



## Louisiana Lifespan RESPITE COALITION

### Background

In 2006, President Bush signed the Lifespan Respite Care Act into law (P.L. 109-442). The Lifespan Respite Care Program (LRCP) provides grants to state agencies to maximize existing resources and ensure that respite is available and accessible to family caregivers by establishing or enhancing statewide respite systems. DHH received a small three-year planning grant of \$200,000 in 2010 to coordinate the coalition through the Aging Disability Resource Centers of Louisiana/LouisianaAnswers.com.

This project is supported, in part, under a grant from the U.S. Department of Health and Human Services, Administration for Community Living, Administration on Aging. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. These contents, however, do not necessarily represent the policy of the U.S. Department of Health and Human Services and endorsement by the Federal Government should not be assumed.



## For Your Information: Louisiana Lifespan Respite Care Program

**FACT:** There are 917,000 men and women in Louisiana who provide 600 million hours of care-giving to a child or adult with special needs at a value of \$5.7 billion a year.

### WHAT IS A CAREGIVER?

A caregiver is an adult aged 18 years of age or older who provides unpaid care to a child or another adult in their home.

### WHO IS THE TYPICAL LOUISIANA CAREGIVER?

There is not one profile to fit all caregivers, but the typical caregiver is a middle-aged female who has some post-graduate education, is employed, and spends at least 20 hours a week providing care to their aged parent.

**FACT:** 10,000 individuals turn 65 every day in America. The average caregiver in Louisiana cares for someone under 75 years of age.

### WHAT IS RESPITE?

Respite Care is defined as planned or emergency relief provided to the primary caregiver of an adult or child with special needs in order to provide temporary rest to the caregiver. Respite services may be provided in a variety of settings including a home, adult day care center or residential care facility.

### STATE OF RESPITE IN LOUISIANA

Nine out of 10 caregivers will not get a break...ever. Most caregivers will go on trying to do too much and not asking for help because they are unable to verbalize or acknowledge their own needs.

- 76 percent do not get help from family members
- 45 percent feel isolated
- 62 percent don't get the financial or training supports they need to be a caregiver
- Most will be a caregiver for five years before reaching out for help

### WHAT IS LOUISIANA DOING TO HELP THE CAREGIVER?

The Louisiana Department of Health and Hospitals is supporting the development of a Louisiana Lifespan Respite Coalition, in association with the U.S. Administration for Community Living/Administration on Aging and the ARCH National Respite Network. The Louisiana Lifespan Respite Network is a completely volunteer network to build and strengthen a systemic approach to provide respite services to caregivers by:

- Identifying and coordinating existing respite resources
- Identifying service gaps
- Creating/identifying new services
- Recruiting and training respite providers
- Connecting families to providers and payment resources for respite care
- Promoting public awareness

### How you can help.

Support the ADRC program in Louisiana.

Spread the word.

- Help family caregivers know that they are not alone; they are part of a rapidly-growing, very large group of people who can help, support, and learn from one another;
- Ensure that family caregivers understand that care giving is an additional role that goes over and above their traditional roles as spouse, child, or parent, so it requires additional support and planning;
- Help family caregivers become more effective problem solvers and motivate them to actively participate in improving their situation.

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# Frequently Asked Questions About Respite Care

## Types of respite services

### Emergency Respite

When a family caregiver becomes ill or cannot provide care for other reasons, emergency respite becomes an invaluable resource.

### In-Home Respite

#### 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 or home health agency. A trained employee of the agency is available to come into the home and offer respite. Ideally, services should be available 24 hours a day, 365 days per year. It is important to ask the agency if the employee is licensed or not.

#### 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 can be a project of a service organization or specialized non-profit agency that is willing to sponsor training and/or maintain a register of trained providers to link to families in need.

#### Consumer-Directed Respite

This model is similar to having a friend or relative volunteer to care for a child or adult 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. If they are paid, it is often through a voucher program offered directly to family caregivers to allow them to locate, hire, train and pay their own providers.

### Out-of-Home Respite

Out-of-home respite provides an opportunity for the care recipients to be in their community. This may be a particularly attractive option for adolescents who are preparing to leave the family home for a more independent living arrangement, for young adults with disabilities who prefer to be with people their own age, or even aging populations with mild to moderate memory loss. Special considerations regarding out-of-home models are:

- Transportation may be required.
- Special equipment may need to be moved.
- The individual 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 care recipient's home, such as special medical centers or nursing homes.

#### Family Care Homes or Host Family

In this model, respite is offered in the service 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 an individual 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 or similar homes used for group care.

#### Respite Center-Based

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. 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. Respite centers utilizing church, mosque or synagogue social halls, community centers, or senior service centers offer similar services for the aging population on a regular, daily or intermittent basis.

#### Adult Day Health Care Centers

Adult day care centers, also known as adult day services, have been providing a form of respite for caregivers for more than 20 years. Such services have expanded dramatically in the last decade as demand has increased but also as new funding sources, such as Medicaid waivers, became available. Some adult day care centers are dementia specific, providing services exclusively to that population.

#### Respite in Corporate Foster Home Settings for Children and Teens

In some states, foster care regulations and licensing accommodate the development and operation of foster care "homes." A non-profit or for-profit corporation manages these homes, so that several children or adolescents who have disabilities may live together in a homelike environment with the help of a trained, rotating staff.

#### Residential Facilities

Some long-term residential facilities, particularly those serving persons with developmental disabilities, have a specified number of beds set aside for short-term respite.

#### Parent/Family Cooperative

Parent and family caregiver 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 model has been used successfully for young veterans with traumatic brain injury or other conditions, who are living at home. This model has proven to be especially effective for families whose children or other family members have similar disabilities.

#### Respitiy Model

Respitiy is an innovative concept developed by United Cerebral Palsy of America whereby participating hotels provide the caregiver and their family with a room, a pleasant dining experience and perhaps entertainment, while a local respite program provides in-home or out-of-home respite for the loved one with needs.

#### Hospital-Based

Facility-based respite occurs primarily in hospitals. It provides a safe setting for children and adults 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. Veterans (VA) hospitals offers respite for eligible veterans.

#### Hospice

Hospice respite can be provided in a hospital or other appropriate setting for those with high care needs.

#### Camps

For children with disabilities, chronic or terminal illnesses, the chance to participate in either an integrated or an adapted camp can be life-expanding. Many places around the country offer either day or overnight camps. Some camp settings are used for adult populations as well.

## Why is Respite Important?

When caregivers use respite services, they are better able to preserve the quality of their own daily life, manage their caregiving responsibilities for their loved ones, and enhance overall family life. We are here to help you find respite opportunities. We have resources for the family caregiver of:

- Children with special needs or disabilities
- Adults with special needs, disabilities, or conditions associated with aging
- Adults with life-threatening conditions or disorders i.e., end stage cancer

### Where can respite take place?

Respite can be provided in a variety of settings, so that caregivers can select the type that best suits their needs, as well as the needs of the care recipient. The length of respite can vary from several hours a day, to a full eight-hours day, up to five days a week. Most programs do not offer weekend or overnight services. Respite centers and nursing facilities do provide overnight services for qualified individuals.

### Where can I find respite care?

Go to [www.LouisianaAnswers.com](http://www.LouisianaAnswers.com)

### How can I pay for respite care?

Respite services are not free unless a volunteer service has been located.

### How can I be sure a respite provider will provide good care?

As the person employing a respite care provider, it is your responsibility to determine how qualified the person or agency is to care for your loved one. Many organizations must meet licensing requirements. For individuals, a criminal background check is recommended. In either case, visiting with the care provider and getting recommendations is a must.