

2023 to 2028

South Carolina Statewide Plan to Address Alzheimer's Disease & Related Dementias (ADRD)



Developed by: The Division of Injury and Substance Abuse Prevention at SC DHEC; The South Carolina Department on Aging's Alzheimer's Resource Coordination Council and Center (ARCC) and The Weathers Group

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Need Additional Information?

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February 1, 2023

To the Honorable Members of the South Carolina General Assembly:

The South Carolina Department on Aging's Alzheimer's Resource Coordination Center Advisory Council is pleased to present the 2023 to 2028 South Carolina State Plan to Address Alzheimer's Disease and Related Dementias.

Our statewide plan to address dementia has not been updated since 2009, when the Purple Ribbon Task Force published their findings and recommendations for action to address the current and future impact of Alzheimer's Disease within the state in a report titled *Conquering the Specter of Alzheimer's Disease in South Carolina*. The Task Force was housed in what was then called the Lieutenant Governor's Office on Aging and was convened through the passage of Senate Concurrent Resolution 1333 by the South Carolina General Assembly in 2008. In the fourteen years following the report's publication, the landscape of Alzheimer's Disease and Related Dementias (ADRD) has changed dramatically, and our citizens need a revised, updated plan of action to address the ever-increasing statistics and concern around ADRD.

The 2023 to 2028 South Carolina State Plan was developed via an intensive six-month strategic planning and data collection process led by the South Carolina Department of Health and Environmental Control's (SCDHEC) Division of Injury and Substance Abuse Prevention. The Alzheimer's Resource Coordination Center Advisory Council (ARCC) served as the representative coalition of experts and stakeholders from throughout South Carolina and provided essential expertise, data analysis, and support throughout the process.

According to the SC Alzheimer's Disease Registry, at least 111,818 individuals are currently living with ADRD in South Carolina. At the state level, we have an Alzheimer's crisis. In 2015, South Carolina had the highest Alzheimer's death rate in America, and it remains in the top 5 causes of death in SC today. In 2020, Medicaid costs for South Carolinians with Alzheimer's amounted to \$652 million — and those costs are expected to increase 25% in just four years.

And then there's the impact on caregiving families. There are an estimated 197,000 caregivers in South Carolina providing almost 300 million hours of unpaid care. That unpaid care provided by family members or friends is valued at over \$4.4 billion. Caregivers of people with dementia indicate substantial financial, emotional, and physical health difficulties. We also know that 1 in 3 dementia caregivers in our state are "sandwich generation" caregivers — meaning that they care not only for someone with dementia, but also for at least one child or grandchild.

These statistics are daunting in their weight and impact, but the picture they paint is unmistakable: Dementia is a large and growing public health crisis for South Carolina, and those facing a dementia diagnosis and their caregivers need support. We cannot afford to ignore this. What can we do as a state to curb the impact of this growing burden on families? While each state has its own unique gaps and needs, South Carolina is uniquely poised to make a huge impact for families facing a dementia diagnosis through collaboration between state agencies, community-based organizations, long term care providers, home and community-based services, research institutions, and health systems. This plan is our new commitment to addressing ADRD through collaboration, data-driven programming decisions, and health equity.

Our strategic planning and stakeholder feedback process has shown us that we must work with our community-based care providers, both long term care and community resources, to improve delivery of dementia informed education to improve outcomes across all settings. Input from stakeholders highlighted the fact that a critical element is missing from South Carolina's current and previous efforts to provide quality care and resources for people affected by and living with dementia — a public health framework. Research shows us that by prioritizing risk reduction, we can prevent people from progressing beyond a mild cognitive impairment into dementia. This, along with early detection and early diagnosis, can help families have longer with their loved one to prepare for care, financially, mentally, and legally. The strategies for action outlined in this plan, along with the collaboration of state agencies to implement and prioritize dementia as a public health issue and a costly problem facing our great state, will help improve the health outcomes, quality of care, and caregiver health for everyone touched by Alzheimer's and other forms of dementia.

Respectfully submitted,

Taylor Wilson

Director of Government Affairs, Alzheimer's Association South Carolina Chapter
Chair, Alzheimer's Resource Coordination Center Advisory Council

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- Dr. Cynthia Port, Coastal Carolina University
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- Ms. Taylor Wilson, Alzheimer’s Association, SC Chapter
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Overview

In the fall of 2021, the South Carolina Department of Health and Environmental Control's (SCDHEC) Division of Injury and Substance Abuse Prevention began the process of developing a five-year statewide strategic plan to address and prevent the impact of Alzheimer's Disease and Related Dementias (ADRD) - hereafter referred to as the "SC Statewide Plan to Address ADRD." This process is part of the Centers for Disease Control and Prevention's (CDC) directive to award funds to state public health agencies under the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act, passed into law on December 31, 2018.

SCDHEC is one of the eighteen state health departments funded to promote a strong public health approach to ADRD through a "Core Capacity" grant. As a Core Capacity grant recipient, SCDHEC is responsible for developing a state plan that not only addresses the current care and treatment needs of people impacted by dementia, but also prepares for the future by developing strategies and objectives that address risk reduction and improve early detection and diagnosis for ADRD. The following plan was guided by the recommendations put forward by the Healthy Brain Initiative's [State and Local Public Health Partnerships to Address Dementia, The 2018-2023 Road Map](#), as well as data from research and academic entities across the state.

The South Carolina Department of Health and Environmental Control worked closely with the South Carolina Department on Aging and relevant public health coalitions and organizations to ensure the plan included input from ADRD stakeholders statewide. To this end, the South Carolina Department on Aging's Alzheimer's Resource Coordination Center Advisory Council (ARCC or Council) was pulled in as a convener and lead partner to ensure that a variety of diverse and representative stakeholders had a voice in guiding the development of the strategic plan. The SC Statewide Plan to Address ADRD is a blueprint for how our healthcare systems, long term care providers, state agencies, community partners, and people and families impacted by dementia will continue to address the growing crisis of Alzheimer's Disease and Related Dementias throughout South Carolina. The objectives and strategies outlined in the plan will allow South Carolina to promote risk reduction and early detection and diagnosis of ADRD, as well as build the infrastructure and accountability necessary to build dementia-capable programs and services for the growing number of people impacted by ADRD every year.

The Changing Landscape of Dementia: A Note on Language

"Dementia" is a general umbrella term for loss of memory, language, problem-solving and other thinking abilities or cognitive abilities that are severe enough to interfere with daily life. It is not a single disease but rather an overall term that covers a wide range of specific medical conditions, including Alzheimer's disease, which is the most common cause of dementia (Alzheimer's Association, 2022).

The term "related dementias" refers to types of cognitive impairment and decline related to stroke, mixed dementia (with both Alzheimer's and vascular dementia), and dementias associated with medical conditions such as Parkinson's disease, Huntington's disease, dementia with Lewy Bodies (DLB), frontotemporal degeneration (or FTD), AIDS, and alcohol or drug abuse.

