Innovations from the Field: How Area Agencies on Aging and Title VI Programs Address Brain Health

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Introduction

To meet the needs of the growing number of older adults living in the United States, Area Agencies on Aging (AAAs) and Title VI Native American Aging Programs (Title VI programs) funded by the Older Americans Act (OAA) offer an array of programs and services that promote healthy aging, including nutrition programs, evidence-based health promotion and disease prevention programs, exercise/movement classes, and social engagement activities. Research indicates that lifestyle factors affect the risk of cognitive decline and potentially dementia,¹ and that brain health is connected to physical health, and can be supported through nutrition, exercise and socialization.² To support the growing numbers of older adults living with dementia and their caregivers, 74 percent of AAAs target services to individuals living with dementia and their caregivers, and 37 percent of AAAs are involved in a dementia-friendly community initiative.³ AAAs and tribal governments are also implementing an array of programs specifically focused on brain health, targeting individuals with and without dementia. Some AAAs have partnered with university researchers or the Alzheimer's Association to develop and/or distribute brain health resource guides containing a variety of activities that may be conducted with older adults in real-time, or, during the COVID-19 pandemic, at home with caregivers or via video. Because evidence-based measures in this field are still being developed, AAAs and Title VI programs are relying on participant feedback and attendance figures to gauge the initial success of these initiatives.

This set of case studies, funded by the U.S. Administration for Community Living (ACL), builds upon a 2019 poll of AAAs conducted by the National Association of Area Agencies on Aging (n4a) about AAA programs and services to address dementia and improve brain health. The findings are described in the report, Dementia and Brain Health: The Role of Area Agencies on Aging⁴ and contextualized for the COVID-19 era in an ACL-n4a joint publication in the Public Policy and Aging Report.⁵ These case studies highlight innovative efforts that are being undertaken by AAAs and Title VI programs to address brain health from the perspective of educating caregivers and families as well as delivering programs to stimulate mental acuity among older adults experiencing Alzheimer's disease and/or related forms of dementia. We hope that sharing these case studies will encourage other AAAs and Title VI programs across the country to develop or implement innovative efforts to address the brain health of older adults in their own communities.
Peer-Reviewed Brain Health Curriculum Guide: AgeOptions, Oak Park, IL

As the Area Agency on Aging for suburban Cook County, IL, AgeOptions has partnered with University of Illinois Extension (Extension), part of the College of Agricultural, Consumer and Environmental Sciences at Urbana-Champaign, to distribute Wits Workout—a brain health resource guide for community leaders working with older adults.

To address a priority in its strategic plan, AgeOptions’ advisory council approached the university a few years ago, specifically seeking information and activities related to brain health. The advisory council was aware that the Extension’s family life educator had been conducting brain “exercise” classes for several years, engaging older African Americans twice monthly in a variety of memory-related activities with successful results and were interested in working with Age Options to expand the effort.

The resulting guide, Wits Workout, was written by the Extension’s current and former family life educators. AgeOptions provided $8,000 to Extension for the guide’s graphic design and the Extension funded the printing costs. Wits Workout is a printed, spiral-bound curriculum and guidebook consisting of 24 themed units addressing a wide range of brain health factors, such as diet, sleep, exercise, stress management, focus, attention and what Extension calls “forgetfulness contributors.” The guide’s two main goals are to provide purposeful opportunities for older adults to engage intellectually and to increase their socialization through ongoing group participation. It is not designed for older adults with dementia or other brain diseases, but rather focuses on the normal changes associated with memory and aging. By improving physical health through improved sleep and nutrition, managing stress, and increasing socialization opportunities, the hope is that the program will delay or reduce the onset of dementia and cognitive decline.

The curriculum was deliberately written using conversational, non-technical language so that lay leaders, such as community members, library staff and others, as well as older adults themselves, could lead their own groups using the guide’s exercises. Each activity within a given unit lasts five to 15 minutes with a single unit being completed in 60 to 90 minutes. The sessions can be modified and offered alone or presented as a series.

