

Serving African American Families

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



alzheimer's 
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A TOOLKIT FOR
THE AGING NETWORK


INTERNATIONAL

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



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About This Toolkit: Serving African American Families

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

Alzheimer's disease has been identified as an emerging public health crisis among African American communities. This silent epidemic of Alzheimer's has slowly invaded the African American community and will continue to grow as numbers of African American baby boomers enter the age of risk. Furthermore, health risks and barriers such as culture, lack of awareness, and limited local services will exacerbate the epidemic. Caregivers will continue to play a major role in providing care. Therefore, families need education about dementia and access to dementia-capable services in their community. **This toolkit outlines actions states can take to elevate awareness about dementia and caregiver support in African American communities, and provides links to local dementia-capable services.**

The Serving African American Families Toolkit:

- Outlines the importance of addressing issues of outreach and support for African American families coping with dementia.
- Defines dementia-capable services and how states can best serve African American families.
- Illustrates how outreach and support play a critical role in increasing home and community-based services while decreasing institutional care.
- Offers a number of resources that are model programs or 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 the States (ADDGS) program.
- Summarizes four key actions states can take when developing successful African American outreach/support programs. These key actions are:
 1. Provide culturally appropriate information on dementia and caregiving.
 2. Increase awareness through community outreach, education, and networking.
 3. Provide access to local dementia-capable resources.
 4. Support caregivers by developing dementia-capable services in the community.

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

Promising Practices: Serving African American Families

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

Why Address Outreach and Care for African Americans with Dementia?

- Alzheimer's disease is a devastating degenerative disease that causes memory loss, challenging behavior problems, and severe functional limitations. According to the Alzheimer's Association's *2008 Alzheimer's Disease Facts and Figures*, an estimated 5.2 million Americans have Alzheimer's disease. But the disease is more prevalent among African Americans than among Caucasians—with estimates ranging from 14 percent to almost 100 percent higher. The number of African Americans at risk for Alzheimer at age 65 or older is expected to more than double to 6.9 million by 2030. African Americans constitute 12 percent of the American population, almost 35 million individuals.
- African Americans experience higher rates of high blood pressure, high cholesterol, and diabetes, which place them at greater risk of developing dementia.
- Caring for persons with dementia poses special challenges, especially the challenge of a prolonged caregiver role. More African Americans than Caucasians care for relatives with dementia, and they are less likely to ask for support. Caring for a loved one is considered a responsibility and not a burden. Therefore, the impact may be greater for this population.
- Many barriers in African American communities prevent early diagnosis and treatment.
 - Lack of awareness. There is a general belief that dementia is a normal aging process or a mental illness. Symptoms are often unrecognized until elders are unable to fulfill their family/social roles. As a result, services are not used until late in the disease, limiting the effectiveness of treatments that depend upon early intervention.
 - Cultural barriers. The general mistrust of traditional medical institutions, culturally insensitive medical professionals, and dissatisfaction with health care systems often leads to care by alternative health care providers. The fear of intrusion by government may compound the problem.
 - Limited services. Culturally proficient care for African Americans is limited in communities.

What Are Dementia-Capable Services?

To be dementia capable, individuals who assist consumers to access home and community-based services (HCBS) must be

- skilled at identifying people with Alzheimer's disease,

- knowledgeable about the kinds of services that can help people with dementia and their caregivers, and
- capable of providing linkages to other agencies and community organizations that can help.

To make informed choices, consumers must be empowered to identify, understand, and access dementia-capable community services.

To best serve African American families, HCBS providers need to recognize that:

- Families are the primary source of support.
- Families make different choices based on cultural perspective.
- Understanding and acceptance of cultural view points are essential when adapting service delivery systems.

Serving African American Families

States can engage in four key activities to provide outreach and support for African American families coping with dementia:

1. Provide culturally appropriate information on dementia and caregiving.
2. Increase awareness through family and community outreach, education, and networking.
3. Link to local dementia-capable resources and services.
4. Support caregivers by developing dementia-capable services in the community.

