Maine Reaching for the Summit: Addressing Alzheimer’s Disease and Related Dementias

Maine State Plan: 2022-2027

Maine Center for Disease Control and Prevention

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Acknowledgments

A special thanks to the people and organizations that helped contribute to and write this plan including Maine Center for Disease Control and Prevention, Maine Office of Aging and Disability Services, the Alzheimer's Association Maine Chapter, and Public Consulting Group.

Note from the Department of Health and Human Services

The recommendations herein reflect the work of contributors within and outside of state government. They do not reflect policy commitments of the Maine Department of Health and Human Services or Maine Center for Disease Control and Prevention, and further do not confer support from the Executive Branch for specific legislative initiatives. Policy proposals will be reviewed and commented on as they arise.

Executive Summary

Maine's Alzheimer's disease and Related Dementia (ADRD) State Plan (Plan) recognizes the value of older adults with dementia and the need for policies aimed at enhancing prevention through early detection and diagnosis, provider to patient communication and care planning, treatment, and appropriate supports for people with dementia and their care partners and family members. The Plan provides the basis for action to be taken jointly by government and non-governmental partners and is integrated within chronic disease public health program work in risk education and reduction, and complements strategies that exist in other state plans: the 2020-2024 Maine State Plan on Aging[1], the 2020 Maine Age Friendly State Plan[2], and the 2021-2025 Maine Cancer Plan[3]. **The Plan seeks to create the necessary infrastructure that empowers, educates, and supports people living in Maine by reducing ADRD risk factors, promoting early detection, and connecting people to resources they need to optimize their wellbeing.**

Recommendations for the Plan were developed over the course of a year (2021-2022) through a rigorous, multi-phased process. Using the U.S. Centers for Disease Control and Prevention's (CDC's) Healthy Brain Initiative's *State and Local Public Health Partnerships to Address Dementia: The 2018—2023 Road Map,* which outlines an action agenda for state and local public health agencies and their partners, Maine assembled a diverse stakeholder group to lead a series of subcommittees that were each tasked with developing a set of recommendations that align with the four essential services of public health: educate and empower, develop policies and mobilize partnerships, assure a competent workforce, and monitor and evaluate. The subcommittees and the respective recommendations that they produced address six focus areas: Access to Care, Care Partners, Legal and Safety Issues, Public Awareness, Research and Data Collection, and Workforce Development and Training. Each subcommittee was led by a Maine-based subject matter expert in their respective fields[4]. Subcommittees followed a formal charter

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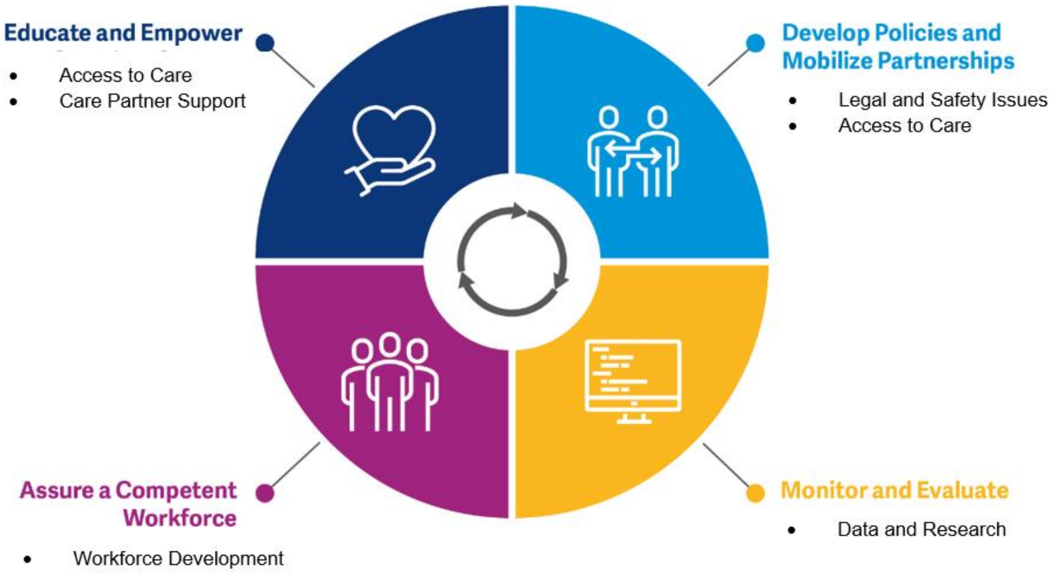
[1] https://www.maine.gov/dhhs/sites/maine.gov.dhhs/files/inline-files/Maine_State Plan on Aging_2020-2024.pdf
[2] https://www.maine.gov/dhhs/sites/maine.gov.dhhs/files/inline-files/Age-Friendly-State-Plan.pdf
[3] https://www.maine.gov/dhhs/mecdc/population-health/ccc/documents/2. Maine Cancer Plan 2021-2025.pdf
[4] A full list of subcommittee leads can be found in the appendices

outlining the specific mission, structure, expectations, and procedural policies to legitimize and organize the subcommittees and obtain buy-in from subcommittee members.

The Plan addresses each focus area and the essential services of the Road Map as depicted in Figure 1.

Figure 1. Maine State Plan on ADRD Focus Areas and Corresponding Subcommittee Workgroups



Background

Alzheimer's disease is the most common type of dementia in older adults. It is an irreversible, progressive brain disorder that slowly destroys memory, cognition, and functional skills and, eventually, the ability to carry out the simplest tasks. It is not a normal part of aging. Dementia is the loss of cognitive functioning like thinking and remembering to an extent that it interferes with daily life. Dementia ranges in severity from mild, where it begins to affect a person's functioning, to severe, when a person must depend completely on others for help with basic activities of daily living.

Age is one factor leading to a higher risk for being diagnosed with ADRD. Maine ranks number one in the United States for the highest population of people aged 65 and older, making ADRD a public health priority[5]. Maine's population also meets other risk factors for ADRD diagnosis, such as higher rates of tobacco use, obesity, comorbidity with other chronic disease, mental health related conditions, and alcohol and drug misuse. Adding to this dilemma are both policy and funding deficiencies in social supports for those with the disease and those who care for them.

Maine is the largest and most rural state in New England. Weather, lack of services in rural areas, isolation, limited and lengthy transportation, and a lack of adequate

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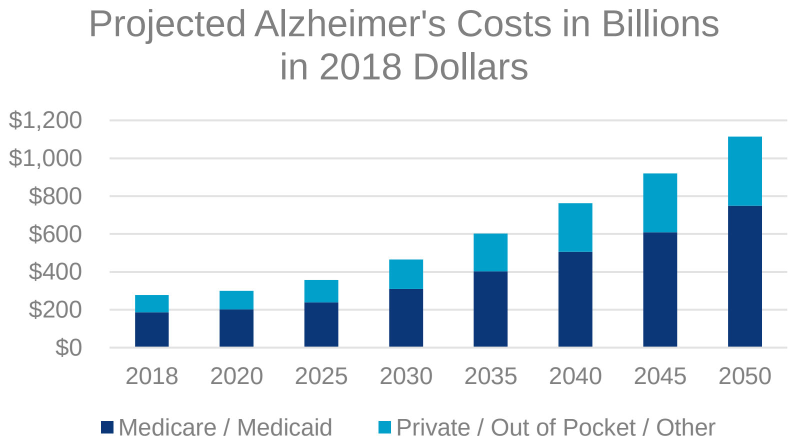
[5] Public Reference Bureau. (2021). 2021 Population Bulletin, Elderly Americans. Retrieved from: https://www.prb.org/resources/which-us-states-are-the-oldest/.

supportive housing are all ‘barriers to older Mainers establishing meaningful connections in their communities and accessing needed services that support their independent lifestyles’ articulated in the Maine State Plan on Aging 2020-2024.

Recent data reveals rapidly increasing trends in both the number of people living with dementia and the cost of health care to address ADRD. The Alzheimer’s Association has compiled data on Alzheimer’s Disease and the costs associated with it. A few of the key takeaways are listed below.

- Alzheimer’s is the most expensive disease in America, with costs nationally exceeding a quarter of a trillion dollars annually.
- By 2050, Alzheimer’s and other dementias will cost $1.1 trillion in 2018 dollars.
- One in five Medicare dollars is spent on the care of people with ADRD. In 2050, it is projected to be one in every three dollars.
- Average per-person Medicare spending for those with Alzheimer’s and other dementias is more than three times higher than average per-person spending across all other older adults. Medicaid payments to address ADRD are 23 times higher.
- In 2015, there were 1,471 emergency department visits for every 1,000 Medicare beneficiaries with dementia.
- In 2018, the direct costs to care for those with Alzheimer’s Disease is estimated at $277 billion.[6]

Figure 2. Projected Alzheimer’s Costs in Billions in 2018 Dollars



[7]

The combined impact of increasing rates of ADRD in Maine and the immense strain it puts on individuals, families, and state resources demonstrates the importance of addressing this disease with renewed focus and enhanced resources using a public health approach.

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[6] Alzheimer’s Association. (2018). 2018 Alzheimer’s Disease Facts and Figures. Retrieved from: [2018 Alzheimer’s Disease Facts and Figures.]()

[7] Alzheimer’s Association. Changing the trajectory of Alzheimer’s disease: How a treatment by 2025 saves lives and dollars. Chicago, IL: Alzheimer’s Association; 2015.

Process

The Plan is informed using a public health approach to addressing ADRD which enables Maine's state government to act quickly and strategically by stimulating changes in policies, systems, and environments (Healthy Brain Initiative Road Map, 2018).

In 2019, as a means to develop a public health approach to address ADRD, Maine Center for Disease Control and Prevention (Maine CDC) was encouraged to apply for the Healthy Brain Initiative (HBI) Planning Lab, a nine-month technical assistance grant sponsored by the Alzheimer's Association and the Association of State and Territorial Health Officials (ASTHO). The grant was intended to educate states on the Healthy Brain Initiative in response to the anticipated 25% increase in ADRD diagnosed individuals by 2025. This grant work enabled the Maine CDC to organize a statewide stakeholder group (HBI Stakeholder Group).

The Federal Building Our Largest Dementia (BOLD) Act provided the legislative push to fund public health agencies to focus on the prevention of ADRD. As created under Public Law 115-406 on December 31, 2018, it amends the Public Health Service Act to authorize the expansion of activities related to Alzheimer's disease, cognitive decline, and brain health under the US CDC's Alzheimer's disease and Healthy Aging Program, and for other purposes through the following:

1. Advancing the awareness of public health officials, health care professionals, and the public, on the most current information and research related to Alzheimer's disease and related dementias, including cognitive decline, brain health, and associated health disparities;
2. Identifying and translating promising research findings, such as findings from research and activities conducted or supported by the National Institutes of Health, including Alzheimer's disease Research Centers authorized by section 445, into evidence-based programmatic interventions for populations with Alzheimer's disease and related dementias and care partners for such populations; and
3. Expanding activities, including through public-private partnerships related to Alzheimer's disease.

BOLD grant funding was awarded to Maine as a three-year core capacity grant (2021 – 2023). Maine CDC focused on three key areas in planning for improved capacity: 1) create a public health infrastructure focused primarily on the prevention of ADRD, 2) create a multisectoral and collaborative stakeholder group, and 3) create and/or update a state ADRD plan.

The BOLD grant also emphasized the need to better understand the current landscape of ADRD in Maine to inform the work of creating a new state plan. Using the U.S. CDC's Healthy Brain Initiative's *State and Local Public Health Partnerships to Address Dementia: The 2018—2023 Road Map,* Maine assembled a diverse stakeholder group to lead a series of subcommittees that were each tasked with developing a set of recommendations pertaining to six focus areas: Access to Care, Family Caregiving, Legal and Safety, Public Awareness, Research and Data Collection, and Workforce Development and Training. Each subcommittee was led by a Maine-based subject matter expert in their respective fields.[8] Subcommittees followed a formal charter outlining the specific mission, structure, expectations, and procedural policies to legitimize and organize the subcommittees and obtain buy-in from subcommittee members.

Subcommittees met on a regular basis over the course of six months to discuss research and data from numerous sources such as current expert knowledge and experience and the 2021 needs assessment. The subcommittees helped to quantify the needs within the state and identify opportunities for improvement which were refined into a set of recommendations that were presented to the Maine CDC for review and consideration in the spring of 2022.

Additionally, Maine Department of Health and Human Services (DHHS) contracted Public Consulting Group (PCG) as the evaluator for its BOLD programs to support CDC with its ADRD grant award. As a part of that work, PCG was charged with completing a needs assessment to identify the characteristics of individuals living with ADRD and their care partners, and gain insight into the resources, services, strengths, and weaknesses of the existing infrastructure that serves people that live in Maine who are living with ADRD and their care partners.

