

REDUCING THE IMPACT OF DEMENTIA IN ALABAMA



Hope
Education
Awareness
Love

Celebrating Alabama's Progress

Certified Public Manager® Program

CPM Solutions Alabama 2023



TABLE OF CONTENTS

Glossary of Acronyms	3
Team Members	4
Acknowledgements.....	5
Introduction.....	6
Background.....	7
Dementia Definition and Types.....	7
Personal Impact	9
Financial Impact	9
Caregiver Impact	10
Awareness and Treatment	11
Funding in Alabama	13
Alabama Initiatives	15
Programs and Services	15
Dementia Friendly Alabama.....	16
PANDA Project.....	17
Alabama CARES.....	18
One Door Alabama.....	18
Home and Community Based Services	19
Alabama Lifespan Respite Resource Network Program	19
Research Findings.....	20
Programs and Services	20
Tennessee	20
Georgia	21
Florida	22
Washington.....	23
Dementia Services Coordinator.....	23
Alzheimer's Disease Registry	25
South Carolina.....	25
West Virginia	26
Georgia	26
Funding Opportunities	26
Recommendations.....	28
Increase Funding/Staff.....	29
Dementia Database Registry	30
Upgrade Online Media	31
Conclusion	33
References.....	34

GLOSSARY OF ACRONYMS

Alabama Department of Public Health (ADPH)

Alabama Department of Senior Services (ADSS)

Alabama Area Agencies on Aging (AAA)

Alzheimer's Disease Programs Initiative (ADPI)

Alzheimer's Disease and Related Dementias (ADRD)

Building Our Largest Dementia Infrastructure for Alzheimer's Act (BOLD)

Centers for Disease Control and Prevention (CDC)

Central Alabama Aging Consortium (CAAC)

Dementia Education Training Act (DETA)

Dementia Friendly Alabama (DFA)

Department of Health and Human Services, Administration for Community Living (ACL)

Department of Labor (DOL)

Georgia Memory Net (GMN)

Middle Alabama Area Agency on Aging (M4A)

National Institute on Aging (NIA)

Older Americans Act (OAA)

People with Dementia (PWD)

West Alabama Regional Commission (WARC)

World Health Organization (WHO)

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INTRODUCTION

Did you know that we rely on memory to get and keep meaning from life? Memory is an essential part of our life experience. It is critical for learning, and without memories we would have no sense of self. So, when a condition robs us of our memory, it can be devastating for the person experiencing this condition and their loved ones. This condition is dementia. Dementia is a general term for loss of memory, language, problem-solving and other thinking abilities that are severe enough to interfere with daily life. Dementia does not discriminate. Everyone has a chance of developing dementia, but some people have a greater chance than others. Increasing awareness of dementia is essential because it helps to increase understanding and support for those affected by memory loss. Additionally, political awareness is vital as policy makers and politicians are key actors in the policy process for new legislation to increase funding for research and support programs for dementia.

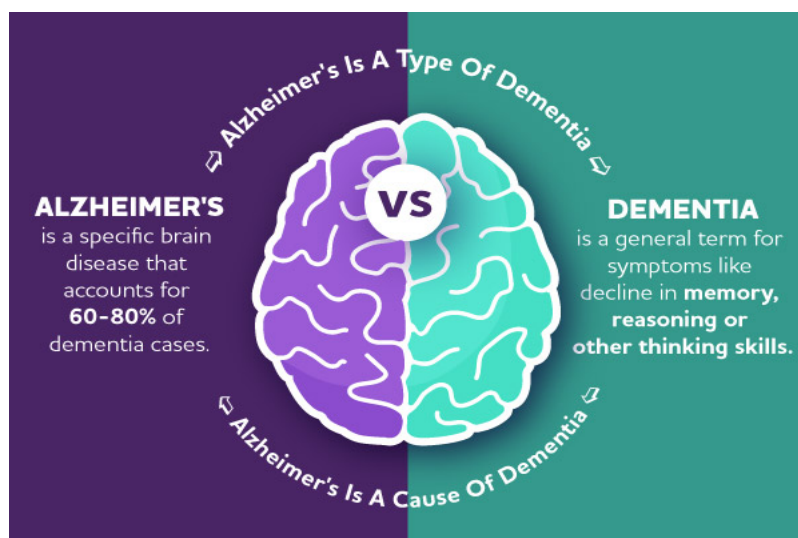
The *Reducing the Impact of Dementia in Alabama* CPM Solutions Project Team will examine Alabama's progress in increasing awareness of dementia and provide recommendations to improve the lives of those living with dementia and their caregivers by:

- 1) Assessing the impact dementia is having on our nation and Alabamians.
- 2) Highlighting the programs and services provided by the Alabama Department of Senior Services (ADSS) to reduce the impact of dementia.
- 3) Proposing ways for ADSS and/or other stakeholders to increase the services available to those who have been diagnosed with dementia and their caregivers, including possible funding sources.

BACKGROUND

Dementia Definition and Types

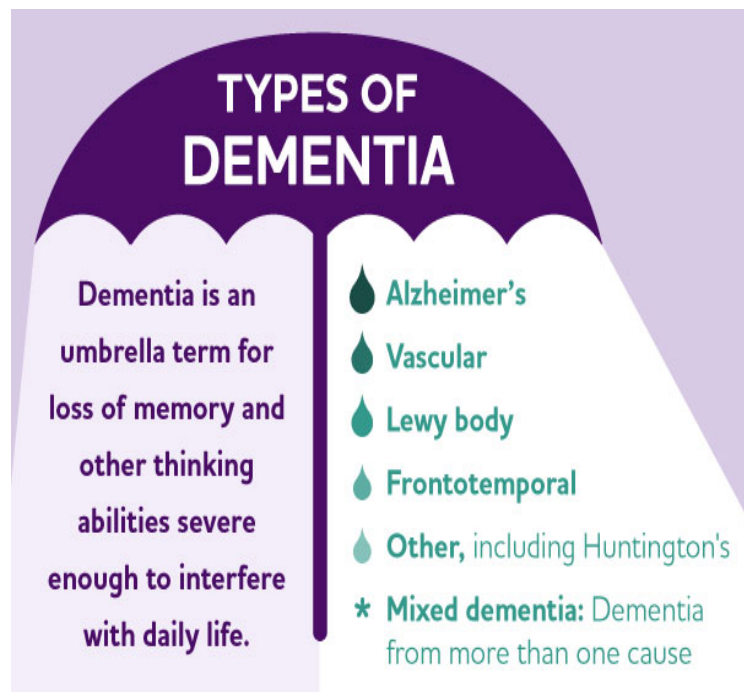
Dementia is not a single or specific disease, but a general term (like “heart disease”) which covers an array of medical conditions and symptoms that affect memory, thinking, and social abilities. It can result from various injuries, infections, or diseases such as HIV infection, stroke, oxygen deprivation, or alcoholism. Some risk factors for developing dementia include, genetics (hereditary), hearing loss, sedentary lifestyle, and age (Alzheimer Society of Canada, 2021). It is caused by damage to brain cells that affects the individual’s ability to communicate, which can impact thinking, behavior, and feelings (Alzheimer’s Association, 2023c).