Promising Practices for Each Key Activity

1. Provide culturally appropriate information on dementia and caregiving

A key element to modernizing aging services is diversity outreach. First steps to creating an effective diversity outreach program to African Americans are to:

- Understand populations and cultures of African American communities.
- Disseminate culturally appropriate information on dementia.

A. Understand populations and cultures of African American communities

Each person and each family are different. However, health care issues and cultural barriers associated with Alzheimer's disease amplify unawareness of the disease among African Americans and the growing risks they face with regard to dementia. An understanding of African American communities is essential to realize how the disease impacts community perceptions, caregiving practices, and health risks. For example, African Americans may have a higher risk for diabetes, a risk factor for Alzheimer's and vascular dementia. In addition, the terms "dementia" and "support

groups” may have negative connotations. The **Kentucky** Alzheimer’s Disease Demonstration Grants to the States (ADDGS) program found that terms such as “memory loss” and “fellowship groups,” respectively, may be more effective. The family plays an important role in the community. African American families often have multigenerational households and multiple decision makers in the home.

The following links offer specific information on African American populations and cultures:

- The [U.S. Census Bureau](#) shows the population trends of African Americans. The [Office on Minority Health](#) provides an overview of demographic information, health conditions, and disparities of the African American population.
- [African Americans and Alzheimer’s Disease: The Silent Epidemic](#), by the Alzheimer’s Association, reports on the scope and nature of Alzheimer’s disease within the African American population.
- The University of **North Carolina’s** Institute on Aging offers an extensive [Bibliography](#) on social and behavioral research on dementia in African American populations.
- Researchers have a better understanding of the linkage between dementia and heart disease and other diseases like diabetes. The [Health Power for Minorities](#) Web site provides authoritative, user-friendly, culturally relevant health information and promotion messages to improve the health of multicultural populations. The Administration on Aging, [National Institutes of Health](#), [Centers for Disease Control and Prevention](#), American Heart Association, and the National Diabetes Association provide options for prevention measures for better health.

The Administration on Aging’s National Resource Center developed cultural outreach tools by analyzing ADDGS programs and interviewing experts who develop or administer these programs:

- ADDGS [Lessons Learned in Cultural Outreach](#): Based on an ADDGS/ Technical Assistance Center teleconference with experts, this paper is an overview of ADDGS-funded programs that focus on the following issues: Identifying, acknowledging, and addressing cultural and organizational obstacles early; developing partnerships; and sustaining relationships.
- *Case Study – ADDGS Program: Cross-State Report on Initiative Targeting Limited English-Speaking Populations and African American Communities* (p. 14–20). This case study observes barriers and challenges, and demonstrates how three ADDGS programs in **Florida, Kentucky, and Washington, DC** overcome these challenges and offer dementia outreach to African American families.

B. Disseminate culturally appropriate information on dementia

States can offer culturally appropriate materials that incorporate traditional norms and values that reflect the community. This can be accomplished by evaluating existing culturally proficient materials and deciding whether to: (1) use existing materials, or (2) develop new materials.

1. Use existing culturally proficient materials

It may be advantageous to use existing culturally proficient educational materials before creating new materials. Information about dementia, caregiving, and educational materials has been developed by reputable organizations. The Administration on Aging's Web site showcases numerous ADDGS programs and products that target diverse families and caregivers. The [Alzheimer's Association](#) created a special section on their Web site called [African Americans and Alzheimer's Disease](#), which outlines information and resources for African Americans. The National Institute on Aging/Alzheimer's Disease Education and Referral (ADEAR) Center, the National Institutes of Health, and the Family Caregiver Alliance offer information on dementia and caregiver assistance. Examples of products geared for the African American community include:

- [Is it Alzheimer's or Just Signs of Aging? 10 Signs Every African American Should Know](#) (Alzheimer's Association)
- *Ageing with Grace: African Americans and Alzheimer's Disease* (District of Columbia Department of Aging and the Alzheimer's Association)
- *The Book of Alzheimer's for African Americans Churches* (Funded by AoA's ADDGS program and produced by the University of Kentucky Sanders-Brown Center on Aging, Division of Aging Services and the Alzheimer's Association)
- [Staying Strong: Stress Relief for the African American Caregiver](#) (Alzheimer's Association)
- [Keeping your Mind Sharp: Brain Health and African Americans](#) (Alzheimer's Association)

