Massachusetts State Plan on Alzheimer's Disease and Related Dementias

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A Public Health Crisis

Overview of Alzheimer's Disease and Related Dementias

According to the National Institute on Aging, "Dementia is the loss of cognitive functioning (thinking, remembering, and reasoning) and behavioral abilities to such an extent that it interferes with a person's daily life and activities."[1] Although dementia has many causes, Alzheimer's disease is the most common cause and the vast majority of people who develop dementia are age 65 or older.

Alzheimer's disease and other dementias (ADRD or dementia) are a large and growing public health crisis that state policymakers cannot ignore. Today, more than 5 million Americans are living with dementia, and that number is expected to triple by mid-century.[2] There are about 130,000 people in Massachusetts living with dementia,[3] supported by approximately 340,000 family caregivers,[4] and that number is growing rapidly. On the current trajectory, Massachusetts will see an estimated 150,000 people living with dementia by 2025.[5] Dementia has wide-ranging adverse consequences, including functional limitations, complications of co-existing medical conditions, increased health care utilization, and substantial caregiver burden.[6]

ADRD not only affects individuals living with the condition, but also affects their families and friends who often assume the role of "informal caregivers." Nearly half of all informal caregivers (48 percent) who provide help to older adults in the U.S. do so for someone with ADRD.[7] Caregivers of people with ADRD not only assist with activities of daily living, but when compared with caregivers of people without dementia, they are more likely to take on the responsibility of

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[1] National Institute on Aging. https://www.nia.nih.gov/health/what-dementia-symptoms-types-and-diagnosis

[2] 2020 Alzheimer's disease facts and figures. *Alzheimer's & Dementia,* 16(3), 391-460. https://doi.org/10.1002/alz.12068

[3] Liesi, H., Rush University Institute on Healthy Aging; based on data from the Chicago Health and Aging Project: Weuve, J., Hebert, L.E., Scherr, P.A., Evans, D.A., Prevalence of Alzheimer disease in U.S. states. *Epidemiology* 2015;26(1): E4-6. https://doi:10.1097/EDE.0000000000000199. PMID: 25437325. This number was similarly reflected in the *Massachusetts Healthy Aging Data Report Community Profiles* (2018), UMass Boston, Gerontology Institute.

[4] Estimated by the Alzheimer's Association using data from the 2009 Behavioral Risk Factor Surveillance System survey, U.S. Census Bureau, Centers for Medicare & Medicaid Services, National Alliance for Caregiving, AARP and U.S. Department of Labor.

[5] 2020 Alzheimer's disease facts and figures. *Alzheimer's & Dementia,* 16(3), 391-460. https://doi.org/10.1002/alz.12068

[6] Bradford, A., Kunik, M. E., Schulz, P., Williams, S. P., & Singh, H. (2009). Missed and delayed diagnosis of dementia in primary care: prevalence and contributing factors. Alzheimer disease and associated disorders, 23(4), 306–314. https://doi.org/10.1097/WAD.0b013e3181a6bebc

[7] Spillman, B., Wolff, J., Freedman, V.A., Kasper, J.D., Informal Caregiving for Older Americans: An Analysis of the 2011 National Health and Aging Trends Study.

managing finances, advocating for the individual with community agencies and care providers, and managing difficult symptoms experienced by the person they care for such as anxiety, apathy, and lack of inhibition.[8]

Due to the progressive nature of ADRD, an individual living with dementia experiences a gradual loss of function and requires more of the caregiver's time and attention over time. The rate of progression is often unpredictable, which can result in additional pressures on the family unit. Compared with caregivers of people without dementia, twice as many caregivers of individuals with dementia indicate substantial emotional, financial, and physical difficulties.[9] Although there are numerous services, supports, and programs available to Massachusetts residents with dementia and their caregivers, families are often unaware of them. This contributes to the already high stress levels experienced by individuals and families affected by dementia.

People living with dementia and their caregivers also face challenges triggered by their physical environment. Regional and municipal planners, architects, and engineers don't always consider cognitive disabilities when engaging in efforts to make physical infrastructure accessible. Examples of physical infrastructure include streets and outdoor spaces; parks and recreational areas; and commercial and residential buildings. According to Dementia Friendly America, dementia-friendly communities are communities that "foster the ability of people living with dementia to remain in the community and engage and thrive in day to day living."[10] Communities can make important strides toward becoming dementia-friendly when they incorporate age-friendly[11] and dementia-friendly design into their physical infrastructure. These efforts ensure that physical infrastructure is familiar, legible, distinctive, accessible, comfortable, and safe for not only people living with dementia and their caregivers, but for all residents.

A particularly critical threat to the health and wellbeing of people affected by dementia is a medical profession that is not fully prepared to meet their pre- and post-diagnosis needs. More than half of primary care physicians report a shortage of specialists such as geriatricians, geriatric psychiatrists, neurologists, and neuropsychologists to meet the needs of their patients with dementia.[12] This contributes to the estimated large number (50 percent) of people living

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[8] National Alliance for Caregiving in Partnership with the Alzheimer's Association. Dementia Caregiving in the U.S. 2017, Bethesda, Maryland.

[9] Kasper JD, Freedman VA, Spillman BC. Disability and Care Needs of Older Americans by Dementia Status: An Analysis of the 2011 National Health and Aging Trends Study. U.S. Department of Health and Human Services; 2014.

[10] Dementia Friendly America. https://www.dfamerica.org/

[11] According to the World Health Organization, age-friendly communities "enable people of all ages to actively participate in community activities and treat everyone with respect, regardless of their age." https://www.who.int/ageing/age-friendly-world/en/

[12] 2020 Alzheimer's disease facts and figures. *Alzheimer's & Dementia,* 16(3), 391-460. https://doi.org/10.1002/alz.12068. Source of data: Primary Care Physician Cognitive Assessment Survey conducted by Versta Research from December 13, 2018, through December 26, 2018.

with dementia who remain undiagnosed[13] and a lack of comprehensive care planning and person-centered care for those who are diagnosed.

Most evidence-based practice guidelines advocate a central role for the primary care physician (PCP) in the detection, diagnosis, and treatment of Alzheimer's disease.[14] Despite this consensus among practice guidelines, a national survey of PCPs in 2018 found that many PCPs choose not to assess a patient age 65 or older for cognitive impairment; 58 percent cited a lack of time during patient visits as the reason.[15] In a review of studies about delayed or missed ADRD diagnosis among PCPs,[16] sixteen studies concluded that a lack of education about dementia care was an important contributing factor. Eighteen studies cited concerns about potential stigmatizing effects of the diagnosis, doubts about the usefulness or desirability of early diagnosis, and the perception of limited treatment options. Five studies cited concerns about a lack of assessment tools and protocols, or a lack of tools perceived as helpful.

Although an estimated 50 percent of individuals living with dementia are diagnosed with ADRD,[17] they are not always told of their diagnosis. According to a review of studies around individual attitudes about a dementia diagnosis, the majority of people with dementia wish to be informed of their diagnosis,[18] however, 40 percent of individuals who are diagnosed with ADRD and their caregivers are not told that they have dementia.[19] When individuals are not informed of their ADRD diagnosis, it prevents them, their families, and caregivers from

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[13] Boustani, M., Peterson, B., Hanson, L., Harris, R., Lohr, K. N., & U.S. Preventive Services Task Force (2003). Screening for dementia in primary care: a summary of the evidence for the U.S. Preventive Services Task Force. *Annals of internal medicine*, *138*(11), 927–937. https://doi.org/10.7326/0003-4819-138-11-200306030-00015

[14] Geldmacher, D. S., & Kerwin, D. R. (2013). Practical diagnosis and management of dementia due to Alzheimer's disease in the primary care setting: an evidence-based approach. The primary care companion for CNS disorders, 15(4), PCC.12r01474. https://doi.org/10.4088/PCC.12r01474

[15] 2020 Alzheimer's disease facts and figures. (2020). *Alzheimer's & Dementia, 16*(3), 391-460. https://doi.org/10.1002/alz.12068. Source of data: Primary Care Physician Cognitive Assessment Survey conducted by Versta Research from December 13, 2018, through December 26, 2018.

[16] Bradford, A., Kunik, M. E., Schulz, P., Williams, S. P., & Singh, H. (2009). Missed and delayed diagnosis of dementia in primary care: prevalence and contributing factors. *Alzheimer disease and associated disorders*, *23*(4), 306–314. https://doi.org/10.1097/WAD.0b013e3181a6bebc

[17] Boustani, M., Peterson, B., Hanson, L., Harris, R., Lohr, K. N., & U.S. Preventive Services Task Force (2003). Screening for dementia in primary care: a summary of the evidence for the U.S. Preventive Services Task Force. *Annals of internal medicine*, *138*(11), 927–937. https://doi.org/10.7326/0003-4819-138-11-200306030-00015

[18] Robinson, L., Gemski, A., Abley, C., Bond, J., Keady, J., Campbell, Samsi K., Manthorpe, J. (2011). The transition to dementia – individual and family experiences of receiving a diagnosis: a review. *International Psychogeriatrics*, *23*(7), 1026–1043. https://doi.org/10.1017/S1041610210002437

[19] U.S. Dept. of Health and Human Services, Office of Disease Prevention and Health Promotion: Healthy People 2030 report states that 59.7 percent of adults aged 65 years and over with diagnosed Alzheimer's disease and other dementias, or their caregiver, were aware of the diagnosis in 2013-15. Source of data: Medicare Current Beneficiary Survey (MCBS), CMS.

adequately preparing for the future and receiving the services and supports they may need to live healthy and meaningful lives.