Additionally, advocates from organizations representing communities affected by the less-common forms of dementia, such as Lewy Body Disease, Frontotemporal Dementia, and others, promote the use of the umbrella term "dementia" instead of ADRD.

Taking into consideration the above context, the terms "ADRD" and "dementia" will be used interchangeably throughout this document. Additionally, dementia-friendly terms are used throughout the plan. Examples of this are replacing 'person with dementia' with 'person living with dementia', recognizing that people do live with dementia and that the individual is more than the disease. Similarly, 'care partner' is being used in addition to the term 'caregiver' in recognition that the language used for people supporting individuals living with dementia is complex. The CDC defines "caregivers" as spouses, partners, adult children, other relatives, and friends providing unpaid help to people living with dementia who have at least one limitation in their activities of daily living and reside in the community. Caregivers often assist with diverse activities of daily living such as personal care, household management, medication and healthcare management, and coordination of financial matters. "Care partner" is a term promoted by dementia advocates and is used to convey the idea that people living with dementia and those who care for them are working together to find solutions that best enhance everyone's quality of life.

For more information on dementia terminology, please refer to Appendix A for a Glossary of Terms and Acronyms used in this document.

About SCDHEC’s Division of Injury and Substance Abuse Prevention:

The Division of Injury and Substance Abuse Prevention (DISAP) is housed in the Bureau of Chronic Disease and Injury Prevention at SCDHEC. Through a two-year cooperative agreement with the CDC to help implement BOLD Public Health Programs to Address Alzheimer’s Disease and Related Dementias, DISAP works with the ADRD Resource Coordination Center Advisory Council to implement a statewide strategic plan and build upon the “Take Brain Health to Heart” educational campaign.

[Take Brain Health to Heart](#) is a campaign that promotes brain health via Public Service Announcements (PSAs) and a webpage with information, tools, and other resources to help educate South Carolinians about the risk factors and early signs of cognitive impairment. The campaign aims to promote the adoption of healthy behaviors that are known to prevent chronic disease, as research continues to show a link between a healthy body and a decreased risk for dementia.

About the Alzheimer’s Resource Coordination Center Advisory Council (ARCC):

In 1994, the state legislature created the ARCC in response to the recommendations of the Blue-Ribbon Task Force on Alzheimer’s disease in South Carolina. The full enabling legislation from 1994 can be found in the SC Code of Laws Section 44-36-320. The mission of the ARCC is to improve the quality of life for persons with ADRD, their families and caregivers through planning, education, coordination, advocacy, service system development and communication. It is guided by a twenty-seven-member Advisory Council appointed by the Governor. The Advisory Council includes representatives from state agencies, professional organizations, universities, and caregivers with an interest in providing and improving care and services for the population.

The ARCC is the only entity in South Carolina that awards grants to start dementia specific respite and education programs in communities. It monitors and provides technical assistance to grantees to ensure that the standards remain at the highest level. It offers information and resources to the grantees as well as the general public. Additionally, now that the ARCC has served as the key convening entity for this strategic plan, they are moving to include risk reduction and early detection and diagnosis efforts to their work, along with the improvement of care and services for ADRD.

The ARCC continues to foster program sustainability and support grantees after their grant award has ended by offering technical assistance to encourage the sustainability of their programs. You can find more information, including the history and bylaws of the ARCC, on their website: <https://aging.sc.gov/programs-initiatives/alzheimers-resource-coordination-center-arcc>

Alignment with Statewide Public Health Improvement Initiatives

Since 2017, the SCDHEC has worked closely with community-based organizations and coalitions to develop data-informed guiding documents to align our state’s efforts to improve public health. These two documents are: The State Health Assessment (SHA), a comprehensive compilation of state level public health data, which provides a description of the health status of South Carolinians and the [2018-2023 State Health Improvement Plan \(SHIP\)](#), developed using data from the SHA and provides a vision for continuous health improvement, outlines priority areas, and promotes key strategies to improve the health of all people in the state. The SHA and SHIP are critical tools for health care providers, public health professionals, government agencies, community-based organizations, advocates, academics, policymakers, and other stakeholders to catalyze action, leverage resources, and focus work towards measurable improvement of the health and wellbeing of our state. Throughout the BOLD Infrastructure Core Capacity state strategic planning process, the DISAP made sure to use the existing relevant data and align this plan with the priorities outlined in the State Health Improvement Plan.

The state is currently in the process of creating a new SHA and SHIP for 2024-2029. SCDHEC and other public health partners across the state are analyzing the most recently available epidemiological data and developing new priorities, goals, and strategies for the state.

A Public Health Framework to Address ADRD

The following plan was guided by the recommendations put forward by the Healthy Brain Initiative’s [State and Local Public Health Partnerships to Address Dementia, The 2018-2023 Road Map](#), (“Healthy Brain Roadmap”) as well as data from research and academic entities across the state. The Healthy Brain Roadmap promotes a comprehensive public health approach described in the Conceptual Framework visual below.

The SC Statewide Plan to Address ADRD uses a public health framework to address upstream factors that may be modified and the systems and environments that can impact risk factors for Alzheimer’s Disease and Related Dementias. Since our strategic plan development and shift to a public health framework was guided by the Healthy Brain Roadmap, it not only addresses the current care and treatment needs of people impacted by dementia, but also prepares for the future by developing strategies and objectives that address risk reduction and improve early detection and diagnosis for ADRD.

This figure of the Healthy Brain Roadmap Conceptual Framework outlines how we can use the four Essential Services of Public Health (Domains)—assure a competent workforce (W), monitor and evaluate (M), develop policies and mobilize partnerships (P), and educate and empower (E) the nation - to develop strategies to address ADRD. Action within each of these four domains is guided by three core principles: 1) to best eliminate health disparities, 2) collaboration across multiple sectors, and 3) leverage resources for sustained impact.



Conceptual Framework Source: Alzheimer’s Association and Centers for Disease Control and Prevention. (2018). Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map. Chicago, IL: Alzheimer’s Association.

Using a public health framework to address ADRD also requires stakeholders to consider and promote efforts that address primary, secondary, and tertiary prevention of ADRD. Within the context of ADRD, primary prevention efforts are those that accelerate risk reduction, specifically, promoting prevention of modifiable risk factors for developing dementia. These risk factors include traumatic brain injury, smoking, diet, physical activity, cardiovascular risk, and other modifiable factors that also correspond with an overall healthy lifestyle and improved quality of life. Secondary prevention for ADRD includes improving rates of early detection and diagnosis of dementia and recognition of cognitive impairment. Tertiary prevention efforts are those that ensure safety and quality of care for all people with dementia and/or that provide support and improve health of all types of caregivers and care partners.