The Wits Workout curriculum was peer-reviewed by subject-matter specialists from Kansas State University and the Center for Brain Plasticity at the University of Illinois at Urbana-Champaign. The curriculum was also extensively pilot-tested over a period of months by AgeOptions and Extension. AgeOptions assisted in recruiting older adults to participate several times in a group setting at a nutrition site in suburban Cook County. As a result of the peer-review and pilot-testing processes, staff were able to update the curriculum before it was rolled out.
After pilot-testing was complete, AgeOptions and Extension held a variety of in-person and virtual train-the-trainer sessions between October and December 2019, with AgeOptions and Extension collaborating on some, and each organization also running its own. Illinois Extension, for example, presented the curriculum at the Illinois Recreation Therapy Association Conference. In total, approximately 285 librarians, nutrition site coordinators and others learned how to use the Wits Workout material.

The COVID-19 pandemic forestalled additional in-person training sessions but it has not stopped the momentum or the demand for the brain health curriculum. To ensure the program continued to be available during COVID-19, AgeOptions has provided stipends to libraries to help implement some of the exercises via Zoom or over the phone. In addition, evaluation of the curriculum is now underway with AgeOptions and Extension now working together to gather and publish research to make Wits Workout an evidence-based program. A virtual train-the-trainer session is also in the works.

Dementia-Friendly Community Action Program: Pyramid Lake Paiute Tribe, NV

Among the general U.S. population, one in 10 people older than age 65 is living with dementia. Among American Indians, however, the prevalence is estimated to be higher, with one study estimating that one in three people older than age 65 is expected to develop dementia, including Alzheimer’s disease. Awareness of this trend prompted the Numaga Senior Services Program of the Pyramid Lake Paiute Tribe to address the fact that it did not provide dementia training, education and awareness programming, nor was this type of programming covered by local tribal health services or the Indian Health Service generally.

The Numaga Senior Services Program, a Title VI grantee, turned to the Dementia Engagement, Education and Research (DEER) Program in the School of Community Health Sciences at the University of Nevada, Reno for assistance. The DEER Program is the administrative home for the Dementia Friendly Nevada effort. The DEER Program’s “research with” rather than “research on” approach empowered the Tribal community to set its own research agenda and create solutions to improve conditions related to dementia care among Pyramid Lake Paiute elders.

To this end, the Pyramid Lake Paiute Tribe, along with other Tribal and county partners, applied in 2018 for a $10,000 grant from the Nevada Aging and Disability Services Division (ADSD), which had been awarded an Alzheimer's Disease Initiative grant from ACL to launch Dementia Friendly Nevada in six communities. Pyramid Lake was the only tribe in Nevada to apply.

The Pyramid Lake Paiute Tribe’s dementia-friendly community action group was launched and led primarily by Numaga Senior Services with support from other Tribal departments, including the health center, diabetes program, social services and a senior advisory board engaging elders.
Initial conversation among these stakeholders gave rise to the Tribe’s new dementia-focused advisory group, **Pesa Sooname**. The group’s Northern Paiute name means “good thought” and “good think.” It is designed to promote good thoughts toward Tribal elders living with dementia and to protect stakeholders’ own good thinking (i.e., brain health).

Once Pesa Sooname launched, the second objective focused on facilitating and mobilizing community-driven change using the Dementia Friendly America model* to convene stakeholders, assess current strengths and gaps, analyze community needs, set goals and evaluate progress. Pesa Sooname partnered with the University’s Sanford Center for Aging to develop and administer a survey that was completed by 43 Tribal residents, caregivers, providers and others to better understand strengths and weaknesses in areas such as family support, clinical services and community-based care. Based on this assessment, Pesa Sooname set two goals: (1) enhance geriatric clinical services within the Tribal health center, and (2) identify gaps in education around dementia.

The community education goal gave rise to a year-long effort to provide formal and informal dementia education to families, elders, Tribal departments and neighboring tribes. In the spring and summer of 2018, a series of short, small-group workshops facilitated by university experts and designated Tribal “champions” explored the myths surrounding dementia, biomedical and social-relational perspectives, empathic communications strategies and more.

