



The Technical Assistance Center for Lifespan Respite Fact Sheet Number 55, July 2014

Respite for Family Caregivers of Persons with Dementia, including Alzheimer's Disease

Introduction

Alzheimer's and related dementias affect millions of people in the U.S. and their families. While some dementia is reversible with proper treatment, Alzheimer's disease is currently incurable and is now the 6th leading cause of death. The 2014 Alzheimer's Disease Facts and Figures produced by the Alzheimer's Association estimates that 5.2 million Americans have Alzheimer's disease, including about 200,000 people who are younger than 65 (Alzheimer's Association, 2014).

Dementias, including Alzheimer's disease, affect a person's ability to communicate and perform everyday activities such as cooking, paying bills, bathing and dressing. Consequently, a diagnosis can result in tremendous physical, psychological and financial stress in the family. Respite care provides temporary relief from such stress and exhaustion, and may ultimately delay nursing home admission.

This fact sheet has been produced to guide the development of high-quality respite for caregivers of persons with Alzheimer's disease and related dementias. It provides background for respite providers and will also help Lifespan Respite grantees better understand the unique needs of this population. Consequently, State Lifespan Respite programs and others will be better positioned to create strategies that address these needs and thereby increase respite access and quality. Family caregivers may also find useful resources here.

What are Alzheimer's Disease and Related Dementias?

The term dementia refers to diseases and conditions characterized by damage to neurons (nerve cells) in the brain. The result of these brain abnormalities is the decline in memory or other thinking skills. Many conditions and diseases cause dementia. The two most prevalent causes are Alzheimer's disease and vascular dementia, a disruption of the blood supply to the brain often caused by a series of strokes.

Alzheimer's disease was first identified more than 100 years ago and currently accounts for 50 to 80 percent of dementia cases. It is a progressive brain disorder that damages and eventually destroys brain cells impacting all brain functions. In a healthy brain, neurons contain long extensions called synapses. The synapses connect neurons together through chemical bursts allowing information and signals to travel through the brain. Alzheimer's disease interferes with the proper functioning of neurons and synapses. Common symptoms include difficulty remembering recent events; challenges in planning and problem solving; inability to complete familiar tasks; confusion about objects, time and place; difficulty selecting words; misplacing items; and impaired judgment.

The Alzheimer's Association identifies the following changes as causing a devastating impact on the functioning of the brain:

- **Plaques** – microscopic clumps of a protein called beta-amyloid peptide outside the neurons in the brain are believed to interfere with neuron communication and contribute to cell death.
- **Tangles** – twisted microscopic strands of the abnormal protein tau inside the brain block transport of nutrients to the neurons.
- **Loss of synapses** – or connections – which transmit information from cell to cell.
- **Inflammation in the brain.**
- **Death of brain cells and severe tissue shrinkage** (Alzheimer's Association, 2014).

Scientists are currently working on ways to diagnose Alzheimer's earlier and more accurately. It is important for respite providers and family caregivers to understand that many conditions may mimic the symptoms of Alzheimer's disease and may be reversible, including chronic alcoholism, depression, vitamin B₁₂ deficiency, tumors, medication interactions, and infections. There are several steps to make a fairly accurate diagnosis and this process may be repeated to assess changes over time. The Alzheimer's Disease Research Centers located at major medical institutions across the country, and funded by the National Institute on Aging, can diagnose and treat persons with dementia, including Alzheimer's disease. Steps for diagnosing dementia and Alzheimer's include the following:

- Completing a thorough case history to explore medical problems and changes in daily activities, behavior and personality;
- Conducting tests of memory, problem solving, and language;
- Administering standard medical tests, such as blood and urine tests; and
- Performing brain scans (National Institute on Aging, nd).

Prevalence and Characteristics

Prevalence

Today, 20 million people are impacted by Alzheimer's disease. More than five million, or one in nine older Americans, are diagnosed with the disease, and more than 15 million caregivers are supporting them (Alzheimer's Association, 2014). Two-thirds of individuals with Alzheimer's and 60% of caregivers are women. African Americans are two times more likely and Hispanics are one-and-a-half times more likely to be diagnosed than whites (Alzheimer's Association, 2013).

Two important developments are converging to impact prevalence data. First, in 2011, the National Institute on Aging and the Alzheimer's Association issued new diagnosis guidelines that may substantially increase this estimate by calling for research to identify people with pre-clinical Alzheimer's changes in the brain. Second, the risk of Alzheimer's increases with age, and the U.S. population is aging. Baby boomers are moving into the age range where Alzheimer's disease is more prevalent. In fact, by 2050, the number of people age 65 and older with Alzheimer's disease may nearly triple, from 5 million today to as many as 16 million, barring the discovery of a cure (Alzheimer's Association, 2014).

Another population group that is hard hit by Alzheimer's disease and related disorders is persons with intellectual disabilities, especially Down syndrome. These individuals are living longer than they did even a few decades ago and are at increased risk for developing dementia as a result. They also are more likely to develop younger-onset Alzheimer's. In fact, postmortem tests reveal that by age 40, the brains of almost all individuals with Down syndrome have significant levels of plaques and tangles and abnormal protein deposits considered Alzheimer's hallmarks (Alzheimer's Association, nd).

It has been projected that there may be at least 54,000 adults with both an intellectual disability and cognitive decline in the United States. For

adults with Down syndrome, studies show that at least 25% of will be affected with dementia after age 40 and at least 50 to 70% will be affected with dementia after age 60 (Keller, 2013).

According to the National Task Group on Intellectual Disabilities and Dementia Practice, about 33,000 adults with developmental disabilities and dementia are currently living at home with older family caregivers (Jokinen, et al, 2012). While these numbers may pale in comparison to the 5.2 million estimated to have Alzheimer's in the general population, this group with high dependencies will have significant impacts on caregivers.

In light of these demographic trends, the federal government and private organizations have committed to building a national response to Alzheimer's disease, emphasizing the coordination of the country's approach to research, treatment and caregiving. The passage of the National Alzheimer's Project Act (NAPA) in 2011 offers an historic opportunity to address the many challenges facing families and people with Alzheimer's disease and related disorders. It requires the Department of Health and Human Services (HHS) to establish the National Alzheimer's Plan to overcome Alzheimer's disease, with input from a public-private Advisory Council on Alzheimer's Research, Care and Services. To inform the National Plan, HHS has partnered with the Department of Veterans Affairs, the National Science Foundation, and the Department of Defense to convene an Interagency Group on Alzheimer's Disease and Related Dementias. The group includes HHS representatives from the Office of the Assistant Secretary for Planning and Evaluation, Office of the Assistant Secretary for Health, National Institute on Aging, Centers for Medicare and Medicaid Services, Centers for Disease Control and Prevention, Administration on Aging, Health Resources and Services Administration, Agency for Healthcare Research and Quality, Substance Abuse and Mental Health Services Administration, Food and Drug Administration, Indian Health Service, and Administration for Children and Families.

Characteristics

In April 2011, the National Institute on Aging/ Alzheimer's Association Diagnostic Guidelines for Alzheimer's Disease were released. The guidelines expanded the definition of Alzheimer's to include (1) pre-symptomatic; (2) mild cognitive impairment; and (3) dementia caused by Alzheimer's. Scientists believe Alzheimer's begins causing measurable changes in the brains of affected people years, perhaps decades, before memory and thinking symptoms are noticeable. The new guidelines reflect a stronger link between changes in the brain and the disease progression and symptoms.

