



*Start a Respite Care Program*

*A Handbook for Developing New Services*

**Presented by:**

**The Alabama Lifespan Respite Resource Network®**

**A Program of**

**United Cerebral Palsy of Huntsville and Tennessee Valley, Inc.**

*The information provided in this manual is for educational purposes only.  
Please seek legal advice and search official websites for guidance.*

## **Table of Contents**

Steps to Developing a Respite Program .....	Pages 1-2
Models for Respite Care Programs.....	Pages 2-5
A Brief Explanation of Specific Types of Respite Programs.....	Pages 5-6
Sources for Developing New Respite Programs .....	Pages 6-7
Help With Writing Your Grant Proposal.....	Page 7

## Steps to Developing a Respite Program

1. Define your service area
2. Assess needs and resources within the area
  - A. Survey the families
  - B. Survey the community agencies
3. Establish an advisory committee board of directors to:
  - A. Help disseminate information about the respite program
  - B. Help gain community support
  - C. Help build coalitions with other family service agencies
  - D. Assist staff in developing and reviewing of program policies and procedures
4. Establish policies and procedures
  - A. These are guidelines for program operation
  - B. Define types of services and the parameters of each type
  - C. Define eligibility criteria
  - D. Establish a maximum allotment of service per family, if necessary
  - E. Define the minimum and maximum service periods
  - F. Determine what your fees will be
  - G. Determine method of payment and related policies
  - H. Develop application or in-take procedures
  - I. Develop priorities for service provision
  - J. Decide on recruitment, selection, and training of workers
  - K. Develop personnel policies and salary scales
  - L. Establish the method of matching families with workers
  - M. Decide how the program will be evaluated - quality assurance checks
  - N. Develop procedures for emergency respite care
  - O. Address liability issues
  - P. State responsibilities of parents, staff, and agencies
5. Secure funding
6. Prepare a budget
7. Obtain insurance and liability
  - A. Insurance is a MUST!
  - B. Parents sign liability release
  - C. Consult your lawyer for advice and assistance
8. Select a program coordinator
  - A. Realize the coordinator is the key to the success of the program
  - B. Coordinator is responsible for the implementation of all policies and procedures
  - C. Coordinator maintains all records and financial data

- D. Coordinator presents information about the program to the public and selected groups
  - E. Coordinator presents information to care providers and plans periodic training events
  - F. Coordinator evaluates services and providers and makes recommendation to the Advisory Committee or Board of Directors.
9. Recruit respite care families
  10. Develop miscellaneous forms
  11. Begin family registration and intake
  12. Develop payment plans
  13. Maintain respite service log and records
  14. Establish emergency 24 -hour respite service process

## **Models for Respite Care Programs**

While knowing respite is a temporary break for the caregiver when approaching your funding challenges, it is necessary to learn about the different types of respite care that can be provided.

Respite includes a broad array of service options, many of which are licensed and/or regulated through other program categories, such as child care, residential care, emergency shelter care, home health care or foster care. Respite programs should accept the responsibility to be aware of and in compliance with specific state licensing requirements that may govern their activities.

### ***In-home Models***

Many families prefer respite that is provided in the home that offers several advantages for the family or primary caregiver:

- The person requiring care is most comfortable in their 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 the person who has specific special needs.
- The cost is relatively economical (voucher systems are frequently used to pay for services).

A program manager, an individual who agrees to recruit, provide basic training, and keep a database of possible respite providers, may take the lead in coordinating in-home care.

Families can be matched with a provider by calling the program manager who will take the lead responsibility for child-specific training, payment, and repeat scheduling.

Listed here is a sampling of the typical models used as 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 provides direct respite services in the home. Ideally, services should be available twenty-four hours a day, 365 days per year, for families to access quality respite when they most need the service.

### **Model 2: Sitter-Companion Services**

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

### **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 adults with disabilities, chronic or terminal illnesses to be cared for outside the home. 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 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 may be paid or unpaid, but a sliding fee schedule is usually offered or a combination of family fees, state and federal funding, and/or private insurance.
- The person receiving care may not adapt well to 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 home environment, 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. Best practice under this model supports homes that seek appropriate licensure 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 or adults with special needs. This is an effective model in rural areas especially, because it allows people with special needs to be in supervised environments in a facility that may be relatively close to home. Clients may be placed in these settings on a short-term "drop in" basis. 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" that 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 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 that 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 were 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**

Respitivity is an innovative concept for providing respite. It provides a cost-effective partnership between the private sector and respite agencies. Respitivity is the process of working with participating hotels to provide 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.

### **Model 10: Hospital-Based**

Facility-based respite occurs primarily in hospitals. It provides a safe setting for children with extensive care needs. This offers a good alternative for a small community with a typically low census using their local hospital, especially on the weekend. A hospital may provide the sense of security parents and caregivers need when considering respite for their loved one. High quality skilled respite care is provided, but usually on a limited basis and must be scheduled in advance.