2. Develop new materials

States can develop dementia-specific materials to incorporate the cultural beliefs and practices of their targeted population. An effective way to attain this goal is to involve key community constituents early in the planning process. The following publications provide cultural guidance information:

- [The Dementia Care Network Replication Manual](#) offers tips to developing written communications. This manual was funded by ADDGS and produced by the Alzheimer's Association, California Southland Chapter.

- [*A Patient-Centered Guide to Implementing Language Access Services in Healthcare Organizations*](#) developed by the Office of Minority Health, U.S. Department of Health and Human Services, provides tips on cultural implications, insights into developing new materials, and other recommendations.

2. Increase awareness through family and community outreach, education, and networking

Most families are not aware of how Alzheimer's disease affects caregivers or the various services that may be available to help them. Raising awareness about dementia and care for families empowers caregivers to make informed choices about the most appropriate care, thus mitigating the impact on family caregivers. Programs can be developed to:

- Reach out to families in their homes to train caregivers about dementia and how to access services.
- Build a presence in community; train local community organizations about dementia and linkages to dementia-capable services.

A. Reach out to families in their homes to train caregivers about dementia and how to access services

By offering individualized support and training to families, states can assist minority caregivers to overcome cultural isolation. Examples of ADDGS-funded programs that provide unique individual connections and training include:

- **Florida's** ADDGS S.T.A.R.S. and Beyond program identifies African American families coping with cognitive impairment in rural areas in the Florida panhandle and recruits volunteers from faith-based congregations to conduct door-to-door outreach in their neighborhoods. Volunteers offer basic information on dementia and distribute the [*Florida Consumer Resource Guide*](#) that lists services available in their communities.
- **Colorado** is building on the work of their successful Savvy Caregiver, an evidence-based dementia care training program that was originally developed by the Department of Family Practice and Community Health at the University of Minnesota and the local chapter of the Alzheimer's Association. The program is designed to train family and professional caregivers about dementia and skills needed to mediate the challenges of caring for a person with cognitive impairment. Colorado is expanding this program to include training for diverse caregivers including African Americans.
- **North Carolina's** ADDGS [*Project C.A.R.E*](#) offers caregivers of people with dementia in urban, minority communities a personalized approach. Through family consultants, families are offered in-home assessment and care planning, a simplified determination of eligibility, a wide degree of flexibility and choice in the use of respite funding, and ongoing case management. The

family consultants also provide education and training for caregivers and respite providers and serve as a link for families to other long-term care resources.

- **Oklahoma's** ADDGS program hired a family counselor who worked directly with churches in the African American community. The family counselor visits homes of potential clients to conduct preliminary needs assessments, connect families with information and services, and schedule family for volunteer respite services.

B. Build a presence in the community; train local organizations about dementia and linkages to dementia-capable services

Families in underserved areas generally respond to community leaders and organizations they know and trust. This trust is extremely important when delivering services to African American communities and can be helpful in overcoming several cultural barriers.

There are many ways to cultivate partnerships with leaders or local organizations. Strategies include: hiring staff from African American communities, supporting ethnic-based organizations and businesses, locating services physically within the community, forming advisory committees of community leaders, and working with faith-based and service organizations. However, community organizations and community leaders often serve a multitude of community needs. Before embarking on a partnership with community leaders or organizations, take into account their many obligations, respect their priorities, and be prepared to adjust arrangements when necessary. Examples of programs that build partnerships with community leaders and organizations include:

- [California's Dementia Care Network](#) with community service providers is a framework to provide resources to diverse communities through collaborative network of partners. A comprehensive manual that includes developing strategic partnerships within multicultural communities was developed. The African American Education and Outreach section includes a how-to guide to community education and outreach, marketing, capacity building, as well as coordination of services and program expansion. One key to California's successful ADDGS programs is the hiring of Care Advocates. These individuals bring culturally appropriate support and coordination services directly to family caregivers in their homes. The Care Advocates receive the training they need to understand the caregiver's needs, provide counseling, and serve as a connection to appropriate community services.
- Many ADDGS programs such as [Kentucky](#), **Florida**, **South Carolina**, **Tennessee**, **Alabama**, **California**, and **Oklahoma** work with African American faith-based organizations to build coalitions of volunteers to provide information, outreach to the community, and provide respite care. Kentucky and community ministers developed a resource manual with comprehensive information under one cover and a chapter on maintaining the spirituality of

the individual with Alzheimer's. This resource guide was provided to African American churches for their libraries.

One key to prolonging home care is to ensure quality care of HCBS. For families coping with dementia, local organizations and HCBS must be dementia capable. However, many service providers lack training and knowledge about Alzheimer's and the capacity to link clients to appropriate care. Programs that provide training to local organizations to identify cognitive changes in older adults and make appropriate referrals include:

- **South Carolina's** ADDGS program trains church congregation members to be family consultants. These family consultants provide outreach and education and are taught to recognize early stages of Alzheimer's.
- **Texas'** ADDGS Systems Navigator program trains system navigators—volunteer workers who provide individualized in-home support and assume the caregiver role for the family.
- **REACHOUT Florida**, a state-funded program partly modeled after ADDGS Florida's S.T.A.R.S program, trained professional staff and volunteers of local organizations about dementia. In turn, they served as community ambassadors at local events educating African Americans about dementia resources and services. This program was implemented by the Florida Department of Elder Affairs and the Alzheimer's Association. The program was a catalyst to incorporating diversity outreach into state-funded Alzheimer services.

3. Link to local dementia-capable resources and services

Many minority families coping with memory loss resist seeking help or feel lost trying to navigate through the maze of the health care system. States and local communities may offer programs that produce a higher quality of life, but the challenge lies in connecting families in need with dementia-capable resources.

Single points of entry, such as [Aging and Disability Resource Centers](#) (ADRCs), reduce service fragmentation and simplify access to dementia-capable long-term support and services. Caregivers no longer have to seek services from multiple locations or providers. ADRCs should be dementia capable and connected to resources with expertise on dementia. ADDGS programs have partnered with ADRCs to assist families with cognitive impairment:

- **Minnesota** used ADDGS funds to make its ADRC dementia capable. For example, it revised the referral database used by staff of the state's telephone information system, [Senior LinkAge Line™](#), so that when contacts about a person with dementia are identified, the caller is referred first to the Alzheimer's Association for help with defining care needs and selecting service providers. Changes were also made to computerized intake and self-assessment forms.

Single points of entry and ADRCs can link to the following resources:

- [Local chapters of the Alzheimer's Association](#) offer a wide range of dementia-specific [services](#), including care consultation, and referrals to community service providers that can accommodate the person's dementia-related care needs, educational programs, family caregiver training, and support groups for the person with dementia and the family. Local chapters have a 24/7 Helpline to help callers at any time.
- [24/7 Helpline](#) provides reliable information and support to individuals affected by dementia. The toll-free number, developed by the Alzheimer's Association, is available any time, day or night, at **1-800-272-3900**. The Helpline's highly trained and knowledgeable staff can help with: understanding memory loss, dementia, and Alzheimer's; challenging behaviors; general information about aging and brain health; skills to provide quality care and to find the best care from professionals; legal, financial, and living-arrangement decisions; and caregiver stress.
- The Alzheimer's Association's [CareSource™](#) is an easy-to-use, one-stop resource about finding and planning 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. Some of the programs include:
 - [Lotsa Helping Hands](#). This interactive calendar 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®, the Senior Housing Finder is the first online nationwide database for locating dementia care. The tool allows you to search for licensed senior housing by geographic area, housing type, availability, and level of dementia care offered.
 - [CareFinder™](#). This site helps you 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. States can integrate CareFinder with their state ADRC or resource system.
 - **Virginia** links the CareFinder to its official state resource on health and aging, [Virginia's Senior Navigator](#). A CareFinder link is located in the Related Links section at the bottom of the Alzheimer's and Dementia Caregiving page.
 - **Arkansas** added the link to their state's [GetCare/Bridging Gap](#) Alzheimer's information and support Web site. The link is located under Other Resources.