Risk Reduction and ADRD (Primary Prevention):

SC has one of the fastest-growing populations of older adults in the country and is in the “Stroke Belt,” a set of southeastern states with a higher burden of stroke and cardiovascular disease than other US regions. Older adults with Alzheimer’s and other dementias are more likely than other older adults to have multiple chronic conditions, with more than 95% of people with dementia having one or more chronic conditions.

Several chronic conditions have been identified by experts as “modifiable risk factors” such as hypertension, diabetes, mid-life obesity, and smoking and have been found to be associated with increased risk of cognitive impairment and possibly dementia. Although many mid-life and older adults are concerned about brain health, they often lack awareness of strategies to best preserve cognitive functioning and reduce risk for impairment. Evidence suggests that addressing modifiable risk factors might reduce the risk of dementia or delay by up to 40%. (HBI Roadmap, p. 5)

According to a 2019 report from the CDC, there are 10 Key Risk Factors: depression, diabetes, hearing loss, mid-life hypertension, physical inactivity, poor diet quality and obesity, poor sleep quality and sleep disorders, tobacco use, traumatic brain injury, and alcohol use (Omura, Patel, et al. 2019).

Early Detection and Diagnosis of ADRD (Secondary Prevention):

Although there is not a cure for ADRD, early detection and diagnosis is still important. Having a formal diagnosis allows people living with ADRD to have access to treatments and support services, build a care team, and potentially have access to clinical trials. (CDC, 2019)

Early detection and diagnosis also allow individuals and their care partners to prepare for future financial needs, make end of life choices, and be part of their care planning decisions. It also provides an opportunity to address the challenges of other chronic conditions.

Nearly **90% of Americans** say that if they were exhibiting confusion and memory loss, they would want to know if the cause of the symptoms was Alzheimer’s disease.

Missed diagnoses of dementia are more common among African Americans than whites. While African Americans are two times more likely to have Alzheimer’s or another dementia than whites, they are only **36% more likely** to receive a diagnosis.

Improving Safety and Quality of Care for People Impacted by ADRD (Tertiary Prevention):

The challenges of caring for persons with Alzheimer’s and other dementias can become difficult and overwhelming, especially when intensive care is needed for long periods of time. For many, however, caregiving is also a rewarding experience, bringing family members closer together in time of great need. Public health approaches can play a central role in offering information, guidance, and supportive resources to caregivers to help them provide effective dementia care and attend to their own well-being. In addition, public health can help improve the health and functioning of people living with dementia by assuring professionals delivering healthcare and other types of care services use evidence-based guidelines and have sufficient training. (Healthy Brain Roadmap, p. 7)

It is also critical to our public health approach to addressing ADRD in SC that special attention is paid to caregivers and care partners. “Caregivers can be unpaid family members or friends or paid caregivers. Informal or unpaid caregivers are the backbone of long-term care provided in people’s homes. In particular, middle-aged and older adults provide a substantial portion of this care in the US, as they care for children, parents or spouses.” (CDC Caregiving for Families and Friends brief)

Health Inequities & ADRD

The Healthy Brain Roadmap emphasizes the need to reduce health disparities and consider the impact of health inequities that contribute to the unequal burden of ADRD on disparate and vulnerable populations. Once data is available from post-COVID-19 pandemic years, South Carolina ADRD stakeholders, the SC Department on Aging, and SCDHEC are committed to developing strategies with an intentional focus on communities of disproportionate burden of disease including: American Indian/Alaskan Native, Black/African American, and Latinx/o/a/Hispanic populations across our state. Our stakeholders have also committed to improving the gaps in care, risk reduction, and early diagnosis that exist between the rural and urban areas of our state. We hope that our implementation plans will allow us to act not only in our own agencies, communities, and organizations, but will also allow us to collaborate across sectors to enact policy, systems, and environmental changes (PSE) that support health equity and sustainable changes to our ADRD systems of care.

It is important to note that although stakeholders across South Carolina are supportive of using a prevention framework for our plan to address ADRD over the next five years, the primary data and input from stakeholders across the state did not always place a high priority on risk reduction strategies to address ADRD. As our state moves from planning to implementation, however, there will be a commitment to include not only efforts to improve access to quality care, but also promote efforts and programs that reduce risk of ADRD and increase early detection and diagnosis of ADRD across the lifespan.



Justification of Need

KEY DATA PARTNERS

The following entities were relied upon to provide the data used in this section and throughout the development of the 2023 to 2028 South Carolina State Plan.

- The South Carolina Alzheimer's Disease Registry, housed in the University of South Carolina's Office for the Study on Aging in the Arnold School of Public Health
- SCDHEC's
 - Vital Records Department
 - Behavioral Risk Factors Surveillance System (BRFSS)
- Medical University of South Carolina's (MUSC) South Carolina Alzheimer's Disease Network (SCAN)

ADRD Impact

In 2022, there were approximately 6.5 million Americans living with Alzheimer's Disease or other Dementias in the United States according to the Alzheimer's Association's 2022 Alzheimer's Disease Facts and Figures Report. It is estimated that about 1 in 9 people (10.7%) age 65 and older has Alzheimer's dementia. As the population of people 65 and older continues to grow, so will the prevalence of ADRD (Alzheimer's Association, Facts and Figures, 2022). The projected number of people 65 and older living with Alzheimer's Disease by 2060 is approximately 13.8 million.

In 2015, SC had the highest Alzheimer's death rate in America. Currently, SC has the 16th highest death rate in the US., and Alzheimer's Disease is the fifth leading cause of death in South Carolina. Over 95,000 people living in SC have Alzheimer's, with an expected 26.3% increase by 2025 (Alzheimer's Association, Facts and Figures, 2022). The percentage of SC's population that were adults aged 65 and older increased by 28% from 2011 to 2020. This is predicted to further increase by 21% from 2020 to 2023.

South Carolina has the oldest Alzheimer's Disease registry in the United States, which keeps a rolling registry of all living, diagnosed cases of ADRD in SC. Individuals with ADRD are usually identified when they or their family members seek provider services. Since no single system identifies all newly diagnosed patients with ADRD, cases in the Registry are collected from several sources. This ensures that the Registry captures as many diagnoses as possible. In 2017, the SC Alzheimer's Disease Registry had information on 111,818 individuals who were currently living with ADRD in South Carolina, and since its creation in 1988, the Registry has identified 304,901 cases ([2021 Annual Report South Carolina Alzheimer's Registry](#)).

ADRD prevalence is increasing according to data from the SC Alzheimer's Disease Registry, and the full impact of COVID-19 on cognitive impairment and other risk factors for ADRD is not yet known ([2021 Annual Report South Carolina Alzheimer's Registry](#)).

Mild Cognitive Impairment in SC

While a person with mild cognitive impairment may be at greater risk of developing dementia, it is not inevitable; a portion of people with mild cognitive impairment eventually develop dementia. Growing scientific evidence demonstrates that healthy behaviors, which have been shown to prevent cancer, diabetes, and cardiovascular disease, also may reduce risk for cognitive impairment and possibly dementia.

