



Dementia and Brain Health

The Role of Area
Agencies on Aging

**NATIONAL ASSOCIATION OF
AREA AGENCIES ON AGING**



advocacy | action | answers on aging



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Introduction to Dementia and Brain Health

As the number of older adults living in the United States grows, the number of individuals living with dementia grows along with it. People who live with dementia and their caregivers often require or benefit from a broad array of services and supports that help them continue living in the community. As a result, Area Agencies on Aging (AAAs), which have decades of experience helping older adults and people with disabilities remain in their homes and communities, are at the front lines of providing critical services to individuals with dementia and their caregivers.

The National Institute on Aging (NIA) defines dementia as “the loss of cognitive functioning—thinking, remembering and reasoning—and behavioral abilities to such an extent that it interferes with a person’s daily life and activities.” There are many types of dementia, but the most common is Alzheimer’s disease.¹ While age is the greatest risk factor for Alzheimer’s disease and other forms of dementia, other risk factors include genetics/family history, smoking and alcohol use, high cholesterol levels, diabetes and mild cognitive impairment.²

Researchers estimate that in 2019 nearly six million Americans of all ages are living with Alzheimer’s disease and that this number could reach 14 million by the year 2050.³ One study reports that 14 percent of individuals older than 71 are living with dementia.⁴ Eighty percent of people with dementia live in the community and nearly a quarter of them live alone.⁵ Additionally, there are more than 16 million caregivers of people living with dementia in the United States.⁶ AAA programs support people with dementia and their caregivers and help them continue living in their homes and communities throughout the various stages of dementia.

Even with the large numbers of people diagnosed with dementia, many individuals who otherwise would likely meet the diagnostic criteria for Alzheimer’s disease or other forms of dementia are undiagnosed.⁷ Additionally, research shows that fewer than half of Medicare



beneficiaries who have a diagnosis of Alzheimer's disease or a related dementia in their Medicare records report having been told of their diagnosis.⁸ Unfortunately, this means that many individuals with dementia remain undiagnosed or unaware of their diagnosis, and may not seek the support they need.

Although dementia is often considered to be a disease faced by older adults, younger people can be diagnosed with dementia as well. Approximately five percent of all individuals living with dementia in the United States have younger-onset (also referred to as early-onset) dementia and are younger than 65.⁹ And because some of those living with early-onset dementia are in their 30s and 40s, the condition can impact their ability to raise children and continue employment, as well as save for retirement, health care, long-term care and other expenses.

Caregiving

People with dementia, particularly those in the middle and later stages of their disease progression, require support, which is a hallmark of all programs provided by AAAs. Eighty-eight percent of individuals with dementia living in the community need assistance with self-care, mobility and household activities, compared to 43 percent of those who do not have dementia.¹⁰ As a result, AAAs, family and friend caregivers, and formal, or paid, caregivers, all play a critical role in supporting individuals living with dementia as they remain in the community.



The Dementia Care Coordination Program: Jefferson Area Board for Aging Charlottesville, VA

The Jefferson Area Board for Aging (JABA), an Area Agency on Aging serving older adults in Central Virginia, in partnership with the University of Virginia's Memory and Aging Care Clinic and the state's Department for Aging and Rehabilitative Services, implemented the Dementia Care Coordination Program pilot. This program, funded by the U.S. Administration for Community Living's Alzheimer's Disease Initiative—Specialized Supportive Services Program between 2015 and 2018, created a replicable model for providing integrated care for individuals living with dementia and their caregivers.

JABA and the Memory and Aging Care Clinic each hired Dementia Care Coordinators, who were certified as Options Counselors and received training on dementia and caregiving, dementia symptoms and best practice management methods, as well as services and resources available through the Aging Network and the University of Virginia Health System.

The program enrolled individuals who had received a dementia diagnosis, largely receiving referrals from the Memory and Aging Care Clinic. Upon enrolling in the program, each participant received a home visit, which allowed Care Coordinators to assess the client's home environment, better understand their needs and develop relationships with them and their families. While Care Coordinators initially provided home visits only to individuals who lived within a 90-minute drive of Charlottesville, program directors quickly realized that the home visit was a vital component of the

program and expanded home visits to all clients regardless of distance.

Dementia Care Coordinators also provided individuals and their caregivers with a starter packet of resources and connected them to services and supports. They held monthly check-in calls with program participants and conducted annual follow-up home visits to collect outcomes data and measures of satisfaction. The program developed a checklist for the monthly calls that included questions on changes in sleep, behavior, appetite and other issues that might suggest a need to return to the clinic or contact a health care provider. If it was recommended that individuals living with dementia return to the clinic, the Dementia Care Coordinators attended these clinic visits to support the individual.

Follow-up reports indicate that the program resulted in positive outcomes for individuals living with dementia and caregivers who participated in the program. After a one-year follow-up consultation, staff reported that rates of depression significantly improved for both participants with dementia and their caregivers. Caregivers also reported significantly lower caregiver burdens, and that participants had significantly fewer behavioral symptoms at the follow-up visit. Program leaders are currently exploring ways to sustain the program. In 2019, Virginia's General Assembly considered a bill, which was not passed, that would have funded two Dementia Care Coordinators to provide the Dementia Care Coordination Program.

Caring for individuals with dementia can be challenging, both physically and emotionally. Research indicates that family members or other informal caregivers provide 83 percent of all care for older adults living in the community with dementia.¹¹ Additional research shows that 22 percent of these informal caregivers report emotional difficulty, compared to 9.5 percent of informal caregivers of older adults who do not have dementia.¹² Other studies have found that caregivers of people living with dementia report higher levels of depression and anxiety, and approximately one-third of these caregivers meet the diagnostic criteria for depression.¹³

Additionally, caregivers of people living with dementia spend more time per week on caregiving responsibilities and assist with more activities of daily living (ADLs) than other caregivers. ADLs are essential functions such as transferring (e.g., getting in and out of beds or chairs), eating, bathing, dressing and going to the toilet. According to the National Alliance for Caregiving, the average caregiver of a person living with dementia provides four more hours of care per week than a caregiver of an individual without dementia.¹⁴ Caregivers of people living with dementia are also more likely to help with more ADLs on average (2.1 out of six ADLs) compared to other caregivers (1.5 out of six) and one in 10 report that they help with six ADLs.¹⁵

Treatment

Despite decades of research, there are no medicines to prevent, cure or slow the progression of Alzheimer's or other dementias. However, there are treatments, such as cholinesterase inhibitors, that can help alleviate the symptoms of dementia.¹⁶ Researchers continue to examine ways to prevent or delay dementia and a 2017 review by the National Academies of Sciences, Engineering, and Medicine found encouraging evidence that three types of interventions—cognitive training, blood pressure control and increased physical activity—could help prevent or slow cognitive decline and dementia.¹⁷ Similarly, the Centers for Disease Control and Prevention (CDC)



supports the concept that brain health is connected to heart health. Reducing risk factors for heart problems can also reduce risk for brain problems, including dementia.¹⁸ The CDC recommends steps such as controlling blood pressure, eating healthy foods, limiting alcohol, managing diabetes, not smoking and staying active as ways to reduce risk factors for dementia.¹⁹

This research points to a need to support efforts that promote brain health, which NIA defines as “the ability to remember, learn, plan, concentrate and maintain a clear, active mind. It’s being able to draw on the strengths of your brain—information management, logic, judgement, perspective and wisdom.”²⁰ While some risk factors for dementia are genetic, studies indicate that controlling certain lifestyle and environmental factors may help individuals overcome some of these risks and maintain cognition.²¹ Brain health focuses on treating the brain in the same way that doctors typically treat other organs such as the heart. Brain health experts believe that it may be possible to keep the brain healthy longer by addressing modifiable risk factors such as diet and exercise.

The Role of Area Agencies on Aging

AAAs provide a wide range of services and supports that are utilized by individuals with dementia and their

caregivers. Through the Older Americans Act (OAA), Medicaid and other sources of funding, AAAs provide a vital array of community services, including congregate and home-delivered meals, evidence-based disease prevention and health promotion programs, the National Family Caregiver Support Program, elder rights protection activities, and supportive services such as transportation, case management and in-home services. According to the *2017 National Survey Report of Area Agencies on Aging*, most AAAs provide services that are highly utilized by people with dementia and their caregivers, including respite care (92 percent), homemaker assistance (74 percent), personal care (74 percent) and chore services (57 percent).²² Another area in which AAAs have an impact is in educating clients on addressing modifiable risk factors for dementia and developing programs that promote brain health.