Many people diagnosed with dementia lack comprehensive, ongoing assessments, care planning and person-centered care. Although dementia care options may seem limited to some clinicians and patients, clinicians can play an important role in treating behavioral symptoms; and preventing injuries, emergency hospital visits, malnutrition, and illness. Additionally, primary care providers can significantly enhance the wellbeing of ADRD patients and caregivers by providing ongoing guidance and referrals to community services and supports. Primary care physicians face significant challenges and demands on their time and individuals affected by dementia have a diversity of medical and psychosocial needs. For these reasons, a body of research suggests that implementation of team-based, collaborative care programs with interdisciplinary approaches can improve the quality of primary care for ADRD patients and their caregivers.[20]

The need to address gaps in comprehensive, person-centered care for people living with dementia are highlighted by the COVID-19 pandemic. People living with ADRD are particularly susceptible to the virus due to their older age; group residential settings; and difficulty remembering or agitation around safety precautions. Furthermore, 95 percent of individuals living with dementia have other chronic conditions,[21] which may increase the risk of severe illness due to COVID-19.

Equitable access and care for underrepresented communities remains a challenge throughout the U.S. African Americans, Hispanic Americans, and Latinx Americans are less likely than white Americans to receive proper ADRD diagnoses and support.[22] This is despite the fact that African Americans are two to three times more likely to develop ADRD than non-Hispanic whites; and Hispanic Americans and Latinx Americans are 1.5 times more likely to develop dementia.[23] Despite these and other racial and ethnic disparities, there is a lack of diversity among ADRD research participants and researchers. To develop diagnostic tools and treatments that work for everyone, it is important that diverse groups participate in the research trials that evaluate their efficacy. Despite efforts to increase the participation of racial and ethnic minority groups in ADRD research, target populations remain underrepresented.[24] As with research participation, a

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[20] Geldmacher, D. S., & Kerwin, D. R. (2013). Practical diagnosis and management of dementia due to Alzheimer's disease in the primary care setting: an evidence-based approach. The primary care companion for CNS disorders, 15(4), PCC.12r01474. https://doi.org/10.4088/PCC.12r01474

[21] U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, A Profile of Older Adults with Dementia and Their Caregivers Issue Brief, 01/24/2019.

[22] U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Racial and Ethnic Disparities: A Literature Review, 2014.

[23] Ibid.

[24] Gilmore-Bykovskyi, A. L., Jin, Y., Gleason, C., Flowers-Benton, S., Block, L. M., Dilworth-Anderson, P., Barnes, L. L., Shah, M. N., & Zuelsdorff, M. (2019). Recruitment and retention of underrepresented populations in Alzheimer's

lack of ADRD researchers who represent a diversity of racial and ethnic minority groups also presents a significant challenge. This phenomena is seen broadly across multiple disciplines and stages of a researcher's career, from graduate school,[25] to early career awards,[26] and large scale grants.[27]

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disease research: A systematic review. In Alzheimer's and Dementia: Translational Research and Clinical Interventions (Vol. 5, pp. 751–770). https://doi.org/10.1016/j.trci.2019.09.018

[25] Hofstra, B., Kulkarni, V. V., Galvez, S. M. N., He, B., Jurafsky, D., & McFarland, D. A. (2020). The diversity–innovation paradox in science. *Proceedings of the National Academy of Sciences of the United States of America*, 117(17), 9284–9291. https://doi.org/10.1073/pnas.1915378117

[26] Biernat, M., Carnes, M., Filut, A., & Kaatz, A. (2020). Gender, Race, and Grant Reviews: Translating and Responding to Research Feedback. *Personality and Social Psychology Bulletin*, 46(1), 140–154. https://doi.org/10.1177/0146167219845921

[27] Ginther, D. K., Schaffer, W. T., Schnell, J., Masimore, B., Liu, F., Haak, L. L., & Kington, R. (2011). Race, ethnicity, and NIH research awards. *Science*, 333(6045), 1015–1019. https://doi.org/10.1126/science.1196783

Why Develop a State Plan on Alzheimer's Disease or Related Dementias (ADRD)?

Each state has its own unique needs and gaps, and a state-specific plan (Alzheimer's State Plan) can recommend tailored policies to better serve those living with dementia and their families. Alzheimer's State Plans establish accountability by helping to ensure policymakers create the infrastructure necessary to address the challenges arising from the prevalence of ADRD throughout the country. When successfully implemented by state Legislatures and state agencies, Alzheimer's State Plans result in a timely and effective response to this public health crisis.

Since 2007, 49 states, the District of Columbia, and Puerto Rico have published Alzheimer's State Plans. Common recommendations in these state plans include increasing education and awareness of the disease, promoting early detection and diagnosis, expanding access to home and community-based services, and addressing workforce shortages. Many states have also addressed other issues, including healthcare system capacity, quality of care, legal issues, funding for medical research, and safety.

The creation of an integrated state plan to address Alzheimer's disease and related dementias was prioritized in comprehensive legislation (Chapter 220 of the Acts of 2018) signed into law by Governor Charlie Baker in August 2018. This legislation also established a permanent advisory council to coordinate government efforts and to ensure that appropriate resources are optimized and leveraged while mandating education and protocols across the medical community.

While Massachusetts faces many challenges associated with ADRD, this state plan was designed to help the Commonwealth remain well positioned to continue to lead with novel approaches and solutions.

Introduction

The Massachusetts Alzheimer's Advisory Council (Council), established under Chapter 220 of the Acts of 2018, developed this state plan, entitled Massachusetts State Plan on Alzheimer's Disease and Related Dementias, April 2021 (Alzheimer's State Plan).[28] The Council, which is charged with advising the Executive Office of Health and Human Services and the state legislature on policies around Alzheimer's disease and related dementias, began convening its meetings in March 2019. The Council is currently chaired by the Secretary of the Executive Office of Elder Affairs and is composed of a diverse panel of caregivers, clinicians, dementia advocates, health care providers, legislators, public health professionals, and researchers.[29]

During their public meetings, the Council identified and discussed issues faced by Massachusetts residents living with dementia and their caregivers. Council members listened to the voices of individuals affected by dementia and shared their own expertise, knowledge, and ideas with each other. The Council's discussions helped to shed light on how to better meet the needs of the Commonwealth's 130,000 residents diagnosed with dementia, their 340,000 family caregivers, and an estimated 130,000 or more residents currently living with dementia without a formal diagnosis.

Based on findings from its discussions, the Council identified seven areas of focus. This state plan includes recommendations and implementation plans approved by the Council for each of the following focus areas, appearing here in alphabetical order:

1. Caregiver Support and Public Awareness
2. Diagnosis and Services Navigation
3. Equitable Access and Care
4. Physical Infrastructure
5. Public Health Infrastructure
6. Quality of Care
7. Research

To ensure that stakeholders pool their knowledge and expertise to align activities around similar or common goals, this document includes a section listing important linkages, including:

- linkages among the focus areas listed above, and
- linkages between this plan and other state plans, and efforts designed to address the needs of older adults in the Commonwealth.

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[28] Chapter 220 of the Acts of 2018 was signed law in August 2018 in Massachusetts General Laws, Chapter 6A, Section 16AA.

[29] To view a list of Council members, see Appendix A

The Alzheimer's State Plan is part of the state's continuous commitment to address the needs of people living with dementia and their caregivers. This is a working document that will be refined on an ongoing basis as the work of the Council and its workgroups continues over the coming years.

Summary of Goals and Recommendations

A Thoughtful, Caring, and Fiscally Responsible Response

The summary of goals and recommendations listed below is the result of deliberation by the Alzheimer's Advisory Council and workgroup members. To view a complete list of Council and workgroup members, see Appendix A.