Prior to the issuance of these new guidelines, Alzheimer's was generally divided into three broad stages: early, middle and late. These stages were based on the individual's abilities to function. Despite the new guidelines, many care providers still use these broad categories to describe the progression of the disease. While the progression of Alzheimer's disease and the order of symptoms may vary from person to person, the following characteristics are most common as described in the National Institute on Aging publication, *Alzheimer's Disease: Unraveling the Mystery*.

Mild Alzheimer's disease

In mild Alzheimer's Disease, a person may appear to be healthy, but is actually experiencing increasing trouble making sense of the world around him or her. The realization that something is wrong often comes gradually to the person and his or her family. Persons with Alzheimer's disease have a number of challenging questions to face in the early stages of the disease. Who do you tell? How do you prepare for the changes that will occur? Are clinical trials right for you? To answer these questions and others, early-onset support groups and information from resource organizations may be helpful. Some characteristics include:

- Memory loss
- Confusion about location
- Taking longer than before to accomplish normal daily tasks

- Trouble handling money and paying bills
- Poor judgment leading to bad decisions
- Loss of spontaneity and initiative
- Mood and personality changes, including increased anxiety and/or aggression

Moderate Alzheimer's Disease

During this stage, the damage impacts language, reasoning, and thinking. Signs and symptoms of the disease become more pronounced and widespread. More intensive supervision and care become necessary. Eventually persons with Alzheimer's may become aggressive, angry, withdrawn or depressed. They may feel lost in familiar surroundings. These behavioral symptoms of dementia are a form of communication. The person with dementia may be experiencing untreated pain, discomfort or fear and communicating distress through their behaviors. As symptoms worsen, they may need help with daily personal activities. Characteristics can include:

- Increasing confusion and memory decline
- Language difficulties and problems with reading, writing and math
- Outbursts of anger
- Problems recognizing friends and family members
- Repeating statements, questions, or movement
- Inability to learn and understand new information and situations
- Restlessness, agitation, anxiety, tearfulness, and wandering in the evenings, also known as sundowning
- Suspiciousness or paranoia and irritability
- Loss of impulse control (undressing at inappropriate times or vulgar language)
- An inability to carry out a task involving multiple steps

Severe Alzheimer's Disease

In the last stage, people with Alzheimer's generally do not recognize family and loved ones. They are completely dependent on others for care. The

person may be in bed much or all of the time. When a person is not able to swallow properly, food or liquids enter the lungs instead of air resulting in death. This is the most frequent cause of death for persons diagnosed with Alzheimer's. Characteristics can include:

- Weight loss
- Seizures
- Skin infections
- Difficulty swallowing
- Groaning, moaning, or grunting
- Increased sleeping
- Lack of bladder and bowel control

Challenges Facing Individuals with Alzheimer's and Their Families

Being diagnosed with Alzheimer's disease or dementia can be frightening for the individual and their families. The diagnosis evokes numerous emotions and, over time, demands changes in daily activities and future plans. Spouses may feel abandoned; adult children may feel overwhelmed; other family and friends may feel helpless; and the person with Alzheimer's may be sad, confused and angry. People living with Alzheimer's must learn how to maximize their independence for as long as possible. They may react differently as they watch familiar people, places and things fade away.

The challenges faced by caregivers can be tremendous as well. Unpaid caregivers are sometimes referred to as the invisible victims of dementia. Yet their contribution to the care of persons with Alzheimer's is extensive. They assist with scheduling care, maintaining medical records, administering medication, completing home health chores, financing care when necessary, and more. All of this is done while they watch someone they love decline. In 2013, 15.5 million family and friends provided 17.7 billion hours of unpaid care to those with Alzheimer's and other dementias – care valued at \$220.2 billion (Alzheimer's Association, 2014).

Caregivers of persons with Alzheimer's also tend to be spouses and may be older and frailer than other caregivers, while the type of care provided can be intense and physically demanding. More than half of caregivers (54 percent) report providing help getting in and out of bed, compared to 42 percent of other caregivers of elders. About one third (32 percent) provide help getting to and from the toilet, compared to 26 percent for other caregivers. Thirty-one percent assist with eating, compared to 14 percent of caregivers of other older people (National Alliance for Caregiving, 2009 Unpublished).

Women are hit particularly hard. They are more likely than men to be the caregivers and care receivers. At age 65, women have more than a one-in-six chance of developing Alzheimer's while men have a one-in-11 chance. Women also have more intense caregiving responsibilities over a longer period of time. In fact, there are 2.5 times as many women providing 24-hour care than men. Similarly, 2.3 times more women than men have been providing care for more than five years. Consequently, women's jobs are also more likely to be impacted by caregiving responsibilities. Nearly 19 percent of female Alzheimer's caregivers had to quit work either to become a full-time caregiver or because their caregiving duties became too burdensome (Alzheimer's Association, March 2014).

Yet caregivers of individuals with dementia are not getting the support they need. Findings from the *Maximizing Independence at Home Study* at Johns Hopkins University reports on a survey of persons with dementia and their caregivers. More than 85% of caregivers had unmet needs for referrals to community resources (e.g., Alzheimer's Association) and caregiver education. Almost half (45%) of caregivers had unmet needs in the area of mental health, "most of whom needed emotional support or respite care" (Black, et al, 2013).

For family caregivers of individuals with Down's syndrome, caregiving may be lifelong and require considerable support. If the care recipient develops Alzheimer's or dementia, the need for support becomes even more pronounced. As parents age,

caregiving may become more difficult as their own health concerns become prominent and concerns escalate about what will happen to their children when they are gone. Siblings frequently step into the caregiving roles when parents can no longer do so. Many of these caregivers are caring for families of their own (Neill, 2007).

In 2014, \$214 billion will be spent to care for those with Alzheimer's, including \$150 billion in Medicare and Medicaid dollars. In fact, almost 20 percent of Medicare spending goes to care for people with Alzheimer's or another dementia. Average per person Medicaid spending for seniors with Alzheimer's and other dementias is 19 times higher than average per person Medicaid spending for all other seniors. According to a 2013 Rand Study, the driving costs of Alzheimer's disease are related to nonmedical expenses (Hurd, 2013). With the aging of the Baby Boomers, the cost of care is expected to increase to an estimated \$1.2 trillion (in today's dollars) in 2050 (Alzheimer's Association, 2014).

Barriers to Respite

Despite the fact that providing care and support for someone with dementia has been associated with significant physical and psychological stresses for primary caregivers, studies have shown that these caregivers tend to underutilize and/or delay the use of respite services (Phillipson & Jones, 2011). The cost of respite can also be a significant barrier, especially if families are already experiencing significant costs related to providing health and supplemental ancillary services for the person in their care. However, feelings of loss of control, sadness, guilt, and a sense of failure if respite care is needed has been documented among family caregivers of individuals with dementia (Cangelosi, 2009). A number of common barriers that might exacerbate these feelings and impact access to respite services are listed below. However, staff working in each state are encouraged to identify barriers that are specific to their geographic region and to the families they serve.

Provider Shortages

Family caregivers who perceive a lack of continuity of care due to the limited availability of providers may forego respite. The difficulty in finding respite providers when and where they are needed is a significant access barrier.