In South Carolina, 11.5% (1 in 9) of those aged 45 and over report they are experiencing confusion or memory loss that is happening more often or is getting worse ("subjective cognitive decline"). More than half of adults aged 45 and over who reported memory problems reported they had not talked to a health care provider about it (BRFSS, 2019).

Disparities

According to the Alzheimer's Association, almost two thirds of Americans with Alzheimer's are women. Women live longer than men on average, and older age is the greatest risk factor for Alzheimer's. This survival difference contributes to higher prevalence of Alzheimer's and other dementias in women compared with men. In 2017, 62 percent of the ADRD cases within the SC Alzheimer's Registry were women. Older non-Hispanic Blacks and Hispanic Americans are disproportionately more likely than older white adults to have Alzheimer's or other dementias. Evidence also shows that missed or delayed diagnoses of Alzheimer's and other dementias are more common among Black and Hispanic older adults than among white older adults (Alzheimer's Association, 2020).

Caregivers, Care Partners, and the Cost Burden of Dementia Care in SC

Over 95,000 people living in SC have Alzheimer's with an expected 26.4% increase by 2025. There are 197,000 caregivers currently in SC, providing over 296 million hours of unpaid care, worth an estimated \$4.3 million in value in 2021 alone. On average, to speak to Medicaid costs, the state spends \$652 million on the care of people with Alzheimer's. The Average per-person Medicaid spending for seniors with dementia is 23 times greater than the average spending for seniors without dementia. In SC, there are only 66 geriatricians, those specializing in the medical needs of seniors, so a 336% increase would be needed to meet the population need by 2050. Without that almost impossible increase, Primary Care Providers (PCPs) in SC will bear the responsibility for early detection and diagnosis for those with subjective cognitive impairment (Alzheimer's Association, 2022).

Dementia Healthcare Workforce – Primary Care Providers in SC

A key partner in the data collection and analysis for the ARCC and the BOLD grant strategic planning process is MUSC's South Carolina Alzheimer's Disease Network (SCAN). The goal of SCAN is to create a network of clinicians, researchers, and state and community care organizations that aims to ensure every patient with Alzheimer's or other dementias in South Carolina has access to:

- Diagnostic expertise
- Co-management with primary care physicians longitudinally
- Clinical trials and research studies; and
- Community resources and education

This network aims to have particular emphasis on rural and underserved patients, which aligns with the health equity framework that the ARCC and other stakeholders agreed was a priority for this plan.

SCAN's first research priority was to assess and understand the needs of PCPs across the state of South Carolina in terms of their educational needs and understanding of dementia diagnosis, care, and referrals. The SCAN team developed and disseminated a survey to a broad mix of primary care practices and practitioners across the state, which had 93 responses. The survey functions as a preliminary needs assessment on the care of people impacted by ADRD in a primary care setting, including families, caregivers, and care partners, and the information collected is critically important to our future plans for a better coordinated and more responsive care system for all people in SC with dementia. The results of that survey are below and have informed the goals and objectives outlined in the state plan. These results highlight the need for improved and intensive efforts to develop educational programs that will help PCPs receive the support they need to help their patients and families affected by ADRD.

What Did We Learn from SCAN's survey?

63% OF RESPONDENTS SPENT **LESS THAN 5%** OF THEIR TIME ON ALZHEIMER'S CARE

SUPPORT FOR INITIAL DIAGNOSIS AND MANAGEMENT OF BEHAVIORAL ISSUES WERE IDENTIFIED AS AREAS OF NEED

49% IDENTIFIED LACK OF LOCAL SPECIALTY AND ANCILLARY RESOURCES TO ASSIST WITH DIAGNOSIS AND MANAGEMENT, & **25%** IDENTIFIED LIMITED RESOURCES FOR PATIENTS THAT REQUIRE INSTITUTIONAL LEVEL OF CARE AS BARRIERS TO EFFECTIVE CARE.

MOST OFTEN, RESPONDENTS INDICATED SPECIALTY REFERRALS FOR COGNITIVE PROBLEMS WERE EITHER MADE TO A GENERAL NEUROLOGIST (**50%**) OR TO NOBODY (**22%**).

MOST OFTEN, RESPONDENTS INDICATED SPECIALTY REFERRALS FOR BEHAVIORAL PROBLEMS WERE EITHER MADE TO A GERIATRIC PSYCHIATRIST (**48%**) OR TO NOBODY (**24%**).

46% OF RESPONDENTS INDICATED THEIR PRIMARY PRACTICE LOCATION IS RURAL, **30%** SUBURBAN, **23%** URBAN, & **1%** SELECTED OTHER.

85% OF PRACTITIONERS ARE INTERESTED IN DEMENTIA EDUCATION.

The 2023 to 2028 SC Statewide Plan to Address ADRD

STRATEGIC PLANNING PROCESS

The input received during the strategic planning process resulted in the development of a Mission, Vision, and Values (MVV) for the next 5 years of work, 5 Strategic Priorities, 3 Key Cross-Cutting Elements that we will address throughout the priorities, and a set of aligned Goals and Objectives that set our state up for implementation. Additional information about the process is detailed in Appendix B: Strategic Planning Methodology.

VISION, MISSION, & VALUES

Our VISION:

All people in South Carolina have the opportunity to live the highest quality of life throughout their life course.

Our MISSION:

To catalyze statewide collaboration to promote a comprehensive approach to risk reduction, early detection and diagnosis, high-quality dementia services, and a coordinated and equitable continuum of care across South Carolina for Alzheimer's Disease and Related Dementias.

Our VALUES:

Dignity - is at the core of what we do.

We respect and support the health and well-being of the whole person throughout their life course, regardless of diagnosis or progression of disease.

Integrity - is foundational to all our work.

In order to ensure our efforts to address ADRD do no harm and maintain the highest of ethical standards, we are committed to continually learning, protecting vulnerable populations, and reducing barriers to education and resources.

Equity - guides our approaches and practices.

We engage in our work with intentionality, recognizing that systemic inequities exist and significantly impact access to information about risk reduction, early detection, and barriers to quality care and support.

Community - is essential to our success.

We build trust and collaborate with a wide range of partners, including researchers, providers, and local organizations, to ensure that all community members have access to the education, services, care, and resources they need to achieve the highest quality of life possible.

Information - is critical to the development of data-driven programs, policies, and procedures.

We must be transparent with our partners and share information freely. Equitable access to information is key to risk reduction and other health promotion efforts. Information from stakeholders, statistics, research and current data allow us to align with best practices, develop culturally relevant programming for caregivers, care partners, health care systems, and persons diagnosed with and at risk for ADRD.