Workgroup	Goals	Recommendations
Caregiver Support and Public Awareness	• Identify short-term approaches to improve awareness of the pathways to available supports and services for dementia caregivers and their care partners • Compare and evaluate the experiences of caregivers of people living with dementia as they navigate the Commonwealth's system of supports and services	• Make and distribute three videos (English, Portuguese, Spanish) of caregivers talking about the help they got, and how they got it • Place on the Massachusetts Executive Office of Elder Affairs (EOEA) website an overview of statewide pathways, services, and supports for people living with dementia and their caregivers • Implement changes at the Aging Services Access Points (ASAPs) to ensure that stressed caregivers get what they need in an effective and consistent manner
Diagnosis and Services Navigation	• Increase the number of people living with dementia who are diagnosed, informed of their diagnosis, and able to effectively attain helpful information, services, and care planning	• Significantly increase the numbers of undiagnosed or cognitively impaired residents who are diagnosed with dementia and informed of their diagnosis • Ensure that after a dementia diagnosis, individuals and their families have access to comprehensive information and care planning services
Equitable Access and Care	• Close gaps in equitable access to information, supports, services and care	• Close informational gap and address fragmentation of care access, care planning, and dementia services

Workgroup	Goals	Recommendations
Physical Infrastructure	• Identify and incorporate dementia-friendly physical infrastructure into age-friendly physical infrastructure work	• Raise awareness of the importance of age- and dementia-friendly design • Incorporate age- and dementia-friendly scoring into all state-funded physical infrastructure projects
Public Health Infrastructure	• Respond to the CDC's Notice of Funding Opportunity (NOFO) around implementing BOLD (Building Our Largest Dementia) Infrastructure	• Seek CDC funding to form a Public Health Workgroup to review the CDC's Healthy Brain Initiative's Road Map, engage stakeholders, review information, and present recommendations to the Alzheimer's Advisory Council
Quality of Care	• Identify gaps in quality of care for people living with dementia in Massachusetts, as well as strategies to close those gaps	• Develop a person-directed care plan framework and template • Develop a plan that ensures that staff in primary care, long-term care and home-care settings across the state receive the training and support needed to build and retain interprofessional dementia care teams
Research	• Advance dementia research in Massachusetts	• Increase diversity of dementia research and researchers

Implementing Effective and Sustainable Solutions

Action Plan for Calendar Years 2021 – 2022

To develop an Action Plan, the Alzheimer's Advisory Council (Council) formed seven workgroups to address the Council's seven areas of focus. Stakeholders from across the Commonwealth volunteered their time to participate in the workgroups, which were led by Council members.[30]

Each of the Council's workgroups began its work by identifying, discussing, and prioritizing the issues, gaps, and underlying problems associated with its focus area. They formulated goals and recommendations to achieve those goals, and proposed plans on how to implement their recommendations in Years 1-2 (i.e., 2021 and 2022). Additionally, the workgroups developed preliminary plans for Years 3-4, and Years 5 and beyond. Each workgroup presented its recommendations and proposed plans for Years 1-2 to the Council at its public meetings, where the Council voted to adopt them, or to change them where appropriate.

The Action Plan is organized by each of the following six areas of focus, which appear below in alphabetical order:

1. Caregiver Support and Public Awareness
2. Diagnosis and Services Navigation
3. Equitable Access and Care
4. Physical Infrastructure
5. Quality of Care
6. Research

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[30] To view a list of workgroup members, see Appendix B of this document

The Council's seventh area of focus, "Public Heath Infrastructure," is addressed later in this document in the section entitled, *Viewing Dementia through a Public Health Lens*.

The Action Plan summarizes the recommendations and strategies that the Council approved for implementation in 2021 and 2022.[31] For each of the six focus areas, the Action Plan lists implementation strategies, the risks associated with implementation, and approaches to address those risks. It also provides information about potential implementation costs and resources and lists the organizations responsible for implementation.

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[31] Preliminary plans for Years 3-4, and Years 5 and beyond, are included later in this document in the section entitled, Looking to the Future.

I. Caregiver Support and Public Awareness

Goals

- Identify short-term approaches to improve awareness of the pathways to available supports and services for dementia caregivers and their care partners
- Compare and evaluate the experiences of caregivers of people living with dementia as they navigate the Commonwealth's system of supports and services

Challenges

- Lack of awareness of pathways to available supports and services for people living with dementia and their caregivers
- Lack of knowledge of caregiver experience as they navigate the system of supports and services while facing the challenges of isolation and loss of routine brought on by the COVID-19 pandemic

Recommendations

Recommendation #1

Make and distribute three videos (English, Portuguese, Spanish) of caregivers talking about the help they got, and how they got it

Recommendation #2

Place on the Massachusetts Executive Office of Elder Affairs website, an overview of statewide pathways, services, and supports for people living with dementia and their caregivers

Recommendation #3

Implement changes at the Aging Services Access Points (ASAPs) to ensure that stressed caregivers get what they need in an effective and consistent manner

Recommendation #1

Make and distribute three videos (English, Portuguese, Spanish) of caregivers talking about the help they got, and how they got it

Implementation Strategies, 2021-2022

1. Identify interviewers and caregivers (interviewees) for a 15-minute interview
2. Select caregivers who care for a person living with dementia and benefited from available support
3. Prepare questions and work with caregivers on responses
4. Include dementia overview at beginning, and contact information at the end (MassOptions and Alzheimer's Association)
5. Disseminate video link widely, including organizations such as:
    - Council member networks, elder services networks, EOEA's mass.gov website, MassAccess (Cable TV), Memory Sunday churches (church bulletins), and senior centers (websites and newsletters)

Responsible Organizations

Video production team composed of representatives from:

- Alzheimer's Association
- Caregiver Support and Public Awareness Workgroup
- Latino Health Insurance Program, Inc.
- Massachusetts Councils on Aging
- Massachusetts Executive Office of Elder Affairs

Costs

No incremental costs in 2021 and 2022

Resources

- MassAccess: Community Access TV
- Massachusetts Councils on Aging

Risks and Risk Response Strategies

It may be difficult to find caregivers who are comfortable talking about their experiences on video. In response to this risk, the video production team will:

- seek out caregivers who have public speaking experience; and
- inform caregivers of assistance available from the team including script writing, practice interviews, etc.

Recommendation #2

Place on the Massachusetts Executive Office of Elder Affairs website, an overview of statewide pathways, services, and supports for people living with dementia and their caregivers

Implementation Strategies, 2021-2022

1. Sort through and identify the most useful information
2. Organize information into a user-friendly format and provide clear eligibility criteria
3. Provide helpline phone numbers and links for MassOptions and the Alzheimer's Association
4. Post on EOEA's website under *Dementia Information and Resources*, which currently exists, but does not include this information
5. Distribute the website's link widely, e.g., the Alzheimer's Association, Council member networks, and elder services networks

Responsible Organizations

Massachusetts Executive Office of Elder Affairs (EOEA)

Costs

No incremental costs in 2021 and 2022

Resources

EOEA has access to, and will refer to, numerous resources about supports and services available for people living with dementia and their caregivers

Risks and Risk Response Strategies

Although the purpose of this change to the EOEA website will be to improve awareness of the pathways to available supports and services, the information on the website may prove difficult to navigate. In response to this risk, EOEA will ensure that caregivers of people living with dementia are involved in the design and testing of the website before it is finalized.

Recommendation #3

Implement changes at the Aging Services Access Points (ASAPs) to ensure that stressed caregivers get what they need in an effective and consistent manner

Implementation Strategies, 2021-2022

1. Conduct a robust evaluation of the caregiver experience when contacting ASAPs, identify areas for improvement at ASAPs, and implement improvements where needed
2. Make cross-referrals a standard practice between ASAPs and the Alzheimer's Association
3. Require that ASAP staff refer caregivers to the Massachusetts Family Caregiver Support Program when appropriate
4. Assess all ASAPs' automated phone messages and make changes to ensure these are clear and make it easy for caregivers to connect to individuals for help

Responsible Organizations

A team from the Massachusetts Executive Office of Elder Affairs will assess caregiver experience, implement improvements at the ASAPs, and report progress to the Alzheimer's Advisory Council.

Costs

No incremental costs in 2021 and 2022

Resources

Family caregivers, staff from Aging Services Access Points, and staff from EOEA

II. Diagnosis and Services Navigation

Goal

- Increase the number of people living with dementia who are diagnosed, informed of their diagnosis, and able to effectively attain helpful information, services, and care planning

Challenges

- About 50 percent of people living with dementia have not received a diagnosis
- After diagnosis, many people do not know where to turn for services and support

Recommendations

Recommendation #1

Diagnosis

Significantly increase the numbers of undiagnosed or cognitively impaired residents who are diagnosed with dementia and informed of their diagnosis

Recommendation #2

Services Navigation

Ensure that after a dementia diagnosis, individuals and their families have access to comprehensive information and care planning services

Recommendation #1

Diagnosis

Significantly increase the numbers of undiagnosed or cognitively impaired residents who are diagnosed with dementia and informed of their diagnosis

Implementation Strategies, 2021-2022

1. Alzheimer's Association MA/NH will work with the Mass. Medical Society and other organizations representing primary care providers to determine the best strategies to refine and distribute a dementia screening toolkit. Working with primary care providers, the Alzheimer’s Association MA/NH will determine the most effective practical approaches to help incorporate into practice, evidence-based protocols for screening and diagnosis. The dementia screening toolkit will:
    - leverage existing resources;
    - ensure equitable access across diverse cultural, ethnic, linguistic, racial, and socioeconomic groups; and
    - include protective service protocols for primary care providers to use when caregiver neglect, safety, and/or self-neglect are a concern.
2. Alzheimer’s Association MA/NH will identify and seek recommendations from executive branch leaders on the following:
    - Engaging the MA Board of Registration in Medicine (BORIM) and medical societies to:
        - inform all primary care physicians of the importance of screening and diagnosing;
        - provide primary care physicians with link to the dementia-screening protocols and toolkit; and
        - inform all physicians that treat adults that they are required by state law to inform patients and families of dementia diagnosis, treatment, and care plans.
    - Engaging the Board of Registration in Nursing and Board of Registration of Physician Assistants (PAs) to provide the information indicated above to nurses and PAs
    - Engaging the MA Department of Public Health (DPH) to inform all hospitals of required implementation of dementia operational plans by 10/2021, including screening protocols for Emergency Departments (ED)
    - Discussing with DPH how best to train all Surveyors to request and review plans
3. Alzheimer’s Association MA/NH will identify partners to work with the largest primary care practices in MA such as Atrius Health, Reliant Medical Group, and major hospital affiliated Physician Health Organizations.