Many AAAs are also involved in the administration of dementia-friendly communities. A dementia-friendly community is a village, town, city or county that is intentionally striving to be informed, safe and respectful of individuals with dementia, their families and caregivers, while providing supportive options that foster quality of life. Dementia-friendly communities work across community sectors to be more supportive of people living with dementia and their caregivers.

This report summarizes the results of a 2019 poll conducted by the National Association of Area Agencies on Aging (n4a) to examine the ways AAAs serve individuals impacted by dementia—both those living with dementia and their caregivers—and how AAAs are addressing the topic of brain health. The report highlights the estimated prevalence of AAA clients who are impacted by dementia and how AAAs respond to their needs through programs, including those exclusively targeted to individuals impacted by dementia, and programs available to individuals younger than 60 living with dementia and their caregivers. Targeted staff training, as well as technical assistance interests of AAAs around these

critical topics are also examined. The report also describes specific AAA programming related to brain health and provides examples of activities that AAAs are currently implementing, as well as more in-depth case examples of AAAs that are actively engaged in this work.

Methodology

Under a grant from the U.S. Administration on Aging (AoA), part of the U.S. Administration for Community Living (ACL), n4a disseminated a poll on dementia and brain health to learn about the programs and services AAAs currently have and are developing to address dementia and improve brain health. The poll consisted of 19 questions and was conducted between February and April 2019. The poll was disseminated to all 622 Area Agencies on Aging and received 155 responses, resulting in a 25 percent response rate.

Topics addressed in the poll included:

- the proportion of AAA clients who have or display symptoms of dementia or who are caregivers of people living with dementia;
- AAA services that are exclusively for people with dementia and/or their caregivers;
- AAA services that are utilized by the general/broader population but are targeted to or highly used by people with dementia and/or their caregivers;
- AAA services for individuals younger than the age of 60 with dementia and/or their caregivers;
- AAA involvement in dementia-friendly communities;
- staff training on brain health and dementia topics;
- AAA services specifically aimed at addressing brain health; and
- training and technical assistance interests of AAAs in serving individuals living with dementia and supporting brain health.

case study

The LGBT Dementia Care Project: San Francisco Department of Aging and Adult Services San Francisco, CA



Legislation passed in 2012 by the San Francisco Board of Supervisors created an LGBT Aging Policy Task Force to study issues affecting LGBT older adults and to issue recommendations to address them. In its 2014 report, the Task Force found that LGBT seniors face unique challenges in accessing dementia care and that service providers lack cultural competency to serve them.

As a result, the San Francisco AAA engaged the Alzheimer's Association, along with partner organizations Openhouse, an LGBT senior housing provider, and Family Caregiver Alliance. Together, they developed and implemented the LGBT Dementia Care Project. The aim of the program is to create a more welcoming environment for LGBT seniors seeking dementia care services by providing training to health and social service providers on the care needs of LGBT seniors living with dementia and their caregivers. The three-hour trainings are free to attendees, who can also access free continuing education credits (CEUs).

The successful program has overcome numerous challenges. The first challenge faced by the Project was in developing the curriculum, because the team knew of no existing trainings on the topic that they could reference. To start, the team refined Openhouse curriculum on cultural humility and blended it with Alzheimer's Association training on

dementia. A primary focus of the training is building awareness of LGBT issues. The team found that simply telling stories of historical discrimination seems to have an impact. Another challenge has been in spreading the word about the program and getting agencies to participate, partially because many agencies find it challenging to set aside staff time for a three-hour training session. This challenge led the Project to develop a shorter, one-hour version of the training. A crucial element of the program is selecting the right people to be trainers. The Project has found that in addition to needing knowledge on dementia, trainers need to be knowledgeable and comfortable discussing LGBT issues or be a member of the LGBT community themselves.

To date, the team has provided 66 trainings to more than 1,300 staff and volunteers. Nearly all attendees said that they would be able to integrate the new information and skills into their work settings, and 68 percent strongly agree that the training improved their awareness and understanding of dementia and caregiving for LGBT older adults. The team has also developed a follow-up 90-minute training focused on communication strategies. As a next step, the Project hopes to develop a Dementia Care Network, which is a model designed to address gaps for dementia care and services in underserved communities.



Findings

AAAs report that they deliver a broad range of programs and services that serve high numbers of individuals living with dementia and their caregivers. In addition to the support provided through their core services, many AAAs have a program or service that is exclusively designed for individuals living with dementia and/or their caregivers. Some AAAs report having a program or service that has broad eligibility criteria but is highly used by or targeted to individuals with dementia. Other AAAs report having programs available to individuals younger than 60 (the eligibility age for many Older Americans Act programs) who are living with dementia. AAAs also shared information on how they are addressing brain health concerns, and how staff are trained on the topics of dementia and brain health. Finally, AAAs identified their top training and technical assistance interests in these areas.

Many AAA Clients Are Impacted by Dementia

As previously noted, knowing that many individuals living with dementia may not have received a formal diagnosis (or have a diagnosis in their medical record but are not informed of it), AAA respondents were asked to estimate the proportion of clients who live with dementia, regardless of whether they have received a formal diagnosis, or the client reported dementia. Forty-four percent of respondents estimated that 21 to 40 percent of

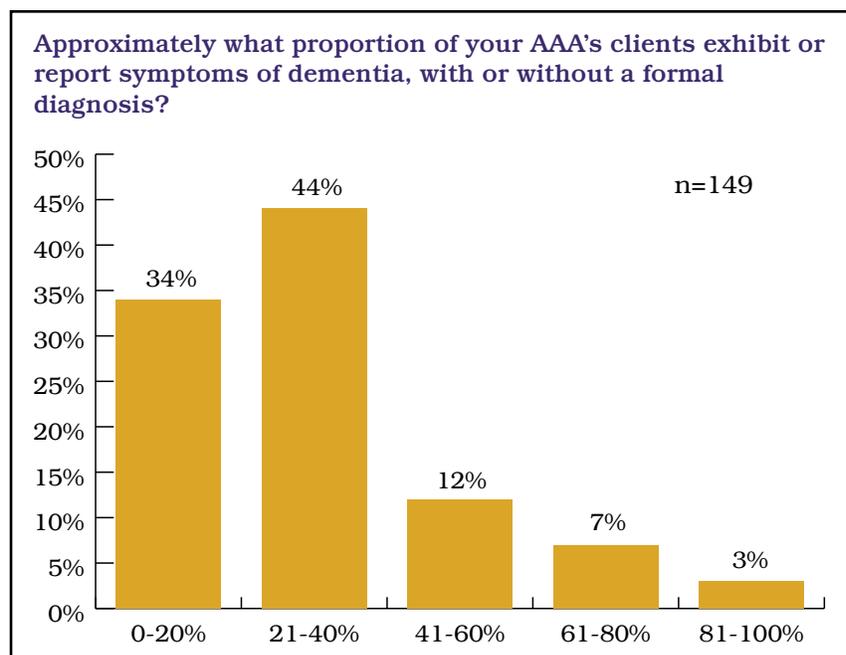
More than half of AAA respondents estimated that more than 40 percent of their caregiver clients are caregivers of people with dementia.

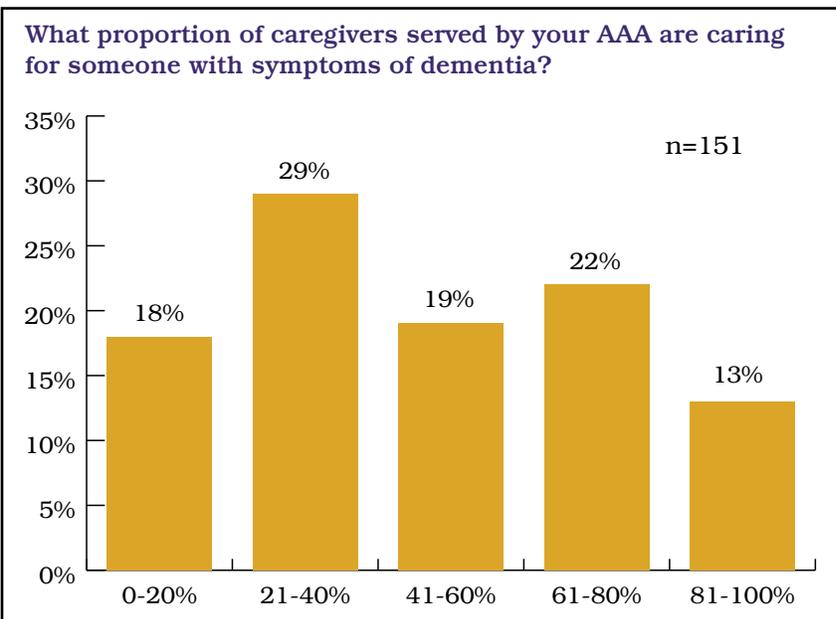
Services that individuals with dementia may benefit from include many of the most commonly provided AAA services, including case management, options counseling, in-home services, personal care, transportation and respite services, as well as other caregiver supports, including education, training and support groups.

their clients are living with dementia while 22 percent of AAA respondents estimate that more than 40 percent of their clients are living with dementia.

