

Supporting Family Caregivers

HOME AND COMMUNITY-BASED SERVICES
FOR PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS



alzheimer's 
association™

A TOOLKIT FOR
THE AGING NETWORK


INTERNATIONAL

HOME AND COMMUNITY-BASED SERVICES FOR PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS



Table of Contents

Supporting Family Caregivers

[Section 1 – About This Toolkit](#)

[Section 2 – Promising Practices](#)

This project was funded by the U.S. Administration on Aging under contract number GS-10F-009L MOBIS, Delivery Order No. HHSP2332004001143U. This report is a product of the Alzheimer's Disease Demonstration Grants to States National Resource Center developed by the Alzheimer's Association. The statements contained in this document are solely those of the authors and do not necessarily reflect the views or policies of the U.S. Administration on Aging.

About This Toolkit: Supporting Family Caregivers

Home and Community-Based Services for People with Dementia and Their Caregivers

Family caregivers are the backbone of the long-term care system. In 2007, caregivers of people with dementia provided 8.4 billion hours of help, valued at \$89 billion. Meanwhile, caregivers need support themselves. Caregiver services can decrease the burden of caregiving, enable family members to continue their responsibilities, and improve their emotional well-being and quality of life. Therefore, family caregiver services should be available in the community and capable of supporting caregivers dealing with dementia. Services can include: caregiver counseling, information, education, and respite services such as adult day care and in-home services. **This toolkit highlights actions that states can take to ensure that family caregiver services are available and dementia capable.**

The Supporting Family Caregivers Toolkit:

- Stresses the need for the availability and dementia capability of caregiver services.
- Describes how caregivers require different services beyond the needs of the individual with dementia.
- Explains how caregiver services play a critical role in increasing the use of home and community-based services while decreasing institutional care.
- Provides an array of resources, including model programs and unique examples for state officials to use when developing programs. Many of these programs are funded by the Administration on Aging through the Alzheimer's Disease Demonstration Grants to States (ADDGS) program.
- Summarizes actions that states can take to make caregivers services available and dementia capable. Information is provided on how to:
 1. Support family caregivers through identification, assessments, information, training, mental services, and respite services.
 2. Ensure dementia training for paid in-home direct care and adult day service workers.
 3. Foster the development of adult day services and respite care programs.

This toolkit provides information on promising practices, with hyperlinks to material available on the Internet.

Promising Practices: Supporting Family Caregivers

Home and Community-Based Services for People with Dementia and Their Caregivers

Why Are Family Caregivers Services Important?

- Alzheimer's disease and most other dementias are devastating degenerative conditions that cause memory loss, challenging behaviors, and severe functional limitations.
- According to the Alzheimer's Association's *2008 Alzheimer's Association Facts and Figures*, an estimated 5.2 million Americans have Alzheimer's disease. One in ten Americans aged 65 and older has dementia and by age 85, nearly half have dementia.
- The challenges of caregiving will only increase in the future. By 2050, it is estimated that 16 million people will have Alzheimer's disease or a related dementia.
- Almost 10 million Americans are caring for a person with Alzheimer's or another dementia. Approximately half of caregivers are over age 50, and 14 percent are over the age 65.
- Caregivers are often physically and mentally exhausted after caring for a loved one. At any one time, almost one-third of family caregivers have been providing help for 5 years or longer, and 37 percent have been providing care for 1 to 4 years. Caregiver exhaustion is among the reasons people with dementia are institutionalized.
- Many family caregivers of individuals with dementia have to quit their jobs, reduce their work hours, or take time off because of caregiver responsibilities.
- People caring for individuals with cognitive impairments have unique needs and require support services distinct from those for people with dementia.

What Are Dementia-Capable Services?

Family caregivers caring for individuals living with dementia need support. For states to provide that support, services need to be available to and capable of serving families with dementia. To be dementia capable, individuals who assist consumers to access home and community-based services (HCBS) must be:

- skilled at identifying caregivers for people with Alzheimer's disease or other dementia,
- knowledgeable about the kinds of services that can help caregivers and people with dementia, and
- capable of providing linkages to agencies and community organizations that can help.