    - Partners (e.g., the Mass. Medical Society and DPH) will work with these large practices to communicate with their primary care providers about the importance and benefits of screening for and diagnosing dementia

Responsible Organizations

Alzheimer's Association MA/NH will help refine and develop the screening toolkit and can provide support to specific hospitals in crafting their dementia operational plans. The Diagnosis and Services Navigation Workgroup will seek collaborative support and commitment from these organizations:

- Health insurance companies that may be interested in joining this effort
- MA Department of Public Health and MA Health and Hospital Association
- Betsy Lehman Center
- Mass. Medical Society and other physician trade organizations
- Coalition for the Prevention of Medical Errors

The workgroup will also reach out to organizations that may be willing to be models for the state such as hospitals that are taking a lead in developing dementia operational plans; Atrius Health; Reliant Medical Group; and major hospital affiliated Physician Health Organizations.

Costs

No incremental costs

Resources

The Diagnosis and Services Navigation Workgroup will refer to resources from the Alzheimer's Association including:

- Cognitive Assessment Guidance and Tools
- Cognitive Impairment Care Planning Toolkit
- Criteria and Guidelines to Diagnosing Alzheimer's disease
- Medicare Annual Wellness Visit Algorithm for Assessment of Cognition
- Operationalizing the Detection of Cognitive Impairment during Medicare Annual Wellness Visit in a Primary Care Setting

Risks and Risk Response Strategies

1. COVID-19 demands on clinicians may impede progress on this recommendation
2. Potential lack of commitment among physicians to continue informing patients and caregivers of treatment and caregiver plans
3. Potential lack of continued commitment among hospitals to sustain and update their dementia operational plans and the MA Department of Public Health Surveyors may stop requesting and reviewing these plans

4. Potential lack of continued commitment among primary care practices to inform and incentivize their physicians to screen and diagnose their patients

In response to the above risks, the Diagnosis and Services Navigation Workgroup will:

- ensure that communications with clinicians reflect the linkage between the need for screening and early diagnosis and the specific needs and challenges faced by people living with dementia in pandemic times;
- ensure that communications to health care professionals make clear that the road to treatment runs through diagnosis. With treatment compounds making their way through clinical trials, these treatments will not come close to fulfilling their promise without significant improvement in the diagnosis rate;
- ensure that a coalition of collaborative partners plays and sustains an essential role in implementing this recommendation, e.g., consider securing more than one communication to primary care providers in 2021;
- convince the MA Department of Public Health (DPH) of the importance of hospitals implementing these legislatively mandated dementia operational plans, e.g., consider including language in new legislation and manage around the COVID-19 challenges that hospitals are experiencing; and
- engage several large primary care practices to embrace this as a model.

Recommendation #2

Services Navigation

Ensure that after a dementia diagnosis, individuals and their families have access to comprehensive information and care planning services

Implementation Strategies, 2021-2022

Create a Road Map

1. Create, identify how to disseminate, and distribute a road map to provide geriatricians and geriatric psychiatrists, neurologists, people living with dementia and their care partners, and primary care providers, on how to proceed depending on the diagnosis. The road map would:
    - include information such as phone numbers and websites of Alzheimer's Association and local resources, i.e., Aging Services Access Point, support groups, etc.; and
    - be developed in a way that ensures equitable access across diverse cultural, ethnic, linguistic, racial, and socioeconomic groups.

2. Seek funding for the printing and delivery of hard-copy versions of the road map. Determine if IT resources are required for any website-related work and seek funding if necessary.

Provide Primary Care Providers (PCPs) with Support and Strategies for Unaccompanied/Unsupported People Living with Dementia

3. Develop and provide PCPs with support and strategies for interacting with unaccompanied/unsupported individuals who are diagnosed.
   - Develop a plan on how to implement this strategy in Years 1 and 2; the plan would reflect:
     - An emphasis on follow-up and referral to MA Aging Services Access Points
     - Educating PCPs around protective service protocols if caregiver neglect, safety, and/or self-neglect are a concern
     - The development of a simple primer for primary care which would include items such as the road map and dementia-screening toolkit
       - The dementia-screening toolkit would include protective service protocols for PCPs to use when caregiver neglect, safety, and/or self-neglect are a concern

Expand Dementia Care Coordination (DCC) Program (Alzheimer's Association MA/NH)

4. In 2021, develop a plan to expand the DCC program while Alzheimer's Association MA/NH will:
   - explore sources of funding; and
   - expand outreach to recruit more dementia care providers to participate in the program.

Responsible Organizations

Alzheimer's Association MA/NH in consultation with the Massachusetts Executive Office of Elder Affairs, Aging Services Access Points, and clinicians

Costs

- No incremental cost for development of deliverables in Years 1-2
- Distribution of deliverables in Years 1-2:
  - IT resources and/or expenses may or may not be required for website-related work, and will be determined in Year 1
  - There will be printing and delivery costs associated with distribution of hard copies of the road map

Resources

- Contact/Call Centers in Massachusetts:
  - Alzheimer's Association: 800-272-3900
  - MassOptions: 800-243-4636
- Websites for Massachusetts Residents:
  - Alzheimer's Association, MA/NH
  - MassOptions

Risks and Risk Response Strategies

- Some may consider the development of a road map as adding to information overload for people living with dementia and their care partners
- The road map may become frequently outdated, making it difficult to keep current
- Clinician participation is needed to achieve the outcomes expected, however, COVID-19 demands may prevent clinician participation
- There are thousands of physicians in the state who need these deliverables; dissemination could become overwhelming

In response to the above risks, the Diagnosis and Services Navigation Workgroup will:

- review, adopt, and adapt materials from the National Institute on Aging (NIA) of the National Institutes of Health (NIH) to support individuals after diagnoses of Alzheimer's disease and related dementias;[32]
- review how the Alzheimer's Disease Education and Referral (ADEAR) Center can appropriately serve the needs of MA residents;[33]
- design the road map as a simple tool that directs individuals to resources where comprehensive and easy-to-access information and support are available; include phone numbers that rarely change; and include links only to websites that are kept current;
- include enough non-clinicians on the team to develop the road map and other deliverables; provide deliverable drafts for clinician review if COVID-19 demands interfere with clinician availability for meetings, stretching out the timeline if necessary; and
- partner with organizations and networks that can share the road map and other deliverables with physicians via events, newsletters, trainings, and websites; develop a realistic year-by-year rollout and communication plan.

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[32] To view relevant materials from the NIA, see https://www.nia.nih.gov/health/alzheimers.

[33] To view relevant materials from the ADEAR Center, see https://www.nia.nih.gov/health/about-adear-center

III. Equitable Access and Care

Goal

- Close gaps in equitable access to care, information, services, and supports

Challenges

- Fragmented access to care, care planning, and dementia services
- Inequitable access to information and knowledge about dementia services

Recommendation

Recommendation #1

Close informational gap and address fragmentation of care access, care planning, and dementia services

Recommendation #1

Close informational gap and address fragmentation of care access, care planning, and dementia services

Implementation Strategies, 2021-2022

1. In March and April of 2021, the Equitable Access and Care Workgroup will work to significantly expand its workgroup to approximately 20-25 members. The workgroup's members will reflect a diversity of interests and will include individuals from a broad range of underserved groups, including individuals with lived experience.
2. By June 1, 2021, the Equitable Access and Care Workgroup will provide the Alzheimer's Advisory Council and all its workgroups with a brief guide composed of definitions around diversity, equity, and inclusion and essential readings.
3. Beginning by mid-2021, up to three members of the Equitable Access and Care Workgroup will provide each of the other workgroups with collaborative consultation. The intention of the consultation will be to enable each workgroup to effectively build a solid foundation of equity and inclusion into its recommendations and implementation strategies.
4. Beginning in mid-2021, and on an ongoing basis, the Equitable Access and Care Workgroup members will review the implementation plans, activities, and outcomes of the Council's other workgroups, holding them accountable for making the connections and doing the work required to sustain policies and programs that are equitable and inclusive.

Responsible Organizations

Working with other key stakeholders as needed, the Equitable Access and Care Workgroup of the Alzheimer's Advisory Council will be responsible for the implementation strategies indicated above.