### **Model 11: Camps**

Camp has been a form of respite for 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 persons 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 that offer such experiences, either as day or overnight camps.

### **Model 12: Church-based**

Many community churches have begun respite care programs that provide out-of-home respite for families. These programs are often run one day a month for a few hours, utilizing teams of volunteers that are trained by the church to care for the special needs of the participants. The frequency of service is determined by the church administration. These facilities offer a wonderful opportunity for caregivers to place their loved ones in a caring facility usually for a nominal fee but often free of charge.

## **A Brief Explanation of Specific Types of Respite Programs**

### **Crisis Nursery Care**

#### **Respite for Children at Risk of Abuse and/or Neglect**

Crisis nursery programs were developed to prevent child abuse and neglect and to increase family stability thus preventing the need for out-of-home placement. Recognizing that there are times when parenting can be difficult, particularly when a family is experiencing a crisis or extreme stress, crisis nurseries offer temporary relief from child care responsibilities which allows time for parents to address their own needs. Traditionally, parents have received this help from extended family members or close

friends. In today's mobile society, a network of extended family members and/or friends is not always available. In these situations, crisis nursery programs can offer assistance to parents in meeting their caregiving responsibilities.

## **Adult Day Care**

### **One Form of Respite for Older Adults**

Adult day care centers provide a break (respite) to the caregiver while providing health services, therapeutic services, and social activities for people with Alzheimer's disease and related dementia, chronic illnesses, traumatic brain injuries, developmental disabilities, and other problems that increase their care needs. Some adult day care centers are dementia specific, providing services exclusively to that population. Other centers serve the broader population.

One difference between traditional adult respite, both group and in-home care, and adult day care is that adult day centers not only provide respite to family caregivers but also therapeutic care for cognitively and physically impaired older adults.

## **Sources for Developing New Respite Programs**

- › [Americorps](#) - Volunteer service organization, offering respite to all ages and disabilities.
- › Some support organizations have discretionary consumer funds that can be used to pay for respite.
- › [The Association of Small Foundations](#) is a resource of foundations offering grants.
- › [Child Care Online](#) - Childcare grants can be a possible source of funding for respite quality program. The main concern to watch out for is to make a distinct difference in your proposal that childcare and respite are not the same service! To assist their visitors, Child Care Online has done extensive research about where to find grants for child care programs. Their database is searchable by nation or state. You will find lists of government grant programs and corporate funds.
- › [The Council of Foundations](#) – Here you will find a list of grant makers and grant programs. This is a membership site “promoting knowledge, growth, and action in philanthropy.”
- › [The Foundation Center's](#) mission is to collect, organize, and communicate information on U.S. philanthropy; conduct and facilitate research on trends in the field; provide education and training on the grant seeking process; ensure public access to information and services through a World Wide Web site, print and electronic publications, five library/learning centers, and a national network of Cooperating Collections.
- › [Grants.gov](#) – A listing of grants available through the U.S. Government covering a wide range of needs and issues is available at this website. You can also find tips on grant writing and other frequently asked questions about government grants.

- › [HealthCare.gov](http://HealthCare.gov) is an Internet application tool for finding and exchanging information about HHS and other Federal grant programs.
- › [Robert Wood Johnson Foundation](http://RobertWoodJohnson.org) is dedicated to improving the health and health care of all Americans. On this site you can find information on their various funding opportunities, as well as search their funding database.

## Help With Writing Your Grant Proposal

- › [ARCH National Website](http://ARCH.org) is the best place to begin your search for information to answer the question, “What is respite?” This website offers a multitude of online documents addressing issues such as presentation of your proposal, background information on the national respite movement, and other fact sheets to assist you in your effort to fund respite programs.
- › Some of the Fact Sheets available from ARCH:
  - [General Principles of Charitable Nonprofit Fundraising](#)
  - [Data Analysis and Presentation](#)
  - [Local Program Survey Report](#)
- › [The Foundation Center](http://TheFoundationCenter.org) website provides an online newsletter with the latest updates on funding searches, writing techniques and a cornucopia of other information for the grant writer. This site also has a searchable database for possible sources of funding. For a nominal monthly fee, you can access additional information about possible funding sources as well.
- › [Grantstech.com](http://Grantstech.com) has helpful information on general grant writing skills and approaches. This website offers a page on grant writing tools, lists of the latest publications on grant writing and the top organizations that offer grants.
- › [Robert Wood Johnson Foundation](http://RobertWoodJohnson.org) offers a wealth of information on many aspects of funding a project. On this particular link you can find grant result reports. RWJ Foundation leads the nation in funding faith-based respite care projects.
- › [Marquette University Funding Information Center](http://MarquetteUniversity.org) provides links to bibliographies on funding resources and lists names of foundations they have collected.
- › [Nonprofit Resource Center](http://NonprofitResourceCenter.org) offers information and insight on grant proposal development geared specifically toward nonprofit organizations.
- › [Treelink.com](http://Treelink.com) is another great resource for basic grant writing information offering basic information about fundraising and grant seeking.