The critical shortage of long term care workers is approaching crisis proportions in the United States. As our population ages, the number of people needing long term care also increases. It is estimated that by 2030, 3.5 million additional health care professionals and direct-care workers will be needed. As people with Alzheimer's disease or a related dementia represent about half of the older persons who need long term care, this reality is particularly challenging because of their need for specialized, direct care (Alzheimer's Association, November 2012).

Limited and Inadequate Provider Training

Persons with Alzheimer's or dementia and their families have unique needs. Caregivers are often particularly concerned with the safety of the person in their care and want to be assured of the provider's training and qualifications. Consequently, respite workers should understand the unique characteristics of the disease and the types of interventions that best address the needs of the person with dementia. However, training requirements vary greatly from state to state.

Training is needed that supports effective communication strategies, behavior management and re-directing, understanding the disease process, managing daily activities, and safety. Training programs should be built on person-centered principles that help each person with dementia, including Alzheimer's disease, live the best quality life in a supportive and safe environment where their capabilities can be maximized. Person-centered principles include a focus on the individual, their strengths, their valued social roles, and their network of family and community support. Unfortunately, many respite and other personal care

aides may not receive adequate training to care for persons with dementia including Alzheimer's.

Identifying Persons with Dementia, Including Alzheimer's Disease

Too often, persons with Alzheimer's disease and other dementias are not identified when symptoms first appear. Many patients and caregivers attempt to hide the disease for as long as possible due to shame and fear. This delay prevents early diagnosis, treatment and support. Caregivers often do not reach out for respite care until they are approaching burnout. Agencies must be able to identify these conditions, as individuals rarely self-identify as having dementia. Respite providers need tools to recognize and objectively screen seniors who appear to be experiencing memory loss. Protocols must be developed to refer persons who may have dementia to partner organizations that can provide professional assessments.

Complicating the caregiving scenario for individuals with Down's syndrome who are also in cognitive decline, is that despite the presence of brain changes indicative of Alzheimer's disease, not everyone with Down's syndrome develops Alzheimer's symptoms. When they do, it may be hard to distinguish from similar symptoms of Down's syndrome. As a result, early specialized screening is highly recommended (Neill, 2007).

Cultural Barriers

Alzheimer's disease is more common in communities of color, but individuals are more frequently diagnosed at a later stage. Alzheimer's disease is also a very different experience in these communities. Cultural beliefs about the disease differ from the mainstream culture. For multi-cultural communities, issues such as trust, access, cultural beliefs, and lack of knowledge about the disease result in barriers to respite utilization. In addition, language barriers and family role expectations interfere with respite utilization.

For example, a qualitative study conducted by AARP Public Policy Institute in 2012 found that Hispanic

family caregivers said they always knew they would be a caregiver in some capacity and that providing care for someone as they get older is a cultural tradition and that they would never consider putting their loved one in a nursing home. However, Spanish-speaking Hispanic family caregivers identified language as a major barrier. In hospital settings, many family caregivers believed they were treated poorly because they were Hispanic (Reinhard & Choula, 2012).

Workers must understand how the multi-cultural audiences they serve view the disease. Often before services can be accepted, the provider must deal with the myths associated with dementias. In addition, family care patterns vary greatly and must be respected. Training is needed in this area in order for providers to successfully reach and serve these populations (Weiner & Mitchell, 2007).

Rural Communities

Rural areas have unique strengths, resources, and challenges. Typically the population is older, somewhat poorer and relies more on Medicaid and Medicare when compared to non-rural communities (Kagan, 2012). Yet, in many rural communities, respite options are extremely limited. The geographic distance and sparse population make it difficult for respite providers to offer services. As a result, only four percent of rural caregivers use respite services compared with five percent of their urban and suburban counterparts. Only three percent of rural caregivers use adult day services, compared to eight percent of urban caregivers and six percent of suburban caregivers (National Alliance for Caregiving and Easter Seals, 2006).

Transportation

Transportation can be a limiting factor for accessing respite for all family caregivers, especially in rural areas where travel distances may be prohibitive or in urban environments where use of public transportation for individuals with Alzheimer's and related disorders may be too stressful. Transportation can be especially problematic for individuals with dementia, who may become agitated, anxious or

confused when being transported, making the ride to respite care a stressful experience for all involved (Easter Seals Transportation Group and Everline Consulting, LLC, 2012).

Respite Program Considerations

When developing or enhancing respite services or improving access to such services, considerations about maximizing the benefits and acceptability of respite for family caregivers, enhancing the health and well-being of the care recipient, concerns about respite quality and safety, and ensuring that services are able to meet the specific needs raised by Alzheimer's disease and dementia, must all be taken into account.

Making the Most of Respite Time for Family Caregivers

Providing a break for caregivers can happen in a number of ways. The caregiver's unique needs should be taken into account when developing new respite options, referring a family caregiver to respite, or helping them maximize use of respite. Research shows that respite that allows and encourages family caregivers to use their respite time in ways most meaningful for them has more long-lasting benefits in terms of stress reduction and improved well-being. Options that maximize this possibility through flexible scheduling and affordability may prove especially useful to family caregivers of individuals with dementia. In addition, providers can help caregivers by teaching them to re-capture or substitute activities during respite that have been lost because of caregiving (Lund, 2011).

Ensuring that respite is planned and occurs in sufficient amounts of time also may help enhance the effectiveness of respite in reducing stress levels of family caregivers of persons with dementia over the long-run. Researchers have identified that there may be a minimum number of hours of respite necessary each week to have a longer lasting impact on family caregiver stress levels, especially for those caring for someone with Alzheimer's disease, and that these respite hours should be available on a

consistent and regular basis so that family caregivers can count on this time (Zarit, et al, 1998).

As importantly, providing a range of respite options that promote flexibility and responsiveness to the needs of family caregivers may increase a caregiver's acceptance and utilization of respite services. The preference for a particular type of respite (in-home, out-of-home, consumer-directed, day or overnight care) may change over time or even from one week to the next for the care recipient as well as the caregiver. Overnight care is in especially short supply and is usually only provided in institutional settings. **Hebrew Home in Riverdale, NY**, provides overnight care to allow exhausted family caregivers the opportunity for a full-night's sleep. An example of a unique non-institutional overnight respite opportunity, **Family Caregiver Alliance of San Francisco** offers **Camp for Caring**, a weekend retreat for individuals with Alzheimer's disease, stroke, Parkinson's disease or a

related disorder. Trained staff and volunteers care for these individuals in a scenic bay area setting near San Francisco (<https://caregiver.org/camp-caring-fca>).

Sometimes just providing a little encouragement and giving the family caregiver the chance to "check out" a respite service may be enough to help them incorporate regular respite time into their caregiving routines. For example, **Range Respite in Minnesota** provides scholarships for 15 hours of respite care to first-time family caregivers of this population. The scholarships allow hesitant caregivers to try respite care before committing to its use.

Programs that specifically address language or cultural considerations or are provided directly by the primary cultural group may also help to invite and encourage family caregivers from multicultural groups to seek out respite services. At the Respite Program for older adults with physical and cognitive disabilities or impairments run by **ACC Senior Services in Sacramento, CA**, Cantonese, English, Hindi, Hmong, Mandarin, Spanish, and Tagalog are spoken by staff and volunteers to ensure communication with participants and family members. As a respite cooperative, family members are actively engaged and participate by volunteering one day a month (<http://www.accsv.org/support-services/respite-care.php>).