Costs

No incremental costs in 2021 and 2022

Risks and Risk Response Strategies

These strategies will require a significant amount of coordination across workgroups and consistent follow-up by this workgroup. Ineffective coordination could result in inconsistent and varied outcomes.

In response to this risk, the workgroup:

- Will develop approaches and tools to track progress and outcomes

- Advises all workgroups to apply consistently the principle of "nothing about us without us"
  - While developing deliverables and processes, workgroups should include people living with dementia who are willing to be advocates and should comprise people of different underrepresented communities.[34] For example, workgroups can consider including people living with dementia in meetings, or pulling together information for their review.
- Developed the following list of approaches for all workgroups to consider as they build sustainable foundations of equity and inclusion into their recommendations, implementation plans, and activities.

Approaches for the Council's Workgroups to Consider

Applicable Workgroup and/or Topic	Approaches	Stage		
		Pre-Diagnosis	Diagnosis	Post-Diagnosis
All Workgroups	1. Before distributing information about current or new programs, curricula, events, and resources, and prior to developing new ones, evaluate how culturally appropriate they are. a. Work to ensure that they meet the needs of underserved groups, and that a diverse set of events, information, and resources is available[35]	✓		

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[34] Specific underrepresented communities for workgroups to keep in mind as they conduct their work: Asian immigrants (in order of number of people in MA: Chinese, Vietnamese, Khmer/Cambodian, Korean, Burmese); Black/African American (not Latinx); blind or vision impaired; Cape Verdean; immigrants and refugees, including other Black immigrant communities; individuals living in rural areas; individuals who are incarcerated; individuals with housing insecurity; individuals with intellectual and developmental disabilities (I/DD); Latinx, including Brazilian/Portuguese speaking; LGBTQ; Native Americans; people living alone with dementia; people with hearing loss/late deafened; and veterans.

[35] Some examples of programs and resources for underserved communities include the “Forget Me Not” play, which was written specifically for African American/Black communities; Dementia Friends Information Sessions, provided by trained Dementia Friends Champions in 7 languages; and “Meeting of the Minds” events.

Applicable Workgroup and/or Topic	Approaches	Stage		
		Pre-Diagnosis	Diagnosis	Post-Diagnosis
	b. Take steps to ensure that written documents reflect "language equity" by adhering to plain language guidelines[36] and making materials available in languages that cover 99 percent of Massachusetts residents[37] c. For in-person events and webinars, work to normalize sign language and real-time interpretation			
Services Navigation **Public Awareness**	2. While spreading awareness of dementia information and services, consider utilizing adult children, partners, or friends to help build a basic level of awareness of dementia information and services among individuals in underserved groups (buddy system)[38]	✓		
Public Awareness	3. Develop ways to raise public awareness among individuals in underserved groups on how to talk with physicians about dementia concerns	✓		

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[36] Plain language guidelines: 5th grade level or below recommended; 8th grade level or below required.

[37] Materials available in the 4 or 5 most common languages in Massachusetts would cover approximately 99 percent of Massachusetts residents.

[38] For example, during the HIV crisis, a buddy system was built, and this is a potential model to use when reaching out to the LGBTQ community. This buddy system helped eliminate the stigma of HIV. (The MA Healthy Living Center of Excellence has an ACL grant to support people with dementia living alone.)

Applicable Workgroup and/or Topic	**Approaches**	**Stage**		
		Pre-Diagnosis	**Diagnosis**	**Post-Diagnosis**
Quality of Care – Staffing and Training	4. Develop approaches to ensure that providers understand how people living with dementia in underserved groups can live well with dementia a. For example, people living with dementia in underserved groups can make a video, speak, or write a letter about how they live well		✓	
Services Navigation	5. Develop processes or approaches that coordinate, empower, and support people of various backgrounds to be public advocates, who help to connect individuals to information and services in their communities		✓	
Quality of Care – Staffing and Training	6. Develop approaches to raise awareness of dementia information and services among primary care providers, specialists, and subspecialists with patients in underserved groups, and link to continuing education credits for clinicians at Community Health Centers and other locations a. Identify which clinicians to target for this effort through floating catchment area statistical analysis using claims data	✓	✓	✓

Applicable Workgroup and/or Topic	Approaches	Stage		
		Pre-Diagnosis	Diagnosis	Post-Diagnosis
Services Navigation **Public Awareness** **Caregiver Support** **Quality of Care – Care Planning**	7. Develop approaches to ensure that information and resources provided to or developed for underserved communities, to help to normalize the act of seeking support and honoring family caregivers a. Ensure that information and resources developed or distributed, highlight the importance of family caregiver selfcare and "staying strong"			✓
Services Navigation **Public Awareness** **Caregiver Support**	8. Develop approaches that ensure culturally appropriate support is provided for underserved groups in a broader range of settings and regions of the state, e.g., prisons, gatherings of veterans			✓
Services Navigation	9. Determine how to increase the availability of culturally appropriate support from the Alzheimer's Association's helpline			✓

IV. Physical Infrastructure

Goal

- Identify and incorporate dementia-friendly physical infrastructure into age-friendly physical infrastructure work

Challenges

- Age-friendly efforts often overlook the needs of people living with dementia
- Massachusetts has many communities working to become dementia-friendly, and very few are addressing the physical infrastructure needs of people living with dementia

Recommendations

Recommendation #1

Raise awareness of the importance of age- and dementia-friendly design

Recommendation #2

Incorporate age- and dementia-friendly scoring into all state-funded physical infrastructure projects

Recommendation #1

Raise awareness of the importance of age- and dementia-friendly design

Implementation Strategies, 2021-2022

1. Strengthen relationships between dementia-friendly movement and stakeholders by identifying gatherings of community planners; develop and deliver at least one presentation that allows for a two-way dialogue
2. In 2021, and every year thereafter, continuously improve the presentation with input from stakeholders
3. Determine feasibility of working with community planners to convene a webinar; if deemed feasible, convene, record, and distribute it

Recommendation #2

Incorporate age- and dementia-friendly scoring into all state-funded physical infrastructure projects

Implementation Strategies, 2021-2022

1. Identify and evaluate options to ensure that scoring on relevant projects includes age- and dementia-friendly criteria by:
    - identifying and working with state agencies that fund physical infrastructure projects;[39]
    - identifying specific projects and programs and/or statutes to include such criteria; and
    - incorporating age- and dementia-friendly scoring criteria into at least one specific project, program, or legislative action.

Responsible Organizations

The Dementia Friendly Massachusetts (DFM) Leadership Team is responsible for implementing the above recommendations in an effective and timely manner, seeking advice from the Physical Infrastructure Workgroup as needed, and reporting back to the Alzheimer's Advisory Council on progress.

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[39] Examples include Board of Library Commissioners; Department of Conservation and Recreation; Department of Housing and Community Development; Department of Transportation; Division of Capital Asset Management and Maintenance; Executive Office for Administration and Finance; and the Executive Office of Housing and Economic Development

The DFM Leadership Team comprises representatives from:

- Alzheimer's Association MA/NH
- Jewish Family and Children's Service
- Latino Health Insurance Program, Inc.
- Massachusetts Councils on Aging (leader of DFM team)
- Massachusetts Executive Office of Elder Affairs (EOEA)
- Massachusetts Healthy Aging Collaborative

Costs

No incremental cost

Resources

Proposed implementation strategies would be included as part of the age- and dementia-friendly portfolio of activities managed by the Executive Office of Elder Affairs and its DFM partners listed above.

Risks and Risk Response Strategies

- Dementia-friendly (DF) physical infrastructure may not be viewed as a high enough priority among local planners and state agency funders of physical infrastructure projects to adopt DF characteristics and scoring criteria
- DF physical infrastructure may be considered costly to incorporate

In response to the above risks, the Dementia Friendly Leadership Team will:

- ensure that the voices of people living with dementia are heard when discussing their challenges and needs around physical infrastructure; and
- provide planners with clear examples and highlight the benefits of age- and dementia-friendly physical infrastructure for people of all ages.

V. Quality of Care

Goal

- Identify gaps in quality of care for people living with dementia in Massachusetts, and identify strategies to close those gaps

Challenges

- Lack of and delayed diagnosis
- Lack of regular, comprehensive, ongoing assessments
- Lack of person-centered and person-directed care planning

Recommendations

Recommendation #1

Care Planning

Develop a person-directed care plan framework and template

Recommendation #2

Staffing and Training

Develop a plan that ensures staff receive training and support needed to build and retain interprofessional teams with expertise in dementia

Recommendation #1

Care Planning

Develop a person-directed care plan framework and template

Implementation Strategies, 2021-2022

1. Begin development of a person-directed care plan framework and template
2. Gather information and examine existing tools
3. Meet with stakeholders and potential partners, including, but not limited to, the Alzheimer's Association, Dementia Friends Massachusetts, and Honoring Choices
4. Seek assistance of a graduate student in public health or nursing for research and writing
5. Seek and identify sources of funding for disseminating and promoting the care plan template

Responsible Organizations

The Quality of Care Workgroup, with guidance from other organizations, including but not limited to, the Alzheimer's Association MA/NH, Executive Office of Elder Affairs, and Honoring Choices

Costs

- No incremental costs associated with the development of the framework and template
- Costs associated with promoting, printing, and disseminating the template
- Potential website development costs

Resources

See Appendix B to view a list of resources and tools that the Quality of Care Workgroup plans to use and refer to as the workgroup develops a care plan framework and template

Risks and Risk Response Strategies

- Lack of participation of partners and stakeholders
- Framework may not be relevant to a wide variety of users
- Competition with COVID-19 for resources

In response to the above risks, the Quality of Care Workgroup will:

- keep meetings brief and focused, and incorporate stakeholder feedback into the framework and template;
- continually refine the framework and template based on user experience and feedback; and
- set up flexible timelines.

