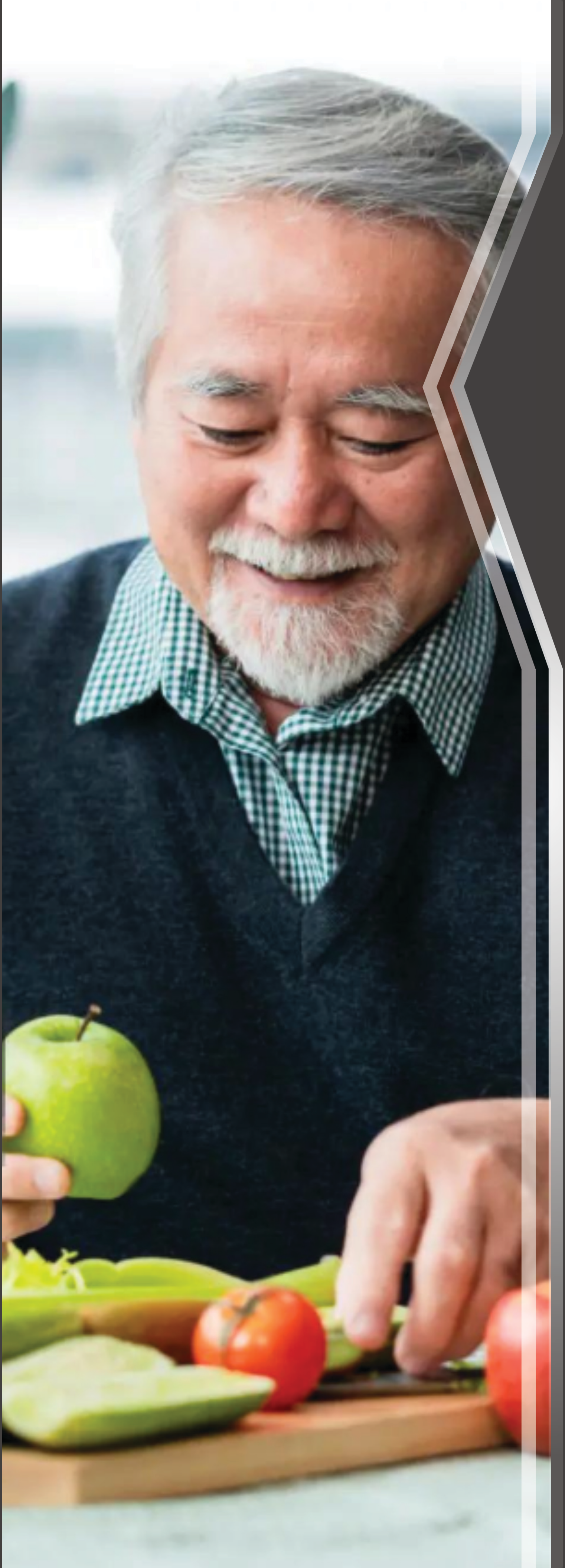

ARIZONA ALZHEIMER'S DISEASE AND RELATED DEMENTIA

STATE PLAN

2024-2029

ARIZONA DEPARTMENT
OF HEALTH SERVICES

1912

Katie Hobbs, Governor
State of Arizona

Jennifer Cunico, Cabinet Executive Officer, Executive Deputy Director
Arizona Department of Health Services

ARIZONA DEPARTMENT OF HEALTH SERVICES
DIVISION OF PUBLIC HEALTH PREVENTION SERVICES
BUREAU OF CHRONIC DISEASE AND HEALTH PROMOTION

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As Arizonans and stakeholders in Alzheimer's & Dementia care, implementing the recommendations outlined in this report will contribute to alleviating the impact of these conditions on individuals and communities across our state. By enhancing support systems and services, we can positively influence the lives of those affected by Alzheimer's & Dementia, offering them greater comfort and quality of life.

The Arizona Department of Health Services (ADHS) extends heartfelt appreciation to all collaborators and stakeholders who contributed to the development of this plan. Your invaluable assistance has been instrumental in shaping this initiative. Thank you for your unwavering dedication and ongoing partnership as we strive to lessen the burden of Alzheimer's & Dementia on the diverse communities throughout Arizona.

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ARIZONA DEPARTMENT
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Dear Reader,

The Arizona Department of Health Services (ADHS) is excited to present the 2024-2029 Arizona Alzheimer's Disease State Plan. In state fiscal year 2024, ADHS received state funds from Senate Bill (SB) 1726 to develop and publish an updated Arizona Alzheimer's Disease State Plan. ADHS is appreciative of our many longstanding relationships and partnerships around the state, and the development of this plan would not be possible without our partners' contributions of our statewide partners, individuals with lived experience and their families, and caregivers.

In Arizona, the number of individuals 65 years of age and older has slowly been increasing since Calendar Year (CY) 2019. In CY 2021, there were approximately 1.347 million individuals 65 of age and older in Arizona, which was approximately 18.5% of the total Arizona population (7.276 million; US Census). With a rising aging population, ADHS has made older adults and healthy aging a priority in our chronic disease work. Yearly, ADHS' State Health Assessment updates data for the older adult population, and in CY 2023 ADHS hired a Population Health Program Administrator to address and coordinate older adult and healthy aging efforts within the department. In addition, the 2020-2025 Arizona Health Improvement Plan (AzHIP) has identified strategies and actions that statewide partners have been addressing to ensure the health and wellness of our older adult population.

Alzheimer's Disease is a chronic disease, and is currently (CY 2023) the 5th leading cause of chronic disease mortality in Arizona. The overall mortality rate of individuals 65 years and older in Arizona for CY 2022 was 3958.9 per 100,000 residents, as compared to the mortality rate of individuals 64 years and younger (324.5 per 100,000 residents). Although individuals 65 years and older in Arizona continue to have a higher mortality rate than individuals 64 and younger, we did see a slight decrease in the overall mortality rate from CY 2021 (4304.3 per 100,000 residents) to CY 2022. As we look closer at the data, we see that females are dying from Alzheimer's Disease more often than males; Black, Hispanic, and White Non-Hispanic females have a higher mortality rate than the American Indian/ Alaska Native and Asian/ Pacific Islander female populations; and urban residents have a higher mortality than rural residents. With this information, ADHS works with our statewide partners, and our sister agencies - Arizona Department of Economic Security (ADES) and the Arizona Health Care Cost Containment System (AHCCCS) and the Governor's Office of Youth, Faith and Families Governor's Advisory Council on Aging - to ensure there is coordination of services and resources for individuals with

Alzheimer's Disease and their families across the care continuum - from prevention, screening, diagnosis, treatment and support services for caregivers (paid and unpaid). The Plan will address the following priority areas over the next five years: Increasing Access to Care, Support & Treatment; Enhancing the Safety and Quality of Care; Improving risk reduction, early detection and diagnosis; in addition to aligning the work with the National Healthy Brain Initiative and the federal Health and Human Services (HHS) National Plan to Address Alzheimer's Disease.

As the implementation of the plan progresses, partners and ADHS will determine the sustainability of our efforts using systems change approaches, and initiatives that support overall outcomes and impact to ensure our continued focus on the health and wellness of all Arizonans.

Sincerely,

Teresa Aseret-Manygoats, MPA
Bureau Chief, Chronic Disease & Health Promotion
State Chronic Disease Director

EXECUTIVE SUMMARY

The state plan for Alzheimer's Disease and Related Dementias (ADRD) was developed in response to Senate Bill 1726 enacted in May 2023 (Appendix A)[1]. This bill designated the Department of Health Services as the lead agency ensuring that specific processes, programs, policies and systems were addressed for Arizonans with dementia in the priority areas of: access to care, improving quality of care, advancement in risk reduction, and ensuring a coordinated statewide response to the disease. This plan embodies the collaborative initiative of various state and local stakeholders committed to enhancing care and support for Arizonans affected by Alzheimer's Disease and Related Dementias (ADRD)[10] as well as their families and caregivers.

Alzheimer's disease and related dementias present irreversible and progressive brain disorders that impact the families and lives of many Arizonans. These conditions gradually erode brain function, leading to cognitive decline, behavioral changes, and diminished functional abilities. Unlike many other leading causes of death in the nation, dementia-related diseases currently lack effective methods for prevention, cure, or treatment. The Centers for Disease Control and Prevention (CDC) ranks Alzheimer's in the top 10 leading causes of deaths in the United States.[3] According to the CDC Wonder data referenced in Appendix E, the Alzheimer's Disease dropped from the 4th leading cause of death in 2018 and 2019 to the 6th leading cause of death in 2021 and 2022, among Arizonans 65 years of age and older.

"According to the Centers for Disease Control and Prevention, in 2020 of those at least 65 years of age, there were an estimated 5.8 million adults with dementia and projected to be nearly 14 million by 2060.[3]"

According to the Centers for Disease Control and Prevention, in 2020 of those at least 65 years of age, there were an estimated 5.8 million adults with dementia and projected to be nearly 14 million by 2060.[3] The recently published 2023 Arizona Aging Report and the Arizona State Plan on Aging 2023-2026 states the population of older adults aged 60 and older in Arizona is rapidly increasing.[8] The 2023 Arizona Aging Report highlights that this demographic is expected to grow significantly in the coming years, contributing to a substantial portion of the state's population. Over the past ten years, the population of Arizonans 65 years and older consistently increased year over year, by age group with a 1% decrease among Arizonans 65-69 years old from 2017 to 2018. The highest increase in population was among Arizonans 75-79 years old (58%). This demographic shift presents numerous challenges and opportunities for Arizona's health care and social support systems.[4]

The 2024 Alheimer's Facts and Figures Report for Arizona shows a prevalence of those 65 and older with Alzheimer's disease in 2020 to be 151,500 individuals. This report further shows the percent of adults over 65 with Alzheimer's disease equates to 11%. This increase underscores a critical need for enhanced health care services and support systems tailored to the unique needs of those with Alzheimer's and other dementias. The Alzheimer's Facts and Figures Report also illuminates the substantial burden on caregivers in Arizona. Many caregivers are family members who often lack adequate support and resources, leading to significant physical, emotional, and financial strain. The report stresses the urgent need for a robust caregiving workforce, which is currently insufficient to meet the growing demands. Caregivers in Arizona face a critical challenge as highlighted by the 2024 Arizona Alzheimer's statistics. A staggering 66.7% of caregivers suffer from chronic health conditions, 27.7% experience depression, and 15.5% are in poor physical health, indicating a workforce under significant strain. With caregivers providing an estimated 483 million hours of unpaid care, valued at over $10.2 billion, and only 292,000 caregivers available, the need to expand and support this essential workforce is urgent. Addressing this need is vital to ensure that the growing demands for care, particularly for those with Alzheimer's, can be met effectively and sustainably. The data reveals a severe shortage in the specialized health care workforce required to support individuals with Alzheimer's. There is a critical need for more health care professionals trained in geriatrics and dementia care, including physicians, nurses, social workers, and in-home care providers. This shortage exacerbates the challenges faced by individuals with Alzheimer's and their families, highlighting the necessity for targeted workforce development initiatives. According to the 2024 Arizona Alzheimer's statistics, the number of Geriatricians in 2021 was 92, to meet the demands, an increase of 294.6% will be required by 2050.[5]

The growing prevalence of Alzheimer's disease among Arizona's aging population places a heavy burden on the state's health care infrastructure. The increase in Alzheimer's cases is expected to lead to higher demand for medical and long-term care services. Hospitals, nursing homes, and community-based care organizations must prepare to accommodate this influx by expanding their capacities and enhancing their care models. Moreover, the economic impact is significant. The rising costs associated with medical care, long-term care, and lost productivity among caregivers add to the financial strain on both families and the state's health care system. Policymakers and health care providers must collaborate to develop sustainable solutions that address these economic challenges while ensuring high-quality care for those affected by Alzheimer's.[6]

ABOUT ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

(Overview provided by the Alzheimer's Association Desert Southwest Chapter)

Dementia is a general term for a particular group of symptoms caused by changes to the brain resulting in damage to nerve cells (neurons). The brain's neurons are essential to all human activity, including thinking, talking and walking. This damage interferes with the ability of brain neurons to communicate with each other, resulting in a loss of cognitive functioning.

Alzheimer's, a degenerative brain disease, is the most common cause of dementia and symptoms progress over years[1]. Increasing age is the greatest known risk factor for Alzheimer's, with risk increasing after age 65. However, Alzheimer's is not limited to those over the age of 65. Much less common, younger-onset (also known as early-onset) Alzheimer's affects people younger than age 65, and is rarely diagnosed[2].

Disease progression and abilities affected vary from person to person. Some common symptoms are difficulties with memory, language, problem-solving and other thinking skills that affect a person's ability to perform everyday activities. The most severe stage of dementia is when the person must depend completely on others for basic activities of daily living (ADLs) due to loss of mobility, balance, and basic bodily functions. Ultimately, Alzheimer's disease is fatal[3].

Proactive management of Alzheimer's and other dementias can improve the quality of life of affected individuals and their caregivers. Proactive management includes actions by the person living with dementia and their caregivers and actions by health care providers and other members of the health care workforce. Additionally, there are now treatments[4] that may slow disease progression for people in the early stage of Alzheimer's, making a timely diagnosis critically important. Early detection of Alzheimer's or another dementia offers significant benefits for the person diagnosed and their loved ones, including greater access to treatment options and the ability to plan for the future.

The table on the following pages provides an overview of the most common causes of dementia, collectively referred to as "Alzheimer's disease and related dementias" or "ADRD" by the scientific and public health communities. The table is reproduced from the Alzheimer's Association's 2024 Facts and Figures Report.

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[1] Alzheimer's disease is the most common cause of dementia, making up 60%-80% of cases. Alzheimer's Association. 2024 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2024;20(5)

[2] Alzheimer's Association https://www.alz.org/alzheimers-dementia/what-is-alzheimers/younger-early-onset

[3] 2024 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2024;20(5) https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf

[4] There are many potential treatments advancing in the pipeline. The Alzheimer's Association is supporting promising research that is tackling the disease from multiple angles. Stay up to date: http://alz.org/treatments

CommonCauses of Dementia*

Cause	Brain changes
Alzheimer's disease	Accumulation of the protein beta–amyloid outside neurons and twisted strands of the protein tau inside neurons are hallmarks. They are accompanied by the death of neurons and damageto brain tissue. Inflammation and atrophy of brain tissue are other changes.
Cerebrovascular disease	Blood vessels in the brain are damaged and/or brain tissue is injured from not receiving enough blood, oxygen or nutrients. People with these changes who develop dementia symptomsare said to have vascular dementia.
Frontotemporal degeneration (FTD)	Nerve cells in the front and temporal (side) lobes of the brain die and the lobes shrink. Upper layers of the cortex soften. Abnormal amounts or forms of tau or transactive response DNA–bindingprotein (TDP–43) are present.
Hippocampal sclerosis (HS)	HS is the shrinkage and hardening of tissue in the hippocampus of the brain. The hippocampus plays a key role in forming memories. HS brain changes are often accompanied by accumulation of the misfolded protein TDP–43.
Lewy body disease	Lewy bodies are abnormal aggregations(or clumps) of the protein alpha–synuclein in neurons. When they develop in a part of the brain called the cortex, dementia can result. This is called dementia with Lewy bodies or DLB.
Mixed pathologies	When an individual shows the brain changes of more than one cause of dementia, "mixed pathologies" are considered the cause. When these pathologies result in dementia symptoms during life, the person is said to have mixed dementia or mixed etiology dementia.
Parkinson's disease (PD)	Clumps of the protein alpha–synuclein appear in an area deep in the brain called the substantia nigra. These clumps are thought to cause degeneration of the nerve cells that produce the chemical dopamine.29 As PD progresses, alpha–synuclein can also accumulate in the cortex.

*This table describes the most commoncauses of dementia. Emerging causes such as limbic–predominant age–related TDP–43 encephalopathy (LATE) are under active investigation.

Source: Alzheimer's Association. 2024 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2024;20(5), Table 1, P6–7

ALZHEIMER'S ASSOCIATION®

Percentage of dementia cases	Symptoms
Alzheimer's is the most common cause of dementia, accounting for an estimated 60% to 80% of cases. Most individuals also have the brain changes of one or more other causes of dementia.21,22 This is called mixed pathologies, and if recognized during life is called mixed dementia.	Difficulty remembering recent conversations, names or events; apathy; and depression are often early symptoms. Communication problems, confusion, poor judgment and behavioral changes may occur next. Difficulty walking, speaking and swallowing are common in the late stages of the disease.
About 5% to 10% of individuals with dementia show evidence of vascular dementia alone.21,22 However, it is more common as a mixed pathology, with most people living with dementia showing the brain changes of cerebrovascular disease and Alzheimer's disease.21,22	Slowed thoughts or impaired ability to make decisions, plan or organize may be the initial symptoms, but memory may also be affected. People with vascular dementia may become less emotional and have difficulty with motor function, especially slow gait and poor balance.
About 60% of people with FTD are ages 45 to 60.23 In a systematic review, FTD accounted for about 3% of dementia cases in studies that included people 65 and older and about 10% of dementia cases in studies restricted to those younger than 65.24	Typical early symptoms include marked changes in personality and behavior and/or difficulty with producing or comprehending language. Unlike Alzheimer's, memory is typically spared in the early stages of disease.
HS is present in about 3% to 13% of people with dementia.25 It often occurs with the brain changes of other causes of dementia. An estimated 0.4% to 2% of dementia cases are due to HS alone.25	The most pronounced symptom of HS is memory loss, and individuals are often misdiagnosed as having Alzheimer's disease. HS is a common cause of dementia in individuals age 85 or older.
About 5% of older individuals with dementia show evidence of DLB alone, but most people with DLB also have the brain changes of Alzheimer's disease.26	Early symptoms include sleep disturbances, well-formed visual hallucinations and visuospatial impairment. These symptoms may change dramatically throughout the day or from day to day. Problems with motor function (similar to Parkinson's disease) are common. Memory loss may occur at some point in the disease.
More than 50% of people diagnosed with Alzheimer's dementia who were studied at Alzheimer's Disease Research Centers had mixed dementia.22 In community-based studies, the percentage is considerably higher.21 Mixed dementia is most common in people age 85 or older.27,28	Symptoms vary depending on the combination of brain changes present.
A systematic review found that 3.6% of dementia cases were due to PD and 24.5% of people with PD developed dementia.30	Problems with movement (slowness, rigidity, tremor and changes in gait) are common symptoms of PD. Cognitive symptoms may develop later in the disease, typically years after movement symptoms.

HISTORICAL MILESTONES - ADRD STATE PLAN BACKGROUND

In September 2011, the Arizona Alzheimer's Task Force (Task Force) was established. The Task Force was responsible for the overall development and implementation of the 2015 Arizona Alzheimer's State Plan, and ensuring alignment with the 2011-2014 State Plan on Aging, to address the growing impact of dementia related diseases on individuals, families, and communities. The goal of the Task Force was to raise awareness, improve care and support services, all while advancing research related to Alzheimer's Disease and related dementias. The Task Force comprised over 100 individuals from government agencies, health care providers, advocacy organizations, researchers, and the community. Under the general direction and guidance of a collaborative Planning Group, comprised of the Governor's Office on Aging (former), the Arizona Department of Economic Security Division of Aging and Adult Services (DES/ DAAS), the Arizona Alzheimer's Consortium, and the Alzheimer's Association Desert Southwest Chapter (AA DSW), the Task Force was the overall planning body with four (4) work teams to address the 2011 - 2014 State Plan on Aging. The four (4) work teams were: 1. Impact of the Disease on the State (State Plan on Aging Goal 3*), 2. Access to Services (State Plan on Aging Goals 1 & 6*), 3. Independence and Safety (State Plan on Aging Goals 4 & 5*), and 4. Quality of Care Promotion and Regulation (State Plan on Aging Goals 7 & 8*).[7]

In 2015, DES/ DAAS updated the State Plan on Aging. The Task Force provided a significant source of input on the growing human and financial cost of dementia in Arizona for the plan. Many of the preliminary recommendations of the Task Force were included in the plan. Among these recommendations were awareness campaigns to educate the public about young-onset dementia; and early warning signs and strategies for obtaining a diagnosis or treatment. In this same year (2015), the Task Force published the 2015 Arizona Alzheimer's Disease State Plan, and it was the "Framework for Action" to address Alzheimer's Disease in Arizona. The Alzheimer's Disease State Plan provided a framework to specifically address the challenges posed by Alzheimer's disease and related dementias in Arizona; and to bring together partners and communities to work on common goals for Arizona. The Task Force's vision in the Plan "is the elimination of Alzheimer's disease and related dementia. Until there is a cure, the vision is that there will be quality care and supportive services available, accessible and acceptable throughout Arizona. The Task Force's mission in the Plan is "To address the growing human and financial cost of dementia in Arizona."

The Arizona Department of Health Services (ADHS) has been a contributing partner in the State's work to address Alzheimer's Disease and related dementias (ADRD). As the state's public health authority, ADHS has provided education and outreach on the prevention of ADRD, in particular through our partnerships with local county health departments. The focus of ADHS' ADRD programming from 2011 to present has focused on the following:

- Raising Public Awareness: Engaging with universities, local county health departments and community partners to disseminate information.
- Early Detection and Diagnosis Linkage: Ensuring rapid referrals in collaboration with the Alzheimer's Association and health systems.
- Risk Reduction of Behaviors: Promoting awareness and education via the website (azhealthaging.com), social media, and community partners on the risks associated with ADRD.
- Collecting and Publishing Surveillance Data: Utilizing the BRFSS Cognitive Decline Module, BRFSS caregiver-added Module (implemented every other year), death records, and additional ADRD health data at ADHS.
- Developing Workforce Competencies: Partnering with universities to support the skill and knowledge development of our current and future workforce.
- Mobilizing Statewide Partnerships.

In addition to this ADRD programming, the Tobacco Revenue Use, Spending and Tracking (TRUST) Commission is tasked to provide annual advice to the ADHS on the top four (4) leading causes of chronic disease mortality in Arizona.[2] In 2019, the TRUST Commission created a work group of the Commission, the ADRD work group. The ADRD work group convened during 2019 -2021 to focus on providing guidance on the following:

- Access to Care: Increasing navigation of services for individuals with Alzheimer's Disease and related dementias, and their family and caregivers.
- Support and Services for Caregivers: Identifying and addressing the needs of Caregivers.

In the State of Arizona Fifty-sixth (56) Legislature First Regular Session 2023, Senate Bill 1726[1] marked a pivotal shift that designated ADHS as the lead agency for addressing Alzheimer's Disease and related dementias (ADRD). This bill tasked ADHS with establishing a dementia services program; allowed ADHS to seek support and assistance in addressing ADRD from statewide partners; and designated ADHS as the lead agency to develop an Alzheimer's Disease state plan by June 30, 2024.

Since the implementation of SB 1726 on July 1, 2023[1], ADHS has hired a Population Health Program Administrator to coordinate older adult and healthy aging programming for dementia risk reduction; and hired an Alzheimer's Disease and Related Dementia (ADRD) Program Manager to develop the Alzhemier's Disease State Plan and coordinate the ADRD services programming. The ADHS ADRD program is responsible for coordinating efforts across state agencies, local county health departments, tribal nations, educational institutions, and community stakeholders. The establishment of the ADRD program allows ADHS to develop and implement a comprehensive approach to addressing the multifaceted challenges of Alzheimer's Disease; leverage public health infrastructures to enhance care, support services, and research efforts with our numerous statewide partners. This transition will ensure a more unified and strategic effort in combating ADRD that reflects the state's commitment to improving the lives of those affected by ADRD.

ADRD STATE PLAN FRAMEWORK - THE PROCESS

The Arizona State Plan for addressing Alzheimer's Disease and related dementias(ADRD) adopts a public health approach to tackle factors upstream that are modifiable. It emphasizes the systems and environments influencing risk factors.

Informed by the Healthy Brain Roadmap,[10] the agency's health improvement plan, among others, this plan not only captures the current care and treatment needs of individuals affected by dementia but also proactively prepares for the future for better data management and sharing. This involves the strategies and recommendations focused on risk reduction and enhancing early detection and diagnosis of ADRD in this plan.

In October 2023, ADHS hired the Alzheimer's Disease and Related Dementia (ADRD) Program Manager who would be responsible for the development of Arizona's Alzheimer's Disease and related Dementia (ADRD) State Plan. In November 2023 the Core ADRD leadership team was assembled and the project timeline was developed. On December 11, 2023, ADHS convened the Core ADRD Leadership Team composed of representatives from various sectors: policy, academia, statewide Associations, state agencies, nonprofit organizations, community members, health systems, Area Agencies on Aging, and local county health departments. The Core team members were provided an orientation, presented with the proposed timeline, and methodology for the development of the plan.

TIMELINE FOR PLAN DEVELOPMENT

DECEMBER 11, 2023

- Project Kickoff

01

JANUARY 25 & 26, 2024

- Listening Sessions

02

FEBRUARY 23, 2024

- Core Group & Live Experience Listening Sessions

03

MARCH 22, 2024

- Identify Goal Areas
- Align on Approach

04

APRIL 26, 2024

- Review workgroup goals, strategies, and provide feedback

05

MAY 31, 2024

- Review Rough Draft of the State Plan

06

June 21, 2024

- Review final draft

07

ADDRESSING THE COMPONENTS OF SENATE BILL (SB) 1726 WITHIN THE PLAN

The Arizona Department of Health Services under Senate Bill 1726[1] was tasked with developing the Alzheimer's Disease State Plan that addresses the following areas:

1. Assess the current and future impact of Alzheimer's disease and related forms of dementia on this state.
2. Assess the existing state services and resources that address the needs of persons who have Alzheimer's disease or a related form of dementia and their family caregivers.
3. Assess the needs of persons of all cultural backgrounds who have Alzheimer's disease or a related form of dementia and how their lives are affected by the disease, including from younger-onset, through mid-stage, to late-stage.
4. Assess this state's capacity and capability to provide effective detection and diagnosis of cognitive impairments and dementia.
5. Identify gaps in the provision of public services and private services for persons who have Alzheimer's disease or a related form of dementia.[1]

To ensure that the plan was inclusive of and assessed each of the areas listed above, the listening session questionnaire included three (3) general overarching questions to kick off the session. Prompts were added for each question to capture each of the five (5) areas above in all eight (8) listening sessions in a tailored fashion to guide the discussion. This process ensured that participants from across the state could share their diversity of responses and experiences with transparency while also capturing assessment of needs for each of the areas above. The first overarching question focused on service delivery gaps for this population with prompts addressing screening program gaps and needs, cultural background, age, geographic locations and stage of disease gaps. The second focused on the systems, policies and programs that align to address the burden of disease. Prompts for this question included assessing state capacity and capabilities, assessing existing infrastructures and data structures, policies, resources, services and limitations to effectively detect and diagnose persons with Alzheimer's disease. Lastly, the third and final question focused on current and future impacts of Alzheimer's disease and related dementia on the state. The prompts supporting this question captured the evolving landscape of health care delivery, society and economy, identifying demographic groups projected to be the most impacted in the future and allocating resources to this population while fostering stigma reduction. To further ensure accountability for each of the five (5) areas, the Core ADRD Leadership team's roles and responsibilities included ensuring that goals, strategies and recommendations that will be included in the Plan aligned with the above areas. **Appendix B and E** of the plan provides available datasets and projects that captures current baseline for mortality, health care utilization, workforce data availability and knowledge gap awareness campaign that further builds upon findings from the listening sessions.

The sixth area stated in this section of the bill required the department to provide a strategic plan including recommendations for the state action to do all of the following:

a. Increase access to care, support and treatment for persons who have Alzheimer's disease or a related form of dementia.
b. Improve quality of care for persons who have Alzheimer's disease or a related form of dementia.
c. Advance risk reduction, early detection and diagnosis of Alzheimer's disease and related forms of dementia.

d. Ensure a coordinated statewide response to Alzheimer's disease and related forms of dementia.[1]

The Goals listed in this plan were guided by this section of the bill along with the themes captured from the listening sessions. Following the listening sessions, the themes were shared with the Core Leadership team and the goals and corresponding work groups were developed. Each work group and Goal area focused on the following: Goal 1- Increase access to care, treatment and support for Arizonans with Alzheimer's disease and related forms of dementia. Goal 2- Enhance the Safety and quality of care for Arizonans living with Alzheimer's disease and related dementias. Goal 3- Improve risk reduction, early detection and diagnosis of Alzheimer's disease and related forms of dementia. By aligning these goals with this required section of the bill, it ensured that strategies developed by work group members were specific to activities that will move each goal forward. The Core Leadership team members serving as experts for this plan wrote and submitted recommendations and rationale that supports each goal as part of their roles and responsibilities. Lastly, though not specifically called out, the Core Leadership team advised that to ensure a coordinated statewide response to Alzheimer's disease, requirement (d) above should be interwoven into each goal area. Therefore, specific strategies or activities under each goal addresses the need for statewide coordination to address disease burden.

Listening Sessions

A series of eight (8) listening sessions were convened by the Arizona Department of Health Services ADRD Program housed in the Bureau of Chronic Disease and Health Promotion (BCDHP). Listening sessions targeted a diverse audience that included representatives from the following:

- Associations and National Partners
- County Health Departments (rural and urban) and Area Agencies on Aging
- Core ADRD Leadership Team (Steering Committee Members)
- Health Systems
- State Agencies
- Community Partners and Community Based Organizations
- Individuals with Lived Experience
- Tribal Partners

Each listening session was facilitated by a consulting firm specializing in strategic planning, quality improvement and large-scale implementations among others. Each scheduled session lasted for a duration of 120 minutes. Many sessions were held in-person at the Arizona Department of Health Services State Lab Conference Center. Sessions that were conducted virtually were hosted via Zoom and Google video conferencing platforms. Attendees were welcomed by ADHS Staff and the facilitator who provided an overview of the goals, timeline, and the work being undertaken to support the development of a Statewide ADRD Plan. The facilitator provided participants with instructions and guidance, setting ground rules intended to create an environment focused on contribution, candor, and courtesy. For virtual listening sessions, participants could communicate verbally (cameras on or off), add comments and questions directly in the chat box to be shared by the chat monitor. For participants unable to attend in person or virtually, responses were collected via google questionnaire. Analysis of the qualitative data from the listening sessions followed a comprehensive and systematic plan consistent with standard research protocols. The qualitative data collected consisted of the observer notes and listening session transcript information. Thematic analysis was used to sort core commonalities and outliers. Analyses also allowed for the identification of new and emerging themes as they appear in the data.

Additional listening sessions facilitated by the Governor's Advisory Council on Aging (GACA) informed the plan focusing on rural and underserved geographic locations in adult day care, senior centers and community centers. During the listening sessions conducted, a diverse range of perspectives and experiences were shared, highlighting both the strengths, barriers, challenges and opportunities to improve the future for Alzheimer's Disease and Related Dementias across Arizona. The sense of well-being and community connection among older adults emerged as a fundamental aspect of their quality of life. Participants stressed the significance of socialization and community engagement for their overall well-being. Instances cited included the sense of community found in 55+ communities, where neighbors regularly gather for shared activities like meals and puzzles. While socialization was acknowledged as vital, especially for women who often prioritize community over isolation, it was also noted that some older male adults may find solace in living independently. However, challenges such as isolation, lack of caregiving support, and limited community resources were identified as barriers to fostering a strong sense of well-being and community connection. The top themes that emerged included: Caregiving needs and support, housing and Alzheimer's disease programming.

The listening sessions provided valuable insights into the needs and concerns of older adults and those burdened by Alzheimer's in Arizona communities, highlighting the importance of community support, access to health care services, and opportunities for socialization and engagement. Summaries for each listening session and key themes were prepared into a report and shared with the Arizona Department of Health Services (ADHS) ADRD Program, Core ADRD Leadership Team and participants of the listening sessions. These key themes, in tandem with Arizona's Alzheimer's and dementia data, guided by the Senate Bill priority areas supported the work groups' development of the Goals and strategies development. Listening session members were engaged to identify work groups of interest for participation and strategies and activities identification. Strategies where possible were aligned with national plans and prevention strategies. Working groups identified critical action steps for supporting the plan and began identifying lead organizations and timelines for implementation.

Informed by the rich insights garnered from the collaborative efforts of various work groups, the Core ADRD Leadership Team leveraged their subject matter expertise to analyze and synthesize the plethora of information into actionable recommendations and well-founded rationales for the outlined Goals of the Alzheimer's State Plan.

Core ADRD Leadership Team

The Core ADRD Leadership team was assembled in November 2023. This team included experts representatives from the following areas of focus:

- Policy (Alzheimer's Association, AARP)
- Health plans/Managed Care Organizations (AHCCCS)
- Arizona Department of Economic Security (ADES) Division of Aging & Division of Developmental Disability Representatives
- County Representatives (specifically from counties with high ADRD prevalence)
- Academia & Research (University of Arizona & Arizona State University)
- Community Based Organizations (Duet: Partners in Aging & Arizona Caregiver Coalition)

- Tribal Representatives
- Governor's Office of Youth, Faith & Family
- Data Lead - ADHS' CDC Epidemiology Assignee
- ADHS' Chronic Disease Program Lead (ADRD Program Manager)

Each team member was sent an invite for participation on this leadership team. Once assembled the Core leadership team hosted a kickoff meeting on December 11, 2023. During this meeting, the team reviewed roles and responsibilities for being a participating team member and shared plan development timeline. These included: Identifying missing stakeholders for various listening session categories, ensuring that all goals, strategies and recommendations met requirements listed in SB1726, providing guidance in narrowing down themes into goal areas, commitment to writing components of the plan that requires subject matter expertise (rationale & recommendations) and commitment to meet at least once a month during the plan development process. [1] Following the kickoff meeting, ADHS Alzheimer's Disease and Related Dementia (ADRD) Program Manager met 1:1 with each core team member to introduce himself, review their duties and stakeholders list and answer any questions they had. This group of experts also participated in a listening session designed specifically for them utilizing the same listening session questionnaire. The Core ADRD leadership met monthly until May. Overview of strategies was shared with leadership members that included additional context on activities and action items discussed by work group members. This team reviewed draft strategies developed by each work group and proposed feedback to share with work group members.

Work Groups

Following the March 2024 Core ADRD leadership team, listening session participants were invited to participate in one or multiple work groups depending on the interest and expertise. Listening session participants were also given the opportunity to serve as work group lead and report out meeting summaries at Core Leadership meetings. Each work group met a total of two (2) times each for 120 minutes at a time. The initial meeting hosted in April 2024 for all work groups focused on reporting the findings from the listening sessions and sharing the themes. This meeting also included a report out of the March meeting and setting the stage for how work group meetings will be conducted. The facilitator shared the overarching considerations for the plan at each first work group meeting. They are as follows:

- **Strategy development** - Strategies and efforts identified should reflect evidence-based, promising, or emerging and innovative practices.
- **Address sustainability** - Ensure long-term plan sustainability by building partnerships, securing ongoing funding, and integrating interventions into existing systems and community resources.
- **Support Health Equity** - Address health disparities and promote equity within the plan. Address under resourced communities, social determinants of health, and those who are disproportionately affected by ADRD. Tailor approaches to be culturally sensitive and inclusive - recognizing and respecting individuals' varied cultural backgrounds, beliefs, and behaviors.
- **Incorporation of new data and information** - Leverage lessons learned, evidence shared from organizations, sectors, and statewide studies to support the evolution of the State ADRD Plan.