- [Eldercare Locator](#) 1-800-677-1116. The U.S. Administration on Aging links those who need assistance with state and local area agencies on aging and community-based organizations.
- [Message Board](#). This online service allows caregivers to share challenges and solutions with other caregivers. Support and advice moderated by Alzheimer's Association care consultants.

4. Support caregivers by developing dementia-capable services in the community

Family caregivers of persons with dementia provide more hours of help, on average, than caregivers caring for individuals with other conditions. As dementia progresses, caregiving hours increase. As a result, caregivers may experience high levels of stress and depression, which increases the likelihood of institutionalization of the recipient. Family caregivers need respite—time away from the recipient. However, in African American communities, a limited number of dementia-capable services provide respite care. The following are services that support a healthier lifestyle for caregivers:

- Care and counseling consultation
- Respite care and adult day care services

A. Care and counseling consultation

Care and counseling consultation for the person with memory impairment offers insight into the best type of services needed for the individual. This process of correctly identifying persons with dementia and their needs is crucial in guiding them to appropriate services.

- The **District of Columbia** and the **Kentucky** ADDGS programs provide comprehensive assessment and service coordination services. The District of Columbia also provides care counseling to family members.

Family caregivers' responsibilities vary depending on what stage of Alzheimer's disease their loved one is experiencing. For this reason, caregivers' needs have to be assessed and reassessed. Caregiver assessments can help to identify what existing resources are available to help them carry out their responsibilities.

- **North Carolina's** ADDGS program [Project C.A.R.E.](#), provides in-home comprehensive assessment of dementia caregivers in urban minority communities.

B. Respite care and adult day care services

States can encourage healthy lifestyles for families by offering African American caregivers an option of dementia-capable respite and adult day care services. Respite care needs range from grocery shopping to doctor appointments.

Caregivers sorely need their own support services and the flexibility to accommodate their busy lifestyles. Many ADDGS programs offer that flexibility by providing a voucher system—a consumer-directed care approach—that gives caregivers a fixed stipend to purchase a range of respite services: adult day services, overnight care, chore/homemaker services, companion services, and in-home services. The following are examples of ADDGS Consumer-Directed Care programs, other respite programs, and adult day care services:

- **District of Columbia’s** ADDGS program continues to offer a consumer-directed care program for African Americans and Sunday respite program. The program trains adult day care staff to implement a Montessori-based program in adult day centers serving mainly African Americans. Montessori-based programming has emphasizes sensory engagement and task completion.
- **Georgia’s** Caregiver Time Out is a respite program that reimburses caregivers of persons with dementia an average of \$100 per month for respite services (up to \$1,200 per year). Caregivers may choose respite services (not to exceed 1 year) in the form of in-home services, adult day care, and overnight respite.
- **North Carolina’s** ADDGS [Project C.A.R.E.](#) uses a consumer-directed, family consultant model to provide comprehensive respite support to dementia caregivers in urban areas. Caregivers may spend up to \$1,500 a year toward respite services. Families may 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.
- **South Carolina’s** ADDGS program also provides vouchers for respite care. Vouchers are used for families to select services from an expanded list of providers, including possible family members or neighbors, and provide information on options about community-based services.
- **Alabama’s** and **North Carolina’s** ADDGS programs have deployed [Support Teams](#) or Caring Teams that assist with in-home respite services for caregivers.
- **New Jersey’s** ADDGS program offers support to caregivers through environmental interventions. This program offers training to care managers, providers and volunteers who provide home safety assessments and home modifications to families coping with dementia.

Additional Information

The U.S. Administration on Aging has developed eight toolkits in this series that focus on different aspects of providing HCBS to people with dementia and their caregivers. These online toolkits are available at [AoA’s Alzheimer’s Program website](#). Toolkit titles 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