The terms “dementia” and “Alzheimer’s” have been around more than a century and are often used interchangeably, but they are not the same. Dementia is a general term for a decline in mental ability severe enough to interfere with daily living.

Alzheimer’s disease is a specific type of dementia that causes memory loss and impairment of other important mental functions. Alzheimer’s is the most common form of dementia. The following are the most common types of dementia:

- Alzheimer's disease is a degenerative brain disease caused by complex brain changes. The main symptom is a reduction in short-term memory retention. However, symptoms gradually worsen and difficulty remembering more distant memories can develop.
- Vascular dementia is the next most common. It is linked to strokes or other blood flow issues to the brain. Risk factors include diabetes, high blood pressure, and high cholesterol and symptoms worsen as the individual has more (mini) strokes. Symptoms include impaired judgment, difficulty concentrating, and problems planning, organizing, or making decisions.
- Lewy body dementia is a form of dementia that causes movement or balance problems like stiffness or trembling. People with this form of dementia experience changes in alertness including daytime sleepiness, confusion or staring spells. They also have trouble sleeping at night or may experience visual hallucinations.
- Fronto-temporal dementia is a rare form of dementia that tends to occur in people under 60 years old. Symptoms are generally associated with changes in personality and behavior because of the part of the brain it affects and may result in inappropriate or embarrassing behavior.



- Mixed dementia is a combination of two or more types of dementia in the brain at the same time. This is most prevalent in people over 80 but is not always obvious since the symptoms of one type of dementia may be dominant or symptoms may overlap (Mayo Clinic, n.d.).

Personal Impact

More than 6 million Americans of all ages have dementia. This number is projected to rise to nearly 13 million by 2050. Dementia kills more people than breast cancer and prostate cancer combined (Alzheimer's Association, 2023b).

In Alabama, 96,000 people aged 65 and older are living with dementia and 14.6% of people aged 45 and older have subjective cognitive decline (Alzheimer's Association, 2023a). These numbers show that a public health approach is necessary to lessen the burden and enhance the quality of life for those living with dementia and their caregivers in Alabama.

Financial Impact

The financial impact of dementia can be simplified into two categories: The cost of unpaid care and payments for care. In 2022, the amount of unpaid care for those diagnosed with dementia was valued over \$339 billion, with Alabama accounting for \$5 billion of that total. The total payments for care for individuals diagnosed with dementia are estimated to reach \$345 billion in 2023. While Medicare and Medicaid account for over 60% of the payments, out of pocket costs account for \$87 billion or 25% of all payments. Dementia diagnosis is expected to rise by 7% in the next two years and the costs are expected to rise as well (Alzheimer's Association, 2023b). Total costs for dementia care are estimated to increase to more than \$1 trillion by 2050. Direct medical costs associated with the treatment of dementia include physician visits, emergency department and

hospital admissions, long-term care or skilled nursing facility care, and medications. Direct nonmedical costs include home healthcare, transportation to medical visits, and modifications to adapt to changes in physical function. Long-term care and nursing home care costs account for most of the direct costs associated with dementia care (Wong, 2020).

Caregiver Impact

Each year, more than 16 million Americans provide over 17 billion hours of unpaid care for loved ones with dementia (National Institutes of Health, 2019). Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial, and physical difficulties. Nearly \$340 billion worth of care is provided by family members and other unpaid caregivers (Alzheimer's Association, 2023b).

Caregivers have a vital role in helping their loved ones maintain quality of life. Studies have shown that dementia caregivers report higher levels of stress, more depression and anxiety symptoms, and lower levels of well-being than caregivers of people with other conditions (Sorensen, S. & Conwell, Y, 2011). It can also affect their physical health which is one of the top reasons families seek nursing care for their loved one. Caregivers may feel they are always needed, resulting in sleep issues and/or a weakened immune system (American Senior Communities, 2023). It is projected that 1.2 million additional direct care workers will be needed to care for the growing population of people living with dementia – the largest worker gap in the United States. In 2017, the Alzheimer's Association completed an extensive survey on the effects of dementia on the family caregiver. The survey and continued studies of dementia found that the disease continues to prove an unsustainable physical, financial, and emotional stress on caregivers (Alzheimer's Association, 2017). Studies have also shown that the services provided to caregivers

“can reduce caregiver depression, anxiety, and stress as well as enable caregivers to provide longer care, thereby avoiding or delaying the need for costly institutional care.” (Administration for Community Living, 2023). Fortunately, there are many excellent resources for caregivers in every state – many of them at no cost. Support groups and programs, respite care, online services and education, counseling, helplines, and more, can help a caregiver provide effective care for their loved one and themselves and help reduce the negative effects of dementia caregiving.

Awareness and Treatment

Most of us know or will know of someone who is living with dementia – a relative, friend, colleague, or neighbor. Raising awareness of dementia can help people recognize the early signs, and the more awareness is raised, the greater potential there is in obtaining help for someone with this disease.