After each work group agreed to the considerations above, they developed 5 year collective visions specific to their work group. Building on this activity, the work group explored areas of focus with the most advantage with consideration for areas of critical need to begin building proposed strategies and action to support each goal. Areas of focus for each work group varied from 4- 5 possible strategies in total. These

identified areas subsequently formed the foundational strategies. Through a facilitated session, the group was guided to narrow down these large areas of focus to 3- 4 draft strategies per work group for key areas to realistically implement, track , measure and monitor over the next 5 years.
Draft strategies from the first work group meeting were shared with the Core leadership team for feedback. The second work group meetings took place in May 2024. The objective of these meetings was to incorporate the Core Leadership team's feedback, refine the strategies, further build out activities for each strategy and set up improvement metrics. During these second meetings, the facilitator provided an overview of the process and reported summaries from the first meeting so that new work group members were up to speed and ready to participate. The last hour of the meeting focused on approving and finalizing the draft strategies and building out the activities under each strategy. Participants listed organizations and partners currently working in each area who could possibly lead specific activities. At the end of the meeting, work group members were encouraged to continue to submit activities specific to each strategy and serve as lead of specific activities and work groups. Lastly, work group members were informed that they will be contacted in July for the implementation phase of the plan and work group activities.

5 Year Collective Vision by Work group:

I. Safety and Quality of Life Work group

To ensure that Arizona has a well-educated workforce for addressing Alzheimer's and other related dementias and caregivers have the support network they need to thrive as well as information being readily accessible and available for community members on Alzheimer's and other dementias.

II. Access to Care, Support & Treatment Work group

We are identifying and diagnosing Arizonans and getting them into the system in a "no wrong door" approach with the necessary resources to appropriately support the individual with ADRD and their caregivers.

III. Risk Reduction, Early detection and Diagnosis Work group

The items below represent the areas identified by work group members that they would like to see addressed to support Arizona's efforts over the next 5-years.

- Community involvement (e.g., bank tellers, community members) seeing/identifying signs of dementia during daily interactions.
- Recognize early signs of dementia and be able to differentiate from other diseases.
- State models what employers should be doing regarding employee benefits. Rigorous campaign or focus built in to employee benefits (ADOA). Employers understand the impacts of chronic stress on caregivers.
- Promotion of value-based messaging to support awareness of why detection is important. Need to understand what types of messaging is meaningful to promote action. Thoughtful communication regarding the disease.
- Early screening for cognition (adding a basic memory test with medical appointments at a certain age or when suspected). Awareness for providers of existing possible billing.
- Increasing the # of those diagnosed. (BRFSS data - improved data collection; Health Systems data)
- Life course approach to risk reduction at County and State-level.

THE PLAN'S ALIGNMENT WITH NATIONAL ALZHEIMER'S DISEASE AND RELATED DEMENTIA INITIATIVES

Arizona's Alzheimer's & Dementia State Plan for 2024-2029 demonstrates a strong alignment with crucial national strategies aimed at tackling the complex challenges posed by Alzheimer's disease and related dementias (ADRD). Rooted in the guiding principles of the Health and Human Services (HHS) National Plan to Address Alzheimer's Disease, the CDC's Healthy Brain Initiative Road Map, and the National Strategy to Support Family Caregivers, Arizona's plan emphasizes a dedication to holistic care, public health interventions, and robust coordinated support networks for individuals living with dementia and their families. Through the incorporation of these national frameworks into our state's strategy, we aim to strengthen disease awareness, champion brain health initiatives, establish quality and safe care, coordinate data sharing and support the caregiver workforce, thereby nurturing a more dementia-capable and empathetic society.

The **National Plan to Address Alzheimer's Disease** outlines six ambitious goals focused on preventing and reducing future incidences of Alzheimer's disease and other related dementias (ADRD) while enhancing assistance for affected families: [14]

- Prevent and Effectively Treat ADRD by 2025
- Enhance Care Quality and Efficiency
- Expand Support for People with ADRD and Their Families
- Enhance Public Awareness and Engagement
- Improve Data to Track progress
- **(NEW)** Accelerate Action to Promote Healthy Aging and Reduce Risk Factors for ADRD

The **Healthy Brain Initiative Roadmap** serves as a strategic blueprint for fostering brain health, addressing dementia, and providing support to individuals with dementia and their caregivers. Central to its vision is the belief that everyone deserves optimal brain health. The HBI Road Map's key areas of focus: (Centers for Disease Control and Prevention, 2022)[10]

- Strengthening Partnerships and Policies
- Measure, Evaluate and Utilize Data
- Build a Diverse and Skilled Workforce
- Engage and Educate the Public

The **National Strategy to Support Caregivers** outlines actionable steps that diverse stakeholders can take to acknowledge and assist family caregivers. Key goals of this strategy encompass: (Administration for Community Living, 2022)[11]

- Increase awareness and outreach
- Build partnerships and engagement with family caregivers
- Strengthen services and supports
- Ensure financial and workforce security
- Expand data, research, and evidence-based practices

The Plan's Alignment with the **Arizona Health Improvement Plan** - State Initiative

Every five years, over a hundred statewide community partners collaborate with the Arizona Department of Health Services (ADHS) to develop the Arizona Health Improvement Plan (AzHIP). In 2021, ADHS, in coordination with the AzHIP Leadership team, developed the 2021-2025 AzHIP. The 2021-2025 AZHIP outlines strategies aimed at addressing Alzheimer's disease and other related dementias within the Pandemic Recovery & Resiliency plan.[12] The Pandemic Recovery & Reliencency plan outlines four key goal areas: Strengthen Public Health Capacity & Infrastructure; Rebuild a Stronger System to Support Health; Advance Health Equity; and Enhance Resilience of Arizona Communities. Many of the goals within the Pandemic Recovery & Resiliency plan intersect with the broader work of prevention, health care and community well-being; and addresses the needs of individuals affected by Alzheimer's disease and other related dementias for a comprehensive approach to public health and resilience. To achieve the goals of the Pandemic Recovery & Resiliency plan, various stakeholders including the ADHS, Arizona State University, Arizona Association of Area Agencies on Aging (AZ4A), and the University of Arizona have collaborated on several initiatives within the plan, including:[12]

- **Strengthen public health capacity and infrastructure (Goal 1)**
  The activity within the plan focuses on assessing funding sources, and ensuring the sustainability of funding to address ADRD. This collaboration includes key stakeholders, such as the ADHS, Arizona State University, the Arizona Association of Area Agencies on Aging (AZ4A), and the University of Arizona.

- **Promoting & Enhancing Access to Mental and Behavioral Health Service Providers (Goal 2, Strategy 3)**
  Incentivizing education and employment opportunities to recruit and retain providers in Arizona is a primary focus of this activity. The mental and behavioral health workforce is crucial for addressing the health needs of individuals affected by Alzheimer's disease, and their caregivers. The plan's focus on promoting mental and behavioral health services, particularly through increased use of telehealth, is relevant to the Alzheimer's Disease and related Dementia space. Many caregivers of those living with ADRD often need ongoing support for their mental health, including counseling, therapy, and cognitive interventions. By leveraging telehealth, mental health services are more accessible. This activity is a collaboration between key stakeholders, such as AHCCCS, Blue Cross Blue Shield of Arizona, and the Pima Council on Aging.

- **Increase Sense of Community (Goal 4, Strategy 3)**
  The plan emphasizes the importance of developing or expanding intergenerational programs to foster a greater sense of community throughout Arizona. Collaborative efforts involving ASU, AZ4A, Diverse Ability Incorporated, and the Pima Council on Aging seek to promote intergenerational relationships through initiatives like home sharing or volunteerism programs. These programs aim to enable older adults to remain in their own homes and communities while leveraging the resources, skills, and value of younger generations.

- **Supporting Family Caregivers (Goal 4, Strategy 7)**
  Recognizing the crucial role of family caregivers in providing support to individuals with Alzheimer's Diseases and Related Dementia. The plan advocates for increased resources, training, and support for family caregivers. This includes supporting and promoting Area Agencies on Aging in their existing Older Americans Act Family, Caregiver Supportive Services Programming, with involvement from AZ4A, AHCCCS, and Pima County Health Department.

TACTIC C

(AzHIP Mental Health Well-being focus)

Which focuses on enhancing resilience in communities, directly impacts individuals affected by Alzheimer's and Dementia. Caregivers and family members often face significant challenges and stressors when caring for loved ones with these conditions. By building stronger, more resilient communities for more vulnerable populations and providing resources such as mental health first aid training, AZHIP contributes to a supportive environment for caregivers and individuals living with Alzheimer's and Dementia.

STRATEGY #7

Strategy #7 from the Arizona Health Improvement Plan (AZHIP) Pandemic Recovery & Resiliency Plan (Goal 4) focuses on increasing resources, training, and support for family caregivers. Each component ties into the broader context of addressing social isolation and loneliness, particularly in relation to Alzheimer's and Dementia:[12]

A

Expand evidence or promising practice-based programming to help family caregivers manage SDOH and stress-related concerns.

Caregivers of individuals with Alzheimer's and Dementia often face significant stressors related to their roles, which can contribute to social isolation and loneliness. By providing evidence-based programs to help caregivers manage social determinants of health (SDOH) and stress-related concerns, AZHIP can support caregivers in maintaining their well-being and connection to their communities.

B

Expand the knowledge and options for respite care.

Respite care offers caregivers a temporary break from their caregiving responsibilities, reducing their risk of burnout and isolation. By expanding options for respite care, AZHIP can provide caregivers with much-needed support, allowing them to engage in social activities and maintain their social connections.

C

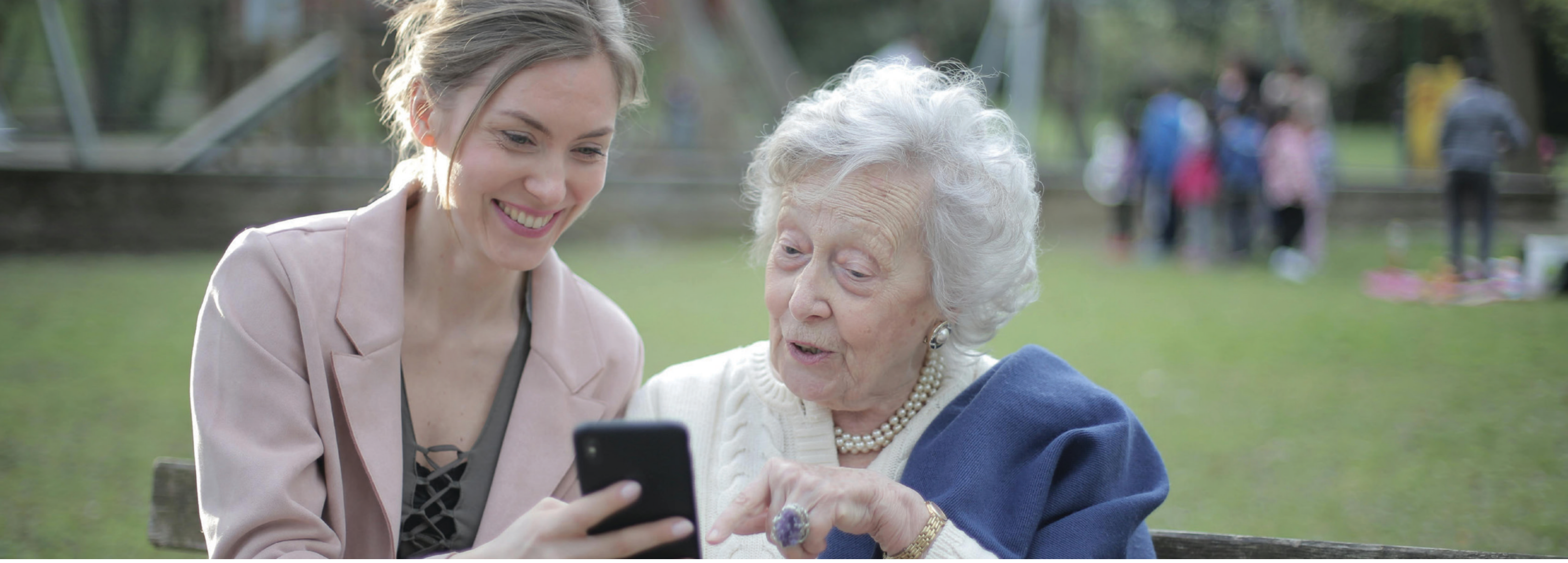
Support and promote Area Agencies on Aging in their existing Older Americans Act Family Caregiver Supportive Services Programming.

Area Agencies on Aging play a crucial role in providing support services to family caregivers, including counseling, support groups, and caregiver training. By supporting and promoting these services, AZHIP can help caregivers access the resources they need to manage their caregiving responsibilities and reduce social isolation.

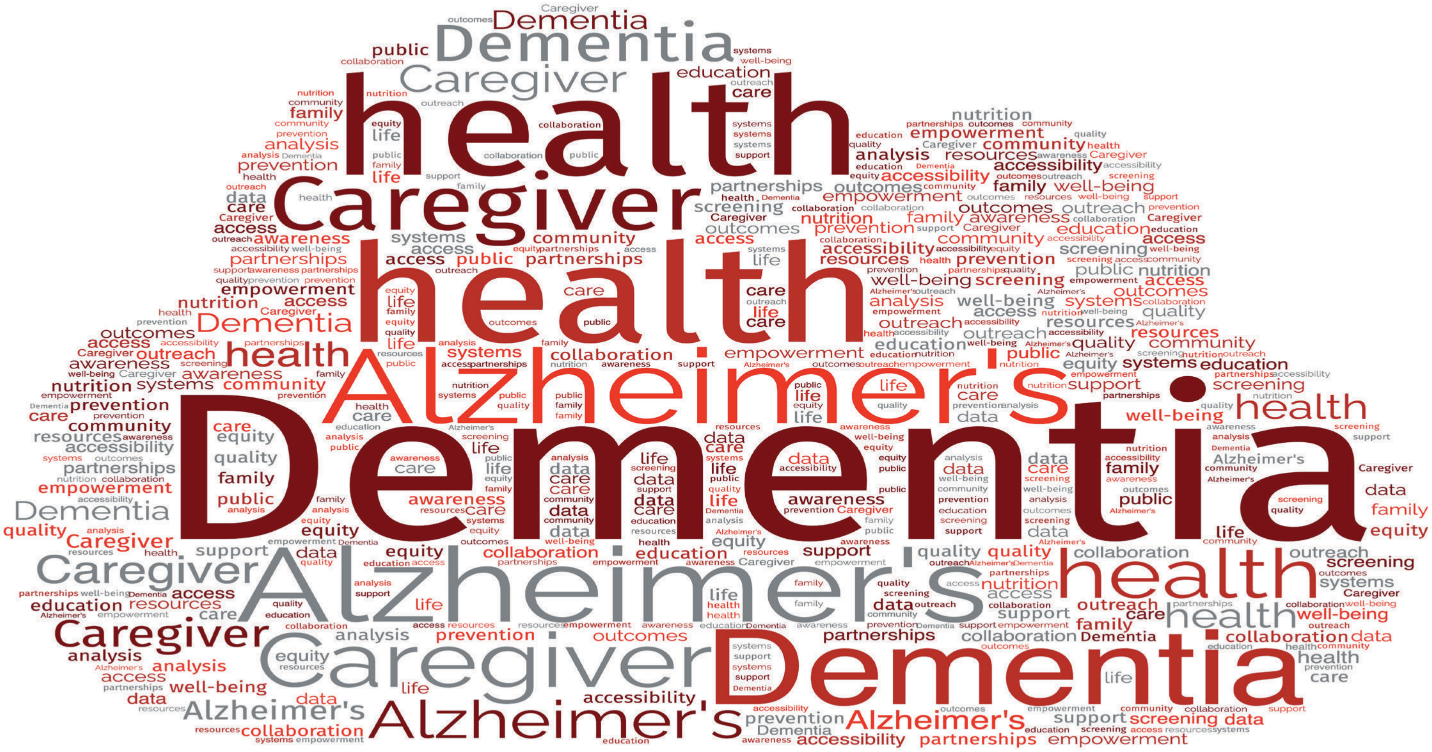
D

Utilize houses of worship and community centers as optimal locations for training and engagement.

Houses of worship and community centers serve as important hubs for social interaction and support within communities. By utilizing these locations for caregiver training and engagement, AZHIP can reach caregivers where they already gather, providing them with valuable skills and resources while also fostering connections with their peers.



The framework laid out in this section ensures the vision of a cohesive and comprehensive statewide public health approach to the plan's development. This framework allows the plan to align with state and national initiatives while creating room for the voices of experts, individual communities and organizations through listening sessions and work group participation. Developed collaboratively and through proactive measures, these initiatives share common goals of enhancing health outcomes, promoting equity, strengthening community resilience, and mobilizing community partnerships. Together, there is synergy with the objectives of the Arizona Alzheimer's State Plan, directly addressing health issues and contributing to the overall well-being of Arizona residents.



2024 MISSION & VISION STATEMENTS

The mission and vision statements of the ADRD State Plan have undergone meticulous crafting and extensive review from our ADRD Core Leadership Team. The ADRD Core Leadership Team ensured that the statements continued to reflect a comprehensive understanding and commitment from the previous Alzheimer's Disease State Plan. Through collaboration and consensus-building, the statements have emerged as a unifying force, developed to guide the efforts of our statewide stakeholders towards a common purpose.

MISSION STATEMENT

To address the growing human and financial cost of dementia in Arizona.

VISION STATEMENT

To eliminate Alzheimer's disease and related dementia. Until there is a cure, the vision is that there will be quality care and supportive services available, accessible and acceptable throughout Arizona.

GUIDING PRINCIPLES

The following guiding principles have been identified to shape the Goals, Recommendations and Strategies of the Alzheimer's Disease and related Dementia State Plan:

- Advocacy for Accessibility and Availability of Services and Care
- Inclusivity and Diversity Integration
- Holistic Statewide Response to Alzheimer's and Related Disorders
- Person-Centered Approach
- Empowerment for Resilience Building
- Stigma Reduction
- Collaboration, Promotion and Resource leveraging
- Care Continuum Integration
- Instilling Hope & Preservation of Cognitive Health
- Ensuring Measurable, Data Driven Strategies and Activities

THE STRATEGIC PLAN - GOALS, RECOMMENDATIONS AND STRATEGIES

GOAL 1

Increase Access to Care, Support & Treatment for Arizonans with Alzheimer's Disease and Related Dementias by June 30, 2029.

Rationale:

According to the Arizona Alzheimer's Association statistics report in 2024, the number of individuals aged 65 years and older living with Alzheimer's Disease has reached 151,500, marking a significant increase from the figures reported in 2018.[5] This increase underscores a potential trend that with the population aging, the prevalence of Alzheimer's disease and related dementia could be on the rise. Arizona, like many other states, is experiencing a demographic shift towards an increasingly older population; and the demand for services related to Alzheimer's Disease and related dementia care may increase in the foreseeable future. Consequently, family caregivers often bear a significant burden when caring for someone with Alzheimer's Disease or related dementia. Moreover, increasing access to support services such as respite care, education, training, and a centralized repository for resources that is accessible and available 24/7 can help prevent family separation, alleviate some of the caregiver burden, and prevent caregiver burnout. Lastly, investment in access to care, treatment and support services means Arizona can potentially reduce long-term health care costs associated with these conditions and improve overall economic productivity. Due to the limited availability of data sets and data systems integration for health care utilization, caregiver support service gaps etc it is paramount that care access and support needs gaps are captured to better prepare for this growing population with the highest risk of this disease. See Appendix E for available hospital discharge data on health care utilization and BRFSS data on Caregiver. Other sources for data in this area is the annual Arizona Alzheimer's statistics developed by the Alzheimer Association.[5]

Recommendations:

- Enhance access to support services: Increasing access to services such as respite care, education, training, and a centralized repository for resources can significantly alleviate the burden on family caregivers and prevent caregiver burnout. This can be achieved by establishing more support centers or online platforms that provide round-the-clock assistance and information.
- Supporting research and innovation: Continued investment in research and innovation is essential for developing new treatments, interventions, and caregiving approaches for Alzheimer's disease and dementia. This could involve funding research initiatives, supporting clinical trials, and fostering collaborations between researchers, health care professionals, and community stakeholders.
- With funding, identify a state agency host for a centralized repository showcasing services and information pertaining to Alzheimer's and other dementias within Arizona state agencies. The

centralized repository could be organized by issues related to Alzheimer’s and other dementias, and should include the Alzheimer’s Association’s 24/7 helpline as a quick resource. Include processes for filing complaints or grievances on state agency action. This repository will address the lack of available Alzheimer’s data in the state making advocacy and decision making easier.

Strategies

Resources & Supports	1. Ensure access to information, data, training, resources and services for Alzheimer’s Disease & Related Dementia needed for all Arizonans.
Dementia-trained or knowledgeable workforce	2. Identify and promote innovative ways to enhance the availability of skilled health care workers across Arizona.
Care Coordination & Referrals	3. Ensure caregivers and individuals diagnosed with Alzheimer’s Disease and Related Dementias across Arizona have a “no wrong door” approach to access the information and resources they need to thrive.
Supportive Experiences	4. Provide evidence-informed training and informational resources for health care providers to facilitate culturally sensitive conversations about brain health with patients and caregivers across the life course.

GOAL 2

Enhance the Safety and Quality of Care for Arizonans living with Alzheimer’s Disease and Related Dementias by June 30, 2029.

Rationale:

Improvement in quality of care for individuals with Alzheimer’s disease or related forms of dementia is imperative due to the profound impact these conditions have on individuals, families, and communities. Developing safe and supportive dementia-capable environments and ensuring caregivers and providers have the necessary information, training, and resources are essential components of this effort. Establishing comprehensive dementia care programs is essential for improving the quality of care for individuals with this disease. By prioritizing person-centered care, caregiver support, and training and education, we can create environments that promote dignity, well-being, and safety for individuals living with dementia and their caregivers. Encouraging dementia-friendly spaces within neighborhoods and systems (airports, fire departments, law enforcement, hospitals etc.) will ensure that those affected by the disease and their caregivers are safe.

Recommendations:

To improve the quality of care for individuals with Alzheimer's disease or related forms of dementia, it is essential that we establish comprehensive dementia care programs. These programs should encompass a multidisciplinary approach that addresses the complex needs of both patients and their caregivers alike. Key components of such programs may include, but not limited to :

- Person centered care
- Caregiver support
- Training and education

By implementing comprehensive dementia care programs, health care systems can significantly enhance the quality of care provided to individuals with Alzheimer's disease and related dementias; this would ultimately improve outcomes and quality of life for patients and their families.

Strategies

Respite	1. Increase the state's capacity to support caregiver's efforts and individuals with Alzheimer's Disease or Related Dementias.
Abuse & Neglect	2. Educate Arizonans on the signs of elder abuse and resources available.
Safe & Supportive Environments	3. Develop and Expand Safe and Supportive Environments.

GOAL 3

Improve risk reduction, early detection and diagnosis of Alzheimer's Disease and Related Dementias by June 30, 2029.

Rationale:

According to data from the 2022 BRFSS Survey, in Arizona, 15% of those aged 45 and older report they are experiencing confusion or memory loss that is happening more often or is getting worse "subjective cognitive decline". More than 44% of them have not talked to a health care professional about it. For those with worsening memory problems, 35.7% say it has created "functional difficulties" – that is, caused them to give up day-to-day activities and/or interfered with work or social activities. Although there is not a currently known cure for Alzheimer's, research shows that the many benefits to early detection and diagnosis include:

- Increased treatment options for patients and families
- Access to information, services, and support

- Opportunity for advance planning for health, care, financial, housing, and legal concerns
- Better overall health outcomes through management of co-occurring conditions
- Establishment of a support system and opportunity to express wishes about care team composition
- Discussions to address driving and safety concerns
- Informed care coordination across treatment teams
- Option to participate in clinical trials

Recommendations:

- Strengthen early detection and intervention efforts: Investing in programs and initiatives aimed at early detection and intervention can help identify Alzheimer's disease and dementia at earlier stages, allowing for timely treatment interventions. This could involve community outreach programs, training health care professionals to recognize early symptoms, and promoting regular cognitive screenings for at-risk populations.
- Ongoing funding for Alzheimer's public health campaigns to educate the public about the early signs of cognitive impairment, the value of early detection and diagnosis, and discussing changes in memory and thinking with health care professionals should be encouraged. Focus on diverse and underserved communities.
- Building ongoing relationships with community groups and partners in diverse and underserved communities, identifying areas of need and opportunities to reduce stigma and increasing early detection and diagnosis of dementia will significantly improve outcomes.
- State agencies like the Arizona Health Care Cost Containment System and Arizona Department of Health Services could integrate information about the early warning signs of dementia, risk reduction activities for chronic conditions, ways to encourage discussions with doctors and the benefits of early detection and diagnosis into education for licensed, registered, and certified health care workers.
- AHCCCS, ADOA, and major health plans should consider exploring reimbursement rates and methods to incentivize care planning for individuals living with dementia and their families.
- Consider statewide approaches to expand dementia services programs and the establishment of statewide dementia care specialists to work with local health departments, AAAs, and underserved communities to help families and individuals living with dementia navigate and access services with funding support.

Strategies

Healthy Aging & Brain Health Promotion	1. Promote Healthy Aging to optimize brain health to support risk reduction.
Screening Programs & Tools	2. Partner with health systems, associations, and agencies to ensure that the appropriate screenings are being trained on and implemented.
Supportive Policies & Programs	3. Promote supportive policies and programs for employees who are caregivers and model healthy worksites for Arizona employers.
Consistent & Coordinated Messaging	4. Develop consistent and ongoing evidence-based messaging across Arizona that normalizes Aging, Alzheimer's Disease and Related Dementias that motivates Arizonans to take action.

NEXT STEPS

Implementation plans incorporate activities designed to assess and track progress on the designated goals and strategies. Additionally, ADHS is committed to conducting reviews and analysis of all available outcome data related to ADRD, ensuring transparency and accountability in our endeavors. The implementation plan document is designed to adapt and evolve over time to adjust to the landscape of action items implementation. While these strategies and action items provide a significant foundation for addressing priorities related to Alzheimer's and dementia, it's anticipated that they will evolve further as teams engage in implementation. Updates on the progress of this plan will be shared through bi-annual reports out to the Core ADRD Leadership team and annual evaluation report.

ADRD Work groups:

The stakeholder work groups are pivotal in the ongoing implementation and evaluation of the Alzheimer's Disease and other Related Dementia (ADRD) State Plan. Work groups will develop and implement a systematic process to collect and measure progress, ensuring the evolution of ADRD priorities and best practices. Utilizing data from available surveillance systems and other sources, the work group will inform responses to cognitive impairment, overall wellbeing and caregiving.

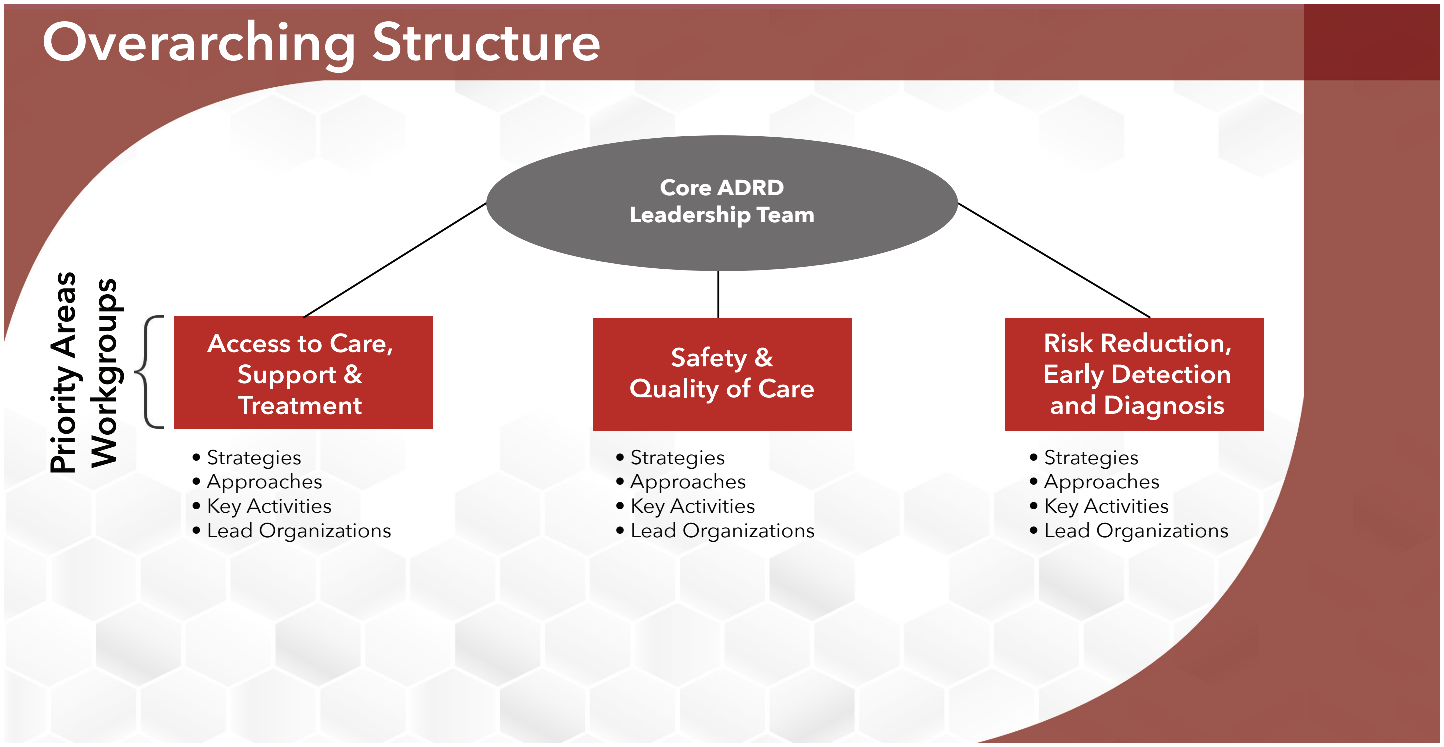
There are three (3) Work groups, each focused-on priority areas in alignment with the three goals of this plan to address Alzheimer's and Dementia-related Diseases (ADRD). The work groups are: Access to Care, Support & Treatment, Safety & Quality of Care, and Risk Reduction, Early Detection, and Diagnosis. Woven throughout each of these work groups is the coordination of care statewide for resources, training and workforce support at the systems and local level.

Work groups will convene quarterly through June 2029 to identify lead organizations for each strategy and implement identified action items listed in the implementation plan. Work group members will continue to align and share work that supports the Alzheimer's Disease and Other Related Dementias State Plan.

Key Work group Responsibilities:

1. Support Data Collection and Define Strategy:
    - Utilize quantitative and qualitative data to inform the ADRD State Plan's ongoing implementation.
    - Share data as agreed upon to support evaluation of plan.
    - Review data to inform implementation and evaluation plans, with input from priority populations.
    - Shape strategies to achieve key measurable deliverables for the state plan.
2. Strategy Plan Implementation:
    - Support the action items defined by work groups through appropriate means of the organization
    - Co-chairs for work groups support convening and leading efforts of working groups.
    - Support efforts to implement strategies, including leading specific activities.
    - Attend ongoing work group meetings quarterly.
    - Share progress, challenges, lessons learned, and best practices with work group members.
3. Ongoing Improvement and Refinement
    - Incorporate Core Leadership Team's feedback to refine strategies and include emerging needs.
    - Attend working groups quarterly to address barriers, challenges, and identify needed support.
    - Collaborate on state agency plans involving aging or other dementia-related programs/activities.

STRUCTURE FOR PLAN IMPLEMENTATION



Overarching Structure

Core ADRD Leadership Team

Priority Areas Workgroups

Access to Care, Support & Treatment
- Strategies
- Approaches
- Key Activities
- Lead Organizations

Safety & Quality of Care
- Strategies
- Approaches
- Key Activities
- Lead Organizations

Risk Reduction, Early Detection and Diagnosis
- Strategies
- Approaches
- Key Activities
- Lead Organizations

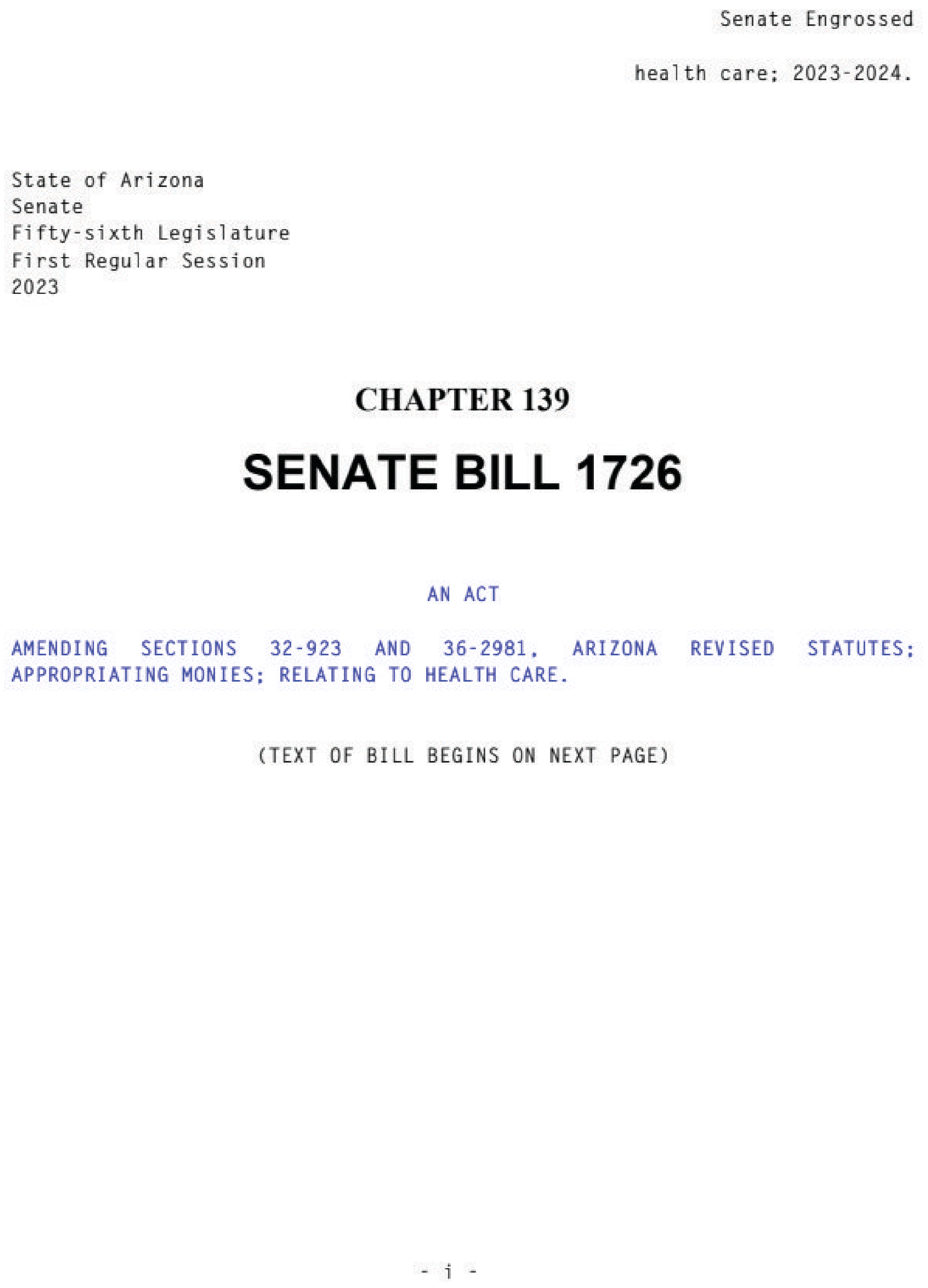
Monitoring the Alzheimer's State Plan: A Two to Five-Year Strategy

The ADRD Program at ADHS will contract the services of an evaluator to capture the two years progress made towards the plan implementation. The contractor will evaluate each strategy and its supporting action items for quantitative and qualitative data, policies, systems and environmental changes made that move towards the accomplishments of each goal listed in this plan. By implementing the below monitoring strategies over the next five years, ADHS will ensure effective oversight, evaluation, and refinement of the Alzheimer's State Plan, ultimately advancing progress in care, and support for individuals affected by Alzheimer's disease and their families.