Supporting Family Caregivers

To ensure that caregiver services are available and dementia capable, states can undertake the following key activities:

1. Support family caregivers with services that provide identification, assessments, information, training, mental health support, and respite care.
2. Ensure dementia training for paid in-home, direct care, and adult day service workers.
3. Foster the development of adult day services and respite care programs.

Promising Practices for Each Key Activity

1. Support family caregivers with services that provide identification, assessments, information, training, mental health support, and respite care

The following steps can assist service providers with providing the most effective support for family caregivers:

- Encouraging HCBS and Single Point of Entry systems to identify families of individuals with dementia
- Conducting individualized assessments of caregiver needs
- Providing basic resources to caregivers or connecting them to resources with extensive information and care options
- Offering evidence-based dementia care training to caregivers
- Making mental health and respite services available to caregivers

A. Encouraging HCBS and Single Point of Entry Systems to identify families of individuals with dementia

The first step to supporting families is to identify caregivers of individuals with dementia. HCBS and Single Point of Entry Systems should first ask for the “primary” caregiver—the family member who is the caretaker of the person with dementia. Services should also identify secondary caregivers.

B. Conducting individualized assessments of caregiver needs

The next step is assessing the needs of caregivers. No two caregivers are alike. Primary caregivers’ responsibilities vary depending on what stage (early, middle, or late) of Alzheimer’s disease the care recipient is experiencing— and whether or not other family members can assist with providing care. As the disease progresses, the relationship between the caregiver and the care recipient changes. For these reasons, caregivers’ needs have to be reassessed over time. Caregiver assessments can help to identify what existing resources are available to help caregivers carry out their responsibilities with increased skill over a prolonged period

of time. Several states under the Alzheimer's Disease Demonstration Grants to States (ADDGS) provide examples:

- **North Carolina's** ADDGS program [Project C.A.R.E.](#) provides comprehensive support to dementia caregivers. Project C.A.R.E. developed two dementia-specific family caregiver assessment tools that are used together. The first tool, the *Client Intake Form*, covers: (1) consumers' living arrangements, needs for assistance, demographic information, and behavioral symptoms of dementia; and (2) caregiver demographics, employment status, service use, and health and emotional status. The second tool, the *Supplemental Information Form*, addresses symptoms of dementia and the need for respite services. This form also collects information about any other government-funded services that the dementia family may be receiving. Families who qualify can receive respite services at home, in adult day care, or in a facility. Respite services are available up to \$1,500 per family per fiscal year.
- Several states, including **Florida, Georgia, Michigan, Washington,** and **Wisconsin**, are field-testing a uniform caregiver screen and assessment tool developed collaboratively by the University of Wisconsin–Milwaukee and the University of Wisconsin–Cooperative Extension Service.

The Tailored Caregiver Assessment and Referral (TCARE) protocol teaches state and community agency care managers to assess caregiver's actual needs rather than delivering a set basket of services. **Michigan's** Aging and Disability Resource Centers conducted trainings on the TCARE Caregiver Screen. The purpose of the screen is to help determine if caregivers are experiencing high levels of stress and depression. Once ADRC staffs identify these caregivers, the caregiver will be referred to community organizations for more complete care consultations. At care consultations, the TCARE Caregiver Assessment will be used to obtain detailed information about the caregiver's unique situation and to identify available services that can help. Additional information about the Ucare training program and protocol is available on the Web site of the [University of Wisconsin–Milwaukee Center on Aging and Community](#).

- In 2006, the National Center on Caregiving at the Family Caregiver Alliance (FCA) issued a report from a national consensus development conference entitled *Caregiver Assessment: Principles, Guidelines and Strategies for Change Volume I*. The report contained a set of *Fundamental Principles for Caregiver Assessment* that can be incorporated into state caregiver assessment tools under development. Additionally, FCA has developed a *Caregivers Count Tool!* tool kit. Section 3, [The Nuts & Bolts of Caregiver Assessment?](#) provides valuable information about establishing caregiver assessment processes.
- [Other states](#) including **California, Massachusetts, Minnesota, Pennsylvania** and **Washington** have developed general caregiver assessment tools.