Raising awareness about dementia requires a comprehensive approach that involves education, collaboration, and support. By working collectively and promoting understanding as well as acceptance, we can help reduce stigma and improve the lives of people with dementia and their families. The success rate of raising awareness of dementia can be difficult to measure as it can vary depending on various factors, including the target audience, the messaging, the approach, and the available resources. However, studies have shown that raising awareness about dementia can have positive effects on public perceptions and attitudes towards people with dementia. It can also increase the uptake of dementia-related services and support. One study conducted in the United Kingdom found that raising awareness of dementia had a positive impact on the public's knowledge and understanding of the condition. The study also found that raising awareness improved the public's attitudes towards people with dementia and reduced the stigma associated

with the condition (U.S. Department of Health and Human Services, n.d.). Another study conducted in the United States found that raising awareness of dementia increased the number of people seeking diagnosis and treatment for the condition. The study also found that people who received a diagnosis of dementia were more likely to seek support and services after participating in an awareness-raising campaign (U.S. Department of Health and Human Services, n.d.). Overall, while the success rate of raising awareness of dementia can vary, it is generally considered to be a critical step in reducing stigma and improving the lives of people with dementia and their families. By increasing understanding and acceptance, we can create a more dementia-friendly society and improve access to services and support. While it may be challenging to measure the success rate of awareness-raising campaigns for dementia, increasing awareness can have a positive impact on individuals, families, and communities. Therefore, it is important to continue efforts to raise awareness about dementia and reduce stigma surrounding the condition through social media, doctor's offices, non-profit organizations, churches, communities, and government agencies (Alzheimer's Disease International, n.d.).

Currently, there is no known cure for dementia. Treatment options include drug and non-drug approaches. Donepezil (Aricept), rivastigmine (Exelon) and galantamine (Razadyne) are cholinesterase inhibitors that work by boosting levels of a chemical messenger involved in memory and judgment. (Mayo Foundation for Medical Education and Research, 2023). These drugs are prescribed in the early or middle stages of Alzheimer's and may reduce or delay symptoms. They may also be given to dementia patients who have Lewy bodies, Parkinson's or mixed dementia but are not suitable for patients with fronto-temporal dementia. Other benefits of using these drugs are they reduce anxiety and increase motivation, memory and concentration which can help improve daily living skills. Side effects include nausea, vomiting, diarrhea, slowed heart rate,

fainting, and sleep disturbances. These side effects only affect about one person in ten (Alzheimer's Society, 2020). Nondrug approaches such as occupational therapy, modifying the patient's environment, and simplifying tasks may also help treat dementia symptoms and behavior problems. Other alternatives include:

- Music therapy, which involves listening to soothing music
- Light exercise
- Watching videos of family members
- Pet therapy, such as visits from dogs, to promote improved moods and behaviors
- Aromatherapy, which uses fragrant plant oils
- Massage therapy
- Art therapy, which focuses on the process rather than the outcome

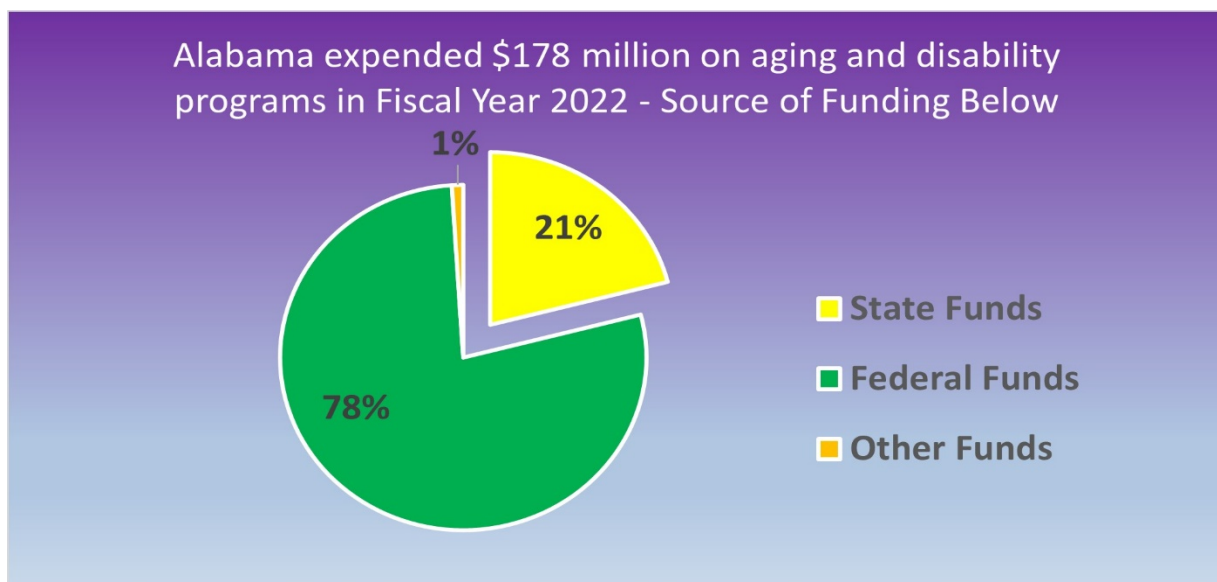
These therapy options can be used to help reduce agitation and promote relaxation in people with dementia (Mayo Foundation for Medical Education and Research, 2023).

Funding in Alabama

A person with dementia will need more care and support as symptoms worsen over time. Funding promotes a strong public health approach to the disease. Alabama recognizes the significance of dementia on its citizens, and funding is necessary to expand services to its citizens. The Alabama Department of Senior Services (ADSS) relies on appropriations from the state's general fund, federal grants, and other non-profit sources to provide resources and services to Alabamians who suffer with dementia and their caregivers. ADSS administers grants to local agencies supporting a variety of programs aimed at serving Alabama's senior and disabled population.

Annual data from Fiscal Year 2022 shows that approximately \$178 million was spent on aging and disability programs. Approximately 21% of this amount was funded by Alabama's State

General Fund, while the remaining 79% came from federal funds (78%) or other sources (1%). Federal grants are the primary source of federal funds, and these funds come from the Department of Health and Human Services Administration for Community Living (ACL), the Centers for Medicare and Medicaid Services, and the United States Department of Labor (DOL) (Alabama Department of Senior Services, 2023c). All programs are operated through Alabama's Area Agencies on Aging (AAAs) throughout the state. ADSS works closely with other state agencies, such as the Alabama Department of Public Health (ADPH), the Alabama Medicaid Agency, and the Alabama Department of Rehabilitation Services to provide funding for dementia services (ADSS, 2023c).