Similarly, when asked to estimate the proportion of caregivers of people living with dementia their agency serves, 29 percent of AAAs indicate that 21 to 40 percent of the caregivers they serve were caregivers of people with dementia. However, more than half of AAA respondents estimated that more than 40 percent of their caregiver clients are caregivers of people with dementia.

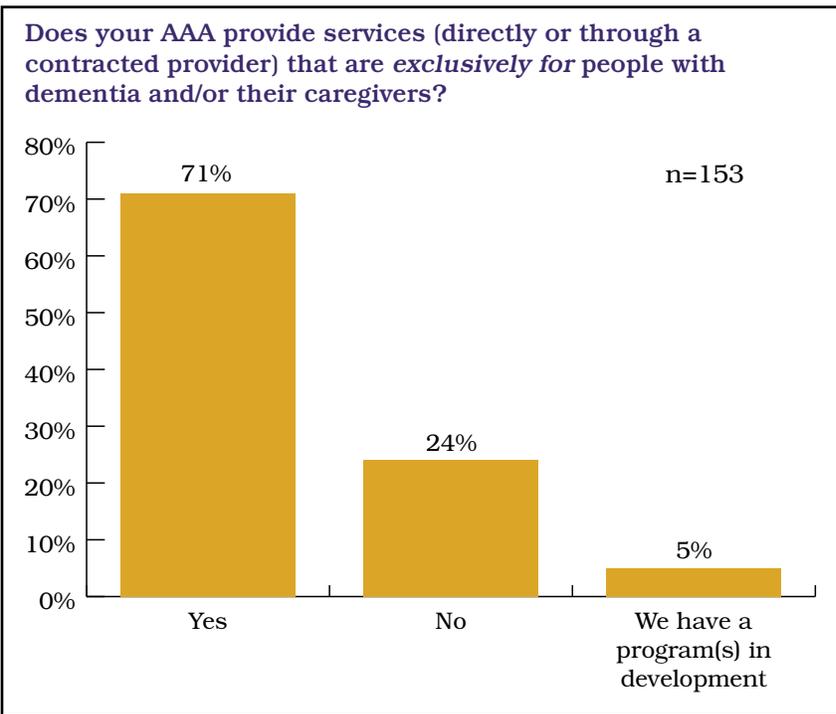
The range of appropriate AAA services and supports used by people living with dementia and their caregivers varies based on the individual's disease course, progression and their support system. Typically, individuals in the early stages of dementia require less assistance than those in the middle or later stages. People living with advanced dementia will likely need assistance with activities of daily living such as eating, using the toilet and dressing. Services that individuals with dementia may benefit from include many of the most commonly provided AAA services, including case management, options counseling, in-home services, personal care, transportation and respite services, as well as other caregiver supports, including education, training and support groups.





Most AAAs Provide Services Exclusively for People With Dementia and/or Caregivers

More than 70 percent of survey respondents indicated that their AAA provides services that are designed for people living with dementia and/or their caregivers.



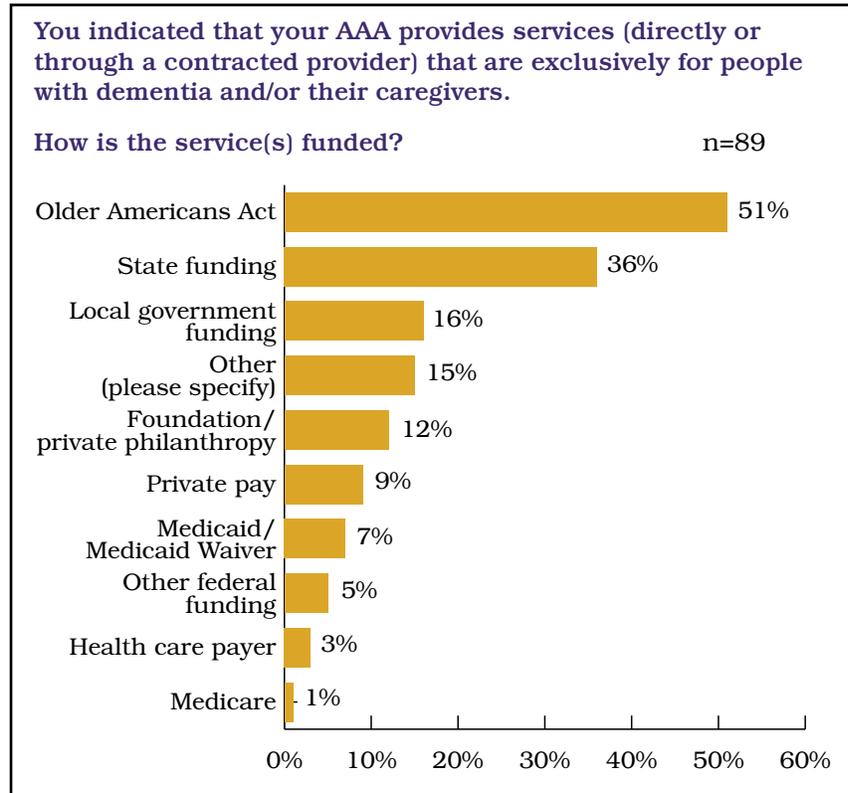
Programs that AAAs reported operating that are specifically targeted for people with dementia and/or their caregivers include:

- **Memory Cafés:** A memory café is a social gathering for people with dementia and their caregivers that can be held at a variety of locations, including community centers, libraries and museums. While memory cafés have varied formats, they all provide opportunities for people with dementia and their caregivers to talk with others who are in similar situations.
- **Respite Care Programs:** Respite programs provide short-term breaks for primary caregivers that can last a few hours, a weekend, several days or weeks. Respite care can be provided at home or in another setting such as a residential care facility or an adult day center.²³
- **Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II):** An evidence-based psychosocial and behavioral training intervention for caregivers of people with Alzheimer’s disease or a related dementia, REACH II is designed to reduce caregiver burden and depression, improve self-care, provide social support and help caregivers learn how to manage difficult behaviors.²⁴

In addition to providing support for individuals with dementia and their caregivers at all stages of the disease progression, several AAAs reported offering programs that provide support to those who are in the early stages of the disease course. These programs include specific classes or social clubs for people with early stage dementia and their caregivers. AAAs also offer workshops and educational events aimed at caregivers of people living with dementia. Other AAAs reported partnering with local Alzheimer’s Association chapters to offer support groups for people impacted by dementia and provide caregiver supports, respite care or other supplemental services.

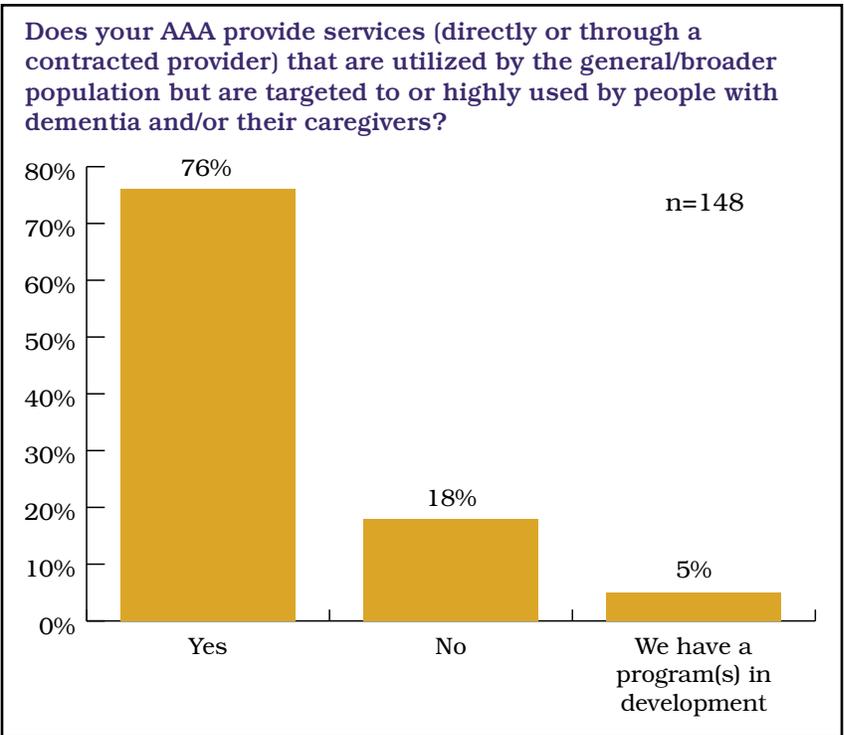
AAAs providing services exclusively for people with dementia and/or their caregivers reported that these services are most commonly funded through the OAA (51 percent), followed by state funding (36 percent). Other sources of funding include funding from local government

(16 percent), foundation/private philanthropy (12 percent) and other sources. AAAs that responded in the “Other” category reported funding sources that include a partnership with a local Alzheimer’s Association chapter, private donations, a partnership with a local university and sales tax revenue.