PCG utilized quantitative surveillance data collected from MaineCare (Medicaid); the Data, Research and Vital Statistics Program of the Maine CDC; and the Behavioral Health Risk Factor Surveillance System (BRFSS) to inform the needs assessment. Qualitative data was also collected via document reviews and research as well as a combination of surveys, focus groups, and interviews with provider resources, care partners and individuals diagnosed with ADRD. The findings were used to identify emerging concerns around the ADRD population and their care partners.

PCG worked closely with Maine CDC and a core group of stakeholders to review the data collected and develop key findings, which are categorized as strengths and gaps. Below is a synopsis of each of the five strengths and gaps:

Strengths

- While data sets for some populations in Maine are limited, MaineCare, which is easily accessible to researchers and state agencies such as the Maine CDC, provides valuable information for one of Maine's most vulnerable disparate health populations, those with low and very low incomes. MaineCare claims are a robust data set that can continue to provide valuable information about this population longitudinally.

- Successful collaboration with Maine DHHS data gatekeepers provides access to data sets that were used to complete quantitative data analysis to provide context to qualitative findings.

- One third of care partners surveyed utilize support groups which was identified as one of the most important resources that they have access to in Maine.

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[8] A full list of subcommittee leads can be found in the appendices

Strengths (cont’d)	➢ Area Agencies on Aging were cited as one of the most robust resources for care partners and individuals in the state that offers assistance with information and referrals to services such as in-home and congregate care services, home delivered meals, educational programming, health insurance, and benefits counseling. ➢ The HBI Stakeholder Group is strong and engaged which is the first step of the U.S. CDC Evaluation Framework (e.g., Maine CDC, Maine Primary Care Association (MPCA), Alzheimer’s Association Maine Chapter, subcommittee members, etc.). An engaged stakeholder group can improve communication and networking to better leverage and align services throughout the state.
Gaps	➢ Limited access to data sources for individuals living with ADRD restricts the amount and breadth of information necessary to inform the state’s understanding of individual needs and opportunities for resource and program development. ➢ Individuals living with ADRD and their care partners report that the system of health care and supportive services targeted to individuals living with ADRD and their care partners in Maine is complicated and finding the right services at the right time can be daunting. ➢ Services and education are needed for stakeholders including care managers and coordinators, respite care, training for family care partners and other health care providers. ➢ There is not a standardized tool that is accessible statewide that adequately addresses the needs of individuals with ADRD. ➢ Accessibility to services is limited by income and rurality of geographic location.

This plan is the result of years of collective work assessing the needed changes in policies, systems, and environments to support people with ADRD and their care partners.

Associated Maine State Plans

While developing Maine’s latest ADRD State Plan, it was important to consider existing state plans that share similar needs and recommendations to leverage and align resources and collaborative partnerships.

Below are the overlapping needs and recommendations from the 2020-2024 Maine State Plan on Aging, the 2020 Maine Age Friendly State Plan, and the 2021-2025 Maine Cancer Plan:

- Use local organizations to provide navigation to services and resources

- Improve access to services for underserved populations
- Improve access to comprehensive in-home services (minimize risks due to transportation, isolation, etc.)
- Improve access to improved nutrition sources (in-home meals, community meals)
- Improve accessible care partner supports and resources
- Increase network of legal and safety education and resources, including those that address abuse, neglect, and exploitation
- Improve safety and emergency planning and protocols in licensed facilities with emphasis on dignified handling of patients with dementia
- Prevent ADRD by minimizing modifiable risks: tobacco use, obesity, (nutrition/physical activity) alcohol, and environmental hazards (radon, arsenic)
- Conduct screening by primary care providers in conjunction with communication about diagnosis and care planning
- Implement best practices in treatment and/or maintaining quality of life
- Enhance palliative care and end-of-life services
- Expand opportunities for inclusion and diversity (improve access of services to underserved populations); autonomy yet minimize isolation through community service
- Improve communication and coordination (No Wrong Door approach)
- Offer opportunities for utilizing older workers and value of their experience, especially in rural areas of state
- Promote education and access to health care services, especially preventive like healthy aging strategies and physical activity
- Improve safety and strategies for healthy housing and/or long-term care facilities

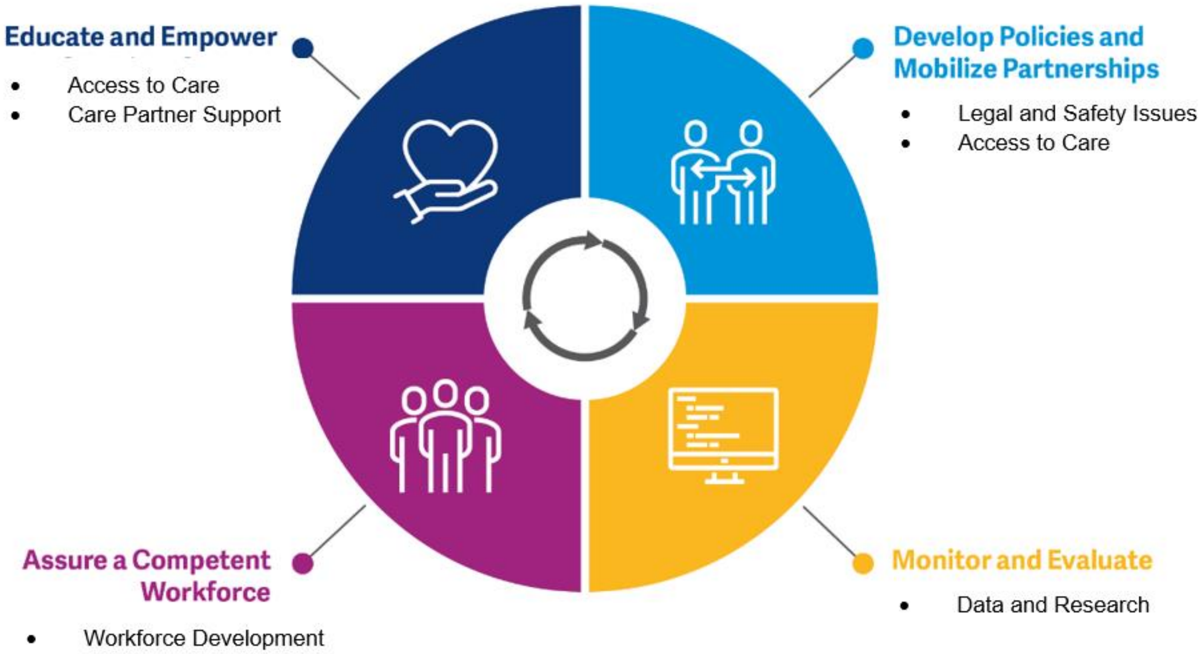
Introduction to the Plan

Maine's ADRD State Plan recognizes the value of older adults with dementia and the need for policies aimed at enhancing prevention through early detection and diagnosis, provider to patient communication and care planning, treatment, and appropriate supports for people with dementia and their care partners and family members. The Plan provides the basis for action to be taken jointly by government and non-governmental partners and is integrated within chronic disease public program work in risk education and reduction and complements strategies that exist in Maine's 2020-2024 Maine State Plan on Aging, the 2020 Maine Age Friendly State Plan, and the 2021-2025 Maine Cancer State Plan. The Plan seeks to create the necessary infrastructure that empowers, educates, and supports people living in Maine by reducing ADRD risk factors, promoting early detection and connecting people to resources they need to optimize wellbeing.

Creating infrastructure that **empowers, educates, and supports people living in Maine** by reducing ADRD risk factors, promoting early detection, and connecting people to resources they need to optimize wellbeing.

The Plan is organized in alignment with the four action areas identified in the Healthy Brain Initiative Roadmap, in the subsequent sections. Below is a depiction of the format of the Plan and alignment of action areas and subcommittee focus areas.

Figure 3. Maine State Plan on ADRD Focus Areas and Corresponding Subcommittee Workgroups



Develop Policies and Mobilize Partnerships

The Healthy Brain Initiative Roadmap emphasizes the critical need for public health to understand the implications of the best available evidence and to promote rapid integration into policies and practice. Planning and policy initiatives provide opportunities to integrate cognitive health and to engage state and local partners.

Annual Screening for Cognitive Impairment

Cognitive impairment can have many possible causes including medication side effects, endocrine disruptions, depression, dementia, and Alzheimer’s disease being the most common. Some of these causes can be treated, others cannot but in either case, individuals and families can be prepared for changes and address safety concerns if they successfully identify cognitive impairment in themselves or their loved one.

Many people who are developing dementia or already have it do not receive a diagnosis according to the National Institute of Health. One study showed that physicians were unaware of cognitive impairment in more than 40% of their cognitively impaired patients[9]. The problem of underdiagnosis is even more pronounced in underserved populations and

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[9] Chodosh J, et al. Physician recognition of cognitive impairment: Evaluating the need for improvement. J Am Geriatr Soc. 2004;52(7):1051-1059. doi: 10.1111/j.1532-5415.2004.52301.x. Retrieved from: https://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients

in those with lower educational attainment – a finding confirmed in Maine in a 2021 needs assessment. Failure to evaluate memory or cognitive complaints is likely to obstruct possible treatment and care management and may present safety issues for patients, their families, and their communities.

The Alzheimer's Association also cites benefits of early detection including:

- ✓ Ensuring patients receive the most benefit at the earliest point possible from treatment options and comprehensive care plans
- ✓ Having more time to plan for the future
- ✓ Lessening anxieties about unknown problems
- ✓ Increasing changes of participating in clinical drug trials, helping advance research
- ✓ Providing opportunities to participate in decisions about care, transportation, living options, financial and legal matters
- ✓ Promoting time to develop a relationship with doctors and care partners
- ✓ Benefiting from care and support services by making it easier for diagnosed individuals and their families to manage the disease

Federally Qualified Health Centers across the state of Maine are working in partnership with the Maine CDC to fully integrate cognitive assessments into existing processes for their health care providers and provide training on how to use them as a diagnostic tool and navigate tough conversations about diagnosis, care planning, and safety with patients and their families. Further work is needed to ensure that all health care providers in Maine have access to cognitive assessment tools, training on when and how to use them effectively, and how to have conversations with patients and families that will maximize early detection and begin supportive care planning for the best possible outcomes.

Care Planning

Care planning helps health care providers map out the possible trajectory of a patient's illness and identify the steps or interventions to take as the illness advances. Every person with an ADRD diagnosis should have a care plan to manage their care and know what to expect at each stage of illness that leverages services that are person-centered. Care planning with individuals with dementia is an ongoing process and a formal update to a care plan should occur at least once per year or when indicated by disease progression.

A care plan typically addresses some or all of the following topics:

- Biography
- Communication
- Mobility
- Toileting
- Eating Patterns
- Orientation/Cognition
- Co-morbidities
- Current medical care
- Medications
- Psychosocial/Behavioral
- Care Partner Support Needs
- Recreational Activities

Each of these areas should include a detailed description of the current functioning, needs and problems, the expected goals and outcomes, what interventions are planned, what services will be provided, and dates for completion of each goal. Health care providers or service providers reading the individual care plan will know what is expected of them when working with the individual and the family will also understand the goals of care.

The Access to Care subcommittee of the HBI Stakeholder Group identified key issues to address in Maine that served as the research basis for developing recommendations for this plan. The key issues examined by the subcommittee are listed in the table below.

Key Access to Care Focus Areas

- Residential care facilities
- Memory care
- Home and community-based services
- Respite care
- End-of-life care
- Behavioral health care
- Telehealth
- Costs/funding and barrier
- Medicaid
- Early detection
- Training
- Financial supports
- Advanced planning

Safety Planning

Safety planning is critical to the wellbeing of individuals experiencing cognitive decline, dementia, or Alzheimer’s disease. Safety planning can prevent injuries and help a person with ADRD feel more comfortable, less overwhelmed and maintain independence longer. Safety preparedness for cognitive decline encompasses many different areas including:

- Wandering
- Home safety
- Driving
- Medication safety
- Disaster preparedness
- Traveling
- Falling
- Living alone
- Firearms
- Abuse, Neglect and Exploitation

The Alzheimer's Association publishes numerous safety assessments that can be used by health care providers or families to identify safety concerns and develop a plan to mitigate them.

The Legal and Safety issues subcommittee of the HBI Stakeholder Group identified key issues to address in Maine that served as the research basis for developing recommendations for this plan. The key issues examined by the subcommittee are provided in the table below.