The chart above depicts the funds spent in Fiscal Year 2022 on aging and disability and reflects the sources of funds in percentages.

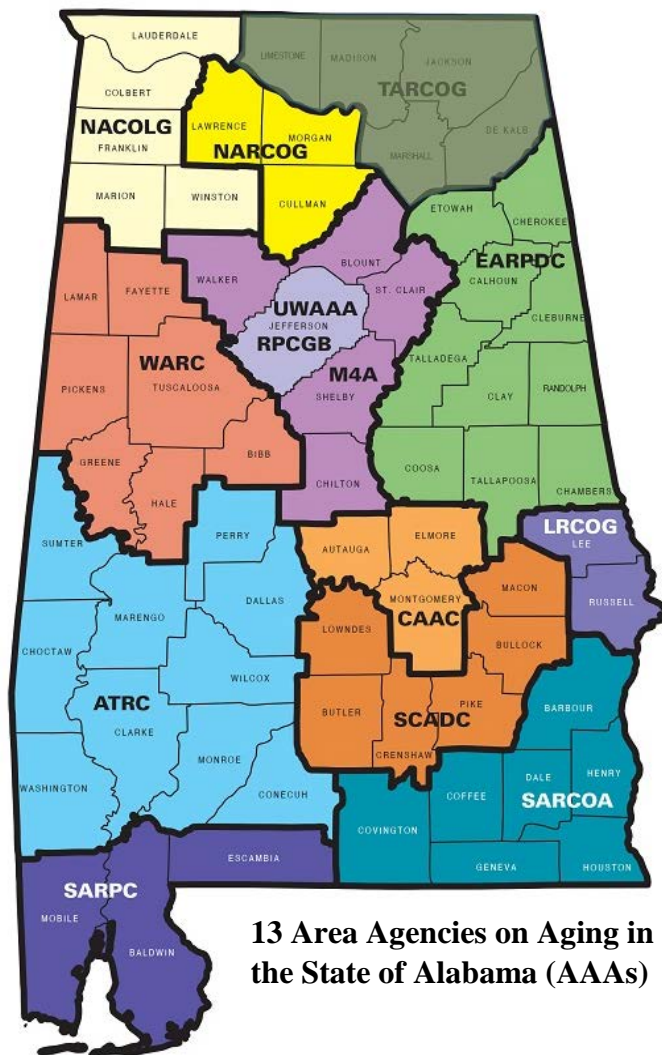
ALABAMA INITIATIVES

Programs and Services

The Alabama Department of Senior Services (ADSS), formerly the Alabama Commission on Aging, was established in 1957 and administers programs for senior citizens, people with disabilities, and caregivers. In 1965, the United States Congress passed the Older Americans Act (OAA) due to concerns about the availability of support services for senior citizens in their homes and communities. ADSS administers the OAA funds through state-wide programs on aging that

cover all 67 counties in Alabama through the Regional Planning Commissions and the local Area Agencies on Aging (AAAs). As shown on the map, there are 13 AAAs across the state, and each provides comprehensive services through contracts and grants to both public and private agencies (ADSS, 2023a).

ADSS is continually committed to providing services and developing strategies to respond to the dementia crisis in Alabama. Alabama has developed several initiatives to serve its citizens who have dementia and their caregivers.



13 Area Agencies on Aging in the State of Alabama (AAAs)

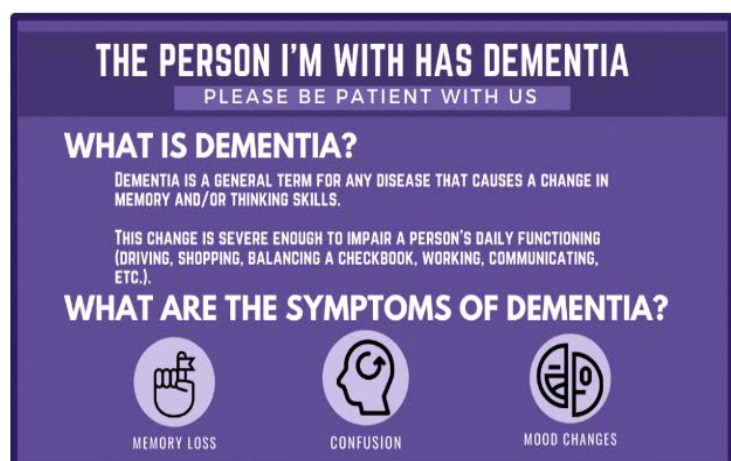
Dementia Friendly Alabama

Dementia Friendly America is a national network of communities, organizations, and individuals seeking to ensure that communities across the United States are equipped to support people living with dementia and their caregivers. Dementia Friendly Alabama (DFA) was born from the



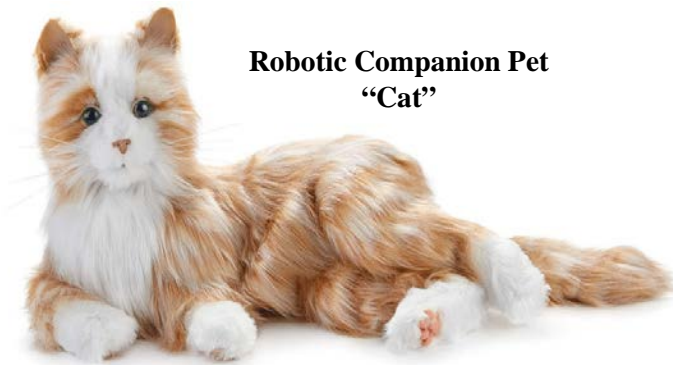
national initiative to bring awareness and support to those living with dementia and their caregivers. The mission of DFA is to cultivate partnerships with those with

dementia, their caregivers, schools, companies, and the community to bring dementia to the forefront (DFA, 2023b). DFA publishes and distributes the *Dementia Resource Guide*, to provide information on dementia, treatment, and services to businesses, medical offices, and other establishments (DFA, 2023a). DFA also offers the following resources to promote a dementia friendly community: 1) Virtual dementia tours, an experience during which participants are outfitted with patented devices that alter their senses while they try to complete common everyday tasks to simulate the challenges of dementia. 2) Project Life Saver/Tracking Technology. This technology is a bracelet to be worn by the dementia patient to help caregivers locate the individual if they tend to wander. 3) Dementia Friendly Wallet



Cards (shown here). These cards are a very discreet way to advise others that extra assistance and

sensitivity is needed in dealing or interacting with a dementia patient. 4) Robotic Companion Pets. The ADSS began a robotic pet project that was quickly embraced by the AAAs. These



**Robotic Companion Pet
“Cat”**

interactive animatronics are designed to look and act like real pets because they are comforting to those with dementia. These pets include cats, dogs, and birds that look, sound, and feel real. 5) Memory

Cafés. These are social gatherings for caregivers and those with dementia to enjoy food, activities, and conversation. 6) DFA also offers web-based training for caregivers, and memory screenings for anyone who wishes to participate (DFA, 2023c).