Recommendation #2

Staffing and Training

Develop a plan that ensures staff receive training and support needed to build and retain interprofessional teams with expertise in dementia

Implementation Strategies, 2021-2022

1. Improve Staff Training in Informal and Formal Settings
    - Develop interprofessional training, ongoing coaching and support; use age-friendly (AF) health system and/or ECHO models
    - Within the AF health system, develop dementia-specific adaptations and approaches of the 4Ms (What Matters, Medication, Mentation, Mobility)
    - Develop a collaborative path with the Institute for Healthcare Improvement (IHI) for AF health systems in Massachusetts
    - Conduct pilot with about six early adopters to determine feasibility; refine approach; plan for scaling
2. Improve Recruitment and Retention of Direct Care Workers
    - Enhance supports and training through developing career ladders, ensuring fair wages, and inclusion in interprofessional team training
    - Launch public relations campaign to elevate perceived value of direct care workers
3. Leverage expertise of existing teams and/or centers of excellence to support interprofessional training and ongoing coaching

Responsible Organizations

The Quality of Care Workgroup along with the Executive Office of Elder Affairs to coordinate and track implementation by Age-Friendly Health Systems/Institute for Healthcare Improvement (IHI); Alzheimer's Association NH/MA; Baystate Geriatrics Workforce Enhancement Program (GWEP); and Aging Service Access Points (ASAPs). Other organizational resources are listed below.

Costs

- Costs associated with release time needed to accommodate staff training, which will be borne by the age-friendly health system
- Costs associated with a public relations campaign

Resources

- Alzheimer's Association Dementia Care Coordination program
- Baystate Geriatrics Workforce Enhancement Program (GWEP)
- Betsy Lehman Center
- Center for Alzheimer Research and Treatment (CART), Brigham and Women's Hospital
- Centers of Excellence in Massachusetts
- ECHO Albuquerque, New Mexico
- Institute for Healthcare Improvement
- Massachusetts Alzheimer's Disease Research Center (MADRC), Massachusetts General Hospital
- Massachusetts Coalition for the Prevention of Medical Errors
- Massachusetts Councils on Aging
- Massachusetts Healthy Aging Collaborative
- Massachusetts Medical Society
- University of Massachusetts Boston Gerontology Institute

See Appendix B for a list of resources on care planning and training programs that the workgroup will refer to while implementing this recommendation.

Risks and Risk Response Strategies

- Lack of protected time to train, plan, and follow-through
- Competing demands among stakeholders, particularly due to COVID-19
- Lack of participation of partners and stakeholders

In response to the above risks, the Quality of Care Workgroup will:

- highlight the value proposition of age-friendly health systems in enhancing care of cognitively impaired patients and COVID-19 patients,
- work with age-friendly health systems to identify potential funding,
- acknowledge organizations involved in the age-friendly health system model,
- incorporate stakeholders into the design of the education plan, and
- launch a public relations campaign to publicize the benefits of receiving care at age-friendly health systems.

VI. Research

Goal

- Advance dementia research in Massachusetts

Challenge

- Lack of diversity among dementia study participants, researchers, and study approaches, limiting perspectives and innovation

Recommendation

Recommendation #1

Increase Diversity of Dementia Research and Researchers

Recommendation #1

Increase Diversity of Dementia Research and Researchers

Implementation Strategies, 2021-2022

Implement the following strategies to increase outcomes around diversity of dementia research participants, researchers, disease stages, and research methodologies:

1. Compile data on the diversity of dementia research at for-profit and non-profit organizations in Massachusetts—include data around diversity of research participants and researchers (race, ethnicity, and other underrepresented group variables), disease stages investigated, and research methodologies used
2. Develop and implement an approach to increase diversity of dementia research at for-profit and non-profit organizations in Massachusetts that results in achieving the following diversity objectives beginning in 2023:
   - *Increase the diversity of participants* each year by 1.5 percent (for-profits) and 3.0 percent (non-profits) until diversity matches catchment area
   - *Pursue therapeutic and/or beneficial research in all disease stages* from preventative and preclinical to severe dementia. For example, such research may include studies of novel drugs, existing drugs for novel indications, strategies for people with dementia, and strategies for caregivers
   - *Increase the diversity of methodologies being used* by 50 percent in the first year, and 10 percent each year thereafter until the number of methodologies used are at least doubled (100 percent increase). Such methods may include adding diverse research contexts, e.g., the built environment; diverse research aims, e.g., health disparities; and diverse research approaches, e.g., new technologies
   - *Increase the diversity of researchers* each year by 1.5 percent until diversity matches catchment area
3. Share the above approach and diversity objectives with all US states and Puerto Rico and encourage them to set up analogous programs of their own
4. Seek and secure private funding for program oversight, program management, and small research support grants; and establish a grant application mechanism for the research support grants.[40]

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[40] Additional information about required funding is provided in the sections below entitled, "Responsible Organizations" and "Costs."

Responsible Organizations

1. A private organization identified by the Research Workgroup will:
    - provide program oversight to ensure effectiveness of implementation strategies
    - provide a grant to a non-profit organization to manage the research grant program
    - regularly report to the Alzheimer's Advisory Council via the Research Workgroup, seeking advice when needed
2. A non-profit organization (to be determined) will be awarded a privately funded grant to cover costs to manage the research grant program; distribute research grants; conduct all outreach; compile data; and deliver education programs around diversity to for-profit and non-profit organizations

Costs (to be funded through private grants)

- $150,000 annual grant to a non-profit organization for program management beginning in Year 2
- $200,000 for research support grants (ten two-year grants at $10,000 each to be awarded in Years 3-4 as seed funding to leverage larger grants and research projects to advance diversity in dementia research)
- Additionally, the organization to be identified by the Research Workgroup to provide program oversight will incur program oversight costs

Risks and Risk Response Strategies

- Companies and non-profit centers conducting dementia research in the Commonwealth may be reluctant to share information around the diversity of their research participants, researchers, disease stages, and methodologies
- If the Alzheimer's Advisory Council provides non-mandatory diversity guidelines rather than state-mandated rules or regulations, organizations may lack interest and/or be reluctant to implement the guidelines
- If state-mandated diversity rules or regulations are established, companies and non-profit centers may complain that the new rules make it more difficult to operate in Massachusetts and they may threaten to leave
- Other states and territories may lack interest in increasing the diversity of research participants, researchers, disease stages, and methodologies and refrain from establishing analogous programs

To achieve increased diversity of dementia research participants, researchers, disease stages, and methodologies and in response to the above risks, the Research Workgroup and responsible organizations will:

- collaborate with the organizations conducting dementia research in Massachusetts to design approaches to effectively achieve the Commonwealth's diversity objectives indicated in the implementation strategies listed above,
- consider providing organizations with incentives to encourage achievement of the diversity objectives,
- consider sharing strategies as well as outreach and recruitment materials with organizations in Massachusetts to ease the work of increasing diversity,
- explain to organizations that such efforts around diversity are important for the benefit of the science, as well as for the citizens of Massachusetts and other states and territories, and
- work to ensure that the Commonwealth's objectives are adopted by many states and territories and help companies and non-profit centers achieve the diversity objectives painlessly.

Looking to the Future

This Alzheimer State Plan focuses primarily on Years 1 and 2 (Calendar Years 2021 and 2022). However, work required to complete these goals will continue well beyond two years. Below are some implementation strategies for future years recommended by the workgroups. These will be presented to the Council during its future meetings, refined, and finalized.

Caregiver Support and Public Awareness

1. Identify implementation strategies around caregiver support based on the outcomes of prior years' strategies
2. Identify additional gaps in public awareness, and implement strategies to close those gaps, including gaps around the public's awareness of modifiable risk factors for dementia

Diagnosis and Services Navigation

1. Work with MA insurers, particularly Medicare Advantage plans, to communicate with their primary care providers (PCPs) about the importance and benefits of screening and diagnosis. Determine the feasibility of insurers surveying their clinician networks about their understanding of dementia, importance of screening/diagnosing, screening tools, etc.
2. Working with EOEA, examine the current practice in MA where the MA Aging Services Access Point (ASAP) network is screening over 30,000 elder clients annually for dementia and sharing any positive results with the client's primary care provider:
    - Currently, there are no follow-up protocols to determine if further screening or diagnostic activities are being conducted, or if a treatment plan is in place
    - Recommend protocols for following up on positive screening results shared with primary care providers by ASAPs
3. Implement a public education campaign so that consumers and families understand the importance of diagnosis and are aware of the 10 warning signs of dementia

Equitable Access and Care

1. Map out the goals, mission, responsibilities, strategic priorities, and vision for a proposed coordinating organization
2. Refer to findings from this workgroup's review of activities conducted by all Council workgroups, and review all workgroups' implementation plans and outcomes around equity and inclusion
3. Design a coordinating organization to lead efforts to work with community-based organizations and grassroots leaders across the state to develop, raise awareness of, and deliver resources and services to underserved communities, using a peer-to-peer approach.

