Maryland State Plan to Address Alzheimer's Disease and Related Dementias: 2022-2026

Pursuant to Health-General Article, §13-3207, Annotated Code of Maryland, and Chapters 410 and 411 of the Acts of 2019

May 2022

The Virginia I. Jones Alzheimer's Disease and Related Disorders Council

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LETTER TO GOVERNOR AND GENERAL ASSEMBLY

January, 2022

The Honorable Larry Hogan
Governor
State of Maryland
Annapolis, MD 21401-1991

The Honorable Bill Ferguson
President of the Senate
State House, H-107
Annapolis, MD 21401-1991

The Honorable Adrienne A. Jones
Speaker of the House
State House, H-101
Annapolis, MD 21401-1991

RE: Maryland Alzheimer's Disease and Related Dementias Plan 2022-2026

Dear Governor Hogan, President Ferguson, and Speaker Jones:

Pursuant to Health-General Article, §13-3207, Annotated Code of Maryland, and Chapters 410 and 411 of the Acts of 2019, the Virginia I. Jones Alzheimer's Disease and Related Disorders Council (the Council) is directed to update and advocate for the State Plan on Alzheimer's Disease and Related Dementias (the State Plan).

Throughout 2020 and 2021, the Council undertook a comprehensive process to update and enhance the existing Alzheimer's Disease and Related Disorders (ADRD) State Plan, which was developed by the former Commission on Alzheimer's Disease and Related Disorders in 2012 (executive order 01.01.2011.21). Working in collaboration with other stakeholders, the Council's revision process included an environmental scan of relevant national, state, and local initiatives, policies, or programs relevant to Alzheimer's disease and healthy brain aging; a systematic review of 18 recently updated Dementia State Plans from other states; a series of Open Council Workgroup Meetings; a series of listening sessions for oral public comment; and the solicitation of public comment via email.

Dementia represents an urgent and costly public health crisis in Maryland. An estimated 110,000 Marylanders 65 and over were living with Alzheimer's disease in 2020, and this is projected to increase by 18% to 130,000 by 2025. Dementia is the most expensive chronic condition in the US, and the direct and indirect costs of care for Marylanders with dementia are extremely high. Maryland Medicaid spent $1.23 billion to care for people age 65 and older with dementia in 2020 and this spending is expected to increase 24.7% by 2025. In 2020, estimates suggest that 238,000 family caregivers in Maryland were providing care for people with dementia, and contributed 364 million hours of unpaid care, amounting to an estimated total economic value of $6.5 billion. In addition, in 2017, Maryland caregivers were estimated to incur $221,000,000 in higher health care costs themselves, as many also suffer from at least one chronic condition.

Given these facts, we call on the Governor and General Assembly to embrace a comprehensive public health approach to mitigate the impact of dementia in Maryland. We put forth five goals in the updated State Plan designed to provide an informed and proactive roadmap for ADRD that addresses key areas critical to people living with dementia or at risk for dementia, families, health systems, and the community at large:

Goal 1: Expand efforts to support public awareness, prevention, and early detection of ADRD;

Goal 2: Enhance quality, access, and coordination of ADRD care;

Goal 3: Enhance and expand supports for family caregivers;

Goal 4: Advance ADRD research and encourage evidence-based practices; and

Goal 5: Enhance data capabilities related to dementia and dementia impact and effects of interventions.

The Council and its partners envision a dementia-capable Maryland that supports the health and well-being of its at-risk citizens and provides care, services, and resources through a whole person, coordinated approach to meet the needs of Marylanders living with dementia and their caregivers across the disease continuum, from diagnosis to end of life. The Council recognizes that the State Plan is a first step in a longer process to realize the goals put forth—a process that will require additional resources, and dedicated oversight for coordination, implementation, and monitoring of progress. The Council believes this vision is achievable through strategic synergies with other ongoing public health efforts, stakeholder and partner collaborations, and collaborative innovation. We welcome and value your thoughts and input.

Sincerely,

Quincy M. Samus, PhD, MS

Virginia I. Jones Alzheimer’s Disease and Related Disorders Council, Chair

CONTRIBUTORS AND ACKNOWLEDGEMENTS

The following individuals contributed significantly to the creation and development of the Maryland ADRD State Plan 2022-2026 through their work on the Council.

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We would like to acknowledge and thank the following individuals for contributing their time, effort, and expertise to supporting the Council and other activities pertinent to the completion of the Plan.

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Disclaimer
The views and recommendations contained in this document are the sole responsibility of the Council and do not necessarily represent the official views of State or private independent agencies/entities in Maryland.

LIST OF ACRONYMS

AD	Alzheimer’s Disease
ADRD	Alzheimer’s Disease and Related Dementias
AAA	Area Agency on Aging
ADL	Activities of Daily Living
BOLD	Building Our Largest Dementia Infrastructure for Alzheimer's Act
BRFSS	Behavioral Risk Factor Surveillance System
CDC	The Centers for Disease Control and Prevention
CCRC	Continuing Care Retirement Communities
CEU	Continuing Education Credit Program
CFL	Communities for Life^{SM}
CME	Continuing Medical Education Credit Program
CMMI	Center for Medicare and Medicaid Innovation
CMS	Centers for Medicare and Medicaid Services
COMAR	Code of Maryland Regulations
DICE	Describe, Investigate, Create, Evaluate
FDA	Food and Drug Administration
FMLA	Family and Medical Leave Act
FTD	Frontotemporal Dementia
GWEP	Johns Hopkins Geriatric Workforce Enhancement Program
HCBOW	Maryland’s Home and Community-Based Options Waiver
HCBS	Home and Community-Based Services
HIE	Health Information Exchange
JHDCNA	Johns Hopkins Dementia Care Needs Assessment
LTSS	Long Term Services and Supports
MAP	Maryland Access Program
MDH	Maryland Department of Health
MDoA	Maryland Department of Aging
MDPCP	Maryland Primary Care Program
NADRC	Administration for Community Living's National Alzheimer's and Dementia Resource Center
NAPA	National Alzheimer’s Project Act
NIA	National Institute on Aging
NIH	National Institutes of Health
PACE	Plan for the All-Inclusive Care of the Elderly
PBPY	Per Beneficiary Per Year
PLWD	People Living with Dementia
REACH	Resources for Enhancing Alzheimer’s Caregiver Health
RDAD	Reducing Disability in Alzheimer’s Disease
TAP	Tailored Activity Program

MISSON, VISION, AND GUIDING PRINCIPLES

The charge of the Virginia I. Jones Alzheimer's Disease and Related Disorders (ADRD) Council (the Council) is to (1) update and advocate for the State Plan on Alzheimer's Disease and Related Disorders (the State Plan); (2) examine the needs of individuals with ADRD and their caregivers, and identify methods through which the State can most effectively and efficiently assist in meeting those needs; (3) advise the Governor and the General Assembly on policy, funding, regulatory, and other issues related to people with dementia and their caregivers; and (4) develop and promote strategies to encourage brain health and reduce cognitive decline.

With this update to the State Plan, the Council aims to provide Marylanders and their leaders an informed and proactive roadmap for ADRD that enhances key areas important to individuals, families, health systems and networks that aligns with national level strategies, resources, and opportunities.

The Council envisions a dementia-capable Maryland which provides and values care and services through a whole-person, coordinated approach. In order to meet the needs of Marylanders living with dementia and their caregivers across the disease continuum, from diagnosis to end of life, this State Plan is guided by a core set of underlying principles related to the quality and delivery of care and services (Figure 1).

Figure 1. Principles Guiding the 2022-2026 State Plan

Equitable	• Ensuring that access to and delivery of knowledge, resources, and care does not vary because of personal characteristics such as gender, race, ethnicity, geographic location, and socioeconomic status.
Evidence-based care	• Using the best available evidence (clinical, research, data) in providing care, interventions, services, and supports, and ensuring these align with the values, preferences, and goals of care of the people receiving them.
Collaborative	• Recognizing that it "takes a village" to effectively address ADRD and will require close collaboration among a wide range of partners and stakeholders.
Person and Family-Centered	• Including and partnering of patients, families, and providers in planning, delivering, and evaluating care so that it serves mutual interests.
Life Course Perspective	• Understanding that cognitive health is impacted by a wide variety of factors that occur over one's lifetime and that prevention should be a focus of public health efforts

EXECUTIVE SUMMARY

Pursuant to Health-General Article, §13-3207, Annotated Code of Maryland, and Chapters 410 and 411 of the Acts of 2019, the Council is directed to develop and monitor the State Plan.

Dementia represents an urgent, high burden, and high-cost public health crisis in Maryland. Dementia is a broad term used to describe a collection of symptoms that involve loss of cognitive function and can be caused by a variety of underlying conditions, with Alzheimer's Disease accounting for about 60-80% of all dementia cases.[1,2] Other types of dementia include vascular dementia, dementia with Lewy Bodies, and frontotemporal dementia.[1,2] Although the course and progression of dementia is associated with a number of complex factors and varies from person to person, ADRD is a progressive neurodegenerative condition, which means the symptoms worsen over time, resulting in greater impacts on a number of areas of life.[3–8] As of 2020, an estimated 110,000 Marylanders 65 and older were living with Alzheimer's disease and this number is projected to increase by 18% to 130,000 by 2025.[2,9] ADRD is the most expensive chronic condition in the US, and the direct and indirect costs of care for Marylanders with dementia are staggering.[10] The Maryland Medicaid program spent $1.23 billion to care for people with dementia in 2020 and this spending is expected to increase 24.7% by 2025.[2] Beyond the economic impacts, ADRD puts Marylanders at high risk for a variety of outcomes, including premature nursing home placement, hospitalizations, serious behavioral problems, general medical complications, and poor quality of life.[11–18] Family caregivers of people living with dementia are at risk themselves for adverse outcomes including physical and emotional strain, depression, isolation, premature retirement, lost wages, and financial burden.[19,20] In 2020, estimates suggest that 238,000 family caregivers in Maryland were providing care for people with ADRD and contributed 364 million hours of unpaid care valued at approximately $6.5 billion.[2] In addition, caregivers were estimated to incur $221 million dollars in higher health care costs themselves, as many also suffer their own chronic health conditions. As the prevalence of ADRD increases, demands on family caregivers and the health care and long-term services and supports (LTSS) network are also expected to increase.

The 2022-2026 State Plan builds upon the current 2012 ADRD State Plan and contains a variety of new recommendations for policy and actions suggested to achieve five major goals:

Goal 1: Expand efforts to support public awareness, prevention, and early detection of ADRD;

Goal 2: Enhance quality, access, and coordination of ADRD care;

Goal 3: Enhance and expand supports for family caregivers;

Goal 4: Advance ADRD research and encourage evidence-based practices; and

Goal 5: · Enhance data capabilities related to dementia and dementia impact and effects of interventions.

The Council envisions a dementia-capable Maryland which supports the health and well-being of its at-risk citizens and provides care, services, and resources through a whole-person, coordinated approach to meet the needs of Marylanders living with dementia and their caregivers across the disease continuum, care settings, and from diagnosis to end of life. The State Plan serves as a roadmap for addressing ADRD in Maryland—one that takes a hopeful, data-guided, evidence-based approach to enhance areas critical to building better infrastructure, public awareness and empowerment, better and more coordinated care, a dementia-capable workforce, comprehensive caregiver support, and care innovations through research. The Council recognizes that the plan is a first step in a longer process to realize the goals put forth—a process that requires stakeholder collaboration, additional resources, and dedicated oversight for coordination, implementation, and monitoring of progress. The Council believes this vision is achievable to ultimately benefit Marylanders living with dementia, their families and caregivers, health systems, and the community at large.

INTRODUCTION TO THE 2022-2026 STATE PLAN

In 2012, the ADRD Commission published Maryland's first ADRD State Plan which documented issues related to ADRD in Maryland and made a set of recommendations to serve as a blueprint to address the needs of people living with dementia, their families and caregivers.

In 2013, the Virginia I. Jones Alzheimer's Disease and Related Disorders Council (the Council) was authorized to continue the work of the Commission. Named in the honor of Virginia I. Jones, a dedicated public servant and Marylander who lived with Alzheimer's Disease for more than two decades, the Council was charged with developing and monitoring the State Plan and reviewing, promoting, and expanding statutes, policies, and programs to improve or enhance the lives of people living with dementia and their families. In 2019, pursuant to Health-General Article, §13-3207, Annotated Code of Maryland, and Chapters 410 and 411 of the Acts of 2019, the Council was re-seated and was directed as part of its charge to update the State Plan and advocate for the State Plan.

Throughout 2020 and 2021, the Council undertook a collaborative process to update and enhance the 2012 State Plan. The Council's revision process included an environmental scan of national, state, and local initiatives, policies, and programs relevant to Alzheimer's disease and healthy brain aging, a systematic review of 18 recently-updated Dementia State Plans, a series of open Council workgroup meetings, a series of listening sessions for oral public comment, the solicitation of public comment via email, and iterative revisions of the State Plan's proposed goals, actions and strategies.