PANDA Project

Previously administered by the Middle Alabama Area Agency on Aging (M4A), the PANDA Project, “Providing Alzheimer’s ‘n Dementia Assistance,” is currently administered by two AAAs,

the Central Alabama Aging Consortium (CAAC) and the West Alabama Regional Commission (WARC) and provides free services for people with dementia and their caregivers. The project provides



home modifications to install grab **Providing Alzheimer’s ‘n Dementia Assistance** bars, transfer benches, ramps, handrails, widening of doors, etc. Remote monitoring technology is available for caregivers to know if the person with dementia falls or to track their location if they become lost. Likewise, the “Care Predict Watch” utilizes sensors in the home to monitor



blood pressure, oxygen level, heart rate, track falls, and detect how often one sleeps and eats. The caregiver can also talk to the dementia patient using the application and watch. An automatic medication dispenser can provide medication at a certain time and alert the dementia patient to take the medication. Other services include fidget pillows, respite care, training and education on dementia,

supplemental supplies, personalized care plans, legal assistance, advocacy, case management, and robotic pet companions (D. Poague, A. Dormido, and A. Scott, personal communication, May 5, 2023).

Alabama CARES

Alabama CARES is offered by the AAAs to caregivers. Caregivers and the public are provided information regarding available resources in their communities in addition to support groups, assistance, respite services, education, and supplemental services (ADSS, 2023b).

One Door Alabama

Each AAA offers counseling and screening for services and support through “One Door Alabama.” This program provides free information, counseling, and access to programs and services provided by ADSS, state agencies, and federal programs. Some services available through One Door Alabama are: support with food assistance, in-home services, crisis support, transportation, legal

assistance, prescription drug assistance, caregiver support services, adult daycare, and Medicare and Medicaid counseling (One Door Alabama, 2023).

Home and Community Based Services

These programs provide individuals with such services as: case management, personal care, home maker services, companion services, respite care, adult day services (where available), nutrition and meals. The services are designed to allow individuals such as those with Alzheimer's or dementia related diseases to remain in the community whose needs would otherwise require care in a nursing facility (ADSS, 2023b).

Alabama Lifespan Respite Resource Network Program

Respite care temporarily relieves caregivers from the demands of providing ongoing care for a loved one in the home with special needs. This is a helpful and economical way for the dementia patient to stay home instead of being placed in a nursing facility. Respite care also lowers the chance of the dementia patient being neglected and abused. Not limited to just the home, it can also be provided at the family's home, a relative's home, adult daycare centers, church respite program, or local community setting (Alabama Lifespan Respite Resource Network, 2023). The Alabama Lifespan Respite Resource Network Program provides respite reimbursement services (planned and emergency), free online/onsite educational opportunities for caregivers, free mental health stipends, gives referrals, and helps non-profit organizations and religious-based groups start or increase caregiver community-based respite services. Additionally, caregivers can apply for the Alabama Respite Reimbursement Program. If the caregiver meets the qualifications for this program, the caregiver can choose the respite care provider, pay them out of pocket, and apply to be reimbursed by Alabama Lifespan Respite Resource Network Program, which is funded from

the Administration for Community Living Lifespan Respite Grant and administered by ADSS (Alabama Lifespan Respite Resource Network, 2023).

The State of Alabama has taken commendable steps to reduce the impact of dementia within its population. Alabama offers a multitude of dementia care programs and services aimed to meet the needs of both patients and caregivers. These programs and services are based in the community for convenient access, and they can continue to live comfortably in the community they choose.

RESEARCH FINDINGS

As part of our research to investigate strategies and funding opportunities currently utilized by other states, the Reducing the Impact of Dementia in Alabama CPM Solutions Alabama 2023 Team contacted several state agencies across the country, investigated their existing programs, and visited websites devoted to these agencies.

Programs and Services

Tennessee

Like Alabama's AAAs, the Tennessee Area Agencies on Aging and Disabilities are reliable points of contact for those with dementia and their caregivers in need of information and resources. The availability of these resources varies from agency to agency as does the qualifying criteria, but the AAAs offer many of the same services and/or resources as Alabama. Like DFA, the Tennessee Department of Health created a Dementia Friendly community toolkit for its-communities to use as a guide to help reduce the negative bias associated with cognitive disabilities by including those diagnosed with dementia in everyday life activities. This "community" is not just limited to neighborhoods but encompasses faith-based groups and other organizations with common interests and beliefs. The focus is to "educate the public, business and government entities, healthcare

providers, first responders, and other key members of the community on effective strategies for working with individuals with dementia and their caregivers (Tennessee Department of Health, n.d.).

Another resource for caregivers in Tennessee is the Tennessee Respite Coalition, which provides a statewide respite helpline to learn about the program and receive details of other respite resources available throughout the state. This project was funded under a grant contract with the Tennessee Department of Mental Health and Substance Abuse Services and the Tennessee Commission on Aging and Disability (Tennessee Respite Coalition, 2021). According to Virginia Holmes of the Respite Coalition, caregivers are reimbursed up to \$600 per year for respite services through the Family Directed Voucher Program. The caregiver and person receiving respite care must reside in the same household and be residents of Tennessee. They also have a Senior Volunteer Program where senior citizens volunteer to go into the homes and serve as companions for those who totally rely upon a caregiver. The volunteers do not provide medical assistance or any type of household chores, only companionship (V. Holmes, personal communication, June 15, 2023).