Key Legal and Safety Issues Focus Areas

- Public Safety including wandering and driving
- Elder abuse and financial exploitation

Key Legal and Safety Issues Focus Areas

- Advanced directives
- Power of attorney
- Supportive decision making for individuals with ADRD and their care partners
- Guardianship
- First responder education
- Approaches to justice that support individuals living with ADRD

End-of-life Planning

Advance care planning discussions ensure patients' values and goals of care, including the freedom to choose their place of death, are respected. The benefits of advance care planning and early end-of-life care discussions are often delayed, as these discussions are not initiated early in patients' disease trajectories. As a result, patients' wishes often would remain unknown. Evidence suggests that many patients inappropriately receive aggressive treatment near the end-of-life, which leads to higher resource utilization, decreased quality of life, and increased cost.[10]

Advance care planning is a patient-centered, voluntary, and ongoing process of communication among patients, family members, care partners, and health care professionals to understand, review, and plan for future health care decisions. Advance care planning promotes shared decision-making in accordance with patients' values and preferences for medical care. It includes the selection of a surrogate decision maker before a medical crisis or the loss of a patient's decision-making capacity through advance directive documents.

Monitor and Evaluate

Surveillance is a fundamental and essential public health tool for understanding the prevalence of disease, health risk factors, preventive health behaviors, and burden of diseases and conditions.

1 in 3 seniors dies with Alzheimer's or another dementia. It kills more than breast cancer and prostate cancer combined.

Source: https://www.alz.org/alzheimers-dementia/facts-figures

Millions of Americans are living with Alzheimer's disease or other dementias. As the size of the U.S. population age 65 and older continues to grow, so too will the number and proportion of Americans with Alzheimer's or other dementias. That is because the risk of dementia increases with advancing age. The population of Americans ages 65 and older is projected to grow from 58 million in 2021 to 88 million by 2050. The baby-boom generation (Americans born between 1946 and 1964) has already begun to reach age 65 and beyond, the age range of greatest risk of Alzheimer's disease and

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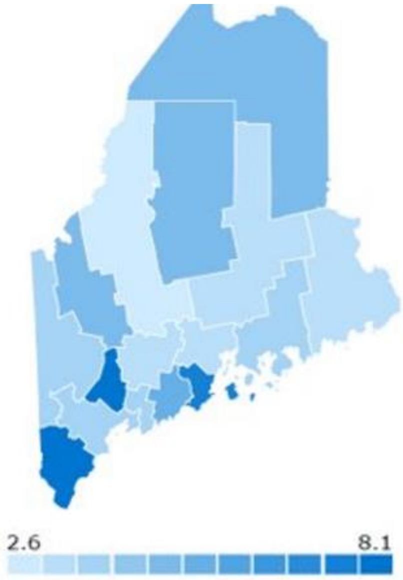
[10] Goswami, P. (2021). Advance Care Planning and End-of-Life Communications: Practical Tips for Oncology Advanced Practitioners. *Journal of Advanced Practitioner in Oncology*. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7844190/

dementia; in fact, the oldest members of the baby-boom generation turned aged 75 in 2021.[11]

Figure 4 demonstrates the severity, and prevalence of ADRD across the country. While the numbers of those impacted by ADRD continues to grow, the financial burden and costs to human lives also increases. Alarmingly, only a small percentage of Americans are able to recognize or are familiar with early stages of Alzheimer's.

Figure 5. Rate of Deaths Due to ADRD per 10,000 Residents by County (Maine Vital Statistics, 2010-2019)



In 2021, the Maine CDC performed a needs assessment as a part of its BOLD Grant. The 2021 needs assessment, using 2017 data, found that Maine ranked the fourth highest in the nation for the rate of dementia deaths and reported a rate that was roughly twice that of New York as demonstrated in figure 6, below. In 2017, Maine had a dementia death rate of 85.5 per 100,000 residents. Within the state of Maine, Knox County (7.55 per 10,000 residents), Androscoggin County (8 per 10,000 residents), and York County (8.14 per 10,000 residents) had the highest rate of deaths per 10,000 caused by ADRD compared to other counties. The rates of death due to ADRD in these counties have been trending upward since 2014.

The number of deaths due to ADRD are not equal for all diagnoses nor is ADRD a standalone illness; it is common for those diagnosed to be diagnosed with other health issues as well. ADRD deaths in Maine are most often attributed to unspecified dementia (54%), followed by Alzheimer's disease (29%), vascular dementia (12%) and other degenerative diseases of the nervous system (5%). However, those under age 65 have a higher percentage of deaths related to other degenerative diseases of the nervous system (19%) compared to those over 65 (5%). Deaths due to ADRD occur most often in hospice or nursing homes, while they occur the least often in medical facilities regardless of the ADRD diagnosis type. The number of deaths due to Alzheimer's disease increases as age increases, with those 85+ (349 deaths) having over double the number of deaths due to Alzheimer's disease as those 75-84 years old (147 deaths).

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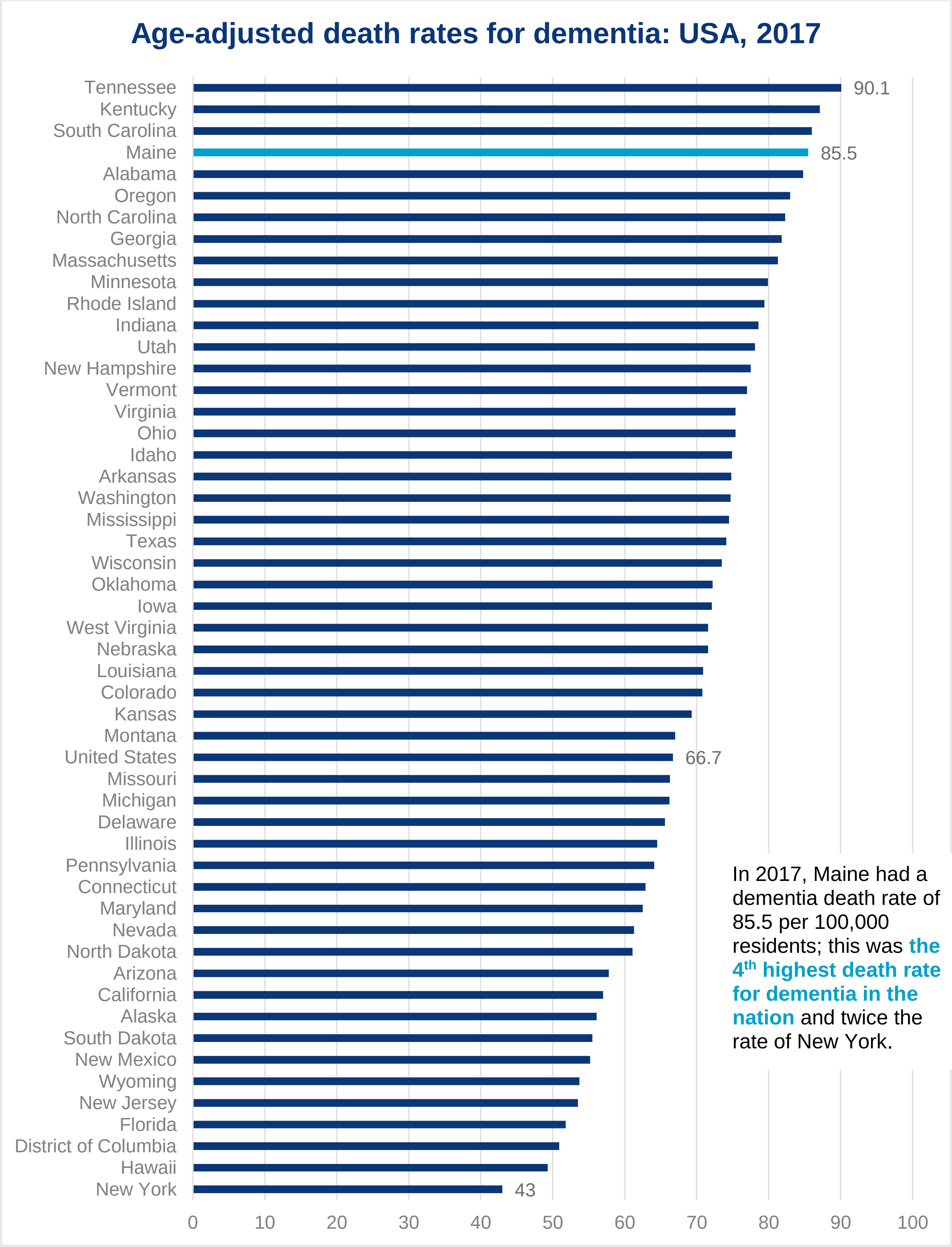
[11] Alzheimer's Association. (2023). 2023 Alzheimer's Disease Facts and Figures. Retrieved from: https://www.alz.org/alzheimers-dementia/facts-figures



In 2017, Maine had a dementia death rate of 85.5 per 100,000 residents; this was **the 4th highest death rate for dementia in the nation** and twice the rate of New York.

Figure 6. Age-Adjusted Death Rates for Dementia[12]

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[12] Source: National Center for Health Statistics

Older Adult Health and Healthy Aging have been identified as priority health needs across the state at both the district and local levels. The figure below highlights the findings of Maine’s 2019 Community Health Needs Assessment where 10 of 16 counties in Maine identified “older adult health” or “healthy aging” as one of their priorities.

Figure 7. Maine’s 2019 Community Health Needs Assessment County Priorities[13]

	Mental Health	Sub-stance Use	Access to Care	Social Deter-minants of Health	Older Adult Health/ Healthy Aging	Physical Activity, Nutrition, Weight	Tobacco Use	Cardio-vascular Disease	Chronic Disease
Androscoggin	■	■	■	■			■		
Aroostook	■	■	■		■	■		■	
Cumberland	■	■	■	■	■				
Franklin	■	■	■	■		■			
Hancock	■	■	■	■	■				
Kennebec	■	■	■	■	■	■			
Knox	■	■	■	■	■				■
Lincoln	■	■	■	■	■	■			
Oxford	■	■	■	■					
Penobscot	■	■	■	■		■			
Piscataquis	■	■	■	■	■				
Sagadahoc	■	■	■	■	■	■			
Somerset	■	■		■	■				
Waldo	■	■	■	■					
Washington	■	■	■	■	■				
York	■	■	■	■		■			

The data and research subcommittee of the HBI Stakeholder Group identified key issues to address in Maine that served as the research basis for developing recommendations for this plan. The key issues examined by the subcommittee are listed in the table below.

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[13] https://www.maine.gov/dhhs/mecdc/phdata/MaineCHNA/documents/2019_Maine_Shared_Priorities_At_a_Glance.pdf

Key Data and Research Focus Areas

- Patient registries and research recruitment
- Surveillance, screening, and the use of biomarkers to identify ADRD
- Assess existing data systems and data sharing agreements
- Clinical trials
- Promoting basic and clinical research
- Recruitment of clinical and basic scientists
- Translating research to the clinic

Support a Well-Trained Workforce

There is a growing demand for talent and workforce in every sector of the U.S. economy and the health care industry faces even greater challenges in the post-COVID-19 landscape where staffing shortages and burnout have exacerbated an already tight labor market. Creative and collaborative solutions will be paramount in assuring a competent workforce with the skills and education needed to address ADRD.

The workforce development subcommittee of the HBI Stakeholder Group identified key issues to address in Maine that served as the research basis for developing recommendations for this plan. The key areas of focus examined by the subcommittee are provided in the table below.

Key Workforce Development Focus Areas

- Health and Human Services (Community and Long-Term Care) Workforce
    - Medical / Hospital / FQHC
    - Long term care / assisted living / congregate housing
    - Primary care / care partner planning
    - Specialized acute care
    - Public health
    - Palliative care and hospice / home care services
    - Primary care
    - Interprofessional practice
    - Social work and case management
- Tribal
- New Mainers
- Law enforcement
- Adult protective services
- Business community
- Municipal government
- Community development organizations
- Architects / planners / interior design
- Education (K-12 / higher education / adult education)

Educate and Empower

Public education plays a fundamental role in public health. Helping people take actions to promote cognitive health requires clear and consistent messages about what is known – and what is yet to be discovered. Target audiences include but are not limited to older adults, adult children, employers, and people supporting an older neighbor or friend.

Public awareness is a key part of public health. It connects information to people so that they know about health and diseases and how it can impact them and their families. Activities such as raising awareness about brain health, shifting mindsets and normalizing discussions about brain health, improving access to information, and reducing stigmas and myths around disease are key elements.