Promising Practices: Overnight Respite

The Hebrew Home at Riverdale. Located in Riverdale, New York, the Hebrew Home offers "ElderServe at Night," a unique overnight respite program for individuals with Alzheimer's disease and other dementias, who require constant night-time supervision. Transportation is provided to the center where they spend the overnight hours under medical supervision, engaged in activities and rest, allowing their caregivers a full night of sleep. Anecdotal reports suggest that the program has benefited family caregivers as well as care recipients, and delayed the placement of some individuals into nursing homes. (<http://www.hebrewhome.org/day-night-programs2.asp>) This program is highlighted in the Agency for Health Care Research and Quality Innovations Exchange at <http://www.innovations.ahrq.gov/content.aspx?id=2662>.

Enhancing the Respite Experience for Care Recipients

For family caregivers reluctant to use respite, demonstrating that respite is beneficial and even enjoyable for the care recipient socially, therapeutically, and even creatively, may go a long way to encourage respite use. Moving from a medical model of respite focused on deficits, more ability-based approaches that allow creative expression and enhance the well-being of the care recipient may be good for the caregiver's acceptance of respite. Some resources for helping respite providers and programs to engage care recipients in music, the arts and other cultural experiences while in respite care include:

- **Culture Bus, Inside and Out, run by CJE SeniorLife, Chicago, IL** offers older adults with early Alzheimer's or other forms of early-stage dementia stimulation, education and recreation through art, drama, history, music, dance, architecture and more. A concept of CJE SeniorLife and Northwestern University's Cognitive Neurology and Alzheimer's Disease Center, Culture Bus participants socialize with peers at a combination of weekly programs and day trips to various cultural sites and events in metropolitan Chicago and nearby suburbs, providing family caregivers time off for their own respite. Culture Bus is a recipient of the Family Caregiver Alliance Rosalinde Gilbert Innovation in Alzheimer's Disease Caregiving Legacy Award. For more information: <http://www.cje.net/assisted-living/weinberg-community-senior-living/friend-center/culture-bus%E2%84%A2>
- **The New York Metropolitan Museum of Art (MoMA) Alzheimer's Project** is the national and international expansion of the Museum's outreach program for individuals living with Alzheimer's disease and other forms of dementia as well as their caregivers. Funded by a major grant from MetLife Foundation, The MoMA Alzheimer's Project broadens the reach of MoMA's programming through the development of resources that can be used by museums, assisted-living facilities, and other community organizations serving people with dementia and their caregivers. For more information on available resources to help develop the program locally, see <http://www.moma.org/meetme/index>.

Additional resources can be found through the **National Center for Creative Aging** and the **Family Caregiver Alliance**. (See Resources section.)

Quality, Safe and Dementia-Capable Respite Services

The quality and safety of available respite options are also of paramount concern to family caregivers. National Respite Guidelines have been developed by ARCH to encourage best practices in respite service delivery (Edgar and Uhl, 2011). Respite or adult day services that employ activities or therapeutic services that help to reduce behavioral challenges or memory issues and improve sleep and overall health status of care recipients with Alzheimer's may be of considerable value to caregivers (Gaugler, et al, 2003; Zarit, et al, 2011).

Moreover, developing dementia capable services and strategies in long term services and supports systems has long been a focus of the US Administration on Aging and many national and

Promising Practices: Rural Respite

Range Respite Caregiver Resources and Services. Located in Virginia, Minnesota, Range Respite serves family caregivers across the lifespan in rural northern St. Louis County. They offer in-home respite, institutional respite through a partnership with a local hospital, and care in The Respite House. The Respite House is a public/private partnership with land donated by the local city government and the house donated by a local mining company. The Respite House is a fully accessible, safe environment for individuals with dementia and scholarships for 15 hours of respite care are available to first-time family caregivers of this population. The scholarships allow hesitant caregivers to try respite care. Funding for the scholarships is provided by the Alzheimer's Foundation of America, The Northland Foundation, Essentia Health Foundation, United Way of Northeastern Minnesota, the Duluth-Superior Area Community Foundation, plus agency fundraising and general donations. Caregivers across the lifespan are served, regardless of the ability to pay. The program also offers caregiver training and support services (<http://www.rangerespite.org>).

state partners in the Aging Network. In striving to ensure dementia-capable programs, efforts are made to tailor services, communication strategies, provider training, resource allocation, and quality assurance to meet the unique needs of people with Alzheimer's disease or other dementias, and their caregivers (Gould & Yuen, 2011). Such approaches should be considered when developing new or enhancing existing respite services or Lifespan Respite systems that will meet the needs of this population.

The unique needs of adults with Down's syndrome experiencing dementia must also be considered. Some respite providers that specialize in dementia care for the aging population may not feel comfortable dealing with the special needs of an adult with Down's syndrome who also has Alzheimer's. Fortunately, guidance has been provided by the National Task Group on Intellectual Disabilities and Dementia Practices. *Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia* discusses respite for this population and can help providers develop the understanding and the skills needed to serve this population (Jokinen, et al, 2013).

Respite Options for Family Caregivers

The following in-home and out-of-home respite options may provide specific benefits for family caregivers and care recipients with Alzheimer's or other dementias depending on individual needs:

- Nursing, homemaker or home health care agencies and volunteer organizations may come into the home of the person with dementia and provide respite for the caregiver. The advantage to the family is that the person with dementia stays in a familiar environment and avoids transportation difficulties. For many caregivers, preparing to take a person with dementia out of the home is exhausting. However, having a worker enter into a consumer's home may open the door for complaints about theft and invasion of privacy. Caregivers may want to ensure that workers are bonded to perform this type of service and that criminal background checks have been done.
- Voucher respite or participant-directed respite allows the family to select and train a respite worker of their choice. They receive a voucher from a funding source and then the family controls when, how and where respite is provided as well as how much to pay. Many caregivers appreciate having some control over services, especially for someone with dementia, because they can personally screen for a worker who they view as compassionate and understanding of the individual's special dementia-related needs. It allows them to make arrangements that best fit their family's needs which might mean scheduling respite during non-traditional hours. On the other hand, this type of respite means caregivers take full responsibility for the management of the worker or volunteer. Caregivers will want to decide in advance if they can handle the added responsibility of screening applicants, interviewing and possibly dismissing workers before considering this option.
- Some providers offer respite in a community residential home, such as an adult foster care home or the provider's home. Some caregivers prefer a home environment for the person with dementia instead of an institutional setting. These homes tend to be smaller with fewer people in care. Caregivers may feel this arrangement provides more one-on-one care. However, community residences may have fewer structured resources available to engage and stimulate the person with dementia. Before using a community home, caregivers will want to explore how they plan to keep the care receiver stimulated and protected from harm. In addition, whether or not the provider is in compliance with state and local regulations for health and safety should be ascertained.
- Adult day care services programs are hosted in a center during the day and typically provide supervised care and support. Some centers are

medical models and deliver nursing, cognitive stimulation and other therapeutic services. Adult day care helps working caregivers feel secure that their relative is cared for during working hours. Center operators may arrange transportation services tailored for individuals with dementia as a convenience for the caregivers. However,

the change in environment may be confusing for some persons with dementia and result in strange behaviors. Understanding how the program operates and how they keep the person with dementia safe will give the caregiver peace of mind. Keep in mind, however, that while most adult day care services are available to provide

