



## The Technical Assistance Center for Lifespan Respite Fact Sheet Number 59, August 2012

### Respite for Family Caregivers of Adults with Neurological Conditions

#### Introduction

Millions of adults in the United States live with various neurological conditions. Many, depending on the severity or progression of their condition, rely on family members, friends, or other volunteers to help them throughout the day. As with caregivers of adults with other conditions, such as aging, mental illness, or developmental delays, family caregivers of individuals with neurological conditions often help their loved ones with Activities of Daily Living (ADLs), including mobility, grooming, toileting, feeding, or dealing with incontinence. They also assist with Instrumental Activities of Daily Living (IADLs), such as transportation, housework, grocery shopping, meal preparation, financial management, and arranging or supervising paid or other volunteer service providers.

The role of the family caregiver can be very rewarding, but the intensity of some caregiving activities can affect the family caregiver's physical and emotional health. By reducing the stress that is often associated with a negative impact on the caregiver's health and well-being, respite can offer significant benefits for the entire family and even assist with keeping the loved one at home and avoiding or delaying facility placement.

However, respite is not always a service that family caregivers are aware of or use. The availability of respite for adults with neurological impairments depends on where the individual lives, the individual's age, and the particular impairment he or she has, as well as the stage of the progression of the condition, if it is progressive in nature. Appropriate and desired respite services specifically targeted for this population are extremely limited,

and public support to help pay for respite for their family caregivers may be even more scarce.

This fact sheet provides an overview of the population of adults with neurological conditions, and discusses considerations that families, respite providers, other program administrators and state Lifespan Respite grantees should take into account in relation to accessing or providing respite to family caregivers of these individuals. This fact sheet is intended also to provide information that will encourage State Lifespan Respite grantees and others to stimulate and provide resources to increase the capacity and affordability of respite services for this population across the lifespan.

#### Definitions

##### General Definition

Neurological conditions are diseases and injuries to the central and peripheral nervous system, which includes the brain, spinal cord, nerves, autonomic nervous system, neuromuscular system, and muscles. They include epilepsy, Alzheimer's disease and other dementias<sup>1</sup>, cerebrovascular disease including stroke and headache, Amyotrophic Lateral Sclerosis (ALS), Multiple Sclerosis (MS), Parkinson's Disease, infections, brain tumors, and acquired (ABI) or traumatic brain injury (TBI). There are more than 600 types of neurological conditions striking a total of 50 million – or 1 in 6 – Americans each year

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<sup>1</sup> See ARCH fact sheet, Respite for Persons with Alzheimer's Disease or Related Dementia, available at <http://archrespite.org/images/docs/Factsheets/archfs55alzheimers.pdf>

(National Institute of Neurological Disorders and Stroke [NINDS], 2005).

Individuals with neurological conditions have a wide range of both abilities and challenges. Some are able to provide much of their own self-care; others are dependent on caregivers for some or all of their activities of daily living (ADL). With some impairments, such as some strokes, functioning can improve over time after the initial event; in progressively debilitating diseases such as Parkinson's disease, Amyotrophic Lateral Sclerosis (ALS) or Multiple Sclerosis (MS), the individual requires increasing levels of care over time.

### *Specific Neurological Conditions*

This fact sheet provides information on a few of the more commonly-occurring neurological conditions in the United States. For information on other specific conditions and diseases, see the website of the National Institute of Neurological Disorders and Stroke at <http://www.ninds.nih.gov/disorders>.

**Degenerative conditions** are neurological conditions which begin or become symptomatic in early or mid-adulthood. Individuals with these conditions experience increasingly severe symptoms over time, although the courses of these diseases are widely variable and generally unpredictable. In addition to the four listed below, examples of other degenerative neurological conditions include Alzheimer's disease, Friedreich's ataxia, Lewy body dementia, and spinal muscular atrophy.

- **Multiple sclerosis (MS)** is believed to be an autoimmune disease with an as-yet unknown environmental trigger, with symptoms generally appearing between the ages of 20 and 50. It is a chronic disease of the central nervous system (brain, spinal cord, and optic nerve). Symptoms may vary from mild muscle weakness to partial or complete paralysis, and may include vision or hearing impairment, numbness, prickling sensations, pain, speech impediment, tremors, dizziness, depression, and mild cognitive impairment. There is no cure, but symptoms may remit or plateau for periods of time. Physical

therapy and drug therapies can be helpful. There are about 400,000 people with MS in the U.S., with more than 200 new diagnoses each week.

- **Amyotrophic lateral sclerosis (ALS)**, commonly called Lou Gehrig's Disease, is a rapidly progressive, fatal disease that attacks the nerve cells which control voluntary muscles. Patients lose the ability to use their muscles, which then weaken, and eventually many lose the ability to move at all. When muscles in the chest and diaphragm fail, the person must rely on a ventilator to breathe. ALS is not thought to affect the individual's ability to see, hear, smell, or taste. In some cases, there are cognitive impairments associated with the disease. There is no known cause and no cure. Most individuals with ALS die within three to five years of diagnosis, although about 10% live for 10 years or more. ALS usually occurs between the ages of 40 and 70, but does occur at other ages. About 30,000 Americans have the disease at any given time.
- **Huntington's Disease (HD)** is a genetic disease in which brain cells degenerate over time, causing uncontrolled movement, loss of intellectual functioning, and emotional disturbance. The individual progresses at an unpredictable rate, but always results in the patient's inability to care for him/herself. Anyone who carries the gene for HD will develop the disease; children of those with the disease have a 50/50 chance of inheriting the gene. Onset usually occurs between the ages of 30 and 50. About 30,000 people in the U.S. have HD, and another 150,000 are "at risk" because one of their parents has the disease.
- **Parkinson's Disease (PD)** is one of a group of conditions that stem from the loss of dopamine-producing brain cells. Primary symptoms are tremors of the hands, arms, legs, jaw, and face; rigidity of the limbs and trunk; slowness of movement; and impaired balance. Symptoms usually occur after age 50 and become progressively worse. Patients may experience wide variation in severity, from mild to severe disability. There is no cure, but there are drug

therapies that may help with symptoms. More than one million people in the U.S. have been diagnosed with PD, and 50,000–60,000 new cases are diagnosed each year.

**Stroke** is the result of an interruption of blood flow to the brain, either from a blockage (ischemic stroke) or from bleeding into or around the brain (hemorrhagic stroke). This causes brain cells to die. Symptoms, which vary depending on the area of the brain affected, may include sudden numbness or weakness, confusion, difficulty speaking or understanding speech, sudden vision problems, sudden difficulty with walking, balance or coordination, dizziness, or sudden severe headache. The extent of recovery after a stroke depends on many factors, including size and area of the brain affected, how quickly the patient receives treatment, and the individual's response to rehabilitative therapy. Some patients recover all or nearly all function; others are significantly impaired physically and/or cognitively. Individuals experience more than 780,000 strokes per year in the U.S. It is the third-leading cause of death, and causes more long-term disabilities than any other disease. Almost three-quarters of strokes occur in people age 65 and older.