Informal or unpaid care partners (family members or friends) are the backbone of long-term care provided in people's homes. While some aspects of caregiving may be rewarding, care partners can also be at increased risk for negative health consequences. These may include stress, depression, difficulty maintaining a healthy lifestyle, and staying up to date on recommended clinical preventive services.
Informal or unpaid caregiving has been associated with:

- Elevated levels of depression and anxiety
- Higher use of psychoactive medications
- Worse self-reported physical health
- Compromised immune function
- Increased risk of early death

Over half (53%) of care partners indicate that a decline in their health compromises their ability to provide care. Furthermore, care partners and their families often experience economic hardships through lost wages and additional medical expenses. In 2009, more than one in four (27%) care partners of adults reported a moderate to high degree of financial hardship as a result of caregiving.[14]

Figure 8. Number of Weekly Hours Spent Caregiving by Care Partner Type (BRFSS, 2019)

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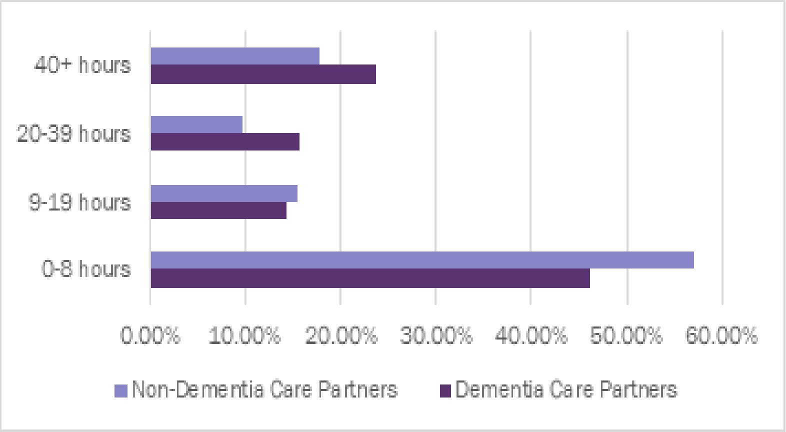
[14] Centers for Disease Control and Prevention. (2023). Division of population health, national center for chronic disease prevention and health promotion. Retrieved from: https://www.cdc.gov/aging/caregiving/index.htm

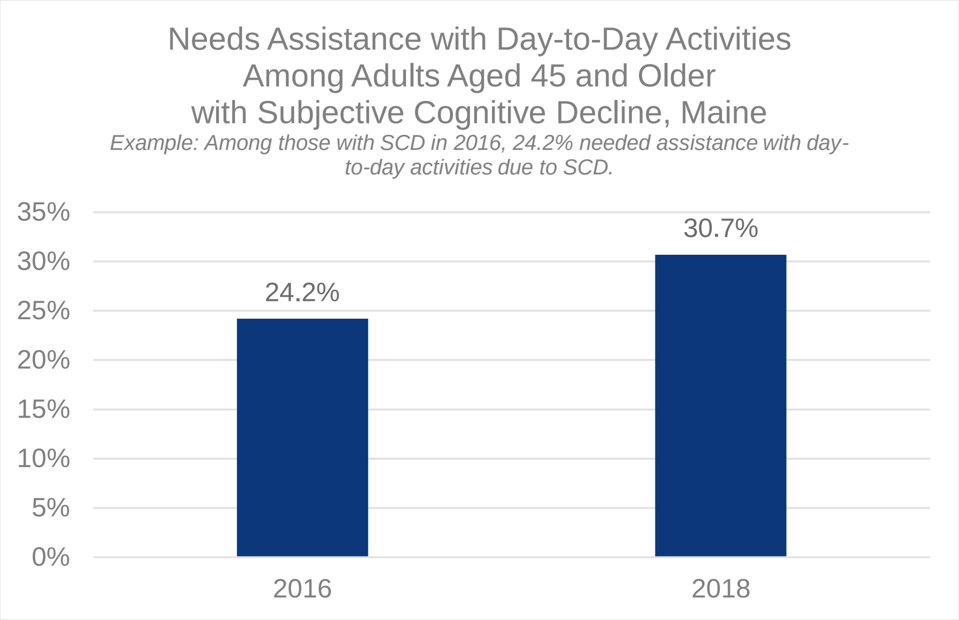


In 2021, the Maine CDC performed a needs assessment as a part of its BOLD Grant to get a better understanding of the environment as it pertains to ADRD throughout Maine. The needs assessment revealed that care partners for individuals diagnosed with ADRD are more likely to be caring for their parent or parent-in-law (47.2%) than for individuals with non-dementia diagnoses (31.3%). The care that is provided to those with ADRD also tends to include more hours per week of caretaking and extend beyond six months of care. Almost 100% of care partners reported providing care for over six months, compared to only 70% of care partners for other conditions. Over half (53%) of the care partners reported that they provide more than eight hours of care per week, a percentage that demonstrated a steady increase between 2015 to 2019 (30% vs 53%) (Figure 8, above). Almost a quarter of respondents reported that they spend 40 or more hours a week caretaking for an individual with dementia.

Care partners for people with ADRD can experience higher rates of depression and poor mental health compared to those providing care for other conditions. Rates of depression are higher among those that are care partners for people living with ADRD (31.1%) compared to those with other conditions (27.4%). The mental health of care partners is also impacted with 19% of ADRD care partners report having 14 or more poor mental health days in the past 30 days compared to 15.7% of other care partners.

Examination of care partners highlights the immense need for services, supports, and resources for both individuals living with ADRD and their care partners as demonstrated in Figure 9, below.

Figure 9. Individuals Needing Assistance with Day-to-Day Activities (Among Adults with Subjective Cognitive Decline), Maine[15]



In 2018, among those reporting cognitive decline, nearly one third of adults 45 and older reported they needed assistance with daily activities; this was a notable increase from 2016 (24%).

Results from the focus groups held as a part of the needs assessment confirmed the quantitative data findings with regard to the need for services and provided additional detail and context to those needs. Focus group participants described a wide array of supports needed to meet their unique situations. Care partners often struggle to identify private or state funded supportive resources that are both available and accessible, at times resulting in the care partner feeling isolated and in need of additional, in-person support. Support groups were reported as a highly utilized resource among the participants, aiding in the feeling of support and community; but they do not occur with the frequency desired and needed by care partners. Participants reported that increased frequency and meeting in person improves the support group experience. Additionally, participants indicated a need for legal advice on topics such as power of attorney.

The care partners support subcommittee of the HBI Stakeholder Group identified key issues to address in Maine that served as the research basis for developing recommendations for this plan. The key areas of focus explored by the subcommittee are listed in the table that follows.

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[15] Source: Maine Behavioral Risk Factor Surveillance System (2016, 2018)

Key Care Partner Support Focus Areas

- Residential care facilities
- Adult Community Day Services
- Memory care
- Home and community-based services
- Respite care
- End-of-life care
- Behavioral care issues
- Telehealth
- Costs/funding and barriers
- Medicaid
- Early detection
- Training for care partners
- Financial supports
- Advanced planning

Frustration was expressed during focus group sessions by care partners with the inability to find a resource that would benefit their loved one with ADRD, including those that would be financially accessible and available when needed most. Many services within the state have income restrictions and waitlists for services which severely limit the number of resources available to people living in Maine with ADRD and their care partners. Examples of services with income restrictions or wait lists addressed in the focus groups were Veteran Affairs' services and resources, residential care, assisted living facilities, in-home health aides and nursing care, neurology, primary care, and dentistry. Geographically, rural areas exacerbate the lack of resources including respite for care partners. Additional challenges corroborated by participants are lack of adequate transportation, and financial burdens for care partners.

The public awareness subcommittee of the HBI Stakeholder Group identified key issues to address in Maine that served as the research basis for developing recommendations for this plan. The key issues examined by the subcommittee are listed in the table below.

Key Public Awareness Focus Areas

- Early detection and diagnosis
- Referrals
- Reducing stigma
- Brain health
- Connecting to diverse populations
- Risk factors

Recommendations

The Alzheimer's Association and the U.S. Centers for Disease Control and Prevention have developed the third in a series of Healthy Brain Initiative Road Maps to advance cognitive health as an integral component of public health. This *Healthy Brain Initiative State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map* outlines how state and local public health agencies and their partners can continue to promote cognitive health, address cognitive impairment for people living in the community, and help meet the needs of care partners. Twenty-five specific actions are proposed in four traditional domains of public health: educate and empower, develop policies and mobilize partnerships, assure a competent workforce, and monitor and evaluate. This "action agenda" speaks to critical issues of risk identification and risk reduction, diagnosis, education and training, care partners, and evidence on impact of the disease. Twenty-one of the 25 actions are rooted in the second Road Map, *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*.

Recommendations for the Maine State Plan on ADRD were developed over the course of a year (2021-2022) through a rigorous, multi-phased process. Using the U.S. CDC's Healthy Brain Initiative's *State and Local Public Health Partnerships to Address Dementia: The 2018—2023 Road Map,* Maine assembled a diverse stakeholder group to lead a series of subcommittees that were each tasked with developing a set of recommendations pertaining to six focus areas: Access to Care, Care Partners, Legal and Safety Issues, Public Awareness, Research and Data Collection, and Workforce Development and Training designed to achieve:

1. A state plan that leads to strategies, policies, and frameworks for prevention of ADRD.
2. Public awareness and understanding of ADRD and reduction of stigma and fear.
3. Integration with other chronic disease state plans to synergize efforts aimed at changing behavior and reducing risks.
4. A clinical infrastructure with expertise that supports the screening, diagnosis, treatment, and care planning for individuals living with ADRD.
5. Improved social fabric supports for care partners through better policies and enhanced funding.

6. Enhanced public health and clinical surveillance systems for ADRD that supports the work of Maine researchers for new, insightful, and innovative research on ADRD.

Each subcommittee was led by a Maine-based subject matter expert in their respective fields.[16] Subcommittees followed a formal charter outlining the specific mission, structure, expectations, and procedural policies to legitimize and organize the subcommittees and obtain buy-in from subcommittee members. The figure below illustrates the connection between the six focus areas in conjunction with the four roadmap action areas.

The graphic below depicts the four action areas as defined in the Healthy Brain Initiative's *State and Local Public Health Partnerships to Address Dementia: The 2018—2023 Road Map* and highlights the need for collaboration to reach success. Collaboration is a key theme of the Plan and a requirement for successful implementation of the Plan's recommendations. Key areas of collaboration include alignment with other state plans as appropriate, community partners, national agencies, non-governmental partners, and others.

Figure 10. Actions and Outcomes: Collaboration, Leverage Resources, and Eliminate Disparities

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[16] A full list of subcommittee leads can be found in Appendix 11.2.

The subcommittees helped to quantify the needs within the state and identify opportunities for improvement which were refined into a set of recommendations that were presented to the Maine CDC for review and consideration in the spring of 2022. The total number of recommendations produced by the subcommittees totaled over 200 initially which can be found in appendix 11.4. Subcommittee leads were asked to work with their teams to refine their recommendations and prioritize those that were deemed most critical for their respective focus area. After identifying overlap between subcommittees, refining, and prioritizing, a total of 22 recommendations were developed for the state of Maine to focus on over the next five years. The recommendations, broken into short and long-term, are listed in figures 11 and 12 directly below. Short-term recommendations are expected to be implemented by 2025, and long-term by 2027.