SOUTH CAROLINA STATE PLAN GOALS & OBJECTIVES

Five Categories for Action as Defined by the ARCC's Strategic Work Group:

1. Education for Healthcare Providers and Community
2. Advocacy and Policymaking
3. Access and Connection to Care
4. Caregiver Support
5. Data and Resources

CROSS-CUTTING Elements: Multi-Sector Collaboration, Equity, and Public Health Framework

KEY:

G = Goal

P = Primary Prevention

S = Secondary Prevention

T = Tertiary Prevention

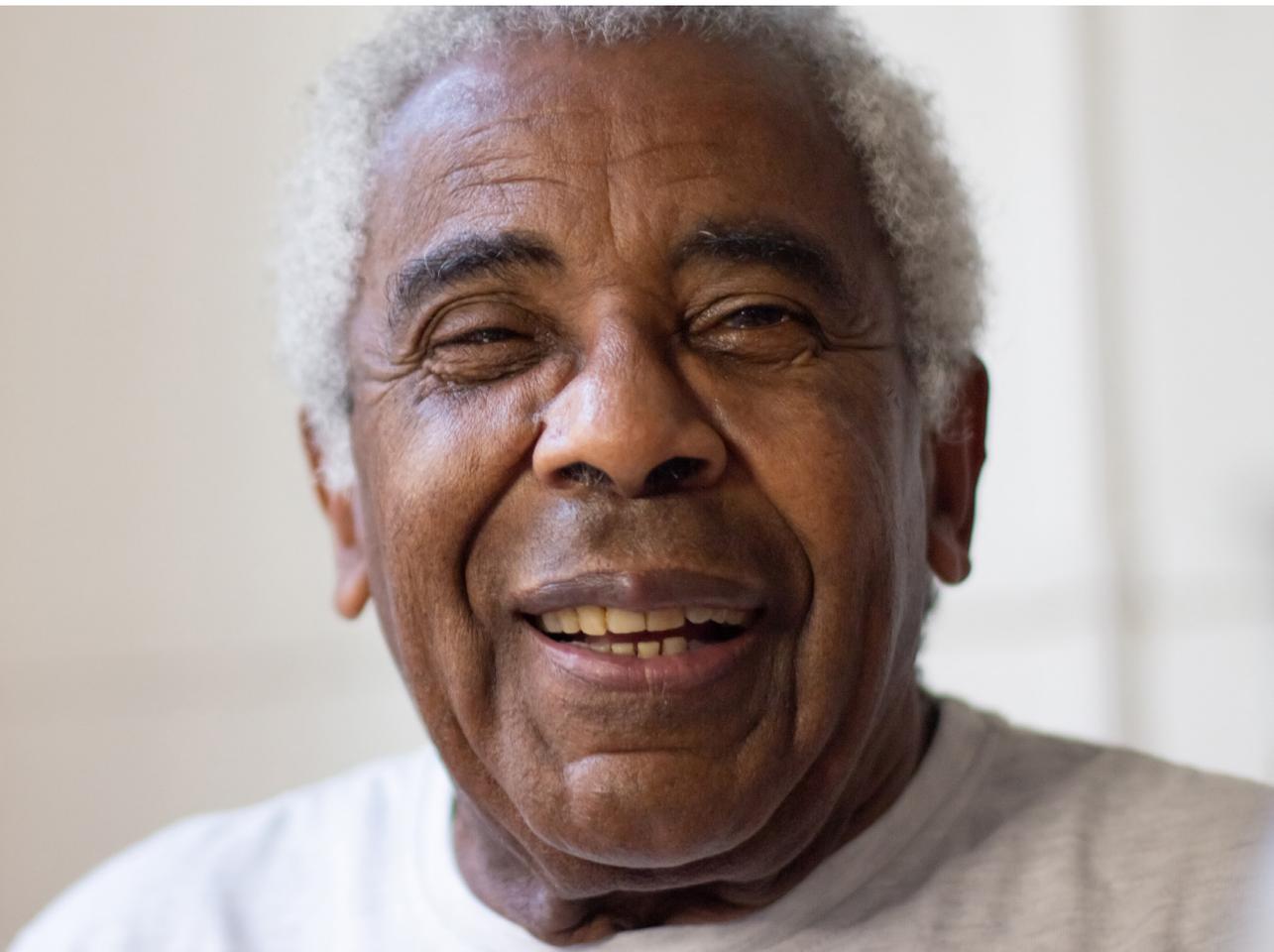
Healthy Brain Roadmap Domains:

E = Educate and Empower

M = Monitor and Evaluate

P = Develop Policies and Mobilize Partners

W = Competent Workforce



EDUCATION - HEALTHCARE PROVIDERS & COMMUNITY

HEALTHY BRAIN INITIATIVE ROADMAP DOMAIN(S): E, W

Goal 1: Improve knowledge, understanding, and awareness of ADRD by educating and empowering all South Carolinians, including every person engaged in the continuum of care.

(Continuum of care roles include: healthcare professionals, public health professionals, first responders, caregivers and care partners, families, policymakers, and the community at-large)

To accomplish this goal, we will achieve the following 13 objectives below:

G1.P1: Increase awareness of existing resources and educational opportunities for all South Carolina citizens currently available through ARCC member organizations, especially the SC Department on Aging, the Department of Health and Human Services, the SC Department of Health and Environmental Control, academic institutions, and others.

G1.P2: Promote the development of standardized, evidence-informed, dementia-specific training for individuals in the medical, health, and social services fields, including all first responders (i.e. law enforcement, emergency management technicians (EMTs), and social workers). This will require collaboration with statewide healthcare education entities to ensure dementia-specific training is available, appropriate, and required for licensure or certification.

G1.P3: Continue and expand the “Take Brain Health to Heart” public health awareness campaign as a key risk-reduction strategy.

G1.P4: Promote and educate all ADRD stakeholders on the importance of an equity lens when considering the needs of people living with dementia. South Carolina has specific, systemic racial challenges and needs in rural areas of the state.

G1.P5: Promote public awareness campaigns and educational offerings that are culturally appropriate for different generations and cultures.

G1.S1: Collaborate with statewide public health efforts such as the State Health Assessment and State Health Improvement Plan and ensure the inclusion and prioritization of risk reduction, early detection, and quality of care for ADRD in statewide public health efforts and funding.

G1.S2: Improve education and awareness around mild cognitive impairment (MCI), including what to do and where to go when cognitive changes are noticed. This requires educating healthcare providers on MCI as well.

G1.S3: Reduce stigma of a dementia diagnosis through community awareness campaigns on disease progression and stages, early-stage support groups and early-stage involvement in advisory capacities for programs and policies, and dementia education.

G1.T1: Improve awareness and understanding about the differences between Alzheimer’s Disease and other less common dementias.

G1.T2: Provide training and education for caregivers and care partners where practitioners and caregivers are using the same language when discussing care.