Continuous Improvement Processes:

- Establish improvement framework: Develop a structured process for ongoing reflection, evaluation, and adjustment of strategies and activities outlined in the Alzheimer's State Plan.
- Conduct regular meetings: Schedule regular bi-monthly work group meetings, forums with stakeholders to review progress, share insights, and identify opportunities for improvement.
- Foster collaboration: Facilitate collaboration and knowledge-sharing among stakeholders, including health care providers, researchers, policymakers, and community members, to leverage expertise and resources for continuous improvement.
- Implement feedback mechanisms: Solicit feedback from stakeholders on the effectiveness of strategies and interventions, and use this feedback to inform decision-making and refine approaches over time.
- Adapt and innovate: Remain flexible and responsive to changing needs, emerging evidence, and evolving priorities in the field of Alzheimer's care and research, adapting strategies and activities as necessary to achieve the goals of the state plan.

APPENDIX A: SENATE BILL 1726: DEMENTIA SERVICES PROGRAM LEGISLATION



Senate Engrossed

health care; 2023-2024.

State of Arizona
Senate
Fifty-sixth Legislature
First Regular Session
2023

CHAPTER 139

SENATE BILL 1726

AN ACT

AMENDING SECTIONS 32-923 AND 36-2981, ARIZONA REVISED STATUTES; APPROPRIATING MONIES; RELATING TO HEALTH CARE.

(TEXT OF BILL BEGINS ON NEXT PAGE)

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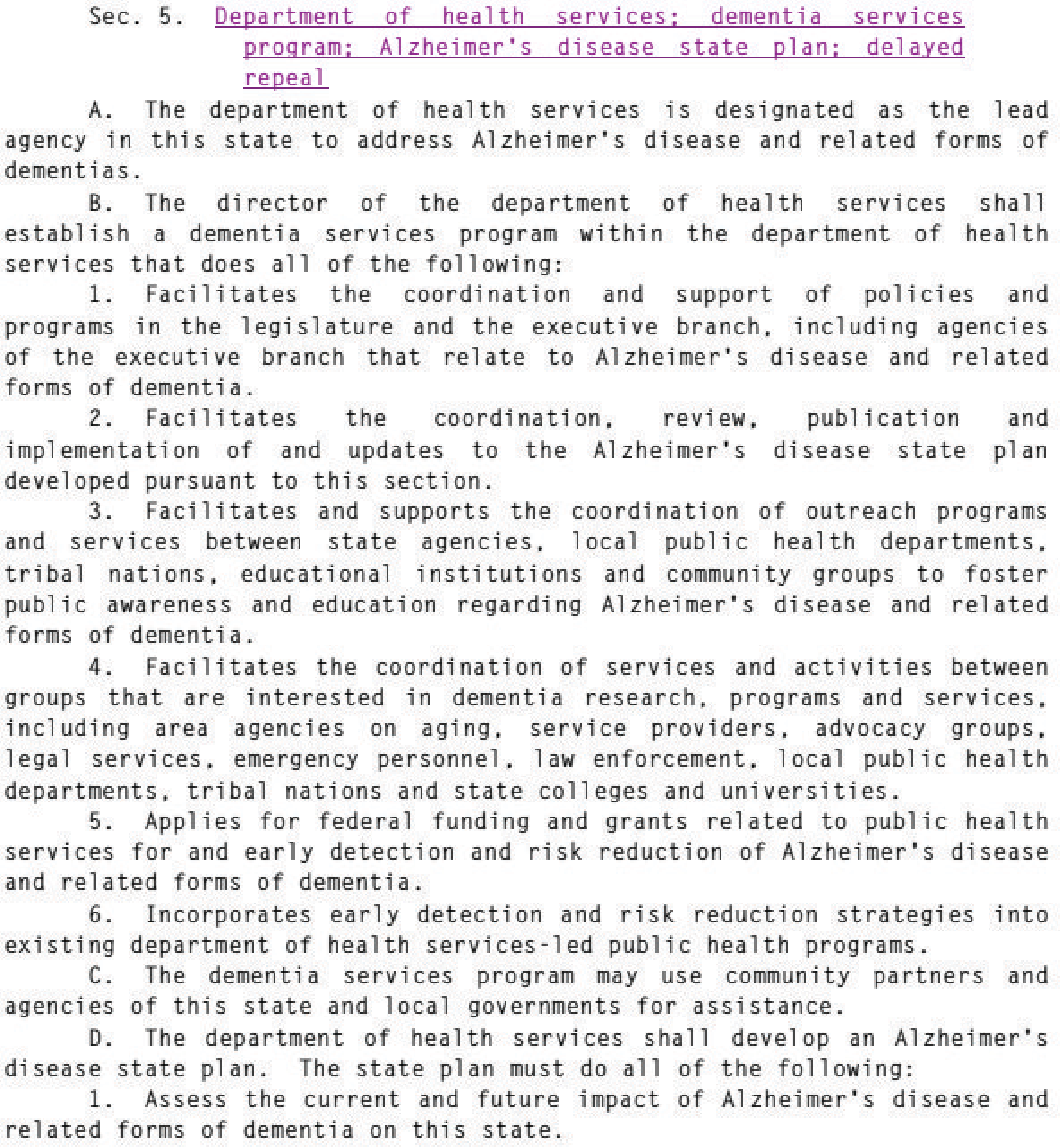


Sec. 5. Department of health services; dementia services program; Alzheimer's disease state plan; delayed repeal

A. The department of health services is designated as the lead agency in this state to address Alzheimer's disease and related forms of dementias.

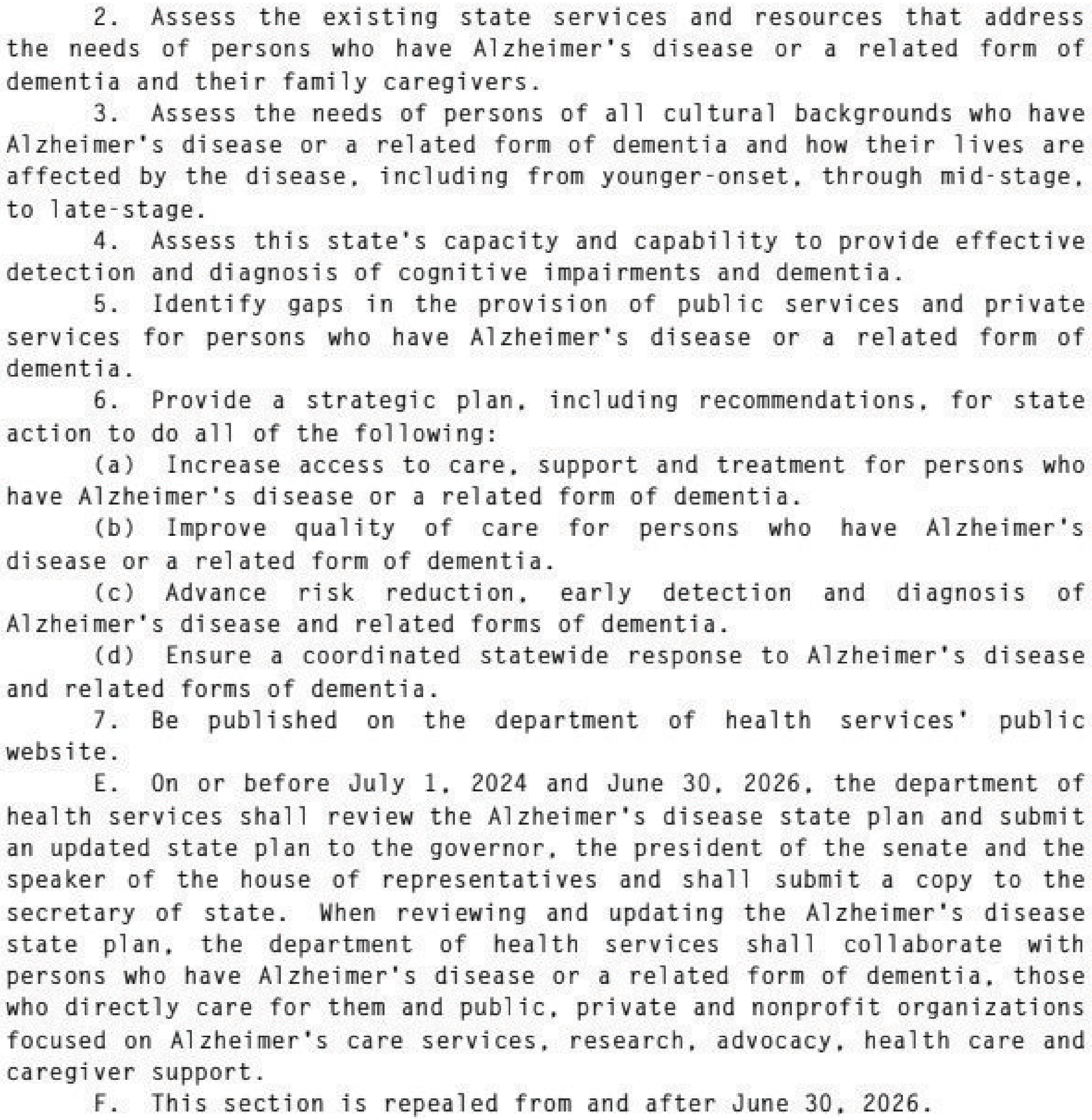
B. The director of the department of health services shall establish a dementia services program within the department of health services that does all of the following:

1. Facilitates the coordination and support of policies and programs in the legislature and the executive branch, including agencies of the executive branch that relate to Alzheimer's disease and related forms of dementia.
2. Facilitates the coordination, review, publication and implementation of and updates to the Alzheimer's disease state plan developed pursuant to this section.
3. Facilitates and supports the coordination of outreach programs and services between state agencies, local public health departments, tribal nations, educational institutions and community groups to foster public awareness and education regarding Alzheimer's disease and related forms of dementia.
4. Facilitates the coordination of services and activities between groups that are interested in dementia research, programs and services, including area agencies on aging, service providers, advocacy groups, legal services, emergency personnel, law enforcement, local public health departments, tribal nations and state colleges and universities.
5. Applies for federal funding and grants related to public health services for and early detection and risk reduction of Alzheimer's disease and related forms of dementia.
6. Incorporates early detection and risk reduction strategies into existing department of health services-led public health programs.

C. The dementia services program may use community partners and agencies of this state and local governments for assistance.

D. The department of health services shall develop an Alzheimer's disease state plan. The state plan must do all of the following:

1. Assess the current and future impact of Alzheimer's disease and related forms of dementia on this state.



2. Assess the existing state services and resources that address the needs of persons who have Alzheimer's disease or a related form of dementia and their family caregivers.

3. Assess the needs of persons of all cultural backgrounds who have Alzheimer's disease or a related form of dementia and how their lives are affected by the disease, including from younger-onset, through mid-stage, to late-stage.

4. Assess this state's capacity and capability to provide effective detection and diagnosis of cognitive impairments and dementia.

5. Identify gaps in the provision of public services and private services for persons who have Alzheimer's disease or a related form of dementia.

6. Provide a strategic plan, including recommendations, for state action to do all of the following:

(a) Increase access to care, support and treatment for persons who have Alzheimer's disease or a related form of dementia.

(b) Improve quality of care for persons who have Alzheimer's disease or a related form of dementia.

(c) Advance risk reduction, early detection and diagnosis of Alzheimer's disease and related forms of dementia.

(d) Ensure a coordinated statewide response to Alzheimer's disease and related forms of dementia.

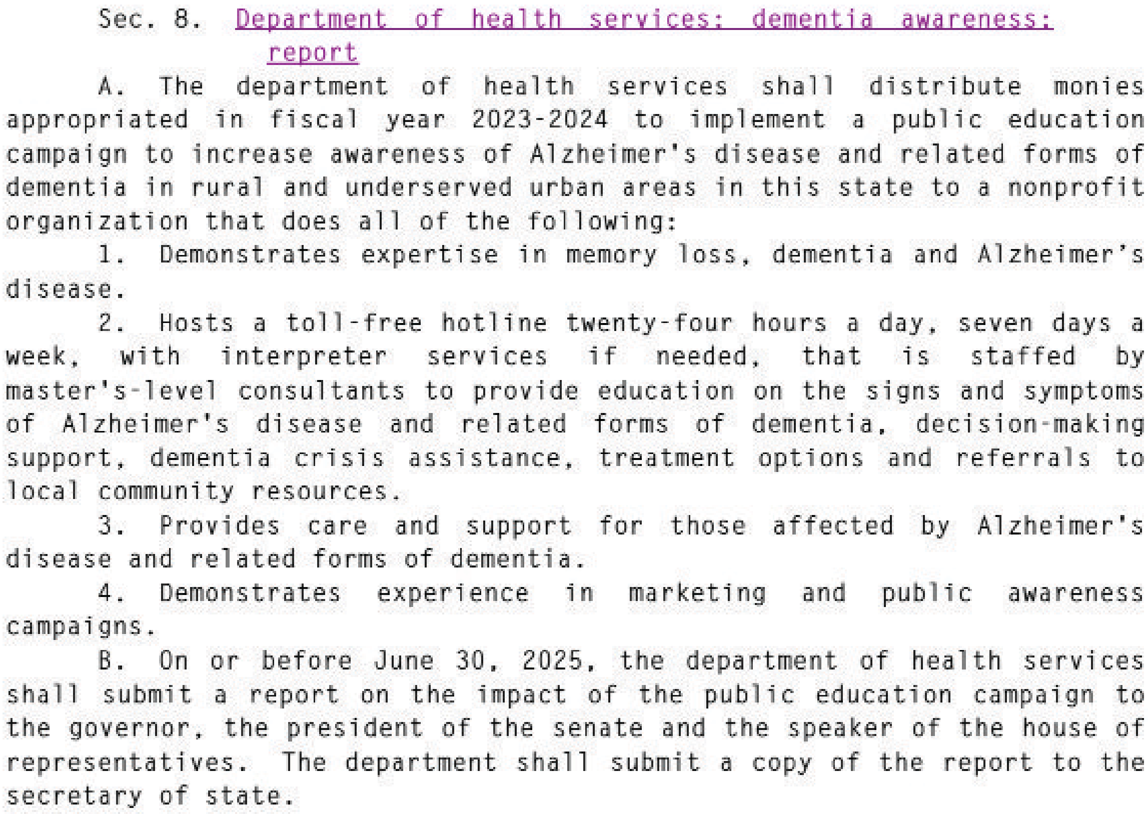
7. Be published on the department of health services' public website.

E. On or before July 1, 2024 and June 30, 2026, the department of health services shall review the Alzheimer's disease state plan and submit an updated state plan to the governor, the president of the senate and the speaker of the house of representatives and shall submit a copy to the secretary of state. When reviewing and updating the Alzheimer's disease state plan, the department of health services shall collaborate with persons who have Alzheimer's disease or a related form of dementia, those who directly care for them and public, private and nonprofit organizations focused on Alzheimer's care services, research, advocacy, health care and caregiver support.

F. This section is repealed from and after June 30, 2026.

APPENDIX B: DEMENTIA AWARENESS CAMPAIGN & LEGISLATION

DEMENTIA AWARENESS CAMPAIGN

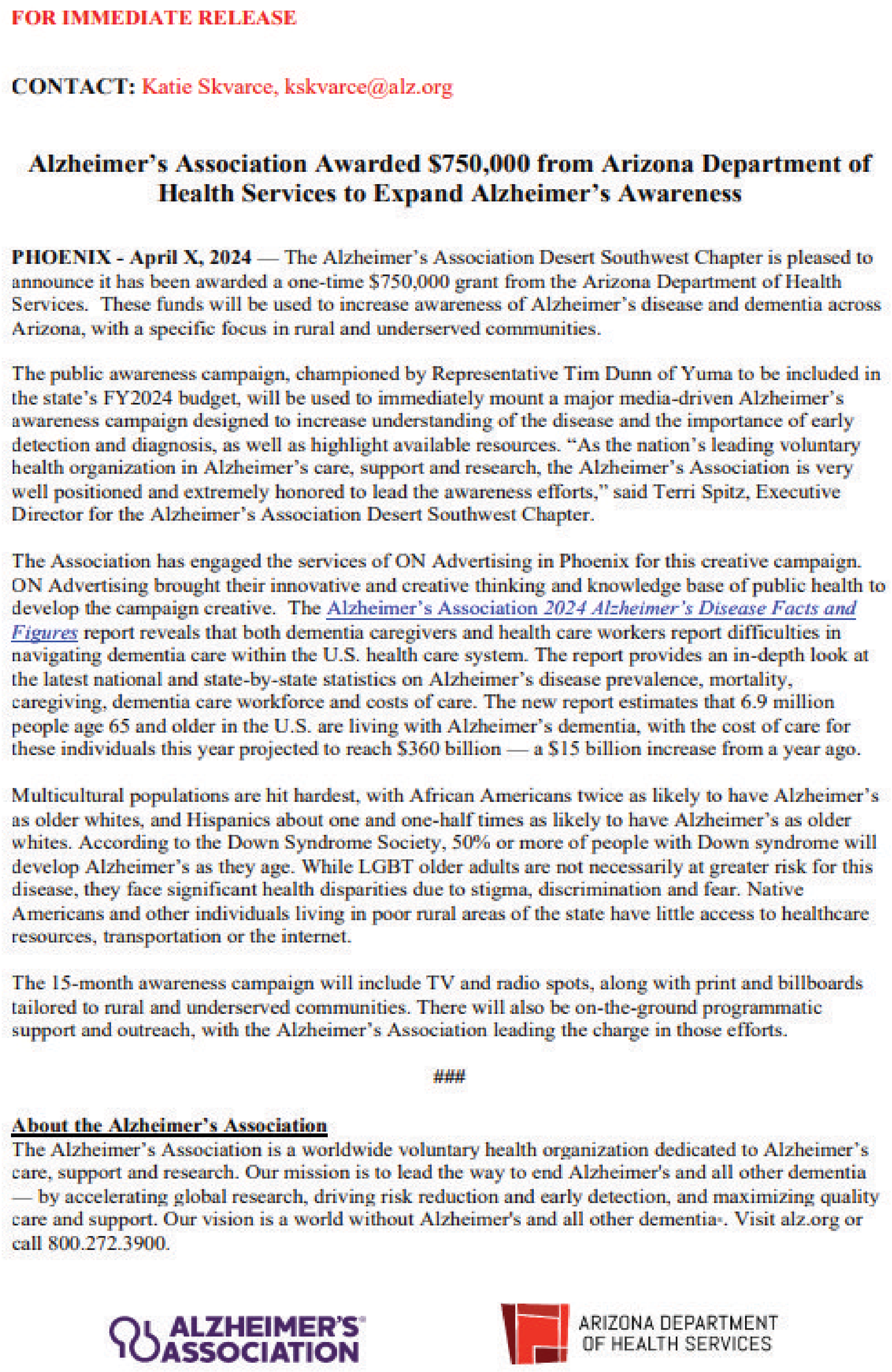


Sec. 8. Department of health services; dementia awareness; report

A. The department of health services shall distribute monies appropriated in fiscal year 2023-2024 to implement a public education campaign to increase awareness of Alzheimer's disease and related forms of dementia in rural and underserved urban areas in this state to a nonprofit organization that does all of the following:

1. Demonstrates expertise in memory loss, dementia and Alzheimer's disease.
2. Hosts a toll-free hotline twenty-four hours a day, seven days a week, with interpreter services if needed, that is staffed by master's-level consultants to provide education on the signs and symptoms of Alzheimer's disease and related forms of dementia, decision-making support, dementia crisis assistance, treatment options and referrals to local community resources.
3. Provides care and support for those affected by Alzheimer's disease and related forms of dementia.
4. Demonstrates experience in marketing and public awareness campaigns.

B. On or before June 30, 2025, the department of health services shall submit a report on the impact of the public education campaign to the governor, the president of the senate and the speaker of the house of representatives. The department shall submit a copy of the report to the secretary of state.



FOR IMMEDIATE RELEASE

CONTACT: Katie Skvarce, kskvarce@alz.org

Alzheimer's Association Awarded $750,000 from Arizona Department of Health Services to Expand Alzheimer's Awareness

PHOENIX - April X, 2024 — The Alzheimer's Association Desert Southwest Chapter is pleased to announce it has been awarded a one-time $750,000 grant from the Arizona Department of Health Services. These funds will be used to increase awareness of Alzheimer's disease and dementia across Arizona, with a specific focus in rural and underserved communities.

The public awareness campaign, championed by Representative Tim Dunn of Yuma to be included in the state's FY2024 budget, will be used to immediately mount a major media-driven Alzheimer's awareness campaign designed to increase understanding of the disease and the importance of early detection and diagnosis, as well as highlight available resources. "As the nation's leading voluntary health organization in Alzheimer's care, support and research, the Alzheimer's Association is very well positioned and extremely honored to lead the awareness efforts," said Terri Spitz, Executive Director for the Alzheimer's Association Desert Southwest Chapter.

The Association has engaged the services of ON Advertising in Phoenix for this creative campaign. ON Advertising brought their innovative and creative thinking and knowledge base of public health to develop the campaign creative. The Alzheimer's Association *2024 Alzheimer's Disease Facts and Figures* report reveals that both dementia caregivers and health care workers report difficulties in navigating dementia care within the U.S. health care system. The report provides an in-depth look at the latest national and state-by-state statistics on Alzheimer's disease prevalence, mortality, caregiving, dementia care workforce and costs of care. The new report estimates that 6.9 million people age 65 and older in the U.S. are living with Alzheimer's dementia, with the cost of care for these individuals this year projected to reach $360 billion — a $15 billion increase from a year ago.

Multicultural populations are hit hardest, with African Americans twice as likely to have Alzheimer's as older whites, and Hispanics about one and one-half times as likely to have Alzheimer's as older whites. According to the Down Syndrome Society, 50% or more of people with Down syndrome will develop Alzheimer's as they age. While LGBT older adults are not necessarily at greater risk for this disease, they face significant health disparities due to stigma, discrimination and fear. Native Americans and other individuals living in poor rural areas of the state have little access to healthcare resources, transportation or the internet.

The 15-month awareness campaign will include TV and radio spots, along with print and billboards tailored to rural and underserved communities. There will also be on-the-ground programmatic support and outreach, with the Alzheimer's Association leading the charge in those efforts.

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About the Alzheimer's Association

The Alzheimer's Association is a worldwide voluntary health organization dedicated to Alzheimer's care, support and research. Our mission is to lead the way to end Alzheimer's and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support. Our vision is a world without Alzheimer's and all other dementia®. Visit alz.org or call 800.272.3900.

ALZHEIMER'S ASSOCIATION

ARIZONA DEPARTMENT OF HEALTH SERVICES

APPENDIX C:

ALZHEIMER'S DISEASE AND RELATED DEMENTIA

(ADRD) Listening Sessions Findings

SPRING 2024

CONTENTS

METHODOLOGY

A series of seven (7) listening sessions were convened by the Arizona Department of Health Services Alzheimer's Disease and Related Dementias (ADRD) Program. These listening sessions targeted a diverse audience to gain individual insights and perspectives to better understand ADRD needs and impacts.

Listening sessions targeted representatives from the groups outlined in the table below.

LISTENING SESSION PARTICIPANT GROUP	NO. OF ATTENDEES
Associations & National Partners	7
Health Systems	8
Community-Based Organizations	26
County Health Departments & Area Agencies on Aging (Virtual)	21
Individuals with Lived Experience	8
State Agencies	16
Steering Committee – ADRD Core Team	9

Each listening session was conducted by an external researcher and scheduled for a duration of 120 minutes. Many sessions were held in-person at the Arizona Department of Health Services State Lab Conference Center. Sessions that were conducted virtually were hosted via Zoom and Google video conferencing platforms. Attendees were welcomed by ADHS Staff and the facilitator who provided an overview of the goals, timeline, and the work being undertaken to support the development of a Statewide ADRD Plan. The facilitator provided participants with instructions and guidance, setting ground rules intended to create an environment focused on contribution, candor, and courtesy.

For virtual listening sessions, participants could communicate verbally (cameras on or off), add comments and questions directly in the chat box to be shared by the chat monitor. The number of attendees for each session is noted in the table below and brief demographic descriptions are available in each section of the report.

Questions (see Appendix B) were developed by the Arizona Department of Health Services and adapted by the facilitator. Analysis of the qualitative data from the listening sessions followed a comprehensive and systematic plan consistent with standard research protocols. The qualitative data collected consists of the observer notes and listening session transcript information. Thematic analysis was used to sort core commonalities and outliers. Analyses also allowed for the identification of new and emerging themes as they appear in the data.

Additional Listening Sessions

An Additional set of listening sessions were conducted by the Governor's Office of Youth Faith and Family and the Arizona Department of Health Services ADRD Program Manager. The information is included at the end of the report. The table below reflects the participating populations.

PARTICIPANT GROUP	NO. OF ATTENDEES
Individuals with Lived Experience – Parker AZ	Unknown
Tribal Listening Session	3

ASSOCIATIONS AND NATIONAL PARTNERS LISTENING SESSION

Addressing Gaps in Education and Awareness Programs

Education gaps exist across all provider types, but the gaps are most impactful among primary care and family care providers. For providers, specifically primary care providers, family practitioners, mid-level providers, and internists, to support accurate diagnoses of ADRD were noted by participants. Addressing critical gaps in education for primary care and family practitioners to support their ability to diagnose ADRD would support earlier diagnosis. One participant added that an opportunity exists with potentially focusing some training efforts on mid-level providers. Since they often engage with the patient for longer periods of time, they would be well positioned to support screening and potentially be a part of creating a screening pipeline.

Another key theme discussed was the **lack of education being directed at consumers regarding signs, symptoms and risks associated with ADRD**. Participants agreed that it is critically important that the information is targeted to specific populations, it is accessible and considers culturally and linguistically diverse populations. Related, participants noted that trusted community navigators or leaders are needed to support education efforts, especially in culturally diverse communities. Known trusted community leaders are able to support information dissemination throughout the community.

Participants also agreed that the relationship shouldn't be looked at as one-way, the trusted partner helping to disseminate information and recruit community members to attend trainings or events and the educator learning from the community member how to best engage with members of their community and fortify relationships to continue perpetuating the information and resources shared.

> **"It can't be a one-way approach to approach these other populations. So, we need to have more people in the communities looking possibly at leaders in the community who can help with that outreach and provide people who can give that information to the leaders or at least the leaders open those doors to allow, get the trust that's needed to be in the community."**

There is also a **lack of targeted and trusted sources of information** to support public awareness of available resources and coping strategies for caregivers and individuals with ADRD. Participants felt that opportunities exist to leverage community health workers and virtual navigators to increase outreach and education.

Addressing the stigma associated with caregivers who need respite and support. Participants discussed the need to address stigma associated with seeking support. In participants' experience, some individuals are more willing to reach out and get support and respite than others. For some this stigma may be rooted in cultural beliefs.

Addressing Gaps in Early Screening and Diagnostics

There is hesitancy to screen for memory issues among primary care providers due to time pressures and inability to provide answers to individuals and caregivers. Emerging screening tools (i.e., blood tests) could increase focus on early evaluation and intervention in the not-so-distant future. More scalable workforce models are needed like patient navigators and coordinating screening questions before appointments.

> **"The other challenge we have among primary care physicians, which is not their fault by any stretch of the imagination. They're awfully busy. If they have eight minutes to see a patient and they ask about memory problems, but they may not have the answers for themselves, they're likely to get a lot of quite understandable questions from family that they may not have the answer to and that may take a lot of their time."**

From a provider perspective, it's hard to expect most primary care providers to do even a relatively brief cognitive assessment due to the **time limitations** they have surrounding patient visits. Additionally, some providers may be ill equipped to respond to patient or caregiver questions due to a lack of dementia focused training. Focused training on dementia diagnosis and care pathways would provide additional knowledge for providers to make the proper diagnosis.

The **contracting workforce** is another challenge for ensuring that patients are being screened for dementia due to the sheer lack of providers in some instances.

Partnering with trusted community members is key to engaging diverse communities. Trusted community members (e.g., Promotoras or CHWs, faith-leaders, etc.) can advise on the engagement and approach for sharing training and support screening. Participants shared examples of how different communities receive information, for example, in the Latino community, if you ask someone about Alzheimer's disease, they'll say, "I don't have a disease, I'm not sick." But if you modify the approach and ask, do you have memory loss? You might receive a response like, "Oh yeah, there have been a couple of times where I had some issues." Additionally, another participant cautioned that what would work for the same racial or ethnic group in one region in Arizona, may not work in another region.

> **"Finding those relationships, building those relationships with communities so that you are accepted, and you can [work with] the community groups."**

Gaps in Safety and Quality

Evidence-based falls prevention programs require more promotion across communities. One participant shared that offering more promotion regarding evidence-based falls prevention initiatives and programs, perhaps even offering information in primary care provider spaces, literature about how to enhance quality or safety at home because I think there are ways, things that a lot of us overlook that could become hazards as we age in our home. Something to kind of explain to them the hazards and ways to increase people's safety within their own home.

Hospitals can be dangerous for dementia patients; education on alternatives is important to keep ADRD patients out of the emergency room when appropriate. Participants agreed that the ER is one of the most dangerous places for individuals with ADRD or memory issues and suggested that providing better education to support caregivers and community members about alternatives to the ER and the situations for when it's appropriate to use the alternatives would support keeping the individual safe.

> **"Maybe they're interacting with individuals without knowing it, they're not going to remember the instructions they're getting, getting unnecessary procedures, the risk of delirium, which is a dangerous medical condition being in those unfamiliar environments."**

Focus is needed on preventative services and risk reduction to support healthy aging, possibly drawing on blue zone models. One participant offered that focusing efforts on risk reduction and healthy brain promotion are important. One example shared was about Blue Zones and the importance of these communities. Individuals who live the longest and have a healthier, better quality of life are plugged into communities with this designation. Also associated with prevention is working to address modifiable risk factors like managing chronic diseases and getting adequate sleep.

Addressing workforce limitations is important to maintain the health of the system. Through the utilization of scalable and potentially less expensive solutions. scalability is necessary to support a contracting health care workforce to support patient screening and navigation. Leveraging existing alternatives and creative problem solving to "think outside the box" to identify unique solutions.

Participants acknowledged that Community Health Workers (CHWs), promotoras, etc. are also vital to supporting and could be leveraged to address screening, even more now that CHWs are able to bill for services, although not all services may qualify as billable.

One participant shared a possible future solution of using generative AI to develop virtual navigators to support responses to common medical and non-medical questions, common questions that most individuals.

Health Systems, Policies, and Programs

Dementia Specialists

Participants suggested examining policies from other states that have been successfully implemented, as well as counties with similar political composition as Arizona would be helpful and provide insight into lessons learned. One example shared was from Wisconsin where they were successful with the implementation of dementia specialists in each of their County Health Departments.

Data Needs

Participants agreed that centralized data sharing or linkages would be beneficial. Data needs identified include:

- Zip-code level data to help support targeted outreach.
- Extend data sharing to include a repository of resources that are accessible and easy to locate. that is a step further and has an accessible resource repository.
- Data reflecting rural, tribal and low-income groups.

Additional Areas to Explore

The following represent ideas shared that could be considered for inclusion during the development process for the ADRD Arizona State Plan.

- Engage champions or prominent community leaders to lead by example or share their experiences with ADRD.
- Leverage community health workers for education and screening support, given new billing options.
- Start dementia specialist pilot programs in counties with highest Alzheimer's prevalence.
- Learn from successful policies in other states to identify those that could be adopted with local adaptations.
- Promote home modifications and fall prevention education for at-risk groups.
- Convene direct care, line staff, professional admin, etc. and others to come together quarterly to share experiences, knowledge, and network.

STATE AGENCIES LISTENING SESSION

Addressing Gaps in Awareness and Education

Gaps in Education and Awareness Specific to Caregivers

Participants discussed critical gaps in public and health care provider awareness, knowledge and understanding of ADRD, especially among minority and rural populations. Key issues include lack of a common vocabulary, not recognizing early symptoms, stigma, and navigating complex systems of care. Individuals in rural Arizona often must travel outside of their home area to access specialized care, e.g., dementia specialists, geriatricians, etc.

Resource education is also key, supporting not only provider awareness of where to direct patients to for support, especially for individuals when they're on Medicare but before needing long-term services, where they could use support to help keep them in their home longer and out of assisted living.

Caregiver Gaps

Participants noted that efforts to educate and bring awareness to caregivers regarding the early signs and symptoms of ADRD is a critical need. Signs and symptoms for dementia start as early as 10 years before it's diagnosed, and **"the caregiver likely observes these changes and knows they're there."** Participants felt that training focused on the signs and symptoms could support earlier identification of ADRD, thus reducing the time it takes to get an individual to a provider for appropriate screening and further diagnostics. Additionally, early identification can support quality of life improvements by connecting individuals and caregivers to the appropriate resources and supports. Early screening would have the added benefit of establishing an initial baseline for cognitive screening.