**Traumatic brain injury (TBI)** results when the brain is damaged, as in a sudden and violent blow to the head, or an object pierces the skull and enters the brain. Symptoms can be mild to severe, depending on the extent of the damage, and may last for a few seconds or be life-long. Resulting disability depends on the location and severity of the injury, as well as the individual's age and health status. Common problems include difficulty with cognition, communication, or ability to process sensory input, changes in behavior or personality, and mental health issues. Serious TBI can result in coma or vegetative state. It is estimated that 1.7 million people in the U.S. sustain a traumatic brain injury each year. The vast majority, 80%, are treated and released from an emergency hospital visit; 275,000 are hospitalized; and 52,000 die. More than 80,000 individuals with TBI suffer a permanent disability of some type. The leading causes of TBI are falls

(35%), motor vehicle accidents (17%), being hit or colliding with an object (16%), and assaults (10%) (Faul, et al, 2010). In addition, veterans of the wars in Iraq and Afghanistan have suffered traumatic brain injuries at a higher rate than in previous conflicts. Between 2000 and 2012, 244,217 cases of TBI occurred. Sixteen percent were deployment related. Of the total number, 2,469 were classified as severe, resulting in confusion or disorientation lasting more than 24 hours, loss of consciousness for more than 24 hours, and memory loss for more than seven days; and 3,877 were classified as penetrating, in which an object enters the brain (Department of Defense [DOD], 2012).

**Spinal cord injuries** occur when the spine is damaged by a sudden blow in which bone fragments or other material bruise or tear into spinal cord tissue. The resulting disability may allow for recovery or be permanent, depending on the severity of the injury and the emergency treatment received. Loss of mobility is connected to the location of the injury on the spine. An injury may be incomplete, in which case the individual retains some motor or sensory function below the injury. In a complete injury, all motor function and sensation is lost. Patients often have medical complications including chronic pain, bladder and bowel dysfunction, and increased susceptibility to respiratory and heart problems. There are over one million people living with paralysis due to a spinal cord injury in the U.S. Of these, 35% reported "a lot of difficulty" in moving and 16% said they were "completely unable to move." (Christopher & Dana Reeve Foundation, 2009).

**Epilepsy** is a brain condition in which nerve cells have a disturbed pattern of activity, which can cause strange sensations or emotions, as well as muscle spasms, convulsions, and loss of consciousness. It can be caused by abnormal brain development, disease, or injury. For the majority of individuals with epilepsy, medication or surgery can control seizures.

## Understanding the Need for Respite

Caregiving can be a very rewarding experience and most family caregivers choose to assume this role to allow their loved one to continue living at home. However, several factors may affect the mental health and well-being of family caregivers who are caring for someone with a neurological condition, including their relationship with the care recipient, the nature of the disability, the stage of the disease, financial concerns, and the lack of social support/social network.

### *Family Caregivers of Individuals with Neurological Conditions Face Special Stressors*

Individuals with neurological conditions may have lost the ability to care for themselves suddenly, as with stroke, TBI, or spinal cord injury, or they may experience a gradual decline in function over time caused by a degenerative disease. In either case, a diagnosis of any of the neurological conditions affects both the individual and his or her family.

Neurological conditions can, by nature, be significantly disabling. The needs of those cared for can be intense, from cognitive changes to unpredictable and often progressive physical disabilities. Providing care for those with neurological conditions can be particularly difficult as the disease progresses. It can be a struggle to not know the course the disease will take, when a relapse may occur, how long it will last, and if the disability will continue or worsen. The intensity of care needed for those with these conditions can be overwhelming as the disease progresses and the care recipient becomes increasingly unable to communicate and experiences more physical disabilities (World Federation for Mental Health, 2009).

Studies show that caregivers of people who have suffered a brain injury may experience feelings of burden, distress, anxiety, anger and depression (Family Caregiver Alliance, 2007). Caregivers may become isolated from family and friends as they are caring for loved ones. Little time is often left to devote to maintaining friendships and social networks. This social isolation can increase as the

disease progresses and caring demands increase. Caregivers who don't have sufficient social support from family and friends often feel isolated and alone in their caregiving, increasing stress. Family conflicts can further exacerbate the isolation and loneliness some caregivers feel. For those living in a rural community, this can be doubly hard, as they may be geographically removed from support and services. While social support may not affect the primary stress caused by the disease, it can change the caregiver's response to the illness. Feeling supported by family and friends can improve the caregiver's psychological response to stress and boost the caregivers' sense of well-being (World Federation for Mental Health, 2009).

### *Unique Respite Needs Faced by Certain Family Caregivers*

Little research has been done to describe or quantify the unique needs of family caregivers who are caring for individuals with specific neurological conditions. However, two recent surveys illustrate the special needs, including the need for respite, of family caregivers of individuals with MS and the needs of family caregivers of veterans with traumatic brain or spinal cord injuries. Family caregivers of individuals with other conditions such as ALS, Huntington's, Parkinson's or other neurological conditions may share some of these needs, but may also face caregiving needs unique to the condition of the person in their care that might require different supports or approaches to respite.

### *Caregivers of Individuals with Multiple Sclerosis (MS)*

A recent survey conducted by the National Alliance for Caregiving in collaboration with the National MS Society found:

- The long life cycle of Multiple Sclerosis (MS) suggests that the total number of years one serves as a caregiver will be longer than for caregivers in general: 9 years for caregivers of people living with MS compared to less than 5 years for all caregivers. Most people with MS are diagnosed between the ages of 20 and 50 and the vast majority live a normal lifespan.

- The most common aspects of MS caregivers' lives which are negatively affected are their overall financial situation, ability to participate in hobbies and/or things they enjoy, and mental health. Caregiving for someone with MS has a negative impact on the family's financial situation in 43% of those surveyed.
- The areas with the biggest positive impacts relate to relationships – those with the care recipient, the children of the caregiver, and other family members.
- For delaying institutionalization, 82% of caregivers say that assistance in paying for in-home care would help and two-thirds say that respite care would help. When the care recipient also has cognitive impairment, the percentage of those saying respite would be helpful to avoid or delay nursing home placement jumps to 75% (National Alliance for Caregiving [NAC], 2012).

### Caregivers of Veterans with Neurological Conditions

A significant proportion of younger veterans have a neurological condition that resulted from their military service. A 2010 survey of family caregivers of veterans whose illness, injury or condition is in some way related to military service conducted by the National Alliance for Caregiving found:

- Almost three in 10 family caregivers surveyed say their veteran has a traumatic brain injury (TBI) (29%), one in five say the veteran in their care has paralysis or a spinal cord injury (20%), 6% report the veteran has Parkinson's, and 4% report they have MS. Spinal cord injuries and TBI occur in higher rates in younger veterans from more recent wars.
- Caregivers whose veterans have TBI are more inclined than others to not know where to turn to arrange a break from caregiving (75% vs. 65%). Other than caregivers whose veterans have PTSD or depression/anxiety, caregivers of veterans with TBI have greater difficulty finding someone to give them time off than those caring for other veterans. Roughly half of each of these groups say it is very difficult, compared to about four in

ten of their counterparts. Many negative health effects are more common when the veteran has TBI compared to caregivers of individuals with no TBI.

- Caregivers whose veteran has paralysis are nearly twice as likely as their counterparts to spend more than 80 hours per week providing care. Caregivers whose veteran has paralysis or a spinal injury are more likely than those without such a condition to be in a high burden situation (80% vs. 61%). High burden caregivers also tend to report greater stress (73% rating it 4 to 5, compared to 55% of low burden caregivers).
- Sixty-eight percent of veterans' caregivers overall reported their situation as highly stressful compared to 31 percent of caregivers nationally who feel the same and three times as many say there is a high degree of physical strain (40% vs. 14%).
- Only 15% of family caregivers had received respite services from the VA or some other community organization within the past 12 months. Veterans' caregivers specifically asked for up-to-date respite resource lists of respite providers in their local communities and help for them to find services (NAC, 2010).