More Than Three-Quarters of AAAs Provide Services for a Broader Population That Are Targeted to or Highly Utilized by People With Dementia or Caregivers

More than 75 percent of responding AAAs indicated that they provide programs or services that have broader eligibility criteria yet are specifically targeted to or highly utilized by people with dementia or their caregivers. These programs include adult day services, respite care, case management, in-home services, and family caregiver support programs, as well as homemaker and personal care services.

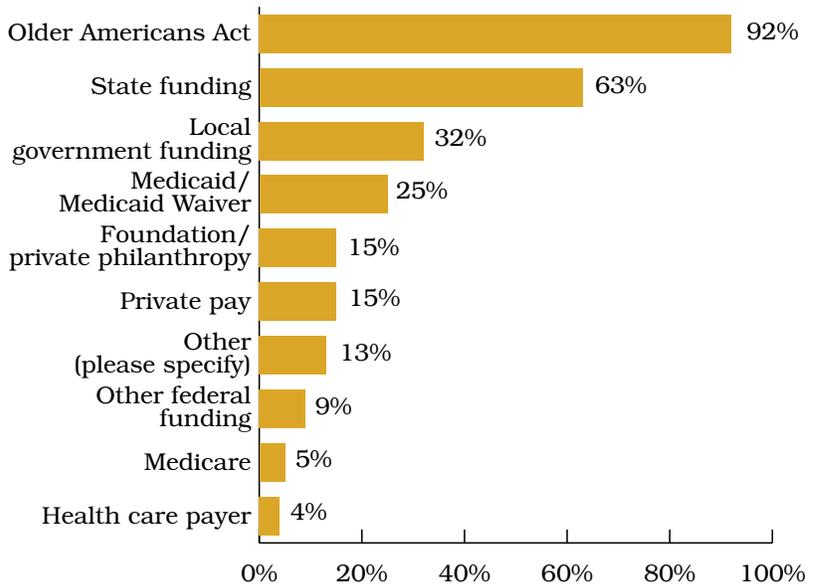


AAA respondents were also asked to share the funding sources for these programs. The top three funding sources are consistent with programs targeted *exclusively* for people with dementia: OAA, state funding and local government funding. Other highly ranked funding sources include Medicaid/Medicaid waiver, foundation/private philanthropy and private pay.



You indicated that your AAA provides services (directly or through a contracted provider) that are utilized by the general/broader population but are targeted to or highly used by people with dementia and/or their caregivers.

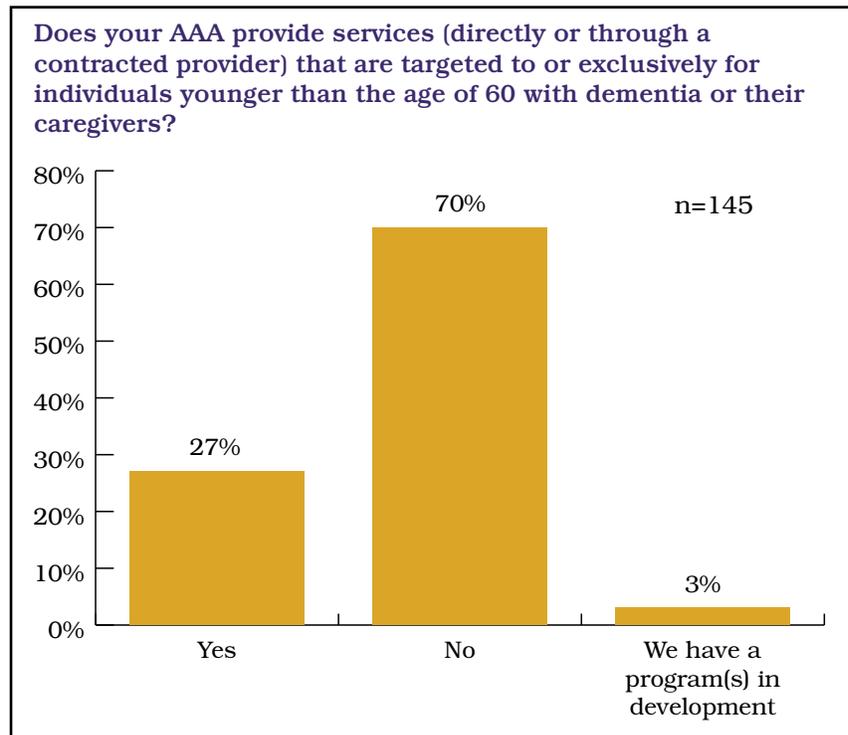
How is the service(s) funded?



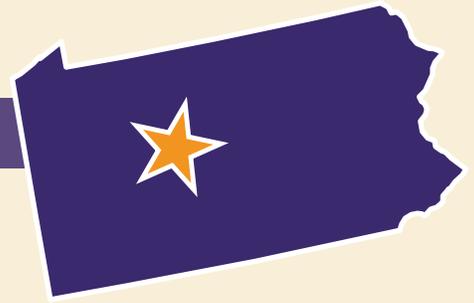
More Than One-Quarter of AAAs Have Programs and Services for Individuals Younger Than Age 60 With Dementia or Their Caregivers

AAAs were also asked to indicate whether they provide services to individuals younger than 60 living with dementia or caregivers of people with dementia who are under the age of 60. In general, OAA, which is a substantial funding source for most AAAs, requires that funds be used for individuals who are age 60 and older. However, funding from the National Family Caregiver Support Program (OAA Title III E) may be used to support adult family members or informal caregivers who provide care to individuals 60 years and older or individuals of any age with Alzheimer’s disease or a related dementia. Additionally, many AAAs have a broader array of funding streams that they can access, including other federal and state resources, to support this population.

Of the survey respondents, 27 percent indicated that they have a program specifically for individuals younger than 60 who are living with dementia and/or their caregivers, with three percent reporting that they have a program in development for this population. Most of these programs provide support to caregivers and include respite care, information and assistance and support groups. Seventy percent of AAAs indicated that they do not yet have a program or service specifically targeted to individuals younger than 60 living with dementia or their caregivers. However, the services traditionally provided by AAAs inherently address the needs of individuals living with dementia and can support this population if the funding source can be secured.



AAA respondents with a program that targets individuals with dementia who are younger than 60 or their caregivers were asked to provide information on how the program is funded. The most common funding source is state funding (68 percent), followed by OAA Title III E funding (63 percent). Other common responses included local government funding (26 percent), Medicaid/Medicaid Waiver funding (24 percent), other funding (18 percent)



Housing and Community Living for Individuals With Dementia: Clearfield County AAA

