Respite programs emerged in the late 1960's as a result of the deinstitutionalization movement with the belief that the best place to care for a child with disabilities was in the child's home and community. Recognizing the effectiveness of respite services, in 1986, Congress passed the Temporary Child Care for Children with Disabilities and Crisis Nurseries Act (as amended). This Act established federal funding to create temporary child care (respite) demonstration projects. Administered through the U.S. Department of Health and Human Services, Children's Bureau, competitive grants have been awarded to States since 1988 to assist private and public agencies in developing model respite services across the United States.

Purpose

Respite programs provide temporary relief for families or caregivers. Additional family benefits include: allowing the family to engage in daily activities thus decreasing their feelings of isolation; providing the family with rest and relaxation; improving the family's ability to cope with daily responsibilities; maintaining the family's stability during crisis situations; helping preserve the family unit by decreasing the pressures that might lead to divorce, institutionalization, abuse and/or neglect; and, making it possible for people with disabilities to establish individual identities and enrich their own growth and development.

What are Respite Care Services?

Respite, temporary relief for caregivers and families, is a service in which care is provided to children with disabilities, chronic or terminal illnesses, and/or to children at risk of abuse and neglect. Respite for families who have children with disabilities, or chronic or terminal illnesses, is further defined by the federal legislation as in-home or out-of-home temporary, non-medical child care. Most of these respite programs offer services to families on a sliding fee scale with hourly and/or daily rates. Respite services can range from a few hours of care up to three months of care depending on the needs of the families and the type of respite program model available in a community. The ages served by respite programs range from infancy to adulthood. Often programs serve a particular disability or illness (e.g., children who have HIV-related conditions, children who are medically fragile, children with mental retardation).

Many respite services are incorporated within larger social service agencies both at the community and/or state levels which provide an array of support services to families. Some of these support services can include: family counseling; family support groups; parent training; service coordination; assistive equipment services; and, access to medical services.

Respite Program Models

Respite program models for families who have children with disabilities, or chronic or terminal illnesses, may differ in each local service area according to the needs of families/caregivers within the community. For example,
some respite programs may utilize an available bed in a health care facility or state institution for families who require extended respite options and whose child requires skilled care; whereas, other respite programs may only offer time-limited (a few hours) services in the family”s home. In addition, respite services may be available to families through formal programs (i.e., trained staff) or may be available to families through informal networks (e.g., parent cooperatives, or cash subsidies from states to purchase respite through relatives and friends). The following descriptions are examples of local respite program models.

**In-home Models**

Many families prefer respite that is provided in the home. There are several advantages to in-home respite:

- The child is most comfortable in the home setting and does not have to adjust to a different environment.
- The parents/caregivers are often more comfortable if the child does not have to leave the home;
- The home is already equipped for any special needs the child may have.
- The cost is relatively economical (voucher systems are frequently used to pay for services).

Sometimes in-home care is coordinated by a broker, an individual who agrees to recruit, provides basic training, and keeps a database of all respite providers. Families can be matched with a provider by calling the broker and are usually responsible for child-specific training, payment, and repeat scheduling.

Listed here are some of the typical models used in in-home respite.

**Model 1: Home-Based Services**

Home-based respite services may be provided through a public health nursing agency, a social service department, a volunteer association, a private nonprofit agency and/or a private homemaker service. A trained and perhaps licensed employee of the agency is available to come into the home and offer respite. Ideally, services should be available twenty-four hours a day, 365 days per year.

**Model 2: Sitter-Companion Services**

Sitter services may be provided by individuals who are trained in caring for children with special needs. Often this type of service can be a project of a service organization or specialized agency (Camp Fire, Jaycees, Junior League, local ARC or United Cerebral Palsy Associations), which is willing to sponsor training and/or maintain a register of trained providers to link to families in need.

**Model 3: Parent-Trainer Services**

This model is similar to having a friend or relative volunteer to care for a child with special needs. The primary difference is that the person providing care is identified or selected by the family and trained by a respite program. Providers may be paid or unpaid.

**Out-of-Home Models**

Out-of-home respite provides an opportunity for children and youths with disabilities, chronic or terminal illnesses to be outside the home and/or with other children or youths. This may be a particularly attractive option for adolescents who are preparing to leave the family home for a more independent living arrangement, because it gives them an opportunity to experience new surroundings and different expectations. Families are free to enjoy time in their own home without the constraints of constant care, and they can devote more attention to siblings.

Listed below are some special considerations regarding out-of-home models.