C. Providing basic resources to caregivers or connecting them to resources with extensive information and care options

Basic information about dementia and support are valuable to caregivers. Regrettably, many people have only a vague understanding of dementia. HCBS and Single Point of Entry Systems such as [Aging and Disability Resource Centers](#) can (1) provide basic information directly to caregivers or people who make dementia-related inquiries or (2) refer dementia inquiries to other community resources that can provide both basic and more extensive information about the disease and care options.

- Provide basic information about dementia and caregiving
- HCBS and Single Point of Entry Systems that provide basic information about dementia and caregiving directly to families can utilize publications and information from the U.S. Administration on Aging, [Alzheimer's Association](#), and [National Institute of Aging's Alzheimer's Disease Education and Referral Center](#). Examples of publications and information from these organizations include:
 - [10 Warning Signs of Alzheimer's Disease](#)
 - [Understanding Memory Loss](#)
 - [Caregiver Guide: Tips for Caregivers of People with Alzheimer's Disease](#)
- **Connect to resources with extensive information and care options**
HCBS and SPOEs can refer families to other sources of information that provide both basic and more extensive information and care options. Examples of resources that HCBS and ADRCs can refer individuals and caregivers to include:
 - [Eldercare Locator](#) can connect caregivers with sources of information on senior services. Additionally, [State Units on Aging](#), [Area Agencies on Aging](#), and county departments of human services and/or aging can provide valuable help. In rural areas, another resource that can direct people to help is the local [USDA Cooperative Extension](#) office.
 - [Local chapters](#) of the Alzheimer's Association can provide a wide range of basic and extensive information and support. The Alzheimer's Association's Web site www.alz.org has a list of almost [150 fact sheets](#) and other supportive information.
 - The Alzheimer's Association's [24/7 Helpline](#), supported in part by the U.S. Administration on Aging, provides reliable information and support to individuals impacted by Alzheimer's disease or related dementias. The toll-free number, **1-800-272-3900**, is available anytime day or night. The 24/7 Helpline serves people with memory loss and their families, caregivers, health care professionals, and the public. To assist citizens needing help after normal business hours, states can post the toll-free number on their Web sites and implement procedures to ensure that state-

operated call centers refer people to the 24/7 Helpline after hours.

The 24/7 Helpline's highly trained and knowledgeable staff can help with: (1) understanding memory loss, dementia and Alzheimer's; (2) dealing with challenging behaviors; (3) obtaining general information about aging and brain health; (4) learning skills to provide quality care and to find the best care from professionals; (5) legal, financial and living arrangement decisions; and (6) caregiver stress. Callers who do not speak English are assisted with the use of a translation service that features over 140 languages.

- The Alzheimer's Association's [CareSource™](#) is an easy-to-use, one-stop resource for everything you need to know about finding and planning for care for a person with Alzheimer's. CareSource's new online suite of services helps coordinate assistance from family and friends, locate senior housing, and identify customized care recommendations.
 - [Lotsa Helping Hands](#) is an interactive calendar that allows anyone involved in care or support to log onto one convenient, private site and organize caregiving activities. It's easy to post dates and times for duties others have agreed to share, such as preparing meals, providing rides, running errands, or keeping the person with dementia company.
 - [Senior Housing FinderSM](#), powered by SNAPforSeniors®, is the first online nationwide database for locating dementia care. The tool allows searches for licensed senior housing by geographic area, housing type, availability, and level of dementia care offered.
 - [CareFinder™](#) helps identify dementia care options to best meet an individual's needs and preferences. CareFinder helps you recognize good care, communicate effectively with care providers, and learn about care payment sources.
 - Other resources include message boards for sharing with others who face similar challenges and links to programs for improving caregiver skills.