For information on respite services and other community supports administered by the US Dept of Veterans Affairs, see the section on Veterans Programs under the Federal Funding section of this fact sheet.

The Defense and Veterans Brain Injury Center has developed a family caregiver curriculum, Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans. The Family Caregiver Curriculum is a source of information and support for caregivers of service members and veterans with moderate to severe TBI. It is the result of Congressional action and cooperation from a panel made up of TBI survivors, family members and experts appointed by the White House, and the departments of Defense and Health and Human Services. To view the curriculum, visit <http://www.dvbic.org/family-caregiver-curriculum>



## Barriers to Respite Access

This section will describe the barriers that exist for individuals with neurological conditions and their caregivers in accessing or using respite. The sections which follow will discuss considerations for family caregivers, respite providers and program administrators, and Lifespan Respite programs as they plan respite services and approaches to overcoming these barriers.

### Too Few Respite Options

Out-of-home respite, such as nursing homes or adult day services, which primarily serve the aging population, are often the most frequently available to individuals with neurological conditions. However, such settings are not often appealing to younger adults who would prefer to be around people their own age engaging in preferred activities that might be more age-appropriate. Also, some nursing homes may not accept people with ALS or others who are more medically involved, particularly those who have progressed significantly and those who are ventilator dependent. Since so few respite funding or service options exist for family caregivers of individuals with neurological conditions, just knowing where to turn to ask for help can be very difficult. Often there is also a reluctance to ask for help or fear that the care recipient may not be receptive to the idea. It is important to help the family caregiver to raise the issue and communicate their needs.

### Provider Shortages

Shortages of well-qualified respite providers or flexibility in allowing family caregivers to choose and train their own providers exist for all age groups and conditions. However, for family caregivers of individuals with neurological conditions, especially those with challenging physical needs or behavioral issues, the difficulty in finding well-trained and willing respite providers, community supports, or innovative respite programs that can meet their needs can be even more dramatic.

## Economic Costs

Too few resources for families to pay for respite can be a significant barrier to access. Medically related expenses for individuals with neurological conditions can be significant, even for individuals with health care insurance. The cost of respite care is often seen as a luxury that will only stress an already overburdened household budget. While some states offer Medicaid Home and Community-based Waiver Services for individuals with TBI, spinal cord injuries and other physical disabilities, many families do not meet the income or other eligibility criteria for the waivers or waiver waiting lists may be very long. Few other public or private resources exist to assist families of individuals with neurological conditions in paying for respite. For more information, see “Funding for Respite Services and Programs” on page 11 at the end of this fact sheet.

## Respite Considerations for Family Caregivers of Individuals with Neurological Conditions

Special considerations for family caregivers include planning ahead for respite and other caregiver support, understanding the available respite options, and knowing when and where to seek referrals and get more information.

### Planning for Respite

All caregivers should develop a plan that helps them provide the best care for their family member while maintaining their own good emotional and physical health. This plan should have three parts:

- 1. Find help coping with day-to-day demands:** It is important for family caregivers to recognize that it is okay to ask for help. Caregiving can be emotionally and physically draining; every caregiver needs a break now and then to rest, recharge, and tend to his or her own needs.
- 2. Create and organize a community of support** to help with the tasks and activities identified. This can be done the “old-fashioned” way, with written schedules, phone trees, and meetings;

or use social media such as Facebook or an online free service such as Lotsa Helping Hands (<http://www.lotsahelpinghands.com>) or Share the Care (<http://www.sharethecare.org>) to communicate with people who will be providing help.

**3. Care for the caregiver:** Caregivers may feel they are not entitled to time off, or that their own needs for personal care are not important because their family member's needs are so great. They should make sure that they spend at least some time regularly in activities that are meaningful and enjoyable, whether that is lunching with a friend, watching a movie, or exercising.

Respite plays an essential role in helping caregivers maintain their own mental and physical health; it also provides opportunities for the individual with a neurological condition to spend time with someone other than the caregiver, either at home, in appropriate community-based or recreational activities, or in a respite care facility. For more information on the importance of respite care, assessing the need for respite and making sure the caregiver makes the most of available respite time, see *Respite Services: Enhancing the Quality of Daily Life for Caregivers and Care Receivers*, available at <http://www.archrespite.org/consumer-information>.

### **Respite Options**

The following respite options may be available in your community.

- In-home services offer a wide range of options, including companion services, personal care, household assistance, and skilled nursing care to meet specific needs of those involved. In-home respite offers the advantages of not having to transport the individual with a neurological condition or their necessary medical equipment, which can be very important if impaired mobility is a barrier.
- Adult day services provide a planned program that includes a variety of health, social, and support services in a protective setting during

daytime hours. These services are often targeted to the aging population, but may be designed to meet the individual needs of adults with functional and/or cognitive disabilities. Make sure that services are age appropriate and that providers are qualified and trained to deal with any special medical needs of the person in your care.

- Community-based respite programs may offer day only or overnight services to a smaller number of individuals, often in a less institutional setting. They may be tailored to the specific needs of a certain age group or serve only individuals with certain conditions or they may be more inclusive of all age groups and conditions. Adult foster homes also may offer community-based respite.
- Some facilities provide overnight, weekend, and longer respite stays so a caregiver can have longer periods of time off. These facilities provide meals, help with activities of daily living, therapeutic activities to fit the needs of residents, and a safe, supervised environment. Examples of such facilities include nursing homes, residential care facilities, and assisted living facilities.
- Emergency respite is often offered in many nursing homes, residential care facilities, and assisted living facilities. Emergency respite care may be needed when a caregiver becomes ill or must go out of town unexpectedly, or if the care recipient is at risk of abuse or neglect. It is best for the caregiver to be prepared for this type of respite by finding the best facility and registering ahead of time. Each community is unique in its response to crisis respite. Some communities have emergency guest houses for such situations, while in other communities, State Medicaid dollars will pay for emergency respite in nursing homes or assisted living facilities.
- Family and friends or a faith-based organization can offer more informal access to respite services.

For more information on the pros and cons of each respite option, and for additional help on how to find, use, select, train providers, and pay for respite,

see ARCH's ABCs of Respite: A Consumer Guide for Family Caregivers at <http://archrespite.org/consumer-information>.

### ***When and How to Seek Referral***

For many families, asking a relative or neighbor to provide respite may be sufficient. For families with an individual with a neurological condition, relief from caregiving may be a much more complicated issue. Adults may have needs ranging from minor assistance with ADLs, to total care of physical needs, to medical interventions such as giving injections or providing emergency medical care. The cognitive functioning, emotional health and stability, and behaviors of the individual may be within a normal range, or pose serious challenges. Caregivers who find that their loved one's behaviors or physical or medical needs cannot be handled without special instruction should seek referral for respite care to ensure that their family member will receive the care needed to keep the patient safe and comfortable.

Referrals to appropriate respite programs may be available through the State Lifespan Respite Program, State Respite Coalition, State Aging and Disability Resource Center, Centers for Independent Living, the individual's health care or mental health care provider, case manager, or community mental health association. The ARCH National Respite Network and Resource Center maintains an online respite locator at <http://www.archrespite.org/respitelocator>.

Private organizations such as Easter Seals, the National MS Society, the Brain Injury Association, The ALS Association, or University Centers for Excellence in Developmental Disabilities (UCEDDs) may also be able to provide referrals in the community. Resource information for each of these organizations and others is included at the end of the fact sheet.

## **Considerations for Respite Providers**

### ***Knowledge, Skills, and Values***

Respite care providers need to be prepared with a set of knowledge, skills, and values that can enable them to effectively care for individuals with neurological conditions and interact with their families.