Georgia

According to websites for dementia care in Georgia, programs available for caregivers are similar to Alabama. Georgia has 12 Area Agencies on Aging that provide services to caregivers. Information specialists at the Georgia's Aging and Disability Resource Connection have access to a diverse number of caregiving and aging resources and can be found in every Area Agency on Aging (Georgia Aging and Disability Resource Connection, n.d.-a).

Like Alabama, Georgia also has Memory Café, which is a relaxing and safe environment where caregivers and their loved ones meet with each other to talk, share, enjoy refreshments, and engage

in activities such as playing games and listening to music. The goal is to get everyone out of their normal routine and connect with others in the same situation (Dementia Society of America, 2023). On the other hand, Georgia has a program sponsored and funded by the Georgia Department of Human Resources called “Georgia Memory Net” (GMN) and it is a program to diagnose and treat those with dementia. This program requires collaboration between hospitals, state, and local agencies, as well as community and education providers. GMN works closely with Emory University’s Cognitive Neurology Clinic and Emory Goizueta Alzheimer’s Disease Research Center to train and support memory assessment clinics. There are currently five of these facilities located in Georgia. Once a physician determines an individual has a memory issue, the individual is referred to a Memory Assessment Clinic for further evaluation, and if diagnosed with dementia, a care plan is developed. Additionally, the individual with dementia and their caregiver meets with a community service educator, and they create a customized care plan for both parties, and they are automatically referred to the AAAs for additional services (Georgia Department of Human Services, n.d.-b).

Florida

Furthermore, Florida has a unique program through the Florida Alzheimer’s Disease Initiative, a statewide program which maintains a variety of education and services for dementia patients and caregivers. The program is known as “Extended Respite,” which allows the individual with dementia to spend up to 30 days in a residential memory care community, allowing the caregiver an extended period of rest. Income determines placement on the waitlist and a co-pay may be required based on income (Florida Alzheimer’s Disease Initiative, 2023).

Washington

Additionally, a unique program and funding allocation in Washington is the “Long-Term Care Trust Act,” passed on July 28, 2019, which is a mandatory payroll premium housed in the state trust fund financing long-term services and support for everyone employed in the state. The eligibility for the program requires that an individual must need assistance in three or more daily activities, including bathing, dressing, eating, bed mobility, and other similar activities. The state will then pay certified and licensed providers to deliver care. Family members may also qualify. It covers \$36,500 (adjusted with inflation) in long-term care benefits per individual over the course of the beneficiary’s lifetime (National Academy for State Health Policy, 2023).

Dementia Services Coordinator

Several states have prioritized their response to dementia by creating the position of Dementia Services Coordinator. A dementia coordinator’s role varies by state but is a state employee who has dementia as a core focus of their job responsibilities and leads efforts to enhance coordination by supporting the implementation of dementia-specific policies across state agencies (Alzheimer’s Impact Movement, 2023). Several states have defined a more in-depth focus of a dementia services coordinator to implement activities related to the state’s strategic plan recommendations, to strengthen partnerships with community stakeholders and other state agencies, identify service gaps within state government, recommend policy and coordinate statewide data collection, research and analysis, and coordinate statewide efforts that increase awareness of dementia for improved access to high quality services (Dementia Services Coordinator Act, 2023).

States with state-funded Dementia Service Coordinators or similar role are California, Delaware, Florida, Georgia, Illinois, Kentucky, New Mexico, New York, North Carolina, Oregon, South

Carolina, South Dakota, Texas, Utah, Virginia, Washington, and Washington D.C. These state-funded positions have a mix of positions, often in either public health agencies or state units on aging. The states of Idaho and Wisconsin established Dementia Services Coordinator positions which are partially state funded and partially funded by the BOLD grant (G. Worthington, personal communication, March 31, 2023). BOLD is the “Building Our Largest Dementia Infrastructure for Alzheimer’s Act” that was enacted by the United States Congress in 2018. The law aims to create an Alzheimer’s public health infrastructure across the country to implement effective Alzheimer’s interventions focused on public health issues such as increasing early detection and diagnosis, reducing risk, and preventing avoidable hospitalizations.

The annual salary for Dementia Services Coordinators ranges from \$62,108 to \$100,000. There is limited salary information available for most states; however, the salary range for this position in Iowa is \$62,108 to \$96,075 (Government Jobs, n.d.); Indiana is \$70,000 to \$100,000 (Legislative Services Agency, 2022); and Connecticut is established at \$81,000 per year (SB1024, 2023 January Session, Conn.). The salary range depends on the cost of living in the area and the experience, skill, and education needed to perform the job.

State legislative action is sometimes necessary to fund a state agency position, although local agency funding and federal funding is a possibility, as well as grant opportunities.

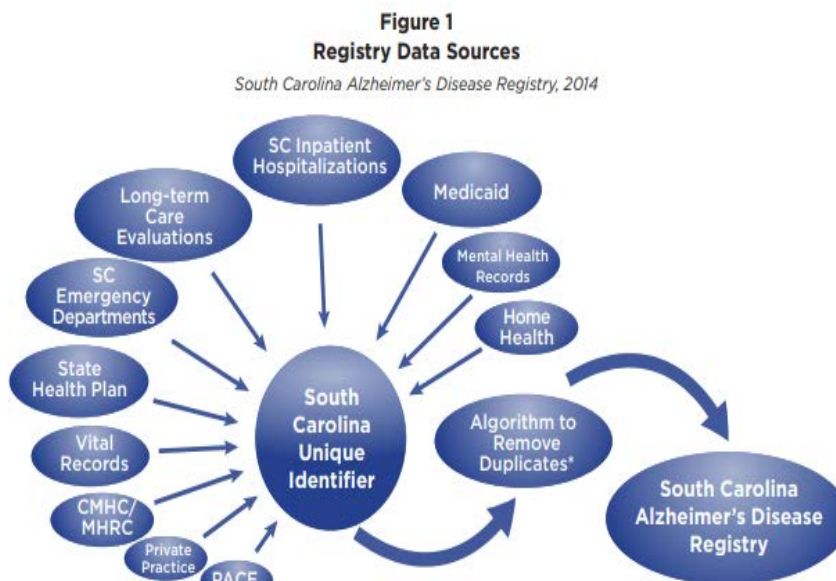
A Dementia Services Coordinator position can accelerate a state’s ability to address dementia (Alzheimer’s Impact Movement, 2023). A coordinator position can also help build working relationships with other service teams, state agencies, and community organizations to effectively organize and coordinate resources and services that ensure dementia capability for the state.