D. Offering evidence-based dementia care training to caregivers

Providing caregivers with dementia education and training can prolong their capacity to provide care at home—thereby delaying institutionalization. Several states have incorporated evidence-based caregiver training programs into their state's Alzheimer's grant activities. Evidence-based programs are programs that research has demonstrated as effective. The following are examples of evidenced-based caregiver trainings:

- **Colorado's** ADDGS Savvy Caregiver program provides dementia care education and training for rural caregivers. Because of constraints of time and distance, rural caregivers are often unable to leave loved ones at home on a

weekly basis to attend regularly scheduled caregiver trainings. The Colorado program addresses this problem by providing caregiver training on a condensed and accelerated schedule. Also available is information for use by trainers. Nearly half of all state ADDGS programs have used Savvy Caregiver as a caregiver education and training program. Savvy Caregiver has also been adapted into a culturally appropriate Spanish-language format entitled *Cuidando con Respeto*.

- The [REACH II](#) caregiver intervention was developed at the University of Pittsburgh and conducted in five states: **Alabama, California, Florida, Pennsylvania, and Tennessee**. Under REACH II, trained project staff conducted caregiver interventions by visiting caregivers at home and conducting telephone support. Telephone support strategies included sharing information, providing instruction, role playing, problem solving, skills training, teaching stress-management techniques, and hosting telephone support groups.

The research assessed the caregivers' quality of life before the service began and 6 months later. Five specific areas were studied: depressive symptoms, the burden of caregiving, engagement in self-care activities, level of social support, and problem behaviors exhibited by the person with dementia. After 6 months, improvements in the caregivers' overall quality of life were significant among Hispanic and Caucasian caregivers and African American spouse caregivers. The research also showed that the rate of clinical depression was significantly lower among caregivers in the intervention group than among those in the control group.

Several state ADDGS programs have developed caregiver support program based on REACH II and its predecessor REACH I. These states include **Alabama, California, Florida, and Tennessee**. For example, the **Alabama** Department of Senior Services (ADSS) and the University of Alabama's Center for Mental Health and Aging (CMHA) partnered to translate a caregiver intervention based on REACH I and II into a feasible package of services that could be used with community caregivers through the Area Agencies on Aging.

E. Making mental health and respite services available to caregivers

Over time, caregivers need support services distinct from care recipients. These services can enhance the caregivers' well-being by reducing depression and burden and allowing caregivers time to attend to their own health and personal needs. Key elements of caregiver services are (1) offering mental health support to caregivers and (2) making respite services available to caregivers.

- Offering mental health support to caregivers

Research shows that caregivers have significantly fewer symptoms of depression after receiving counseling and support, and reducing caregiver depression can delay institutional placement of older care recipients with dementia.

ADDGS programs in **Maine** and **Washington** have offered caregiver support services that address caregiver depression and stress.

- **Maine** offers mental health counseling to caregivers coping with depression. The program provides individualized support and education to the caregiver through a combination of in-home visits, telephone calls, and other activities. Caregiver companions: (1) provide information about the disease; (2) take the caregiver out for a meal; (3) assist the caregiver to re-engage in meaningful activities; and (4) remind the caregiver to engage in mental, physical, and spiritual self care.
 - The program is based on research conducted by Mary Mittelman, DrPH, and colleagues at New York University who found that counseling and social support can increase the time caregivers are able to care for persons with Alzheimer’s disease at home, especially during the early to middle stages of dementia.
 - **Washington’s** ADDGS Dementia Partnership Project integrates dementia-capable services into existing state programs that provide home-based services. Based on research conducted by Mary Mittelman, DrPH, key elements of the program include *Dementia Family Support Consultation* and *Family Caregiver Counseling*. This program is intended to build on families’ capacity to manage the challenges inherent to caring for persons with Alzheimer’s and other dementias. It provides therapy focused on family caregiver solutions with the content of each counseling session determined by the unique needs of individual caregiving situations.
- Making respite services available to caregivers

Caregivers require time to attend to their own personal needs. These needs range from having important doctor’s appointments to attending family events. In order to take care of their own needs, caregivers must have the capacity to leave a loved one in a safe environment. Time away from the care recipient is often referred to as respite time.