Short Term Recommendations

Guiding Principles

- Human rights of people with dementia
- Empowerment and engagement of people with dementia and their care partners
- Evidence-based practice for dementia risk reduction and care
- Multisectoral collaboration on the public health response to dementia
- Universal health and social care coverage for dementia
- Equity
- Appropriate attention to dementia prevention, cure and care
- Quality Assurance and Accountability

Recommendations

SHORT TERM (2022 – 2025)

1. Expand access to interdisciplinary dementia diagnostic clinics
2. Integrate cognitive impairment and care partner support into hospital operational plans for acute care of patients with ADRD
3. Provide training, education and counseling services to ADRD care partners
4. Train public safety professionals in engagement approaches for ADRD individuals
5. Train court-related personnel on engaging, supporting, and seeking justice for victims living with ADRD
6. Develop culturally competent, ADRD training for health professionals
7. Develop and train regional & municipal officials in ADRD, service needs, and supports
8. Create a widespread, culturally sensitive public awareness campaign for ADRD
9. Create connections with financial institutions and legal entities to support autonomy of those with ADRD
10. Create non-discrimination resources for workforce focusing on ADRD
11. Facilitate and promote collaboration among research organizations, stakeholders, and investigators
12. Educate legislators about the need for policies that support funding for ADRD services and supports
13. Incorporate cognitive health messaging into existing state health priorities
14. Establish a full-time Dementia Coordinator within Maine CDC
15. Establish a permanent Alzheimer's and Dementia Council to advise state agencies, lead and oversee state plan implementation

Outcomes

- Educate and empower
- Advance policies and mobilize partnerships

- Increase public awareness
- Assure a competent workforce

- Develop and foster safe, dementia friendly communities
- Enhance methodologies to actively monitor and report cases of ADRD

- Enhance and expand accessibility of ADRD services and resources

Long Term Recommendations

Guiding Principles

- Human rights of people with dementia
- Empowerment and engagement of people with dementia and their care partners
- Evidence-based practice for dementia risk reduction and care
- Multisectoral collaboration on the public health response to dementia
- Universal health and social care coverage for dementia
- Equity
- Appropriate attention to dementia prevention, cure and care
- Quality Assurance and Accountability

Recommendations

LONG TERM (2025 – 2027)

1. Develop care navigator program, to include a "no wrong door" referral system
2. Expand funding streams for ADRD services
3. Integrate recreational programming into community-based programs
4. Promote regional public safety groups to discuss safety needs and support for individuals with ADRD and care partners
5. Expand domestic violence and sexual assault services for individuals with ADRD
6. Increase outreach and collaboration of Maine's ADRD statewide network to primary and secondary venues
7. Create methodologies for actively monitoring and case reporting of ADRD

Outcomes

- Educate and empower
- Advance policies and mobilize partnerships
- Increase public awareness
- Assure a competent workforce
- Develop and foster safe, dementia friendly communities
- Enhance methodologies to actively monitor and report cases of ADRD
- Enhance and expand accessibility of ADRD services and resources

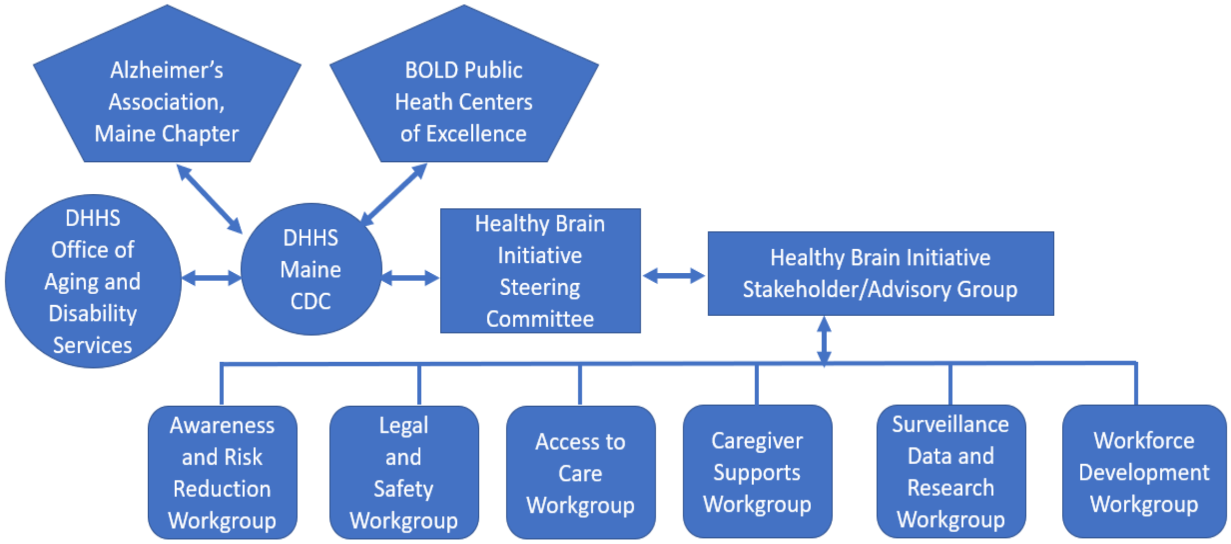
Implementation Planning

The recommendations in this plan are targeted for implementation over the next five years, 2022-2027. Maine CDC will oversee implementation of this plan in coordination with expertise and input from the Maine Office of Aging and Disability Services, the Alzheimer's Association Maine Chapter, the BOLD Public Health Centers of Excellence, the Maine Cabinet on Aging, and the Maine HBI Stakeholder Group.[17] The HBI Stakeholder Group will be charged with supporting implementation of the recommendations of this Plan and therefore will be key to the Plan's success. They will be formalized and meet quarterly to review timelines, prioritize recommendations to be implemented, identify dependencies, and coordinate partnerships with strategic partners.

Collaboration with partners will be the key to the successful implementation of the Plan.

The organizational oversight and administration structure is depicted in in Figure 13.

Figure 11. Implementation Organizational Oversight and Administration Structure



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[17] Governor Mills established the Cabinet on Aging by Executive Order in 2022 (Cabinet). The Cabinet brings together State government agencies to coordinate and advance policy and programming that supports Maine people to age safely, affordably, and in settings and ways that meet individual preferences and needs. The recommendations and strategies outlined in the Plan fit within the overall strategic priorities of the Cabinet.h

Table 7. Recommendations and Potential Partners for Implementation Efforts

In developing this implementation plan, potential partners were identified based on their participation on the state plan subcommittees, or if they did not directly participate, they showed interest in working on the plan, or that their organization mission statement aligned with the state plan. All potential partners will be asked to engage in the implementation plan and certainly can decide to withdraw.

Recommendation	Potential Partners
1. Expand access to interdisciplinary dementia diagnostic clinics	Hospitals and Healthcare Clinics
2. Integrate cognitive impairment and care partner support into hospital operational plans for acute care of patients with ADRD	Maine CDC Hospitals and Clinicians Stakeholder Group
3. Provide training, education, and counseling services to ADRD care partners	Alzheimer's Association Maine Chapter Maine CDC Area Agencies on Aging
4. Train public safety professionals in engagement approaches for ADRD individuals	Maine CDC Local, County, and State Public Safety and Emergency Management Agencies Municipalities Stakeholder Group Elder Justice Coordinating Partnership
5. Train court-related personnel on engaging, supporting and seeking justice for ADRD victims	Maine CDC Office of the Attorney General Legal System Training Network Elder Justice Coordinating Partnership Alzheimer's Association Maine Chapter Stakeholder Group
6. Develop culturally competent ADRD training for health professionals	Maine CDC Higher Education Institutions Alzheimer's Association Maine Chapter Stakeholder Group
7. Develop and train regional & municipal officials in ADRD, service needs and supports	Maine CDC Maine OADS
8. Create a widespread, culturally sensitive public awareness campaign for ADRD	Maine CDC Maine OADS Alzheimer's Association Maine Chapter
9. Create connections with financial institutions and legal entities to support autonomy of those with ADRD	Maine CDC Attorney General Elder Justice Coordinating Partnership
10. Create non-discrimination resources for workplace on ADRD	Office of the Attorney General Maine CDC

Recommendation	Potential Partners
	Maine OADS Legal Services for the Elderly Maine Council on Aging Stakeholder Group
11. Facilitate and promote collaboration among research organizations, stakeholder, and investigators	Research Consortium Stakeholder Group
12. Educate legislators about the need for policies that support funding for ADRD services and supports	Alzheimer’s Association Maine Chapter Stakeholder Group
13. Incorporate cognitive health messaging into existing state health priorities	Alzheimer’s Association Maine Chapter
14. Establish a full-time Dementia Coordinator within Maine CDC	Maine CDC
15. Establish a permanent Alzheimer’s and Dementia Council to advise state agencies, lead and oversee state plan implementation	Alzheimer’s Association Maine Chapter Stakeholder Group

Appendices

Glossary of Terms

ADRD: Alzheimer's Disease and Related Dementia

Adult Community Care Services (Adult Day): Adult Day Services are social and health services provided in community settings to older adults and adults with disabilities. Services may include meals; socialization; physical and educational activities; information and referral; assistance with personal care and activities of daily living; and health monitoring. Individual care plans are developed with participants to outline services to address identified needs.

Alzheimer's Association: a national organization that leads the way to end Alzheimer's disease and all other dementia by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.

Alzheimer's Disease: Alzheimer's disease is the most common type of dementia. It is a progressive disease beginning with mild memory loss and possibly leading to loss of the ability to carry on a conversation and respond to the environment. Alzheimer's disease involves parts of the brain that control thought, memory, and language.

Area Agencies on Aging (AAA): The five Area Agencies on Aging in Maine serve as "one-stop-shops" to answer questions from older adults, individuals with disabilities and their care partners about a wide range of in-home, community-based, and institutional services.

Behavioral Risk Factor Surveillance System (BRFSS): The nation's premier system of health-related telephone surveys that collect state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventative services.

Care Partner: Also known as caregiver, care partnering includes aiding an individual with a health condition to meet their self-care deficits, the commitment to a care partner relationship, and the recognition that people with self-care deficits are care partners contributing to their own care.[18]

US Center for Disease Control and Prevention (CDC): The nation's leading science-based, data-driven, service organization that protects the public's health.

Centers for Medicare and Medicaid (CMS): A governmental organization that provides health coverage to more than 100 million people through Medicare, Medicaid, the Children's Health Insurance Program, and the Health Insurance Marketplace.

Chronic Disease: According to the U.S. National Center for Health Statistics, a chronic disease is one persisting for a long time (usually three months or more) and generally cannot be prevented by vaccines or cured by medications, nor do the symptoms disappear on their own. Health-damaging behaviors or modifiable risks—particularly tobacco use, lack of physical activity, and poor eating habits—are major contributors to chronic disease.

Dementia: Dementia is the loss of cognitive functioning — thinking, remembering, and reasoning — to such an extent that it interferes with a person's daily life and activities. Some people with dementia cannot control their emotions, and their personalities may change.[19] Dementia is a term used to describe a group of symptoms affecting memory, thinking and social abilities severely enough to interfere with your daily life. It isn't a specific disease, but several diseases can cause dementia. Alzheimer's disease is the most

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[18] https://pubmed.ncbi.nlm.nih.gov/27993361/

[19] https://www.nia.nih.gov/health/what-is-dementia#

common cause of dementia, about 60%. Other types include vascular dementia (associated with a stroke), Lewey Body dementia (associated with Parkinson's disease), frontotemporal, and mixed or combination.

Geriatricians: Physicians concerned with the diagnosis, treatment, and prevention of disease in older adults. They specialize in managing conditions specific to aging, including dementia.

Gerontologists: A gerontologist studies the physical, cognitive, social, emotional, psychological, and societal effects of the aging process.to improve quality of life and promote well-being of people as they age.

Guardian: Guardianship is established by a court order. The court grants the guardian authority and responsibility to act on behalf of another person. The relationship is fiduciary, which means that the guardian is obliged to act in the best interest of the individual for whom he/she is a guardian.

Healthy Brain Initiative: A partnership between the Centers for Disease Control and Prevention and the Alzheimer's Association to examine how best to bring a public health perspective to the promotion of cognitive health. Resulted in the creation of the publication, The Healthy Brain Initiative: A National Public Health Road Map to Maintaining Cognitive Health, published in 2007, with the most recent update being published in 2018.

Hospice: A hospice program offers support for dying individuals to live as fully and comfortably as possible. Hospice care is generally provided to individuals with a life expectancy of six months or less. Rather than seeking a cure, hospice care aims to make an individual's remaining time as comfortable and as meaningful as possible. Hospice is a type of palliative care.

Long-Term Care Facility: A long-term care facility is a nursing home or assisted living center designed to provide a variety of services, including both medical and personal care, to individuals who are unable to manage independently in the community.

Maine CDC: Maine Center for Disease Control and Prevention, the state public health agency within the Maine Department of Health and Human Services.

Medicaid (MaineCare): Medicaid is a joint federal and state program that helps with medical costs for qualified individuals with limited income and resources. Medicaid can also provide benefits not normally covered by Medicare, including long-term nursing home care and personal care services.

Mild Cognitive Impairment (MCI): Mild cognitive impairment (MCI) causes a slight but noticeable and measurable decline in cognitive abilities, including memory and thinking skills. A person with MCI is at an increased risk of developing Alzheimer's or another dementia.

Medicare: Medicare is a federally funded government health insurance program for people aged 65 and older and for certain younger individuals with disabilities.

Palliative Care: Palliative care is specialized medical care for people living with a serious illness, like cancer or heart disease. It is meant to enhance a person's current care by focusing on quality of life for them and their family.

PCG: Public Consulting Group

PCP: Primary Care Physician

Person-Centered Care: This term refers to health care and social services designed to reflect the individual's unique preferences, values and needs, identified and agreed upon in partnership with the medical providers, the patient, and other family members when appropriate. The goal is for people to be treated as individuals and to receive appropriate and timely care that meets their needs.

Power-of-Attorney Form: A power of attorney form is a legal document designating someone to act on someone’s behalf when making major decisions such as medical and financial decisions when the individual is unable to make those decisions him/herself.

Respite Care: Respite care provides a care partner temporary relief from the responsibility and stress of caring for individuals with chronic physical or mental disabilities. Examples of respite care include in-home assistance, a short or long-term care facility stay, or day programs for adults.