Promising Practices: Faith-based Respite

- **Edisto Island Missionary Alzheimer's Support.** On Edisto Island in South Carolina, fewer than 4000 residents, predominately African American, live in an unincorporated rural community. Edisto Island Missionary Alzheimer's Support (EIMAS) operates a community-based adult respite center, called the Tender Loving Care Club, serving seniors coping with memory loss, dementia and Alzheimer's disease. This all-volunteer effort is operated by missionaries from 17 churches on the Island. Funding is provided through donations and fundraisers. The mission of EIMAS is to provide the underserved "memory loss" community members with opportunities to be cared for in a safe environment while providing respite services to their caregivers. The Respite Program focuses on providing stimulating social and recreational activities in a secure, supportive environment. The program operates three days a week and offers meals, an exercise program, music and singing, quilting, arts and crafts, bird watching, field trips, and memory enhancement activities. Caregivers can attend monthly trainings, support groups, social events and exercise programs. EIMAS has also become a catalyst in the community educating residents about Alzheimer's disease and other forms of dementia (<http://www.eimastlc.com/index.html>).
- **First Circle Friends.** A day respite program for caregivers of people with early- to mid-stage memory loss, First Circle Friends features

a collaborative partnership with churches to provide low-cost respite services in the community. Churches can participate by hosting the service at their facility twice a month or by providing meeting space, volunteers or marketing support. The program is an adaptation of The Gathering program model developed and operated by Lyngblomsten in the Minneapolis/St. Paul area. Lyngblomsten is a Christian nonprofit social ministry organization affiliated with the Evangelical Lutheran Church in America.

The Gathering, the inspiration for First Circle Friends replication efforts, has several coalitions with a total of 31 congregations working together in Minneapolis/St. Paul to assist caregivers across the community. Volunteers are an integral part of this social model program, many of whom have been touched by Alzheimer's disease or dementia. Volunteers attend a four hour training delivered by a registered nurse to better understand dementia. They are matched one-on-one with a program participant for the entire length of time a participant is able to attend, thereby providing continuity of care. The respite sessions are five-hours long. The volunteers plan and conduct all activities, but are supervised by a nurse. In the Twin City Area alone, over 200 volunteers are engaged. A nurse and program assistant provide oversight and quality assurance. (<http://www.lyngblomsten.org/fcf>)

care during regular daytime work hours to allow family caregivers to be employed full-time, few public respite streams will pay for adult day care used on more than a part-time or temporary basis.

- Some nursing homes set aside a number of beds for short-term respite. Respite may be offered overnight, on weekend or for extended stays. These services support caregivers who need a break for a full day up to a couple of weeks. Caregivers may choose to take a vacation, have medical procedures performed or simply rest during their respite time. This form of respite may offer the caregiver of someone with dementia additional comfort because nursing staff is available and staff may have a significant experience with dementia.
- Out-of-home community-based or volunteer and faith-based respite initiatives may offer services that are more affordable for family caregivers caring for someone with less severe symptoms of dementia. With adequate training, well supervised volunteers can provide respite options for individuals with early or mid-stage dementia who may not need as structured an environment as provided by adult day care services or nursing home respite options.
- Some VA hospitals also offer respite for eligible individuals for short term in-person stays as well as in-home and other out-patient respite options.

Current Respite Landscape

Too often, persons seeking a break from the grueling job of caregiving face long waiting lists or complex application processes that are unresponsive to their needs. In many cases, the eligibility requirements may be too difficult for families to navigate. Far too often when respite is secured, the expertise, compassion and reliability of the direct care provider workforce is under par. Yet, despite these discouraging observations, solutions are being developed.

The federal government has made sustainable progress on the **National Alzheimer's Plan**, which is updated annually. The Plan's goals are to:

- Prevent and effectively treat Alzheimer's disease by 2025
- Optimize care quality and efficiency
- Expand supports for people with Alzheimer's disease and their families
- Enhance public awareness and engagement
- Track progress and drive improvement

Several of the tactics within the Plan will foster development of respite care services for Alzheimer's caregivers. Of particular note is the provision of information and education about special respite considerations for persons with intellectual disabilities with early onset dementia or Alzheimer's disease. *The National Plan to Address Alzheimer's Disease: 2014 Update* reflects the nation's progress toward accomplishing goals set in 2012 and current action steps to achieving them. To view the 2014 Update, see <http://www.hhs.gov/news/press/2014pres/04/20140429a.html>.

Federal, State, and Private Funding Sources

Understanding funding for respite within a state is important for both providers and consumers. Providers can use this information to identify funding opportunities to develop or enhance services. Similarly, consumers can learn about funding for the respite services they are eligible for within the local community.

Federal Funding

Medicaid

- The most significant funding for respite care is through the various **Medicaid Home and Community-Based Services (HCBS) 1915 (c) Waivers**. Medicaid waivers are a joint federal and state program that provides services in the home and community for people who would otherwise

be in a nursing home or hospital. Forty-four states and the District of Columbia offer respite for dementia caregivers through HCBS waivers. The types of waivers offered vary from state to state as do eligibility criteria (Perrin, 2012).

- The **Programs of All Inclusive Care for the Elderly (PACE Programs)** provides a continuum of services that allow persons who are certified to need nursing home care to remain at home for as long as possible. Respite care and adult day services are provided in addition to medical services, therapies, counseling, personal care, and prescription drugs. As of January 2013, 31 states offer the PACE model. For a list of states with PACE programs, see http://www.npaonline.org/website/download.asp?id=1741&title=PACE_in_the_States

Medicare

Medicare is the national health insurance program for citizens 65 and older and persons with a disability. Limited funding for respite is available through the Medicare Hospice benefit. Medicare will cover up to five days of respite in a Medicare-approved facility for caregivers of terminally ill patients. Respite also may be covered under some Medicare Advantage Special Needs Plans for non-institutionalized persons.

National Family Caregiver Support Program (NFCSP)

Through the National Family Caregiver Support Program, respite is one of the five core services made available to caregivers. NFCSP funds a range of supports to help families maintain their loved ones at home for as long as possible. Eligibility for program services includes family caregivers of persons of any age with Alzheimer's disease and related disorders.

Lifespan Respite Program

This program seeks to meet the respite needs of caregivers of both children and adults with special needs by supporting coordinated systems of community-based respite care services within the

states. Through the ARCH National Respite Network and Resource Center, resources are available to service providers and state coalitions that offer guidance in program assessment, development and evaluation. For Lifespan Respite state contacts, see <http://archrespite.org/lifespan-programs>.

Social Services Block Grants (SSBG)

Title XX of the Social Security Act, the Social Services Block Grant (SSBG), enables each state or territory to meet the needs of its residents through locally-relevant social services. The SSBG funds a variety of initiatives for children and adults and can be used to fund respite for caregivers of people with dementia, including Alzheimer's disease. For example, Delaware offers the Alzheimer's Day Treatment program funded through a combination of SSBG and state funding.

Funding for Veterans

A number of programs provide respite for caregivers of aging eligible veterans. The Millennium Health Care and Benefits Act funds respite and other health care benefits through Geriatrics and Extended Care in the Veterans Health Administration. For more information, see http://www.va.gov/geriatrics/guide/longtermcare/respice_care.asp. Respite also can be paid for through Aid and Attendance and Housebound Benefits available to eligible veterans and their spouses.

Alzheimer's Disease Supportive Services Program

The Alzheimer's Disease Supportive Services Program supports states in expanding the availability of community services for persons with Alzheimer's disease and related disorders and their caregivers. Although the programs do not focus on respite care, respite is made available so caregivers can attend support services provided by the program such as training programs and support groups.