A lack of awareness for the terminology and subsequent definitions associated with caregiver descriptions may be excluding caregivers from educational opportunities. **"When we say caregivers, we're referring to certified caregivers, paid caregivers, trained caregivers, and we're also referring to informal caregivers (i.e. family members, friends)."** If caregivers are unsure of how to identify where they fit in the caregiver spectrum, it's likely that they would have difficulty identifying training or resources specific to their needs. Participants also shared that it's possible caregivers could be turned away from a training because of a need **"to meet a specific [caregiver] criterion to attend."** In addition, an individual who is turned away may not realize that they are eligible for other education and may be less inclined to seek out other educational opportunities due to being turned away. Related to this, caregivers or individuals seeking services often approach the Arizona Long Term Care System (ALTCS) and are denied. As a direct result of the denial, a misperception that they are not eligible for other services exists. Creating clear guidance regarding resources, supports, and when an individual is eligible for them would be helpful.

> **"If the caregiver is denied services, it's usually always ALTCS. If they're denied, they think they are not eligible for any of [the other services]. And they give up."**

One participant did share that there is existing work happening via the Respite Network's Language Subcommittee to actively address the complexities of navigating the terminology around ADRD. Other initiatives that are active in the State include an effort by DES to do a resource mapping to support a "No Wrong Door" approach to navigation.

Provider Gaps

Training for providers is a complex issue exacerbated by an environment that requires them to perform increasingly more work in less and less time. This is especially prevalent among PCP providers. Some participants felt that there is a need to help reframe provider thinking to support a holistic view of diagnosis and treatment for practitioners. One participant shared, **"We hear a lot that practitioners are missing out on potentially [identifying signs and symptoms] of ADRD"**, because they're compartmentalizing their approach to diagnosis and treatment and **"we're missing some opportunities for [early intervention]."**

Additionally, participants who have experience working with the Intellectual or Developmentally Disabled (IDD) population or Severe Mental Illness (SMI) populations felt that gaps in provider education exist for supporting the complexities of ADRD in addition to another condition. Participants felt that providers need specialized training to address the complex issues exacerbated by a lack of time and being asked to do more and more, especially among PCP providers.

Participants agreed that general resource education for providers is also needed. Participants felt that resource education would help providers understand available supports that would prolong quality of life for individuals with ADRD, especially by being able to help identify specific supports to help keep individuals with ADRD in their homes for as long as possible in lieu of them moving to assisted living facilities.

> **“There’s that gap between when [individuals with ADRD] are on Medicare before they need long term services but could use support at home to help keep them in their home and out of assisted living.”**

Participants considered opportunities that might exist to have pseudo-practitioners, for example, case managers, trained to supplement and support early screening. It would be necessary to clearly define the role the case manager would play in screening, how far they would go with completing the screening, and what the next steps would be for referral.

Topics that participants would like to see ADRD training on includes:

- Identifying normal aging versus signs and symptoms of Alzheimer’s Disease and Dementia - Caring for the caregiver
- Holistic view of the patient
- Training pseudo-practitioners (e.g., case managers) to support screening
- Resources for caregivers and providers

Gaps in Services Affecting Persons with ADRD of Different Cultural Backgrounds

Participants emphasized providing culturally and linguistically appropriate screening tools, interventions, and caregiver support tailored to diverse populations based on locality, tribes, languages, beliefs on dementia, and historical trauma.

Communication and language barriers were seen as critical gaps for both tribal and refugee populations in Arizona.

> **“I think for tribes in general, I know within outpatient, there’s no word for dementia. So how do you train on something when there’s not a word [or a definition to describe] dementia. Right now, it is just a description of the symptoms.”**

Additionally, participants felt that strategies and approaches for how to address stigma were needed to support engagement among populations where caregivers feel that it would dishonor their role as a caregiver to ask for support.

One participant also shared efforts to develop a screening tool specific to the indigenous population as an item to explore to support appropriate and supportive dementia screening in tribal populations.

Utilizing Community Health Workers to support engaging the culturally diverse landscape in Arizona to support navigation. There is now an opportunity to reimburse CHWs for services and there may be an opportunity to expand the CHW presence or train individuals to be CHWs where they do not currently exist or where more are needed. Additionally, expanding the service codes that are reimbursable may be needed to support more traditional care among our culturally diverse populations.

> **"Looking at even going into acceptance, adoption of traditions, traditional care, that hasn't been, there's no coding for traditional care."**

Finding better ways to engage and approach working with tribal partners is also key. The State often has very specific timelines that are tied to other processes (e.g., grants), but those timelines don't always align with how tribal communities operate.

> **"It's almost like the State sent a lot of challenges to the tribes because our processes and our timelines were so set and different and not considerate of their processes."**

Addressing Gaps in Safety and Quality of Care

Participants linked quality and safety of care back to the lack of training on ADRD and the diminishing workforce.

Workforce Shortages and Access Disparities

The group examined shortages among health care and direct care workforces, high turnover, and disparities in access faced by tribal, rural, and socially isolated populations. Transportation barriers and uneven broadband availability also limit access.

Several participants shared that workforce limitations impact the safety and quality of care. The workforce, whether paid or non-paid, is not adequate to support the diagnosis, treatment, and ongoing support needs of the caregiver and the individual with ADRD, **"it just seems like the [workforce] hole gets bigger every day."** Additionally, turnover impacts the continuity of care related to diagnosis and ongoing treatment for individuals with ADRD and support for caregivers potentially impacting the quality of care and safety during those transitions.

> **“When you’re looking at the turnover, whether it be direct care providers or state coordinators or case managers, the turnover is so high it leaves [the ADRD] population without a consistent advocate.”**

Caregiver Background Screening

Screening caregivers for criminal history is statutorily required for paid caregivers through fingerprint clearance, however there are some gaps that exist for screening in the **“long-term care population when served by certain health plans, AAA’s or DDD contracted providers,”** where caregivers just receive a basic background check. Additionally, when someone chooses their own caregiver, “**there’s very little [state agencies] can do to ensure the individual’s safety.”** Additional protections could be achieved through adding licensing or fingerprinting requirements; however, these changes would require legislative change to enhance the safety of individuals with ADRD.

Use of Technology

Identifying ways to utilize technology, **“not to take the place of the workforce, but to augment it,”** was largely seen as a positive way to alleviate workforce strain and provide additional support to improve safety for individuals and caregivers. Leveraging technology to support supervision could provide some independence for those individuals with ADRD who are staying in their home and allow them to stay out of assisted living facilities longer. Additionally, Electronic Visit Verification (EVV) systems already utilized around the State for paid caregivers to individuals receiving services from AHCCCS could be further used to impact the quality of care or services received. One participant shared that EVV systems have ways for a caregiver to report back to the agency and alert someone that the individual they are caring for is having an off day or requires additional follow-up due to a recently diagnosed condition (e.g., Urinary Tract Infection).

Addressing Gaps in Systems, Policies and Programs

Data Needs to Understand the Impact of ADRD

Data is an essential need for many participants to better support their work and see it as a critical need for driving system improvements to be able to identify, **“What’s going on and where the gaps are”** for planning, delivering services, and improving systems. Participants noted the long timelines and burdensome process for establishing data sharing agreements across state agencies create challenges.

> **“I found it challenging just doing data sharing from other agencies, the timeline, getting it processed at all, or setting up an agreement of ongoing data sharing.”**

Additionally, navigating the complexities of engaging tribes to discuss the use of tribal enrollment data was brought up. **"Data from tribes is an area that we miss entirely"** in planning efforts and funding structures. Participants often rely on census data for establishing needs and in developing funding strategies, and unfortunately, that is not a reliable source for accurate tribal data. Participants shared that trust is a challenge for our indigenous communities, especially due to more recent instances where trust regarding data was abused. breaches and relationship building are needed to bridge this gap and

Along with the data, participants noted that data quality is essential and training to mitigate misclassification and support data entry are needed. Defining the important data elements for evaluating ADRD across the State would also be beneficial for understanding ADRD's impact and planning for future efforts to lessen that impact.

Participants talked about potential data sources that could potentially support planning or other programmatic efforts, including economic data and population characteristics or projections that may exist that they don't know a lot about.

> **"And if we know what they have, they're making projections about different things and so forth to support the state. I think there are probably a lot of data sources we don't know about and that would be good for us to have as far as looking at."**

Cross-Agency Collaboration

Agencies shared the need for increased collaboration across various state and county agencies on ADRD related to data sharing, policies, education, screening tools, training programs and service delivery. Each agency currently has separate funding streams and plans that could benefit from "**cross-walking"** efforts to stay aware of each other's activities. Additionally, convening regularly to share updates was identified as a need, but participants saw a need to have a dedicated convener or commitment among others to engage in the collaborative. One participant shared that working together as state agencies to fund a position or team to support a more collaborative inter-agency approach could be beneficial to this work and reduce duplication across the State.

Geographic Limitations of ADRD

Lack of transportation was echoed by all participants as impacting individuals who live in rural areas for their ability to be screened, receive treatment, and gain access to other supports. In rural areas and tribal communities, it can sometimes take an hour or more for someone from emergency services to reach someone in need of help. Additionally, to see a specialist or sub-specialist patients must travel to Phoenix.

Infrastructure

Enhancing the infrastructure in rural Arizona is key to supporting individuals and caregivers. One participant shared that supports like the TruAlta platform for caregivers exist in rural Arizona for providing access to virtual training, peer to peer connections, and other resources. It's great for those that can access it, but in some areas, we run into the "digital divide" where broadband limitations exist and acts as a barrier to reaching needed supports (e.g., caregiver platforms, telehealth, access to apps). During the pandemic participants saw that already exhausted anybody who has the existing bandwidth, infrastructure or lives in a place that can afford the costs to expand digital infrastructure. Arizona didn't see a huge increase in people in rural or non-urban communities using telehealth and other digital supports because they were already using them.

Addressing Gaps in Systems, Policies and Programs

Participants highlighted a need for supportive employer policies for those who are caregivers to support retention.

Impacts of Comorbidities on Individuals with ADRD

Memory care and support for individuals diagnosed with Severe Mental Illness (SMI) or individuals with intellectual disability and other disabilities (IDD) when coupled with ADRD are virtually nonexistent. A need exists to adapt long term and memory care facilities to be inclusive of these populations in the future. These facilities need to not only support memory care services, but also the full spectrum of services needed for the SMI and IDD populations.

Addressing Impacts of ADRD on Law Enforcement

Unique to this session, several participants voiced specific challenges that exist from the position of law enforcement and its role in protecting and effectively interacting with individuals affected with ADRD. The lack of centralized training, information collection and sharing, and variations in available legal remedies based on jurisdictional boundaries creates a dysfunctional environment with severe limitations for law enforcement. Crimes against the elderly have no MDTs ("multidisciplinary teams"), which serves to ensure the affected parties in cases regarding children are receiving the proper treatment and services from law enforcement and State and Federal agencies when necessary. Each law enforcement agency acts independently and with limited resources and training for managing cases concerning the elderly and those affected by ADRD. One detective may have proper training and experience, and that person could be promoted or transferred, leaving a gap in time before a replacement can be identified and trained. Furthermore, there is no centralized information sharing, which is a particular concern in resolving Silver Alerts and related circumstances. Cases become more complicated as jurisdictional boundaries are crossed, such as a person entering, leaving or being a resident of Tribal Territory. Law enforcement is limited in the aid and assistance it can provide when these boundaries are crossed.

> **"I can't log into Phoenix's PD system and pick up DPS's reports to just see if just down the road, because the jurisdictional timeline is right here, if something happened, that's related to my case."**

Participants were very concerned about how law enforcement would be able to effectively serve the increasingly growing aging population without a centralized infrastructure, increased training and education, and a uniform approach to recognizing and managing cases with individuals affected by ADRD. Additionally, participants noted turnover as a significant impact.

> **"I mean right now it's just the incredible turnover we're experiencing. As soon as you train someone up in being a detective for a vulnerable adult detail. They promote the move out of that, and that vacuum, it takes a while for it to fill back in. And that knowledge just isn't gained overnight."**

Participants also shared that they **"wish that there would be a round table like this [listening session] for law enforcement specific to [preparing for the] wave that is coming 5, 10, 15, 20 years from now because it will be problematic and not just the silver alerts, but worse, the victimization too in elder or financial abuse."**

Additional Areas to Explore

The following represent ideas shared that could be considered for inclusion during the development process for the ADRD Arizona State Plan.

- Explore a shared case management system for different agencies serving individuals with ADRD
- Crosswalk existing state agency activities and plans related to aging, dementia, disabilities, etc. to identify collaboration opportunities and align approaches
- Support opportunities for unpaid family caregivers to access training, respite, counseling and stipends
- Engage the business community to identify strategies to enhance supports for caregivers in the workplace
- Conduct additional sessions with tribal communities and law enforcement leadership to gather additional perspectives
- Develop a campaign to support caregiver needs and consider the inclusion of the following:
- Centralized place for resources and supports
- Integrate with other health issues (i.e., mental health, social connectedness, and isolation etc.)

COMMUNITY PARTNERS AND COMMUNITY BASED ORGANIZATIONS LISTENING SESSION

Gaps in Existing Education and Awareness

Participants noted gaps in ADRD education and awareness including a lack of dementia-related training for hospital staff and first responders, and the need for better communication and implementation of existing training programs. Participants identified the need for a centralized place to access existing resources and training and suggested the development of a statewide training or curriculum for health providers. As one participant noted, **"Originally there was a fundamentals module on aging, physical disability, and Alzheimer's. Alzheimer's was sort of forgotten."**

There was also discussion about including the caregiver perspective in provider training to better understand what someone in this role experiences, allowing a non-clinical perspective to be included.

> **"There's an opportunity there for looking at the training that exists and making sure that the caregiver perspective is embedded. So, it's always beneficial to see what someone is experiencing in their own shoes, right?**
>
> **Versus...this is the disease process."**

Another topic discussed is how commonly providers find that family caregivers do not identify themselves as caregivers, and further, that these caregivers are unable to identify that the person they care for has ADRD. This can create significant barriers to treatment since caregivers and ADRD patients do not readily present or accept treatment options associated with ADRD. Participants explained that, alternatively, in some cases, caregivers know what they need to do to address ADRD symptoms, but their family members will not listen to them because they do not believe they have ADRD. To address this, participants recommended training for first responders and caregivers on creative strategies for working with resistant patients.

The conversation transitioned to the related need to better **educate families about ADRD symptoms and onset**, so that they can adequately assess warning signs, know when to bring the person they care for to the doctor, and understand what questions to ask the doctor when they get there. The overall idea being to help family members and caregivers better understand and identify the difference between normal aging and aging issues like ADRD. Additionally, participants proposed facilitated training for families on ADRD care and mobility issues in the same way that CPR and First Aid training is provided.

Gaps In Early Screening and Diagnostics Programs for ADRD

In discussing gaps in screening and diagnosis, participants discussed the need for patients to **establish a Primary Care Physician [PCP] as their primary point of care.** They explained that many patients who end up in the hospital do not have a PCP and thus do not receive regular primary care which would prevent trips to the hospital. Moreover, a lack of routine ADRD screening at hospitals furthers challenges with ADRD identification and diagnostic issues. Another prevention effort identified by participants was to begin providing people with ADRD education and awareness in their 40s and 50s.

Addressing the Safety and Quality of Care for ADRD Patients

A main gap identified around safety and quality of care was the barriers to implementing falls prevention education with ADRD patients. One participant explained, **"The Alzheimer's population can be very challenging to do falls prevention education with because of their disease process and learning and their retention."** This gap also ties back to the suggestion by participants to provide prevention information to patients before the early onset time frame.

Participants raised the issue that falls are the number one reason that patients with traumatic injuries are admitted to the emergency room and suggested implementing training for first responders on interacting with ADRD patients. This led to the recommendation for training tailored to EMTs and hospital staff so that they can help connect patients to the appropriate level of care needed. One participant noted that social workers are often left to address caregiver concerns in hospital settings and emphasized the importance of comprehensive ADRD training in coordinated care settings.

> **"When [EMTs] come to a call at a house to understand and be able to either A) work with that individual where they are, so however they might be behaving, and (B) be identifying flags for somebody else. So, kind of a quality needs in how we bring on this individual. How we get them connected to their care."**

Participants also discussed the need for licensing to cover minimum standards of care, especially for memory care facilities. Participants felt that there should be training for nursing and care facilities specific to treating patients with ADRD. Participants also recommended implementing regulatory oversight to ensure facilities, organizations, and programs are meeting the required quality of care for ADRD patients. In fact, multiple participants expressed negative personal experiences with their loved ones in memory care facilities which could have been prevented or significantly affected by better and standardized training and effective oversight and regulation.

Another theme identified in the discussion was the gap in services such as adult daycare centers and respite programs. Participants noted that when these programs are available, there is often a long waitlist. Moreover, participants emphasized that challenges accessing in-home services and respite care are especially prominent in rural geographies and on the state's reservations. To better address safety and quality of care, participants recommended the development of more comprehensive care facilities with services and activities onsite. One participant provided an example of an existing program, **"... they have an onsite nurse. They have an onsite social worker. They're the instructional assistant or coordinator. They have an activities coordinator that they find valuable, and the hospital provided funding for that position."**

Participants went on to discuss challenges with this idea, such as ensuring services are reimbursable by AHCCCS, including transportation. Participants also explored a world where nothing is done to address the safety and quality of care issues currently present in our state. Participants painted a grim future picture, expressing that eventually hospitals will reach max capacity, along with acute care and rehab settings. Similarly, caregiver services and home health care will become unavailable.

Gaps in Services Affecting Persons with ADRD of Different Cultural Backgrounds

Numerous cultural considerations were raised in the listening sessions, including stigma in certain communities viewing dementia as a spiritual rather than medical issue, and a need for in-home services that are compatible with cultural norms for caring for elderly at home.

> **"Program services that can come to the home. And not just like caregiver respite support now, but a lot of variations. Because different cultures have different beliefs in how you care for the elderly, and many want to have them live together and age together and not send them to an adult day center."**

One participant provided specific context about gaps in services for ADRD patients on the Navajo Nation, explaining that home health care isn't available on many remote reservations. The participant went on to elaborate, **"We discharge people all the time from the hospital. We don't have a health agency that will go to some of our more remote reservations...So, [the patient] ends up going home with the family completely unprepared, and they...won't have it any other way. That's our culture."**

Participants also discussed the need to craft education and awareness in a culturally responsive way. For example, participants identified opportunities to make programming more linguistically inclusive such as by integrating interpretation services and linguistically appropriate materials/resources into care as well as valuing staff with diverse language skills. Additionally, one participant discussed how age is

also a cultural factor to consider. This participant explained,

"I think depending on the age and where they're at in their dementia journey, if they do go to community centers or senior service centers or adult day programs, looking at it from a more inclusive perspective from the food, to the activities, to the music, to the celebration so that it's not just a single way of interacting with those folks in those environments."

Addressing Systems, Policies and Programs

Throughout the listening session, participants also identified a multitude of additional items including: missing partners, system and policy linkages, and program needs, and data gaps to address the complex challenges of ADRD.

Missing Partners or Linkages

As mentioned in **Gaps in Existing Education and Awareness**, participants emphasized the need for a centralized place to access resources on ADRD in Arizona and identified strategies such as a collaborative statewide plan to address aging issues.

Participants discussed how other states (e.g., California) have a formally adopted master plan on aging that includes ADRD and includes allocated funding to allow stability and longevity. Participants elaborated that a centralized plan would provide a "united set of goals" where partners can work toward the same goals and connect **"in a collaborative format to discuss where we are and share resources."**

Similarly, participants discussed how it can be challenging for providers to navigate the many community organizations and services across the state. Participants emphasized the immense benefits of creating a centralized repository of ADRD resources, support, and services to assist providers with navigating the landscape of care for ADRD patients and their families. Participants envisioned the potential of a virtual "one-stop-shop" to help bridge the gap in patients receiving comprehensive ADRD services. Participants identified Adult Protective Services (APS) and statewide Alzheimer's Associations as critical partners in working toward this type of goal.

Another primary theme identified is the numerous barriers to billing AHCCCS for ADRD services by community health service agencies. Furthermore, participants also indicated that patients face substantial barriers in qualifying for AHCCCS benefits. One participant emphasized the significance of this issue, noting that there is a "**very large gap between having plenty of money to pay for whatever your person needs and qualifying for AHCCCS."**

Other important linkages discussed by participants include the need for more services and programs specifically for patients at the early onset stage of ADRD and a general need for more funding for older adult programs. Participants also identified an opportunity to leverage community health workers in their positions as trusted partners in the community to bridge gaps in ADRD education and awareness. Additionally, participants felt that community health workers deserve to be compensated for the important roles they play in the health care landscape.

Data Gaps

Participants identified multiple data gaps that could help address challenges related to ADRD. For example, participants felt there is a need to capture better data on diagnosis rates, living situations, and access to services to provide a clear landscape of Arizona's ADRD population and service settings.

> **"How many people in the state have a diagnosis? How many of those Are people living at home? How many of those people are in skilled nursing facility? How many of those people have AHCCCS? How many of [the facilities] are AHCCCS funded?"**

Specifically, one participant explained that there is not a realistic understanding of the cost of ADRD care for Arizonans. This participant explained that a substantial gap exists between what a patient needs and what they will qualify for under AHCCCS in addition to how much patients can afford to pay out of pocket.

> **"I don't think we have a real grasp of the actual impact and the severity [of ADRD] and... the need for something like this because of [the impacts of ADRD] on families in Arizona."**

Participants went on to discuss how there is potential to pool existing data sources to use in decision making related to ADRD programs and services. Additionally, participants recommended a standardized reporting format for health providers statewide.

Participants would also like access to data on funding streams, so they can identify what efforts are being funded and where the most funding is allocated, allowing a targeted approach to funding opportunities in underserved geographies.

Impacts of Alzheimer's Disease

Participants identified some of the complex impacts of ADRD seen in their work. Participants discussed the mental toll on caregivers and family members caring for patients with ADRD, and the difficulty that caregivers experience trying to access services. Participants also cautioned on the future impacts of ADRD, including increased strain on hospitals and first responders from more ADRD patient cases, greater need for guardianship services from public fiduciary, more people who are unable to live independently requiring external care, and the growing pressure to meet the housing demands of this population.

Additional Areas to Explore

Additional areas to explore and potential strategies to address ADRD challenges were discussed by participants. Key ideas included more adult daycare facilities, better communication between providers and families, standardized quality reporting metrics, improved data collection efforts, shifting public narratives through media campaigns, and increased emotional/mental health support for ADRD patients and their families. Below are specific recommendations that resulted from the listening session:

- Create more adult daycare facilities and increase access to existing ones
- Implement regular communication protocols between care facilities and families
- Develop standardized quality metrics and reporting for organizations serving ADRD patients
- Conduct a statewide needs assessment around ADRD prevalence, services, and costs
- Launch public awareness campaigns on ADRD early warning signs and reducing stigma through arts, literature, and media
- Use a targeted communication approach to avoid "awareness fatigue"
- Expand access to mental health services and counseling for people with dementia and their caregivers
- Increase wages for community health workers or similar staff and leverage their position as a trusted partners in the community
- Create a digital one-stop resource for providers to call and get help with navigating services and resources, potentially in partnership with statewide Alzheimer's Associations
- Development of a statewide ADRD curriculum or training for providers
- Include benefits and resources for caregivers as a part of Employee Assistance Programs
- Create comprehensive care facilities with diverse wraparound services and onsite activities

COUNTY HEALTH DEPARTMENTS AND AREA AGENCIES ON AGING LISTENING SESSION

Addressing Gaps in Existing Education and Awareness

Participants first discussed existing gaps in education and awareness programs for ADRD in Arizona. The primary themes illuminated relate to service and resource awareness, general understanding of ADRD, and stigma associated with ADRD.

Service and Resource Awareness

Participants discussed how there is a need for enhanced awareness about existing resources and supportive services for caregivers of people with ADRD. In particular, a potential gap in existing information and support related to pre-diagnosis was identified. Participants felt that more information about the first signs and steps to take when early signs of ADRD are noticed would be beneficial.

> **"I wish I had known more about what's available for not just treating but diagnosing and understanding some of the things that happen before a diagnosis is given."**

In addition, participants mentioned an opportunity to raise awareness about the different therapies (e.g., art, music) and adult support groups that are available which many caregivers are unaware of. For example, one participant noted that caregiver support, such as respite programs or support groups, are "vital" for those caring for people with ADRD in their home. Participants explained that increased awareness about ADRD and ADRD services/supports can help caregivers better care for their patients and reduce stigma around ADRD.

General Understanding and Stigma of ADRD

Participants noted a lack of understanding or awareness of ADRD among the general public which often leads toward the perpetuation of stigma related to these conditions.

> **"I feel like there needs to be a larger concerted effort towards reducing the stigma, helping people understand that it's okay to talk about it and starting those conversations a decade earlier than we have been."**

Additionally, lack of education about ADRD conditions and diagnoses can lead to families not recognizing early onset symptoms and may delay or prevent them from seeking a neurological consult when first symptoms arise.

Addressing Gaps in Early Screening and Diagnostics Programs for ADRD

Participants were also asked to identify gaps in early screening and diagnostics programs for ADRD. Overall, participants felt that there were opportunities to improve coordinated diagnosis and care among multidisciplinary health care teams as well as opportunities to better coordinate early screening and education for health care professionals, patients and their caregivers.

In particular, participants mentioned that there are few multidisciplinary health care teams who coordinate diagnosis and care which creates a large gap in early screening and diagnostics for ADRD patients. Participants felt that there are opportunities to include ADRD early onset screening questions on health care clinic intake forms across numerous disciplines and specialties, which could lead to coordinated screening and value-added patient education efforts.

> **"There really needs to be a multidisciplinary approach to community education and awareness about dementia for the health care professionals that are working with it, identifying it to include the physicians, the nurses, the RNs, behavioral health [etc.]."**

Several participants emphasized the significant barriers to early screening and diagnostic care for people in rural parts of the State. This includes a lack of health care specialists in rural areas, hesitancy of Primary Care Physicians to diagnose ADRD, wait times for appointments with specialists like neurologists, and a lack of access to transportation to/from appointments with specialist or providers in urban areas such as Phoenix (see Geographic Limitations of ADRD).

Addressing the Safety and Quality of Care for ADRD Patients

When participants were asked about ways to address gaps in ADRD patient safety and quality of care, discussion points were concentrated around improved training and education for health care practitioners and staff at care facilities and the need to bolster the pipeline of professionals who will provide care to ADRD patients.

Training and Education

Participants mentioned a need for increased training and education for staff and leadership at nursing and assisted living care facilities. At the same time, participants acknowledged how this need is often combatted with the challenge of high staff turnover among caregiver agencies.

Participants also identified a gap in training and education among the many practitioners and community navigators that older adults interact with and receive care from. In particular, participants felt that there was an opportunity among behavioral health professionals to expand their expertise and training to include ADRD conditions and symptomology.

> **"I had an elderly member in a behavioral health hospital who had a dementia diagnosis and the provider there, who was a psych practitioner, told me that the member was, it was all [manipulation]."**

Workforce

Within the realm of quality of care, participants felt that it would help ADRD patients and their caregivers if there was a focus on building a pipeline for caregiving professions and encouraging more people to engage in direct care work. Again, the topic of high turnover among care workers arose, and participants suggested that workforce participation could be strengthened by offering compensation and benefits that are commensurate with the services that care workers provide.

As another potential solution to enhance support and professional quality of care for people with ADRD, one participant mentioned a unique example of double training professionals, such as training them to be community health workers and direct care workers. The participant noted that this method is currently being implemented in rural parts of western Arizona where workforce gaps require that practitioners acquire additional knowledge and offer more robust service delivery to meet the needs of the aging population.

Gaps in Services Affecting Persons with ADRD of Different Cultural Backgrounds

Participants were asked about how gaps in services affect persons with ADRD of different cultural backgrounds, ages, stages of disease, and geographic locations.

Overall, participants felt that there is an absence of programs and materials tailored or designed for minority populations. To meet this gap, participants indicated that there is a need for culturally responsive materials that are co-created with trusted community partners (i.e., Community Health Workers), along with additional research and evidence-based approaches for serving diverse communities. For example, one participant suggested that interventions for ADRD should be treated like other chronic health condition awareness campaigns – by partnering with organizations who have "roots" in the community – to enhance community buy-in and ask the target community directly about their needs. Another participant suggested a partnership between Indian Health Services and universities to adapt health education for indigenous communities.

Participants also highlighted how collaboration with trusted partners (e.g., churches) could provide effective methods for distributing information and raising awareness about ADRD. Related, one participant discussed the need to consider the age groups and primary languages of caregivers who are often the ones navigating the system of care for an ADRD patient or loved one. This participant noted that it is also important to keep the diverse needs of caregivers in mind too when delivering health information.

As discussed in **Gaps in Early Screening and Diagnostics Programs for ADRD,** participants also felt that there are significant gaps in early screening and diagnostic care for ADRD patients.

Geographic Limitations of ADRD

Several participants discussed the prominent access barriers for rural residents seeking ADRD services and care. For example, participants mentioned a lack of transportation and caregiver support that many rural residents experience. One participant explained that Primary Care Physicians (PCP) are often not comfortable making an ADRD diagnosis which requires patients to wait for and travel to see a neurologist. Combined with the fact that an ADRD diagnosis often requires multiple visits for screening and imagining, rural residents face considerable barriers to treatment compared to their urban counterparts.

Addressing Systems, Policies and Programs

Next, participants were asked about how the State can better work together to ensure systems, policies, and programs address the burden of Alzheimer's Disease and Dementia. Participants highlighted opportunities for bolstering existing patient infrastructure (i.e., intake forms) and knowledge of ADRD risk factors to enhance policies and programs for ADRD patients and caregivers. Participants identified gaps in ADRD data that could strengthen ADHD systems and support and illuminated partners and linkages that are important for doing so.

Missing Partners or Linkages

Several missing partners or linkages that arose out of the discussion that participants felt are important for ensuring that policies and programs are meeting the needs of ADRD patients and caregivers, including a communication feedback loop involving government and community partners, bolstered prevention efforts, and greater caregiver voice or consideration when developing policies and programs.

Participants emphasized the need for coordinated communication between various levels of government (i.e., federal, state, county,) and community partners and organizations.

> **"The county health department…we serve kind of as a conduit between community partners, community organizations, community members and the state and national partners. So I think just ensuring that that we're mindful of the strategies or what's happening at the state level, what the political environment looks like…and being able to have a space where we can - at the county level - reflect that with state partners, with national partners, but also share that information back with the community partners and organizations within our own county."**

This participant explained that this feedback loop also provides opportunities to update policies, processes, or services with room for improvement as identified as a part of ongoing communication. Another participant added that this process allows for opportunities to share successes among partners, so that other agencies/organizations can adopt interventions and services that have worked for other health settings.

Participants also felt that there are opportunities to expand and improve prevention efforts through the inclusion of ADRD screener questions on questionnaires aimed at identifying conditions that are known to be modifiable risk factors for Alzheimer's (e.g., heart disease, sleep issues, falls, etc.). Similarly, these questionnaires could be used to identify patients who need support and may not know how to ask for it or where to find it, allowing health care providers to help patients "**connect the dot[s]**."

Finally, participants noted that caregivers need a **"voice at the table in a bigger way."** At numerous points in the conversation, participants discussed the many challenges and barriers that caregivers encounter when seeking care for loved ones and support for themselves. Participants felt that it is important for caregivers to understand the health services landscape as this will **"impact how they drive their city forward when it comes to healthy community initiatives."** Also, participants felt there is room to better accommodate services and support for caregivers working and trying to navigate care options. An example raised is ensuring support groups are available after regular working hours.

Data Gaps

Participants also felt that quantitative and qualitative research is needed to address gaps in systems and policies focused on the ADRD population. Participants shared that research is needed to determine the best ways to integrate screening procedures into existing health infrastructure and to ensure that methods allow for open communication between providers and patients. As noted in **Gaps in Services Affecting Persons with ADRD of Different Cultural Background,** participants also see a need for research to identify evidence-based interventions with diverse populations.

In addition, participants discussed the benefits of creating a statewide dashboard that integrates all available ADRD health information and data. Several participants voiced agreement with the idea of a data dashboard providing digestible and accessible information that can be used to inform policy and funding decisions related to ADRD diagnosis, treatment, and care. Participants also felt that the dashboard could be useful for ADRD caregivers as it would be helpful to have a better understanding of the number and the names of organizations, businesses, agencies providing ADRD services.

Impacts of Alzheimer's Disease

Participants outlined wide-ranging impacts of ADRD, including increased health care utilization and costs and the negative effects on employers through lost productivity and absenteeism when employees act as caregivers. Participants also identified a lack of safe housing discharge options for patients, limited funding and research on minority groups disproportionately affected by ADRD, and data gaps around unpaid caregivers and disease prevalence. As one participant explained, **"When you have employees that are caregivers, it's significant. And that can...potentially impact how the organization operates. If you have a number of employees that are engaged in trying to provide support, their bandwidth is very spread thin."**

Additional Areas to Explore

Numerous recommendations and strategies for addressing gaps were identified by participants. Proposed strategies emphasize leveraging community health workers and existing chronic disease efforts to promote awareness and ADRD screening, using public-private partnerships with pharmacies on ad campaigns, promoting cross-sector collaborations between health care, behavioral health, social services, and policymakers, and the adoption of workplace policies supporting caregivers and enumerating the caregiver workforce. Specifically, participants recommended the following actions to address gaps in service delivery, research, provider training, and coordinated screening and diagnosis of ADRD:

- Share existing dementia care training programs like Project ECHO and IHI university models for wider adoption.
- Conduct focus groups or qualitative research to identify effective ways to integrate dementia screening questions into routine patient intake processes.
- Build a repository listing organizations providing ADRD-related services across Arizona for
- improved coordination.
- Partner with pharmacies running advertising campaigns to jointly promote dementia awareness and

stigma reduction.

- Leverage community health workers (CHWs) to disseminate culturally appropriate education
- and information on respite programs or similar supports.
- Create a "Caregiver Census" to survey employees on caregiving duties and costs to quantify absenteeism and productivity impacts.
- Develop a statewide data dashboard for decision-makers and those impacted by ADRD[28]

HEALTH SYSTEMS ADRD LISTENING SESSION

Addressing Gaps in Existing Education and Awareness

Participants began by discussing gaps in ADRD education and awareness. A key theme that arose from the Health Systems listening session is the fragmentation and lack of coordination of existing services, such as specialized support, day programs and respite care. Participants emphasize the need for better coordination, awareness of available resources, and assistance navigating services.