Subcommittee Leads and Participating Organizations

Maine ADRD State Plan Subcommittee Leadership and Participating Organizations	
Subcommittee Name	Leadership
Access to Care	Peter Baker, LCSW Program Manager: Geriatrics | Healthy Aging MaineHealth
Caregiving and Care Partner Supports	Michelle Cloutier Healthy Aging Manager, Long Term Services and Support Maine DHHS Office of Aging & Disability Services
Legal and Safety Issues	Jessica L. Maurer, Esq. Executive Director Maine Council on Aging
Public Awareness	Tamara H. Herrick, Ph.D. Program Manager: Healthy Aging: Brain Health Initiatives and Evaluation MaineHealth Leigh Riley, MPH Public Health Educator, Alzheimer's & Cardiovascular Health Maine DHHS Maine CDC
Research and Surveillance Data	Clifford Singer, MD Chief of Geriatric Mental Health and Neuropsychiatry Northern Light Acadia Hospital Gareth R. Howell, PhD. Associate Professor, Diana Davis Spencer Foundation Chair for Glaucoma Research The Jackson Laboratory
Workforce Development and Training	Judith A. Metcalf, APRN, BC, MS Associate Program Director, Geriatrics Workforce Enhancement Program College of Osteopathic Medicine, University of New England Lenard W. Kaye, D.S.W., Ph.D. Director, UMaine Center on Aging Professor, UMaine School of Social Work
State Plan Organization and Coordination	Emily Theriault, MHA Chronic Disease Program Manager Maine DHHS Maine CDC Alfred May, MPH Downeast Public Health District Liaison Maine DHHS Maine CDC

Organizations Participating in Maine ADRD State Plan Subcommittees		
AARP Maine	Alzheimer’s Association National	Alzheimer’s Association Maine Chapter
Androscoggin Home Health care and Hospice	Aroostook Agency on Aging	Aroostook Mental Health Services Sexual Assault Services
City of Bangor	Bangor Region YMCA	Downeast Community Partners Friendship Cottage
Eastern Area Agency on Aging	Eastern Maine Development Corporation	Elder Abuse Institute of Maine
Health Reach Community Health Centers (FQHC)	Healthy Living for ME	The Jackson Laboratory
Kennebunk Police Department	LeadingAge Maine and New Hampshire	Legal Services for the Elderly
Lincoln Health’s Cove Edge	Maine DHHS MaineCare	Maine DHHS Division of Licensing and Certification
Maine DHHS Maine CDC BRFSS	Maine DHHS Maine CDC Cancer Registry	Maine DHHS Maine CDC Epidemiology
Maine DHHS Maine CDC Public Health Nursing	Maine DHHS Health care Workforce Development	Maine DHHS Office of Aging and Disability Services
MaineGeneral Health	Maine DHHS Maine CDC ADRD/BOLD Program	Maine Emergency Medical Services
Maine Elder Law Firm	Maine Office of State Fire Marshal	MaineHealth
Maine Public Health Association	Maine Dartmouth Geriatric Medicine	Maine Department of Labor
Medical Care Development (MCD Public Health)	Maine Council on Aging	Maine Medical Association
Maine Primary Care Association	Maine Office of Securities	Maine Seacoast Mission
Care Partner for Family Member	Care Partner for Non-Family Member	Northern Light Acadia Hospital
Northern Light Home Care and Hospice	Maine Health Access Foundation	City of Portland Office of Elder Affairs
Patient and Family Advisory Council (Maine Medical Center)	Public Consulting Group (PCG)	Sagadahoc County Sheriff’s Office
Seniors Plus	Southern Maine Area Agency on Aging	Southern Maine Family Medicine
Spectrum Generations	University of Maine Center on Aging	University of Maine Machias
University of Maine Orono	University of New England College of Osteopathic Medicine	Wabanaki Public Health and Wellness
York County Elder Abuse Task Force	York Public Health Council	

Limitations of the Needs Assessment

The initial needs assessment completed as a part of the BOLD grant activities in 2021 produced valuable data and identified opportunities for improvement within the Alzheimer's disease infrastructure in the state of Maine. However, there were limitations that reduced the reach of the assessment and reduced the impact of the findings.

- PCG was able to utilize a variety of data sources to identify trends in the ADRD population; however, non-identifiable medical claims data was limited to MaineCare. MaineCare is available for Mainers that have low or very low income. A data request was placed with the Maine Health Data Organization (MHDO) to acquire information about the demographics and prevalence of ADRD outside of the Medicaid system. Due to the timeline of this report and the lengthy approval process through MHDO, the MHDO data was not yet available to be analyzed. The MHDO data will, however, be analyzed and shared with stakeholders upon receipt. Lack of comprehensive data sets for the entire population of Maine reduces full representation across the state.

- Collecting data from individuals living with ADRD is challenging and was difficult to collect for this assessment. Only 12 diagnosed individuals responded to the survey and of those, approximately six responded to any given question, which made the data collected lacking in representation of the population of Maine. The difficulty of collecting data from this population is well documented. There are five common challenges faced by researchers working with this cohort:
  a. Effective communication,
  b. Fluctuating capacity,
  c. Distress to individuals,
  d. Time pressures, and
  e. Support staff availability.

- Access to patient registries were requested for the purpose of recruiting survey and interview participants but no response was received. As this work continues, gaining access to this cohort will be a valuable resource that will provide a myriad of additional data around the lived experience of individuals diagnosed with ADRD. Program stakeholders should consider developing ongoing relationships with the data keepers of patient registries and expanding their outreach efforts to this population to ensure data sets are complete and representative.

- As cited in the survey section of this report, no emergency responders participated in the survey. Maine Emergency Medical Services (EMS) was asked to participate in the survey to share their perspective and experiences but due to the overwhelming demand on EMS from the rise of the delta variant of the COVID-19 pandemic, the agency declined to participate.

- The needs assessment was delayed in implementation due to the timing of receiving a waiver from the Paperwork Reduction Act.[20] The BOLD grant is administered by the U.S. CDC and as such, any surveys to be administered are subject to the Paperwork Reduction Act. While Maine CDC finally received exemption from the Paperwork Reduction Act, the unforeseen delay impacted the time to complete this assessment.

Clinical Overview

Alzheimer's disease is the most common cause of dementia in older adults. It is an irreversible, progressive brain disorder that slowly destroys memory and thinking skills and, eventually, the ability to carry out the simplest tasks. It is not a normal part of aging. Dementia is the loss of cognitive functioning like thinking and remembering to an extent that it interferes with daily life. Dementia ranges in severity from mild, where it begins to affect a person's functioning, to severe, when a person must depend completely on others for help with basic activities of daily living.

Alzheimer's disease is named after Dr. Alois Alzheimer. In 1906, Dr. Alzheimer noticed changes in the brain tissue of a woman who had died of an unusual mental illness. Her symptoms included memory loss, language problems, and unpredictable behavior. After she died, he examined her brain and found many abnormal clumps (now called amyloid plaques) and tangled bundles of fibers (now called neurofibrillary, or tau, tangles).[21]

These plaques and tangles in the brain are still considered some of the main features of Alzheimer's disease. Another feature is the loss of connections between neurons in the brain. Neurons transmit messages between different parts of the brain, and from the brain to muscles and organs in the body.

Review of Dementia

Mild cognitive impairment and dementia can be diagnosed with simple office tests and routine studies. Yet the opportunity to diagnose remains complicated by many factors including reluctance to report cognitive problems due to fear and embarrassment, a lack of sensitive and efficient office tools to assist with cognitive assessment, a confusing lexicon for dementia and the diseases that cause dementia, and therapeutic nihilism on the part of clinicians who do not feel that existing treatments are useful.

The diseases that commonly cause dementia include amyloidopathies (neuritic plaques) and/or tauopathies (neurofibrillary tangles), synucleinopathies (Lewy bodies), prionopathies (spongiform degeneration), or strokes (cerebrovascular disease). These pathological entities destroy cortical and subcortical grey matter and produce impairment in various cognitive domains depending primarily on which specific areas are damaged.

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[20] https://www.govinfo.gov/content/pkg/PLAW-104publ13/html/PLAW-104publ13.htm

[21] https://www.maine.gov/dhhs/sites/maine.gov.dhhs/files/documents/ALZ-State-Plan.pdf

Cognitive impairments usually present in patterns and these patterns, or syndromes, are identifiable in an office environment.

The earliest signs of dementia are in the form of mild cognitive impairment and personality changes such as becoming more irritable or apathetic. When the threshold of dementia is crossed, the cognitive impairments are obvious.

The final stage is the loss of abilities to independently perform basic activities of daily living such as toileting, hygiene, dressing, and eating. Drafted by John J. Campbell, MD, FANPA Medical Director for General Hospital Psychiatric Services at Maine Medical Center, each syndrome has its own particular name or diagnosis. Thus, we have dementia of the Alzheimer Type, frontotemporal dementia, dementia with Lewy bodies, progressive aphasias, subcortical dementia, and vascular dementia. The nomenclature for these syndromes is non-uniform in that some conditions are named after people (Alzheimer, Lewy), others after locations of pathology (frontotemporal, subcortical, vascular), and still others based on pathological findings (Lewy bodies), or symptoms (aphasias). Further confusing the picture is the fact that the syndromes are not entirely predictive of the pathologies. For instance, dementia of the Alzheimer type is often, but not always, caused by neuritic plaques and neurofibrillary tangles (Alzheimer's disease).[22]

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[22] https://www.maine.gov/dhhs/sites/maine.gov.dhhs/files/documents/ALZ-State-Plan.pdf

Complete List of Recommendations Developed by the Healthy Brain Initiative Stakeholder Group.

*These recommendations are the original output of the HBI Stakeholder Group Subcommittees and were the foundation for the final 22 recommendations that are included in the Plan. These are not recommendations of the full group or the Department of Health and Human Services/Maine CDC.

Access to Care Subcommittee Recommendation
Ensure adequate access to interdisciplinary dementia diagnostic clinics statewide by: • Establishing mobile diagnostic team(s) to support regular clinic access to underserved areas of the state • Utilizing technology to create access to a wider pool of specialists who can support/conduct diagnostic workups with people living with suspected cognitive decline • Centralize/streamline laboratory and imaging studies • Establish Medicaid billing code to allow reimbursements for cognitive assessments and care planning
Establish an interdisciplinary consortium, including multiple professional schools/programs in medicine, psychology, social work, nursing, PT/OT to create clinical experiences/placements that would provide needed manpower for assessing more people.
Review, modify and adopt dementia education standards to educate health care providers on the importance of early detection and timely diagnosis of cognitive impairment, validated cognitive assessment tools, and pathways for further evaluation.
Ensure providers are aware of the Medicare care planning billing code for individuals with cognitive impairment and the value of a Medicare Annual Wellness visit for cognitive health.
Ensure providers have access to the specialized training needed to carry out the comprehensive evaluations recommended for accurate diagnosis of dementia/ADRD and how to document the evaluations. This training should also include specific guidance on how to initiate and conduct conversations about cognitive health, the assessment of cognitive health and changes in cognition as well as functional assessment.
Ensure clinicians have access to specialty care or other resources to assist in evaluation and diagnosis of ADRD.
Ensure that patients diagnosed with dementia and their care partners are provided with printed materials and web resources about dementia, care planning, symptom management, respite care, and community resources.
Utilize telehealth more to support patients living with dementia and their care partners.
Utilize innovative training opportunities (fellowships, mini-fellowships, micro credentialing/certification, apprenticeships) to increase specialist's dementia knowledge.
Increase the number of geriatricians and neurologists in the state by building upon the existing scholarship/loan repayment programs and dedicating slots (and funding) for new geriatricians and neurologists.
Ensure advanced dementia training programs available to allied health team members (i.e. social workers, OT's, etc.) so that they may also specialize in supporting these patients.
Develop an educational/training program of 3 to 9 months in length in collaboration with a school of social work to prepare Certified Dementia Practitioners. These practitioners could take on responsibilities for care management after a diagnosis of dementia has been made and initial treatment recommendations are in place. This could include patient and care partner education, resource identification, coordination of services, safety evaluations and interventions, and assisting patients and care partners in the management of dementia-related symptoms, especially neuropsychiatric symptoms.
Convene appropriate state agencies and stakeholders to provide written recommendations regarding the integration of cognitive impairment and care partner support into discharge planning procedures at hospitals and specialty medical and surgical facilities.
Require dementia hospital operational plans to identify dementia and/or delirium in the emergency room and/or inpatient settings and to create a specialized care plan if these conditions are detected,