Through this review process the Council found that much has been accomplished in Maryland over the past 10 years to support brain health and improve care and outcomes for Marylanders living with dementia. This includes, but is not limited to, programs/initiatives/resources/policies such as:

- Maryland Total Cost of Care Program and the Total Cost of Care All-Payer Model,
- Baltimore City Healthy Brain Initiative,
- Age-Friendly and Dementia Friendly Community Initiatives,
- AARPs Staying Sharp Program,
- Maryland Access Point (expansion and enhancement),
- Dementia Capable Community Connections,
- Johns Hopkins Geriatric Workforce Enhancement Program (GWEP),
- Community for Life^{SM} (CFL),
- State Health Information Exchange (CRISP), and
- Alzheimer's Association Health Systems and Clinicians Initiative to Enhance Care and Improve Outcomes.

The 2022-2026 State Plan aims to build on, enhance, and extend these ongoing efforts in Maryland and to align with and leverage important new policies and opportunities happening across the country, such as:

- The Centers for Disease Control and Prevention (CDC) Healthy Brain Initiative,
- The Affordable Care Act,
- Building Our Largest Dementia Infrastructure for Alzheimer's (BOLD) Act Funding,
- The National Alzheimer's Project Act (NAPA),
- Younger-Onset Alzheimer's Disease Act as part of the Older Americans Act,
- Centers for Medicare and Medicaid Services Health Care Innovation Center (CMMI),
- RAISE Family Caregivers Act,
- Dementia Friendly America, and
- American Rescue Plan Act.

This 2022-2026 State Plan builds on these positive changes, takes advantage of opportunities for improvement, and most importantly, offers hope to Marylanders now and in the future through the promotion of healthy brain aging and brain health, early detection and diagnosis, a better and more holistic approach to ADRD treatment and management.

BACKGROUND

Dementia is a general term for the loss of memory, language, problem-solving and other cognitive abilities that represent a change from previous functioning, are severe enough to interfere with daily life, and are not better explained by other medical or mental health conditions.[21] Dementia is caused by a variety of underlying progressive neurodegenerative conditions, with Alzheimer's Disease (AD) being the most common form, and leads to greater cognitive impairment and functional dependence in completing everyday activities over time. Behavioral and psychological symptoms, sometimes referred to as neuropsychiatric symptoms, occur in almost all cases over the course of dementia, with agitation, aggression, depression, anxiety, apathy, and trouble with sleeping the most common types of symptoms.[2] More than half of people living with dementia are either undiagnosed by their health care providers or unaware of their diagnosis.[22] The length of time between the development of symptoms and AD diagnosis can be years in some cases, with an estimated average of about 2.8 years.[23] While the course and trajectory of symptoms and lifespan of individuals diagnosed with dementia can vary widely based on a number of factors including type of dementia, studies suggest that someone with the most common form, AD, will live a median of 8.2 years following diagnosis.[23, 24] While some changes in memory are normal as people age, dementia is not part of normal aging—in fact, many older people live their entire lives without developing dementia. The CDC recommends that individuals experiencing memory concerns should consult with their health care provider.[25] Table 1 lists the Alzheimer's Association's 10 Warning Signs of Alzheimer's Disease.[26]

Table 1. 10 Warning Signs of Alzheimer's Disease [26]

1. Memory loss that disrupts daily life	Forgetting events, repeating yourself or relying on more aids to help you remember (like sticky notes or reminders).
2. Challenges in planning or solving problems	Having trouble paying bills or cooking recipes you have used for years.
3. Difficulty completing familiar tasks at home, at work, or at leisure	Having problems with cooking, driving places, using a cell phone, or shopping.
4. Confusion with time or place	Having trouble understanding an event that is happening later or losing track of dates.
5. Trouble understanding visual images and spatial relations	Having more difficulty with balance or judging distance, tripping over things at home, or spilling or dropping things more often.
6. New problems with words in speaking or writing	Having trouble following or joining a conversation or struggling to find a word you are looking for (saying "that thing on your wrist that tells time" instead of "watch").
7. Misplacing things and losing the ability to retrace steps	Placing car keys in the washer or dryer or not being able to retrace steps to find something.
8. Decreased or poor judgment	Being a victim of a scam, not managing money well, paying less attention to hygiene, or having trouble taking care of a pet.
9. Withdrawal from work or social activities	Not wanting to go to church or other activities as you usually do, not being able to follow football games or keep up with what is happening.
10. Changes in mood and personality	Getting easily upset in common situations or being fearful or suspicious.

Prevalence

An estimated 50 million people currently live with ADRD worldwide.[2] In the absence of access to curative or disease altering therapies, the prevalence will be nearly 153 million by 2050 worldwide. In the US, over 6.2 million adults ages 65 and older are living with dementia, with the prevalence doubling by the year 2050.[2] AD accounts for 60-80% of the dementia cases in the United States. Other types of dementia, including vascular dementia, Lewy body dementia, frontotemporal dementia, and mixed dementia (Table 2) account for smaller but significant proportions of cases.[1,2,27] Different types of dementias are associated with different patterns of symptoms, and it is not uncommon for more than one type of disease condition to be present in the brain at the same time, especially in those 80 years and older. At any given time, over 80% of persons with dementia in the US reside in the community, although nearly three-fourths of persons with dementia receive care in a nursing facility at some point over the course of the illness. Black or African Americans develop AD at a higher rate than any other group of older Americans and are twice as likely to have AD and other forms of dementia compared to non-Hispanic Whites.[2,28–30] Hispanic Americans are also at a disproportionately higher risk and are about are 1.5 times as likely to have ADRD compared to older non-Hispanic Whites.[2,28–30]

An estimated 110,000 Marylanders 65 and over were living with AD in 2020, which is projected to increase to 130,000 by 2025, representing an 18% increase from 2018. [2,9,31] According to the Behavioral Risk Factor Surveillance System (BRFSS), one in 10 Marylanders (10%) over the age of 44 report experiencing subjective cognitive decline, including increased confusion or memory loss, with the prevalence of reported cognitive decline being much higher among (22% vs. 10% overall) lower income older Marylanders. Marylanders reporting subjective cognitive decline are also significantly more likely to have comorbid conditions such as diabetes, hypertension, cardiovascular disease, and depressive disorder compared to those without. Half of the Marylanders with subjective cognitive decline have not discussed their condition with a health care professional.[9,31]

Table 2. Description of Specific Types of Dementia [2,27]

Types	Definition	Symptoms
Alzheimer's Disease	Brain disorder that slowly destroys memory and thinking skills and eventually the ability to carry out simple tasks.	- Severe forgetfulness - Changes in mood - Confusion - Difficulty concentrating or multitasking - Getting lost in familiar places
Lewy Body Dementia	Disease associated with abnormal deposits called alpha-synuclein in the brain. These deposits called Lewy bodies, affect chemicals in the brain whose changes can lead to problems with thinking, movement, behavior, and mood.	- Memory loss - Confusion - Difficulty with movement - Excessive sleepiness - Hallucinations
Vascular Dementia	The most common form of dementia in older adults resulting from injuries to vessels that supply blood to the brain, often after a stroke or series of strokes.	- Memory loss - Difficulty focusing/concentrating - Confusion - Symptoms occurring suddenly then stabilizing before occurring again
Frontotemporal Dementia	This is the result of damage to neurons in the frontal and temporal lobes of the brain.	- Personality changes - Difficulty with judgment and social skills - Poor financial or personal decisions - Feelings of disconnectedness - Difficulty with language and communication
Mixed Dementia	A combination of two or more types of dementia.	- Memory loss - Difficulty focusing/concentrating - Confusion

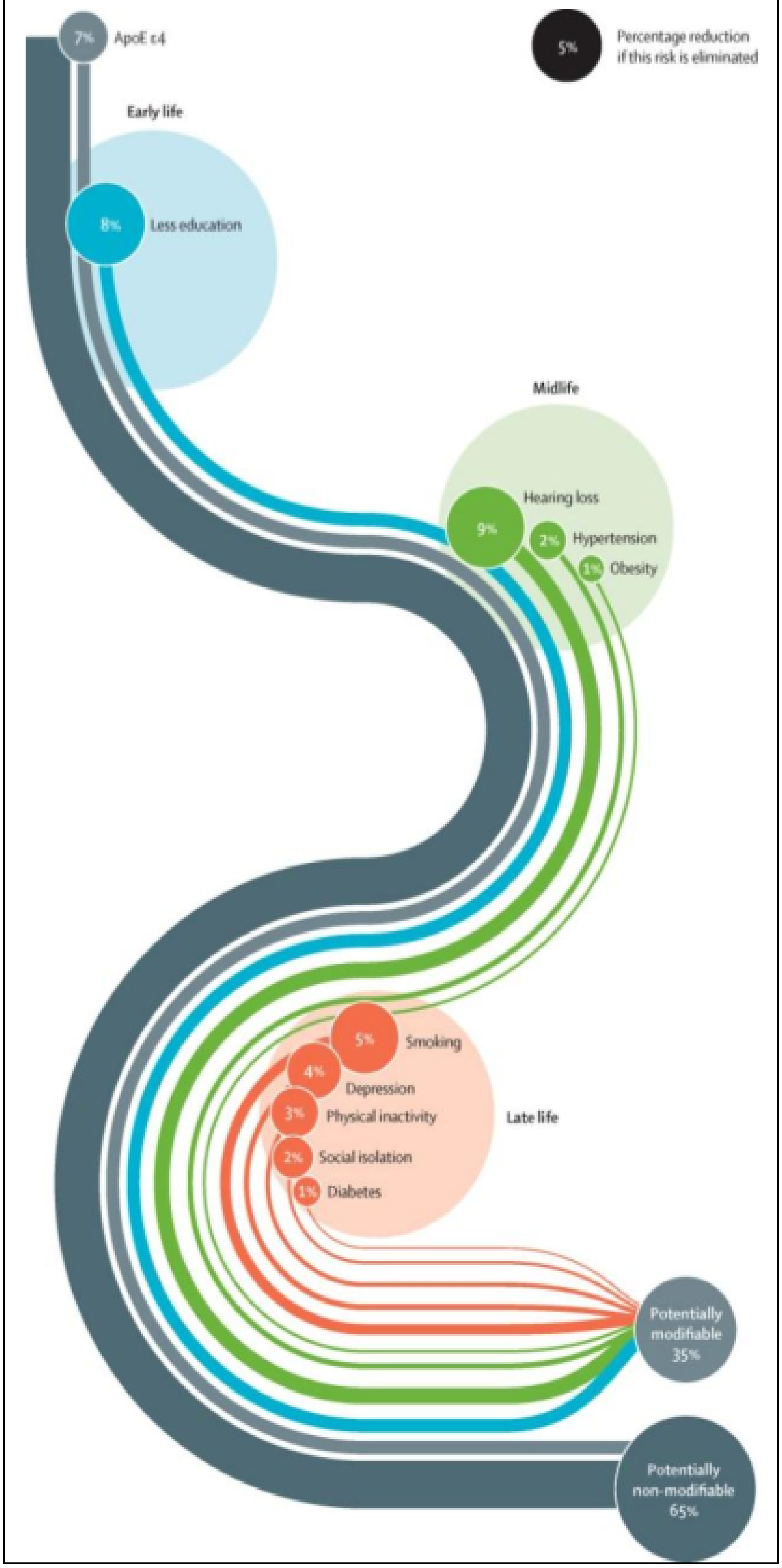
Risk Factors

A number of risk factors associated with ADRD have been identified, some of which are modifiable and some of which are not. Increasing age, female biological sex, being Black/African American race or Hispanic/Latinx ethnicity, and having genetic factors (eFAD: myloid precursor protein [APP], presenilin-1 [PS1], and presenilin-2 [PS2], APOE*4 load, genetics related to other morbidities such as cardiovascular disease), having certain conditions such as Down Syndrome, and history of a traumatic brain injury, are all linked to higher risk of ADRD.[1,2,7,8]

The good news is that recent studies and reviews of the best available evidence suggest the potential for reducing risk for ADRD is significant. An international group of dementia experts published in The Lancet note that the number of new dementia cases could be reduced by up to 35%, by modifying risk factors over the life course (Figure 1).[7,8]

While targeting early childhood education (thought to build cognitive reserve and resilience in later life), hearing and sensory impairments, medical conditions such as diabetes, hypertension and obesity, physical inactivity, tobacco use, depression, and social isolation are believed to reduce risk in and of themselves, the authors suggest the greatest impact will be through addressing multiple factors simultaneously.[7,8] Given these risk factors tend to cluster around populations experiencing health inequities, people living in poverty, Black/African Americans, and other racial and ethnic minority populations may derive the greatest impacts from public health interventions addressing these factors.[7,8]

Figure 1. Modifiable risk factors for dementia over the life course[7]