- **Knowledge:** Providers should have an overview of the strengths and challenges of individuals with neurological conditions in general, and access to information about specific diseases, as well as specific information about the individual for whom they will be providing respite. They should have an understanding of any relevant culturally congruent practices for the population they serve, and be able to communicate in the language the consumer and family speaks. They should be familiar with liability and confidentiality issues, and have resources to help them with any issues in those areas. They should also know how to reduce their own stress and prevent burnout as they work with adults and families under difficult conditions.
- **Skills:** Providers should be competent in the skills needed to adequately care for the personal and health care needs of the individual with a neurological condition. These skills will vary depending on the needs of each person and may change as the disease progresses.
- **Values:** Providers should understand challenges faced by families. Having a respite provider come into a family's home may feel intrusive. It is important for respite providers to remember that things they see or hear in a family's home should not be shared with anyone (with the exception of issues of abuse or neglect). Establishing a level of trust between consumer, family, and respite provider will enhance the care the individual receives and insure a trusting and meaningful relationship.



## **Patient-centered/Family-driven Services and Supports**

Respite services, like all health and support services accessed by individuals with neurological impairments, should be patient-centered and consumer/family-driven. The concept of family-driven care comes from the field of children's mental health (Spencer, et al, 2010) and has been applied to adults with mental illness (President's New Freedom Commission on Mental Health, 2003) and developmental disabilities (Heller, et al, 1999). The basic definition of this concept also applies to the care of all individuals, regardless of age. Individuals with neurological conditions may be able to be the driving force behind their own care, or they may need the support or intervention of family members to advocate on their behalf.

It is critical that individuals with neurological conditions and their families be included in the development of services and training of providers. Consumer and family participation can range from the development of the individual's service plan as an equal partner on the treatment team, to service delivery and service system assessment activities, to membership on statewide policy and planning groups. Families accessing respite should be active participants in the development and implementation of those services.

## **Considerations for Respite Program Administrators<sup>2</sup>**

Specific considerations for respite program administrators include the following:

**Referrals:** Respite programs should receive referrals for respite from all participants in the local service delivery system: agencies on aging, mental health, social and rehabilitation services, medical services, and families.

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<sup>2</sup> For additional direction on ensuring the quality of respite services delivered, see ARCH National Respite Guidelines, 2011, at <http://archrespite.org/productspublications/products-and-publications#Guidelines2011>

**Intake and screening:** Some programs may want to use an interagency team, consisting of representatives of all referring parties, to screen referrals for appropriateness and then triage for delivery of respite. In addition to specific screening to determine diagnostic and financial eligibility for the program, administrators may want to consider questions such as the following in order to determine if the respite available (as well as other supports and services offered) are appropriate to the consumer and family:

- Where is the consumer currently living?
- Is he/she eligible for respite or other services from other programs?
- If he/she is already receiving services, what are they and who is delivering them?
- Is the consumer in imminent risk of placement in an institution?

## **Recruitment, preparation and ongoing support (retention) of respite providers:**

Program administrators should ensure that respite providers are adequately screened, prepared, and trained to meet the needs of the adults and families they serve. Training needs include:

- CPR and first aid certification
- General information about family caregivers and respite needs and benefits
- Specific information on the conditions or disabilities of care recipients
- Communication and boundary setting skills
- Client rights
- Confidentiality
- Program's liability/risk management policies
- Individual dignity and choice
- Signs of abuse or neglect

Providers should receive both initial training to prepare them for their role and regular in-service training to keep knowledge and skills up to date.

**Matching families and respite providers:** To insure the continuity of care, the matching of respite providers and families is critical. An effective matching process may take as many as three stages.

1. The first stage is to make a match on paper. The strengths, interests, and values of the care recipient and family are matched to the respite provider pool.
2. In the second state, the match is made in the home on a trial basis. This provides an opportunity for the care recipient, family, and respite provider to gain familiarity and security with each other. It also begins a dialogue between the family and respite provider and follow-up dialogue with the respite coordinator. Perhaps most importantly, it allows the respite provider to be trained by the family in their own environment.
3. The third stage concludes with a final match. Based on the information gathered from the application(s) and the success of the trial match, the final match between respite provider, care recipient, and family is made. It is important that family members feel comfortable with the provision of care and that the respite provider feels comfortable and capable of managing the care recipient's needs. If either the family or the respite provider is uncomfortable, it is best for all concerned to match a different provider with the family.

**Consumer Input:** It is important for respite programs to incorporate family perspectives during the training of respite providers. While potential respite providers may have had some experience working with adults with neurological conditions, it is rare that their experience has taken them into a family's home over an extended period of time. It is a different dynamic when the service is delivered on the "family's turf." There are fears and expectations held by both the family and respite provider.

To address any concerns, it is recommended that a team approach be used in the training of respite providers. A health or mental health professional and a family member can co-facilitate the training

and use service providers, siblings, and other family members as needed. As respite providers are assigned to particular families, it will be important for the family to provide information that is specific to their family member's needs.

An ongoing discussion regarding confidentiality and boundary issues between family and respite provider needs to be woven throughout the training of respite providers.

### Considerations for Lifespan Respite Programs

Appropriate, desirable or affordable respite services for family caregivers of individuals with neurological conditions are not always readily available in the community and there is a shortage of qualified and well-trained providers. Too few respite programs or providers are equipped specifically to deal with the unique needs of this population. As conditions become more debilitating and the health care needs greater, the respite options may become even fewer. This population also is the most likely to not qualify for any existing public respite funds.

#### Improved Education and Training for Respite

**Providers:** It is essential that education and training opportunities be made available to those providing respite for individuals with neurological conditions. Because many neurological conditions, such as ALS or MS, may involve medical interventions, many family caregivers may be particularly concerned about leaving their loved one with a respite provider who they feel may not be qualified to provide this type of assistance. Ensuring that respite providers have specific knowledge regarding the care of individuals with neurological conditions, may make it easier for family caregivers to utilize respite care and get a much needed break from their caregiving duties.

### **Maximize Flexibility and Consumer Control:**

Not all family caregivers have the same respite care needs. They may have very different family relationships, caregiver resources and stressors, care recipient needs, and caregiving responsibilities. Therefore, a wide array of policy and programmatic options are needed to address these diverse needs. Efforts should be made to match the individual family need with available services or develop new services to meet caregiver needs. For care recipients with more severe medical involvement, respite options that are prepared and qualified to offer services to this population need to be developed.

### **Promote Culturally and Linguistically Competent Care:**

The U.S. population is becoming increasingly racially and ethnically diverse. Layered on top of issues related to the difficulty of finding and paying for respite for this population, a failure to address cultural needs of families may add another barrier to respite access. For more information and resources related to ensuring culturally and linguistically competent care through training, see *ARCH Volunteer Respite Manual: Creating Valuable Options for Family Caregivers*, pp. 41–43.

**Ensure Age-Appropriate Services:** There are very few adult day programs or overnight respite services in nursing homes or assisted living facilities around the country that are equipped to serve younger adults living with disabilities and chronic conditions. Instead the majority of these services are targeted to the aging population. Such services are not always appropriate for younger individuals living with neurological conditions or diseases such as multiple sclerosis (MS), which is typically diagnosed between the ages of 20 and 50. It is essential that Lifespan Respite programs work to develop more age-appropriate and desirable services for younger individuals with neurological conditions or diseases.