Clearfield, PA

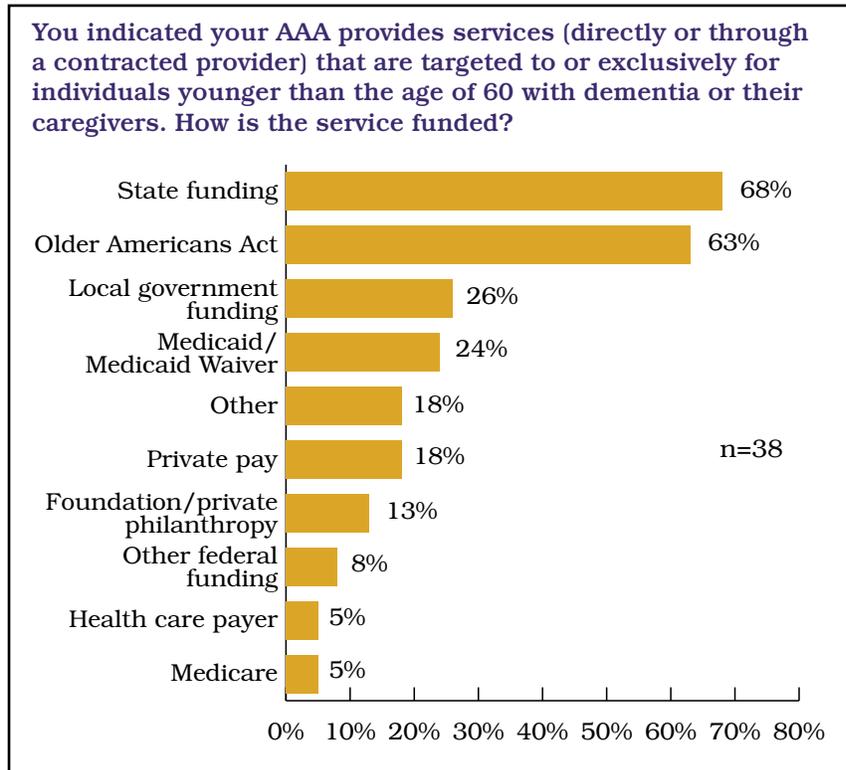
When the Clearfield County AAA performed a gap analysis in its region, it discovered that shortages in housing and the number of direct care workers were major challenges affecting older adults in the area, especially those living with dementia. There were waitlists for all the senior housing options. In addition, the senior housing in the community consists solely of high-rise buildings, which the AAA found to be less appealing to most of the older adults in the area, who were used to living in single-family homes. To address this gap, the AAA began seeking alternative housing in the area, which led to the development of a long-term rental agreement between the AAA and a local church, allowing three older women, two of whom have dementia, to transition out of a nursing home and into a house owned by the church. Each of these residents qualifies for Medicaid home and community-based services for eight hours a day, allowing the residents to have combined 24-hour coverage in the home. Once residents transitioned from the nursing home back to the community, staff observed that they experienced positive health outcomes, including no increase in medication use and the fact that the residents were able to maintain their weight. In addition, two of the participants transitioned to using walkers after having arrived in wheelchairs.

The Clearfield County AAA also explored purchasing Elderly Cottage Housing Opportunity (ECHO) Cottages. ECHO Cottages are accessory dwelling units that

families can install on their properties for older relatives, which can provide housing for older adults in a mutually convenient location near family, thus reducing the need for paid care. Clearfield County AAA purchased its first ECHO Cottage in 2018. The cottage has since been placed on a local family's property for an older family member.

After these successes, Clearfield County AAA turned its focus to developing and implementing its broad community vision for community living for individuals with dementia, Village of Hope. Conceived as a MAGIC community, Village of Hope will offer Multi-Ability, Multi-Generational, Inclusive Community/Co-Living. Developed in partnership with Dr. Bill Thomas and the Minka Team, Village of Hope will offer Minka homes, which are compact, easily-assembled, pre-fabricated homes designed using universal design principles. Universal design is the theory that products and environments should be designed to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. Village of Hope will also include shared community space for art, music, other activities, amenities, and home and community-based services. Mature Resources Foundation, a nonprofit affiliate of the AAA, has purchased an empty elementary school building to serve as the community center, along with 23 acres of land for the community. The Foundation has purchased the first Minka cottage and is in the process of securing additional units.

and private pay (18 percent). Examples of other funding sources include financial support from the local Alzheimer’s Association chapter, state sales tax, and AAA sub-contractors that provide additional funding to support this population.



Nearly Half of AAA Respondents Are Involved in or Leading a Dementia-Friendly Community Initiative

Dementia-friendly communities are villages, towns, cities or counties that are intentionally striving to be informed, safe and respectful of individuals living with dementia, their families and caregivers, and to provide supportive options that enhance their quality of life. Dementia Friendly America, administered by n4a in collaboration with a national council that consists of more than 40 organizations, supports a national network of communities working to ensure that they are equipped to support people living with dementia and their caregivers. Since Dementia Friendly America launched in 2015, more than 250 communities in the United States have

Many AAAs recognize the need for communities to adopt practices that support the ability of individuals with dementia to continue living in their homes and communities.

Forty-four percent of AAAs indicated that their community is involved in a dementia-friendly community initiative.

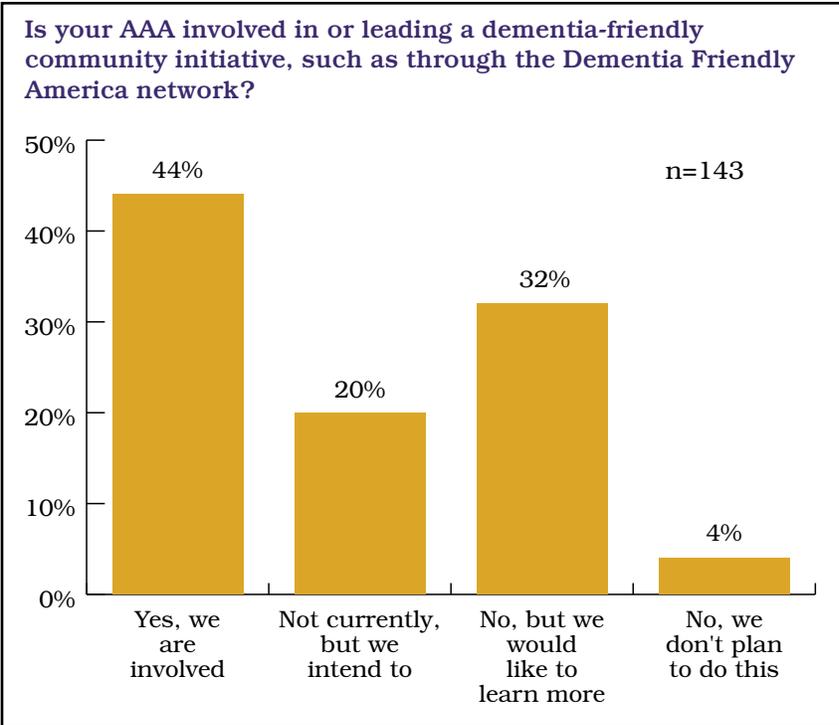
embarked on this work and are examining how their communities can be better places to live for people with dementia and their caregivers.

Many AAAs recognize the need for their communities to adopt practices that support the ability of individuals with dementia to continue living in their homes and communities. When asked whether their AAA is involved in, or leading, a dementia-friendly community initiative, such as through the Dementia Friendly America network of communities, forty-four percent of responding AAAs indicate yes. Twenty percent indicated that they are not yet involved in or leading a dementia-friendly community initiative but that they intend to do so. Thirty-two percent indicated they are interested in learning more about this topic. Only four percent of survey respondents indicated they do not plan to engage in dementia-friendly community work.

Examples of AAA leadership in supporting dementia-friendly community initiatives include:

- Providing community education on dementia by serving as Dementia Champions or Master Champions through the Dementia Friends program;ⁱ
- Partnering with a local Alzheimer's Association chapter to spearhead a dementia-friendly community initiative;
- Partnering with local law enforcement and first responders to offer training and develop a Dementia Friendly Law Enforcement and First Response toolkit; and
- Integrating dementia friendliness into existing age-friendly work to ensure it permeates throughout the community's efforts.

ⁱ Dementia Friends is a global movement to help everyone in a community understand what dementia is and how it affects people. A Dementia Friend is someone who, through viewing a series of online videos or attending an in-person session, learns about what it's like to live with dementia and then turns that understanding into action. Learn more at www.dementiafriendsusa.org.



AAA Staff Training on Dementia and Brain Health

Ninety-one percent of AAA respondents provide training to staff that focuses on ways to recognize the signs and symptoms of dementia in clients.

The poll also asked AAAs to share information on how they provide training on dementia and/or brain health. Given the fact that approximately one in 10 people older than 65 have Alzheimer’s disease (the most common form of dementia), ensuring that AAA staff have knowledge of dementia is critically important.²⁵ AAAs need information and training on the needs of people living with dementia, as well as services and supports that can be used to address them.

As research supports the idea that some risk factors for dementia and other cognitive issues are related to lifestyle and environmental factors that can be controlled and altered to help maintain cognition,²⁶ the poll also focused on how AAAs are promoting brain health.

Ninety-one percent of AAA respondents indicated that they provide training to staff that focuses on ways to recognize the signs and symptoms of dementia in clients.



The Model for Alzheimer’s/Dementia Services: United Way of Tarrant County AAA

Fort Worth, TX

The United Way of Tarrant County/Area Agency on Aging (UWTCAAA) began the Model for Alzheimer’s/Dementia Services (MAS) in 2015 with funding from the U.S. Administration for Community Living’s (ACL) Alzheimer’s Disease Initiative—Specialized Supportive Services grant program. As part of The MAS program, UWTCAAA aimed to identify and connect with people living with dementia who live alone and their caregivers. The goal of the program is to support and prolong safe and independent living in the community for people with dementia who are living alone. Key project partners include Meals on Wheels, Inc. of Tarrant County, Alzheimer’s Association—North Central Texas Chapter, the Aging and Disability Resource Center of Tarrant County, and a host of community-based providers.