Early Detection and Diagnosis

Diagnosing dementia, especially early in the condition, is challenging. Although the prevalence of dementia is considerable among persons age 65 and older, over 50% of people living with dementia (PLWD) are undiagnosed or unaware of their diagnosis.[22,32] There are many factors which contribute to under-diagnosis of ADRD.[33] For many patients and families, there may be misconceptions that the cognitive or behavioral symptoms of dementia are just a normal part of "getting older." Stigma, shame, and concealing symptoms for fear loved ones, friends, and neighbors will "find out" are other significant barriers to obtaining an accurate diagnosis. In addition, a general lack of public education about the signs and symptoms of ADRD leads to under-diagnosis.[33,34] At the provider and health system level, surveys consistently show that providers often report difficulty making a conclusive diagnosis and express uncertainty about differentiating between a disease process and normal aging.[33,34] The Alzheimer's Association 2021 Alzheimer's Disease Facts and Figures report finds that although nearly 9 in 10 primary care physicians (87%) expect to see an increase in PLWD over the next five years, 50% of those physicians surveyed say the medical profession is not prepared to meet this demand.[2] Some health care providers may have negative attitudes about the benefits of an early dementia diagnosis as they may feel that there is "little that can be done." Further, due to the limited time for patient visits, lack of resources, and inadequate training of primary care physicians, along with the disconnect between medical care and non-medical services networks and fragmented health care financing systems, the long-term care continuum is currently ill-prepared to assess and address the wide-ranging medical, social, and supportive care needs unique to dementia.[35–37] For example, the time allotted for an annual wellness doctor's visit for Medicare beneficiaries may not provide enough time to address comorbid medical conditions, let alone the complexities of managing care needs for PLWD. Health care providers may perceive comprehensive dementia management for both patients and their family caregivers as too time-consuming and difficult to tackle (e.g., referrals to home care, adult daycare, psycho-social services, behavioral health).[35–37]

There are a number of potential benefits of an early dementia diagnosis. Many experts believe that early and accurate diagnosis can lead to better disease management, improve overall care and quality of life, and possibly lead to better outcomes.[38,39] Earlier diagnosis can provide the patient and family with time to prepare, plan, and make important and informed decisions about future care. It also provides time to address care needs, to obtain dementia care education and information (e.g., what is dementia, what to expect, signs of medical conditions such as urinary tract infections that can exacerbate cognitive or behavioral symptoms), to address to legal and financial matters, as well as opportunities to participate in research studies.[37–39] Confirmation of a dementia diagnosis may provide individuals with some relief and closure about changes and symptoms and may also allow patients and family caregivers time to adjust and set expectations while adapting to the new caregiver role. An earlier dementia diagnosis will facilitate more interventions, information, and supports to proactively address care needs and improve outcomes. Experts believe that any disease-altering therapies on the horizon will have a limited window of opportunity for benefit; thus, it will be critical to increase early dementia detection abilities in the future.[40] The potential drawbacks of early diagnosis for patients and families include patient fear of stigma or social isolation, and the concern that disclosure of the new diagnosis may lead to burden for patients and families. The best available research today actually shows that disclosure does not result in a catastrophic reaction in most people, and only a minority of patients and caregivers report feeling shocked or threatened, particularly those who did not expect it (for example, a mildly-impaired, early-stage individual who may be in denial). [41–43] However, most people report feeling as though the diagnosis has confirmed their assumptions, and it is a relief. [41–43] Health providers may experience concern about misdiagnosis and uncertainty about prognosis and rate of progression, which can vary widely by individual patient.[44] Further, the use of universal standard screening of all patients at-risk, even in cases of no subjective or objective cognitive impairment concerns, is resource intensive.

Impacts of ADRD

ADRD places Marylanders at high risk for a variety of undesirable outcomes including premature nursing home placement, hospitalizations, serious behavioral problems (e.g., agitation, aggression, depression, anxiety, delusions, hallucinations, sleep disturbances), general medical complications (e.g., urinary tract infections, falls, delirium), and poor quality of life.[11–18] Family caregivers of PLWD are at risk themselves for physical and emotional strain, depression, isolation, premature retirement, lost wages, and financial burden.[19]

The economic costs of dementia are enormous. ADRDs are the most expensive set of chronic conditions in the US, surpassing heart disease and cancer.[10] The total costs (direct and indirect) for all Americans with ADRD was estimated at $305 billion in 2020, with $155 billion (50%) paid by Medicare, $51 billion (17%) by Medicaid, $66 billion (22%) out of pocket, and $33 billion (11%) from other sources.[45] Medicare, which is federally financed, pays for much of the medical care for those over 65, but rarely covers the cost of home and community-based services (e.g., adult day care programs, care management, personal care, home health aides, transportation, caregiver respite, nutritional services) and residential long-term care services (long stay nursing facility care, assisted living care), both of which are crucial components of dementia care. Medicaid pays for most LTSS in an institutional setting for low-income persons with disabilities such as those resulting from dementia, but this only reaches a small percentage of those in need.[46] Only about a quarter (24%) of PLWD in the community have Medicaid coverage over the course of a year.[47] There is substantial variation, however, in costs of caring for persons with dementia, and costs differ by care setting.[48,49] National average annual per-person spending in 2020 for Medicare beneficiaries 65 and older with dementia compared to those without was more than three times higher for Medicare ($26,358 Per Beneficiary Per Year [PBPY] vs. $8,102 PBPY) and 23 times higher for Medicaid ($9178 PBPY vs. $391 PBPY), with inpatient hospital care and skilled nursing home care as major cost drivers.[2,50] Delaying placement in nursing homes or other long-term care facilities can have a great impact on Medicaid spending. Maryland Medicaid spent $1.23 billion on individuals aged 65 and older living with dementia in 2020, and these costs are projected to increase by 24.7% from 2020 to 2025.[2]

Out of pocket spending for health and long-term care services was estimated to be nearly five times higher for beneficiaries with dementia versus those without ($11,571 per year vs. $2,503 per year) in 2020, and informal family members often provide financial support and unpaid time.[2] In 2020, estimates suggested that 238,000 family caregivers in Maryland were providing care for PLWD and contributed 364 million hours of unpaid care, amounting to an estimated total economic value of $6.5 billion.[2] In addition, in 2017, caregivers were estimated to incur $221,000,000 in higher health care costs themselves, as many also suffer from at least one chronic condition.[51]

Alzheimer's disease is the 5th leading cause of death in the US, and the 7th leading cause of death in Maryland in 2017 according to the CDC. Maryland's 2017 annual mortality rate for Alzheimer's disease was 17.1%, with 1,191 deaths per 100,000 people.[31,52] Expansion of hospice care at the end of life can allow individuals to die with dignity and without pain and other distressing symptoms, avoid unnecessary transitions of care and hospital stays, and is associated with fewer PLWD having more than two hospitalizations for any reason, or more than one hospitalization for pneumonia, urinary tract infection, dehydration or sepsis in the last 90 days of life.[2,53] For Maryland, the number of people in hospice with dementia was 4,072, and the dementia patient hospital readmission rate was 24.4% in 2020.[2]

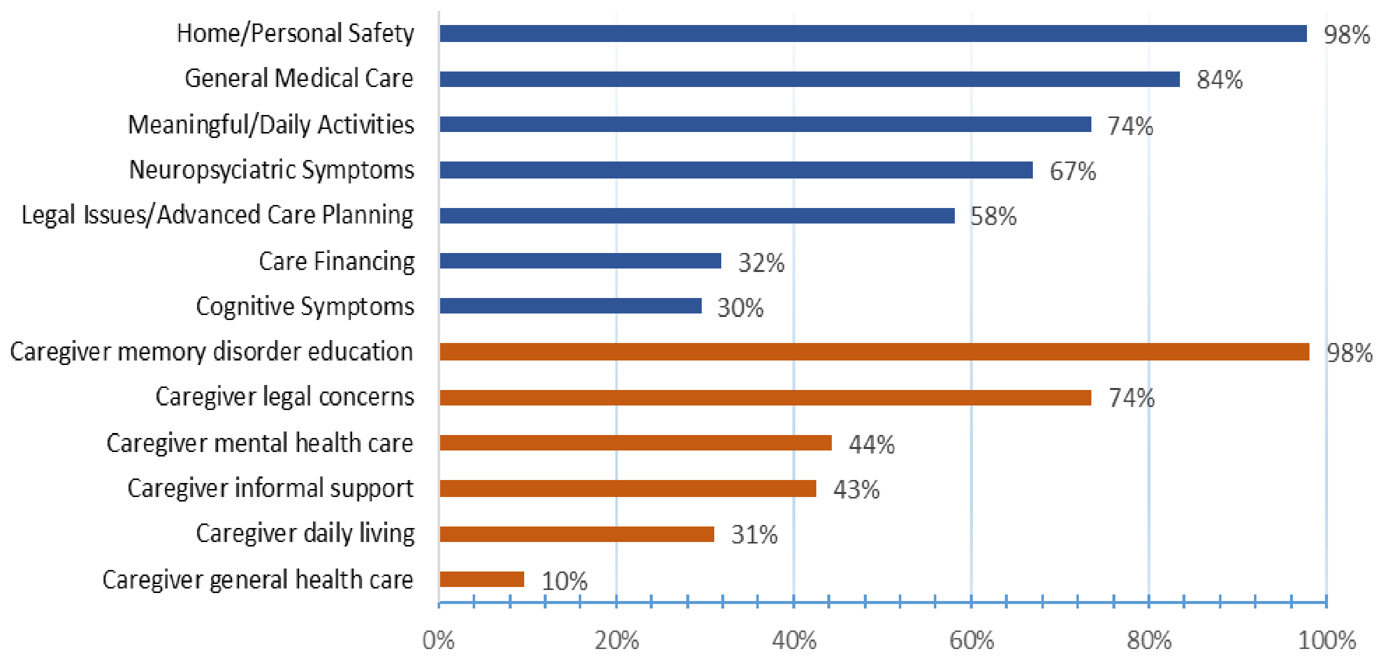
Mounting evidence shows that persons with cognitive impairment and ADRD were differentially impacted by the emergence of the novel coronavirus disease (COVID-19).[2] Preliminary CDC Mortality and Morbidity reports estimate there were at least 42,000 more deaths from ADRD in 2020 compared with the average of the five years before, about 16% more than expected, indicating higher vulnerability of this group.[54] Additional excess critical illness and hospitalizations in older adults was very high in 2020 compared with prior years.[2,54] These hospitalizations and treatments (e.g., mechanical ventilation which increases risk of delirium) have the potential to increase the number of cases of cognitive impairment and dementia following critical illness in the coming years.[2]

Care Needs Among People Living with Dementia (PLWD) and Their Caregivers

Despite the high spending, PLWD still experience significant disparities in care and excesses in adverse outcomes and higher costs.[55,56] Primary care, the hub of care for most PLWD, faces significant time and resource challenges, making it difficult to assess and respond to the complex and multidimensional care needs of both PLWD and caregivers including non-medical, supportive care needs.[57,58] Unfortunately, dementia care needs commonly go unevaluated and unmet.[57–64] Common, modifiable, dementia-related needs including lack of dementia recognition and diagnostic evaluation, safety (e.g., home safety, wander risk management, driving, fall-risk), medical care and multimorbidity management, management of behavioral symptoms, medication management, and social and supportive care in daily living (e.g., meaningful activities, activities of daily living [ADL] assistance).[57–61,64–67] Family caregivers have a number of needs as well, including education about memory disorders and what to expect, knowledge of and access to medical and community-based resources, self-care, social support, and emotional health.[62,63,68]

Two recent Maryland-based studies from Johns Hopkins University between 2014 and 2019 provide detailed data on care needs for Marylanders with ADRD who are living at home and with their caregivers.[62,69,70] The studies included 646 community-residing PLWD (n=646) and informal caregivers (n=637) in the greater Baltimore and Maryland suburban District of Columbia region (Anne Arundel, Baltimore, Carroll, Harford, Howard, Montgomery, and Prince George's Counties, and Baltimore City). The study utilized the Johns Hopkins Dementia Care Needs Assessment (JHDCNA), and found that unmet needs for community-living PLWD and their caregivers are extremely common, modifiable, and often non-medical,[71] validating an earlier Maryland-based ADRD needs study.[63,67,68,72] Marylanders living with dementia had high prevalence rates of non-medical needs such as home and personal safety (98%), meaningful/daily activities (74%), and caregiver informal support (43%). Other common needs were for neuropsychiatric behavior management (67%), medical condition management (84%) and caregiver mental health (44%) (Figure 2). Unmet JHDCNA needs are related to poor outcomes like caregiver burden.[67,71]

Figure 2. Prevalence of Marylanders with ADRD and their caregivers with at least one unmet care need by types of need domain. [71]



Caregivers of PLWD in these studies (n=641) reported a number of areas where they desired more support. The most prevalent priority areas were knowledge of and access to community resources for memory problems (37%), education about memory disorders (36%), support for themselves (30%), and how to manage dementia-related problem behaviors (29%) (Figure 3). A supplemental survey (n=65) asked caregivers to rank their top three concerns related to caregiving and found that uncertainty about being able to keep the PLWD at home, financial difficulties, and respite time were consistently ranked as the most common top three concerns (Figure 4).[62]