Many ADDGS programs have sought to expand the availability of respite services. A substantial number of these programs implement a consumer-directed care approach, such as a voucher system, to provide caregivers with a stipend to purchase a range of services. Examples of states that have taken this approach include **Alabama, Colorado, Idaho, Indiana, Maryland, Montana, Nebraska, North Carolina, North Dakota, Puerto Rico, Tennessee, Utah, and Virginia**. Respite services include adult day services, overnight care, homemaker services, and in-home services provided by a trained respite volunteer.

- **Colorado’s** Virginia Behr Grant program uses ADDGS funds to provide respite grants of \$1,000 to caregivers who live with the person with dementia, do not receive Medicaid/HCBS benefits, and have a physician’s statement to verify the diagnosis. The grants are intended to increase access to supportive services such as respite care, day care, and in-home services. The Colorado Chapter of the Alzheimer’s Association administers the program.
- **Nebraska’s** ADDGS program emphasizes a consumer-directed approach to caregiving. A study of the program conducted by the College of Public Affairs and Community Services at the University of Nebraska at Omaha found that in addition to traditional respite and adult day services, caregivers also required assistance with activities such as going places beyond walking distance, managing money, cooking/preparing meals, buying/getting food and clothing, and light-to-heavy housework. Caregivers received \$300.00 each month to use as they saw fit with the expectation that 50 percent of the funds would be used for traditional direct services, including respite, adult day care, and in-home support. All other moneys could be used for such nontraditional items as incontinence products, groceries, and medications.
- **North Carolina’s** ADDGS [Project C.A.R.E.](#) uses a consumer-directed, family-consultant model to provide comprehensive respite support to dementia caregivers. The goal of the program is to increase access, choice, and quality of respite care to lower-income rural and minority communities. Caregivers may spend up to \$1,500 a year toward respite services. Families are able to choose among a full continuum of consumer-directed care options, including adult day services, group respite, private or agency in-home care, and overnight residential respite.

2. Ensure dementia training for paid in-home, direct care, and adult day service workers

Families are very protective of their loved ones with dementia and are reluctant to leave them with strangers. Placing individuals with dementia in a trusted and safe environment can alleviate the anxiety and stress that caregivers may be experiencing. Therefore, in-home and adult day service workers need to be educated about dementia, its progression, and how to manage challenging behaviors. Unfortunately, many direct care workers lack training specifically in Alzheimer’s disease and other dementias—even though people with the disease account for a substantial portion of their caseload. To address this problem, many states have adopted the following programs:

- ADDGS programs promoting dementia care training
- State policies and programs supporting dementia care training

A. ADDGS programs promoting dementia-care training

Many states have integrated dementia-specific training for direct care workers into their ADDGS programs or have adopted state policies.

- **Maine** uses the [Best Friends™](#) training program to train professional caregivers to use a person-centered approach that accentuates the value of the individuals who are being cared for. Through the Best Friends™ training, staff including administrators, Registered Nurses (RNs), Certified Nursing Assistants (CNAs), and Personal Care Assistants (PCAs)—along with dietary, maintenance, and housekeeping personnel—learn new ways to solve problems, encourage positive behavior, and improve communication. The concepts and components of the training apply to any person with dementia. The training components provide an overview of the Best Friends™ model, which includes acquiring a basic understanding of dementia and assessing the person with dementia in terms of abilities rather than disabilities.
- **Oklahoma's** ADDGS program provides training to respite volunteers to transition to the workforce and has developed a new certificate program and dementia-management courses for health care professionals. Working in partnership with Tulsa Community College, Oklahoma fostered development and enrollment in a [Certified Nursing Assistant \(CAN\)/Geriatric Training Program \(NUR 1154 and NUR 1216\)](#) that provides specific dementia care training.
- **West Virginia's** ADDGS program developed dementia care training materials for both family caregivers and paid professional direct care staff. *The Person Comes First: A Practical Approach to Alzheimer Care* provides a comprehensive instructor's guide for dementia training. The guide includes information on: (1) defining dementia and Alzheimer's disease; (2) communicating effectively with people with dementia; (3) managing behaviors; (4) understanding the impact of dementia on activities of daily living (ADLs); (5) making activities meaningful; and (6) working with families.