> **"It's not so much that there isn't education available. It's knowing where to go... There's a lot of people doing a lot of great things, but I feel like we need to come together and do something...more widespread and coordinated and cohesive."**

The stigma around ADRD was discussed as a continued barrier, with multiple participants providing examples of the way they tailor their approach or written materials with this in mind,

> **"...in my programs is to, you know, instead of saying, Alzheimer's... It's, let's talk about brain health, let's talk about what normal aging is, not rely on labels..."**

> **"...'during your visit today, we noticed that there's a brain change, and this is normal with aging' you know, just trying to put together something that's not saying 'Alzheimer's dementia' because of the stigma."**

Moreover, participants explained that organizations are often understaffed, leaving few opportunities for practitioners to connect with community members in a way where sufficient education and awareness can be provided. Multiple participants discussed how their service teams are small and unable to comprehensively serve their clients, including with effective education about ADRD. As one participant emphasized, **"I feel like we need to be more urgent about training caregivers and community health workers because we need more people to do that...if we had more people that could do some of the hands-on stuff."**

Addressing Gaps in Early Screening and Diagnosis

Another primary theme that arose is how Primary Care Physicians (PCPs) play a critical gatekeeping role for diagnostics and specialty care, but they often lack specific dementia training or, unintentionally, use suboptimal screening tools. Participants explained how this can commonly result in diagnostic delays and under-diagnosis. Additionally, one participant discussed how stigma around ADRD can also impact the way a PCP perceives the presenting symptoms of the patient or interprets their diagnostic results.

> **"[A PCPs] perception of the stigma [of ADRD] can dictate how their patient gets the services. So even if you're, as a [PCP], you know normal aging a certain way, you kind of minimize a screening or [you don't] understand what a screening means and what that measure is telling you, then that limits the referral...you're not getting referred to the right spot..."**

Participants also explored complications with differential diagnosis, explaining that differentiating between Dementia and Alzheimer's disease remains a challenge in the field. Thus, complicating screening and diagnostic efforts across medical specialties. There was also discussion about the limitations of screening tools and the need for education and awareness around understanding how to use tools in a culturally appropriate way to reach the right diagnosis.

Addressing the Safety and Quality of Care

One of the first themes identified around safety and quality of care was related to health care navigation. Participants discussed how patients often struggle to navigate the health care system, especially low-income patients who often lack personal connections or resources to sidestep obstacles. As one participant elaborated,

"...what we need to focus on is figuring out how to ...[help] people navigate the [health care] system and be able to provide additional steps along the way. Whether it's increasing access to telehealth to get it, trying to figure it out more, or to make it easier for people to get a provider to refer people for issues, or just getting access to health aids."

Another issue related to safety and quality of care was the lack of effective and adequate group homes. Participants explained that settings like adult group homes often provide inadequate stimulation and oversight. One participant shared a personal experience where a loved one is not able to leave the group home because there are no outings or activities outside the home. Participants felt that behaviors are addressed primarily through medication rather than non-pharmacological approaches.

They also indicated a need for specialized clinician guidance on appropriate use of medications.

Participants mentioned a need for clinics or placements for patients with moderate symptoms who might not need the highest level of care available. This type of placement may serve people with numerous diagnoses (i.e., TBI, ADRD), if the level of care is appropriate. Examples include group homes,

day clinics, and "adult day care." Within this, participants highlighted a need for a "standardization" of care, where facilities across the state are equipped with providers and navigators for patients. In an ideal scenario, participants shared that transportation would be provided to patients for easy access to medical care and social outings. As one participant coined the phrase, "Dementia-friendly transportation" would greatly benefit ADRD patients in Arizona, as this would allow opportunities for physical, mental, and social stimulation.

> **"I had a patient with a knee replacement, and I told them to go to Walmart every day. You don't have to buy anything just go there but it gets you out of the house, you're meeting people organically… These are all forms of cognitive stimulation at the most basic simplified level, but when you meet new people, you have a new environment."**

More about the standardization of care is discussed in **Addressing Systems, Policies and Programs.**

In sum, participants emphasized a need to "prioritize cognition" in provider training, medical education, and service delivery to address gaps in safety and quality of care. Participants also felt there are opportunities to expand treatment options/placements for ADRD patients that might allow them to circumvent logistical barriers to service, such as transportation.

Oral Health and Dementia Connection

The connection between oral health and ADRD was explored by participants. They discussed how poor oral health correlates with cognitive impairment, yet dental care is often neglected for those with dementia. Additionally, dental care is not covered by Medicaid and often patients cannot afford additional insurance. Participants explored potential solutions like designating age- and dementia friendly dentistry practices and training caregivers on oral hygiene best practice.

Addressing Cultural Differences Among Individuals with ADRD

Participants identified a need for ensuring education and services are produced and disseminated in a way where they are accessible to the diverse population of our state. As one participant put it, **"there should be some baseline expectations and protocols and policies in place that allows that individual to have the accessibility and quality of care, so their lives thrive."**

Within the same line of thinking, participants emphasized the need for resources that speak to a person's culture in a language they are most comfortable with and at a literacy level they understand. One participant explained that resources should be "approachable" for all communities.

> **“So, it’s really looking at how to tailor the information...from a cultural competency perspective, and for others, how do we truly serve underserved communities or rural communities.”**

Another topic that arose to address cultural differences in care is the need for more bilingual specialists (i.e., neurologists), or easy access to medical interpreters. However, one participant explained that medical interpretation is very expensive for clinics to use.

Geographic Limitations of ADRD

Participants identified substantial access barriers for rural residents in Arizona, including lack of family support and transportation in addition to limited options for health services without traveling a significant distance. In general, participants noted that rural areas are under-resourced and small community agencies are often unable to meet the demands of their communities due to a lack of resources and staff capacity.

One participant provided an example of how there is currently one company in Nogales that offers caregivers, usually resulting in a wait for people to receive the service. Even after a patient is able to overcome the hurdles to service (availability, insurance), the participant felt that the amount of services that patients receive is not sufficient, noting, **“even if patients do get qualified, it’s only two hours that are given to the patient once a week, or if you’re lucky, it’s twice a week.”**

Addressing Systems, Policies and Programs

Access to care was a primary theme among participants in the listening session, both in regard to physical access to care (i.e., transportation, availability) as well as practical access to services via insurance and options such as sliding scale fee structures.

Insurance and Public Assistance

Issues with insurance were identified as a major barrier to accessing ADRD services and care. Major barriers discussed by participants include insurance coverage limitations or denial of claims, and problems qualifying for public assistance programs. There was large agreement among session members that there are major gaps in services for those who do not qualify for Medicaid but cannot afford private pay options.

Missing partners or linkages

The largest theme relating to missing partners or linkages arose at numerous points in the listening session. That is, the critical need for a **“minimum standardization of care and access to services across the state, particularly in rural areas.”** Participants brainstormed what this might look like. One participant noted, “every primary care office would have either a social worker or a care navigator on staff.” Other baseline standards discussed include having home care aids, day care programs, and day respite available via regional coordination across the state. This participant explained that these services could require less regulation than an adult day health center (and as an extension, fewer barriers to access) by offering ADRD patients a place to get out of the house and socialize.

Another idea for the standardization of care was to pair PCPs with navigators, Promotoras, or other home health visitors. Further, the participants shared the need to focus on employment and training of caregivers, so they are motivated and effective in their roles, noting, **"When you train people and get them passionate about something, they're better employees and they're more satisfied."**

Finally, an additional missing link identified by participants is the limited funding and research on minority groups who are disproportionately affected by ADRD. Without fully understanding the nuances in onset, progression, and treatment between different cultural groups (e.g., gender, race/ethnicity), it is impossible to adequately meet the needs of all of Arizona's communities.

Data Gaps

The main data gap illuminated by participants related to gender and ADRD. Participants explained that although women are more susceptible to ADRD, there is a lack of research to better understand women's issues as they relate to ADRD. For example, more data is needed about the impacts of different medications on women, and the role that hormonal and physiological factors, like menopause, play in disease development and progression. As one participant noted, **"this huge data gap for the most at-risk community, over 50% of our population."** This participant added that, similarly, people of color are not typically the focus of clinical trials despite also being at greater risk for ADRD.

Additional Areas to Explore

Several potential strategies for addressing the gaps identified by the group were discussed throughout the listening session. Participants identified opportunities to expand reimbursement for quality screening, improve standard of care requirements for adult group homes to provide activity programming, and update screening and licensing protocols to improve quality of care. Specific recommendations from the listening session include:

- Develop a statewide standardization of care implemented through regional coordination with PCPs and other health providers.
- Gather data about the impacts of ADRD medications on women and the role that hormonal and physiological factors play a role.
- Increase access to telehealth services, especially for rural patients.
- Train PCPs on how to use appropriate ADRD screeners and health measures.
- Clarify differing medication recommendations by race/ethnicity.
- Develop student training programs and partnerships with schools and medical training programs to build a pipeline of quality professionals entering the health care field.
- Utilize programs like Project ECHO for training opportunities, especially for rural communities.
- Tailor resources to meet the needs of rural and diverse patients statewide.
- Create dementia-friendly dentistry practices and oral hygiene training for caregivers.
- Design placements that serve people with numerous diagnoses (i.e., TBI, ADRD) with varying levels of care available to the patient.

CORE COMMITTEE LISTENING SESSION

Addressing Gaps in Education and Awareness for ADRD

Availability, Accessibility and Acceptability of Resources & Education

Participants agreed that raising awareness of available programs and resources, education opportunities, etc. are important, but participants highlighted that these programs and resources must not only be accessible to individuals, communities, and caregivers across Arizona, they must also be available, and acceptable, meaning they are culturally and linguistically appropriate for their intended audience.

> **"We also need to be talking about when programs are available. Once you increase awareness, are they available to people in rural communities? Are**

> **Are they available to people when they're not working? Are they accessible where they can get to them? And then once they're accessible … are they acceptable?"**

Building relationships with community-based organizations or trusted community leaders (e.g., promotoras, faith-leaders, etc.) to enhance community engagement was discussed as ways of supporting ADRD awareness and education that is also culturally appropriate and inclusive. Many organizations have already started building these relationships.

To further support individuals and caregivers facilitating training, support groups, or other activities at times beyond the normal day for caregivers who have other obligations (i.e., work) in addition to caregiving was also viewed as important. Regarding tailoring approaches for education, one participant wanted to utilize focus groups to better understand how to provide education, resources, and support in a culturally significant way to meet the needs of the intended audience.

Participants also discussed leveraging existing campaigns or programs like the American Heart Association's Heart initiatives and the Healthy Arizona Worksite Program (HAWP) to engage in coordinated messaging for children and adults. Participants shared the AHA's Heart initiatives offer an example of effective campaigns to support outreach and awareness in schools.

> **"Start in elementary school … Heart health is brain health and ties in to these other campaigns that have been established for a long time."**

Provider Focus

Education for providers to better understand the complexities of ADRD, appropriate screening tools, and diagnosis and the Lack of provider understanding about ADRD was a key theme discussed during the session. Participants shared that ADRD has transformed from a disease where a rapid decline occurred 30 years ago to a disease where there is a lifespan, and the disease must be managed, and the individual supported. **"Providers don't understand this, or if they understand the disease, they don't understand the impact on [the patient and caregiver]."**

Participants also agreed that providers have limited time to spend with patients, and as a result, instead of addressing the underlying screening needs, they refer the patient directly to a specialist (i.e., neurologist or geriatrician) thus removing a slot for someone who really needs to get in to those specialists.

Targeted training to support the recognition of signs and symptoms of ADRD for individuals who may come into first contact with someone with ADRD, for example, health care front office staff, CNAs, RNs and first responders. Especially first responders, who may be engaging with someone in a critical or crisis situation and they're unprepared with the tools or knowledge to support an individual with ADRD. Additionally, the incorporation of dementia education into community health worker required training would provide another line of trusted support to engaging with communities across Arizona. CHWs don't need to be prepared to diagnose dementia but having them be aware of the signs and symptoms and how to engage with family to ask, "did your loved one get their cognitive exam at their last annual visit?" to be able to connect the individual with the appropriate next step.

Build Partnerships

Partnerships and Community Based Organizations are critical to reaching refugee, underserved and rural communities Participants agreed that building these relationships and identifying new partnerships, building connections with trusted community leaders is important to continuing to lessen the impact of ADRD in Arizona.

> **"It's less about, you know, one group coming into an area and it's more about meeting with groups in that area that are already there. They're established… So then, these [CBOs] spread the information out because they're more of a trusted source than an unknown organization."**

Additionally, engaging these partnerships to recruit volunteers within the organization to be able to support education delivery extends the reach of awareness of ADRD signs and symptoms.

Participants saw a need for consistent and coordinated messaging to support individuals and caregivers that are disseminated from a "trusted messenger" to support navigation and connection, as well as an opportunity to create messaging across all partners to create a collective message that participants support. This also ties back to building partnerships across trusted community organizations.

Over the course of the conversation, participants shared a variety of topics to address with providers and caregivers during training and education, including:

- Supportive communication strategies for caregivers that center on ways to engage the individual with ADRD that is supportive and non-triggering.

- Aging over the lifespan, identifying early signs and symptoms of ADRD.
- Early identification of symptoms and how to engage families in supportive conversations to identify the screening need.

Addressing the Shortcomings in Early Screening and Diagnosis

Challenges raised around screening and diagnostics include stigma concerns, limitations of cognitive assessments, paucity of geriatric specialists, and confusion navigating health systems.

Barriers and Challenges Experienced

Stigma from the patient's perspective, **Fear** of the diagnosis, and **Access** to screening were seen as the primary barriers to early screening and diagnosis. Access to screening focused around rural and non urban areas in Arizona and the lack of specialty providers in those communities. Most individuals outside of an urban area must travel long distances (an hour or more) to see a specialist. In addition to the distance traveled, families are often left to figure out navigation or their next steps on their own in rural areas.

> **"My mom traveled six hours round trip … We go to primary care locally, but then it falls on the family to go through the insurance portal [to find a specialist]."**

Ways to Improve Screening and Early Diagnosis

Regarding screening, one participant suggested "lowering the initial screening age for dementia similar to other health care screenings like breast and colon cancer." An additional added benefit observed would be the potential to establish a cognitive baseline on a screening exam to identify changes later.

Participants also noted that front desk staff need to be looped in to signs and symptoms for ADRD and need appropriate tools to support them.

Other solutions to improve screening and diagnostics include incentives to improve early detection in primary care, practical guidance to assist caregiver advocacy, and alignment of provider approaches.

Existing resources that support diagnosis, treatment and referral for PCPs exist, but "you might have one health system that is like, yes, let's [implement it]. And then another one that's like, well no, and then another one is kind of doing their own thing." It can make things difficult when everyone is not on the same page on how to address ADRD diagnosis and treatment. This also leads to challenges for individuals navigating the system.

Addressing Gaps in Safety and Quality of Care

The participants emphasize shortfalls in adequately training caregivers and care providers on communication approaches and disease progression that ultimately impact the safety and quality of care. Other priorities include making health facilities more dementia-friendly and reviewing reporting procedures around suspected elder abuse or neglect cases.

Incentivize health systems to become Age-Friendly Health Systems and really commit to looking at the evidence-based approaches like the 4Ms of an Age-Friendly Health System (What Matters, Medication, Mentation, and Mobility) to support assessment and action on critical issues in caring for older adults across settings and transitions of care.

> **"[Over six weeks], my dad was in the hospital seven times because no one was talking to each other. He's sitting in there 81 years old septic and no one's seeing him. If he'd been in a geriatric emergency department, just like a pediatric emergency department, just think how it would behoove the system [not only financially, but also keep them safe]."**

Addressing Gaps in Health Systems, Policies, and Programs

Workforce

A key challenge to health system capacity impacting both care coordination and diagnosis for ADRD is the lack of workforce. Participants noted that having a patient navigator or better care coordination in every provider space would be ideal to support individual and caregiver needs to lay out next steps, support follow-up, and connect individuals with the appropriate resources. Additionally, participants discussed the idea of a centralized place for caregivers and individuals diagnosed with ADRD to obtain information and support.

Participants expressed that the lack of providers (i.e., PCPs, nurses, geriatricians), is likely driven by the cost of education. **"People don't want to go into medicine, especially post-Covid. You go into so much debt."**

Looking at alternative ways to foster interest and support in health care careers by engaging high school counselors and college counselors, as well as looking at creative ways to engage in early training or exposure to health-related professions, is needed. **"One hospital system has a high school inside the hospital for people that are interested in health care so that they receive hands-on experience."**

Navigation

Navigation support is also needed to support caregivers, **"people are getting so lost in the system"** and doing their best to try to figure out where they go and how to find the things needed to support their next step. Individuals and caregivers, especially caregivers, are overwhelmed and having a single place to go to get information would be helpful.

Additionally, participants noted that there are supportive tools, e.g., Care Pathways and Diagnosis Pathways (Alzheimer's Association) that exist to try to assist and streamline handoffs for PCPs. These tools exist to help with navigation from the diagnosis to making the connection to a specialist for the individuals with ADRD, however "it's just getting harder" to make these connections. While some health systems are onboard with using the available tools, not all are, and each health system does things a little differently.

Sustainability

Sustainability is also critical to supporting all the programs that exist to support individuals with ADRD and their caregivers in communities across Arizona, especially in Arizona's underrepresented communities. **"When you start something, you get in there and you start building relationships and you've got to stay in there ... you can't just pull out [of the community]"** as it affects the trust and the relationship that has been established with that community.

Sustainability also extends into the grant space with a need to address the cyclical nature of grants. Grants often want new interventions or the **"next big thing"** just when you are already implementing a new program or intervention and have evidence-based results that show they are working to support individuals with ADRD and their caregivers. **"Even though I have evidence to support the tools that I just started using, now I have to change what I'm doing to obtain more funding."** We need funding that is sustainable and supportive of the work that's happening.

Importance of Cross-Sector Collaboration

The group stressed the need for regular interagency meetings to report on planned progress as well as build partnerships within the organization's expanded community partnerships. Other ideas include common messaging platforms, linking various groups to statewide resources, and coordinating dementia efforts with broader health initiatives.

Data Gaps

Participants expressed that data is needed to understand **"the depth of the problem"** in Arizona. When trying to ascertain the most basic information on ADRD, for instance, the number of individuals in Arizona with a dementia diagnosis, **"that data point doesn't seem to exist."** Additionally, one participant shared that there are Behavioral Risk Factor Surveillance Survey (BRFSS) question(s) that are being looked at for adding to the Arizona specific survey.

Examples shared regarding data that participants would like to have to support a more comprehensive understanding of ADRD and what system transformations are needed include:

- Number of people with ADRD served by AHCCCS.
- Long term care data for the number of times that 911 is called.
- Comorbidity data - how many people have ADRD and another condition.
- Information highlighting underserved communities.
- Emergency room data – how many ED visits result from ADRD associated falls, injury, etc. - Data from Health Systems, Pharmacies, insurance to assist with identifying disparities and equity issues for ADRD populations.

Additional Considerations for Framing the State ADRD Plan

Participants also offered their perspective on what they would like to see the State plan consider.

- Ensure sustainability is integrated into the plan. The previous plan was never implemented due to a lack of funding and a lack of support.

- Identifying actionable items v. aspirational items that State agencies can implement in the next one to two years. For things that are aspirational make sure to outline the immediate steps that we need to take to get there.
- Cadence for convening and reviewing the plan and reviewing progress. Although the State is required to review in 2 years the plan should be reviewed more regularly to support problem solving, share successes, and address challenges impacting implementation.

Additional Areas to Explore

- Improve coordination across state agencies and partners on consistent messaging and information sharing regarding available services and supports.
- Utilize community leaders and trusted messengers to increase education and awareness around brain health and reduce stigma associated with cognitive decline.
- Develop practical tip sheets and resources tailored to diverse populations on navigating health care and long-term service systems as well as legal and financial planning.
- Advocate for expanded health care provider and direct care worker training on dementia screening, safety practices and compassionate, culturally appropriate communication approaches.
- Identify funding mechanisms and policy solutions to improve sustainability of community education programs, care navigation resources and ongoing plan implementation.

INDIVIDUALS WITH LIVED EXPERIENCE LISTENING SESSION

Individuals participating in the listening session represented direct caregivers and individuals living with an Alzheimer's Disease or Related Dementia Diagnosis. Participants were predominantly female caregivers caring for their spouses or daughters caring for a parent. Two additional listening sessions (see Appendix A for session notes) were held by State staff, one in rural Arizona for individuals with lived experience facilitated by the Governor's Office for Youth Faith and Family and one for tribal members with lived experience facilitated by the Arizona Department of Health Services, ADRD Program Manager.

Addressing Gaps in Existing Awareness and Education

First, participants were asked about the gaps that exist in awareness and education for ADRD in Arizona. A key theme that arose from the listening session was the importance of connecting caregivers to quality supportive resources, support systems and information early on. **"Knowing where to go to get information is key"** and having it in one place would be helpful to caregivers. Caregivers also offered examples of the information that would have been helpful to them, examples include:

- How to talk to family members about the diagnosis and what to expect.
- What quality care looks like and what to look out for in care settings.
- Navigating the diagnosis, **"a roadmap"** to help identify what type of provider to seek out, what tests are needed, where to get supportive information.

Identifying trusted and reliable resources is key for caregivers. One caregiver shared that they had a **"negative experience"** with their initial support group and as a result they reconsidered future participation.

> **"Early on I went to a different [caregiver] support group. After one of the sessions where everyone was having a hard time and just dumping, I spoke to the facilitator and shared my concerns that I wasn't sure that I wanted to go back. Ultimately, I didn't go back to that group but found a support group that was better suited to me."**

Participants also shared concerns about engaging individuals who **"are not social"** and do not want to leave their homes to attend activities (i.e., support groups, adult day care, etc.). Finding alternative methods for these individuals to engage groups and events remotely, using technology, can be paramount to their success and overall progress. Participants noted the benefits of engagement for both themselves as caregivers, and for the individual they are caring for. One participant shared that they "liked attending support groups and other activities via Zoom," especially when transportation can be a challenge. Participants also acknowledged that not everyone may be comfortable using technology or have access to the internet or other support.

Prepare Early On

Participants acknowledged that they were not prepared for the diagnosis or how to best support the person they were caring for initially. Caregivers felt that speaking with family, friends or loved ones early on about **"what aging looks like"**, medical decisions, and planning for the future is important and should be an ongoing conversation that occurs earlier in life.

Addressing Gaps in Early Screening and Diagnostics

Connecting with the appropriate provider is a critical sentiment expressed by the participants. The lack of PCP education regarding the importance of a diagnosis of Dementia v. Alzheimer's is a prime example. One participant made a point to state that **"not every neurologist specializes in Alzheimer's Disease or Dementia."** Participants also experienced delays in reaching the appropriate diagnosis as a result of, **"being handed off from provider to provider."**

Compassionate and Culturally Inclusive Care

Compassionate delivery of the diagnosis is important to caregivers and individuals living with a dementia diagnosis. One participant shared, **"I learned about my dementia diagnosis from reading a one pager that was emailed or faxed to me. The first time I read it I misinterpreted the information on lifespan data and thought I only had 2 years left to live."** Caregivers want providers to **"Remember that [the patient] in front of [them] is receiving life altering information"** and that delivering that diagnosis with care and providing a warm hand off and extra support during the follow-up period would be very supportive. This extra support may be accomplished through enhanced care coordination in provider offices and hospitals.

Caregivers also want to see culturally inclusive services provided to support caregivers and the individuals they are caring for. Participants acknowledged the lack of underserved communities and communities of color being represented in this conversation and wanted to make sure that was addressed in the plan.

Supportive health care models

Caregivers suggested looking at the Hospice model, **“[caregivers] felt very supported when the individual they were caring for entered Hospice”** and felt a sense of relief and comfort. Examining this model may provide insights for how to approach the treatment and care for individuals living with an ADRD diagnosis.

Addressing the safety and quality of care

Caregivers shared that they “**didn’t know what quality care really looked like”** for ADRD. One caregiver shared that, **“Seeing the Alzheimer’s Association logo on the door [of the memory care facility] brought them peace of mind, however it quickly became clear that staff were ill equipped to provide quality dementia care.”** Caregivers expressed interest in having roadmaps for navigating care available.

Emergency Room Visits

Keeping individuals out of emergency rooms was shared as a key concern, as one caregiver put it, **“the Emergency Room is the worst place for a person with dementia to end up.”** During the pandemic, caregivers noted that during medical emergencies they struggled with hospital staff to allow them to accompany the person they were caring for into the Emergency Department. “Individuals with an Alzheimer’s or Dementia Diagnosis can’t advocate for themselves” and caregivers felt that impacted the safety of the individual since they were not always able to “advocate and provide an accurate medical history.” Communication challenges during the transfer of ADRD patients also pose significant safety and quality risks. One caregiver shared that during an after-hours transfer that they were not permitted to travel on, critical medical information was not transmitted to the receiving facility that ultimately resulted in a catastrophic event that was preventable. Caregivers would like to see the State institute plans for future pandemics to allow caregivers to accompany individuals living with an ADRD diagnosis during emergency situations.

Health Systems

Navigation support is a key theme that would have been beneficial to many caregivers after diagnosis and during times of medical crisis. **“I was in the hospital with my Mom for 10 days. It was a prime opportunity for someone to come speak with us.”** Caregivers would like to see dementia specialists in hospital settings to help support navigation for connecting to follow-up resources and supports.

Associated with navigation, caregivers shared that it was challenging to understand what individuals qualify for among the available services, and how adding one service may impact the ability to be eligible for other services, an example being in-home support. Additionally, the significant costs associated with care were noted, with one caregiver stating, **“twenty-four-seven care costs $25,000 per month.”** There was also a perceived need to enhance oversight and screening to protect individuals and caregivers. It was suggested that, at minimum, all paid caregivers should be required to submit to a background check as a condition of employment.

Missing Partners

Caregivers expressed that the inclusion of employers and faith-based organizations as partners in the development and implementation of the plan was critical. Additionally, caregivers were concerned that there were no individuals from communities of color attending and participating in the listening session.

Additional Areas to Explore

- Create dementia specialist roles in hospitals to support navigation.
- Enhance oversight and regulation for paid caregivers to include at minimum criminal background checks.
- Identify strategies for connecting caregivers who are not usually interested in joining group activities and who may not have access to technology or feel comfortable using it.
- Develop roadmaps to support navigating the ADRD diagnosis and health care system.
- Create a public health directive that during public health emergencies, like the recent COVID-19 pandemic, caregivers are able to accompany the individual with an ADRD diagnosis into the Emergency Room.

Listening Session Questions:
Summary: This initiative aims to gather invaluable insights through a series of comprehensive listening sessions dedicated to the development of the 2024 Alzheimer's and Dementia State Plan. These sessions, designed to engage stakeholders from diverse backgrounds, will serve as a crucial foundation for crafting a comprehensive and inclusive plan
Guiding Principle: Emphasizes a comprehensive and inclusive approach to addressing the needs and challenges associated with Alzheimer's and Dementia. It recognizes the importance of considering primary, secondary, and tertiary prevention strategies, as well as the unique characteristics of individuals affected by Alzheimer's and Dementia, such as cultural background, age, stage of disease, and geographic location.
Listening Session Question #1:
1.) What service delivery gap exists for this population (those burdened by Alzheimer's & Dementia), to address primary (*think risk reduction and brain health promotion*), secondary (*think early detection and diagnosis activities*) and tertiary prevention (think *improving safety and quality of care*)?

Prompt A. **Prompt B.** **Prompt C.**	Consider existing screening programs? What gaps exist here Consider existing education and awareness programs. What gaps exist here Consider the needs of persons with ADRD by cultural background, age, stage of disease and geographic location? What gaps exists here • How can we tailor support services to address the specific cultural backgrounds of individuals with Alzheimer's or related forms of dementia? • Are there cultural nuances that significantly impact caregiving and access to resources? • Are there unique challenges or opportunities in each geographic location that should be considered in our planning?

Listening Session Question #2:	
2.) How can we work together to ensure systems, policies, and programs align to address the burden of dementia?	
Prompt A. **Prompt B.** **Prompt C.**	Consider missing partners/links and existing policies Consider existing data structures, sources and their limitations to make this possible Consider state's capacity and capabilities
Listening Session Question #3:	
3.) What are the current and future impacts of Alzheimer's disease and related forms of dementia on the state?	
Prompt A.	Consider the health care system, economy and society? 1. How might the evolving landscape of health care delivery impact the ability to provide effective care for individuals with Alzheimer's disease? 2. What current strategies can be employed to promote societal awareness and understanding of Alzheimer's disease, reducing stigma and fostering a more supportive environment for individuals and families affected by dementia? 3. What demographic groups within the state are projected to be most affected by Alzheimer's disease in the future, and how can we strategically allocate resources to support these populations?

Appendix A. Additional Listening Sessions

Additional live experience listening sessions were conducted by the Governor's Office for Youth, Faith and Family as well as a tribal listening session facilitated by the ADHS ADRD Program Manager. The following information was shared as a part of the discussion captured during these sessions.

I. Tribal Listening Session

1. What service delivery gap exists for this population (those burdened by Alzheimer's &

Dementia), to address primary (*think risk reduction and brain health promotion*), secondary (*think early detection and diagnosis activities*) and tertiary prevention (think *improving safety and quality of care*)?

- There is only one radio station, sometimes it depends on where you are located as to whether or not you get service.
- There are no billboards, advertising could be in places where residents frequent.
- *Post office*
    - *Local supermarket*
    - *Events*
    - *Schools*
- With limited health care resources, this would be a large delivery gap. Care for basic services is limited, and the providers in many cases do not know what to look for with regards to this disease.
- Time would be considered a gap that needs to somehow be bridged. Because things are so spread out, it takes time to travel from one place to another.
  EX. If there is an emergency, it may take an entire hour for an ambulance or law enforcement to arrive.
- Transportation issues to get to and from appointments. Services that were being provided are no longer.
- Limited communication between agencies

2. How can we work together to ensure systems, policies, and programs align to address the burden of dementia?
    - More representation advocating at the Federal and State levels.
    - Better training for providers and first responders (they are not qualified to make assessments when it comes to Alzheimer's and Dementia)
    - Information sharing, in a central location
    - When it comes to programs and systems, we must think about the culture, and the role it plays regarding this disease.
        - *Some resist treatment, believing that it is just a part of getting old.*
        - *Some do not feel comfortable if they are being treated by someone that may not look like them.*
        - *Sometimes there are language barriers (translators provided)*
        - *Caregivers often have to choose between work and caregiving. There should be policies in place providing aid or resources to caregivers that pull double duty.*
        - *Employers that are forgiving and understand this disease and wish to support caregivers.*
        - It is not an option to put elders in a group home.

3. What are the current and future impacts of Alzheimer's disease and related forms of dementia on the state?
   - Currently, there seems to be an increase in the number of elderly, and a lot suffering from this disease. (more emergencies, a greater burden on the health care system.)
   - The caregivers themselves may become burden by stress or illness due to a lack of respite care (stress)
   - Shortage in the workforce.
   - Lack of experience in the workforce

Appendix B. ADHS Listening Session Questions

Focus Area #1: Service Delivery Gaps

What service delivery gaps exist for those with ADRD in Arizona?

- What are the existing gaps in education and awareness programs (primary prevention)?

- What about gaps in early screening and diagnostics programs (secondary prevention)?

- What about gaps for improving the safety and quality of care (or tertiary prevention)?

Focus Area #2: Gaps in Services - Demographics

What specific gaps in services affect persons with ADRD of different cultural backgrounds, ages, stages of disease, and geographic location?

- Are there ways that services could be tailored to address the specific cultural backgrounds of individuals with ADRD?
- Are there cultural nuances that significantly impact caregiving and access to resources?
- Are there unique challenges or opportunities in each geographic location that should be considered in our planning?

Focus Area #3: Systems, Policies and Programs

How can we [the State and each listening session group] better work together to ensure systems, policies, and programs address the burden of Alzheimer's Disease and Dementia?

- Are there missing partners or linkages needed to better address ADRD? What about policy needs?
- Are there gaps in existing data (or needed data) that would better help to address Alzheimer's Disease in Arizona?
- Consider state's capacity and capabilities

Focus Area #4: Impacts of ADRD

Next let's think about the current and potential impacts of Alzheimer's Disease and Related forms of Dementia in Arizona:

- How is Alzheimer's Disease (& related forms of dementia) currently impacting our health care system? Economy? Society?
- How might the ability to provide effective care for individuals with Alzheimer's disease or related forms of dementia change as the health care system evolves?
- Are there strategies that would support promoting awareness and understanding of Alzheimer's disease?
- What about strategies to help reduce stigma and foster a supportive environment for individuals and families affected by dementia?
- What demographic groups within the state are projected to be most affected by Alzhemer's disease in the future, and how can we strategically allocate resources to support these populations?
- Are there cultural nuances that significantly impact caregiving and access to resources?
- Are there unique challenges or opportunities in each geographic location that should be considered in our planning?

APPENDIX D: DEMENTIA RISK REDUCTION & MODIFIABLE RISK FACTORS

Dementia is not a normal or inevitable part of typical brain aging (2022, CDC, Dementia Risk Reduction). It is common to experience some cognitive decline as we grow older, such as subtle changes in thinking, reasoning, and memory. However, while these changes can be frustrating they should not be bad enough to affect one's daily life. While there are some risk factors such as age, family history, and heredity that cannot be modified, there is a growing body of research that has identified modifiable risk factors for Alzheimer's disease and related dementia (ADRD). Research suggests that strategies to reduce the burden of these risk factors may delay onset or slow progression of ADRD and its symptoms.

When considering risk reduction and modifiable risk factors for Alzheimer's and dementia specific to Arizona, several key strategies and factors come into play:

1. **Physical Activity:** Encouraging regular physical activity among Arizona residents can significantly reduce the risk of developing Alzheimer's and dementia. With Arizona's abundant sunshine and outdoor recreational opportunities, promoting activities like walking, hiking, biking, and swimming can help improve cardiovascular health and cognitive function.
2. **Healthy Diet:** Emphasizing the importance of a nutritious diet can play a crucial role in reducing the risk of Alzheimer's and dementia in the state. Arizona's diverse agricultural landscape can support the promotion of locally grown fruits, vegetables, whole grains, and lean proteins. Encouraging the consumption of foods rich in antioxidants, omega-3 fatty acids, and vitamins can help support brain health.
3. **Brain-Healthy Lifestyle:** Promoting brain-healthy lifestyle habits such as engaging in mentally stimulating activities, socializing regularly, and getting an adequate amount of sleep can contribute to reducing the risk of cognitive decline in Arizona's population. Community programs and educational initiatives can raise awareness about the importance of these habits and provide resources to support their adoption.
4. **Management of Chronic Conditions:** Addressing and managing chronic health conditions such as diabetes, hypertension, and obesity can help mitigate the risk of Alzheimer's and dementia among Arizona residents. Access to quality health care services, preventive screenings, and chronic disease management programs can support individuals in maintaining optimal health and reducing their risk of cognitive impairment.
5. **Smoking Cessation and Substance Abuse Prevention**: Implementing tobacco control programs and substance abuse prevention initiatives can help reduce the prevalence of Alzheimer's and dementia risk factors associated with smoking, excessive alcohol consumption, and substance abuse. Arizona's public health efforts can focus on promoting smoking cessation resources, enforcing tobacco-free policies, and raising awareness about the risks of substance abuse on brain health.
6. **Environmental Factors:** Addressing environmental factors that may contribute to cognitive decline, such as air pollution and exposure to toxins, is crucial for Alzheimer's and dementia risk reduction in Arizona. Implementing policies to improve air quality, promoting sustainable practices, and reducing exposure to environmental toxins can help create a healthier environment for all residents.
7. **Access to Health care and Support Services:** Ensuring equitable access to health care services, including preventive care, diagnostic screenings, and early intervention for cognitive impairment, is essential for reducing Alzheimer's and dementia risk in Arizona. Expanding access to health care coverage, promoting culturally competent care, and enhancing support services for individuals living with dementia and their caregivers can improve outcomes and quality of life.