These two studies also examined whether there are disparities in care by race.[64,73] Data suggest Black Marylanders with ADRD had greater overall percentages of unmet needs (27%) compared to Whites (22%) ($p<0.001$), as did Black ADRD caregivers compared to their White counterparts. The largest gaps by race were in unmet needs related to advance care planning and other legal issues (71% vs. 42%), caregiver-related legal issues (82% vs. 63%), meaningful/daily living activities for the PLWD (79% vs. 67%), and management of the PLWD's neuropsychiatric symptoms (71% vs. 62%) (Figure 5). Black ADRD caregivers also tended to use fewer community resources for dementia care, with the exception of in-person conferences/health fairs (Figure 6).[64,73]

Figure 3. Survey of self-report areas related to ADRD care that Maryland informal caregivers (n=641)

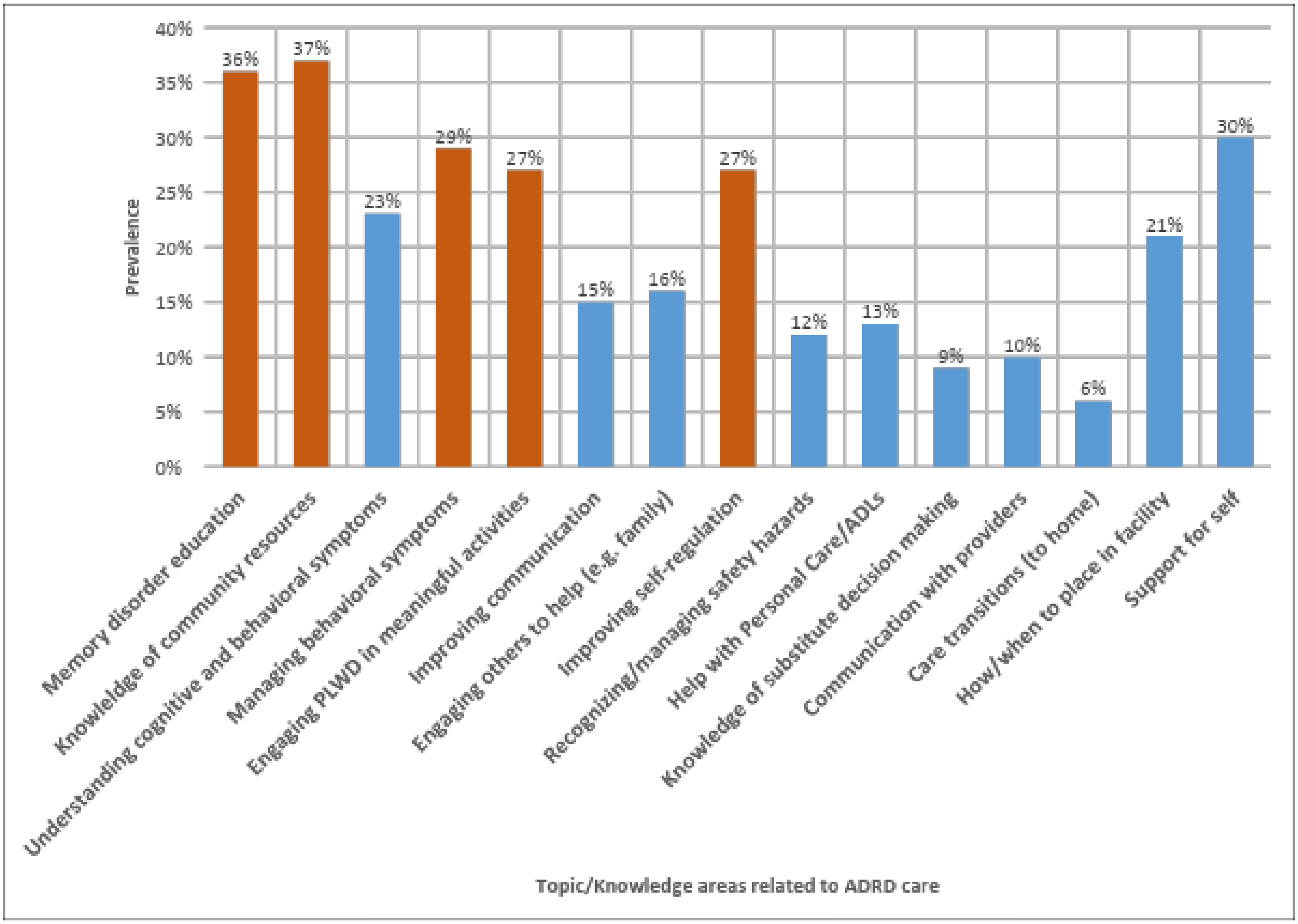


Figure 4. Frequency of main concerns related to caring for PLWD among informal caregivers in Maryland (n=65)

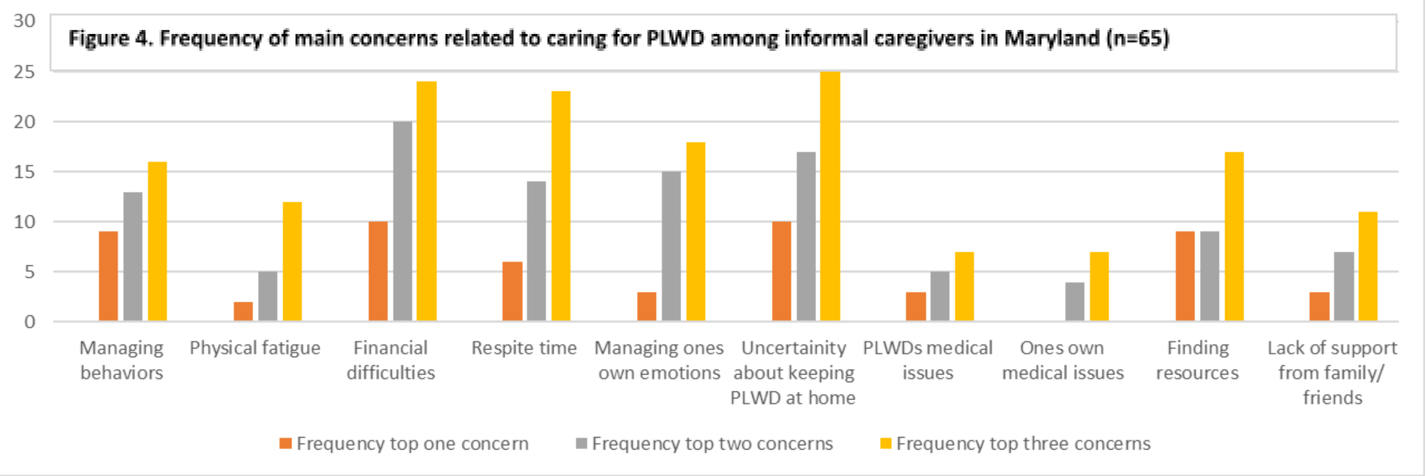


Figure 5. One or more unmet care needs for persons living with dementia and their caregivers by race and need domain (n=608)

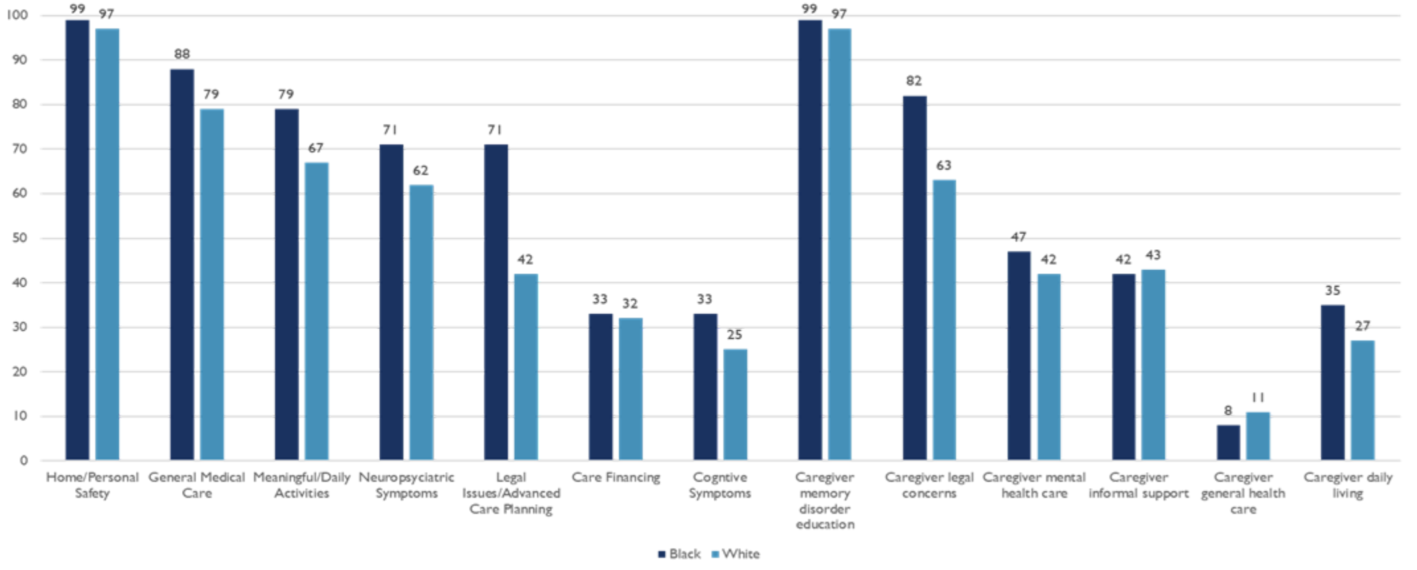
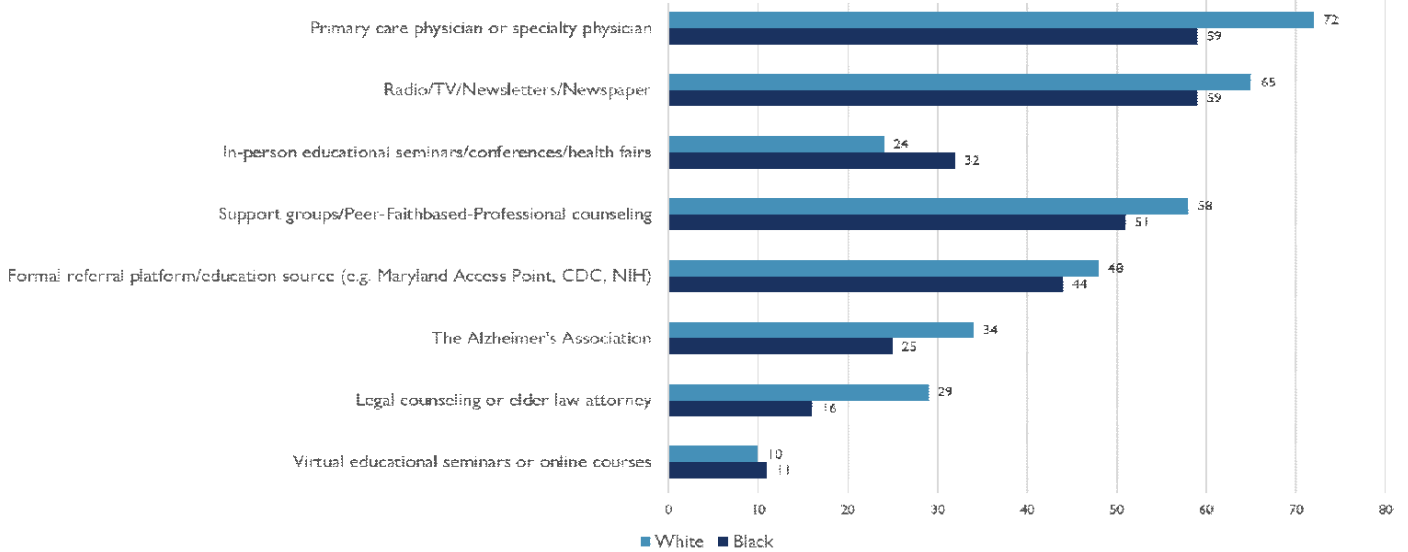


Figure 6. Caregiver reported resources used related to dementia caregiving in the past year (n=608)



Dementia Care and Treatment

Currently there are no pharmacological treatments available to slow or stop the progression of most dementias, which makes these conditions fatal. Five drugs approved by the US Food and Drug Administration (FDA) for the treatment of AD include: rivastigmine, galantamine, donepezil, memantine, and memantine combined with donepezil.[2] These drugs temporarily relieve the cognitive symptoms of dementia but have relatively modest impacts on certain outcomes, are time limited, and benefits vary by individual.[74,75] Exact causes of brain cell death and neurodegeneration in AD are not fully understood, though amyloid plaques are a marker of the disease and a potential contributor. Several anti-amyloid monoclonal antibody treatments are currently under development, as are several other novel therapeutics, but additional research is needed to validate clinical benefit of these treatments. As new treatments with proven clinical effectiveness emerge, access to specialty care, affordability of medications, and disparities in access and affordability will increase in importance. There are no drug therapies specifically approved by the FDA to treat the neuropsychiatric symptoms associated with dementia, however, if non-pharmacological approaches are unsuccessful, drugs such as antipsychotics may be used to treat symptoms such as agitation, aggression, and psychosis.[2] It is strongly recommended that antipsychotics be used as a last resort as these drugs are associated with serious adverse events such as death and stroke in persons with dementia.[76] It is generally recommended individuals and caregivers discuss potential medications with their health care providers to ensure they are appropriate for the stage and type of dementia.