G1.T3: Improve and expand efforts to include the voices of people diagnosed with dementia and mild cognitive impairment. Emphasize the importance of having people living with dementia engaged in their future care planning as they are cognitively capable including living wills, advanced directives, medical decisions, financial and legal planning.

G1.T4: Improve the quality of and access to dementia education and resources available through relevant state agencies, especially for caregivers and care partners.

G1.T5: Provide training and education of first responders about ADRD, including how to communicate with someone with dementia or cognitive impairment, how to support families and caregivers, and how to discern if neglect is occurring.

ADVOCACY & POLICYMAKING

HEALTHY BRAIN INITIATIVE ROADMAP DOMAIN(S): E, P

Goal 2: Support policy and advocacy efforts that improve the health and wellbeing of all people in South Carolina.

To accomplish this goal, we will achieve the following 10 objectives below:

G2.P1: Provide information to support the development of policies that incentivize and advance dementia risk reduction across provider and community settings.

G2.P2: Inform policymakers about needs to ensure allocation of the state budget adequately supports the specific goals outlined in this strategic plan.

G2.S1: Advocate for a comprehensive continuum of care with legislators and key community stakeholders, including allocation of resources for early diagnosis and intervention.

G2.T1: Educate state and local legislators on the importance of this strategic plan document to ensure their support and buy-in for passing priority policies and reducing barriers to care.

G2.T2: Promote the development of an advocacy campaign or tactics that target employers and insurance companies that may create barriers to care, to include messaging that ensures the funding and support of risk reduction and early detection programs and services.

G2.T3: Ensure voices of people living with dementia and all people affected by ADRD are included in grassroots campaigns for inclusive and effective community advocacy efforts.

G2.T4: Assess policies of payers, employers, hospitals and other healthcare systems and identify those policies that may create barriers to education and healthcare access. Based on the result of this assessment, develop a plan to address and eliminate barriers to care and health inequities.

G2.T5: Coordinate with ADRD stakeholders and academic institutions across the state to increase the ability of health care providers to deliver person-centered care through dementia-specific and culturally competent training.

G2.T6: Provide information for developing policies that can reduce barriers and ensure individuals living with dementia have adequate access to residential and home and community-based services.

G2.T7: Advocate for the expansion and continued funding of programs that provide support to informal caregivers and care partners of individuals living with dementia.

ACCESS & CONNECTION TO CARE

HEALTHY BRAIN INITIATIVE ROADMAP DOMAIN(S): E, W

Goal 3: Improve the quality of ADRD care and ensure all people in South Carolina are able to access the resources, healthcare, and support they need for reducing risk and all other issues related to ADRD.

To accomplish this goal, we will achieve the following 11 objectives below:

G3.P1: Identify key partners with broad reach in every county and collaborate with those community partners to increase awareness about local ADRD-related services.

G3.P2: Increase awareness about ADRD and promote preventative and risk reducing activities at the community level across the state.

G3.S1: Support and champion the implementation of statewide primary care provider training and education for early detection, diagnosis, and diagnosis disclosure for care planning.

G3.S2: Work with ADRD stakeholders statewide to outline a plan for advanced care coordination that involves co-management with primary care, local specialists, counselors, and others.

G3.T1: Champion the development of memory treatment centers with expertise across the state that involves inter-institutional coordination, with each center responsible for providing care across their region, including the use of telehealth.

G3.T2: Promote the development of a state-funded clinical care coordination program that includes enough funding for high quality care, interdisciplinary health care teams, and a fully coordinated, integrated care system that interfaces with research.

G3.T3: Identify a recommended list and promote the use of culturally appropriate programs that address quality of care and care navigation, including ensuring funding for evidence-based programs through The Aging Network (formerly the Area Agencies on Aging).

G3.T4: Identify key barriers and develop a recruitment plan to improve the health care workforce and ensure they are better able to address ADRD through primary, secondary and tertiary prevention. Special attention needs to be paid to increasing the number of paid caregivers, cognitive specialists, primary care providers of all kinds, neurologists, and mental health professionals.

G3.T5: Collaborate statewide to improve virtual care, including the expansion of telehealth and broadband access, such as use of electronic consults (informal, early on in diagnosis) to improve access to services in rural and urban areas.

G3.T6: Improve post-diagnosis access and systems of referral to affordable legal services for families, care partners, and persons diagnosed. (i.e. Durable Power of Attorney, Health Care Power of Attorney, Will/trust, etc.)

G3.T7: Improve communication and coordination regarding people impacted by dementia among Primary Care Providers and the full spectrum of healthcare providers and physician specialists across the state.

CAREGIVER SUPPORT

HEALTHY BRAIN INITIATIVE ROADMAP DOMAIN(S): P

Goal 4: Improve, expand, and develop multidimensional support and health promotion programs for professional and family caregivers and care partners.

To accomplish this goal, we will achieve the following 10 objectives below:

G4.P1: Develop strategy for community awareness campaigns about promoting health and reducing risks of dementia and cognitive impairment among those who anticipate entering into caregiving.

G4.P2: Develop programs and work with partner organizations to improve and expand resources for caregivers and care partners that will reduce stress, improve coping, and improve overall health (i.e. Easily-accessible online support and resource centers, peer support groups, and community-based programs to promote physical activity and chronic disease management).

G4.S1: Increase awareness and expand presence of early-stage support groups statewide to ensure support for caregivers as soon as possible.

G4.T1: Provide access to all necessary resources and information needed to optimize care, support, and crisis management, including emotional support for caregivers.

G4.T2: Task the ARCC and other relevant agencies and organizations with developing specific goals to address quality of support and care for caregivers.

G4.T3: Create a statewide crisis response system that supports the unique behavioral needs of individuals living with dementia.

G4.T4: Work to consolidate resources for caregivers through a "No Wrong Door" system.

G4.T5: Provide workshops (in person and virtually) that support caregiver education on additional caregiver skills including wound care, nutrition, socialization, etc.

G4.T6: Establish a partnership with the SC Office of Rural Health to identify and develop a plan to address specific needs of caregivers and care partners in rural communities, including lack of access to specialists, respite programs and other resources.

G4.T7: Coordinate with appropriate community organizations (including faith-based organizations), state agencies, and insurance companies to improve adult day care availability and affordability.

DATA & RESOURCES

HEALTHY BRAIN INITIATIVE ROADMAP DOMAIN(S): M

Goal 5: Improve access to, coordination, and use of ADRD data and resources statewide.

To accomplish this goal, we will achieve the following 9 objectives below:

G5.P1: Use research, data collection and analysis to inform policy and programming.

G5.P2: Develop a partnership with MUSC's Office of Health Care Workforce in order to develop strategic reports about the specific gaps, needs, and barriers to recruiting, retaining, and training all levels of health care providers needed to help address the full spectrum of ADRD needs for the incoming 'Silver Tsunami' in South Carolina.