By addressing these risk reduction strategies and modifiable risk factors specific to Arizona's context, public health efforts can effectively promote brain health and reduce the burden of Alzheimer's and dementia on individuals, families, and communities across the state.

Alignment With the 2023 Updated National Plan to Address Alzheimer's Disease

Arizona will align its dementia risk reduction and modifiable risk efforts with goal six (6) of the HHS National Plan to Address Alzheimer's Disease, which focuses on accelerating action to promote healthy aging and reduce risk factors for ADRD (2023, HHS, National Plan to Address Alzheimer's Disease). With special emphasis on ensuring that research, interventions, and infrastructure to address modifiable risk factors for ADRD are culturally responsive and grounded in improving equity by addressing social determinants of health (SDOH). In addition to ensuring inclusion of strategies to best reach those populations with disproportionately higher burden of risk factors for ADRD (e.g., Black, Hispanic, AI/AN, and adults with lower SES).

Under this goal, there is a focus on disseminating information about risk factors, interventions to reduce the burden of risk factors, and related health promotion activities to health care providers, community-based providers, and public health networks. Accordingly, efforts will focus on understanding not only what actions individuals can take to reduce their risks, but also what community and system-level investments are needed to facilitate risk reduction and support healthy aging.

Integrating Brain Health Messages Into Chronic Disease Risk Reduction Programs

Arizona will utilize the integrated messages and campaign materials provided by the National Association of Chronic Disease Directors (NACDD) and the Centers for Disease Control and Prevention (CDC) under their Healthy Aging/Healthy Brain project (2023, CDC/NACDD, Integrating Alzheimer's Messages Into Chronic DIsease Programs). This project seeks to adapt chronic disease risk reduction messages to include information about how behaviors related to these topics can also reduce the risk for cognitive decline. Promoting understanding and awareness of key risk factors for ADRD such as diabetes, hypertension, obesity, nutrition, physical inactivity, smoking, social isolation, hearing loss, air pollution, alcohol, depression, and traumatic brain injury (TBI). By including brain health information within chronic disease health messages, people are equipped with knowledge that supports their physical and cognitive wellbeing.

To further integrate brain health messaging into chronic disease risk reduction efforts, Arizona will leverage ADHS internal chronic disease and nutrition and physical health programs to incorporate modifiable risk reduction approaches for ADRD prevention and ensure alignment of messaging in program activities.

Heart Disease and Stroke Program

Some of the strongest evidence links brain health to heart health (2024, Alzheimer's Association, Causes and Risk Factors for Alzheimer's Disease). Among those modifiable risk factors identified for ADRD, prevalence was highest for high blood pressure and not meeting the United State's aerobic physical activity guidelines. It's important for individuals to manage blood pressure to not only reduce the risk for heart disease and stroke, but risk for cognitive decline and ADRD (2023, CDC/NACDD, Integrating Alzheimer's Messages into Chronic Disease Programs). Arizona will leverage the strategies and Learning Collaboratives under the ADHS Heart Disease and Stroke Program to drive awareness about the link between heart health and brain health.

Diabetes Prevention and Management Program

The risk reduction strategies to prevent getting type 2 diabetes (e.g., staying physically active and eating healthy foods) also help reduce the risk for developing ADRD (2023, CDC/NACDD, Integrating Alzheimer's

Messages into Chronic Disease Programs). Diabetes can damage blood vessels, which results in reduced or blocked blood flow to the brain. This can increase an individual's risk for cognitive decline and ADRD. It is important to keep blood sugar levels under control for brain health. Arizona will leverage strategies under the ADHS Diabetes Program to collaborate with the Arizona Diabetes Coalition and National Diabetes Prevention Program suppliers to incorporate messages about the impact of blood sugar management on reducing the risk for ADRD. In addition to collaborating with pharmacies and pharmacist associations to educate about the impact of diabetes self-management on reducing the risk of ADRD.

Nutrition and Physical Activity

Engaging in physical activity and maintaining a healthy diet can improve an individual's overall health, including brain health (2023, CDC/NACDD, Integrating Alzheimer's Messages Into Chronic Disease Programs). Evidence shows that a healthy diet, containing foods such as those found in the Mediterranean and Dietary Approaches to Stop Hypertension (DASH) diets, can reduce risk for cognitive decline and ADRD. Physical activity can improve the ability to think, learn, and problem solve, as well as improve memory and reduce anxiety or depression. Engaging in physical activity, particularly leisure-time physical activity, can also reduce the risk of cognitive decline and ADRD. Arizona will leverage strategies and work groups under the ADHS Bureau of Nutrition and Physical Activity to incorporate messages about the importance of engaging in physical activity and maintaining a healthy diet to reduce the risk for ADRD. In addition to working with the ADHS Chronic Disease programs to promote physical activity and a healthy diet as risk reduction for heart disease and stroke, diabetes, and cancer, as well as ADRD.

APPENDIX E: ALZHEIMER'S DISEASE AND RELATED DEMENTIA SURVEILLANCE DATA

Population Estimates

Alzheimer's ranks as the seventh leading cause of death for all Arizonans and the 6th leading cause of death for those adults 65 years and older for 2022.

Table 1: Ten (10) Leading Causes of Death, 2022	Rate, All Arizonans	Rank, All Arizonans	Rate, Arizonans 65+ Years	Rank, Arizonans 65+ Years
Diseases of the Heart (I00-I09, I11, I13, I20-I51)	148.5	1	938.2	1
Malignant Neoplasms (C00-C97)	132.9	2	755.7	2
Accidents (Unintentional Injuries) (V01-X59, Y85-Y86)	75.6	3	139.5	7
COVID-19 (U07.1)	47.4	4	267.7	3
Chronic Lower Respiratory Diseases (J40-J47)	35.1	5	240.7	4
Cerebrovascular Diseases (I60-I69)	34.5	6	227.5	5
Alzheimer's Disease (G30)	28.4	7	221.6	6
Diabetes Mellitus (E10-E14)	25.1	8	123.9	8
Intentional Self-Harm (suicide) (*U03, X60-X84, Y87.0)	20.6	9		
Chronic Liver Disease and Cirrhosis (K70, K73-K74)	17.5	10		
Parkinson's Disease (G20-G21)			76.2	9
Essential Hypertension and Hypertensive Renal Disease (I10, I12, I15)			72.5	10

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics. National Vital Statistics System, Mortality 2018-2022 on CDC WONDER Online Database, released in 2024. Data are from the Multiple Cause of Death Files, 2018-2022, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed at http://wonder.cdc.gov/ucd-icd10-expanded.html on May 30, 2024.

Table 2: 10 Year Population Growth

Total population and Percent Change From Previous Year of Adults 65 years and older by age group – Arizona, 2012-2022

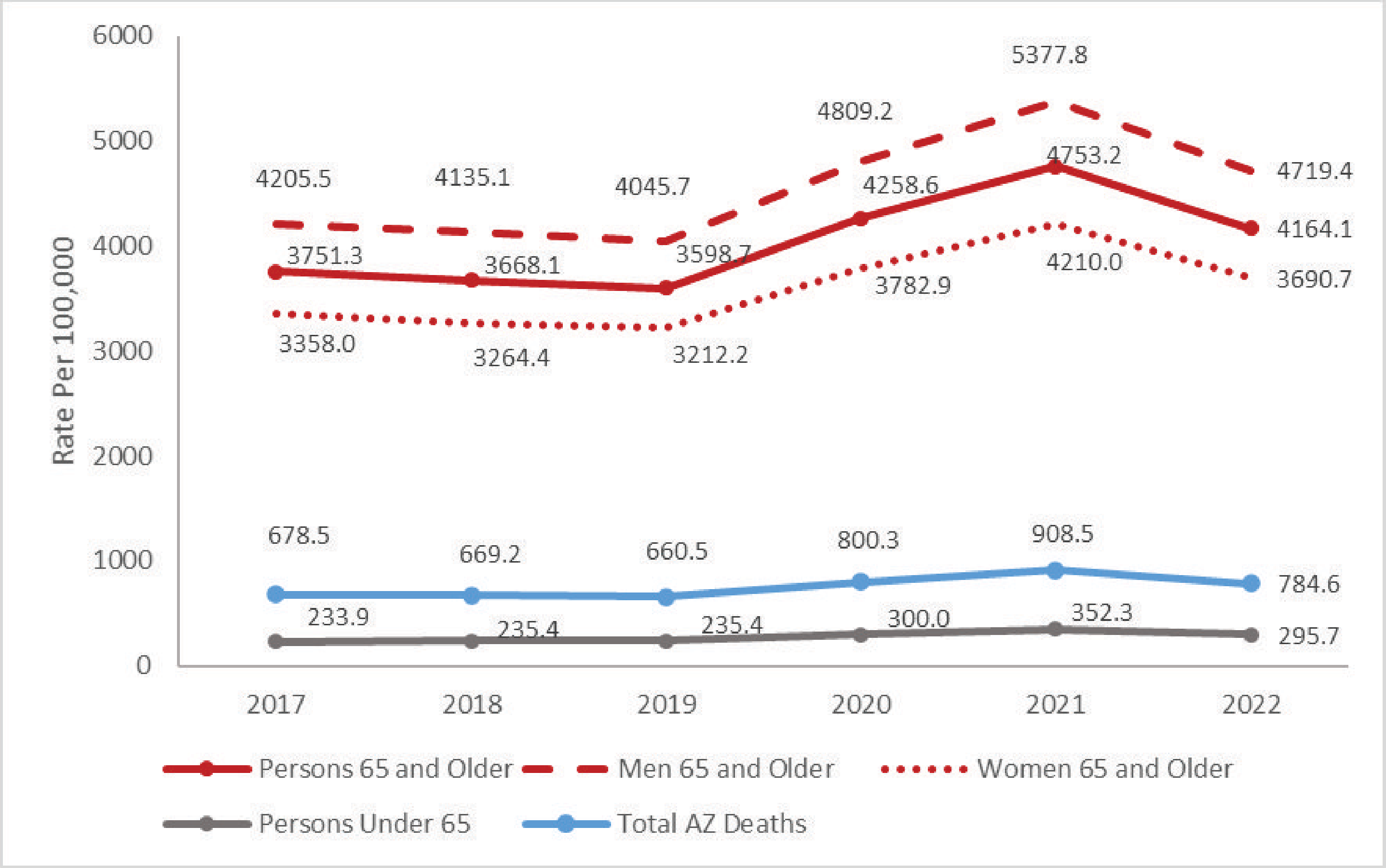
Year	65-69 years Population (% Change)	70-74 years Population (% Change)	75-79 years Population (% Change)	80-84 years Population (% Change)	85+ years Population (% Change)
2012	306,544 (-)	232,175 (-)	169,948 (-)	123,380 (-)	108,457 (-)
2013	321,008 (+4.7%)	245,805 (+5.9%)	176,196 (+3.7%)	125,760 (+1.9%)	112,360 (+3.6%)
2014	335,910 (+4.4%)	257,816 (+4.9%)	182,344 (+3.5%)	129,095 (+2.7%)	119,940 (+6.8%)
2015	352,655 (+5.0%)	272,757 (+5.8%)	192,968 (+5.8%)	131,672 (+2.0%)	125,255 (+4.4%)
2016	369,373 (+4.7%)	284,953 (+4.5%)	201,999 (+4.7%)	135,183 (+2.7%)	130,946 (+4.5%)
2017	389,725 (+5.5%)	297,536 (+4.4%)	213,385 (+5.6%)	140,550 (+4.0%)	137,663 (+5.1%)
2018	385,998 (-1.0%)	322,476 (+8.4%)	223,671 (+4.8%)	144,052 (+2.5%)	138,064 (+0.3%)
2019	391,275 (+1.4%)	338,038 (+4.8%)	240,854 (+7.7%)	151,171 (+4.9%)	142,880 (+3.5%)
2020	393,041 (+0.5%)	348,046 (+3.0%)	248,829 (+3.3%)	156,161 (+3.3%)	143,733 (+0.6%)
2021	405,067 (+3.1%)	367,153 (+5.5%)	261,719 (+5.1%)	164,580 (+5.4%)	149,281 (+3.9%)
2022	411,957 (+1.7%)	373,441 (+1.7%)	266,179 (+1.7%)	167,367 (+1.7%)	151,777 (+1.7%)

Data Source: Arizona Population Health and Vital Statistics & Aging in Arizona: Leading Causes and Risk Factors of Death Among Arizona Residents 65 Years and Older, 2021. Phoenix, AZ. Arizona Department of Health Services; 2022 (https://www.azdhs.gov/prevention/chronic-disease/healthy-aging/index.php)

- A majority of adults in Arizona 65 years and older are between the ages of 65 and 74 years of age.
- Over the past ten years, the population of Arizonans 65 years and older has consistently increased year over year, with a slight 1% decrease among Arizonans 65-69 years old from 2017 to 2018.
- The highest increase in population from 2012 to 2022 was among Arizonans 70-74 years old (60.8%).

Figure 1: Total Population Mortality

Overall Mortality Rate (per 100,000 residents) stratified by Age and Sex - Arizona 2017-2022

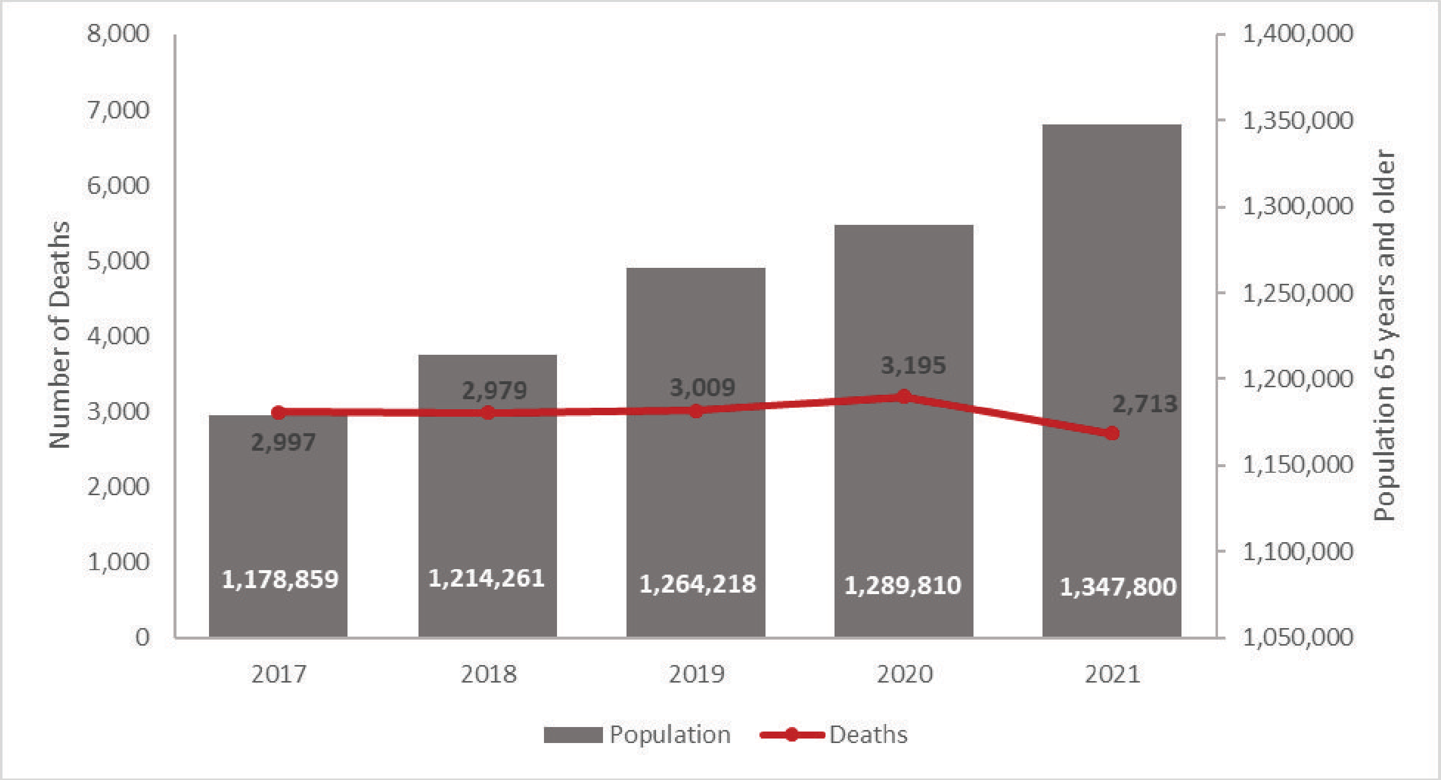


Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics. National Vital Statistics System, Mortality 2018-2022 on CDC WONDER Online Database, released in 2024. Data are from the Multiple Cause of Death Files, 2018-2022, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed at http://wonder.cdc.gov/ucd-icd10-expanded.html on May 30, 2024.

The data for mortality were generated at the Arizona Department of Health Services (ADHS). The data that supports the findings of this plan are available at **https://pub.azdhs.gov/health-stats/index.php** and **https://wonder.cdc.gov/.**

- The mortality rate among all adults 65 years and older is more than 10 times the rate of all adults 64 years and younger.
- The mortality rates among all adults 65 years and older increased 32.1% from 2019 to 2021; and decreased 12.4% from 2021 and 2022.
- Among all adults 65 years and older, males have a higher mortality rate as compared to females.

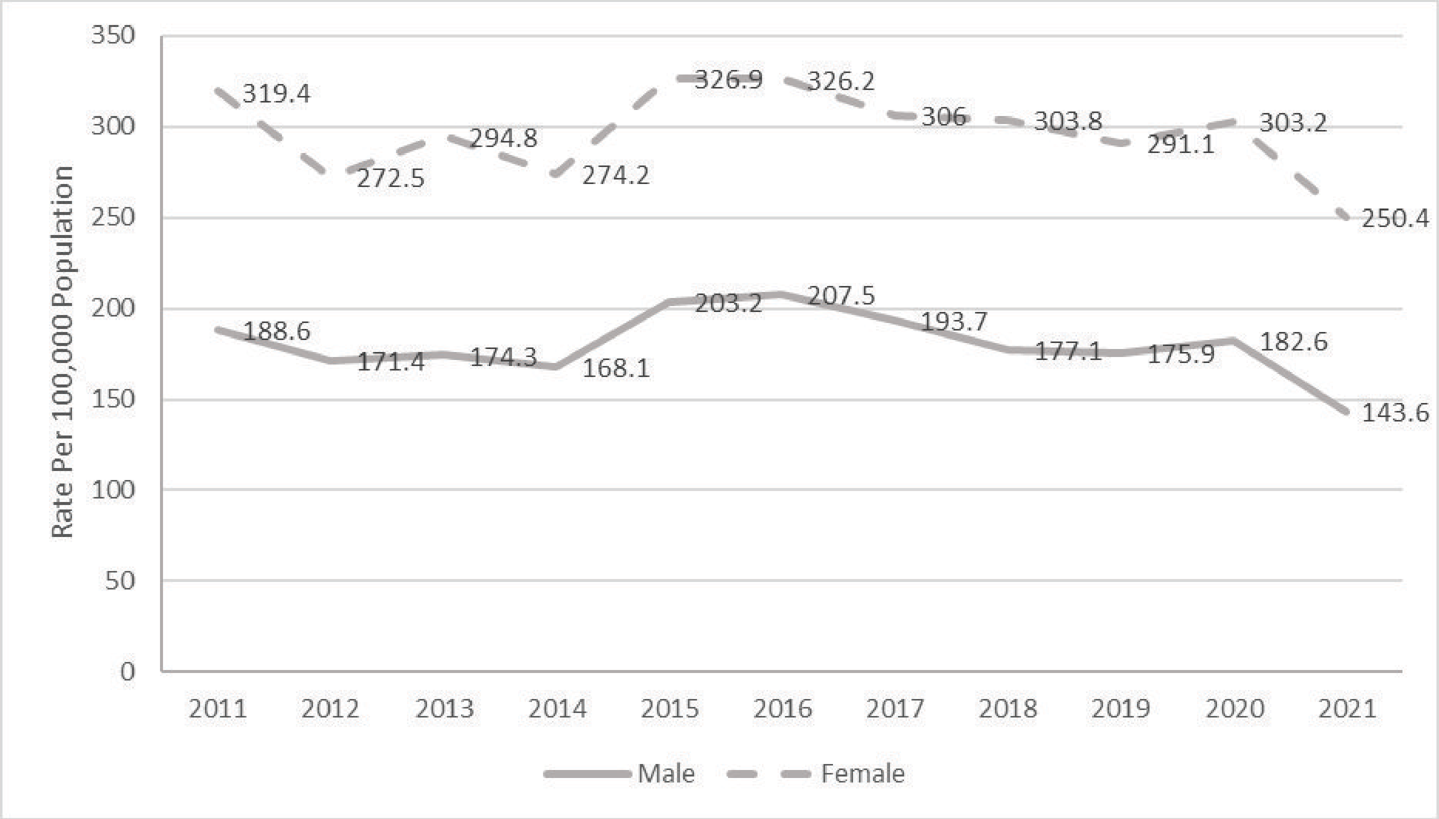
Figure 2: Number of Alzheimer's Disease deaths, and **total population** of Adults 65 years and older, 2017-2021



Data Source: Comprehensive Arizona Health Status and Vital Statistics Annual Report (https://pub.azdhs.gov/health-stats/report/ahs/index.php)

- The number of deaths among Arizonans 65 years and older decreased by 9% from 2017 to 2021, while the population size increased by 14% during the same time period.

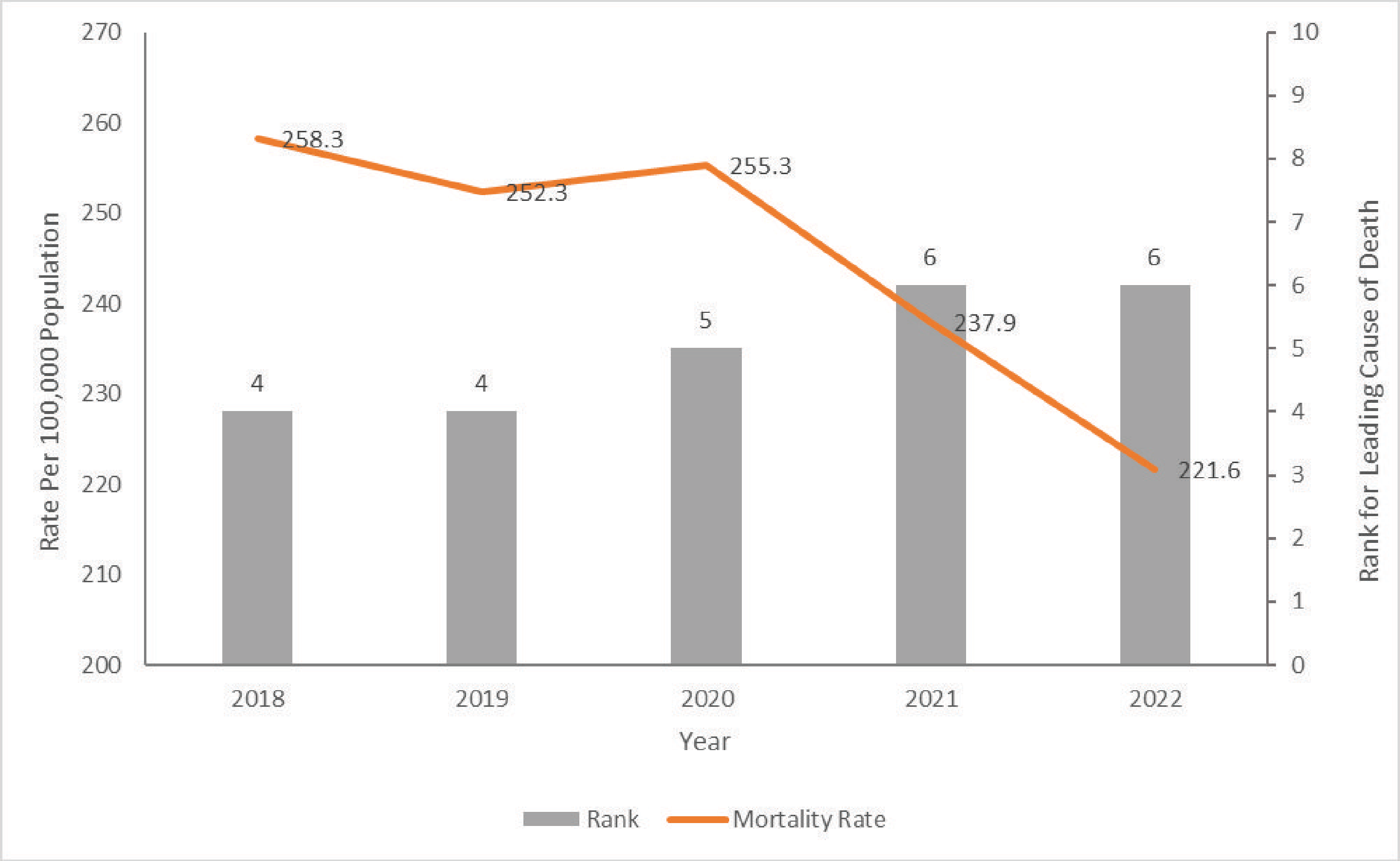
Figure 3: Mortality Rates by Sex for Adults 65 Years and Older with Alzheimer's Disease, Arizona 2011-2021



Data Source: Comprehensive Arizona Health Status and Vital Statistics Annual Report (https://pub.azdhs.gov/health-stats/report/ahs/index.php)

- Females 65 years and older are more likely to die of Alzheimer's Disease as compared to males.
- Between 2011 and 2021 the mortality rate from Alzheimer's Disease decreased twenty one point six percent (21.6%) among females 65 years and older, and twenty three point nine percent (23.9%) among males 65 years and older. The Alzheimer's Disease mortality rate among both males (143.6 per 100,000) and females (250.4 per 100,000) in 2021 was at its lowest over the 10-year period (2011- 2021).

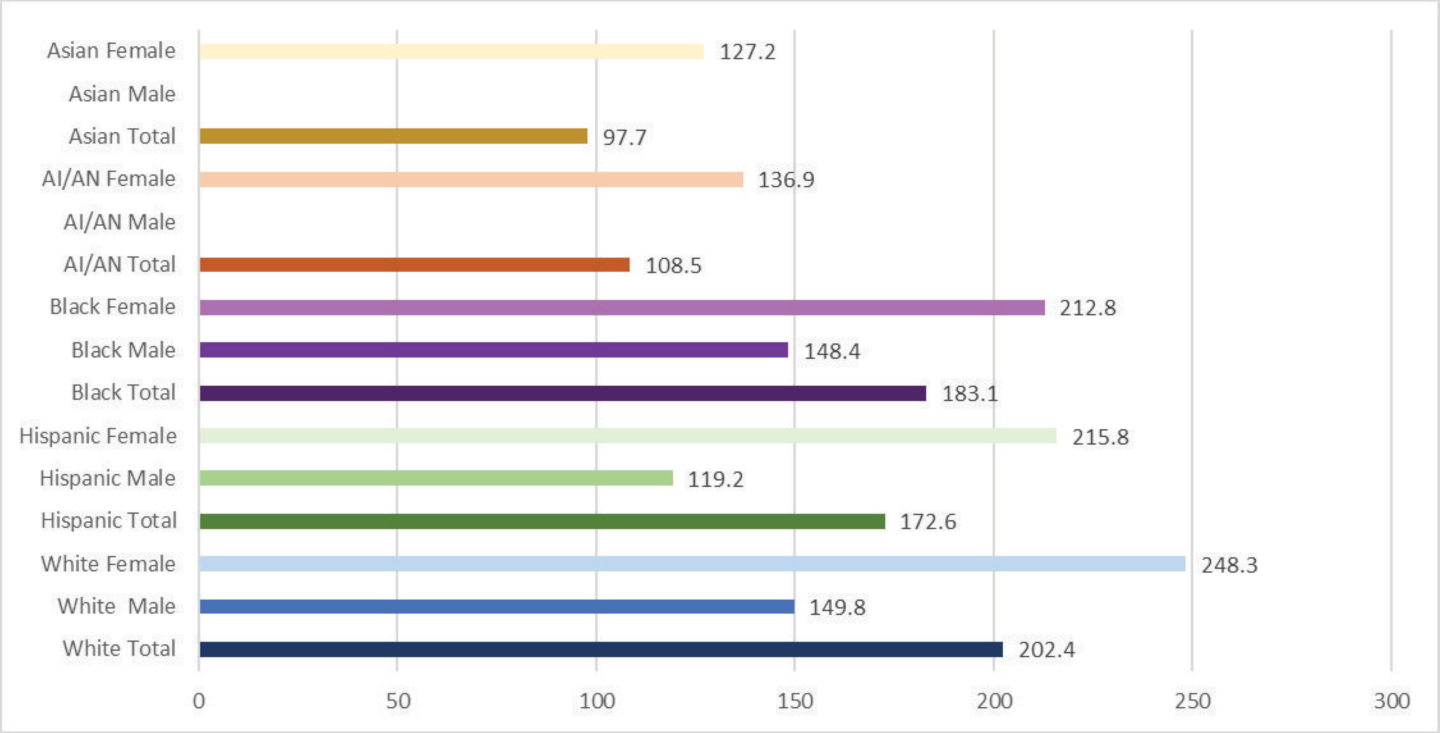
Figure 4: Mortality Rate of Alzheimer's Disease, and **Rank** For the Leading Causes of Death Among Adults 65 Years and Older, Arizona 2018-2022



Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics. National Vital Statistics System, Mortality 2018-2022 on CDC WONDER Online Database, released in 2024. Data are from the Multiple Cause of Death Files, 2018-2022, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed at http://wonder.cdc.gov/ucd-icd10-expanded.html on May 30, 2024.

- There was a decrease in the Alzheimer's Disease mortality rate between 2018 and 2022.
- Arizonans 65 years of age and older, Alzheimer's Disease dropped from the 4th leading cause of death in 2018 and 2019 to the 6th leading cause of death in 2021 and 2022.

Figure 5: Age-Adjusted **Mortality Rates** for Alzheimer's Disease (per 100,000) among Adults 65 years and older by Race/Ethnicity and Sex, Arizona 2022

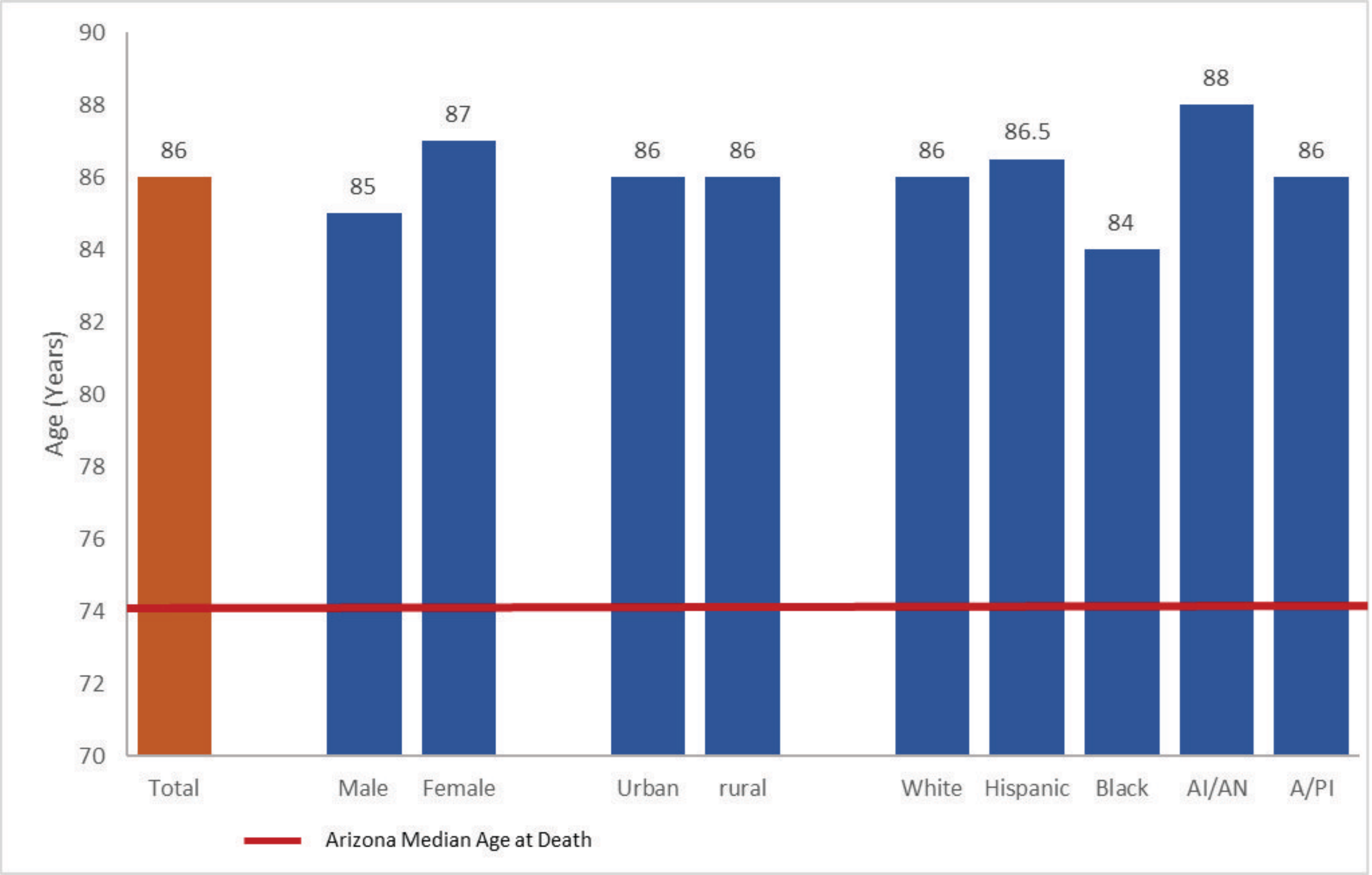


Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics. National Vital Statistics System, Mortality 2018-2022 on CDC WONDER Online Database, released in 2024. Data are from the Multiple Cause of Death Files, 2018-2022, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed at http://wonder.cdc.gov/ucd-icd10-expanded.html on May 30, 2024.