Referrals to the MAS program come primarily through Meals on Wheels staff who are trained to identify possible

dementia by using the Eight-Item Interview to Differentiate Aging and Dementia (also known as an AD8 screening).^{iv} Meals on Wheels staff also ask individuals for a caregiver’s contact information, which they then provide to the AAA’s Dementia Options Counselor along with the individual’s AD8 score. After referral, the Dementia Options Counselor works with the caregiver to create a person-centered plan to discuss long-term plans and available resources and supports, including respite care. The Dementia Options Counselor helps caregivers identify immediate goals that can be accomplished within a month. Once these goals are met, the Dementia Options Counselor and caregiver then establish longer-term, three-month goals.

^{iv} The AD8 is a brief, eight-item screening tool used to distinguish individuals with normal cognitive function from those with dementia or mild cognitive impairment. Learn more at www.ncbi.nlm.nih.gov/pubmed/16116116.

Other common training topics include an overview of the forms of dementia (72 percent) and steps to take if a client identifies concerns related to dementia, or if a screening tool indicates potential dementia (69 percent). Forty-four percent of AAAs provide staff training on brain health issues, including risk reduction and prevention strategies. Forty percent of AAAs provide staff training on cognitive assessments for individuals. Twelve percent of AAAs indicated they provide other trainings to staff, including

The MAS program has identified 106 individuals with dementia who live alone, exceeding its goal of 100 individuals. UWTCAAA also far exceeded its target of connecting 30 percent of individuals living alone with dementia to services, doing so for nearly 87 percent of individuals.

The MAS program also provides respite for caregivers through partner organizations, as well as the evidence-based Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II) intervention through the Alzheimer’s Association’s North Central Texas chapter. During the grant period, UWTCAAA added additional respite providers, in addition to adult day care and institutional respite, after it discovered that there were not enough respite providers to meet the need. To increase access to culturally sensitive, evidence-based support services, the MAS program also added Spanish-speaking respite providers.

The program received an 18-month expansion grant from ACL to focus on the population of individuals with dementia living alone, called the Model for Alzheimer’s/Dementia Services Focused on People Living Alone (MASPLA). In

addition to identifying caregivers and connecting them to services, they will be working with the University of North Texas Health Science Center to provide medical residents to visit participants in their homes along with the case managers. Many individuals with dementia do not have a diagnosis, and UWTCAAA found that some services, such as adult day centers, require a formal diagnosis for admittance into the program. The medical residents will be able to assess and, as appropriate, provide a dementia diagnosis which will enable individuals with dementia to use these services. The MASPLA program also will include money management services through Guardianship Services and the Financial Exploitation and Prevention Center of Tarrant County and HomeMeds,^v an evidence-based, in-home medication management intervention. After a three-month planning period, the MASPLA program began providing services in June 2019.

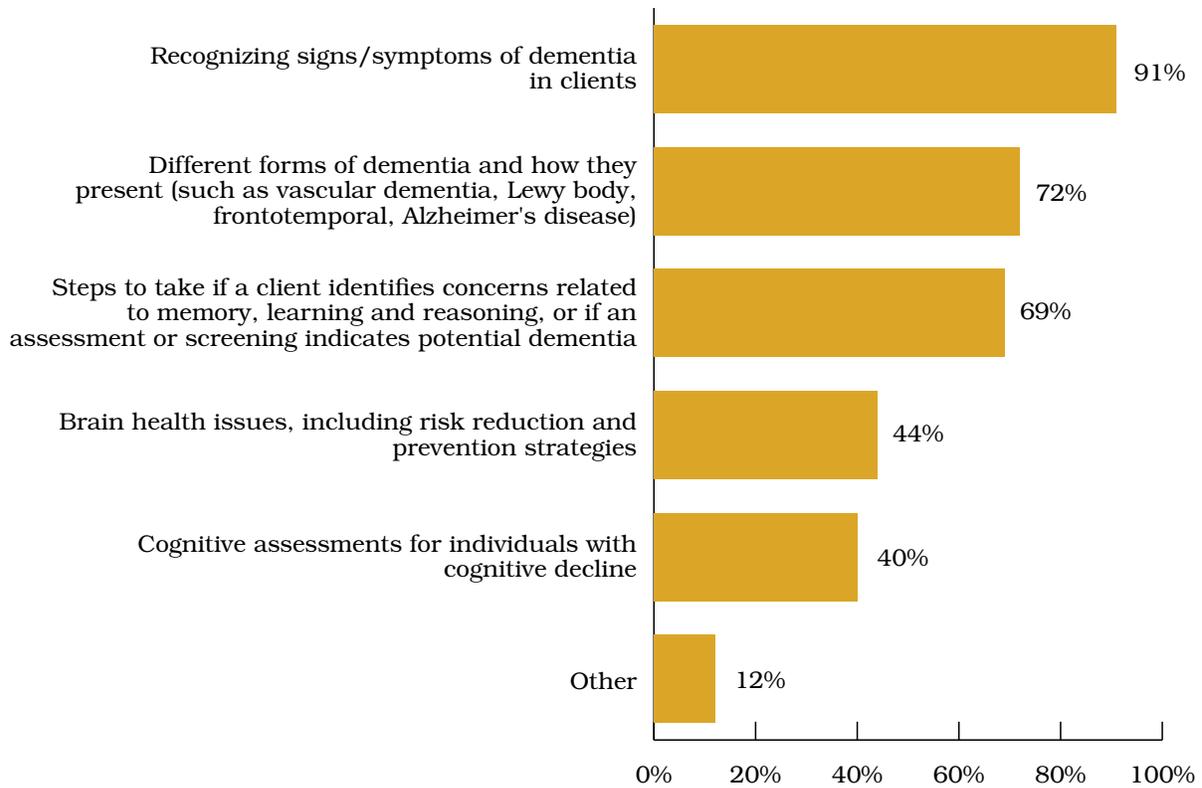
v HomeMeds is an evidence-based, in-home, medication review and intervention that includes a computerized risk assessment and alert process, plus a pharmacist review and recommendation for improvement. Learn more at <https://www.picf.org/homemedes>

Positive Approach to Careⁱⁱ developed by Teepa Snow; having staff attend or lead Dementia Friends sessions; and/or providing staff with opportunities to become certified in Dementia Dialogues.ⁱⁱⁱ

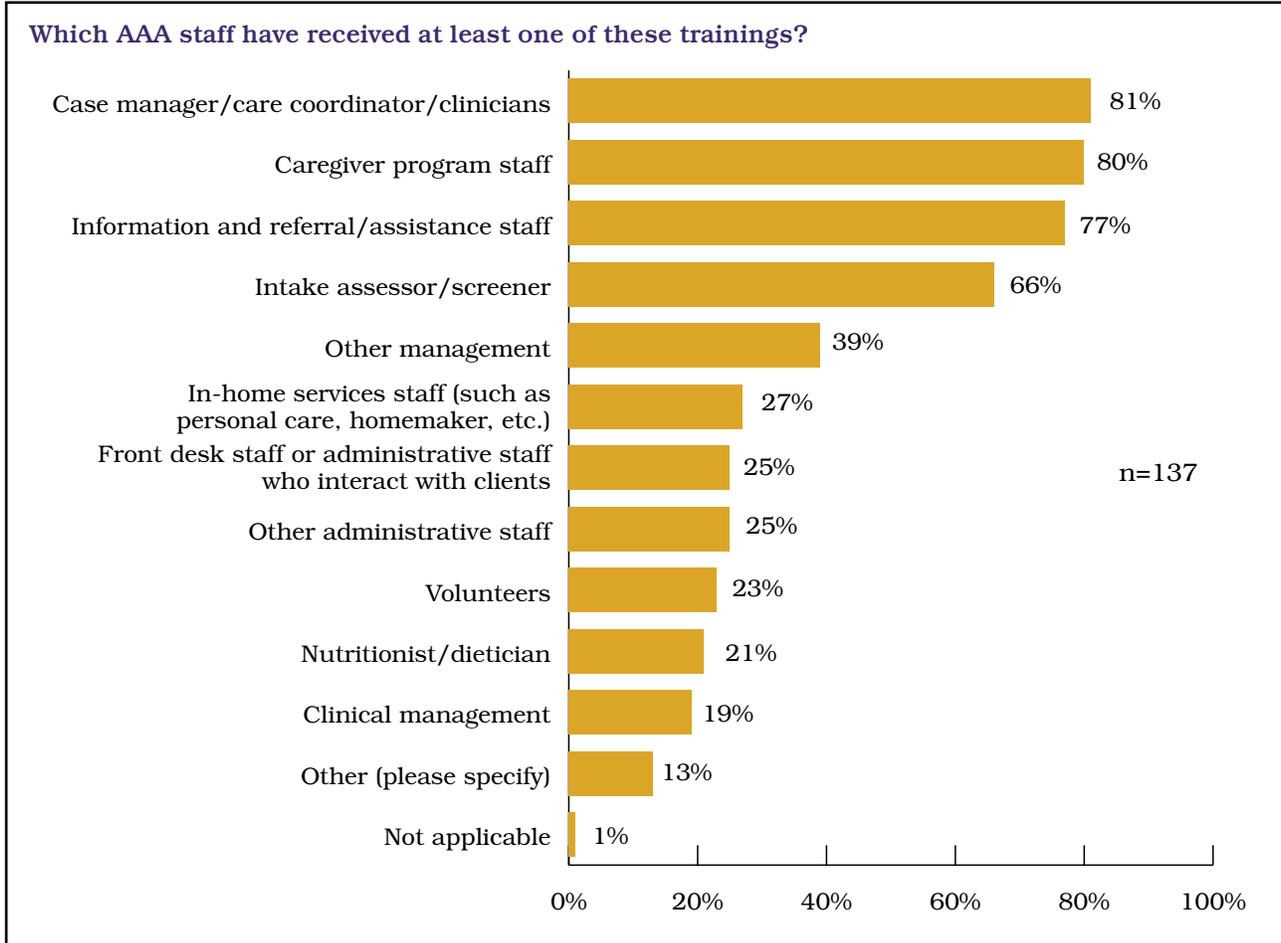
ii Positive Approach[®] to Care (PAC) provides a wide variety of services to enhance awareness and increase dementia care skills, including PAC Speakers, Trainers, Teepa Talks, and Certifications. Learn more at www.teepasnow.com.