Alzheimer's Disease Registry

An Alzheimer's disease registry is a statewide database and registry of residents diagnosed with Alzheimer's disease and related dementias. A registry generally comprises multiple data sources, including, but not limited to, hospitalizations, mental health records, Medicaid records, emergency departments, memory clinics, chart abstracts, vital records, long-term care records and more (University of South Carolina, 2022b). Currently, the United States has only three state-wide population-based registries in South Carolina, Georgia, and West Virginia, with South Carolina being the oldest and most comprehensive and the ideal blueprint for other states to mimic.

South Carolina

The South Carolina Alzheimer's Disease Registry was established in 1988 and is maintained by the Office for the Study of Aging to gather information on Alzheimer's Disease and Related Dementias (ADRD). As noted above, it is the oldest and most comprehensive database registry in the United States and has identified over 340,921 dementia cases since inception (USC, 2022a).



Data is collected monthly from a variety of sources such as hospitals, medical centers, and Medicaid, and any personally identifiable information is stripped (C. Finney, personal communication, May 24, 2023).

Additional data could be obtained from Medicare but is only available incrementally as opposed to a regular data stream and is not affordable due to a lack of sustained funding for that purpose (M. Miller, personal communication, May 9, 2023). Requests may be made for aggregate data from the database and, if approved, a separate database is created containing the requested information, provided a confidentiality agreement is signed and an hourly fee provided (C. Finney, personal communication, May 24, 2023).

West Virginia

The West Virginia Alzheimer's Disease Registry was established in 2011, but the data was collected via manual entry, so by 2013 there were only about 3,500 cases in the registry. However, based on a request from the state to receive ADRD beneficiary data from Medicare, the number of cases in the registry increased to 28,000 by 2015 (West Virginia University, n.d.).

Georgia

Established in 2014, the Georgia Alzheimer's and Related Dementia State Plan Task Force has a workgroup tasked with healthcare, data, and research collection. Although the database registry is not currently active, part of the state plan is to establish a database registry by 2027 (S. Hannah, personal communication, May 31, 2023).

Funding Opportunities

As the ADSS's commitment to address the effects of dementia grows, it will need additional funding. The nature of how dementia has been addressed in the past leads us to believe that not only does ADSS need to continue its current strategy of obtaining funding, but also seek to expand its efforts to provide additional support to meet the challenges of this disease.

First, it appears ADSS is doing well with obtaining and administering dementia-related grants currently in use. These grants include state funds for the DFA program, which disburses mini grants to the thirteen AAAs around the state. Three AAAs (M4A, CAAC, & WARC) have applied for and received federal Alzheimer's Disease Programs Initiative (ADPI) grants from the ACL. ADPH has recently applied for the BOLD grant, a funding opportunity through the Centers for Disease Control and Prevention (CDC). This is a five-year award that is intended to build public health infrastructure, as well as enhance dementia caregiving.

Next, in seeking other opportunities, ADSS has recently partnered with ADPH in the application process for the BOLD grant. ADSS has entered in agreement with ADPH to receive legislative funds through the Dementia Education Training Act (DETA) to develop services and educational programs concerning Alzheimer's disease, ADRD, and to offer those programs to individuals with those diseases, their families, and the general public. In addition, ADSS has also recently applied for the ADPI grant from the ACL with the goal of expanding and enhancing the successful PANDA Project as well as to sustain a dementia-capable home and community-based service care model for people with dementia (PWD) and their caregivers. We discovered CAAC hosts an annual golf tournament in support of DFA, where businesses both sponsor and have teams in the tournament. The goal is to expand the tournament over time through effective marketing, publicity and increase sponsorships, which could be a viable source of funding (A. Woodard, personal communication, June 6, 2023).

Additionally, seeking partnerships with Alabama colleges and universities may perhaps be a new opportunity for funding for ADSS. Recently, the Wisconsin Coalition for Collaborative Excellence in Assisting Living, along with the Wisconsin Department of Health Services, partnered with the University of Wisconsin-Madison School of Medicine and Public Health on obtaining the

Wisconsin Partnership Program Community Impact Grant (Wisconsin Department of Health Services, n.d.). It is one of various grants facilitated by the university aimed at improving the health and well-being of those in the state. (University of Wisconsin-Madison, n.d.). Exploring similar partnerships with local colleges and universities for dementia-specific funding could prove to be fruitful for funding purposes for ADSS. Continuous funding is essential for programs and services that improve quality of life for people living with dementia and their families, while also supporting awareness and education about dementia.

Lastly, it is evident that Alabama policy makers must take bold action to increase the state's budget to address dementia. According to the statistics in Alabama for the number of cases and costs, including projections, which are expected to rise exponentially in the future, dementia-specific funding should be a top priority in Alabama's government. Requesting an appropriation for dementia-specific funding from the state legislature appears to be a viable means to increase funding.

RECOMMENDATIONS

Several services, programs, and initiatives have been highlighted that could help reduce the impact of dementia in Alabama, including exploring funding opportunities to further support the dementia support systems. To further assist ADSS in raising awareness of dementia and ways to reduce the impact of the disease, our team recommends that: 1) Alabama increase funding for ADSS to continue programs and services and continue to raise awareness of dementia, including hiring additional staff; 2) implement a dementia registry; and 3) upgrade ADSS's online media presence.