* Data not available, or number is less than 10.

- Alzheimer's Disease mortality rates among Adults 65 years and older in Arizona vary among racial/ethnic groups.
- Alzheimer's Disease mortality rates are highest among White males (149.8 per 100,000) and Black males (148.4 per 100,000) as compared to other racial/ethnic male groups.
- In 2022, Alzheimer's Disease mortality rates among White females (248.3 per 100,000), Black females (212.8 per 100,000) and Hispanic females (215.8 per 100,000) were higher compared to American Indian (AI)/ Alaska Native (AN) (136.9 per 100,000) and Asian/ Pacific Islander (A/PI) (127.2 per 100,000) females.

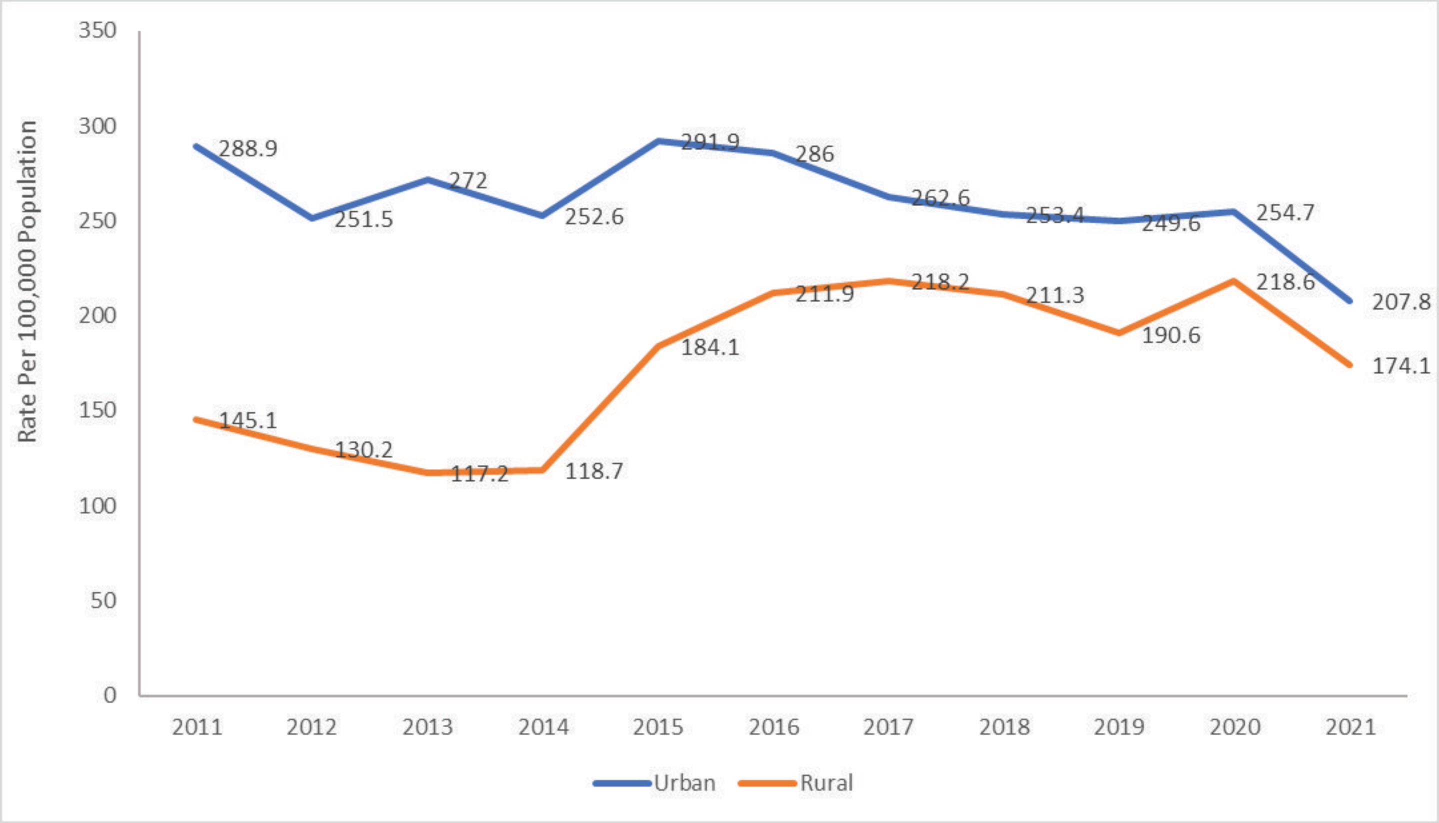
Figure 6: Median Age at Death by Sex, Urban/Rural Areas and Race/Ethnicity for Adults 65 years and older who had Alzheimer's Disease, Arizona 2021



Data Source: Comprehensive Arizona Health Status and Vital Statistics Annual Report (https://pub.azdhs.gov/health-stats/report/ahs/index.php

- Arizona's media age at death is 74 years.
- Among all Arizona adults 65 years and older who had Alzheimer's Disease, the median age of death in 2021 was 86 years.
- The median age at death for adults 65 years and older with Alzheimer's Disease was lowest for Black (84 years) and male (85 years).

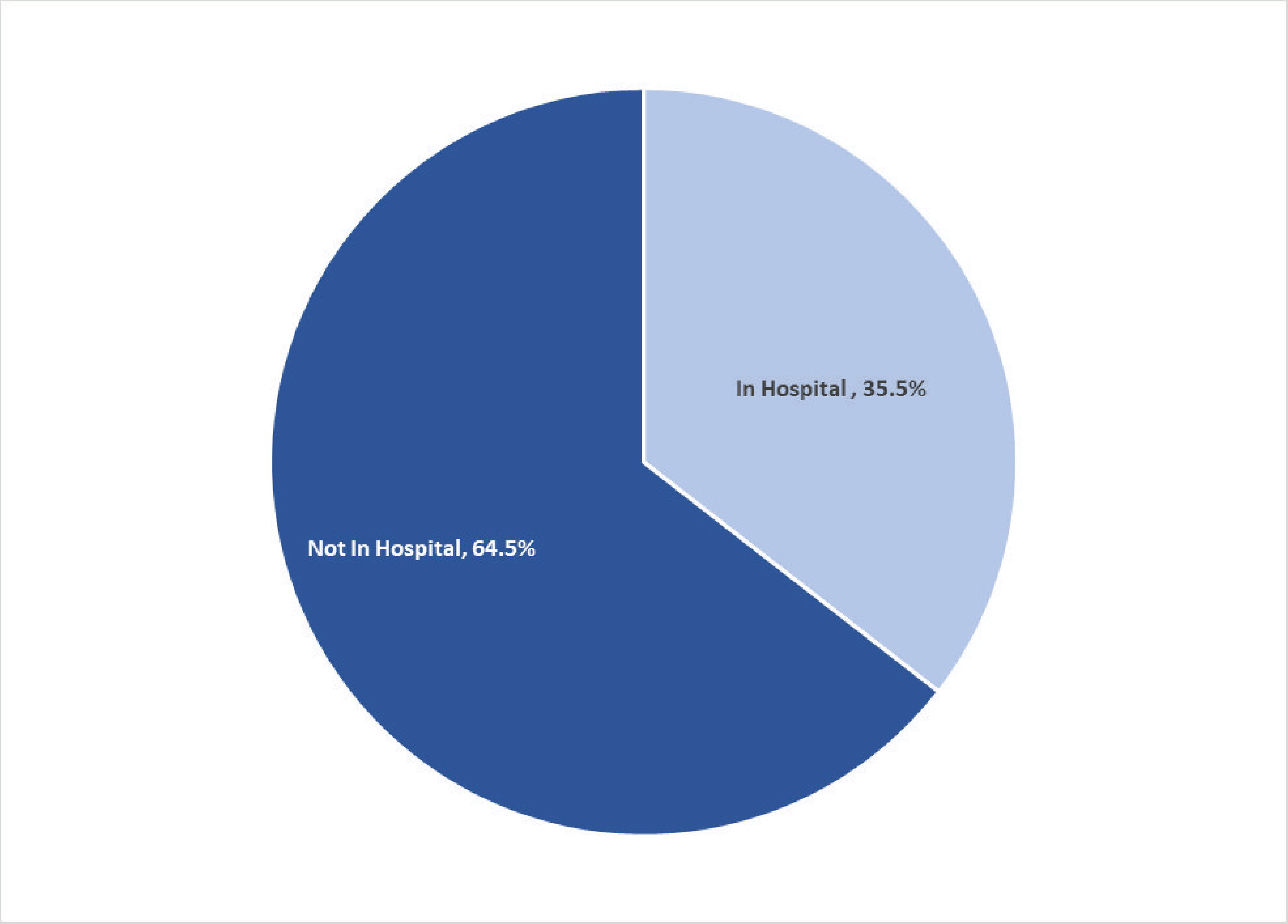
Figure 7: Trends in Mortality Rates for Alzheimer's Disease by Urban/Rural Area Among Adults 65 Years and Older, Arizona 2011-2021



Data Source: Comprehensive Arizona Health Status and Vital Statistics Annual Report (https://pub.azdhs.gov/health-stats/report/ahs/index.php

- Alzheimer's Disease mortality rates differ by geographic location. Between 2011 and 2021, mortality rates in urban areas have been consistently higher than rates in rural areas.
- Over the 10-year period Alzheimer's Disease mortality rates decreased twenty eight point one percent (28.1%) in urban areas, and increased by twenty percent (20.0%) in rural areas.
- In 2011, the Alzheimer's Disease mortality rate for urban areas was nearly 2 times greater than the mortality rate in rural areas.

Figure 8: Hospitalization Data /Location of Deaths Caused by Alzheimer's Disease,
Arizona 2021



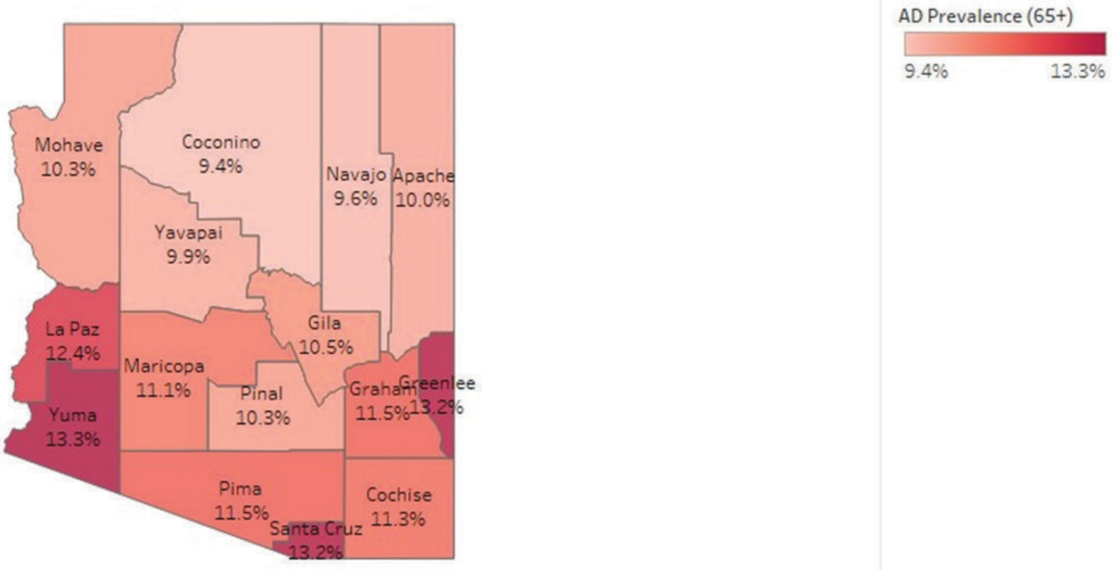
Data Source: Comprehensive Arizona Health Status and Vital Statistics Annual Report (https://pub.azdhs.gov/health-stats/report/ahs/index.php)

- Approximately sixty five percent (65%) of Alzheimer's Disease deaths occurred in non-hospital settings. Not in hospital data includes nursing homes (N=113), residence (N=960) and other (N=703).
- Approximately thirty five percent (35%) of Alzheimer's Disease deaths occurred in hospitals. In-hospital deaths include in-patient (N=36), out-patient (N=10) and status unknown (N=932).

Prevalence rates

Behavioral Risk Factor Surveillance Survey (BRFSS) data were used to assess the prevalence of behavioral risk factors. Data used to support the findings are available from ADHS and openly available at https://www.azdhs.gov/preparedness/public-health-statistics/behavioral-risk-factor-surveillance/index.php#data-code-book

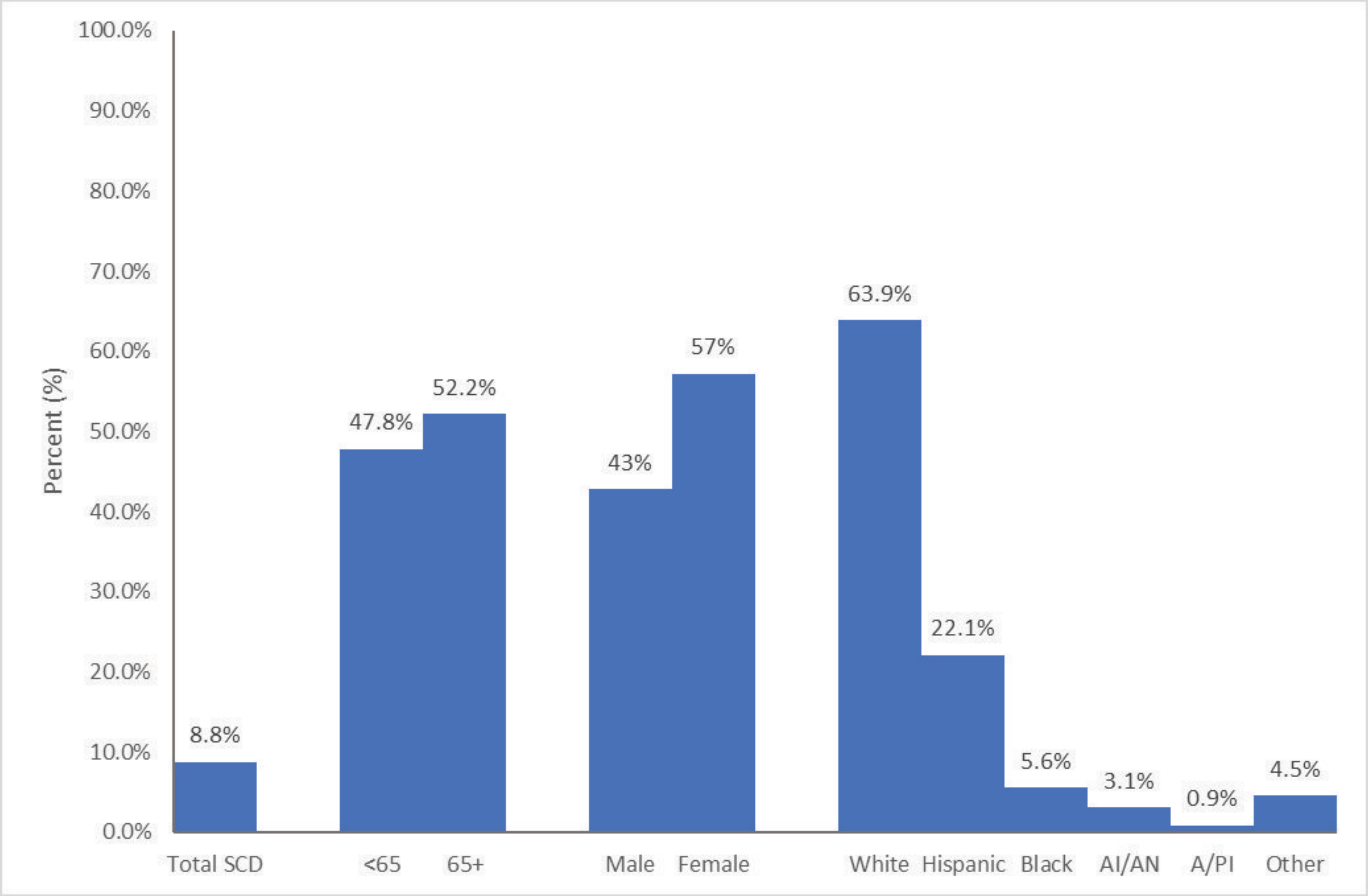
Figure 9: Estimated Prevalence of Alzheimer's Disease Among Adults Age 65 and Older,
Arizona 2020



Source: Dhana et al. Prevalence of Alzheimer's dementia in the 50 U.S. states and 3142 counties: A population estimate using the 2020 bridged-race postcensal from the National Center for Health Statistics. Alzheimer's & Dementia. 2023 Oct;19(10):4388-4395. 19:s22;1552-5260 (2023). Available at https://doi.org/10.1002/alz.13081

BRFSS Question: During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?

Figure 10: Prevalence and Demographics of Subjective Cognitive Decline (SCD), Arizona 2020



Data Source: Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Questionnaire. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, [2020]

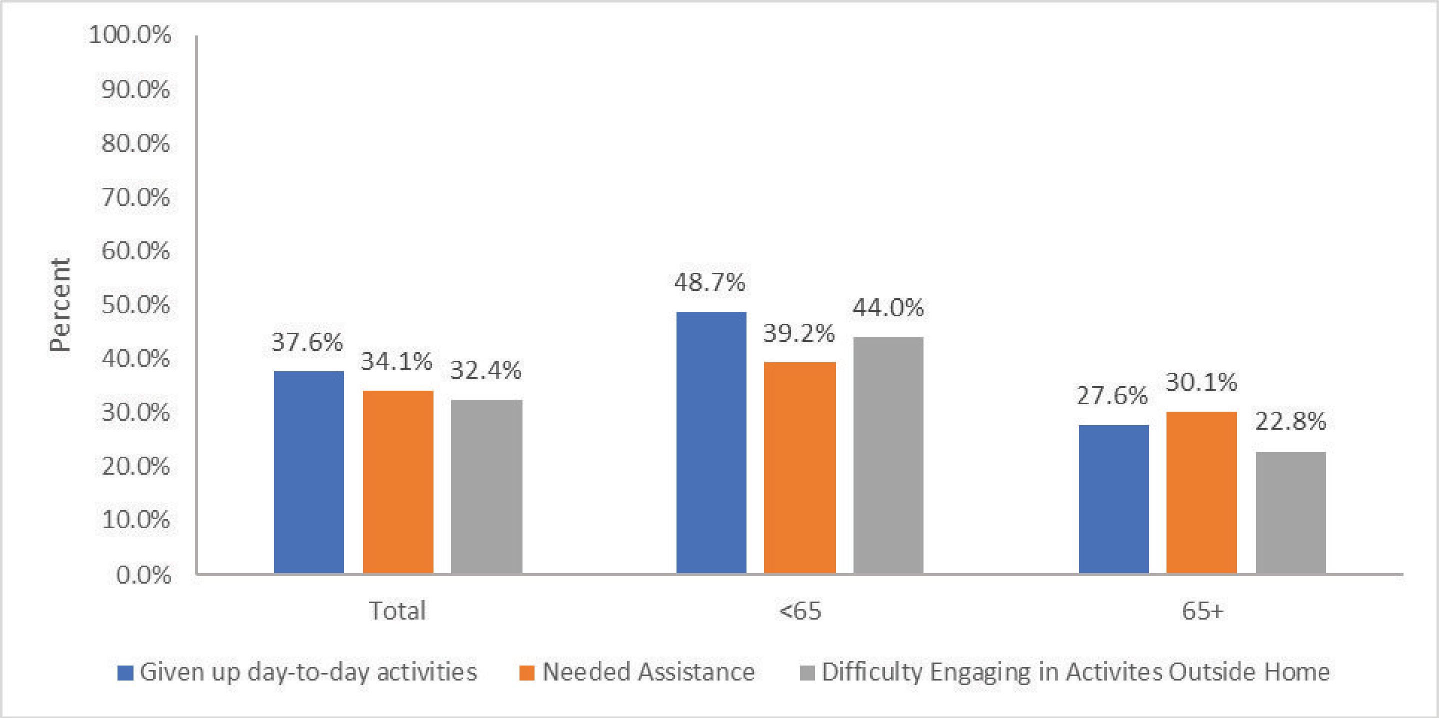
- Subjective Cognitive Decline (SCD) is defined as the self-reported experience of worsening or more frequent confusion or memory loss. It is a form of cognitive impairment and one of the earliest noticeable symptoms of Alzheimer's disease and related dementias. CDC (2023)
- The prevalence rate of adults 18 years and older with subjective cognitive decline (SCD) in 2020 was 8.8%; or about 1 in 11 adults 18 years and older.
- Among adults 18 years and older with SCD, fifty two percent (52%) were 65 years and older, fifty seven percent (57%) were female, and sixty four percent (64%) were White.

BRFSS Question: During the past 12 months, as a result of confusion or memory loss, how often have you given up day-to-day household activities or chores you used to do, such as cooking, cleaning, taking medications, driving, or paying bills?

BRFSS Question: When you need help with these day-to-day activities, how often are you able to get the help that you need?

BRFSS Question: During the past 12 months, how often has confusion or memory loss interfered with your ability to work, volunteer, or engage in social activities outside the home?

Figure 11: Percent of Adults with Subjective Cognitive Decline (SCD) related to functional Difficulties, Arizona 2020

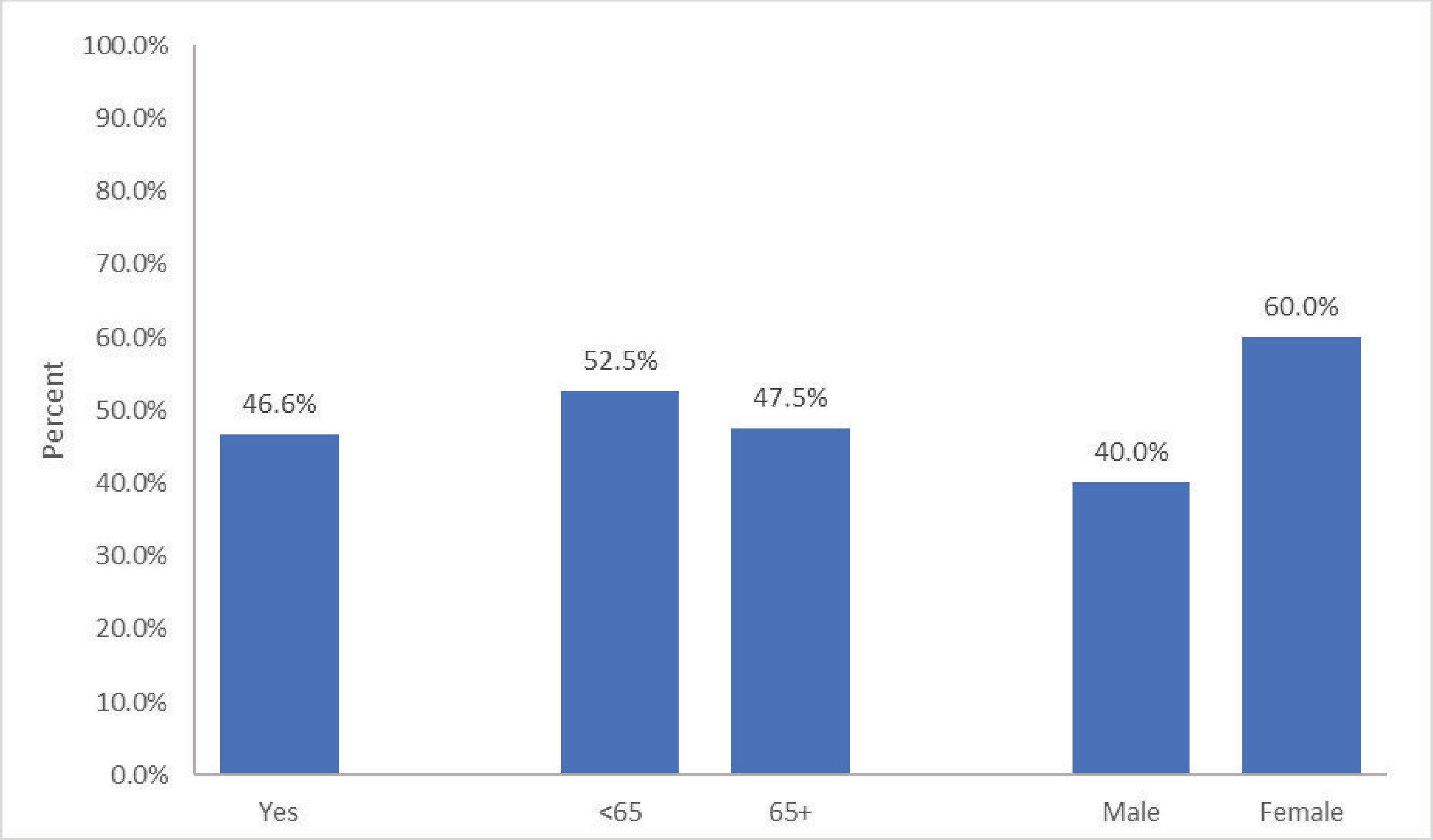


Data Source: Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Questionnaire. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, [2020]

- Forty eight point seven percent (48.7%) of adults 64 years and younger with SCD indicated that they *"gave up their day-to-day household activities or chores"* compared to twenty seven point six percent (27.6%) of adults 65 years and older.
- Of adults 64 years and younger, thirty nine point two percent (39.2%) *"needed assistance with day-to-day activities"* compared to thirty point one percent (30.1%) of adults age 65 years and older.
- Nearly one in three adults 18 years and older who report having SCD (32.4%) reported *"difficulty engaging in activities outside the home."*
- *"Difficulty engaging in activities outside the home."* were more common among adults 64 years and younger (44%) than among adults 65 years and older (22.8%).

BRFSS Question: Percent of Adults with Subjective Cognitive Decline, who discussed their symptoms of memory and confusion with a health care professional

Figure 12: Percent of Adults with Subjective Cognitive Decline (SCD) who report discussing symptoms of memory and confusion with a health care provider, Arizona 2020.

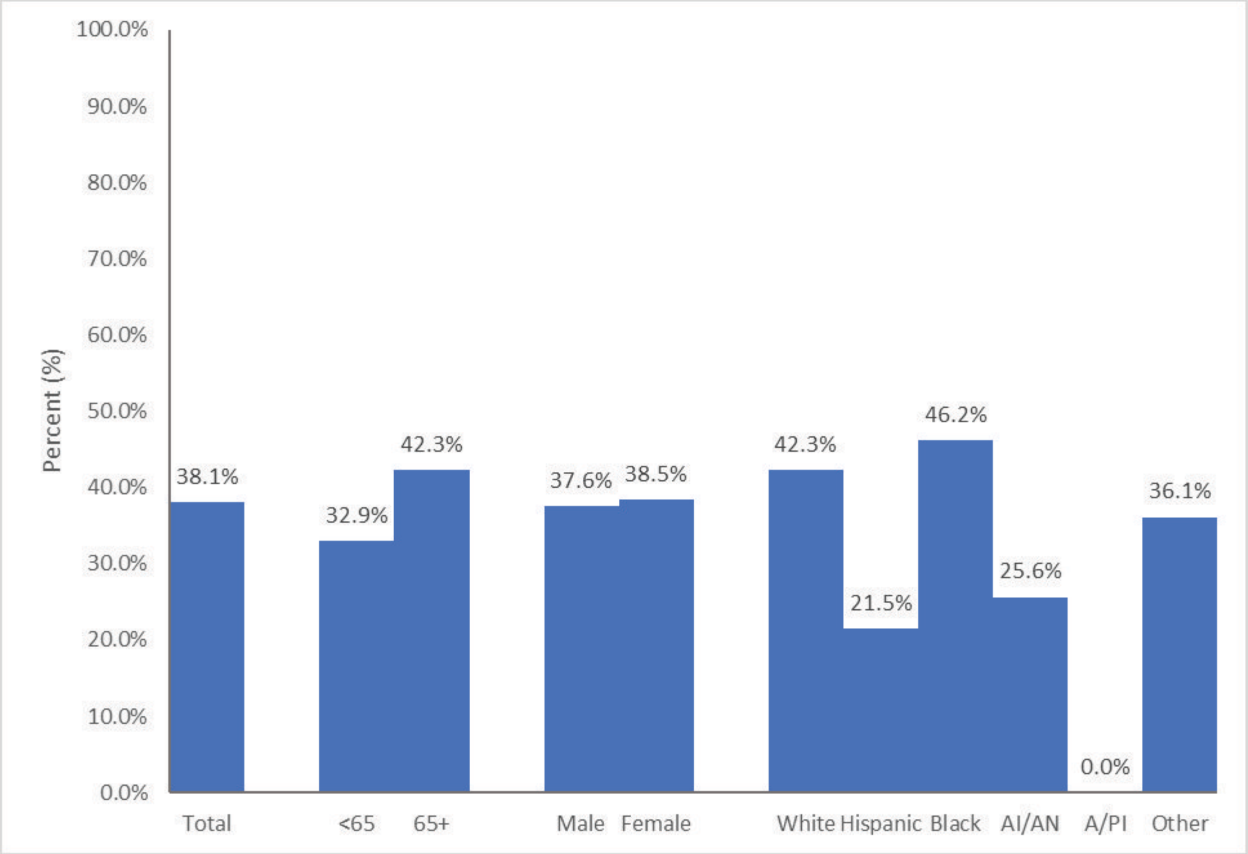


Data Source: Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Questionnaire. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, [2020]

- Among adults 18 years and older reporting SCD, forty six point six percent (46.6%) reported discussing their memory loss or confusion with a health care professional.
- Of adults 18 years and older with SCD, fifty two point five percent (52.5%) of adults 64 years and younger discussed their memory loss with a health care professional as compared to forty seven point five percent (47.5%) of adults 65 years and older.
- Sixty percent (60%) of females reported discussing their memory loss or confusion with a health care professional as compared to forty percent (40%) of males.

BRFSS Question: Has a doctor, nurse or other health professional ever told you that you had one of the following: coronary heart disease (including angina and/or myocardial infarction), stroke, asthma (still have), cancer (skin, other types of cancer), COPD, arthritis, depressive disorder, kidney disease, diabetes?

Figure 13: Percent of Adults with Subjective Cognitive Decline who report having two or more chronic diseases, Arizona 2020.



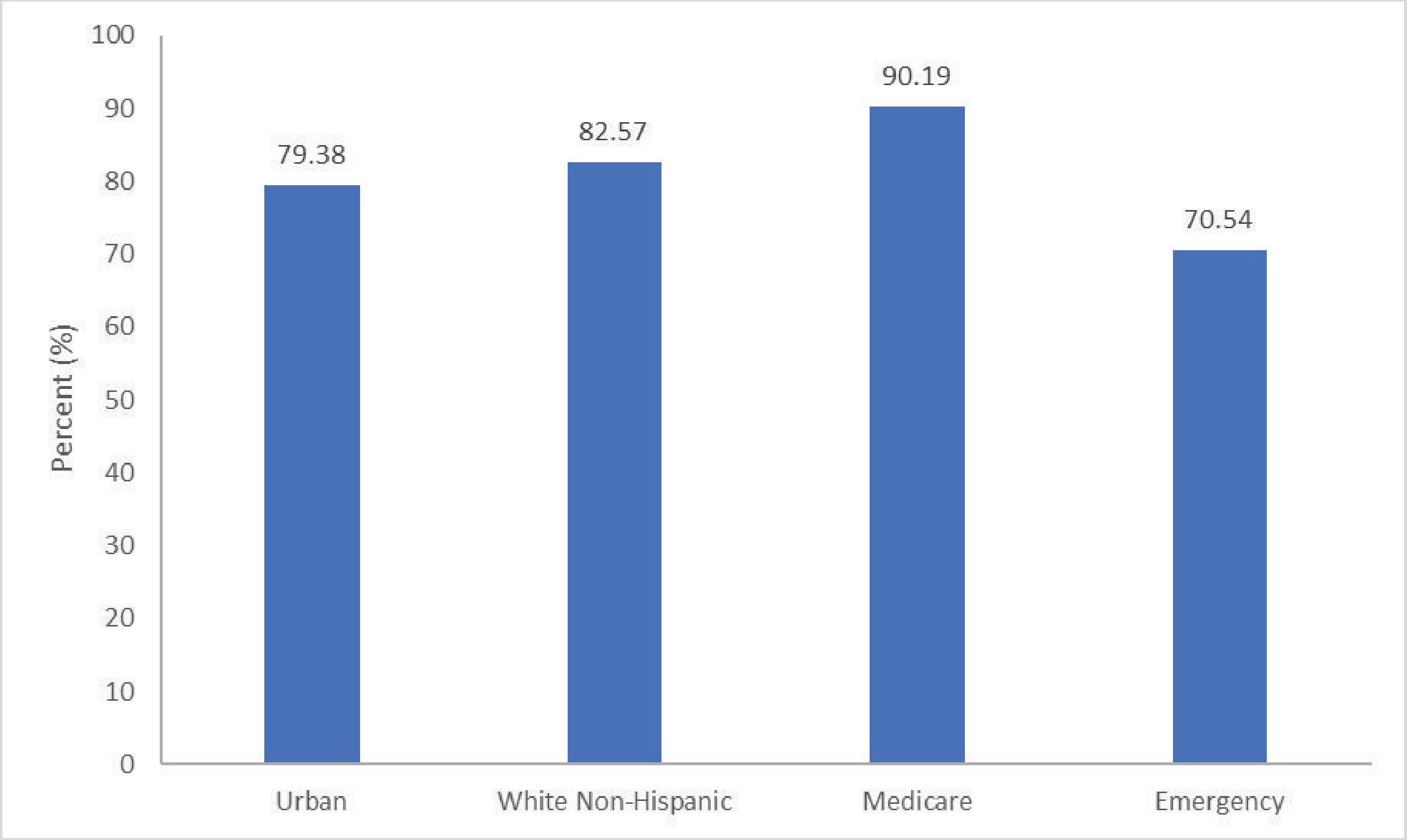
Data Source: Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Questionnaire. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, [2020]

- More than one-third (38.1%) of adults 18 years and older in Arizona with SCD have two or more chronic diseases.
- Forty two point three percent (42.3%) of adults 65 years and older who have SCD also have two or more chronic diseases, as compared to thirty two point nine percent (32.9%) of adults 64 years and younger.
- Thirty eight point five percent (38.5%) of females 18 years and older who have SCD reported having 2 or more chronic diseases, and thirty seven point six percent (37.6%) of males 18 years and older who have SCD reported having 2 or more chronic diseases..
- Among White adults 18 years and older with SCD, forty two point three percent (42.3%) reported having 2 or more chronic diseases, as compared to twenty one point five percent (21.5%) of Hispanic adults 18 years and older, forty six point two percent (46.2%) of Black adults 18 years and older, and twenty five point six percent (25.6%) of American Indian/ Alaska Native adults 18 years and older.