## **Funding for Respite Services and Programs**

A range of possible state and federal funding sources may be available to help pay for respite services. States with a State Lifespan Respite

Program or State Respite Coalition should be able to provide links to existing funding sources or assist with possible funding sources that may be unique to the state. Unfortunately, public funding sources for individuals with neurological conditions, especially if they fall in the age range of 18–60, are extremely limited.

## **Federal Funding**

### **Medicare**

Medicare covers individuals age 65 and older, people under age 65 with certain disabilities, and individuals with end-stage renal disease. Coverage of respite care is limited to Medicare Hospice benefits and Medicare Advantage Special Needs Plans.

- **Medicare Hospice Benefits.** Hospice care is a program of support and care for individuals who are terminally ill and their families. Hospice is chosen to provide comfort at the end-of-life, rather than cure. Medicare covers a range of hospice services, generally at home, from a team which may include doctors, nurses, counselors, other medical professionals, social workers, aides, homemakers, and volunteers. In addition, inpatient respite care from a hospice in a Medicare-approved facility is available when the patient's usual family caregiver needs a rest. Individuals receive hospice care in a Medicare-approved facility, allowing family caregivers a break. Such respite stays can last up to five days at a time, and there is no limit to the number of times respite can be used. There is a co-payment for respite services, which is 5% of the Medicare-approved amount for inpatient respite care. The hospice benefit is only available to individuals who:
  - are eligible for Medicare Part A (Hospital Insurance)
  - have been certified by a doctor and hospice medical director to be terminally ill with six months or less to live if the illness runs its normal course

- have signed a statement choosing hospice care instead of other Medicare-covered benefits that would treat the illness; and
  - receive care from a Medicare-approved hospice program.
- **Medicare Special Needs Plans (SNPs).** SNPs are a specialized Medicare Advantage (Part C) program. They must cover all of the medically necessary services and preventive services covered under Medicare Parts A and B, and prescription drug coverage under Part D. They may cover additional services tailored to the special groups being served, including respite for family caregivers of patients not living in institutions. Chronic conditions currently approved for SNPs include the following neurologic conditions: ALS, epilepsy, extensive paralysis, Huntington's Disease, Multiple Sclerosis, Parkinson's Disease, Polyneuropathy, spinal stenosis, stroke, and stroke-related neurologic deficit. Not all SNP's provide the same coverage; use the Medicare Plan Finder at <http://www.medicare.gov/find-a-plan/questions/home.aspx> to find out specific information about any plan or call 1-800-MEDICARE (1-800-633-4227) to find a SNP.

## Medicaid

Medicaid is a federal and state entitlement program that pays for medical assistance for certain individuals and families with low incomes and resources. Federal regulations limit the ability of states to cover the cost of respite care directly as a regular Medicaid benefit, because it is considered a non-medical expense. The exception, begun in 1985, is the Medicaid Hospice option. However, there are a number of research, demonstration and waiver programs under Medicaid that have allowed states to provide respite as a low-cost alternative to treatment in a medical facility.

- **Medicaid Hospice Benefits.** For Medicaid-eligible individuals, hospice care is an optional benefit which may be available if chosen by the state. Respite is available to family caregivers who are caring for the patient at home on an

occasional basis and for no more than five days at a time. Respite is not available if the patient is a resident of a nursing facility. As with the Medicare Hospice Benefit, the consumer must be terminally ill, elect to receive palliative care (rather than treatment) for that illness, and receive care from an approved program.

- **Section 1915(c) Home and Community-Based Services Waivers (HCBS).** In addition to traditional medical services, states can also provide services not usually covered by the Medicaid program, as long as these services are required to keep a person from being institutionalized. Services covered under waiver programs can include respite care. Generally, every state offers some respite assistance though various home and community-based Medicaid Waivers. Each state's eligibility criteria and funding for waivers is different; check with your state's Medicaid office or visit state information on the [National Respite Locator Service](#). Many states have HCBS waivers that will fund respite for adults with physical disabilities. In 2012, at least 11 states were funding respite through Medicaid waivers that specifically mention traumatic brain injury as a condition of eligibility (GA, IL, IN, KY, MA, MS, NM, NY, ND, PA and SC), and two states fund respite through Medicaid waivers that specifically mention spinal cord injury (MS, SC). (Perrin, 2011)

## National Family Caregiver Support Program

Funding may also be available for caregivers providing care for someone over the age of 60 or someone of any age with Alzheimer's disease or other neurological conditions. The National Family Caregiver Support Program is administered through local Area Agencies on Aging (AAA). The Elder Care locator service at <http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx> provides links to local AAAs.

## Veterans Programs

Veterans eligible for outpatient medical services can also receive non-institutional respite, outpatient geriatric evaluation and management services, and therapeutically-oriented outpatient day care. Respite care may be provided in a home or other non-institutional setting, such as a community nursing home. Ordinarily, respite is limited to no more than 30 days per year. The services can be contracted or provided directly by the staff of the Veterans Health Administration (VHA) or by another provider or payor. A new program administered by the Department of Veterans Affairs, the Family Caregiver Program of the Caregivers and Veterans Omnibus Health Services Act of 2010, provides additional support to eligible post-9/11 veterans who elect to receive their care in a home setting from a primary family caregiver. For more information about the VA Caregiver Support Program, visit the Department of Veterans Affairs website at <http://www.caregiver.va.gov>.

Additional veterans' benefits may exist to provide financial assistance for veterans with neurological conditions. Such benefits could be used to pay for respite or other family caregiver supports. For example, Aid and Attendance and Housebound Benefits are two benefit programs that provide supplemental financial support to veterans with special needs who are receiving general Veterans Benefits (Dougherty, 2012).

## Military Families

Military families should look to the military health insurance program, TRICARE's Extended Care Health Option (ECHO), which includes a respite benefit. The Military Exceptional Family Member Program (EFMP) is another military program that offers respite care to anyone in the military who is enrolled in the EFMP and meets the criteria.

## Lifespan Respite

Since 2009, the Administration on Aging has awarded federal Lifespan Respite grants to 29 states and the District of Columbia. Lifespan Respite grants are awarded to states to implement or enhance

statewide coordinated systems of community-based respite for family caregivers of children and adults. In 2011, the Administration on Aging awarded expansion grants to focus on service delivery to seven of the thirty state Lifespan Respite grantees. Many of the states elected to first begin providing services to individuals who do not qualify for existing public respite resources or funding streams, such as individuals with neurological conditions, or individuals on waiting lists for Medicaid waivers. A few examples are:

- **Nevada's Lifespan Respite Balancing Initiative** establishes a respite voucher program that is directed primarily at under-served populations state-wide. This program provides a reimbursement voucher award to those who qualify of up to a maximum of \$600/year to pay for respite services. High priority will be given to rural caregivers, Hispanic families, and those caring for adult care recipients between ages 18–64. Vouchers can be used to pay for respite services only from a respite program, agency, or facility that the caregiver wants to use for respite (requires approval); a friend, neighbor, or relative who will provide care in the care recipient's home but does not live there themselves; or an independent caregiver/respite provider selected by the family.
- In **North Carolina**, the goal of their one-year expansion project is to sustain the state's "Just One More" initiative to bring new or enhanced respite services to each of NC's 100 counties. Selected public agencies and non-profit organizations that have a history of successfully delivering respite services were awarded mini grants in two areas: direct respite service funding for new recipients across the lifespan; and "Just One More" funding to enhance and/or expand respite in underserved counties. The direct service funding will be targeted to those with incomes slightly above NC's Medicaid threshold who do not qualify for other publicly-funded resources; caregivers whose family member requiring care is between the ages of 18 and 59; caregivers of individuals with a traumatic brain



injury or sudden disabling condition; caregivers whose family member is on a waiting list for CAP services; and, caregivers who live in counties with few or no respite providers.