iii Learn about Dementia Dialogues here: https://www.sc.edu/study/colleges_schools/public_health/research/research_centers/office_for_the_study_of_aging/projects_programs/dementia_dialogues/index.php.

Does your AAA staff receive formal training on any of the following topics? Please base your response on staff who interact with clients (e.g., case managers, clinicians, nurses, social workers, information and referral staff, or other client-facing staff).



According to AAA respondents, the staff most likely to receive these trainings include case managers, care coordinators or other clinicians (81 percent), followed by caregiver program staff (80 percent), information and referral/assistance staff (77 percent) and intake assessors/screeners (66 percent). Other staff roles that rank fairly highly for training include other management (39 percent), in-home services staff (27 percent) and front-desk or administrative staff who interact with clients (25 percent).



Brain Health Programs or Services at AAAs

Nineteen percent of responding AAAs indicated that they currently have a specific brain health program or service, with an additional seven percent indicating they have a program in development. Most AAAs (70 percent) indicated they do not currently have a specific brain health program or service. A small number of AAAs (four percent) indicated “other.” These AAAs tend to be indirectly involved in a brain health program or service or have an offering that does not meet the threshold for a standalone program or service. These activities include participating in Brain Games, a Tennessee initiative that promotes social activity and brain health education; mailing information on brain health to clients; and hosting speakers to deliver presentations on brain health.



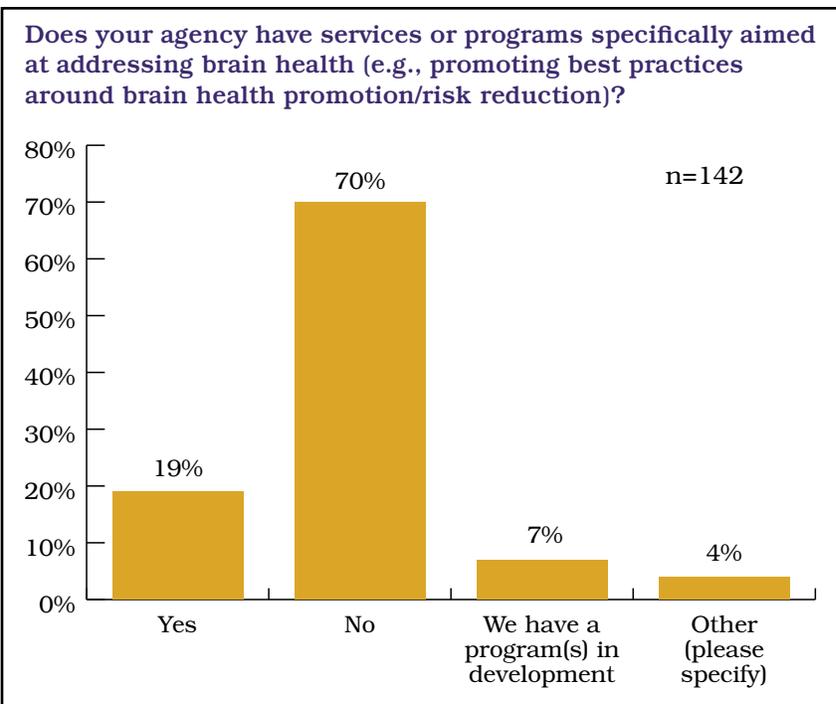
Examples of activities reported by AAAs that currently have specific brain health programs or services include:

- Organizing an annual brain health fair or periodic brain health presentations
- Offering Cranium Crunches^{iv} and health talks related to brain health and dementia at senior centers
- Working with a Cooperative Extension partner to implement a pilot program called Wits Workout at congregate meal sites

Although the percentage of AAAs reporting that they currently have or are developing a program specifically tailored to brain health is relatively low (nearly one in five agencies), the *2017 National Survey Report of Area Agencies on Aging* indicated that nearly all AAAs offer a range of services and supports that research indicates directly support brain health, including nutrition programs, evidence-based health promotion programs targeted to heart health and physical activities, and social engagement opportunities, which can be used as a foundation to advance AAA efforts in this space. In fact, one responding AAA indicated that it is in the early stages of developing a brain boot camp program that will share information on the latest research in the areas of diet and nutrition, exercise, cognitive activity and social engagement, and using hands-on tools to help individuals incorporate these recommendations into a plan for healthy aging.

^{iv} Learn more about Cranium Crunches at www.activityconnection.com/ccbook.

Nearly all AAAs offer a range of services and supports that directly support brain health.