Access to Care Subcommittee Recommendation
ensure designated care partners are involved in hospital processes, particularly related to transfer and discharge planning for individuals with dementia, and ensure clinical and relevant non-clinical staff receive routine Alzheimer's and dementia training. <Dementia Friendly Hospitals: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2955811/ >
Recommend additional training/education of hospital personnel and providers about effective and therapeutic strategies for working and communicating with patients and families when dementia is part of the medical picture.
Highlight the value of a full interdisciplinary team including social workers and care partners are involved in care plan development.
Ensure coverage under MaineCare and Maine-based health insurance plans for all hospitals.
Establish care navigators with specialized training in supporting people living with dementia and care partners to assist with accessing person-centered resource needs, disease education, supports, and symptom management (similar to other models such as cancer care).
Expand access for people with dementia to MaineCare funded home and community-based services; specifically ensure financial eligibility criteria (income, assets, spousal impoverishment standards) reflect the federal maximums.
Review and adjust reimbursement rates as appropriate for dementia-specific services provided by MaineCare and other state administered programs. This review should include adult day, homecare, assisted living and nursing home services.
Engage service providers, agencies, and stakeholders to increase the number of adult day, home care and other long term supports and services (LTSS) providers, particularly in areas without adequate care options.
Provide person-centered, dementia-competent, and dementia-specific home and community-based services for individuals with Alzheimer's and other dementias.
Strengthen or establish policies to protect persons with dementia who display common behavioral symptoms from improper placement in assisted living and nursing home settings.
Establish incentives or other policies to encourage greater development of adult day facilities.
Ensure that state reimbursement levels also consider transportation needs for these services.
Incorporate social programs/memory cafés into community libraries, community centers, churches, senior centers/consult dementia friendly towns.
Promote model for social programs (e. g., Bangor YMCA) to increase social model options for services and less demanding memory cafe/social program options.
Broaden definition of who can provide care to include trained family members.
Maintain and increase the direct care workforce through retention efforts, educational opportunities, career ladders, etc.
Increase and retain the direct care workforce through scholarships/incentives and ensure dementia training standards for all assisted living and memory care to increase retention and thus prevent closures.
Conduct updated time-study to inform reimbursement rates for long term care providers with a focus on the cost/time it takes to provide dementia specific care. Prior studies focused on physical care provided and did not recognize good dementia care for early/middle stages people living with dementia and is often more cueing than hands on care.
Create financial incentives for private pay only centers to establish/purchase more MaineCare beds.
Ensure that all staff in residential care settings have been provided with dementia education and training in order to provide optimal dementia informed care.
Review and increase reimbursement rates for care to people with dementia provided by MaineCare and other state administered programs.
Establish dementia-specific reimbursement rates to reflect the higher cost of dementia care.
Increase the direct care workforce through scholarships/incentives and ensure dementia training standards for all assisted living and memory care to increase retention and thus prevent closures.
Establish policies to limit the involuntary transfers and discharge of people with dementia-related behaviors.
Consider creating mechanisms to provide geriatric psychiatry and dementia specialized interdisciplinary team support to centers to reduce P6 transfers.

Access to Care Subcommittee Recommendation
Develop integrated, environmentally savvy residential care. Shift paradigm from one focused solely on safety, security, and medical needs to prioritize mental, social, spiritual wellbeing and active engagement.
Reduce the use of antipsychotics and increase the utilization of behavioral interventions in the management of neuropsychiatric and behavioral symptoms in patients with dementia.
More upstream work on advance care planning so PLWD and care-partners are best able to plan for future needs.
Utilize palliative care models more in the care of people living with dementia.
Create an online resource/tool that lists funding opportunities (public, private entities that fund ADRD programs) for all the Maine-based stakeholders and what they have to offer so partnerships for programs in specific geographic regions can be easily built.
Closer look at C-SNPs (Medicare Advantage Special Needs Plans)and really build meaningful array of services; need access to strength-based assessments not just deficit assessment.
Establish dementia care specialists (similar to Wisconsin) within the AAAs and ADRCs to support people with dementia and their family care partners to access services and age in place.
Increase funding for and services within the Medicaid home and community-based services waivers.
Add dementia case management within existing waivers and state programs.
Create quick sheet with educational information about the signs of Alzheimer's and dementia compared to normal aging that could be distributed to EMTs and other allied health professionals. In The GSA KAER Toolkit for Primary Care Teams developed by the Gerontological Society of America (GSA), they provide a link to a document from the Alzheimer’s Association, “10 Warning Signs of Alzheimer’s” that includes “what’s typical age-related change” with each.
Establish dementia education standards (requirements) to educate health care providers on the importance of early detection and timely diagnosis of cognitive impairment, validated cognitive assessment tools, the value of a Medicare Annual Wellness visit for cognitive health, and the Medicare care planning billing code for individuals with cognitive impairment;
Conduct public health campaigns directed to health care providers around early detection, diagnosis, and the importance of sharing the diagnosis.

Care Partner and Caregiving Recommendations
Easily accessible support services including training/education and counseling for care partners to be provided through trained dementia specific counselors with the AAAs in various venues (i.e., technology- based options, as well, as, in-person support).
Increase the opportunities for more day respite care to allow families to recharge.
Create a volunteer-based dementia support service that provides opportunities for social and physical activities.
Provide easy to understand and accessible educational resources for local community organizations most frequented by community members that capture the attention of care partners.
Create a public awareness campaign to help reduce the stigma of dementia and create more dementia friendly environments.
Offer additional evidence-based programs that engage care partnering.
Create connections with financial institutions and legal entities to help support the value of legal documents in supporting autonomy of those with dementia.
Promote supporting documents such as guides developed by The Conversation Project for addressing end-of-life care wishes for those living with dementia; providers; and family, including a “Guide for Care partners of People with Alzheimer’s or Other Forms of Dementia”.
Recognition of care partners in the need for support as equivalent to those living with dementia.
Work collaboratively with a broader array of trained professionals and include family as an ‘assigned’ guide to care in the initial care plan development. Assess those plans of care for necessary changes and updates with the ease of a simple tool that creates less burden for all involved.
Increase awareness of Medicare care planning billing code among health care providers; establish a Medicaid billing code for cognitive assessments and care planning.

Care Partner and Caregiving Recommendations
Support and access to those professionals that may help determine capacity of the person living with dementia.
Reduction in financial burden for respite and legal matters for care partners.

Legal and Public Safety Subcommittee Recommendations
Develop outreach materials and public service announcements intended to encourage individuals to engage in conversations with trusted family members and advisors during an early life stage to develop appropriate plans to assist with future decision making.
Increase the number of people using supported decision-making tools. Promote Disability Maine's Supported Decision-Making tool.
Increase the number of people who have both a health care advance directive and a power of attorney. Promote the Maine form available on Maine Hospital Association website: http://www.themha.org/policy-advocacy/Issues/End-of-Life-Care/advdirectivesform.aspx
Create a "no-wrong door" referral system that ensures people with mild cognitive impairment gain access to legal planning resources and support, including through their health care professionals. Referrals should include Legal Services for the Elderly, the Maine State Bar Association, the area agencies on aging, specifically including information on Money Minders and Care partner Support Programs, Maine CITE (assistive technology), and the Alzheimer's Association Helpline.
Better training for facility staff about engaging with power of attorney agents.
Create a simple and neutral on-line resource that answers basic questions about best practices related to power of attorney and legal planning (e.g. gifting provisions, joint bank accounts).
Collaborate with state health care associations to increase training for anyone who is authorized to complete form PP505 – a form that specifies the level of a person's capacity for certain activities. The training should include the potential impacts on completing the form.
Create options for trustworthy fiduciary outside of family structure and increase number of representative payee organizations serving Maine.
Expand emergency support services available under MaineCare Section 17 to people with neuro-cognitive disorders and/or create a new emergency service for them under different MaineCare sections.
Require that any conclusion of incapacity made by a medical provider is specific as to the type of incapacity (e.g. physical, financial, and cognitive) and the scope and extent of incapacity in order to preserve the right to autonomy to its fullest extent.
Require two physicians to determine competency or one with neuro-psych examination.
Create an ombudsman program for power of attorney.
Expand the number of social workers supporting people living in the community with cognitive impairment and to create resource navigators within various systems.
Create resources for employees and employers related to workplace protections from discrimination for employees with cognitive impairment and their care partners.
Amend 18-C M.R.S. §5-922 to prohibit financial institutions including those engaged in banking, securities, and insurance activities, from refusing to accept an acknowledged power of attorney and requiring the execution of the financial institutions own power of attorney form absent a showing that the acknowledged power of attorney is inconsistent with a specific federal or state law.
All public safety professionals, including law enforcement, fire, EMS, and wardens should incorporate training specific to engaging with people experiencing cognitive decline into all initial training curriculum and into on-going training opportunities. Training should include identifying people who may be experiencing cognitive decline, risk reductions strategies, interviewing, and core referral sources. These trainings should be done by field experts in the discipline in partnership with experts on cognitive decline.
All regular on-going domestic violence, sexual assault, and elder abuse training curricula already in use by public safety professionals should be updated to include specific information for victims who are experiencing cognitive decline.
Encourage regional public safety groups, like community associations, that meet regularly to include regular conversations about supporting the safety of people in the community living with dementia.

Legal and Public Safety Subcommittee Recommendations
Utilize existing training videos, or create new training videos, that can be viewed by public safety volunteers on their own time. Videos should include topics on wandering, interviewing, and for law enforcement officers, traffic stops.
Fire safety professionals should know about voice smoke and carbon monoxide alarms, Kidde technology that provides alerts to others, and other kinds of safety devices that can be used to increase fire safety in homes with people with dementia. They should also be trained on other technologies people can deploy to reduce fire hazards for people living with dementia.
Research and best practices from other countries and states regarding fire safety and people with dementia should be shared with fire safety professionals annually. Specifically, research from England on carbon monoxide poisoning impacting cognition should be shared more broadly and homes should be checked for these issues.
Fire Marshal's Office should create and regularly update a fire safety checklist specifically for care partners of people living with dementia, said checklist to be widely circulated to municipal officials and aging services providers.
The law enforcement officers manual should be updated to include a chapter on engaging with community members, crime victims, and offenders who are experiencing cognitive decline.
Create and maintain mechanism to share best practices with other officers – like a community wanderer board, Project Life Saver, Project Safe Return, Silver Alert, etc.
It's recommended that code enforcement officers also receive routine training on engaging with people in the community who may be experiencing cognitive decline, said training to specifically include information on referral sources.
Provide support for and assist with the implementation of recommendations contained in the Maine Elder Justice Roadmap that are consistent with the vision of the ADRD Plan.
Increase justice for crime victims with MCI and dementia.
Create a system of expedited investigation and prosecution of crimes involving victims with MCI and dementia.
Provide training on dementia annually at Maine Prosecutor's Conference.
Domestic violence investigators in district attorney offices trained on engaging with victims with MCI and dementia.
Victim advocates across all services are trained to support victims with MCI and dementia.
Victim services available to victims of domestic violence and sexual assault should be available to serve victims with MCI and dementia.
Enhance and grow the elder advocate model, a partnership between Maine Adult Protective Services and the Elder Abuse Institute of Maine.
Create expedited legal proceeding provisions for both civil and criminal trials involving victims with mild cognitive decline and dementia.
Increase reporting of abuse, neglect, and exploitation of people with MCI and dementia by promoting a helping call as a support to workers who are concerned about reporting.
Resources should be allocated to promote and sustain people with mild cognitive impairment and dementia, and their care partners, throughout the course of their disease, and to help them maintain their autonomy as much as possible.

Public Awareness Subcommittee Recommendations
Tailor clear and concise public awareness messaging for the general public that emphasizes self-determination.
Ensure cognitive health messaging uses the best available evidence about brain health and risk factors and is culturally appropriate.
Advocate for equity in technological access to cognitive health messaging.
Increase awareness of the important role of family care partners in supporting people living with ADRD.
Reduce stigma by busting myths and perceptions about cognitive impairment and people living with an ADRD diagnosis.