B. State policies and programs supporting dementia care training

Driven by the importance of dementia-trained in-home direct care workers and the success of ADDGS programs, two states, **Missouri** and **Florida**, have enacted statutes requiring dementia specific training for in-home direct care workers.

- **Missouri** law requires all employees involved in the delivery of care to persons with dementia to be trained in dementia care. Missouri's Dementia Training Requirements apply to home health agencies, hospice, adult day care providers, and independent contractors. For employees providing direct care to people with dementia, the training includes: (1) getting an overview of Alzheimer's disease and other dementias, (2) communicating with persons with dementia, (3) managing behavior, (4) promoting independence in ADLs, and (5) understanding and dealing with family issues. For employees who do

not provide direct care but may have daily contact with people with dementia, the training includes an overview of Alzheimer's and related dementia and techniques to communicate with persons with dementia.

- **Florida** mandated dementia care training for providers delivering adult day care, hospice, and home health direct care services. For adult day care and hospice workers, the law requires all employees having direct contact with individuals with dementia to take at least 1 hour of initial training during their first 3 months of employment—with direct care personnel being required to take an additional 3 hours of training within their first 9 months of employment. Individuals working for home health agencies are required to take 2 hours of training within the first 9 months of their employment.

To assist Florida's providers in complying with the law, the [Florida Department of Elder Affairs](#) works in partnership with the [University of South Florida](#) to ensure that providers implement training curricula that conform to statute.

3. Foster the development of adult day services and respite care programs

In order to delay institutionalization of people with cognitive impairment, dementia-capable adult day and respite services must be available. The availability of these services can determine if caregivers can continue to work or how long they can care for a loved one at home. At least half of the individuals utilizing adult day services have Alzheimer's disease or other dementias. Information on the development of adult day services and respite care programs is found below.

- Information about developing adult day services
- Resources for developing respite care programs

A. Information about developing adult day services

- The Robert Wood Johnson Foundation supported an extensive initiative called [Partners in Caregiving](#) that helped foster the creation and expansion of adult day services for people with dementia. The Wake Forest School of Medicine implemented this initiative to focus on the essentials for success in sustaining an adult day service program and published key lessons learned. The National Study of Adult Day Services revealed that people with dementia had the highest use rate for all types of adult day services.
- Another tool for states and communities seeking to increase the availability of adult day services is the report by the U.S. Department of Health and Human Services, [Adult Day Services: A Key Community Service for Older Adults](#). The report's executive summary provides an overview of states' requirements for required and optimal services, staffing, training, operational and policy issues, and regulatory issues. The executive summary also presents conclusions and recommendations regarding state regulation, program models, funding, reimbursement, and operational issues. The report provides

detailed information on the approaches to adult day services taken by **Georgia, Illinois, Maryland, North Carolina, and Washington.**