- **South Carolina** will also target underserved populations for receipt of respite services. The Lt. Governor's Office on Aging is the grant recipient, but project management has been delegated to the SC Respite Coalition. The focus is on family caregivers caring for adults between 18 and 60 years old who are not receiving respite now.

### Federal Traumatic Brain Injury Program

The Federal TBI Program, created by the TBI Act of 1996 (Public Law 104-166) as amended, is designed to improve access to rehabilitation and other services for all individuals with brain injury

and their families through grants to State Agencies and Protection and Advocacy Systems. It resides at the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB) within the U.S. Department of Health and Human Services. The goals of the program focus on helping State and local agencies develop resources so that all individuals with TBI and their families will have accessible, available, acceptable, and appropriate services and supports. For state fact sheets on each of the state grantees, see <http://www.mchb.hrsa.gov/programs/traumaticbraininjury/statefactsheets.html>.

### State Funding

#### State Funded Family Caregiver Support

Some states have state-funded Family Caregiver Support Programs, through which respite may be

### Mississippi Traumatic Brain Injury (TBI)/Spinal Cord Injury (SCI) Trust Fund

In 1996, the Mississippi Legislature established the Traumatic Brain Injury/Traumatic Spinal Cord Injury (TBI/SCI) Trust Fund. The goal of the Trust Fund Program is to assist individuals with severe traumatic spinal cord injury or traumatic brain injury to resume activities of daily living and to reintegrate into the community.

**Eligibility** – Any resident of Mississippi, regardless of age, with severe disabilities resulting from traumatic spinal cord injury or a traumatic brain injury, is eligible for services from the TBI/SCI Trust Fund Program. The Trust Fund Program is the payer of last resort. An individual must seek assistance from all available resources prior to the Trust Fund's participation in a service.

**Funding** – Motor vehicle accidents are the leading cause of both traumatic spinal cord injuries and traumatic brain injuries in Mississippi. Funding for the TBI/SCI Trust Fund is provided through fees and surcharges on moving traffic violations. A \$25 surcharge is collected from every violation of the Mississippi Implied

Consent (Driving Under the Influence) Law, and \$6 from all other moving vehicle violations. Collection of these surcharges began July 1, 1996.

The Trust Fund will support a broad array of services, including respite for a family member or other caregiver that regularly assists the individual of TBI or SCI. Payments are made for the following levels of respite care, based on a physician's determination of need: 1) Companion, 2) Nurse Aide, 3) Licensed Practical Nurse and 4) Registered Nurse. An individual may receive up to 288 hours of respite services per year.

*Traumatic Brain/Spinal Cord Injury Trust Fund Program  
P.O. Box 1698  
Jackson, MS 39215-1698  
Allison Lowther, Coordinator  
601-853-5397  
[alowther@mdrs.ms.gov](mailto:alowther@mdrs.ms.gov)*

available. For more information, visit the Family Caregiver Alliance Family Care Navigator Program at [http://www.caregiver.org/caregiver/jsp/fcn\\_content\\_node.jsp?nodeid=2083](http://www.caregiver.org/caregiver/jsp/fcn_content_node.jsp?nodeid=2083) or the Eldercare Locator at [www.eldercare.gov](http://www.eldercare.gov).

### State Trust Funds for TBI or SCI

A number of states support State Trust Funds (as a payor of last resort) to pay for a broad array of supportive and rehabilitative services, often including respite, for individuals with TBI and/or SCI. The sources of state funds frequently come from surcharges on traffic ticket convictions for speeding, Driving Under the Influence, violations of helmet laws or other moving vehicle violations.

States may have other respite funding sources administered by various state agencies (Dougherty, 2011).

### Private Funding

#### The ALS Association

The ALS Association administers various respite programs to give caregivers of individuals with ALS temporary relief from caregiving. ALS Respite Care is implemented by local ALS Association Chapters that are able to offer it, as well as education and counseling to individuals with ALS and their families about the importance and availability of respite care. While the program is nationally “branded” to provide a consistent quality of care wherever it is offered, individual chapters have options regarding:

- **Reimbursement for services:** Chapters may choose to have families pay for respite services, and then reimburse them for an amount up to the grant maximum; or they may contract with and pay home care or adult day-care agencies to provide respite services.
- **Respite care provider selection:** Chapters may offer any of three options of provider selection to families:

### Examples of the ALS Association Chapters’ Respite Initiatives

ALS Chapters are able provide respite services in ways that are appropriate to their own community resources. Some examples of the many possibilities are:

- **The Rocky Mountain Chapter of the ALS Association** provides \$1,000 per ALS patient each year through its Doris Lakner Respite Care Program, funded through an initial gift of stock from two sisters, in honor of their mother. The Chapter encourages additional financial support for its respite program through fundraising, car donations, and bequests. [http://webco.alsa.org/site/PageNavigator/CO\\_8b\\_respite.html](http://webco.alsa.org/site/PageNavigator/CO_8b_respite.html)
- **The Greater Philadelphia Chapter** provides up to 68 hours of respite in a twelve-month period, with custodial care provided by a home health aide and a potential 90 hours of specialized respite care for patients requiring medical interventions. The program is designed to give caregivers temporary relief for planned events. <http://www.alsphiladelphia.org/page.aspx?pid=286>
- **In Minnesota, North Dakota, eastern South Dakota, and Superior, Wisconsin** the Jack Norton Family Respite Program pays for up to 18 hours of month of respite provided by a contracted respite agency. This program has been in operation since 1998. [http://webmn.alsa.org/site/PageServer?pagename=MN\\_8\\_PS\\_Respite\\_Program](http://webmn.alsa.org/site/PageServer?pagename=MN_8_PS_Respite_Program)
- **The Alabama ALS Chapter** supports respite for family caregivers of individuals with ALS with respite vouchers. Respite grants cover 72 hours of respite care in a 12-month period. The Alabama ALS Chapter was appointed by the Governor to serve on the Alabama Lifespan Respite Coalition. [http://webal.alsa.org/site/PageServer?pagename=AL\\_8\\_patient\\_family\\_services](http://webal.alsa.org/site/PageServer?pagename=AL_8_patient_family_services)

1. The individual with ALS, or his/her family, can select the respite worker or agency of his/her own choosing.
  2. The Chapter can maintain a list of individuals and agencies from whom the patient/family can choose.
  3. The Chapter can contract with agencies that provide respite, and the patient/individual makes a selection from that group.
- **Guidelines to determine who should receive available respite services:** Chapters look at the number of hours per day the primary caregivers devotes to care, the disability level of the person with ALS, the number of additional dependents in the home, the availability of respite care insurance benefits, and the health status of the primary caregiver. The ALS Association suggests a minimum annual budget of \$15,000 per year, which would allow a Chapter to provide 10 to 30 families with individual respite grants of between \$500 and \$1,000.
  - **Funding:** Individual Chapters may fund their respite programs through fundraising, grants from foundations, or specifying a portion of their operating budget toward funding respite care.

### The ALS Association's Care Connection Program

The ALS Association has developed a manual of information about their Care Connection program, providing an easy-to-use guide for individuals interested in creating a Care Connection network. It offers step by step advice for creating a network, setting up and conducting meetings of the persons who will perform the caregiving tasks, dealing with potential issues, and scheduling and communicating using either web-based or paper/telephone systems. This helpful guide is available upon request through local ALS Association chapters.