- Transportation may be required and special equipment may need to be moved.
Services are usually offered on a sliding fee schedule, or there may be a combination of family fees, state and federal funding, and/or private insurance.

- Providers may be paid or unpaid in many of the models.
- The child receiving care may not like the unfamiliar environment or may have difficulty adjusting to the changes.
- The services may be offered in a variety of settings more restrictive than the child's home, such as special medical centers or nursing homes.

**Model 4: Family Care Homes or Host Family Model**

In this model, respite is offered in the provider's home. This could be the home of a staff person from a respite program, a family day care home, a trained volunteer's family home, or a licensed foster home used only for respite stays. Offering respite in a provider's home enables a child to receive services in a more familiar setting. It is recommended that homes used under this model be licensed under state regulations governing foster homes.

**Model 5: Respite Family Day Care or Center-based Model**

Some respite programs contract with existing day care centers to provide respite to children with special needs. This is an effective model in rural areas, because it allows children to be in a supervised environment in a facility that may be relatively close to home. Children may be placed in these settings on a short term "drop in" basis, as well. Day care centers may be housed in churches, community centers, and after school programs. Not all centers are licensed by the state to provide services.

**Model 6: Respite in Corporate Foster Home Settings**

In some states, foster care regulations and licensing accommodate the development and operation of foster care "homes" which are managed by a non-profit or for-profit corporation. In this situation, several children or adolescents who have disabilities are placed outside their family homes and live together in a homelike environment with the help of a trained, rotating staff. These corporation operated foster homes may provide respite care, either as vacancies occur in the homes, or as the sole purpose for which the "home" exists. Some adolescents adapt especially well to this situation, enjoying a setting which is like semi-independent living.

**Model 7: Residential Facilities**

Some long-term residential care facilities, particularly those serving persons with developmental disabilities, have a specified number of beds set aside for short-term respite. Some examples of such facilities are community residences (such as group homes and supervised apartments), nursing homes, and state institutions.

**Model 8: Parent Cooperative Model**

Parent cooperatives have been developed in communities, especially rural areas, where respite services are very limited. In this type of model, families of children with disabilities and/or chronic illnesses develop an informal association and "trade" respite services with each other. This exchange program allows families to receive respite on scheduled dates. In most parent cooperatives, fees are not assessed. This model has proven to be especially effective for families whose children have similar disabilities.

**Model 9: Respitality Model**

Respitality is an innovative concept for providing respite. It provides a cost-effective partnership between the private sector and respite agencies. During Respitality, participating hotels provided the family with a room, a pleasant dining experience, and perhaps entertainment while a local respite program provides respite either in the family's home or in an out-of-home respite situation. The Respitality concept was developed by United Cerebral
Model 10: Hospital-Based

Facility-based respite occurs primarily in hospitals. It provides a safe setting for children with high care needs. It can be a good alternative for a small community that has a hospital with a typically low census or a hospital with low weekend occupancy. Children can receive high quality care while remaining in a familiar setting with familiar people. In larger communities, a hospital provides the sense of security parents and caregivers need when considering respite.

Model 11: Camps

Camps have been a form of respite for many families for many years. 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. For children with disabilities, chronic or terminal illnesses, the chance to participate in either an integrated or adapted camp can be life-expanding. There are many places around the country which offer such experiences, either as day or overnight camps.

Summary

Respite for families who have children with disabilities, chronic or terminal illnesses, may occur in out-of-home and in-home settings for various lengths of time depending on the needs of the family and available resources. As an important part of the continuum of services for families, respite helps preserve the family unit and supports family stability.

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Starting a Respite Care Program, ARCH National Resource Center, Coordinating Office, Chapel Hill Training-Outreach Project, 800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514; 1993.

Resource Centers

Texas Respite Resource Network (TRRN), Santa Rosa Children's Hospital, P.O. Box 7330, San Antonio, Texas 78207-3198; (512) 228-2794

National Information Center for Children and Youth with Handicaps (NICHCY), P.O. Box 1492, Washington, DC 20013: 1-800-999-5599

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Revised March, 1994

This factsheet was produced by the ARCH National Resource Center for Respite and Crisis Care Services funded by the U.S. Department of Health and Human Services.
Respite for Children with Disabilities and Chronic or Terminal Illnesses

Services, Administration for Children and Families, Administration on Children, Youth and Families, Children's Bureau Cooperative Agreement No. 90-CN-0121
under contract with the North Carolina Department of Human Resources, Mental Health/ Developmental Disabilities/Substance Abuse Services, Child and Family
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