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Respite Care

What is respite?

"Respite" refers to short term, temporary care provided to people with disabilities in order that their families can take a break from the daily routine of caregiving. Unlike child care, respite services may sometimes involve overnight care for an extended period of time. Respite care enables families to take vacations, or just a few hours of time off. Respite is often referred to as "a gift of time."

Who provides respite services?

Most programs are managed by affiliates or chapters of national organizations such as The Arc, Easter Seals and United Cerebral Palsy. Many other programs are provided by local organizations such as churches, schools and other non-profit groups. Sometimes families arrange for care with neighbors or other people they know.

As of April 2001, three states passed Lifespan Respite Acts (OR, NE, WI), which establish state and local infrastructures for developing and providing respite services to eligible individuals. Maryland passed a bill establishing a statewide respite coordinator, and other states are considering piloting similar programs or legislation (National Respite Coalition, 2001).

What kinds of services are provided?

Services are provided in many ways depending on the provider, the needs of the family and available funds. The two primary categories of respite include in-home and out-of-home services. The following are typical services provided in each category:

In-Home Respite

- **Home-based services:** A trained and perhaps licensed employee of an agency comes to the home, and services are ideally available 24 hours a day, 365 days a year.
- **Sitter-companion services:** Provided by individuals who are trained in caring for children with special needs, this type of service is often provided through a non-profit or service organization (such as The Arc, Camp Fire, Jaycees, Junior League or United Cerebral Palsy).
- **Parent-trainer services:** Similar to having a friend or relative volunteer to care for a child with disabilities, the difference is that the caregiver is selected by the family and trained by a respite program. Caregivers may be paid or unpaid.

Out-of-Home Respite

- **Family Care Homes:** Respite is provided in the provider's home (homes should be licensed under state regulations governing foster homes.)

- **Respite Family Day Care:** Respite programs that contract with existing day care centers to provide respite to children with disabilities. Day care centers may be housed in churches, community centers and after school programs.
- **Respite in Corporate Foster Home Settings:** Some states have foster care "homes" which are managed by a non-profit or for-profit corporation, and these homes may provide respite care.
- **Residential Facilities:** Some long-term residential facilities (such as group homes and supervised apartments), particularly those serving persons with developmental disabilities, have a specified number of beds set aside for short-term respite.
- **Parent Cooperative Model:** Families of children with disabilities develop an informal association and "trade" respite services with each other.
- **Respitiy Model:** Participating hotels provide the family a room, dinner and perhaps entertainment while a local respite program provides respite care for the child.
- **Hospital-Based:** Facility-based respite occurs primarily in hospitals, and provides a safe setting for children with high care needs.
- **Camps:** Whether or not a child has a disability, camp can be a positive experience for any child, as well as a break for parents/caregivers. Both day and overnight camps are available (Cernoch, 1994).

How are respite services funded?

Many programs receive public funding for their services. Some charge fees on a sliding scale based on the family's income. Other programs may be operated by non-profit organizations, which receive funding from donations or other sources. Many programs must use a combination of funding sources in order to meet their financial needs.

Are there eligibility requirements for respite services?

In almost all state-funded programs, eligibility is based on the child's age and disabilities. Family income is usually considered as well. In a survey of 33 caregiver support programs in 15 states, it was found that service definition, eligibility, mode of delivery and funding vary widely across programs and within states (Feinburg & Pilisuk, 1999).

How do families benefit from respite services?

More than providing direct relief, the benefits of respite care can also include:

- **Relaxation:** Families can relax, gain peace of mind and renew their humor and energy.

What do you need to know when seeking respite services in your community?

Some questions you may want to ask yourself when considering respite services include:

- What kind of services do I need? (long or short-term or both and why?)
- Do I prefer services in my home, a cooperative, or an outside setting?
- Can I donate my time to a cooperative, or is it better for me to obtain help from a respite agency?
- Does this agency provide the type of services I need?
- What is the cost of services? How is payment arranged?
- What is the training and level of experience of the care providers? Will they need additional training to meet specific family needs?
- How, and by whom, are the care providers supervised?
- What happens during the time the children are receiving services? Are there organized activities? How are the meals handled?
- Does the program maintain current information about each child's medical and other needs? Is there a written care plan?
- What procedures does the program have for emergencies?
- Can parents meet and interview the people who care for the children?
- How far ahead of time do parents need to call to arrange for services?
- Are families limited to a certain number of hours of services?
- Does the program provide transportation?
- Can the provider take care of siblings as well?

FOR MORE INFORMATION, CONTACT:

National Respite Locator Service operated by the ARCH National Resource Center: 1-800-773-5433 or www.respitelocator.org

NICHCY (National Information Center for Children & Youth with Disabilities): 1-800-695-0285 or www.NICHCY.org

References

- National Respite Coalition (August 2001). "Lifespan Respite" available on line at www.archrespite.org/NRC-Lifespan.htm. Annandale, VA.
- Feinburg, L. & Pilisuk, T. (1999). *Survey of fifteen states' family caregiver support programs: Final report*. Family Caregiver Alliance. San Francisco, CA.
- NICHCY (1996). *NICHCY Briefing paper: Respite care*. Washington, D.C.
- Cernoch, J. (1994). ARCH National Resource Center for Respite and Crisis Care Services Factsheet Number 2: *Respite for children with disabilities and chronic or terminal illnesses*. Chapel Hill, NC.

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- **Enjoyment:** Families can enjoy favorite pastimes and pursue new activities.
- **Stability:** Respite can improve 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:** Families can become involved in community activities and be less isolated.
- **Time Off:** Families can take that needed vacation, spend time together and time alone.
- **Enrichment:** Respite makes it possible for family members to establish individual identities and enrich their own growth and development.

Respite care not only provides caregivers a break, but also gives the child a change in his or her daily routine. It can provide the child opportunities to build new relationships and move toward independence (NICHCY, 1996).

Respite is also important since forty-two percent of families of children with disabilities lack basic workplace supports such as paid sick leave and vacation time. (National Respite Coalition, 2001).

How do families obtain services?

Although respite care is a need most often requested by families and caregivers, it remains to be in critically short supply for all age groups, for families in crisis, and for caregivers of the elderly and individuals with disabilities (National Respite Coalition, 2001).

Many agencies and organizations have information on respite care services. For a referral, contact the National Respite Locator Service (see box for contact information). You can also contact your state's planning council on developmental disabilities, community mental health/mental retardation center or a local chapter of The Arc and ask them to refer you to a program. Programs have been developed when families made their needs known to community mental retardation advocates and service providers.

What can I do to get a respite program started in my community?

- Ask other parents in the community about their needs for respite services: Do they need or want in-home care, or could care be provided at a community center? Determine if overnight or weekend care is needed.
- Find a respite provider in another community that already provides these types of services and ask them how they started their program.
- Contact state licensing agencies to find out licensing requirements for operating a respite program.
- Find an organization in your community that might be interested in helping you start a program. Churches, schools, local Red Cross chapters and disability organizations may provide the personnel, experience and/or financial resources necessary to start or operate a new program.