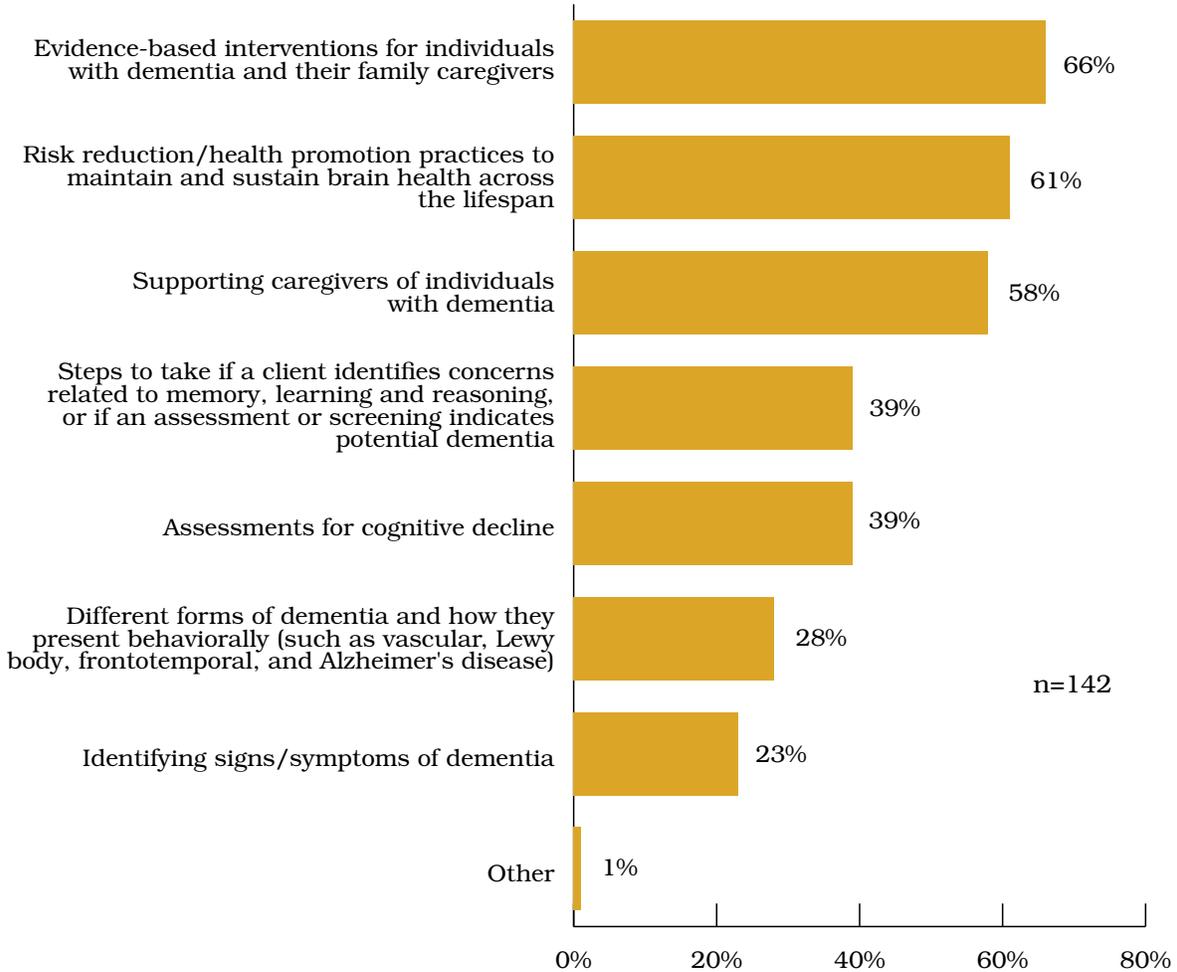


AAA Training and Technical Assistance Interests

AAAs realize that staff training is an essential component of the ability to effectively deliver services to people with dementia and their caregivers. When asked about their interests in training and technical assistance related to brain health and dementia, AAAs most often responded that they would like training and technical assistance on evidence-based interventions targeted to individuals with dementia and their family caregivers (66 percent). Also highly rated were risk reduction/health promotion practices to maintain and sustain brain health across the lifespan (61 percent), and supporting family caregivers of people living with dementia (58 percent).

Less highly ranked training and technical assistance interests include steps to take if a client identifies dementia concerns or if a screening indicates potential dementia (39 percent); assessments for cognitive decline (39 percent); information on the different forms of dementia (28 percent); and signs and symptoms of dementia (23 percent).

Select up to three areas of training and technical assistance related to dementia that would most benefit your staff/agency.



Summary

The core OAA services provided by AAAs are critical for supporting the needs of individuals with dementia as they continue living in their homes and communities.

AAAs provide vital support to America’s growing population of people living with dementia and their caregivers. A large proportion of their AAA clients have dementia or are caregivers of people living with dementia, and these numbers are expected to rise dramatically as the nation’s population of older adults continues to grow. Most AAAs are meeting the needs of these individuals through the development and delivery of programs and services exclusively for individuals with dementia and their caregivers.

More than three-quarters (76 percent) of AAA respondents reported having services that were highly utilized by people living with dementia and their caregivers.

While only 19 percent of AAAs currently have specialized brain health programs, nearly all AAAs provide a range of supportive services such as nutrition, evidence-based health promotion and social engagement programs that can promote brain health.

While more than 70 percent of responding AAAs have developed programs specifically for individuals with dementia and their caregivers, the core OAA services provided by AAAs are critical for supporting the needs of individuals with dementia as they continue living in their homes and communities. More than three-quarters (76 percent) of AAA respondents reported having services that were highly utilized by people living with dementia and their caregivers. These services include programs such as adult day services, respite services, case management, in-home services, family caregiver support programs, and homemaker and personal care services. In addition, 44 percent of responding AAAs reported that they are involved in a dementia-friendly community initiative.

The most common funding source for dementia programs offered by AAAs is the Older Americans Act, with the exception of direct services to individuals younger than 60 with dementia. However, government funding, whether from OAA, state or local sources, is the most common source of funding for all programs.

The vast majority, 91 percent, of AAAs provide training on signs and symptoms of dementia to their client-facing staff, and a majority provide training on different types of dementias, as well as steps to take if a client identifies concerns related to memory, learning and reasoning, or if an assessment or screening indicates potential dementia. The AAA staff most likely to receive training on dementia and brain health are those who typically are the first point of contact for individuals with dementia or their caregivers. These staff positions include case managers/care coordinators/clinicians, caregiver program staff, information and referral/assistance staff, and intake/assessment staff.

While only 19 percent of AAAs currently have specialized brain health programs, nearly all AAAs provide a range of supportive services such as nutrition, evidence-based health promotion and social engagement programs that can promote brain health.

Additionally, nearly half of AAAs (44 percent) indicated that they provide training on brain health issues to staff,



case study

Brain Health Fair: Bergen County Division of Senior Services

Hackensack, NJ

Learning about brain health doesn't have to be boring, as the Bergen County Division of Senior Services demonstrates with its Brain Health Fair. To fill gaps in knowledge about brain health, the AAA, located in Hackensack, NJ, has held a brain health fair for the past three years.

While there is a lot of information on Alzheimer's disease and other dementias, there is not nearly as much information available on modifiable risk factors for dementia. Therefore, the goals of the brain health fair are to educate older adults about modifiable risks, to provide a better understanding of how to optimize brain health through lifestyle changes, and to empower older adults to incorporate these changes into their lives—in an interactive and engaging format.

Located in a local library, the annual event features a series of speakers on topics such as the brain-body connection, nutrition for brain health, the importance of sleep and stress reduction. The fair also includes a variety of interactive activity stations that allow participants to put what they have learned into practice.

These stations feature activities such as kayaking, beanbag tosses and gardening—physical activities that are fun, but which also promote exercise and social engagement. Other activities have included brain games, yoga and a station demonstrating how to infuse water with herbs and fruit to make water more appealing to encourage hydration. The fair also hosts volunteers from an animal shelter who bring dogs that participants

with responses indicating that AAAs are eager to learn more about addressing this issue. Sixty-one percent are interested in learning more about risk reduction/health promotion practices to maintain and sustain brain health across the lifespan.

Given their vital role in supporting individuals with dementia and their caregivers as they continue living in the community, AAAs are well-positioned to address brain health by raising awareness and providing education on the ways that individuals can mitigate their risks for cognitive decline and dementia.

can interact with, and who discuss the benefits of pet ownership or fostering. Each interactive station has an accompanying fact sheet that describes how the activity encourages brain health.

Included in the event booklet is a “My Brain Health Plan” worksheet. This sheet features a table showing components of brain health including nutrition, physical activity and social engagement, providing information on how these factors contribute to brain health and a space that individuals can use to create a plan by filling in “what I will do” for each category. This worksheet encourages participants to apply what they have learned at the fair.

The speakers and activity leaders are volunteers from the community. Bergen County Division of Senior Services identifies the topics that local older adults are most interested in and contacts professionals who can address those areas. The fair is funded through the Older Americans Act and local resources.

The fair is attended by approximately 200 people, largely older adults. A combined report of survey responses from 2017 and 2018 found that 91 percent of respondents reported a better understanding of how to improve their brain health after attending the event, and 91 percent of attendees indicated that they were likely to use the ideas and techniques presented at the event.

The AAA also developed a presentation on the content of the brain health fair that can be provided in community centers, libraries and other locations across the county. To learn more about this program, contact Lorraine Joewono, Director of the Division of Senior Services, at 201.336.7418 and ljoewono@co.bergen.nj.us.

As trusted providers and coordinators of services in communities across the country, AAAs have always played a critical role in addressing the needs of older adults. This commitment is especially evident in how AAAs address dementia and brain health—by educating older adults and their caregivers on ways to prevent and slow dementia’s progress and supporting individuals and their caregivers with vital home and community-based services.



Further Reading

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About n4a

The National Association of Area Agencies on Aging (n4a) is a 501(c)(3) membership association representing America's national network of 622 Area Agencies on Aging (AAAs) and providing a voice in the nation's capital for the more than 250 Title VI Native American aging programs.

The fundamental mission of the AAAs and Title VI aging programs is to develop services that make it possible for older adults to continue living in their homes and communities as they age, thereby preserving their independence and dignity. These agencies coordinate and support a range of home and community-based services, including information and referral, home-delivered and congregate meals, in-home assistance, transportation, caregiver supports, evidence-based health promotion/disease prevention programs, employment services, adult day care and more.

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To learn more about trends in AAA programs and services, read the following reports produced by n4a's Capacity Building initiative. All are available online at www.n4a.org/buildingcapacity.

- **Housing and Homelessness: Services and Partnerships to Address a Growing Issue (2018)**
- **Rural AAAs: Structure and Services (2018)**
- **Measuring the Value of AAA Services: Making the Case to Health Care Partners (2018)**
- **Supporting America's Aging Prisoner Population: Opportunities & Challenges for Area Agencies on Aging (2017)**

Coming in 2020: National Survey of Area Agencies on Aging 2019 Report and Toolkit.



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