G5. P3: Strongly encourage all research partners to commit to the equity stratification of all ADRD data collection, analysis and dissemination, and to use the results of that equity-stratified data to inform policy and programming decisions.

G5.S1: Incorporate into data collection efforts intentional tracking of early detection and diagnoses statewide to look for gaps in the continuum of care and to identify communities in need of more resources and/or education.

G5.T1: Use data gleaned through available surveillance strategies and other sources to inform the public health program and policy response to cognitive health, impairment, and caregiving.

G5.T2: Coordinate with state licensing agencies to collect data on the professions, facilities and providers that can provide services for people with dementia and mild cognitive impairment.

G5.T3: Develop a formal assessment to determine the challenges and needs of caregivers and care partners; begin with a baseline assessment on the range of caregiving activities happening throughout the state.

G5.T4: Encourage statewide data collection entities and research institutions to analyze and report on the impact of COVID-19 on people impacted by ADRD, including families, caregivers, and care partners.

G5.T5: Improve the collection, availability and utilization of dementia-related data by the relevant state agencies.

Moving from Planning to Implementation

The 2023 to 2028 SC Statewide Plan to Address ADRD outlines the overarching goals and objectives that we intend to implement over the next five years that we hope will help us to accomplish each broad goal. Beginning in the summer of 2023, and in following years, an implementation plan with SMARTIE Goals to track our progress on the desired objectives will be developed and updated with key stakeholders, collaborating organizations, and people directly impacted by ADRD (Note: SMARTIE stands for Specific, Measurable, Ambitious, Realistic, Time-bound, Inclusive, and Equitable). Our implementation plans will include activities that will allow us to evaluate and monitor our collaboratively decided action steps and tactics. We also commit to annual review and analysis of all available outcome data on ADRD.



Appendix A:

GLOSSARY OF ACRONYMS & DEMENTIA TERMS

Acronyms used throughout the document:

ADLs – Activities of daily living

ADRD – Alzheimer’s Disease and Related Dementias

ARCC – South Carolina Department on Aging’s Alzheimer’s Resource Coordination Center Advisory Council

BOLD – Build our Largest Dementia

CDC – Centers for Disease Control

DISAP – Division of Injury and Substance Abuse Prevention (housed in the Bureau of Chronic Disease and Injury Prevent at SCDHEC)

DLB – Dementia with Lewy Bodies

FTD – Frontotemporal degeneration

MUSC – Medical University of South Carolina

PCPs - Primary Care Providers

PSA – Public Service Announcement

PSE – Policy, systems, and environmental changes

SC – South Carolina

SCAN – MUSC Health’s South Carolina Alzheimer’s Disease Network

SCDHEC – South Carolina Department of Health and Environmental Control

SCORH – South Carolina Office for Rural Health

SHIP – State Health Improvement Plan

SHA – State Health Assessment

Glossary of Dementia Terms

This glossary of terms was selected from the Healthy Brain Initiative’s State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map and the online dementia glossary developed by The Alzheimer’s Association.

Activities of daily living (ADLs)

Activities of daily living (ADLs) include eating, bathing, grooming, dressing and going to the toilet. People with dementia may need aid to perform these tasks. Questions about ADLs help decide what type of care a person needs.

Adult day centers

Adult day centers offer people with Alzheimer's and other dementias the opportunity to be social and to participate in activities in a safe environment.

Advance directive

An advance directive is a legal document. It tells what kind of medical treatment a person would like when he or she cannot communicate wishes.

Assisted living

Assisted living is a residential care facility that generally provides 24-hour staff, recreational activities, meals, housekeeping, laundry and transportation. Definitions of assisted living and the specific regulations differ from state to state. Residents may choose which services they receive from the residence such as house cleaning, help with grooming or medication reminders.

Alzheimer's Disease

An irreversible, progressive brain disorder that develops across a continuum and slowly destroys memory and thinking skills and, eventually, the ability to carry out the simplest tasks. Symptoms usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks.

ADRD – Alzheimer's Disease and Related Dementias

ADRD is the current standard acronym used by the National Institutes of Health (NIH) to refer to the most common forms of dementia. According to the NIH, those dementias include:

Frontotemporal degeneration (FTD), Lewy body dementia (LBD), Vascular contributions to cognitive impairment and dementia (VCID), and Multiple etiology dementias (MED).

Brain Health

A concept that involves making the most of the brain's capacity and helping to reduce some risks that occur with aging. Brain health refers to the ability to draw on the strengths of the brain to remember, learn, play, concentrate, and maintain a clear, active mind.

Caregivers

Spouses, partners, adult children, other relatives, and friends providing unpaid help to people living with dementia who may need help with everyday activities. Caregivers often assist with diverse activities of daily living such as: Personal care, Household management, Medication and health care management, Coordination of financial matters.

OR: Caregiver (alternative definition)

Anyone who provides care to a person with Alzheimer's disease or dementia. Caregivers can be family members or friends or paid professional caregivers. Caregivers may provide full- or part-time help to the person with Alzheimer's.

Care Partner

A person who provides care, similar to "caregiver," however, "care partner" implies that the person who is living with the disease and the person providing care are equal. This term promotes the autonomy and dignity of people living with dementia.

Cognition

The mental functions involved in attention, thinking, understanding, learning, remembering, solving problems and making decisions. Cognition is a fundamental aspect of an individual's ability to engage in activities, accomplish goals, and successfully negotiate the world. It can be viewed along a continuum — from optimal functioning to mild cognitive impairment to dementia.

Dementia

Dementia is not a specific disease. It's an overall term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities. 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. These functions include memory, language skills, visual perception, problem solving, self-management, and the ability to focus and pay attention. Alzheimer's is the most common cause of dementia. Other types include vascular dementia, dementia with Lewy bodies and frontotemporal dementia.

Early Detection and Diagnosis

Identifying cognitive issues as early as possible. The earlier dementia is diagnosed, the sooner people and their families can receive information, care and support. A formal diagnosis allows people to have access to available treatments and interventions, build a care team, participate in support services, and potentially enroll in clinical trials.

Early Onset (or Younger Onset)

Early-onset (also known as younger-onset) Alzheimer's or Related Dementias affects people younger than age 65. Many people with early-onset are in their 40s and 50s. They have families, careers or are even caregivers themselves when ADRD strikes.

Functional impairment

Functional impairment means being unable to dress, use the toilet, eat, bathe or walk without help.

Hospice

A program that offers support for dying persons to live as fully and comfortably as they can.

Mild Cognitive Impairment (MCI)

A slight but measurable decline in cognitive abilities that includes memory and thinking. A person living with MCI is at increased risk of developing dementia.

Power of Attorney

A power of attorney is a legal form that names someone to act as your substitute.

Respite care

Respite care provides temporary relief from caregiving tasks. Such care could include in-home assistance, a short nursing home stay or adult day care.