A range of evidence-based non-pharmacological intervention options exists to address neuropsychiatric/behavioral symptoms, function, quality of life, and caregiver coping, skill-building, well-being, and burden.[13,77–81] The different types of interventions include lifestyle (e.g., exercise, social activities), psychosocial, psychoeducational, cognitive stimulation, behavioral, skill building, and meaningful activity-based.[53,3,15,78,79,82,83] Examples of evidence-based programs currently in practice include Resources for Enhancing Alzheimer's Caregiver Health (REACH), New York University Caregiver Intervention, Reducing Disability in Alzheimer's Disease (RDAD), Savvy Caregiver Program, STAR-Caregivers (STAR-C) (also known as the Seattle Protocols), and Tailored Activity Program (TAP).[84–90] Overall, evidence supporting the effectiveness of such programs is growing and the magnitude of the intervention benefit may vary by outcome. The most effective non-pharmacological options for neuropsychiatric symptoms appear to be behavior management techniques, environmental modifications, structured activities, and caregiver skills training and education.[77,82,91–95] For optimal quality of life, social connection, activities, environmental modifications, and caregiver coping strategies and communication skills interventions appear to work best.[3,13,79,96,97] Respite care, cognitive behavioral therapy, and problem solving interventions appear to work best when the desired outcome of interest is reduction of caregiver burden and improving caregiver well-being.[98–101] The evidence base for the use of other types of integrative and complementary interventions such as music, arts-based, and equine therapy interventions is growing.[102–105]

Despite the existence of effective care options, the reality is that PLWD and their families rarely receive dementia care as a comprehensive, coordinated set of services. Medical organizations and best practice guidance support the integration and coordinated use of evidence-based approaches (including combinations of both non-pharmacological and pharmacological) to maximize effectiveness on outcomes.[3–6,44,106] Care coordination and care management approaches are a tool to create effective dementia care "pathways." Most management models include a comprehensive assessment of care needs for both the person living with dementia and their family caregiver, individualized care planning that is linked to appropriate evidence-based interventions, help facilitating or coordinating needed care or support services, referrals to resources, regular monitoring, as well as education, emotional support, and services for family caregivers.[69,70,107–116] Given that most PLWD live in the community, the availability, delivery, and affordability of home and community-based services are a critical aspect of the LTSS system.

Key points

- ADRD is very common and the prevalence in Maryland will increase substantially over the next several decades.
- Risk reduction or prevention of ADRD in later life may be possible by taking a life course approach to public health and by addressing modifiable risk factors.
- Dementia is a highly stigmatized group of conditions and continues to be under-detected and under-diagnosed.
- ADRD is strongly associated with high health care and long-term care costs and with high burden for individuals and families.
- People belonging to minority groups, women, and those living in poverty are disproportionately affected by ADRD and have significantly more health care disparities and worse outcomes.
- Currently there are no pharmacological treatments available to slow or stop the progression of most dementias, which makes these conditions fatal.
- Effective care management and symptom treatment options exist, however most PLWD and their family caregivers have care needs that go unevaluated and unmet. Many of these are non-medical needs.
- The provision and coordination of dementia care is inadequate, although effective care and treatment strategies have been developed.

THE 2022-2026 STATE ADRD PLAN

Overview

The 2022-2026 State Plan builds on the 2012 Maryland ADRD State Plan and contains a variety of new recommendations for policy and actions suggested to achieve five major goals:

Goal 1: Expand efforts to support public awareness, prevention, and early detection of ADRD;

Goal 2: Enhance quality, access, and coordination of ADRD care;

Goal 3: Enhance and expand supports for family caregivers;

Goal 4: Advance ADRD research and encourage evidence-based practices; and

Goal 5: Enhance data capabilities related to dementia and dementia impact and effects of interventions.

The Council and its partners envision a dementia-capable Maryland which supports the health and well-being of its at-risk citizens and provides care, services, and resources through a whole-person, coordinated approach to meet the needs of Marylanders living with dementia and their caregivers across the disease continuum, care settings, and from diagnosis to end of life.

Using the State Plan as a Roadmap: 2022-2026

The State Plan serves as a roadmap for addressing ADRD in Maryland—one that takes a hopeful, data-guided, public health approach to enhance areas critical to support and enhanced infrastructure, more robust public awareness and empowerment, better and more coordinated care, a more dementia-capable workforce, comprehensive caregiver support, and care innovations through research. Because of the complex and broad nature of the State Plan, implementation will require a phased, multi-step approach, involving strategic engagement of a number of partners along the way. The Council submits the State Plan as a first step in a longer process to realize the goals put forth—a process that will require stakeholder collaboration, additional resources, and dedicated oversight for coordination, implementation, and monitoring of progress. The Council believes this vision is achievable and will ultimately directly benefit Marylanders living with dementia, families, health systems, and the community at large. As such, the Council has suggested broad and flexible timeframes for implementation of recommendations, but these may be adjusted based on the availability of resources and other factors. Within the State Plan, the use of the following language is: Short-term refers to years 1-2, Mid-term refers to years 2-3, and Long-term refers to years 3-4.

It is imperative, as the State Plan recommends in Goal 1.A.1, to appoint a director-level position (i.e., “Director of Dementia Services and Brain Health”) within a relevant state agency (e.g., Maryland Department of Health, Maryland Department of Aging, or other relevant agency) charged with the oversight, coordination, and implementation of the activities laid out in the State Plan. This will include identification and coordination of public and private partners involved, and development and monitoring of activity timeframes, milestones, and metrics of success.

Development Process

Pursuant to Health-General Article, §13-3207, Annotated Code of Maryland, and Chapters 410 and 411 of the Acts of 2019, the Virginia I. Jones Alzheimer’s Disease and Related Disorders Council (the Council) is directed to:

1. Update the State Plan on ADRD and advocate for the State Plan;
   (I) Examine the needs of individuals with ADRD and their caregivers; and

   (II) Identify methods by which the State can most effectively and efficiently assist in meeting those needs;

2. Advise the Governor and the General Assembly on policy, funding, regulatory, and other issues related to individuals with ADRD and their caregivers; and
3. Develop and promote strategies to encourage brain health and reduce cognitive decline.

In 2019, the Council, with a fully appointed membership, elected Quincy Samus, PhD, to serve as Chair. The Council prioritized the task of the updating of the 2012 State Plan, and undertook a comprehensive process to review and revise the existing ADRD State Plan, which was developed by the former Commission on ADRD in 2012 (executive order 01.01.2011.21). The Council organized into five workgroups based on the goal areas of the original 2012 State Plan and worked collaboratively to prepare an environmental scan of relevant national, state, and local initiatives, policies, or programs related to ADRD, and healthy brain aging, categorizing these items by goal/theme. Once the scan was complete, the Council revised the five goals for the updated State Plan, and each workgroup drafted a set of strategies and actions related to their assigned goal. A systematic review was conducted of 18 State Dementia Plans from other states that had been updated or adopted in the last four years to inform and support the Workgroups. Workgroups then presented their proposed strategies and actions for their assigned goal to the full Council for feedback and updated them based on comments received. The updated goals, actions, and strategies were then collated and released for public comment on the Council website hosted by the Maryland Department of Health (MDH) and through professional networks of members, community partners, and state organizations. Public comments were solicited via email as well as through two virtual listening sessions. The Chair and Council staff reviewed each comment and maintained a written log of the requested change status.

Goal 1: Expand efforts to support public awareness, prevention, and early detection of ADRD.

Introduction: Increasing public awareness of ADRD can help to reduce the stigma surrounding memory problems and empower families to connect to information, resources, and services, and to seek early assessment about memory concerns. Seeking out an early evaluation of any cognitive or behavioral symptoms and obtaining accurate diagnosis can enable access to treatment and services which will result in better health outcomes and quality of life.

Further, while there are currently no definitive strategies proven to prevent ADRD, research shows there are several modifiable risk factors that, when addressed over the life course, can add up to substantial opportunities to reduce risk of developing dementia.

Three key strategies are recommended as a focus over the next four years to expand public awareness, prevention, and early detection of ADRD: (A) Increase public awareness about ADRD, (B) Increase early detection and diagnosis, and (C) Advance prevention strategies and healthy brain aging.

GOAL 1: EXPAND EFFORTS TO SUPPORT PUBLIC AWARENESS, PREVENTION, AND EARLY DETECTION OF ADRD

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
A. Increase public awareness about ADRD	1. Allocate State funds in 2022 legislative session for Fiscal Year 2023 to support a director-level position (e.g. “Director of Dementia Services and Brain Health”) and resources within a relevant state agency (e.g., Maryland Department of Health, Maryland Department of Aging, or other relevant agency) that would coordinate implementation of the actions outlined in the State Plan. This dedicated staff member would coordinate, oversee, and monitor the recommendations (Goals 1-5), including the creation of implementation milestones, selection and use of measurable outcomes and timeframes, and work with the Council and stakeholders to identify and apply for additional funding opportunities to enable further planning and implementation of the recommendations laid out in the State Plan.	X		
	2. Implement a multi-pronged public awareness campaign about dementia and healthy brain aging and coordinate the public health education campaign and messaging with other State initiatives including efforts related to the Maryland State Plan on Aging. Messaging should be employed across multiple mediums including social media, single print, digital media, public presentations, in-person educational sessions/workshops, virtual sessions, television, Maryland Access Point (MAP), and service networks. Dementia education topics could include: a. Normal aging versus dementia; b. Warning signs; c. Benefits of early evaluation of subjective cognitive decline; d. Early diagnosis and early intervention; e. Cognitive screening benefits under Medicare Annual Wellness Visits;		X	

GOAL 1: EXPAND EFFORTS TO SUPPORT PUBLIC AWARENESS, PREVENTION, AND EARLY DETECTION OF ADRD

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
	f. Providing guidance and support for newly diagnosed persons and their families for what to expect/prognosis after diagnosis and symptoms (e.g., memory and functional impairment and neuropsychiatric/behavioral symptoms) and illness duration; g. Strategies to maximize quality of life; and h. Education about healthy brain aging preventive factors, such as diet, nutrition, physical activity, social engagement, cognitive stimulation, management of medical conditions, sensory impairment, and other lifestyle factors (e.g., drinking, smoking).			
	3. Ensure educational campaigns effectively target and reach rural populations (who may not have equal access to care and information) as well as minority and under-resourced populations (who are disproportionately impacted by ADRD).		X	
	4. Ensure State and local information centers such as MAP, the Maryland Department of Aging (MDoA), MDH, Area Agencies on Aging (AAAs), and community-based organizations have access to and utilize culturally appropriate and trusted information.		X	
	5. Identify trusted national, State, and local information centers available to Marylanders living with ADRD and their caregivers. Ensure these trusted resources are known to and disseminated through State agencies and community partners (e.g., health and long-term support services, community, advocacy, and faith-based organizations and networks) to support ADRD and healthy aging-focused education (e.g. 10 Warning Signs of Dementia-Alzheimer's Association, CDC's Health Brain Initiative, and Go4Life-National Institute on Aging (NIA)). Educate State agencies and community partners on where to refer persons for further education and consultation on ADRD and brain health (e.g., Alzheimer's Association, AARP Maryland, NIA, National Institute of Neurological Disorders and Stroke, Alzheimer's Foundation of America, local memory clinics/geriatric psychiatrists/ geriatricians/neurologists).	X		
	6. Provide education about ADRD research and the benefits of participating in clinical trials through www.clinicaltrials.gov and TrialMatch.	X		
	7. Communicate Maryland-specific cognitive and behavioral health and caregiver data from the Maryland Behavioral Risk Factor Surveillance System (BRFSS) to partners in state and local	X		