4. While developing a framework and infrastructure for the coordinating organization:
   - examine findings with respect to equity and inclusion derived from this workgroup's review of activities, implementation plans, and outcomes of the Council's workgroups
   - examine, address, and apply lessons learned from organizations with similar objectives including the "Access, Equity and Cultural Inclusion" efforts of the MA Healthy Aging Collaborative; the former MA Multicultural Coalition on Aging; and the four MA food banks, which have a complex, yet effective infrastructure consisting of city-level and grassroots-level components
5. Identify, seek, and secure resources and any funding required to establish the coordinating organization and any resources/funding necessary for effective implementation of its activities
6. Identify and launch the coordinating organization
7. Identify specific leaders within each underserved community to be a part of a grassroots network across the state while developing ways to support these leaders (perhaps by a stipend program) and connect them with the identified coordinating organization

Physical Infrastructure

1. Identify additional approaches and audiences for raising awareness of the importance of age-and dementia-friendly physical infrastructure
2. Continue identifying opportunities for incorporating age- and dementia-friendly design into state-funded physical infrastructure projects

Quality of Care

1. Further test and refine the care plan framework and template
2. Develop education sessions for those partners who will be disseminating the care plan template to the public
3. Further disseminate the care plan template across settings
4. Revaluate usage and update the care plan framework and template

Research

1. Compile data around diversity of dementia research participants, researchers, disease stages, and methodologies
2. Inform and educate companies and non-profit centers of the Commonwealth’s diversity objectives, and beginning in 2023, compile data on their adoption
3. Fund and evaluate small research support grants
4. Examine activity in other states and Puerto Rico, identifying those that have set up analogous programs of their own

Viewing Dementia through a Public Health Lens

Enhancing the Commonwealth's Public Health Infrastructure to Address Dementia

On December 31, 2018, the Building our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act was passed into federal law. As part of the law, the Centers for Disease Control and Prevention (CDC) was directed to provide funds to support public health departments. In Calendar Year 2020, the CDC released a Notice of Funding Opportunity (NOFO) to support public health departments in implementing effective interventions for Alzheimer's disease and related dementias (ADRD). The funding was also intended to support public health departments in implementing strategic actions identified in the *Healthy Brain Initiative's Road Map for State and Local Public Health*.[41]

In response to the CDC's funding opportunity, the Alzheimer's Advisory Council (Council) formed a temporary "Public Health Infrastructure" workgroup that worked with the Massachusetts Department of Public Health (DPH) to develop a proposal that was submitted to the CDC in May 2020. Massachusetts DPH did not receive the funding. The Council will continue to seek funding and other opportunities to support its commitment to integrate planning and action strategies that enhance the Commonwealth's public health infrastructure to address ADRD. Despite the outcome, members of the Council and DPH derived valuable benefits from their work on the BOLD Infrastructure proposal.

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[41] CDC and Alzheimer's Association, *State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*: https://www.cdc.gov/aging/healthybrain/roadmap.htm

First, they became familiar with the *Healthy Brain Initiative's Public Health Road Map* (Road Map). The Road Map is a valuable resource for DPH, the Council, and key stakeholders across the state. It provides a solid framework and guidance for reducing the risk of cognitive decline among Massachusetts residents, while optimizing the well-being of people living with dementia and their caregivers.

Second, through its work on the CDC proposal, DPH and the Council became more familiar with the benefits of incorporating the caregiver module into the *Behavioral Risk Factor Surveillance System (BRFSS)*.[42] As a result, DPH has included the caregiver module in the 2021 implementation of BRFSS in Massachusetts.[43] This will provide the state and the Council with improved information on the scope of caregiving and its impact on the Commonwealth's families and economy.

Prevention and Intervention Framework

As the Council and its workgroups continue to move forward with their work, they will do so with a focus on the three categories of prevention: primary, secondary, and tertiary. The Council has agreed to use the prevention and intervention framework depicted in the table below as a guide to ensure that all three prevention categories are addressed.

Prevention and Intervention Framework for Alzheimer's Disease and Other Dementias (ADRD)

Primary Prevention	Secondary Prevention	Tertiary Prevention
Prevent or Delay Occurrence of ADRD	**Reduce Short-Term (<12 months) Impact on Individuals Living with Dementia and their Families, Including Early Diagnosis of ADRD**	**Reduce ADRD's Long-term (>12 months) and Broad Impact on Families and Communities**
	Audience	
• The public • Primary care providers	• Healthcare providers who diagnose and encounter patients and families affected by ADRD • Supportive care providers in the community for	• Individuals engaged in informal or formal social supports for individuals and families affected by ADRD

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[42] CDC, *About BRFSS:* https://www.cdc.gov/brfss/about/index.htm

[43] CDC, *BRFSS Caregiver Module, Frequently Asked Questions:* https://www.cdc.gov/aging/healthybrain/brfss-faq-caregiver.htm

Primary Prevention	Secondary Prevention	Tertiary Prevention
	individuals and families affected by ADRD • Recently diagnosed individuals with ADRD and their families	• Healthcare providers who encounter individuals and families affected by ADRD • Individuals and families living with the chronic impact of ADRD
Objectives		
• Improve awareness of risk factors • Communicate prevention strategies • Encourage screening to improve early detection	• Ensure access and availability of diagnostic capacity • Connect individuals and families to financial and social supports • Inform patients and families about disease course, treatments available, and treatments in research	• Improve dementia-friendly fixed infrastructure (housing, hospitals, restaurants, transportation, etc.) • Inform and develop policies to protect caregivers from long-term negative impacts to employment, financial security, and health • Ensure coordination across the care continuum to reduce costs due to acute or long-term consequences of ADRD (Prevent Emergency Department readmissions, and ensure available supply of supportive care professionals)

Reducing the Risk of Alzheimer's Disease and Related Dementias

Rates of Alzheimer's disease and related dementias (ADRD) are increasing, as is the concern of developing these disorders.[44] As such, researchers have sought to identify and maximize modifiable factors that reduce the risk of developing ADRD. The Research Workgroup of the Alzheimer's Advisory Council compiled key findings described below, which were derived from cross-sectional, epidemiological, intervention, and longitudinal studies that target reducing ADRD risk and improving cognition in older adulthood.

12 Modifiable Risk Factors

A recent commission identified the following risk factors for dementia.[45] Together, targeting these risk factors could prevent or delay up to 40 percent of dementias.[19]

1. Less education
2. Social isolation
3. Depression
4. Obesity
5. Physical inactivity
6. Excessive alcohol consumption
7. Smoking
8. High blood pressure
9. Diabetes
10. Traumatic brain injury (including concussion)
11. Untreated hearing loss
12. Air pollution

A Life-Course Perspective

Dementia Prevention Can Occur at Any Time in the Life Course

Dementia prevention can start in early-life (younger than 35 years), continue through mid-life (between 35-65 years), and into later-life (over 65 years). The focus of prevention efforts differs depending on these life stages, because of the way factors in each life stage affect ADRD risk. Targeting early-life factors primarily seeks to preserve cognition and everyday functioning (or increase one's cognitive reserve), while targeting factors after early-life aims to prevent age-related cognitive decline and development of ADRD pathology.[19]

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[44] Tang W, Kannaley K, Friedman DB, et al. Concern about developing Alzheimer’s disease or dementia and intention to be screened: An analysis of national survey data. *Arch Gerontol Geriatr*. 2017;71:43-49. doi:10.1016/j.archger.2017.02.013

[45] Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet*. 2020;396(10248):413-446. doi:10.1016/S0140-6736(20)30367-6

Early-Life Factors

Prenatal Conditions

Importantly, it is never too early to aim to reduce ADRD risk. In fact, adverse prenatal conditions such as maternal stress and poor nutrition are associated with the individual's cognitive decline in older adulthood.[46] For example, prenatal exposure to stressful naturally occurring events (such as famine), has been shown to increase risk for the development of dementia.[47] The reality that risk factors can be present even before birth, underscores the importance of a life-course perspective to dementia prevention.