The ALS Association also supports the Care Connection, networks of individuals who provide assistance with caregiving tasks. The individual with ALS or his/her caregiver identifies one person to serve as a Care Coordinator, who ascertains the needs of the patient and the caregiver, and helps them identify people and local organizations who are willing to perform one or more of the tasks needed. The Care Coordinator schedules these volunteers to cover those tasks. Individual chapters may support these networks, providing training and other assistance to Care Coordinators, who use the Lotsa Helping Hands online community site (discussed above) to organize their networks.

### The National MS Society

The National MS Society's 50-state network of chapters helps people with MS and their families move their lives forward. Many of these chapters serve as important linkages to respite services for family caregivers in the community and often work in partnership with State Lifespan Respite programs to offer assistance and expertise in developing new respite resources. Some National MS Society chapters also help families pay for respite services. For example, the Financial Assistance Program of the Society's National Capital Chapter, serving the Washington, D.C. metropolitan area, offers guidance and financial resources to help contain the financial impact of MS on the family. This chapter leverages resources and offers limited funding for in-home services not covered by insurance or other community programs. In-home services may include personal or companion care or household help, as well as assistance to family caregivers to help pay for a respite stay for their loved one in an assisted living or nursing home facility. Contact the National MS Society at 1-800-344-4867 to see if your local chapter provides such support.

### The Multiple Sclerosis Foundation

The MS Foundation maintains a Home Care Assistance Grant Program, which acts as a liaison between the individual with MS and local services and resources. Available services include in-home care with personal hygiene, light housekeeping,

grocery shopping, meal preparation and transportation; visits by occupational, physical, or speech therapists; transition care when returning from a hospital to home; and respite care. Respite is provided on a short-term basis at scheduled times. Where resources are not available in the community, the program can also provide direct support on a temporary basis.

Individuals can complete an application for this program online or via postal mail. A Home Care Coordinator will then assess the needs of the individual and determine what services can be provided directly or through referral. For more information, call 888-MSFOCUS (888-673-6287) or see the online application at <http://www.msfocus.org/Homecare-Grant-Program.aspx>.

### **Alabama Head Injury Foundation**

The Alabama Head Injury Foundation makes funds available for caregivers of persons disabled by traumatic brain injury and/or spinal cord injury. The foundation is appointed by the Governor to serve on the Alabama Lifespan Respite Coalition. <http://www.ahif.org/services.htm#respite>

### **Recommended Strategies**

Expanding respite options and improving respite access, appropriateness, acceptance and cultural relevance for those caring for individuals with neurological conditions will take the work and expertise of health professionals, government agencies, community providers and many others diligently working in partnership with family caregivers. There are steps that Lifespan Respite Programs, state organizations and respite coalitions, respite providers and even family caregivers can take to improve the situation. For more detail, see “Respite Considerations” above.

#### **For State Lifespan Respite Programs:**

1. Grantees, charged with public education and education of family caregivers, can take the lead in bringing experts together to develop public awareness and education materials that

focus on the special needs of individuals with neurological conditions.

2. While conducting needs assessments in your states to identify service gaps, include questions to determine the specific barriers to respite for this distinct population and work toward strategies to overcome these barriers.
3. In developing training materials to recruit and train respite providers and volunteers, seek expertise from the health professional community, from condition specific organizations such as the Epilepsy Foundation, the National MS Society and the ALS Association and their state chapters, and family caregivers, to develop training modules that will result in more respite providers able to serve this population. Specifically, train providers and caseworkers to respect the dignity of the client and their family and be well trained to provide the medical support necessary for individuals who are more medically involved. Include family caregivers as part of the training team for professionals.
4. Offer participant-directed respite so that family caregivers have greater choice in hiring and training their own providers from their trusted communities of support.
5. In increasing the overall capacity of respite services and options, help develop out-of-home adult day or overnight respite opportunities that are age-appropriate for this population, a significant number of whom are under age 60.
6. Train family caregivers to recognize the warning signs of burnout and how to recognize when the person in their care may be in need of additional care.
7. Develop training programs for peer mentors to assist other family caregivers having similar caregiving experiences. They understand what others coping with neurological conditions are experiencing.

### **For Respite Programs, Community Agencies, and Health Care Providers:**

1. When looking for volunteers to assist in respite service delivery, consider reaching out to university or community college students who are pursuing careers in the nursing or health field or look to state professional associations to find volunteers with experience in working with individuals with neurological conditions.
2. Develop and use training modules that educate the respite workforce in the special needs and concerns of individuals with neurological conditions and their caregivers and offer additional supports to encourage respite workers to engage with this population.
3. Include family caregivers as a member of the consumer's support team and encourage their input in the development of individual service plans.

### **For State Public Health Agencies or State Respite Coalitions:**

1. Provide information sessions for family members focused on particular neurological conditions, what to expect, and how to seek support.
2. Engage your state chapters of professional and membership associations that advocate for individuals with neurological conditions for guidance and oversight.
3. Encourage State affiliates of organizations representing individuals with neurological conditions to co-sponsor educational events that allow for caregiver/care recipient feedback and input.

### **For Family Caregivers**

1. Become involved with your state Respite Coalition and/or your State Lifespan Respite Program to share input regarding your specific respite needs.
2. Seek support and information from your state chapters of the organizations that represent specific neurological conditions, such as the Brain Injury Association, the Epilepsy

Foundation, the National MS Society, the ALS Association and others.

3. If your state programs are already working on these issues, stay involved to offer your expertise and input as new respite services are developed and new providers are trained and recruited.
4. Seek support and use respite early and as often as appropriate!

## **Conclusion**

Individuals with neurological conditions and their family caregivers have long been under served in terms of respite and other family caregiver supports. Respite care can give the caregiver the time and assistance needed to meet personal needs as well as other responsibilities. Respite benefits both the caregiver and the care receiver. Whether a caregiver receives respite in the home or outside the home, the individuality of the person being cared for needs to be taken into consideration to make the respite experience successful for both the respite provider and the person with a neurological condition.

## **Resources**

The following resources may be helpful to Lifespan Respite Programs, respite providers, mental health consumers and their family caregivers.

### **General**

#### **Medline**

*A Service of the U.S. National Library of Medicine*

**National Institutes of Health**

*Neurologic Diseases*

<http://www.nlm.nih.gov/medlineplus/neurologicdiseases.html>

#### **National Institute of Neurological Disorders and Stroke (NINDS)**

**National Institutes of Health**

[http://www.ninds.nih.gov/disorders/disorder\\_index.htm](http://www.ninds.nih.gov/disorders/disorder_index.htm)



For information on specific disorders, visit the NINDS website, select the disorder, and follow links provided to organizations devoted to each disease.

## Condition-Specific

### Amyotrophic Lateral Sclerosis (ALS)

#### **The ALS Association**

1275 K Street NW, Suite 1050

Washington, DC 20005

Phone: 202-407-8580

Fax: 202-289-6801

Email: [alsinfo@alsa-national.org](mailto:alsinfo@alsa-national.org)

Website: <http://www.alsa.org>

**For Caregivers:** <http://www.alsa.org/als-care/caregivers>

Established in 1985, The ALS Association is the only national non-profit organization fighting Lou Gehrig's Disease. The mission of The ALS Association is to lead the fight to treat and cure ALS through global research and nationwide advocacy, while also empowering people with Lou Gehrig's Disease and their families to live fuller lives by providing them with compassionate care and support. The Association's nationwide network of chapters provides comprehensive patient services and support to the ALS community.