GOAL 1: EXPAND EFFORTS TO SUPPORT PUBLIC AWARENESS, PREVENTION, AND EARLY DETECTION OF ADRD

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
	government and community organizations to increase use of data for program planning. Results should be made available in multiple mediums (e.g., through blog, webinar, or fact sheets/digital media).			
B. Increase early detection and diagnosis	1. Include training in progressive neurocognitive disorders in the curricula of all State-funded educational institutions including medical, nursing, social work, and other health professional education programs, continuing education credit programs (CME, CEU), the Maryland Primary Care Program (MDPCP), and through educational summits and conferences for health care professionals.			X
	2. Facilitate systematic outreach to and engagement with health care professionals (e.g., primary care providers, internists, specialty physicians, allied health professionals) and health care leaders to provide education and training on the indicators of dementia, the value of early diagnosis and related treatment/management pathways, and how to incorporate this into provider visits. These actions would include a series of “Dear Colleague” letters sent from trusted Maryland-based health care professional organizations or programs partners (e.g., MedChi, MD Board of Physicians, MDPCP).		X	
	3. Educate health care professionals about and promote the use of the Medicare Annual Wellness Visit, which includes an assessment of cognitive function, and the follow-up Cognitive Assessment and Care Plan Services (if cognitive impairment is identified)--which are Medicare-reimbursable utilizing Medicare billing codes.	X		
	4. Educate health professionals about available standard ADRD screening assessments and diagnostic tools and ensure primary care providers are adequately prepared to evaluate, diagnose, and discuss ADRD-related diagnoses with patients and their families or caregivers. Promote the importance of an early and accurate diagnosis and include resources, assessment tools and education on other related dementias (e.g., FTD, Lewy Body disease, vascular dementia, Huntington’s Disease, Parkinson’s Disease, and chronic traumatic encephalopathy (CTE)) and early-onset dementia.	X		
	5. Secure funding to implement these recommendations to improve early diagnosis, and promote risk reduction through federal funding opportunities (e.g., CDCs federal Building Our Largest Dementia [BOLD] Public Health Programs Awards authorized through Public Law 115-406), State funding (e.g., in the Governor’s annual State budget and budget bill passed by the Maryland General Assembly), and through public private partnerships.	X		

GOAL 1: EXPAND EFFORTS TO SUPPORT PUBLIC AWARENESS, PREVENTION, AND EARLY DETECTION OF ADRD

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
C. Advance prevention strategies and healthy brain aging.	1. Include brain health messaging in existing publicly-funded health promotion and chronic disease management activities and identify higher-risk populations as a specific target for increased outreach efforts. Messaging should include topics such as risk and protective factors, benefits of early evaluation of subjective cognitive decline, impact of diet and nutrition, social engagement, cognitive stimulation, mental health management of medical conditions, sensory impairment, and other lifestyle factors such as physical activity, drinking, and smoking.	X		
	2. Add lifespan brain health messages to school-based health programs. Messaging should include topics such as risk and protective factors, impact of diet and nutrition, social engagement, cognitive stimulation, mental health, management of medical conditions, sensory impairment, and other lifestyle factors such as physical activity, drinking, and smoking.			X
	3. Access publicly available resources and seek additional funding from national initiatives that promote brain health including the CDC Healthy Brain Initiative and the Center for Medicaid and Medicare Innovation (CMMI) to fund innovative projects.	X		

Goal 2: Enhance quality, access, and coordination of ADRD care.

Introduction: High quality, evidence-based practice and coordinated care for people living with dementia must be available and affordable across outpatient, acute care, and long-term care settings, as well as in Maryland communities and homes. Care needs will vary by individual and across the course of the illness, and must take a holistic, family-centered approach that considers cognitive, behavioral, medical, and psychosocial needs of both the person living with dementia and their family caregivers. Equitable access to dementia-capable and evidence-based care regardless of location, race/ethnicity, sex, or income level is paramount to ensuring high quality care and reduction of health inequities and disparities that currently exist and that lead to excessive burden and poor outcomes among certain groups.

Building a highly skilled, interdisciplinary, and culturally diverse ADRD workforce in Maryland, creating a dementia care "pathway" that takes a palliative care approach and that involves greater care coordination and integration of care across the care continuum and during transitions of care, developing measurable standards of quality of care specific for dementia, and promoting the use of innovative practices and effective evidence-based programs are key areas that would support the enhancement of quality, access, and coordination of ADRD care in Maryland.

Thus, four major strategies are recommended to achieve this goal: (A) Build a diverse, interdisciplinary dementia-capable workforce; (B) Increase access to high quality home and community-based services and promote coordination of services across the spectrum of disease and settings of care; (C) Enhance quality of care in nursing homes, assisted living facilities, and other residential care settings; and (D) Promote innovations in the financing and incentivization of high quality medical and LTSS that improve quality and coordination of ADRD care across the health care continuum.

GOAL 2: ENHANCE QUALITY, ACCESS, AND COORDINATION OF ADRD CARE

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
A. Build a diverse, interdisciplinary dementia-capable workforce.	1. Increase the dementia-capable workforce by encouraging health care and direct service workers (e.g., health care providers, allied health professionals, community health workers, public health educators) to pursue careers focused on geriatric populations and specialties through financial incentives such as loan forgiveness, tuition assistance, stipends, and scholarships. Establish formal collaborations with State-based academic institutions (e.g., community colleges and universities) to support development of new geriatric-focused programs and/or expand and update existing program curricula. Provide additional incentives and public recognition for institutions that specifically focus on recruitment of trainees from minority populations and individuals and groups with diverse backgrounds and under-served and under-resourced Maryland communities.		X	
	2. Educate health care professionals about best practice guidelines for ADRD and how to provide care using a comprehensive, interdisciplinary, team-based, person-centered approach. This would include undertaking comprehensive assessments of dementia-related and other needs for both the person living with dementia and caregivers, developing clear goals of care, and conducting periodic re-evaluations and treatment modifications throughout disease progression.		X	

GOAL 2: ENHANCE QUALITY, ACCESS, AND COORDINATION OF ADRD CARE

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
	3. Establish standardized ADRD training for health care professionals and all direct service workers (e.g., non-clinical, administrative, and supervisory) working in the following areas: medical, health care, social services, State and county aging services, public health, intellectual and developmental disability services, financial, and legal. Require evidence of competency in the topic areas for which training is provided. Ensure primary care and frontline health care provider education are best-practice driven, and include topics such as basic/memory disorder, dementia-capable communication, warning signs of dementia, dementia-related neuropsychiatric symptoms, and available community resources. Training should be free of cost and provide continuing education credits (CME, CEU, CEC), when applicable.		X	
	4. Educate professionals working with families of people with early-onset ADRD (e.g., CTE), including those with developmental disabilities, about special challenges, issues, and types of diagnostic assessments, as well as available resources.		X	
	5. Promote retention of direct care workers in home health, assisted living facilities, and nursing homes through incentives including financial assistance, ADRD training, worker engagement, promotion of health care career pathways, and culture change initiatives. Such incentives could include completion of ADRD/professional training for free college credits or development and promotion toward more advanced roles. Engage with partner organizations working on these issues such as the Leading Age Center for Workforce Solutions.	X		
	6. Engage and offer certification/training to State and local first responders, including law enforcement, fire and rescue, emergency medical services, and public works, on ADRD. Education should include recognizing possible dementia symptoms, including neuropsychiatric symptoms and behaviors, and detecting abuse, neglect, and exploitation, as well as use of appropriate communication techniques.		X	
	7. Address current and projected workforce shortages by building a network of trained and certified community health workers skilled in engaging PLWD, their families, and health care providers. Assess current availability and ADRD training for community health workers and establish programs to address gaps.	X		
	8. Build partnerships with community-based organizations and academic institutions to identify ongoing and potential strategies			X

GOAL 2: ENHANCE QUALITY, ACCESS, AND COORDINATION OF ADRD CARE

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
	and programs to address workforce, care access, and care quality strategies and actions.			
B. Increase access to high quality home and community-based services and promote coordination of services across the spectrum of disease and settings of care	1. Educate PLWD, family caregivers, other members of the public, health care providers, allied health professionals, and community public health services staff about the range of LTSS needs that persons with ADRD and caregivers may require over the course of the illness. This should include how to refer PLWD and their caregivers to appropriate medical, LTSS, social services, palliative care, and hospice supports available in Maryland. This should be inclusive of direct service staff from community-based organizations and State-based resources/programs including AAAs, MAP, Communities for Life^{SM}, and Employee Assistance Programs.		X	
	2. Increase the availability of critical types of health-related LTSS in the community (e.g., adult daycare centers, home health care, case management, care coordination, personal care, and medication review and management) to better meet medical needs of PLWD. Target populations disproportionately or uniquely affected by ADRD, including racial/ethnic minorities, individuals living with developmental and intellectual disorders, those living alone or socially isolated, people with young-onset AD, those with related non-Alzheimer's dementias (e.g., FTD, Lewy Body disease, vascular dementia, Huntington's Disease, Parkinson's Disease, and CTE), minority populations, and those residing in under-served and under-resourced communities.		X	
	3. Increase the availability of critical types of daily living, social, and supportive LTSS in the community such as respite care services for family caregivers that include in-home and facility-based options and respite care grants, adult daycare centers and day programs, home delivered nutrition programs, home modifications/repairs, home safety evaluations, driving evaluations, legal services and consultation, health care and long-term care insurance coverage and financial consultation, and intervention programs (e.g., social/activities/wellness/ADRD-specific). Target populations disproportionately or uniquely affected by ADRD, including racial/ethnic minorities, individuals with developmental and intellectual disabilities, those living alone or who are socially isolated, people with early or young-onset ADRD, those with non-Alzheimer's dementias (e.g., FTD, Lewy body disease, vascular, dementia), and those residing in under-served and under-resourced communities. Promote evidence-based programs		X	

GOAL 2: ENHANCE QUALITY, ACCESS, AND COORDINATION OF ADRD CARE

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
	and interventions specifically developed for use with ADRD populations to improve outcomes (e.g., psychosocial interventions, care management, physical activity/exercise programs, cognitive stimulation, social engagement, environmental modifications, and integrative/complementary therapies (e.g., music, dance, arts, movement, comedic improv, massage, or animal-assisted therapy).			
	4. Enhance availability of person-centered case management and care coordination services, that include assessing and addressing the needs for PLWD and their caregivers, including family caregivers; developing meaningful goals of care; and promoting communication with health care and direct services providers. Availability of person-centered case management and care coordination should be available across the stages of illness, with particular attention to promotion of aging in place and support during transitions of care. Leverage and integrate with Maryland-specific evidence-supported care coordination tools (e.g., CRISP) and programs of care (e.g., MDPCP service navigation options counseling provided by MAP, AAAs, CFL, MIND at Home care coordination), to improve coordination and outcomes.		X	
	5. Ensure access to community- and facility-based behavioral health services and supports, as well as evidence-based programs/strategies to address dementia-related neuropsychiatric symptoms, such as the DICE method (describe, investigate, create, evaluate) and WeCareAdvisor™, that employ both pharmacologic and non-pharmacologic approaches.		X	
	6. Expand access to specialty care and ADRD-oriented health coaching for PLWD (e.g., geriatric, geriatric psychiatry, and neurological), with a focus on expanding access for minorities and other under-served populations, and individuals residing in low-resource or under-served communities, through the use of emerging technologies such as telehealth, telemedicine and other web or smartphone-based services.		X	
	7. Facilitate education on and access to palliative care services for PLWD and their caregivers that focus on assessment and management of symptoms, stress, and pain to maximize quality of life and reduce caregiver burden over the course of illness. Provide education on and access to hospice care for PLWD, as appropriate.		X	
	8. Continue to strengthen the availability of alternative service delivery options (e.g., virtual, in-person, telephonic, and hybrid) for LTSS programs as appropriate, to ensure safety for at-risk individuals during the on-going COVID-19 pandemic, and to better			X

GOAL 2: ENHANCE QUALITY, ACCESS, AND COORDINATION OF ADRD CARE

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
	accommodate those who are homebound, lack adequate transportation, or live in under-served and low-resource areas.			
C. Enhance quality of care in nursing homes, assisted living facilities, and other residential care settings.	1. Distribute free educational materials on ADRD care guidelines to care facilities to promote appropriate ADRD care and person-centered approaches.	X		
	2. Re-establish community advocacy groups to encourage culture change in long-term care and services.		X	
	3. Provide incentives for person-centered ADRD care in nursing homes and assisted living facilities.			X
	4. Review State legislation and regulations for licensing of professions, residential facilities, and providers. Convene stakeholders including but not limited to advocacy groups, caregivers, and providers to identify gaps and opportunities to enhance evidence-based ADRD care.		X	
	5. Review, revise, and promulgate State regulations for assisted living that address the disclosure of services, admission/discharge policies within assisted living facilities generally as well as those specifically offering ADRD/memory care programs. Ensure regulations require assisted living facilities to provide: (1) a full listing of services that are specific to memory care units, and (2) information on admission and discharge policies, especially as they relate to the presence or emergence of ADRD symptoms (e.g., neuropsychiatric behavior problems, cognitive impairment). Support the promulgation of regulations provided for in Code of Maryland Regulations (COMAR) 10.07.14 - Assisted Living Programs (statutory authority for the regulations is: Health-General Article, Title 19, Subtitle 18, Annotated Code of Maryland).	X		
	6. Establish a consumer-facing information platform that provides users with a method for selecting assisted living services in Maryland and a method for comparing facilities. This should include up-to-date information on assisted living facilities offering dementia care services to assist consumers in making an informed decision. Sources of information available on the platform could include cost, State quality and safety assessment data, staffing ratios, scope of services, and resident care quality metrics.			X
	7. Convene stakeholder groups, including established nursing home and/or assisted living resident and family councils, to understand experiences and challenges related to COVID-19 in long-term care facilities. Establish a Maryland entity (e.g., "Epidemic Response	X		