Health care utilization

Primary diagnosis codes for hospital discharge data (HDD) are specified in accordance with the International Statistical Classification of Diseases and Related Health Problems, 10th Edition (ICD-10). ICD-10 codes were identified from the leading cause of death and primary diagnosis field for HDD records related to Alzheimer's hospital visits. The following ICD-10 codes were used to identify Alzheimer's/Dementia hospital cases: F03.90, G30.9, G30.0, G30.1, and G31.0.

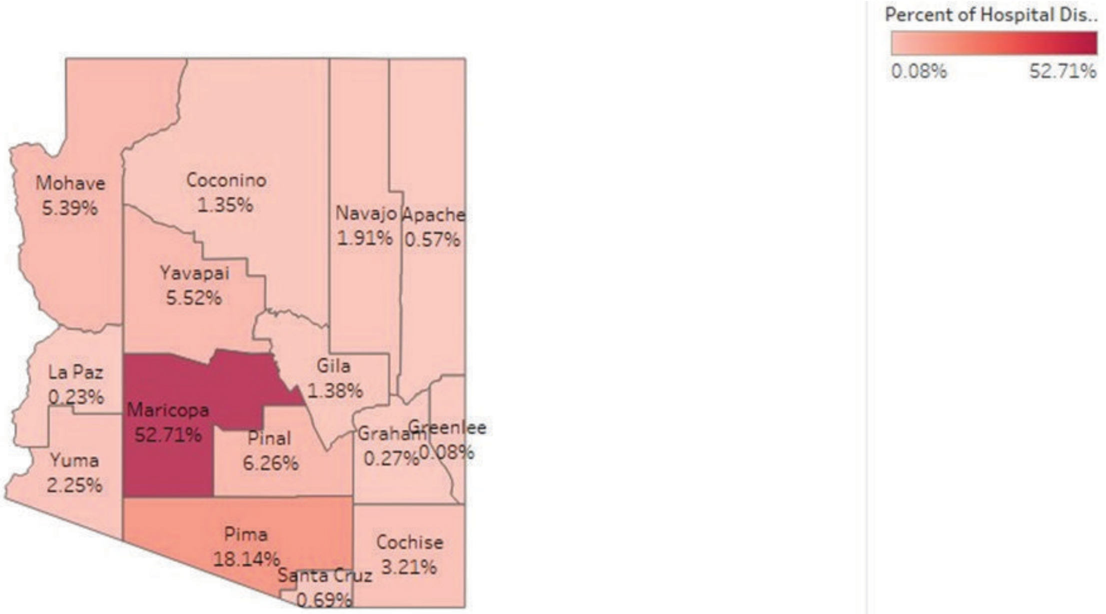
Figure 14: Hospital Visits Related to Alzheimer's Disease Among Adults 65 Years and Older - Arizona 2015-2023



Data Source: Arizona Hospital Discharge Data (2015-2023)

- Between 2015 and 2023, a majority of hospital visits related to Alzheimer's were in urban areas (79.4%), non-Hispanic White (82.6%), had Medicare insurance (90.2%), and at the hospital for an emergency visit (70.5%, compared to inpatient visits).

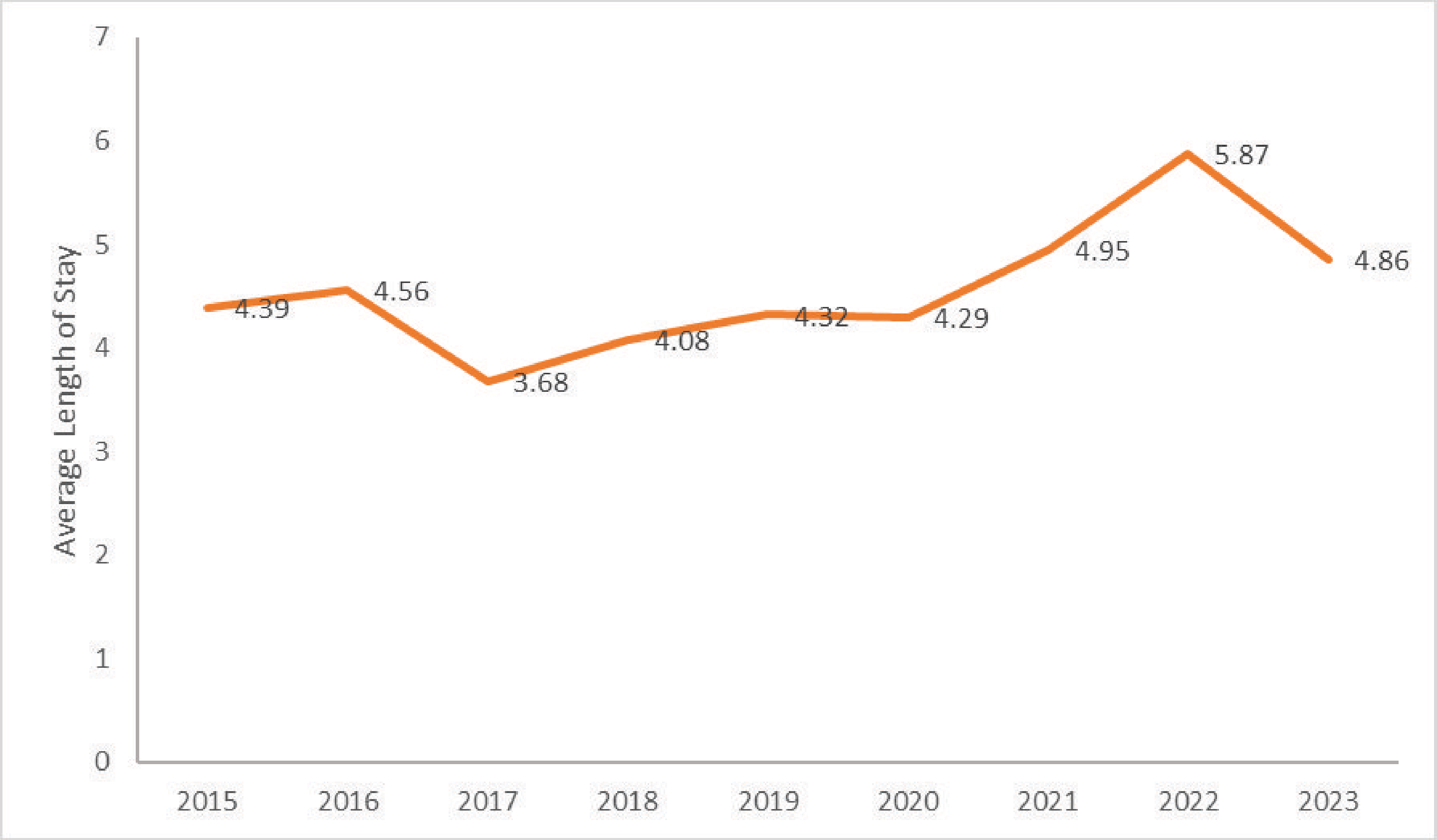
Figure 15: Percent of Alzheimer’s Disease Related Hospital Discharges Among Adults 65 Years and Older by County - Arizona 2015-2023



Data Source: Arizona Hospital Discharge Data (2015-2023)

- A little over seventy percent (70%) of Alzheimer’s Disease related hospital discharges occurred in Maricopa (52.71%) and Pima (18.14%) counties.

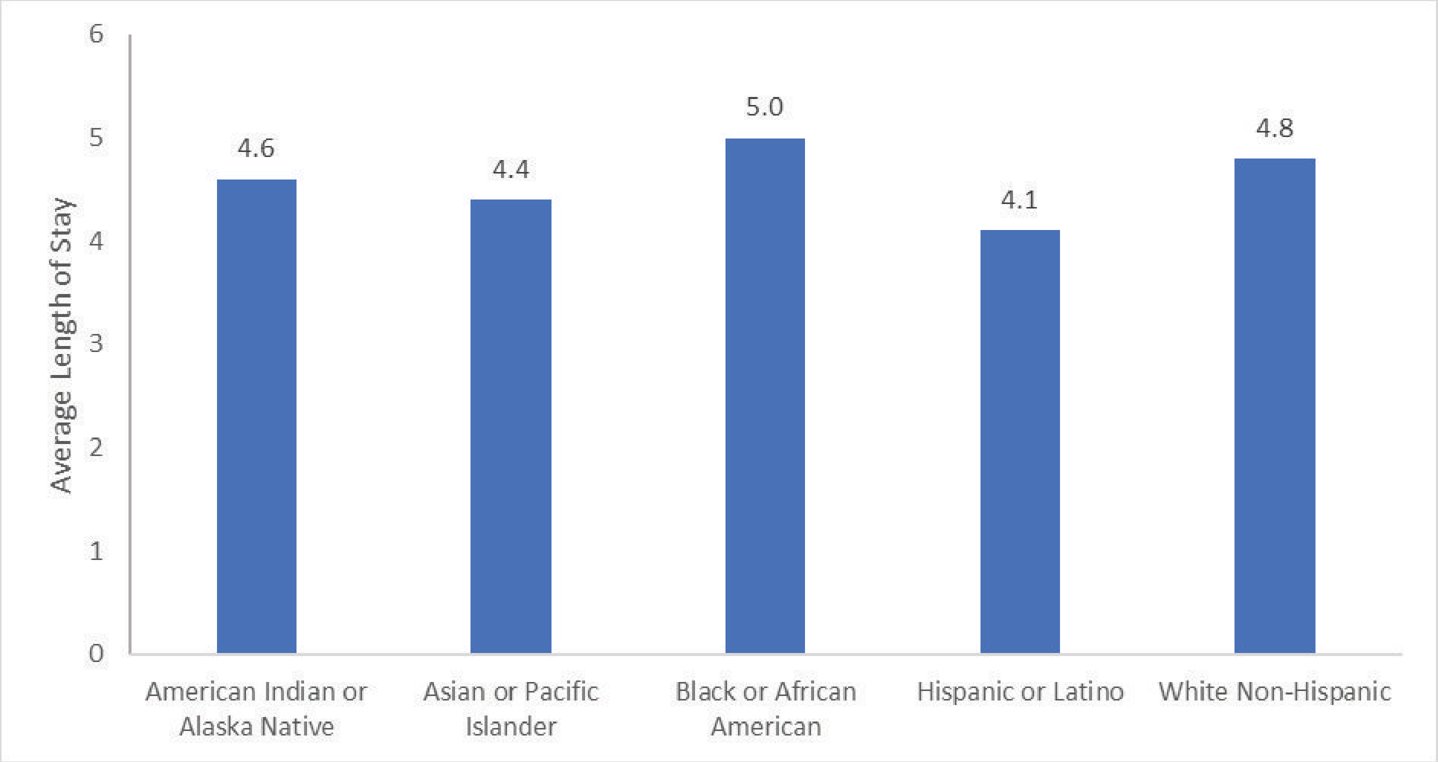
Figure 16: Average Length of Hospital Stay for Alzheimer's Disease Related Issues Among Adults Age 65 and Older by Year – Arizona 2015-2023



Data Source: Arizona Hospital Discharge Data (2015-2023)

- The average length of hospital visit stay for adults 65 and older with Alzheimer's Disease in 2023 was four point eight six (4.86) days.
- Between 2015 and 2023 the average length of hospital visit stays for adults 65 and older with Alzheimer's Disease increased nearly eleven percent (11%).

Figure 17: Average Length of Hospital Stay for Alzheimer's Disease Related Issues Among Adults Age 65 and Older by Race/ Ethnicity - Arizona 2015-2023



Data Source: Arizona Hospital Discharge Data (2015-2023)

- The average length of stay in the hospital for Alzheimer's Disease related issues was five (5) days among Black adults 65 years and older, as compared to four point eight (4.8) days among White adults 65 years and older, four point six (4.6) days among American Indian/Alaska Native adults 65 years and older, four point four (4.4) days among Asian/Pacific Islander adults 65 years and older, and four point one (4.1) days among Hispanic/Latino adults 65 years and older.

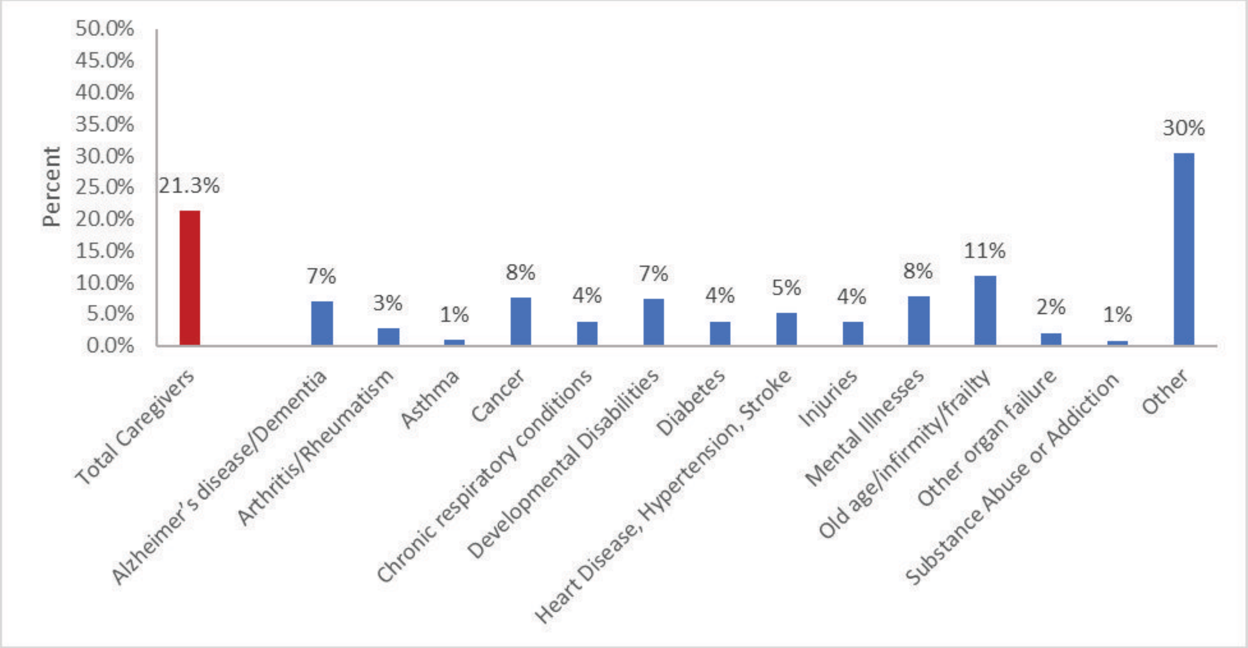
Caregivers

Behavioral Risk Factor Surveillance Survey (BRFSS) data were used to assess factors surrounding caregivers. Data used to support the findings are available from ADHS and openly available at https://www.azdhs.gov/preparedness/public-health-statistics/behavioral-risk-factor-surveillance/index.php#data-code-book

BRFSS Question: During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?

BRFSS Question: What is the main health problem, long-term illness, or disability that the person you care for has?

Figure 18: Percent of Adults 18 years and older that Indicated they were a Caregiver by Main Type of Health Problem(s) They Provide Care For – Arizona, 2018

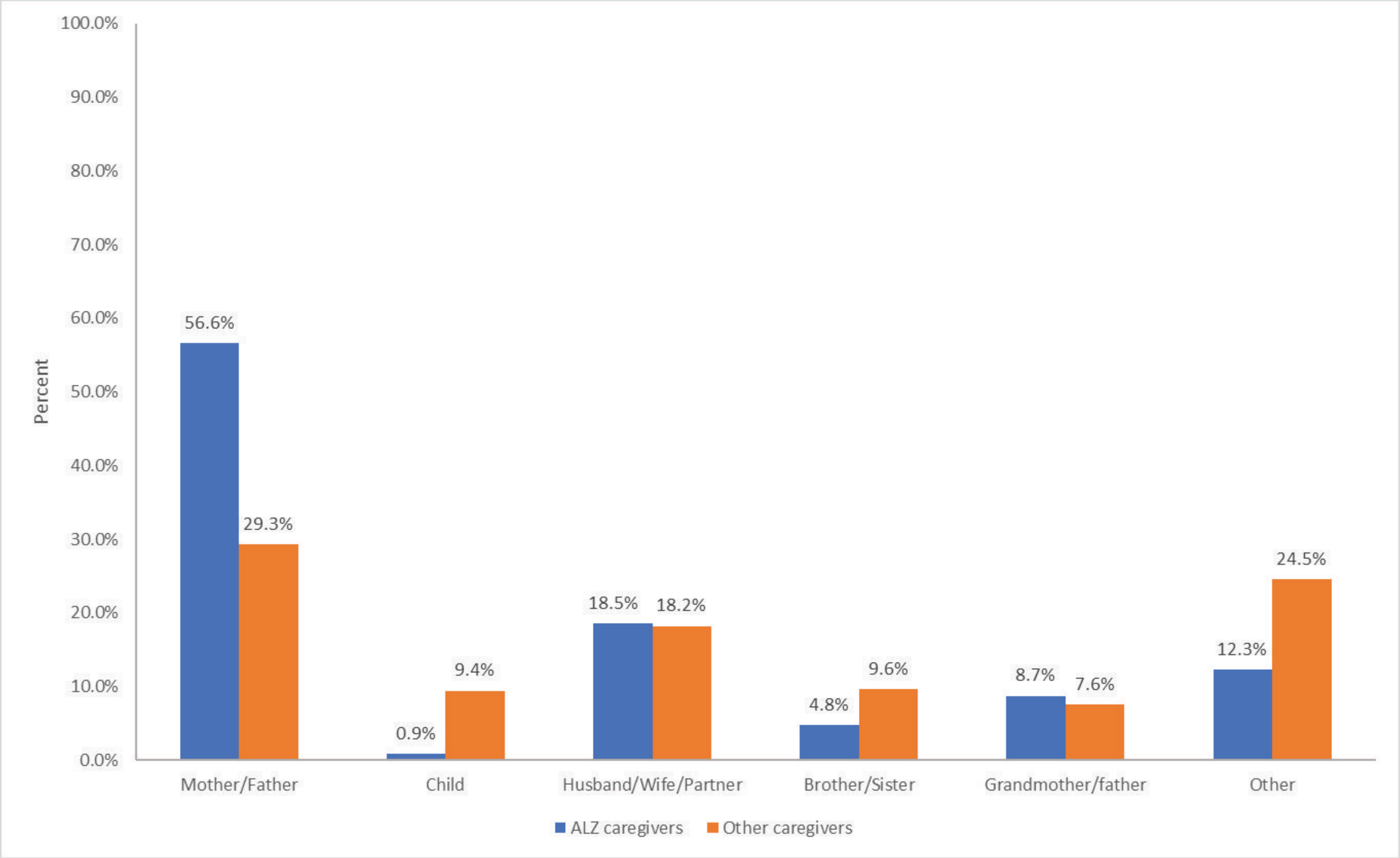


Data Source: Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Questionnaire. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, [2018]

- In 2018, twenty one percent (21%) of BRFSS respondents reported that they provide regular care or assistance to a friend or family member who has a health problem.
- Of those who were caregivers, seven percent (7%) cared for people with Alzheimer's Disease/Dementia.

BRFSS Question: What is his or her relationship to you?

Figure 19: Caregiver Relationship to Person Needing Care by Type of Caregiver – Arizona, 2018

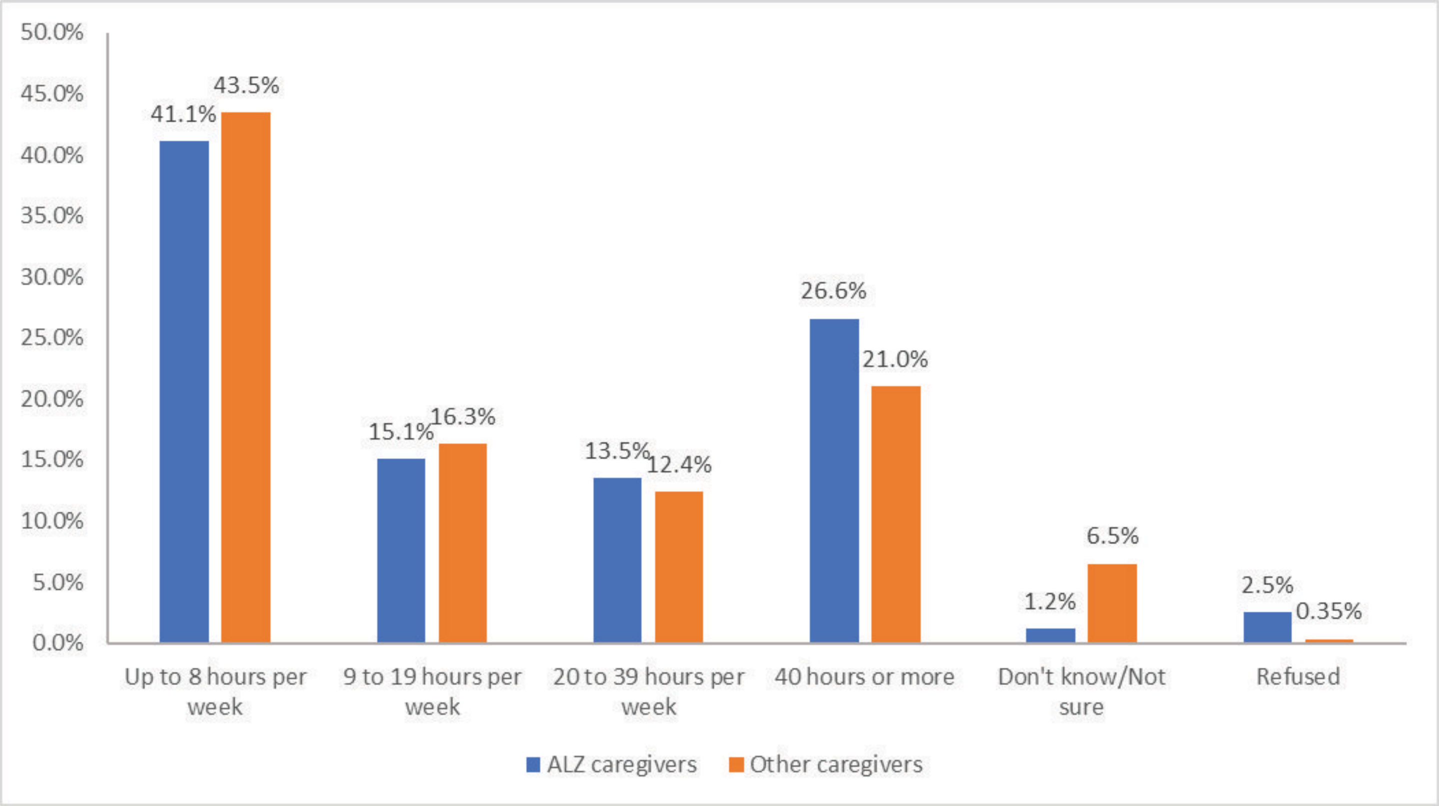


Data Source: Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Questionnaire. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, [2018]

- Among caregivers for people with Alzheimer's Disease (ALZ caregivers), fifty six point six percent (56.6%) reported caring for a mother or father as compared to twenty nine point three percent (29.3%) of caregivers of other people with other health conditions (Other caregivers).

BRFSS Question: In an average week, how many hours do you provide care or assistance? Would you say...

Figure 20: Average Number of Hours Care or Assistance is Provided by Type of Caregiver – Arizona, 2018

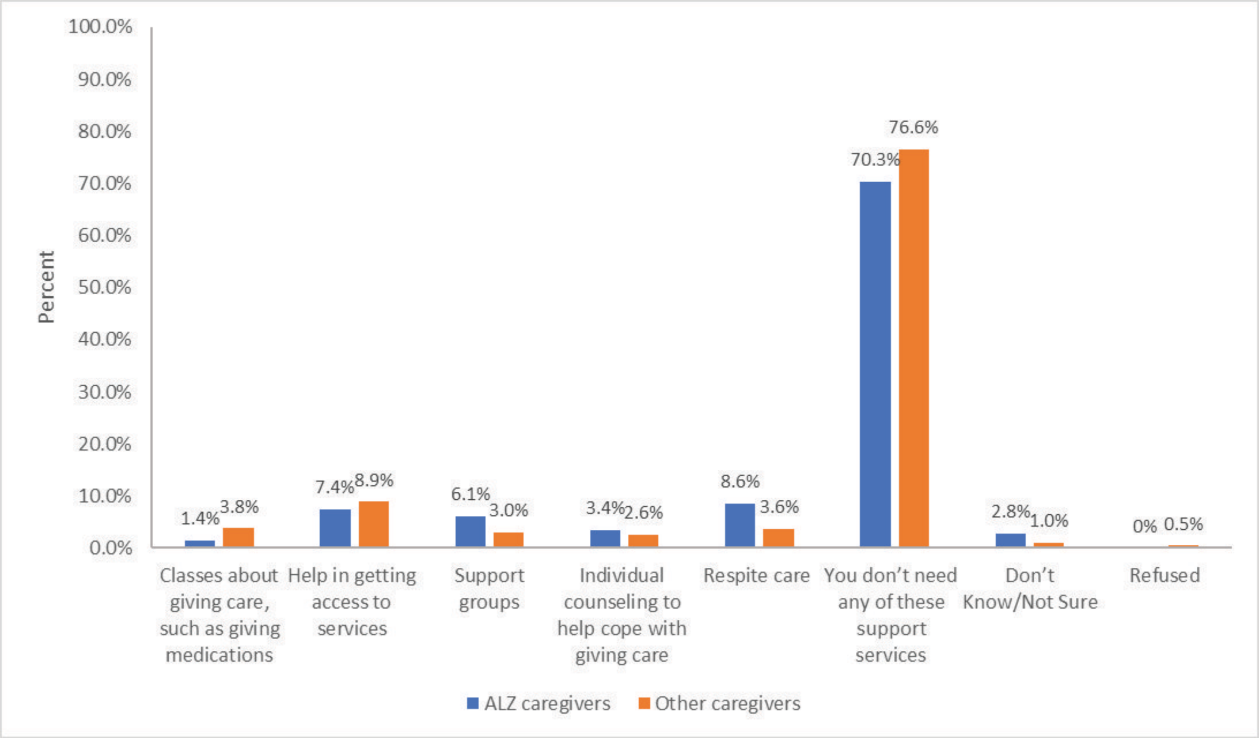


Data Source: Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Questionnaire. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, [2018]

- In 2018, forty one point one percent (41.1%) of Alzheimer's Disease caregivers (ALZ caregivers) reported that they provided up to 8 hours per week of care, compared to forty three point five percent (43.5%) of caregivers for people with other health conditions (Other caregivers).
- The proportion of Alzheimer's Disease caregivers (ALZ caregivers)who spent 40 hours or more was twenty six point six percent (26.6%) compared to twenty one percent (21.0%) of caregivers providing care for people with other health conditions (Other caregivers).

BRFSS Question: Of the following support services, which one do you, as a caregiver, most need that you are not currently getting?

Figure 21: Needed Support Services for Caregivers by Type of Caregiver – Arizona, 2018



Data Source: Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Questionnaire. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, [2018]

- Over seventy percent (70%) of caregivers of individuals with Alzheimer's Disease (ALZ caregivers) reported "*not needing any of the listed support services*."
- Among caregivers providing care for Alzheimer's Disease (ALZ caregivers), eight point six percent (8.6%) needed "*respite care support*," seven point four percent (7.4%) needed help with *"getting access to services*," and six point one percent (6.1%) needed "*a support group*."

Data Limitations (Vital Statistics, Hospital Discharge Data (HDD), Behavioral Risk Factor Surveillance System (BRFSS)

All of the observed trends for emergency department visits should be interpreted cautiously. In 2020, there was a significant decline in emergency department visits for health concerns other than COVID-19[1]and it is unclear to what extent the COVID-19 pandemic may have impacted trends of Alzheimer's Disease.

Hospital discharge data do not capture hospital visits for Arizona residents who use Federal hospitals or hospitals in another state. ADHS only collects inpatient and emergency hospital discharge records from Arizona licensed hospitals.

The true prevalence of Alzheimer's Disease cannot be calculated. Data from a population-based study[2] and the Behavioral Risk Factor Surveillance System (BRFSS)[3] Surveys were used to estimate the prevalence of

Alzheimer's Disease and Subjective Cognitive Decline. In using BRFSS data there may be reporting, recall and social desirability bias from participants. Data includes only those who choose to participate.

Misclassification of persons by race may occur, especially for American Indian/Alaska Native persons.[1] This misclassification could lead to an over or underestimation of persons among this group. Hospital discharge data is an administrative dataset, and may include misclassification of characteristics at the hospital-level.

Caregiver data presented in this report should be viewed cautiously as this module has not been available annually and represents the time frame when the module was asked. The caregiver module was available in 2018, and in 2022 and 2023 but data for later years was not available for analyses during the time of this report. However, the BRFSS Caregiver Module is a useful tool for identifying caregivers who provide care for people with Alzheimer's disease, dementia, or other cognitive impairments. (source: https://www.cdc.gov/aging/healthybrain/brfss-faq-caregiver.htm)

In addition, the data in this report is based on encounters, and may include duplicate cases for the same person resulting in an overestimate of the number of cases and associated rates.

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APPENDIX F: DEFINITIONS & ABBREVIATIONS

DEFINITIONS

Alzheimer's Disease: A progressive neurological disorder that affects memory, thinking skills, and behavior. It is the most common cause of dementia.

Dementia: A general term for a decline in mental ability severe enough to interfere with daily life. It is not a specific disease but rather a group of symptoms characterized by memory loss, impaired reasoning, and personality changes

Cognitive Impairment: Refers to a decline in cognitive function,including memory loss, difficulty in reasoning, and changes in behavior.

Neurodegeneration: The progressive loss of structure or function of neurons, including death of neurons.

Amyloid Plaques: Abnormal clusters of protein fragments that build up between nerve cells in the brain and are a hallmark of Alzheimer's disease.

Neurofibrillary tangles: Twisted fibers composed of a protein called tau that accumulate inside nerve cells in the brain, disrupting communication nrurons.

Mini-Mental State Examination (MMSE): A commonly used test to measure cognitive impairment and screen for dementia. It assesses various cognitive functions such as memory, attention, and language.

Mild Cognitive Impairment (MCI): A transitional stage between normal age-related cognitive decline and more serious cognitive decline associated with dementia. People with MCI have mild but noticeable memory or cognitive problems.

Modifiable Risk Factors: Lifestyle and behaviors that can reduce or increase one's chances of developing a disease.

Caregiver Burden: The physical, emotional, and financial strain experienced by individuals who provide care for someone with dementia.

Respite Care: Temporary care provided to relieve caregivers of their responsibilities for a short period, allowing them to rest and recharge.

Wandering: A common behavior among individuals with dementia, characterized by aimless or purposeless movement, often resulting in the person getting lost or being unable to find their way back home.

Sundowning: A phenomenon in which individuals with dementia experience increased confusion, agitation, and restlessness in the late afternoon or early evening.

Advance Directive: Legal documents that outline a person's wishes regarding medical treatment and end-of-life care in the event that they become unable to communicate or make decisions for themselves.

Long-Term Care: Services and support provided to individuals who need assistance with activities of daily living over an extended period, often due to chronic illness or disability, including dementia.

Adult Day Care: Programs that provide supervised care and activities for older adults who require assistance or supervision during the day, allowing their caregivers to work or take a break.

Behavioral Risk Factor Surveillance Survey (BRFSS): It is a state-based system of health surveys conducted by the Centers for Disease Control and Prevention (CDC), in collaboration with state health departments. BRFSS collects data on health-related risk behaviors, chronic health conditions, and use of preventive services among adults in the United States. The data collected through BRFSS is used to monitor health trends, identify emerging health problems, and inform public health policies and programs.

Medicare: A federal health insurance program primarily for people who are 65 or older, certain younger people with disabilities, and people with end-stage renal disease (permanent kidney failure requiring dialysis or a transplant). Medicare helps cover various health care services, including hospital stays, doctor visits, prescription drugs, and preventive care. It is divided into several parts:

- Medicare Part A: Hospital Insurance, which covers inpatient hospital stays, skilled nursing facility care, hospice care, and some home health care.
- Medicare Part B: Medical Insurance, which covers outpatient care, doctor visits, preventive services, and medical supplies.
- Medicare Part C: Medicare Advantage, which offers an alternative way to receive Medicare benefits through private insurance companies approved by Medicare.
- Medicare Part D: Prescription Drug Coverage, which helps cover the cost of prescription drugs.

Medicaid: A joint federal and state program that provides health coverage to low-income individuals and families who meet certain eligibility requirements. It is the largest source of funding for medical and health-related services for people with limited income in the United States. Medicaid covers a wide range of health care services, including doctor visits, hospital stays, prescription drugs, preventive care, and long-term care. Eligibility for Medicaid varies by state and is based on income, household size, age, disability status, and other factors. Each state operates its own Medicaid program within federal guidelines, so benefits and eligibility criteria may differ from state to state.

Risk Reduction: The process of lowering the chance of developing a disease.

ABBREVIATIONS

ADCA - Alzheimer's Disease Core Capacity

ADHS - Arizona Department of Health Services

ADOA - Arizona Department of Administration

ADRD - Alzheimer's Dementia and Related Diseases

AHCCCS – Arizona Health Care Cost Containment System (Arizona's Medicaid Program)

APS - Adult Protective Services

ASU - Arizona State University

ATSU- A.T. Still University

AZHIP - Arizona Health Improvement Plan

AZ4A - Arizona's Area Agencies on Aging

BCBSAZ - Blue Cross Blue Shield of Arizona

BRFSS – Behavioral Risk Factor Surveillance System

CDC – Centers for Disease Control and Prevention

CEU’s - Continuing Education Units

DASH - Dietary Approaches to Stop Hypertension

DASTCS- Division of Aging & Long-Term Care Support

HAWP - Healthy Arizona Worksites Program

HBI - Healthy Brain Initiative

HHS - United States Department of Health & Human Services

HIE - Health Information Exchange

HSPA - Hospital Service Planning Area

ITCA- Inter Tribal Council of Arizona

KAP - Knowledge, Attitude, and Practice

LGBTQ - Lesbian, Gay, Bisexual, Transgender and Queer

MEZCOPH- Mel and Enid Zuckerman College of Public Health

MCI - Mild Cognitive Impairment

MMSE - Mini-Mental State Examination

NACDD - National Association of Chronic Disease Directors

NAU - Northern Arizona University

NCEA - National Center on Elder Abuse

PCHD - Pima County Hospital District

SCD- Subjective Cognitive Decline

SDOH - Social Determinants of Health

SES - Socioeconomic Status

SEAG- SouthEastern Arizona Governments Organization

TBI - Traumatic Brain Injury

TRUST - Tobacco Revenue Use Spending and Tracking

U of A - University of Arizona

UA COM - University of Alabama

WACOG- Western Arizona Council of Governments

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