Public Awareness Subcommittee Recommendations
Integrate brain health messaging into existing health communications that promote mental health, substance use and chronic disease management across the life span.
Educate the public about brain health and cognitive aging changes that should be discussed with a health professional to promote early detection and diagnosis.
Integrate brain health messaging into K-12 school health curricula.
Develop a public outreach plan to share information about social determinants and lifestyle risks and what people can do to reduce risk as individuals and communities.
Develop a centralized online portal for educational resources and online programs including information regarding prevention of ADRD through diet, exercise, management of chronic illnesses like diabetes and hypertension, tobacco cessation, social engagement, and other lifestyle modifications.
Facilitate ADRD outreach and education to rural and minority communities including information about Medicare annual wellness visits, the warning signs of ADRD, the benefits of early detection and diagnosis and care planning.
Educate family care partners on ADRD.
Educate family care partners on how to communicate with people living with ADRD as dependence status changes over time.
Increase education about the importance of maintaining care partners' health and wellbeing.
Educate allied health professionals, government (tribal, state, county and municipal) and employers on how to recognize the signs of ADRD and how to communicate with people living with ADRD.
Educate health care professionals about early detection and diagnosis and the importance of referrals to support services for people living with ADRD and their care partners.
Educate legislators about the need for policies that support funding for ADRD services and supports including adult day services, respite and transportation for patients, their families and care partners.
Build workflows that promote bidirectional communication between health care providers and support service organizations.
Increase awareness about the importance of advanced care planning, goals of care planning and how to talk to patients and families about end-of-life.
Align messaging with the Maine Age-Friendly Dementia Plan, Maine State Aging Plan, and the Healthy Brain Initiative.
Incorporate cognitive health messaging into existing state health priorities.
Establish a full-time, permanent dementia coordinator position within Maine CDC to work across agencies to implement the state plan.
Establish a permanent Alzheimer's and Dementia Council to advise the state agencies, oversee state plan implementation and lead updates to the state plan every 3-5 years.

Workforce Development and Training Subcommittee Recommendations
All medical/health professional programs require a foundational course in ADRD and related dementias prior to graduation, including Institute for Health care Improvement 4Ms (What Matters, Medication, Mobility, and Mentation) age-friendly concepts, Geriatrics Workforce Enhancement Program (GWEP), and Frameworks Institute.
Train student learners to participate in the annual wellness visit and perform standardized assessments integrating the 4Ms framework.
Consider using the Gerontological Society of America (GSA) KAER Model and Toolkit in providing education for health care professions faculty and students.
Care partner role, screening for risk/depression, culturally appropriate caregiving strategies, programs and resources is critical, essential and should be included in all ADRD education and training.
ADRD and related dementias education and training should be interprofessional and team based.
Train a statewide panel of expert standardized patients and care partners in ADRD and related dementias to be used in medical/health professions patient simulation activities to train interprofessional student learners and shared among medical and health professions programs throughout Maine's counties, regions and/or statewide.

Workforce Development and Training Subcommittee Recommendations
Leverage Maine's robust statewide network of expertise including academic, grant-funded, community-based organizations, health care, and research institutions to develop a wide variety of experiential field placement opportunities for all students in all disciplines at all levels that focus on persons living with ADRD and related dementias, care partners and referral/resource networks.
Create a portal/warehouse of available state/national ADRD and related dementia organizations, best practices, programs, resources, research, and clinical trials for persons living with ADRD, care partners, health professions faculty, student learners and health professionals.
Provide additional education in areas identified as often receiving necessary but limited training such as: dementia with behavioral/psychologic disturbance and how to work effectively with integrated health and specialists to address these issues; utilization of dementia and ACP codes to access reimbursement in primary care; capacity evaluations and early intervention; driving and dementia; and dementia quality measures including disclosure of diagnosis.
Ensure ADRD curriculum for student learner providers, include knowledge and utilization of dementia and ACP codes to access reimbursement in primary care to support ADRD and related dementias such as codes for billing Medicare annual wellness visit and cognitive assessment and care plan services for patients with cognitive impairment.
Recommend greater emphasis on development of interprofessional ADRD education, training, and clinical placement opportunity for student learners. Also recommend critical clinical placement training shift for nursing students from inpatient clinical experiences to outpatient, community, and home-based opportunities.
Incorporate education, training, and experiential learning in telehealth for all faculty and student learners that will be providing screening, consultation, referral, Medicare Annual Wellness Visits and/or other related assessments and evaluations for persons with ADRD and related dementias and their care partners.
Recommend all medical/health professions curriculum include coursework in health literacy and plain language which enables students to learn and use evidence-based techniques for clear communication when communicating with persons with ADRD and related dementias and their care partners.
Maine hospital systems could emulate the Mount Desert Island Hospital unique model of medical education and recruit residents who have training in geriatrics and valuable experience in working in a rural environment.
Encourage junior faculty at accredited schools of allopathic medicine, osteopathic medicine, nursing, social work, psychology, dentistry, pharmacy, or allied health to apply for the Geriatrics Academic Career Award Program (GACA), focusing on training in geriatrics and working within interprofessional teams.
Recommend the Accreditation Council for Graduate Medical Education (ACGME) requirement for family medicine and internal medicine residents to receive training in the care of older adults, be expanded to emergency department, surgery, and all other specialists.
Recommend PharmD curriculum integrate Geriatric Pharmacology into the core curriculum as a required course versus an elective for which only interested students enroll. Create greater opportunity and ease for pharmacists to become board certified in geriatrics by developing curriculum, study guides and supports that are not currently readily available.
Consider replicating new and innovative models to train nurses to become dementia care specialists, such as the University of Washington School of Nursing Dementia Palliative Education Network (DPEN).
Consider replicating Oregon's behavioral health initiative to "improve the population's access to behavioral health providers, services and benefits; improve the knowledge and skills of people who provide services or care to the population; and Improve the population's knowledge about signs and symptoms of behavioral health problems and how to address them by training behavioral health specialists.
Consider needs analysis to determine what are the perceived core educational needs among those with ADRD and related dementias and their care partners. Recommend Maine Senior College Network and/or network of public libraries perform needs assessment.

Workforce Development and Training Subcommittee Recommendations
Recommend collaboration with University of Maine Cooperative Extension Service to offer opportunities to participate in indoor, outdoor recreational workshops, programs and resources that engage persons with ADRD and related dementias and their care partners.
Engage the subject matter experts such as the Alzheimer's Association, AAAs, National Digital Equity Center (NDEC), and the Dementia Action Alliance to partner with and develop curricula that could be offered throughout Maine's adult education networks. Encourage person centered, enriching, fulfilling and fun classes, courses, and other opportunities in programs such as dance, theater, music, art, writing, poetry, outdoor sports, and recreation such as hiking and snowshoeing, and others designed to bring joy and a sense of community to both the person with ADRD and related dementias and their care partners.
Consider replicating the Dempsey Center as an organizer/hub of adult education with a focus on supportive programming and resources for persons with ADRD and their care partners.
Encourage the development and submission of an ADRD-focused NIH Science Education Partnership Award, potentially with UNE as lead institution.
Partners in the Maine ADRD plan should collaborate on a plan to increase outreach. For example, outreach in concert with existing programs like the Maine Science Festival, or in collaboration with public libraries.
Inventory Maine CTE programs that are seeding the direct-care workforce.
Establish a high school teacher professional development program in neurobiology.
Create pathways for Maine undergraduate neuroscience students to engage as near-peer mentors and leaders of in-class outreach programs.
Reduce/Prevent loss of third-party reimbursement to case management and other provider organizations due to patient no-show or missed appointments.
More evenly distribute the availability of adult day care services throughout the state based on research that identifies the needs, gaps, and needed points of access and utilization.
Training needed regarding what Adult Protective Service (APS) is, how to report to APS in Maine, the process of an APS referral, and mandated reporting.
Increase the reimbursement rate to cover the true cost of adult day services.
Expand mental health case management to include dementia as a qualifying medical diagnosis for receipt of MaineCare services.
ADRD training for law enforcement and other first responders.
Make ADRD resources and services available in multiple languages across the state.
Obtain feedback from communities across the state to learn how ADRD services and resources can become more culturally inclusive and safe.
Training for providers to become competent in the needs of LGBTQ older adults and honoring chosen family as part of the care team.
Explore potential reimbursement mechanisms for small, community-based programs providing medical management, transportation, friendly visiting, navigators, meals delivery, pain medicine, volunteer, and chore services.
Support the development of increased evaluation and data collection capacity of small, community-based organizations to enable them to compete as grantees and subgrantees in federal funding opportunities.
Make available training and provision of in-home, and congregate-delivered respite care services for care partners..
Increase the flexibility of payment mechanisms for home help including the eligibility of family members serving as reimbursable personal care assistants.
Make less restrictive rules that restrict patients/clients opting out of certain personal support services.
Make more consistent and uniform the rules and terminology across community delivered personal care services.
Support the increase in availability of patient navigator programs to assist older adults in negotiating available entitlements and benefits.
Make community paramedicine services a Medicare-reimbursable expense.
Make CRMA classes more accessible in rural communities including the offering through adult education and on-line offerings.

Workforce Development and Training Subcommittee Recommendations
Make the Best Friends Approach to ADRD more widely available including increasing family and community-based focused training.
Consider expanding the focus of Savvy Care partners training to include individuals with mild cognitive impairment.
Make available a statewide, easily accessible clearinghouse of ADRD services and training resources.
Focus on the translational implications and contributions of ADRD research for educational and training resources.
Increase the availability of ADRD support services and trained staff in Maine Housing to address resident cognitive impairment issues.
Expand training to enable more effective assessment and recognition of self-neglect in vulnerable individuals (i.e., low income, isolated, substance use, mildly cognitively impaired, and those with co-morbid conditions).
Explore the establishment of low barrier ADRD care models utilizing local, indigenous individuals who know the community well.
Improve provider education on ADRD and billable codes.
Review IHI mentation component in hospital operational plans.
Define standardized workflows and core expectations for work through the development of protocol for the delivery of the screening and referral.
Improved reimbursement and wages (direct care wages).
Review age-friendly recommendations for regional and municipal comprehensive plans.
Review dementia-friendly recommendations for regional and municipal comprehensive plans.
Develop and implement training for regional and municipal officials (planners, code enforcement officers, local health officers) on understanding ADRD and persons with ADRD to develop protocols on mitigating impacts of potential housing or other issues.

Research, Data, and Surveillance Subcommittee Recommendations
Engage stakeholders and service providers in developing the surveillance system.
Determine needed resources and responsible parties to implement and sustain the surveillance system.
Designate a standing advisory committee to confirm existing data sources in Maine, evaluate potential models used in other states and develop conceptual schematic for data related to ADRD, including specific indicators needed to advise interventions to improve outcomes and assess functionality and use of system over time.
Explore use of HealthInfoNet for surveillance and clinical data mining for prevalence, incidence, and health outcomes data.
Explore approaches that other states have taken to enhance ADRD surveillance.
Determine the need for specific types of ADRD registries (e.g., research registries, (pre-clinical, people with diagnoses, care partners), epidemiological registry (incidence, prevalence, etc.), and quality of care registries (utilization, cost, and quality)).
Develop dissemination tools to make data accessible for key stakeholders, such as the state Office of Aging and Disability Services' (OADS) care partner programs, health care providers, researchers, and public health actions.
Develop and/or use a Community Information Exchange (CIE) for partner organizations to be informed of diagnosis and information associated with social determinants of health for diagnosed individual. Having this exchange and information will help investigate population trends and service usage and evaluate care for patient and care partners.
Work with Maine public health districts as dissemination mechanism to meet goals of the CDC Healthy Brain Roadmap.
Employ Dissemination and Implementation Science (DIS) research that adapts practices to address adherences issues in the general population, as well as increasing uptake of evidence-based practices in more rural and socioeconomically diverse communities.

Research, Data, and Surveillance Subcommittee Recommendations
Create a standing work group or advisory committee of local and regional experts as to advise and monitor best practices on prevention and dissemination of recommendations.
Coordinate efforts with existing organizations, such as Healthy Living for ME, to create programs with an ADRD prevention focus to help bring CDC and healthy brain initiatives to rural and diverse communities.
Coordinate efforts with other elements of the State Plan for Alzheimer's disease created by the access to care and family care partners, public awareness, legal and safety issues, and workforce development subcommittees.
Organize an annual research and data conference or summit to bring stakeholders together, evaluate progress and make mid-term corrections.
Start work in year 1 to establish a research collaborative of interested parties to work on necessary contracting arrangements of collaboration.
Demonstrate effective collaboration through pilot research projects.
Hold annual summit to report on progress and achievements of Maine ADRD research collaborative members.
Work with Maine CDC and Maine's stakeholders to establish a standing committee to create a process by which we can do high quality, standardized, protocol-driven assessments of diverse research subjects seen at multiple sites.
Create a research collaborative to ensure a large cohort of potential research subjects of sufficient diversity with high quality, protocol-driven, biomarker-confirmed diagnoses of ADRD and risk for ADRD is available for recruitment into research studies.
The use of community-based participatory research (CBPR) may increase the ecological validity of research findings and the diversity of study subjects.
Create method of annual assessment and report of progress on this and other objectives.
Establish collectively supported ADRD research center with administrative, clinical, data, analytic cores to support research of accomplished investigators to support and mentor new scientists.
Establish collaborative agreements between research and health care organizations for joint recruitment of clinical scientists.