- State examples of adult day services models:
 - **California's** Department of Aging supports [Alzheimer's Day Care Resource Centers](#) statewide. The centers provide services that support the physical and psychosocial needs of people with dementia. The centers are designed to prevent premature institutional placement of people with dementia, serve as model day care programs for people with dementia, train professional and family caregivers, and increase awareness of Alzheimer's disease and related disorders.
 - **Georgia** and **Louisiana** have a Mobile Day Care program that provides adult day care services in rural communities that may not need or be able to support a full-time adult day care program. Although the name suggests a moving facility, it is actually the program staff that travels to different communities to provide adult day care from 1 to 3 days per week in local facilities such as senior centers and churches.
 - **Virginia's** [Alzheimer's Family Day Center](#) provides adult day health care, training for caregivers, support groups, and preventive services. One of the leading centers nationwide to provide programs for people in the later stages of Alzheimer's disease, the center serves as a clinical site for students attending public institutions of higher education, including George Mason University and Northern Virginia Community College.
 - A component of **Washington's** ADDGS program involves developing and demonstrating a dementia day services model called Memory Care and Wellness Services. The program includes two project sites—one urban and one rural—and three providers (two adult day health providers and one adult day care provider). It is designed to evaluate the feasibility of a new dementia services model and to examine the challenges of implementing services among diverse communities. The program provides dementia training for staff at all sites.
- Adult Day Services Nationwide:
 - [Easter Seals](#) is a leading nonprofit provider of center-based daytime care services for seniors and people with disabilities. The organization has a distinguished history of providing adult day services to people with dementia. [Centers](#) operate in 20 states.
 - [The National Adult Day Services Association](#) (NASDA) publishes information on trends in adult day services nationwide.

B. Resources for developing respite care programs

Group respite programs can be faith based or designed to complement a range of community-based social service programs. A number of well-respected national

organizations have developed information to assist communities to develop group respite programs:

- [The Robert Wood Johnson Foundation](#) released a study in 2003, conducted by Public/Private Ventures (P/PV) to identify program characteristics associated with the survival of interfaith volunteer caregiving programs. Key sections of the report related to practices associated with successful programs and critical issues facing interfaith voluntary care giving programs.
- Since 1989, the [Brookdale National Group Respite Program](#) has awarded seed grants to organizations to develop and implement social model group respite programs. The goals of the program are to (1) offer opportunities for persons with Alzheimer's disease or a related dementia to engage in a program of meaningful social and recreational activities in a secure and supportive setting in order to maximize their cognitive and social abilities and (2) provide relief and support to family members of and other primary caregivers for individuals with Alzheimer's disease or related dementias. In addition to providing respite care and enjoyable group activities, the programs offer family caregivers access to services such as counseling, support groups, information and referral, and training and education. Typically, the foundation awards 15 grants of \$7,500, annually. The availability of seed grants is announced in March with grant applications due in early July. Many existing programs [nationwide](#) originally received Brookdale grants.
- ARCH (Access to Respite Care and Health) National Resource Center has issued a set of [guiding principles](#) to assist community organizations in developing group respite programs.
- Several states have engaged in efforts to enhance in-home respite services:
 - **Alabama** and **North Carolina** have employed [support teams](#) to assist in the provision of in-home respite services. [Alabama's](#) project uses support teams or "caring teams" to provide in-home and community-based support for caregivers and persons with Alzheimer's disease and related dementias. Caring teams have monthly meetings to coordinate the time and tasks of the team and reflect on their experiences with the client. [North Carolina's](#) family caregiver support programs and community-based organizations have partnered together to implement support teams as part of their outreach to community organizations.
 - **Virginia's** ADDGS program supports the [Caregivers Community Network](#) that is part of James Madison University's Institute for Innovation in Health and Human Services. The program provides training to the institute's nursing and social work students to conduct respite services for people with Alzheimer's in the community.
 - **Michigan's** ADDGS grant enables care recipients and caregivers to receive "[wraparound](#)" services. These are services that extend beyond respite services. Wraparound is an approach in which mental health,

public health, and aging services systems collaborate in developing community models of support for people with dementia and family members involved in their care. This project links individuals with dementia who exhibit acute behavioral symptoms of distress and their families with an array of wraparound services and support.

Additional Information

The Administration on Aging has developed eight toolkits in this series that focus on different aspects of providing home and community-based services to people with dementia and their caregivers. These online toolkits are available at [the Administration on Aging Alzheimer's Disease Program webpage](#). Toolkit subjects include:

1. Consumer-Directed Care
2. Disaster Preparedness
3. Resources for Individuals and Families
4. Serving African American Families
5. Serving Asian and Pacific Islander Families
6. Serving Hispanic Families
7. Single Point of Entry Systems
8. Supporting Family Caregivers