GOAL 2: ENHANCE QUALITY, ACCESS, AND COORDINATION OF ADRD CARE

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
	Action Network") to develop future emergency preparedness plans for facility- and community-dwelling persons living with dementia that consider the unique challenges related to ADRD. Emergency preparedness plans should support health service delivery programs and communal living settings serving high concentrations of vulnerable older persons with ADRD.			
	8. Elicit stakeholder input, including the input of persons with ADRD and their caregivers, to identify high priority issues where care quality improvement efforts should be targeted. Such efforts should include effective management of neuropsychiatric symptoms, facility workforce training and education about ADRD, workforce engagement and retention, reducing social isolation and increasing social engagement, person-centered care and continuity, and infection prevention.	X		
D. Promote innovations in the financing and incentivization of high quality medical and LTSS that improve quality and coordination of ADRD care across the health care continuum.	1. Continue the Total Cost of Care Initiative and explore additional strategies to create financial incentives for hospitals, health systems, outpatient settings, and long-term care facilities to implement evidence-based geriatric and ADRD care models.	X		
	2. Advance ADRD care quality through the Maryland Total Cost of Care Model and creation of specific dementia quality measures (e.g., number of attributed Medicare beneficiaries with documented cognitive screen, number of attributed Medicare beneficiaries with cognitive assessment and care planning services) within the payment model.	X		
	3. Provide education and tools that health systems and providers can use to leverage underutilized Centers for Medicare and Medicaid Services (CMS) incentives to provide ADRD care.		X	
	4. Develop a Maryland Dementia Friendly Endorsement to recognize workforce quality and evidence-based program implementation in health systems, post-acute and long-term care facilities, adult day services, and home health care agencies.			X
	5. Explore the expansion of scope of Maryland's Long-Term Care Insurance Partnership program to include an insurance program subsidy benefit for Marylanders. This could involve subsidized insurance through a State-supported website (i.e. "marketplace" or "exchange") that offers long-term care plan shopping and enrollment, strategic partnerships with private companies or advocacy organizations (e.g., AARP), Employee Assistance Programs, or other mechanisms to help Marylanders purchase			X

GOAL 2: ENHANCE QUALITY, ACCESS, AND COORDINATION OF ADRD CARE

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
	affordable long-term care insurance to cover long-term care needs. Continue Maryland’s Long-Term Care Insurance Partnership Program’s assistance and education activities to educate Marylanders on the importance of long-term care planning.			
	6. Review current Medicaid eligibility requirements to determine how coverage could be expanded to cover more PLWD in need and including use of Medicaid Home and Community Based Services (HCBS) (e.g., Maryland's home and community based options waiver (HCBOW) to better serve more PLWD who require HCBS but who may not yet meet the financial requirements to offset future long-term care costs to families and to the health care system (e.g., acute health care services and long-term nursing homes).		X	
	7. Increase the number of assisted living facility beds available to Maryland’s Medicaid program to reduce premature and costly admissions to long-term nursing homes from the community and provide beneficiaries with options of care settings that align with their needs and preferences for care.			X
	8. Provide continued support for the expansion of Program for the All-inclusive Care of the Elderly (PACE) to new service areas, including support for new PACE providers serving rural sites.		X	

Goal 3: Enhance and expand supports for family caregivers.

Introduction: Marylanders living with dementia require a range of cognitive, functional, behavioral, psychosocial, and environmental supports over the course of the illness, much of which is provided through millions of hours of unpaid care provided by informal caregivers in Maryland every year. Informal caregivers include family, extended family, and friends who assist with the multidimensional and changing needs of persons living with dementia. These individuals often themselves need access to a variety of supports and resources by nature of serving as a caregiver. Unfortunately, the health care system is not currently set up to provide family-centered ADRD care that purposefully involves supporting the caregiver both in services and education, as well as in ways to maintain their own medical and mental wellbeing along the way. As such, many ADRD caregivers find themselves thrust into the unfamiliar territory of dementia, having to learn on their own what it means for them and their loved one, and how to navigate a complex and disjointed network of health care services and LTSS. Common needs of ADRD caregivers and families may include education about dementia and what to expect; how to plan for the future; skill-building and training for how to communicate effectively; personal care or how to best manage behavioral health needs (neuropsychiatric symptoms associated with dementia); education about care financing options; and information on how to find and access resources (e.g., appropriate services, education, guidance, and tools). Because dementia caregiving is associated with increasing intensity over a prolonged period of time, it can be very physically and emotionally taxing. Caregivers must also be provided with support to reduce stress, avoid burnout, and to maintain physical and mental well-being.

Goal 3 is focused on enhancing caregiver support to directly address needs that exist among Maryland dementia caregivers. Our vision is that every Marylander who finds themselves as a dementia caregiver can be provided with a roadmap and a coordinated network of support that helps them take care of both their loved ones living with dementia and themselves in the process. Five strategies are recommended to enable the enhancement and expansion of supports for family caregivers: (A) Identify unmet needs for family caregivers; (B) Assist families in planning for ADRD care needs; (C) Promote and expand family caregiver supports across care settings; (D) Address caregiver health and wellness; and (E) Address the COVID-19 pandemic and other emergency/natural disaster events.

GOAL 3: ENHANCE AND EXPAND SUPPORTS FOR FAMILY CAREGIVERS					
Strategy		Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
A. Identify unmet needs for family caregivers	1.	Conduct a comprehensive needs assessment that includes diverse, under-represented, and under-resourced groups of PLWD, their family caregivers, and the multi-disciplinary providers who serve them to identify unmet service and supportive care needs (e.g., health and wellness programs, health care and medical LTSS, respite/daily living/social/palliative care service needs, and residential and long-term care). This needs assessment could use focus groups, interviews, and surveys to evaluate the impacts of COVID-19 on ADRD family caregivers. Partners including the State Commission on Caregiving, the State Commission on Aging, and experts on diversity and health care inequities could be engaged to assist in designing and conducting this assessment.	X		
	2.	Use data gained from the needs assessment to identify barriers, guide services planning, and identify existing resources, with a focus on bridging services and support gaps and enhancing availability and accessibility, particularly among ADRD family caregivers who are under-represented and under-served. Share			X

GOAL 3: ENHANCE AND EXPAND SUPPORTS FOR FAMILY CAREGIVERS

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
	assessment findings with partners and the public in a manner that is easily understood by a general audience.			
B. Assist families in planning for ADRD care needs	1. Increase the utilization of MAP as a referral source for community services and a resource for persons with ADRD and their caregivers through curated content and expanded listings within the MAP/ 211 Maryland provider directory (including the Alzheimer's Association, Alzheimer's Foundation of America, Family Caregiver Alliance, respite care, overnight care, drop-in daycare, volunteer programs, crisis/emergency respite, support groups, and wellness promotion programs such as memory care and wellness services). Promote the resource through an annual social media consumer education campaign.	X		
	2. Further develop MAP self-guided assessment and resource tools embedded within the MAP website, to include tools specific to ADRD care needs for Marylanders with an existing diagnosis, with consideration for the range of needs that a family and/or caregivers may have over time, including financial support, respite, caregiver skills training, legal supports, access to health care, and support for their psychological and emotional needs.			X
	3. Encourage the use of validated non-clinical ADRD screening tools among MAP sites and a process for referral to a health care provider for evaluation for ADRD.		X	
	4. Increase the inclusion of family caregivers for people with ADRD in all aspects of care planning for PLWD during health care visits (e.g., understanding prognosis, health care, LTSS, social, and financial, legal, and advance care implications). Provide educational, referral, and supportive resources at the time of diagnosis (and at regular intervals afterward) to ensure family caregivers receive information and support from providers regarding diagnosis, treatment at different illness stages, long-term care, community supports, and caregiver wellness.		X	
	5. Disseminate information from the CDC educational series on topics including care planning tools, help for PLWD and their caregivers to stay physically active, heart and brain health, and facts about aging and ADRD.	X		
	6. Promote dissemination of information to caregivers and persons living with ADRD about the Family and Medical Leave Act (FMLA), long-term care insurance, the benefits of advanced legal and financial planning, and support programs through agency websites, educational forums, service networks, and media.		X	

GOAL 3: ENHANCE AND EXPAND SUPPORTS FOR FAMILY CAREGIVERS

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
	7. Educate family caregivers on long-term care and support needs and options, what services are provided in different settings of care, costs, and how to select long-term care options based on personal preferences and circumstances.		X	
	8. Enhance financial literacy and preparedness through statewide dissemination channels focusing on potential short and long-term ADRD-related costs (medical, services, out-of-pocket).		X	
	9. Provide information to families about non-statutory and statutory authority of caregivers for individuals needing LTSS.		X	
C. Promote and expand family caregiver supports across care settings	1. Promote adoption and use of evidence-informed programs and interventions among Maryland State agencies, aging services partners, and home and community-based services (e.g., AAAs, local health departments, and nonprofits). Focus on and prioritize programs/interventions addressing known and emerging areas of needs among Marylanders living with dementia and their families and caregivers such as caregiver memory disorder education and knowledge of/access to resources, respite care (e.g., facility-based, in-home), home and personal safety issues including home hazard, fall-risk and wander risk prevention, caregiver skills (dementia communication skills, dementia-related neuropsychiatric behavior management, home care activities such as managing medications and using effective approaches for managing personal care and oral health needs, addressing sensory deficits and incorporating meaningful activity into the day), social support, maintaining caregiver wellness and stress management, and financial assistance to cover LTSS. Examples of evidence-informed programs identified by Maryland State agencies and national agencies can be found in the Administration for Community Living's National Alzheimer's and Dementia Resource Center (NADRC) and include Building Better Caregivers, Powerful Tools for Caregivers, REACH, Savvy Caregiver, STAR-C, DICE, SKILLS2CareWeCareAdvisor™.		X	
	2. Disseminate information on effective caregiver interventions to family caregivers and the public through ADRD-capable systems and diverse channels (including MAP, social networking websites, government and community websites, colleges and universities, nonprofit organizations, religious institutions, and conferences).			X
	3. Expand the delivery and accessibility of free statewide ADRD-capable caregiver workshops and training in the			X

GOAL 3: ENHANCE AND EXPAND SUPPORTS FOR FAMILY CAREGIVERS

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
	community to better equip family caregivers to deliver quality care at home through education and skills training offered by existing national organizations (e.g., Administration on Aging through the Administration for Community Living, Family Caregiver Alliance, the Alzheimer’s Association, and the Alzheimer’s Foundation of America) and local partnerships (e.g., Dementia Friendly Communities, AAAs, Community for Life^{SM}, and MDPCP). Education topics could include memory disorder education, what to expect after a diagnosis, ADRD-capable communication, neuropsychiatric behavior management, problem solving and behavior management skills, provision of daily living assistance skills, patient advocacy, and legal and advanced care planning issues			
	4. Identify and engage leaders of faith communities to explore ways in which these entities may serve as resources for ADRD family caregivers. Provide educational materials, resources, and supports to faith community partners to implement ADRD-focused education and support programs.	X		
	5. Facilitate distribution of equitable and culturally-sensitive education, training, and support materials for family caregivers to better serve under-resourced areas and increase the number of racially, culturally, and linguistically diverse caregivers receiving such education and support programs. Utilize appropriate existing federal and State-developed educational materials. Ensure materials are available in non-English languages to reflect the prevalence of Maryland’s non-English speaking population (e.g., Spanish, Indo-European languages, Korean, and other Asian and Pacific Island languages).		X	
	6. Identify and engage leaders of diverse communities to explore ways in which these communities may serve as resources for ADRD family caregivers. Provide educational materials, resources, and supports to community partners to implement ADRD-focused education and support programs.	X		
	7. Work to develop dementia friendly public spaces and Dementia Friends initiatives. Distribute information on such initiatives through State and partner-based communications and convene stakeholders to develop, plan, and implement initiatives.		X	
	8. Continue to promote use of the National Alzheimer's Association Call Center (1-800-272-3900) to provide reflective listening, problem solving, education, action planning, and crisis intervention to people with ADRD or their caregivers.	X		

GOAL 3: ENHANCE AND EXPAND SUPPORTS FOR FAMILY CAREGIVERS

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
	9. Expand and promote implementation of early-stage memory loss groups for people with cognitive impairment and/or ADRD and their care partners.		X	
	10. Expand programs that focus on collaborative models of social engagement that include both the person living with dementia and their family caregivers, such as Alzheimer's Cafés, Sibley Memorial Club Memory, dementia friendly recreation programs, intergenerational programs, and civic engagement initiatives that encourage engagement of multiple generations and/or volunteerism throughout the State.			X
	11. Promote the expansion and reimbursement for telehealth, telemedicine, and web-based resources for family caregivers, including use in rural and under-resourced communities.		X	
	12. Leverage financial/payment models and/or policy to incentivize hospitals to design and provide care models that include family caregiving in discharge planning and specific discharge instructions to the family.			X
D. Address caregiver health and wellness	1. Promote education and public awareness of caregiving as a behavioral and physical health risk factor that requires public health attention and include caregiving in public health campaigns and programs.	X		
	2. Increase availability and access to caregiver-focused wellness and support programs that include evidence-informed interventions and therapies, especially among under-served and under-resourced communities, family caregivers of persons with early-onset ADRD, and those from culturally and linguistically diverse backgrounds. These programs may include cognitive behavioral therapy or psychosocial programs (i.e., support groups and integrative health practices that promote self-care and/or trauma-informed practices to reduce stress and increase resilience, such as meditation, mindfulness, and acupuncture) combined with access to traditional medical support. Programs should be available across multiple mediums including in-person, virtual, and hybrid.		X	
	3. Promote the expansion of coverage of behavioral health services targeting PLWD and family caregivers via employment-based health plans and health insurance.			X

GOAL 3: ENHANCE AND EXPAND SUPPORTS FOR FAMILY CAREGIVERS

Strategy		Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
E. Address COVID-19 pandemic and other emergency/ natural disaster events	1.	Assess the impact of COVID-19 on family caregivers and consider their experiences in the establishment of a Maryland Epidemic Action Network (see 2.C.5) to support communal living settings serving high concentrations of vulnerable PLWD and delivery of ADRD care in home-based settings. Facilitate the provision of free training and mentorship to nursing homes, assisted living communities, continuing care retirement communities (CCRC), communal living residences, and individual family caregivers to increase the uptake of evidence-based infection prevention and safety practices to protect PLWD, family caregivers and staff, while concurrently balancing quality of life issues such as social isolation and mental health impacts as recommended by the Agency for Health Care Research and Quality.	X		

Goal 4: Advance ADRD research and encourage evidence-based practices.