State Funding

Many states use state general funds to provide respite care through their aging networks, departments of health, disabilities and mental health programs, and departments of human services. For example:

- **Mississippi** uses state general funds through the **Department of Mental Health** to offer adult day for Alzheimer's caregivers. For more information, see <http://www.dmh.ms.gov/service-options/alzheimers-disease-and-other-dementia/>.
- Similarly, **Florida's Alzheimer's Disease Initiative (ADI)** funded entirely with state general revenue funds, was legislated in 1985 to provide a continuum of services to meet the changing needs of individuals with Alzheimer's disease. Administered by the Office of Elder Affairs, the Alzheimer's Respite Care programs are established in all of Florida's 67 counties. ADI respite includes in-home, facility-based (usually at adult day care centers), emergency, and extended care (up to 30 days) respite for caregivers of individuals with dementia. For more information, see http://elderaffairs.state.fl.us/doea/pubs/pubs/sops2014/SOPS%202014_Section%20D.pdf.
- Another **Florida** respite initiative funded by state general revenue is the **Respite for Elders Living in Everyday Families (RELIEF)**. A trained corps of volunteers is used to serve this population in 11 counties in the state. RELIEF respite is provided primarily during evenings and weekends. For more information, see <http://elderaffairs.state.fl.us/doea/relief.php>.

In addition, some states use tax levies and casino and lottery revenue to support respite services. In 2009, 15 used property tax levies for senior services including respite. Six states used sales taxes and another six used income taxes for this purpose. For example, West Virginia funds the Family Alzheimer's In-Home Respite program through state lottery licensing fees. The program provides trained workers that offer companionship and activities to

the patient while the caregiver takes a break (ARCH National Respite Network and Resource Center (ARCH), 2013).

More information on federal and state funding sources can be found in the following ARCH resources, *Federal Funding and Support Opportunities for Respite: Building Blocks for Lifespan Respite Systems* and *State Funding Streams for Respite across the Lifespan, 2013 Update*. Full citations and links can be found in the References section at the end of the fact sheet. State-by-state funding and program eligibility information is available through an interactive US map as a function of the ARCH National Respite Locator Service (<http://archrespite.org/respitelocator/respite-locator-service-state-information-map>).

Private Funding Sources

Some disability and disease organizations provide funding for respite care. Dementia caregivers can receive these services through local and state chapters of the Alzheimer's Association and member agencies of the Alzheimer's Foundation of America. If the care recipient has a dual diagnosis, they may also be able to receive support from the national organization that addresses the other disabilities or conditions, such as The Arc or Easter Seals. In local communities, some faith-based organizations, caregiver groups and volunteer organizations provide respite. Local homecare agencies, assisted living facilities and nursing homes may also offer respite for Alzheimer's and dementia patients.

Recommended Strategies

For Family Caregivers

Families of persons with Alzheimer's disease and dementia face unique challenges that many other caregivers do not. Moreover, the supply of respite workers who are trained to deal with the behaviors commonly exhibited by persons with dementia is limited. Although the nation has made great strides in developing a dementia-capable system of care,

caregivers must be identified in a timely fashion, trained to understand dementia and encouraged to take advantage of respite care and the other available supports. Specific recommendations for caregivers include:

- Begin using respite services before stress sets in. This will help avoid burnout, and begin a routine of self-care that will be helpful over the long run.
- Use good consumer skills in selecting respite services:
 - Prepare a list of questions about the services offered, cost and hours of operation.
 - When possible, meet the care provider in advance to ask questions and share information about the person with dementia.
 - Make sure the service or program selected meets the state's requirements for licensing and training.
 - Assess whether or not the program provides activities and services that the care recipient will enjoy and ensures a safe and comfortable environment.
 - When selecting an adult day care service or institutional service make sure the program is convenient and the atmosphere is appropriate and satisfactory.
- Take advantage of the numerous supports that are available. Contact the Eldercare Locator, the online ARCH National Respite Care Locator Service (NRLS), State Respite Coalitions, State Lifespan Respite Programs, local VA caregiver coordinators, Area Agencies on Aging, Aging and Disability Resource Centers and the local Alzheimer's Association or member agencies of the Alzheimer's Foundation to identify respite resources and other types of supports. Visit their websites to learn more about the disease and tips to make caregiving easier. For help to connect to these entities or organizations, see the Resources at the end of this fact sheet.

- Plan how you will use your respite time. Engage in activities during that time that are most meaningful for you.
- Explore if a clinical trial is right for you. A clinical trial is a research study to find out whether new medicines or other treatments are both safe and effective. There are strict rules to protect the safety and privacy of participants. Call or visit the ADEAR Center at 1-800-438-4380 or go to www.nia.nih.gov/alzheimers for information to find out about available studies.
- Get involved with the state Lifespan Respite Program and share caregiver insights. Help them create a system that addresses the common needs and concerns of caregivers.

For Respite Programs, Community Agencies, and Health Care Providers

Adequate numbers and types of respite care services that specialize in dementia care may not be available in every area around the country. Specifically, caregivers may need services outside of traditional business hours. Providers can be creative in addressing this issue by implementing the following:

- Investigate the possibility of offering services during non-traditional hours. Engage the entire staff to make this possible. Partnering with other organizations might help.
- Be creative when recruiting volunteers and staff. Reach out to community colleges, faith communities, employment departments and community service clubs. Reach out to nursing organizations to recruit retirees.
- Provide cultural competency in-service trainings in addition to recruiting staff from different ethnic groups.
- Cross train staff on the respite needs of caregivers of individuals with Alzheimer's and other dementias. When possible, match caregivers with workers who have been trained to support the care receiver's condition.
- Use a nationally-recognized training program to educate staff working directly with persons with Alzheimer's disease or another dementia.

Promising Practices: Intergenerational Components

- **Triple-R Adult Day Program.** This program provides respite for people with mild to severe memory loss. Operating three programs within Sacramento County, California, the Triple-R Program has been recognized by the state as the Alzheimer's Day Care Resource Center. The unique aspect of the program is the many opportunities for intergenerational interaction. One program operates twice-a-week and is located on an elementary school campus. The program room is situated near the school play areas so that participants can watch the children play outdoors while they go about their own activities. Interns and volunteers come from California State University, City College, and a local art school bringing their experience in areas such as physical therapy and art to the program. Most of the students are studying gerontology or are in the medical field. Art is another unique aspect of the program. In fact, the lead staff member is a local artist with training in gerontology. Older adults interact with students on art and music projects. Participants are encouraged to draw and paint to the best of their abilities. Annual surveys reveal that caregivers believe their own health improved after their loved one started attending Triple-R (<http://tripler.org>).
- **GEM (Gentle Expert Memory Care) Adult Day Services, Inc.** GEM is a non-profit community-based program serving Dare & Currituck Counties in the Outer Banks of North Carolina. GEM provides services, including respite, for adults with memory loss, physical and mental disabilities and those in need of socialization and their family caregivers. GEM provides training, a support group and educational workshops for caregivers and people with memory loss, and also provides them opportunities to engage in the community through planned activities. In the Caring Teens Program, teens are trained in person-centered care and are available to engage people with memory loss in activities such as chair exercise classes, bowling, baking cookies, and arts and crafts. The executive director is an Alzheimer's Foundation of America "Qualified Dementia Care Specialist" and provides expertise in overcoming cognitive challenges as well as case management to families. (www.gemdayservices.org)

The Alzheimer's Foundation of America (AFA) offers Dementia Care Professionals of America, a membership organization providing practical training in group settings and on-line, along with other benefits, for healthcare professionals involved in dementia. AFA offers two qualifications for persons completing their training – the Qualified Dementia Care Provider and the Qualified Dementia Care Specialist recognition. Respite providers may use these qualifications in their marketing campaigns.