Risk Reduction

Preventing or delaying the onset of cognitive decline or dementia. Growing evidence shows that modifying certain risk factors, especially hypertension, and promoting healthy behaviors, particularly heart healthy behaviors, can reduce the risk of developing cognitive decline and may also reduce the risk of dementia.

Stages/Life Course Perspective on ADRD

A framework for the progression of Alzheimer's Disease and Related Dementias. According to the CDC, the course of Alzheimer's disease and other dementias should be viewed as a continuum across the life course that begins with healthy cognitive functioning and ends in dementia. The stages of dementia in the continuum, in order, are: Healthy Cognitive Functioning, Pre-Symptomatic, Mild Cognitive Impairment, and Dementia.

Subjective Cognitive Decline (SCD)

Self-reported difficulties with thinking or memory that happen more often or get worse. People experiencing SCD are at increased risk of later developing dementia.

Appendix B:

Strategic Planning Methodology

To ensure a thorough process and that extensive stakeholder input was included in the five-year strategic plan, SCDHEC's Department of Injury and Substance Abuse Prevention contracted with The Weathers Group, a consulting firm with decades of experience developing strategic plans for agencies and organizations in South Carolina and across the nation. The strategic planning process in coordination with contractors was initiated during the summer of 2022. To develop the draft strategic plan, create alignment with existing public health and ADRD programming, and ensure all grant deliverables are met, The Weathers Group (TWG) worked closely with the BOLD Project Manager housed at SC DHEC and the ARCC chair, as well as with a Strategy Work Group (SWG) made up of key stakeholders.

At the beginning of their process, the Weathers Group reviewed over 40 key documents provided by staff at SCDHEC and the ARCC chair from July through November 2022. Key documents included CDC BOLD grant guidance, previous statewide ADRD implementation plans, data and research briefs from SCDHEC's epidemiological department and universities and research entities across the state, as well as multiple documents pertaining to the development, requirements, and ongoing work of the South Carolina Department on Aging's ARCC. The ARCC guiding documents include: the original statute that established the ARCC, coalition bylaws, policies and procedures, meeting minutes, and subcommittee meeting recordings.

The plan development involved multiple phases:

Phase 1 & 2: Information Gathering and Environmental Scanning, including:

- A comprehensive document review
- An ADRD programs and services assessment
- Internal and external stakeholder surveys
- Two focus groups
- Four in-depth interviews with content experts and key stakeholders
- Review of prior and attendance at current quarterly ARCC meetings and select subcommittee meetings to provide updates and collect information on the ongoing work of the coalition and its partners

Phase 3 & 4: Sense-making and Strategic Conversations

- Compilation and review of stakeholder input
- Assembly and meetings of strategic work group in order to:
 - Review document assessment and stakeholder input findings
 - Identify themes and priorities
 - Identify potential indicators of success
 - Draft strategic framework to guide plan implementation, including Vision, Mission, and Values

Phase 5: Strategic Direction and Statewide Plan Development

- Completion of pinnacle planning session with statewide ADRD coalition, including presentation of draft strategic framework and strategic priorities at the end of the calendar year 2022

The input received during the strategic planning process has been summarized below. Although stakeholders across South Carolina are supportive of using a prevention framework for our plan to address ADRD over the next five years, it is important to note that the input from stakeholders across the state did not always place a high priority on primary and secondary prevention strategies to address ADRD. As our state moves from planning to implementation, however, there will be a commitment to the inclusion of not only tertiary prevention efforts and improvements to accessing quality care, but also promote efforts and programs that reduce risk of mild cognitive impairment and increase early detection and diagnosis of ADRD across the lifespan.

Key Findings from Strategic Planning Process:

- Document review and stakeholder feedback key findings:
 - Need for statewide collaboration and coordination with diverse groups, including community-based partners and local providers, to develop a comprehensive strategy for addressing ADRD
 - There is widespread agreement and buy-in among stakeholders to develop and implement a public health approach to addressing ADRD in the 2023 to 2028 statewide plan with a particular emphasis on clearly outlining:
 - Risk reduction for cognitive decline
 - Improved early detection/diagnostic and care capabilities
 - Equitable access to high quality ADRD services and support, especially for caregivers
 - Alignment, partnership, communication, and coordination of efforts to address ADRD are necessary for long term success, especially among state agencies, healthcare systems, and research institutions to avoid costly duplication of efforts
 - Currently, the collective will to work together is strong, but various barriers prevent smooth, strategic program planning and implementation – barriers include lack of consistent communication between and among state agencies and key stakeholders, outdated regulations and practices, and a limited history of collaboration
 - The ARCC is the ideal entity to serve as the statewide coalition for this BOLD Infrastructure grant, both for the current Core Capacity stage and following grant opportunities from the CDC
 - Prioritization of increased public and community-level education, awareness, and collaboration especially to ensure early diagnosis
 - The education and communications campaign developed by SCDHEC, “Take Brain Health to Heart,” has been well-received by the ADRD community and is a prime example of a program that serves as a primary prevention intervention
 - There is significant support and data to justify expanding and building on the existing campaign and website materials
 - Importance of achieving equitable access to services and resources to address statewide disparities, including removing barriers for marginalized and rural communities
 - There is significant need to be more intentional about including the voices of caregivers, care partners, and persons diagnosed with dementia
 - These voices are not fully represented on the statewide coalition or in the planning or evaluation of ADRD programs and services
 - Health Equity concerns are significant and crosscutting, but more information from research entities is needed to develop strategic priorities for vulnerable populations in South Carolina

- Environmental assessment key findings:
 - Major statewide strengths identified are the dedicated advocates, who are invested in doing the work and providing a foundation for support and ARCC’s strong committee structure and momentum
 - Primary weaknesses in the state were identified as relating to care, including:
 - Lack of access to and funding for care
 - Lack of provider education (“provider education” refers to providers at all levels, not just health care providers)
 - Lack of caregivers
 - Concerns around maintaining current momentum and attaining sustainable funding, with funding identified as the biggest threat to successfully plan implementation
 - Access to care is a primary concern when taking in the changing technology landscape with the rural divide as a particular concern for South Carolina, resulting from lagging internet, which limits telehealth access and increases risk of isolation
 - Partnerships are critical to navigating social changes, requiring collaboration between community-based organizations, research institutions, legislators, and institutional providers such as Veterans Affairs
 - Addressing health equity requires:
 - Reliable, well-trained care teams (whether they consist of medical professionals or community partners such as EMTs or caregivers without healthcare backgrounds) with knowledge of local resources and current best practices for ADRD risk reduction, diagnosis, and treatment
 - Dignity as a central focus, with the dignity of every person elevated through storytelling
 - Funding and policymaking at local, state, and federal levels will be instrumental for navigating political and economic landscapes, with a particular focus on workforce development to improve access to and quality of care

A visual timeline of our process is below



Appendix C: References

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