Introduction: Ongoing ADRD research is vital to developing effective treatments, discovering better ways of caring for those living with dementia, and preventing dementia by understanding and addressing the causes of the disease. Research takes many forms and includes clinical trials that test new treatments or care strategies, prevention trials aimed at reducing risk of developing dementia, epidemiological studies to understand the natural course of dementia and contributing factors, diagnostic studies aimed at developing accurate ways to diagnose dementia early on, and health services/policy studies to look at how well health care systems serve people with dementia and their care partners, whether health-related policies are working, and how care delivery can be more equitable, effective, and cost-efficient.

Furthermore, it is essential that discoveries and knowledge gained from research are shared and incorporated into everyday practices so that Marylanders can benefit from these research advances. This includes efforts to effectively communicate research results to the community and key stakeholders as well as efforts to ensure evidence is successfully translated into practice.

Three key strategies are recommended as a focus over the next four years to advance ADRD research and to encourage evidence-based practices in Maryland: (A) Identify high priority ADRD-related research need areas; (B) Enhance funding and resources to support ADRD research and grow public-private research networks in Maryland; and (C) Enable and incentivize the translation of research to practice.

GOAL 4: ADVANCE ADRD RESEARCH AND ENCOURAGE EVIDENCE-BASED PRACTICES

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
A. Identify high priority ADRD-related research need areas.	1. Convene a stakeholder group to plan and facilitate a biennial special interest summit to identify specific high-priority research areas related to ADRD and ADRD prevention. The stakeholder group should consist of representatives from State-based planning groups, councils, and commissions, individuals from relevant State agencies, public and private research institutions, community-based organizations, consumer advocacy groups, hospitals, health care providers and payers, regulators and policy makers, and academic institutions. Priority research areas may include: understanding differential health burdens, health inequities and disparities in ADRD, early-onset dementia research, developmental disability and dementia, cost of financing care, indirect financial impacts for family and care partners, premature or unwanted retirement, and systems/plans to cover LTSS unique to ADRD care and management.		X	
	2. Explore the creation of an interstate ADRD Research Consortium to identify other states facing similar ADRD-related challenges. Facilitate collaborative partnerships to leverage and share research resources and funding to advance research in high priority areas.			X
B. Enhance funding and resources to support ADRD research and grow public-private research networks in Maryland	1. Work with key stakeholders to identify existing State funds and grant programs that can be accessed, applied, and/or leveraged to address key areas of ADRD research or service program evaluation needs (e.g., the Office of Health Care Quality's Civil Money Penalties fund grants). Core stakeholders would include the Director of Dementia Services and Brain Health (new position recommended in Goal 1.A.1), Virginia I. Jones ADRD Council, MDH, and MDoA.	X		
	2. Convene and foster a public-private Collaborative ADRD Research Network to: (a) Apply for and secure State, federal, and private research funding to conduct collaborative ADRD research in Maryland, (b) Increase opportunities for interdisciplinary collaboration (e.g., strategic alliances among researchers, practitioners, businesses, regulators, payers, public health officials, etc.), (c) Support the development of a diverse research workforce that reflects multiple perspectives and the diversity of culture/race/ethnicity, interests and issues of Marylanders, and (d) Promote the dissemination and uptake of collaborative research in practice. This research network could create strategic alliances that support the piloting and evaluation of culturally specific and/or relevant services or the engagement of multi-site research trials, promote research awareness and encourage patient referral to and participation in clinical trials.		X	

GOAL 4: ADVANCE ADRD RESEARCH AND ENCOURAGE EVIDENCE-BASED PRACTICES

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
	3. Support the engagement of PLWD, care partners, and other stakeholders that are historically under-represented in research, including a campaign for the outreach, identification, recruitment, and ongoing engagement of potential research volunteers.		X	
	4. Support the participation of hospitals, health care systems, and community health services organizations in clinical trials and evaluation studies designed to accelerate the effectiveness of testing and uptake of evidence-based research and best practices.		X	
	5. Allocate funding to support staff effort for a Grants Manager at the State-level responsible for creating, managing, and distributing a regularly updated list of ADRD and Brain Health research and quality improvement funding opportunities (e.g., NIH, CDC Bold Act, ACL, State-based, private foundation/endowment monies) and serving as a liaison to the Collaborative ADRD Research Network (4.B.2), the Director of Dementia Services and Brain Health (1.A.1), MDH, MDoA, and the Virginia I. Jones ADRD Council.	X		
	6. Recommend legislation which authorizes a voluntary Maryland income tax checkoff to fund Alzheimer's research in Maryland.	X		
C. Enable and incentivize the translation of research to practice.	1. Convene an expert panel of stakeholders to identify, define, and endorse a set of evidence-based standards for diagnosis, treatment, supportive care and advance planning for PLWD.	X		
	2. Require use of evidence-based practices (using standardized definition in action 4.C.1) in new or revised regulations across all State licensed and registered programs covered by MDH and MDoA that provide diagnostic, treatment, supportive care, and/or advanced planning services to PLWD.		X	
	3. Hold an annual ADRD Innovation Summit where Maryland-based researchers and research networks can present new ADRD research and evidence-based practices to State and other stakeholders (payers, providers, state representatives, etc.) to encourage translation of evidence-based practice.			X
	4. Translate research findings into useful information for the general public, services, and community practices and disseminate this information via State-based channels (e.g., MDH, MDoA websites).			X

Goal 5: · Enhance data capabilities related to dementia and dementia impact and effects of interventions.

Introduction: Effective methods for capturing and using population-based data are needed to improve care and support for Marylanders currently living with ADRD and to adequately plan for the growth in both persons at risk of ADRD and who develop ADRD in the future. Data routinely collected through surveillance and evaluation are vital to providing insight into population trends (e.g. ADRD prevalence and incidence rates), raising ADRD awareness, understanding service and support needs and how needs differ among diverse groups, identifying and addressing health care inequities and gaps in care, evaluating and monitoring the impact of health programs and policies over time, and informing the evolution of Maryland's ADRD State Plan and other Maryland State Plans (e.g. Aging).

Three key strategies are recommended as a focus over the next four years to enhance Maryland's ADRD-related data capabilities: (A) Collection, analysis, and use of statewide surveillance and evaluation data from multiple sources; (B) Development and implementation of a set of dementia-related outcome-based performance measures; and (C) Development of infrastructure and policies that increase capability to share and link population-based surveillance and evaluation from a variety of sources.

GOAL 5: ENHANCE DATA CAPABILITIES RELATED TO DEMENTIA AND DEMENTIA IMPACT AND EFFECTS OF INTERVENTIONS				
Strategy	**Actions (*Recommendations for needed policies or responses*)**	**Short**	**Mid**	**Long**
A. Collection, analysis, and use of statewide surveillance and evaluation data from multiple sources.	1. Support the continued implementation, use, and reporting of data from the BRFSS cognitive and caregiver modules at least once every two years by MDH. This would include both an emphasis on routine data collection as well as the analysis and dissemination of data using published CDC analytic guidance to examine prevalence of subjective cognitive decline and its associated effects on function, daily living, and service needs as well as examining the characteristics, risk factors, service needs, and disparities of PLWD and their caregivers.	X		
	2. Utilize the regional CRISP Health Information Exchange (HIE) in Maryland and the District of Columbia to characterize, track, and evaluate health characteristics of Marylanders with an ADRD diagnosis and their linked health utilization outcomes (e.g., emergency department visits, hospitalizations, and home health utilization) and create a publicly available annual report.	X		
	3. Track, analyze, and report the prevalence of ADRD, health care costs, and the use of Medicare billing codes for cognitive assessment (as part of the Medicare Annual Wellness Visit) and Care Planning Visits among Medicare beneficiaries attributed to the MDPCP Total Cost of Care Program.	X		
	4. Integrate cost and health care utilization data from the MDPCP program (Medicare beneficiaries and Medicare-Medicaid dual eligible beneficiaries) with Maryland's Medicaid data (Medicaid only, Medicare-Medicaid dual eligible individuals) to better understand which groups of persons with ADRD are higher utilizers		X	

GOAL 5: ENHANCE DATA CAPABILITIES RELATED TO DEMENTIA AND DEMENTIA IMPACT AND EFFECTS OF INTERVENTIONS

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
	in order to better target health interventions to improve care quality and reduce costs.			
	5. Support a dedicated staff person at the State-level or within a relevant private agency in Maryland (e.g., MDH or qualified vendor such as the Hilltop Institute at UMBC) to manage the collection of ADRD-related data from disparate data sources, conduct data analysis, and undertake data reporting.	X		
	6. Collaborate with relevant stakeholders (State agencies, community-based organizations, public health professionals, health care providers, academic programs, universities) and other State-based planning groups/councils/commissions to conduct a coordinated systematic review of ongoing data needs related to ADRD and prevention, available data sources, and current surveillance gaps (e.g., prevalence and impact of neuropsychiatric symptoms, caregiver impacts, health care spending). This group could then identify existing sources of population-based surveillance or evaluation data that could be utilized to fill data gaps or leveraged to address other areas of Maryland's public health needs (as outlined in Maryland's State Plan on Aging and in the Letter to the Joint Council on Cognitive and Behavioral Health) or that are high priority for future development.	X		
	7. Standardize a broader limited data set of dementia-specific tracking metrics for ADRD LTSS services in Maryland to better track and identify gaps in supply and demand for PLWD and their care partners, e.g., standardized State-based indicators including current and projected ADRD prevalence among individuals living in Maryland, number of individuals with dementia and family caregivers served in specific types of LTSS (both community and residential settings), volume of eligible ADRD beneficiaries receiving and on Medicaid waiver waiting lists, and ADRD-attributable health care use and costs.			X
B. Development and implementation of a set of dementia-related outcome-based performance measures.	1. Using a stakeholder panel, develop and endorse a set of dementia-specific tracking and performance metrics for the individual with dementia and their care partners to drive improvements in care practice.	X		
	2. Working with State partners, promote the inclusion, tracking, and incentivizing of ADRD-related performance metrics within Medicaid Waiver programs, local AAAs, MAP, and within the Maryland Total Cost of Care/alternative payment models (e.g., Maryland's All-Payer		X	

GOAL 5: ENHANCE DATA CAPABILITIES RELATED TO DEMENTIA AND DEMENTIA IMPACT AND EFFECTS OF INTERVENTIONS

Strategy	Actions (*Recommendations for needed policies or responses*)	Short	Mid	Long
	Model, which focused initially on hospitals but now extends to primary care and other settings in Maryland through the MDPCP).			
C. Development of infrastructure and policies that increase capability to share and link population-based surveillance and evaluation from a variety of sources	1. Expand funding support of public-private partnerships (e.g., MDH Medicaid and UMBC Hilltop Institute) and the development of secure data repositories that enable an efficient platform for ADRD data management, analysis, sharing, and linking of data to promote health program and policy evaluation and planning.		X	
	2. Develop a strategic plan for the ongoing and systematic communication of surveillance and evaluation data results to key stakeholders through a combination of general public health announcements in relevant settings (e.g., senior centers, adult day care, CCRCs, residential care communities), virtual and in person events (professional summits, health fairs), and social media.			X
	3. Increase access and linking of health care system data, administrative data, and other types of community data through policy and data use agreement authorizations.			X
	4. Provide streamlined access to Maryland's population-level surveillance data related to ADRD and other related chronic and behavioral conditions for Maryland-based pre- and post-doctoral students to enrich their training experience and to accelerate the use, analysis, and dissemination of Maryland's surveillance data.			X

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