- Implement a public awareness campaign to educate the community about respite services

and how they benefit caregivers. Share funding opportunities to pay for respite.

- Develop partnerships with resource organizations to make referrals to other needed resources.
- Consider incorporating arts, music or cultural engagement for care recipients. Visit the Directory of Creative Aging Programs in America through the National Center for Creative Aging (<http://www.creativeaging.org>) for ideas.
- Consider guidelines from national organizations, such as National Task Group on Intellectual Disabilities and Dementia Practices, that may help develop appropriate respite options for

individuals with Down's syndrome who also have dementia. Partner with organizations such as local chapters of The Arc, Easter Seals, or the National Down Syndrome Association or the National Down Syndrome Congress to help provide services to this population or assist with training of new providers.

- Work with caregivers to ensure that they are using their respite time in a way most meaningful to them.
- Include family caregivers on your advisory board to gain the perspective of caregivers and improve services.

For State Lifespan Respite Initiatives

Creating a dementia-capable system encompasses development of a single-point of entry or "no wrong door" approach to identify and link caregivers with needed information and high-quality services delivered by trained staff. Specific recommendations for State Lifespan Respite Initiatives to improve the situation include:

- In every aspect of building or enhancing respite services for family caregivers of individuals with Alzheimer's, or improving access to respite through statewide Lifespan Respite systems, check to ensure that every effort is made to ensure dementia capability. Important guidance can be found in AoA's Dementia Capability Issue Brief, *Making the Long-Term Services and Supports System Work for People with Dementia and Their Caregivers* (Tilley, et al, 2011). Valuable tools for ensuring dementia-capable services can be found in the *Dementia Capable Staff Training Toolkit* developed by the Alzheimer's Disease Supportive Services Program (ADSSP) National Resource Center (Gould, et al, 2013).
- Promote hiring of a diverse pool of respite providers to meet the growing needs of the aging population. Since the U.S. population is becoming more diverse, it is necessary to address the barriers that prevent multi-cultural communities from accessing respite. Likewise, cultural competency training should be offered to all staff.
- To increase the supply of respite workers, advocate for apprenticeships and career ladders. Inform local providers about the Department of Labor's Registered Apprenticeship system, which can help stimulate the supply of qualified workers. The Registered Apprenticeship system has been successfully implemented in many industries and could be quite valuable in the long-term care industry.
- Conduct a state-wide needs assessment that examines the preferences and availability of respite services for persons with dementia, including Alzheimer's, and their families as well as other special populations. Questions should be posed that examine barriers and gaps in services.
- Create a state-wide best practices database for improving availability, access and quality of respite services. Sponsor educational opportunities on this topic.
- Partner with state chapters of the Alzheimer's Association, member agencies of the Alzheimer's Foundation or other local providers with expertise in providing respite to this population to help address the training needs of family caregivers. Help prepare them to understand the disease and implement strategies to prevent burnout. Teach them how to maximize respite services. Pursue collaborations with these organizations to expand training opportunities for new respite providers as well.
- Increase emergency respite options as few are currently available. Create a state-wide taskforce to address this issue so insights can be gathered from multiple stakeholders. (See ARCH Fact Sheet on Emergency Respite at http://archrespite.org/images/docs/Factsheets/FS_61-EmergencyRespite.pdf).
- Host conferences where caregivers and respite providers can discuss quality issues. Help them develop care agreements to work together for the best respite outcomes.

Summary

Caring for someone with Alzheimer's disease and related dementias may result in tremendous emotional, physical and financial stress for the whole family. The myths held by many, especially people of color, have hidden the disease and its impact for far too long. Respite care is a way to provide some relief to caregivers and strengthens their ability to continue in that role. It is the most requested service by caregivers coping with dementia. Yet our current system is in jeopardy. The labor shortage of trained respite workers is daunting, making it difficult for families to find suitable services. Eligibility requirements are confusing and limiting. Emergency services are sorely lacking.

Providing respite care for dementia caregivers is a huge challenge for our nation. Today, nearly 5.2 million Americans over 65 are suffering with Alzheimer's disease. By 2050, approximately 16 million persons are projected to have this incurable condition. This is a heartbreaking disease that robs its victims of their memory, personality and autonomy. Economically, the cost of caring for Alzheimer's patients is considerable. The cost to family caregivers is immeasurable.

Federal and state governments, recognizing the public policy implications of caregiving especially for persons with dementia, including Alzheimer's, have funded the National Family Caregivers Support Program, the Lifespan Respite Program, the Alzheimer's Disease Supportive Services Program and most recently the National Alzheimer's Project Act. Additionally, Medicaid state waivers continue to multiply or states are adopting state plan options for home and community-based services. All of these efforts will serve to build a system of awareness, diagnosis, treatment and support for persons with dementia and their families.

Government agencies, foundations, private institutions and public organizations are all encouraging creative approaches to deal with this care crisis. Through enhanced funding options, it is easier to test new forms of respite. Training

is encouraged for paid workers as well as family caregivers. With the advent of the National Alzheimer's Plan to Address Alzheimer's Disease, we can rest assured that supports for persons with dementias and families are being improved and expanded.

Resources

Alliance for Aging Research

<http://www.agingresearch.org/Home>

The Alliance for Aging Research is dedicated to accelerating the pace of scientific discoveries and their application to improve aging and health. A useful tool for caregivers produced by the Alliance is *Alzheimer's Disease: Helping Yourself Help a Loved One – Caregiver Workbook*. It can be downloaded at: <http://www.agingresearch.org/Publications/view/22#.U2-hwcrQf9Q>

Alzheimer's Association

<http://www.alz.org>

1-800-272-3900

The Alzheimer's Association is a nonprofit organization offering information and support services to people with Alzheimer's disease and their caregivers. The Association also sponsors research. *Respite Care Guide Finding What's Best for You* is available at: https://www.alz.org/national/documents/brochure_respitecareguide.pdf

Alzheimer's Disease Education and Referral (ADEAR) Center

<http://www.nia.nih.gov/alzheimers>

1-800-438-4380

This Center, a service of the National Institute on Aging, provides information on diagnosing, treating, and caring for persons with the disease. It also helps individuals find long term care services and research studies. A resource from ADEAR, *Caring for a Person with Alzheimer's Disease*, provides information for caregivers of individuals with Alzheimer's. It can be downloaded at <http://www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease/about-guide>

Alzheimer's Disease Research Centers

<http://www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers>

The National Institute on Aging funds Alzheimer's Disease Centers at major medical institutions across the nation. These centers work to improve diagnosis and care for persons with Alzheimer's disease.

Alzheimer's Disease Supportive Services Program (ADSSP) National Resource Center

<http://www.adrc-tae.acl.gov/tiki-index.php?page=AboutADSSP>

AoA funds a National Resource Center to provide technical assistance to ADSSP grantees. This assistance includes national meetings, monthly conference calls, and individual consultation.

Alzheimer's Foundation of America

<http://www.alzfdn.org>
1-866-232-8484

This nonprofit group serves people with Alzheimer's disease and their caregivers and families. Services include a toll-free hotline, publications, and online resources.