The workshops were a warm-up for a more ambitious statewide Tribal Summit on Brain Health and Dementia, convened by Pesa Sooname in August 2019. The Tribe used its ADSD grant to help fund the summit, including international speakers. OAA Title VI funds and Numaga Senior Services program funds provided nearly $4,000 in supplemental funding for the day-long event.

The summit, the first of its kind in Nevada, brought together 114 representatives from agencies, tribal organizations, and elders who represented 14 tribes in Nevada and other states. The gathering marked the roll-out of the Centers for Disease Control’s **Healthy Brain Initiative Roadmap for Indian Country**, a public health guide designed to support discussion about dementia and caregiving within tribal communities and to encourage a public health approach as part of a larger holistic response. The summit served as a networking hub, enabling Tribal representatives to connect on the issue for the first time. A hallmark of the summit was an appreciation and awareness of cultural traditions that the tribes can use to promote brain health, such as convening talking circles to discuss dementia. Prayer, song and other cultural traditions were incorporated into the event, along with a heart-and-brain healthy lunch.

During the COVID-19 pandemic, Dementia Friendly Nevada community actions groups, including Pesa Sooname, continue to meet online and plan to continue exploring cultural practices that can support risk reduction, education and care practices. The University is working with Pesa Sooname to identify new funding sources to continue the work.

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* Dementia Friendly America is a national network of communities, organizations and individuals seeking to ensure that communities across the U.S. are equipped to support people living with dementia and their caregivers. Dementia-friendly communities foster the ability of people living with dementia to remain in community and engage and thrive in day-to-day living. Dementia Friendly America is administered by n4a. Visit [www.dfamerica.org](http://www.dfamerica.org) for more information.
In South Carolina it is estimated that 11 percent of those age 65 years or older have Alzheimer’s or a related disorder. The South Carolina Appalachian Council of Governments (SCCOG), an Area Agency on Aging serving six upstate counties, teamed up with nearby Clemson University’s research-based Institute for Engaged Aging (IEA) to develop programming for adults living with early to mid-stage dementia.

The collaboration grew out of a series of community meetings sponsored by Clemson University that focused on ways to best deliver dementia services in the region. SCCOG and Clemson University’s IEA pooled resources with Pickens County (within SCCOG’s planning and service area) and the town of Central to raise matching funds for a $42,500 Permanent Improvement Project grant from the State Unit on Aging to renovate and re-open a closed senior center in Central. Central provided $14,500 toward the match in the form of a lease-free building, utilities, insurance and other services, while Clemson provided thousands of dollars’ worth of in-kind funding in the form of faculty time and supplies. The center re-opened in the fall of 2018 as the Central Community Center offering congregate meals, home-delivered meals and exercise programs to adults age 60 and older, a daily after-school program and a newly created Brain Health Club for adults living with dementia. The Club itself was publicized through brochures and the Alzheimer’s Association’s ongoing outreach.

Prior to its temporary closure in March 2020 due to COVID-19, the Brain Health Club regularly reached 10 to 11 people with two-hour sessions held twice weekly. Clemson University’s IEA placed up to five undergraduate students onsite to help staff the program, which was also supplemented with local volunteers. Club activities were guided by Alzheimer’s Association recommendations for promoting brain health, in combination with research conducted by Clemson students. Activities included music therapy, art therapy, crafts and social interactions. On occasion, participants were invited to read or perform music for the group to supplement other scheduled activities. These programmatic activities may have positive effects on disruptive behavior and anxiety among the participants with dementia, as well as reducing depression and improving quality of life. An added benefit of the program was respite for the participants’ caregivers.

The Brain Health Club’s operations, including the director’s salary, were supported for the first two years by funding from the state’s Department on Aging Alzheimer’s Resources Coordinating Center ($30,000). Group respite waivers from the Alzheimer’s Association provide continued coverage of the director’s salary ($10,000 per year).

