UAPs have staff with expertise in a variety of areas and can provide information, technical assistance, and inservice training to agencies, service providers, parent groups, and others. For information on a UAP in your area, write: AAUAP, 8630 Fenton Street, Suite 410, Silver Spring, MD 20910. Telephone: (301) 588-8252.

The Beach Center on Families and Disability — This center conducts research and training, and disseminates information relevant to families who have members with developmental disabilities or serious emotional disturbances. Write: The Beach Center on Families and Disability, The University of Kansas, 3111 Haworth Hall, Lawrence, KS 66045. Telephone: (913) 864-7600.

Children and Adolescent Service System Programs (CASSP) — CASSPs are federally-funded programs located throughout several states and localities, designed to improve service delivery for children and adolescents with emotional disorders. CASSP provides funding to states for research and training centers and for technical assistance activities. To contact a CASSP in your area, or to obtain a publications list and additional information, write: National Technical Assistance Center for Children’s Mental Health, 3307 M Street, NW, Suite 401, Washington, DC 20007. Telephone: (202) 687-5000.

National Clearinghouse on Family Support and Children’s Mental Health — The Center provides research and training, and disseminates information relative to serious emotional disorders and family support issues, including a newsletter. Write: National Clearinghouse on Family Support and Children’s Mental Health, Portland State University, P.O. 751, Portland, OR 97207-0751. Telephone: 1-800-628-1696; (503) 725-4040.
NICHCY Briefing Paper is published several times a year in response to questions from individuals and organizations that contact the Clearinghouse. In addition, NICHCY disseminates other materials and can respond to individual requests for information. For further information and assistance, or to receive a NICHCY Publications List, contact NICHCY, P.O. Box 1492, Washington, DC 20013. Telephone: 1-800-695-0285 (Voice/TT) and (202) 884-8200 (Voice/TT).

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