Alzheimer's.gov

<http://www.alzheimers.gov>

The federal government's site managed by the US Department of Health and Human Services provides free information resources about Alzheimer's disease and related dementias. Here you can find links to authoritative, up-to-date information from agencies and organizations with expertise in these areas.

Alzheimer's Locator

<http://www.alzheimerslocator.com>

A resource that helps families find Alzheimer's and dementia care, this online tool allows consumers to compare the costs and services of memory care facilities, get customized results, and access expert information and advice on choosing a facility.

The Alzheimer's Project

<http://www.hbo.com/alzheimers>
(212) 512-7467

"Caregivers," is one of 15 short supplemental films developed as part of The Alzheimer's Project, which looks at groundbreaking scientific discoveries and seeks to increase public understanding of AD research and caregiving. This multimedia public health series is co-presented by HBO Documentary Films and the National Institute on Aging in association with the Alzheimer's Association, Fidelity Charitable Gift Fund, and the Geoffrey Beene Gives Back Alzheimer's Initiative.

AlzTalk.org

<http://www.alztalk.org>

An Alzheimer's Social Network, created by The Fisher Center Foundation, AlzTalk.org offers a fun, personal environment for families, friends, and medical professionals to chat, post messages, share favorite links, and view forums, blogs, pictures and videos.

American Association on Intellectual and Developmental Disabilities

<http://www.aaidd.org>

AAIDD promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities.

ARCH National Respite Network and Resource Center

<http://archrespite.org>

The ARCH National Respite Network includes the National Respite Locator, a service to help caregivers and professionals locate respite services and funding sources in their community, and the National Respite Coalition, a service that advocates for preserving and promoting respite. To access state-by-state information on respite programs and possible funding sources, visit <http://archrespite.org/respitelocator>

California Alzheimer's Disease Centers (CADC)

<http://cadc.ucsf.edu/cadc>

CADCs, a network of ten dementia care Centers of Excellence at California medical schools, provide specialized training and education to health care professionals, students, persons with dementias, caregivers and the community.

Dementia Capability Issue Brief, Making the Long-Term Services and Supports System Work for People with Dementia and Their Caregivers

<http://www.adrc-tae.acl.gov/tiki-index.php?page=PersonCentered>

States serve a substantial number of people with dementia and their family caregivers in their Aging Networks and LTSS systems. Serving this population effectively involves accommodating the needs of a population that, in addition to memory loss, experiences a variety of physical, cognitive, and behavioral symptoms resulting from dementia, along with other medical conditions. In model dementia-capable systems, programs are tailored to the unique needs of people with Alzheimer's disease or other dementias, and their caregivers.

Dementia Capability Toolkit

http://nasuad.org/sites/nasuad/files/hcbs/files/211/10517/DementiaCapabilityToolkit__12_2_11.pdf

This toolkit, targeting state and local health networks, includes resources for providing dementia services in communities. The Administration on Aging sponsored the development of the toolkit.

Dementia Capable Staff Training Toolkit

http://www.aoa.gov/AoA_Programs/HPW/Alz_Grants/docs/Staff-Training-Toolkit_September_2013.pdf

The toolkit was developed by the ADSSP National Resource Center to provide training tools for information and referral/assistance staff, options counselors, and care managers in Aging and Disability Resource Centers (ADRCs) and Area Agencies on Aging (AAAs), and would be very useful in developing training curricula for respite providers.

Easter Seals

<https://www.easterseals.com>

Easter Seals programs include a variety of respite services including adult day services and in-home support and services.

Eldercare Locator

<https://www.eldercare.gov>
1-800-677-1116

The Eldercare Locator, funded by the Administration on Aging, helps families find resources in their community, such as home care, adult day care, and nursing homes.

Family Caregiver Alliance (FCA)

www.caregiver.org

FCA was founded in the late 1970s as the first community-based nonprofit organization in the country to address the needs of families and friends providing long-term care for loved ones at home. Through education, services, research and advocacy, FCA offers expertise and technical assistance on family caregiving through its National Resource Center on Caregiving, the Innovations Clearinghouse, the Family Care Navigator, and more.

Foundations for Engagement with Art

http://www.moma.org/momaorg/shared/pdfs/docs/meetme/Guides_Foundations.pdf

This guide, developed by the New York Museum of Modern Art (MOMA), explains how to engage individuals with dementia and their caregivers with art. The methods can be used with groups or one-on-one, and can be adapted for various settings, from art museums and galleries to care organizations and private homes.

National Center for Creative Aging (NCCA)

<http://www.creativeaging.org>

NCCA is a national clearinghouse on creativity and aging and focuses its efforts within three target areas: Health and Wellness; Lifelong Learning; and Community Engagement. The Center provides technical assistance, education, research, and

advocacy. They maintain a searchable Directory of Creative Aging Programs in America.

National Down Syndrome Association

<http://www.ndss.org>

The National Down Syndrome Society is the national advocate for the value, acceptance and inclusion of people with Down syndrome. For more information, contact the NDSS Helpline 800-221-4602 or through email at info@ndss.org

National Down Syndrome Congress (NDSC)

<http://www.ndsccenter.org>

The NDSC operates the NDSC Center which serves as a clearinghouse for information on Down syndrome. The Center provides up-to-date information on topics of interest to people with Down syndrome, family members, friends, professionals and interested others.

National Institute on Aging

www.nia.nih.gov

NIA, one of the 27 Institutes and Centers of NIH, leads the federal government in conducting and supporting research on aging and the health and well-being of older people. The Institute seeks to understand the nature of aging and the aging process, and diseases and conditions associated with growing older, in order to extend the healthy, active years of life.

National Task Group on Intellectual Disabilities and Dementia Practices

<http://aadmd.org/ntg>

This coalition of interested persons and organizations ensures that the needs of adults with intellectual and developmental disabilities and their caregivers who are affected by Alzheimer's disease and related dementia are represented in the National Plan to Address Alzheimer's Disease.

Respite Services: Enhancing the Quality of Daily Life for Caregivers and Care Receivers

http://www.lifespanrespite.memberlodge.org/Resources/Documents/Performance%20measurement%20tools/Lund_Respite_Brochure_2010.pdf

Prepared by Dale Lund and colleagues at California State University at San Bernardino and University of Utah, College of Nursing, Gerontology Interdisciplinary Program, to assist family caregivers in making the best and most effective use of respite time.

The Arc

<http://www.thearc.org>

The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. The organization encompasses all ages and all spectrums including autism, Down syndrome, Fragile X and various other developmental disabilities.

US Department of Veterans Affairs Caregiver Support Program and Respite Services

<http://www.caregiver.va.gov>

The VA offers a number of supports and services for caregivers. Respite Care can be offered in a variety of settings, including in-home or through temporary placement of a veteran at a VA Community Living Center, a VA-contracted Community Residential Care Facility, or an Adult Day Health Care Center.

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Acknowledgements: ARCH would like to thank Jane Tilly, Dr.PH, Subject Matter Expert for Brain Health and Dementia, and Greg Link, MA, Aging Services Program Specialist/Team Lead, both with the Office of Supportive and Caregiver Services, Administration for Community Living/ Administration on Aging in the US Department of Health and Human Services for reviewing the fact sheet and providing extremely useful comments.

Note: Programs described in this fact sheet as promising practices are offered for illustrative purposes only and are not necessarily endorsed by ARCH.

The ARCH National Respite Network and Resource Center is funded, 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.

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