Overall, SCCOG and the IEA considered the program a success, based on participants’ ongoing participation, the involvement of trained university students and volunteers, and the ability to offer scheduled respite to the participants’ caregivers. This program is meeting a critical need for brain health activities and caregiver respite in a rural area where such services are often limited. The long-term plan is to replicate the Brain Health Club model along with the programming for older adults and children in other rural counties in South Carolina. It is considered a cost-effective and financially sustainable model that does not rely exclusively on OAA funds.
As the county aging unit for Douglas County, WI, Senior Connections delivers the full range of OAA services on behalf of the Greater Wisconsin Agency on Aging Resources, Inc., the Area Agency on Aging that in turn provides aging programs and services for 70 counties and 11 tribes in Wisconsin. Brain health is a particular area of focus for Senior Connections, as the population of older Americans living with Alzheimer’s disease and related forms of dementia in Wisconsin is expected to increase from 115,000 in 2015 to 242,000 in 2040.

To respond to the growing needs of older adults in its community, Senior Connections crafted a flexible, relaxed brain health program that was based on research in the field. The program Senior Connections developed is a weekly brain health exercise program that engages approximately 15 older adults per session. The Whole Brain Workout is based on a curriculum (officially titled Whole Brain Workouts) written by Marge Engelman, PhD, a Wisconsin-based adult education specialist who has taught “aerobics of the mind” and similar topics to groups in retirement centers, senior centers and adult day centers. The entire curriculum includes 125 exercises that encompass humor, creativity, vocabulary, puzzles and numbers, as well as tools to help strengthen smell and taste, build spatial ability and more. These activities address several important aspects of brain health by engaging participants’ motor function, emotional function and tactile function.

In 2019, Senior Connections invited regular participants in the physical exercise programs it held at the senior center to join the brain health program once a week. Designed to run in the fall, winter and spring only, the program was open to all older adults in the community, with about 15 participants per session. Outreach was supplemented by posted flyers and a notice in the organization’s newsletter. The brain health program complemented ongoing programs already underway with this population, including promoting healthy nutrition, managing balance and other services focused on managing chronic conditions.

Senior Connections customized its Brain Health Workout to meet the specific needs of its participants. The sessions, run by the organization’s deputy director, include specific printed exercises focused on a particular part of the brain. The variety of material, such as activities ranging from identifying state shapes on a map to doing blind taste tests to identify sweet, salty and sour flavors, help keep participants interested and engaged in the program. Special guests are brought in, including a choral director who encouraged the group to sing. The participants are encouraged to work alone or in groups. Feedback from participants was positive, and many of them returned each week.

The program utilizes flexible Older Americans Act Title III B Supportive Services funds. The costs to run the program are modest: about $60 for the curriculum; $70 for a companion book, Mind Your Mind (an Oregon-based initiative focused on mental health); and $50 per week to provide a healthy snack for 15 participants.

After the senior center closed in March 2020 due to the COVID-19 pandemic, Senior Connections distributed brain health exercise sheets to older adults and caregivers arriving to pick up a to-go meal. The next step is to contact clients receiving home-based meals to learn if they would like to receive brain health materials.
Conclusion

Research indicates that the core services provided by AAAs and Title VI programs may support brain health through nutritious meals, evidence-based health promotion programs targeted to chronic disease management, physical activities and mental health, and social engagement programs. However, given the importance of this issue, AAAs and Title VI programs are also implementing more targeted programs to address brain health and raise awareness of the ways that older adults can mitigate their risks for cognitive decline and dementia.

The case examples featured in this report have a number of similarities. Brain health is intertwined with overall physical and emotional health. As such, AAAs expanded their existing program activities to include cognitive exercises along with a renewed focus on healthy lifestyle factors. By partnering with universities, some programs were able to leverage expertise in brain health research as well as having a consistent stream of student volunteers to staff the program. These mutually beneficial partnerships can help agencies collect outcome data to evaluate the program, and may contribute to developing new evidence-based programs. Another common factor is a person-centered approach to program development and delivery. As we learn more about the ways to maintain brain health and healthy cognition, we anticipate that increasing numbers of AAAs and Title VI programs will address this critical issue.
Endnotes


7 http://go.illinois.edu/buywitsworkout.


14 https://www.scacog.org/aging-services.


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