### Epilepsy

#### **Epilepsy Foundation**

8301 Professional Place

Landover, MD 20785-7223

Phone: 1-800-332-1000

Email: [ContactUs@efa.org](mailto:ContactUs@efa.org)

Website: <http://www.epilepsyfoundation.org>

**For Caregivers:** <http://www.epilepsyfoundation.org/livingwiththeepilepsy/parentsandcaregivers/caregivers/index.cfm>

**Friends, Family & Loved Ones Forum:** <http://epilepsyfoundation.ning.com/forum/categories/friends-family-loved-ones/listForCategory>

The Epilepsy Foundation of America® is the national voluntary agency dedicated solely to the welfare of the almost 3 million people with epilepsy in the U.S. and their families. The organization works

to ensure that people with seizures are able to participate in all life experiences; to improve how people with epilepsy are perceived, accepted and valued in society; and to promote research for a cure. In addition to programs conducted at the national level, epilepsy clients throughout the United States are served by 48 Epilepsy Foundation affiliates around the country.

### Huntington's Disease

#### **Huntington's Disease Society of America (HDSA)**

Email: <http://www.hdsa.org/contact-us.html>

Website: <http://www.hdsa.org>

**For Caregivers:** <http://www.hdsa.org/living-with-huntingtons/family-care/caregivers.html>

HDSA is national non-profit voluntary health agency dedicated to finding a cure for Huntington's Disease. HDSA provides support, information and educational services to improve the lives of those affected by HD, offers resources and guidance for HD families through a national network of volunteer-based chapters and affiliates as well as through our HDSA Centers of Excellence for Family Services, and promotes and supports research to find a cure for HD.

### Multiple Sclerosis

#### **National MS Society**

733 Third Ave

3rd Floor

New York, NY 10017

Phone: 800-344-4867 (800-FIGHT MS)

Email: [ContactUsNMSS@nmss.org](mailto:ContactUsNMSS@nmss.org)

Website: <http://www.nationalMSsociety.org>

**MS Connection:** <http://www.msconnection.org>

MS Connection is an online community that allows you to find, store and share meaningful updates, posts, videos, articles and other content about MS and the topics you care about most. Connect with

people, groups and discussions that relate to the topics that shape your world.

**A Guide for Caregivers: Managing Major Changes**

[www.nationalmssociety.org/download.aspx?id=155](http://www.nationalmssociety.org/download.aspx?id=155)

**Caring for Loved Ones with Advanced MS: A Guide for Families**

[www.nationalmssociety.org/download.aspx?id=789](http://www.nationalmssociety.org/download.aspx?id=789)

The National MS Society addresses the challenges of each person affected by MS. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides programs and services designed to help people with MS and their families move forward with their lives.

### Parkinson's Disease

**National Parkinson Foundation (NPF)**

1501 N.W. 9th Ave/Bob Hope Rd  
Miami, FL 33136-1494

Phone: 800-4PD-INFO (473-4636) Helpline  
305-243-6666/800-327-4545  
Headquarters

Fax: 305-243-6073

Email: [contact@parkinson.org](mailto:contact@parkinson.org)

Website: <http://www.parkinson.org>

NPF's global network includes: 43 Centers of Excellence at top medical centers across the globe, including 28 in the U.S. and 15 internationally; 14 Care Centers at leading community hospitals in North America; 39 U.S. chapters and 900 support groups serving 100,000 people with Parkinson's and their families.

Guide for Caregivers: **The Michael J. Fox Foundation for Parkinson's Research**

<https://www.michaeljfox.org/understanding-parkinsons/supporting-caregiving.php>

### Spinal Cord Injury

**Christopher & Dana Reeve Foundation**

636 Morris Turnpike

Suite 3A

Short Hills, NJ 07078

Phone: 800-225-0292

Email: [prc@ChristopherReeve.org](mailto:prc@ChristopherReeve.org)

Website: <http://www.christopherreeve.org>

**Spinal Cord Injury and Paralysis Community:**

[http://www.spinalcordinjury-paralysis.org/app/render/go.aspx?xsl=tp\\_community.xslt](http://www.spinalcordinjury-paralysis.org/app/render/go.aspx?xsl=tp_community.xslt)

The Reeve Foundation is dedicated to curing spinal cord injury by funding innovative research, and improving the quality of life for people living with paralysis through grants, information and advocacy.

**United Spinal Association**

75-20 Astoria Blvd.

East Elmhurst, NY 11370

Toll-free: 800-404-2898

Phone: 718-803-3782

E-mail: [info@unitedspinal.org](mailto:info@unitedspinal.org)

Website: <http://www.unitedspinal.org>

United Spinal Association's mission is to improve the quality of life of all people living with spinal cord injuries and disorders (SCI/D). United Spinal is the largest non-profit organization dedicated to helping people living with SCI/D. They provide active-lifestyle information, peer support and advocacy that empower individuals to achieve their highest potential in all facets of life. National Spinal Cord Injury Association (NSCIA) is the membership arm of the organization.

### Stroke

**American Stroke Association (ASA)**

7272 Greenville Ave.

Dallas, TX 75231

Phone: 888-4-STROKE (888-478-7653)

Website: <http://www.strokeassociation.org>

**For Family Caregivers:** [http://www.](http://www.strokeassociation.org/STROKEORG/LifeAfterStroke/ForFamilyCaregivers/For-Family-Caregivers_UCM_308560_SubHomePage.jsp)

[strokeassociation.org/STROKEORG/](http://www.strokeassociation.org/STROKEORG/LifeAfterStroke/ForFamilyCaregivers/For-Family-Caregivers_UCM_308560_SubHomePage.jsp)

[LifeAfterStroke/ForFamilyCaregivers/For-Family-Caregivers\\_UCM\\_308560\\_SubHomePage.jsp](http://www.strokeassociation.org/STROKEORG/LifeAfterStroke/ForFamilyCaregivers/For-Family-Caregivers_UCM_308560_SubHomePage.jsp)

Created in 1997, the American Stroke Association is dedicated to prevention, diagnosis and treatment to save lives from stroke – America’s No. 4 killer and a leading cause of serious disability. ASA funds scientific research, helps people better understand and avoid stroke, encourages government support, guides healthcare professionals and provides information to enhance the quality of life for stroke survivors.

### Traumatic Brain Injury

#### **Brain Injury Association of America (BIAA)**

1608 Spring Hill Road, Suite 110

Vienna, VA 22182

Phone: 703-761-0750

Fax: 703-761-0755

Email: [info@biausa.org](mailto:info@biausa.org)

Website: <http://www.biausa.org>

**Family and Caregivers:** <http://www.biausa.org/brain-injury-family-caregivers.htm>

The Brain Injury Association of America (BIAA) is the country’s oldest and largest nationwide brain injury advocacy organization. Their mission is to be the voice of brain injury through advocacy, education and research. To locate your state’s chapter of the Brain Injury Association of America’s, visit the online listing of state affiliates at <http://www.biausa.org/state-affiliates.htm>

#### **National Association of State Head Injury Administrators (Nashia)**

PO Box 878

Waitsfield, Vermont 05673

Phone: 802-498-3349

Fax: 773-945-2341

Email: [execdirector@nashia.org](mailto:execdirector@nashia.org)

Nashia’s mission is to assist state governments in promoting partnerships and building systems to meet the needs of individuals with brain injuries and their families.

**Caregiver Guides:** Center of Excellence for Medical Multimedia Defense Health Board  
<http://www.traumaticbraininjuryatoz.org/getdoc/d79e7156-01be-407c-802b-aa530b1adff3/Caregivers-Guides.aspx>

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