Increase Funding/Staff

Currently programs and services like those offered and available through DFA, PANDA Project, Alabama CARES, One Door Alabama, and the Alabama Lifespan Respite Resource Network Program all have the potential to significantly improve the lives of those living in Alabama with dementia and their caregivers. However, not all Alabamians with dementia and their families are aware of the programs and services available. As previously noted, raising awareness of dementia helps those diagnosed and their caregivers, and helps society at large have a better understanding of this disease which helps to avoid stigmatization and barriers to diagnosis and care. Additionally, awareness of dementia has been shown to lessen the physical, psychological, social, and economic impact of the disease. To realize the full potential of these services and programs and to raise awareness of dementia and the availability of these programs, Alabama must address funding. Funding is necessary to continue these services and programs and to expand efforts to seek additional funding, so that those with dementia and their families have greater access than ever before to critical care and support services. We suggest that ADSS, through its AAAs, expand its pursuit of partnerships with the business community and seek out more corporate partnerships. ADSS and its partners have either applied for or received federal grants that are generally used by states seeking resources to fight the effects of dementia. Discovering new resources should be top priority for ADSS and finding new resources will involve reaching out to new and interested parties. We also recommend that ADSS seek partnerships with local colleges and universities for funds by working together to improve the health and well-being of those with dementia and their families.

As previously noted, several states have created a state agency position for Dementia Services Coordinator, with dementia as a core focus, to ensure coordination of dementia programs and

policies across state agencies. Last October, 26 states with established Dementia Services Coordinator positions came together at the Alzheimer's Association First State Dementia Services Coordinator Summit in Washington, D.C. to celebrate the successes in advancing policies and discussed solutions to help those with dementia and their caregivers (Alzheimer's Association, 2022). We recommend that Alabama create a position and obtain specific, state allocated, funding to hire a full-time Dementia Services Coordinator to coordinate the services provided to persons with dementia, working in conjunction with ADSS. A coordinator position can review existing programs and work with other Alabama agencies to deliver services more effectively to Alabamians living with dementia and identify gaps and reduce duplication in those services. The position should be supported and made permanent by Alabama's general fund. According to the Lieutenant Governor's Office, Alabama's economy is doing well, and the state's budgets are in a \$3 billion surplus (Office of the Lieutenant Governor of Alabama, 2023). It is the right time, maybe the perfect time, to request the Legislature's support for a position that will benefit the state, ADSS, and the community. The BOLD grant is also an option for partial funding of the position, because, as previously mentioned, Idaho and Wisconsin have Dementia Services Coordinator positions partially funded by the BOLD grant.

Dementia Database Registry

An increase in funding alone will not be sufficient to better serve patients and caregivers within our state. A state-based dementia registry should be created to collect and house information on residents diagnosed with dementia. The state registry would comprise multiple data sources such as hospitals, Medicare, Home Health, etc. With this data, Alabama would have the ability to:

- Identify disease prevalence among certain demographic groups and bridge the gaps among patients that may be unknown or overlooked

- Connect patients and caregivers with needed resources in an efficient manner and improve the quality of life for both patient and caregiver
- Use data to implement safety and prevention programs
- Reduce state expenses by reducing hospital readmissions

According to ADSS, there is no formal procedure for collecting data from hospitals, doctor's offices, home health, etc. in Alabama. Therefore, it is our recommendation that a state-based dementia registry be created to collect and house this information. Creating a registry would require state legislative action allowing an agency such as the ADPH, the Alabama Department of Mental Health or ADSS to request and store collected data. Records will then be transferred to the registry staff to be reviewed and assigned a unique identifier. The legislature will also need to require data sources to report the data. Discussions with several state agencies revealed that their biggest challenge in implementing a registry is receiving records from the data sources. Data sources had no desire to spend time and energy submitting information that was not required by the state. It was not deemed important enough. If the legislature does not require data sources to provide data, registry staff must have a solid plan to obtain the data which may include providing guidance during the reporting season. Data registries provide a positive return on investment. However, the establishment and maintenance of a registry will require continuous support from the government, policymakers, research funding bodies, clinicians, individuals with dementia, and their caregivers (Krysinska, Sachdev, Breitner, et al., 2017).

Upgrade Online Media

Ensuring that information is readily accessible is a key component to raising awareness of dementia. To reach more people, we recommend providing a page on the current website dedicated specifically to raising dementia awareness, with updated information and links for

dementia patients as well as caregivers. Further, providing education and information about dementia is crucial in raising awareness. These are some ways to promote dementia awareness by providing tabs and/or links on the ADSS webpage: 1) Social media campaigns. Social media can be an influential tool to raise awareness about dementia. Adding social media icons to ADSS's homepage can bring attention to the social media campaigns such as Facebook, Twitter, YouTube, Instagram, LinkedIn, and Pinterest. 2) News and events. Public events and conferences can provide an opportunity to reach a larger audience and raise awareness of dementia. 3) Collaboration with local communities. We recommend for ADSS to continue collaborating with local communities and organizations in Alabama that can help raise awareness about dementia. 4) Involving people with dementia. We also recommend including videos of those with dementia and their caregivers sharing their stories, experiences, and perspectives to help encourage others and to raise awareness and increase understanding. Additionally, there are various resources available that can be added to the ADSS resources tab or even on a dedicated page for dementia: 1) CDC; 2) World Health Organization (WHO); and 3) National Institute on Aging (NIA).

It is difficult to quantify the success rate of bringing awareness of dementia as it can be a gradual and ongoing process. Raising awareness about dementia, whether it is through a website, browser search, social media platform, face to face, or an event, it can have a positive impact on individuals, families, and communities in several ways. Overall, by advertising awareness of dementia, we can promote early detection, increase access to support, reduce stigma, empower caregivers, advance research, and improve the quality of life for individuals with dementia and their families. A comprehensive review and upgrade of ADSS's website will be a significant step towards raising awareness of dementia in the state.

CONCLUSION

Dementia is a large and growing epidemic that has a huge impact on our state and nation. Expanding efforts to support public awareness of dementia, prevention, and early detection is a high priority. Alabama has made significant progress towards addressing the dementia crisis, including providing programs and services like Dementia Friendly Alabama, the PANDA Project, Alabama CARES, One Door Alabama, and Alabama Lifespan Respite Resource Network Program. Alabama's focus is enhancing quality, access, and coordination of care by expanding programs and improving services through available funding for those with dementia and their caregivers. In addition, Alabama's goal is to improve quality of life for those living with dementia and their families while also supporting awareness and education about dementia. The state must continue to invest, promote, and expand services and programs if they are to succeed. The Reducing the Impact of Dementia in Alabama CPM Solutions Project Team believes that the recommendations provided herein will help Alabama succeed in its endeavor to provide sufficient dementia care to all its citizens.

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