Education

Evidence for the role of other early-life factors, such as educational attainment, is well-established. Higher childhood education levels are associated with reduced dementia risk,[48] therefore increasing education and overall cognitive ability is an effective risk reduction strategy. Recent evidence suggests that this strategy is most effective early, as there is no further risk reduction associated with increased educational attainment after the age of twenty.[49]

Physical Activity

Physical health and activity can also be targeted in early life. The World Health Organization (WHO) recommends that adults aged 18 to 64 years old engage in 150-300 minutes of moderate-intensity or 75-150 minutes of vigorous-intensity aerobic physical activity per week to reduce the risk of cognitive decline and to increase overall health benefits.[50]

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[46] de Rooij SR. Prenatal Influences on Cognitive Aging. In: Thomas AK, Gutchess AH, eds. *The Cambridge Handbook of Cognitive Aging: A Lifecourse Perspective*. Cambridge University Press; 2020:423-439. doi:10.1017/9781108552684.027

[47] Kang Y, Zhang Y, Feng Z, et al. Nutritional Deficiency in Early Life Facilitates Aging-Associated Cognitive Decline. *Curr Alzheimer Res*. 2017;14(8). doi:10.2174/1567205014666170425112331

[48] Norton S, Matthews FE, Barnes DE, Yaffe K, Brayne C. Potential for primary prevention of Alzheimer's disease: An analysis of population-based data. *Lancet Neurol*. 2014;13(8):788-794. doi:10.1016/S1474-4422(14)70136-X

[49] Kremen WS, Beck A, Elman JA, et al. Influence of young adult cognitive ability and additional education on later-life cognition. *Proc Natl Acad Sci U S A*. 2019;116(6):2021-2026. doi:10.1073/pnas.1811537116

[50] WHO. *Global Recommendations on Physical Activity for Health*.; 2010.

Lifestyle Factors in Mid- and Later-Life

In mid- and later-life, lifestyle factors become a prominent means of risk reduction; these include cognitive stimulation, healthy habits, nutrition, physical activity, and social engagement.

Social Isolation and Depression

To begin, engaging in novel cognitively stimulating activities (such as playing games, playing music, speaking a second language, or traveling) are associated with better late-life cognition.[51] Of note, many of these activities include a social component. High social contact (such as large social network size and greater numbers of social activities) is considered a protective factor.[52] Relatedly, there is evidence to suggest that dementia risk is increased in single and widowed individuals.[53] Although depression is a risk factor for dementia, treating depression with antidepressants does appear to have beneficial effects on risk.

Obesity and Physical Inactivity

Obesity (body mass index equal to or greater than 30) is a risk factor for dementia. Recommendations include losing weight through physical activity and good nutrition with healthy menus. In terms of nutrition, the most promising line of research has investigated whole food, minimally processed diets, and, in particular, the Mediterranean diet. The traditional Mediterranean diet consists of a high intake of fish, vegetables, legumes, fruits, nuts, unrefined grains, and olive oil, a low-to-moderate intake of dairy products, and a low intake of saturated lipids, meat, and poultry. This diet is associated with decreased risk of dementia,[54,29] as is the related MIND (Mediterranean-DASH [Dietary Approaches to Stop Hypertension] Intervention for Neurodegenerative Delay) diet, which is similar to the Mediterranean diet but includes poultry.[55]

Physical activity has a beneficial effect on cognition, reducing the risk of cognitive decline. The benefits are thought to be derived from aerobic exercise, and its effect on other modifiable risk factors, including hypertension. Aerobic exercise can also release brain growth factors which can

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[51] Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet*. 2020;396(10248):413-446. doi:10.1016/S0140-6736(20)30367-6

[52] Evans IEM, Martyr A, Collins R, Brayne C, Clare L. Social Isolation and Cognitive Function in Later Life: A Systematic Review and Meta-Analysis. *J Alzheimer's Dis*. 2019;70(s1):S119-S144. doi:10.3233/JAD-180501

[53] Sommerlad A, Ruegger J, Singh-Manoux A, Lewis G, Livingston G. Marriage and risk of dementia: Systematic review and meta-analysis of observational studies. *J Neurol Neurosurg Psychiatry*. 2018;89(3):231-238. doi:10.1136/jnnp-2017-316274

[54] Rahi B, Raji CA, Meysami S, Merrill D. The Role of Nutrition in Cognitive Decline. In: Thomas AK, Gutchess AH, eds. *The Cambridge Handbook of Cognitive Aging*. Cambridge University Press; 2020:612-627. doi:10.1017/9781108552684.038

[55] Budson AE, O'Connor MK. *Seven Steps to Managing Your Memory: What's Normal, What's Not, and What to Do About It.* Oxford University Press; 2017. Accessed August 26, 2020. https://global.oup.com/academic/product/seven-steps-to-managing-your-memory-9780190494957?cc=us&lang=en&

actually grow new brain cells.[56] WHO guidelines suggest that adults aged 65 years or older engage in at least 150 minutes of moderate-intensity or 75 minutes of vigorous-intensity aerobic physical activity per week to reduce the risk of cognitive decline.[57] A combination approach (for example, targeting both nutrition and physical activity) may be the most successful at reducing dementia risk.

Excessive Alcohol Consumption and Smoking

Other lifestyle risk factors include alcohol consumption equal to or greater than 21 drinks per week and smoking.[58] Recommendations to target these other factors naturally include reducing alcohol consumption to less than 14 drinks per week in mid-life, less than seven drinks in late-life, and stopping smoking. Individuals who stopped smoking earlier in life or smoke fewer than 27 packs a year demonstrate reduced risk of ADRD compared to those who quit smoking later in life or smoke more than 27 packs a year.[59] Importantly, even with a long period of smoking cessation, the risk of ADRD is greater in previous smokers as compared to those who have never smoked,[33] making the prevention of smoking key to risk reduction efforts.

Health Factors in Mid- and Later-Life

High Blood Pressure and Diabetes

There are several health factors that are associated with increased dementia risk. Among these are high systolic blood pressure (greater than or equal to 140 mm Hg in midlife) and diabetes. Some, but not all, of these effects can be mitigated. For example, blood pressure medications can reduce risk,[60] and one study showed the best protection against cognitive decline was found with systolic blood pressure less than or equal to 120 mm Hg.[61] Unfortunately, diabetic medications and intensive diabetic control have not been shown to reduce risk,[32] so the prevention of diabetes is the best approach.

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[56] Budson AE, O'Connor MK. *Seven Steps to Managing Your Memory: What's Normal, What's Not, and What to Do About It.* Oxford University Press; 2017. Accessed August 26, 2020. https://global.oup.com/academic/product/seven-steps-to-managing-your-memory-9780190494957?cc=us&lang=en&

[57] WHO. *Risk Reduction of Cognitive Decline and Dementia: WHO Guidelines*.; 2019.

[58] Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet*. 2020;396(10248):413-446. doi:10.1016/S0140-6736(20)30367-6

[59] Durazzo TC, Mattsson N, Weiner MW. Smoking and increased Alzheimer's disease risk: A review of potential mechanisms. *Alzheimer's Dement*. 2014;10(3 SUPPL.):S122-S145. doi:10.1016/j.jalz.2014.04.009

[60] Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet*. 2020;396(10248):413-446. doi:10.1016/S0140-6736(20)30367-6

[61] Williamson J, Pajewski N, Auchus A, Bryan R. SPRINT MIND Investigators for the SPRINT Research Group: Effect of intensive vs standard blood pressure control on probable dementia: a randomized clinical trial. *JAMA*. 2019;321:553-561.

Untreated Hearing Loss, Sleep Disturbance and Traumatic Brain Injury

Other risk factors involve hearing loss, sleep disturbance, and traumatic brain injury (TBI). Evidence for these is continuing to emerge, but some key findings are of note. Hearing impairment (≥ 25 dB) is associated with an increased risk of dementia. Encouragingly, hearing aid use can protect against cognitive decline. Regarding sleep, we now understand that everyone's brain makes a bit of beta amyloid (one of the pathologic proteins in Alzheimer's disease) during the day, but the brain clears it away each night during sleep. Without enough high-quality sleep, the brain may not be able to clear away this potentially toxic protein. However, there is also much evidence that sleeping medications may actually be harmful,[62] so nonpharmacological approaches to improving sleep quality are best. In terms of TBI, all severities (e.g., mild [concussion], multiple, severe) are associated with increased risk.

Environmental Factors

Noise and Air Pollution

Finally, risk factors can extend beyond the individual. To target these, it is recommended that one reduce exposure to noise as well as to air pollution and secondhand smoke. These environmental issues contribute to individual factors discussed above, including hearing impairment and cardiovascular health.

Ineffective Methods of Reducing Dementia Risk

Research has also shown that some factors, in particular supplements and "brain training" programs, are ineffective at reducing dementia risk. To start, while some micronutrient levels (such as B vitamins, vitamin K, vitamin D) are associated with cognitive function, taking

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[62] Islam Md, M, Iqbal U, Walther B, Atique S, Dubey N, K, Nguyen P, -A, Poly T, N, Masud J, H, B, Li Y, -CShabbir S, -A: Benzodiazepine Use and Risk of Dementia in the Elderly Population: A Systematic Review and Meta-Analysis. Neuroepidemiology 2016;47:181-191. doi: 10.1159/000454881. Sophie Billioti de Gage (PhD Student), Antoine Pariente (Professor) & Bernard Bégaud (Professor) (2015) Is there really a link between benzodiazepine use and the risk of dementia?, Expert Opinion on Drug Safety, 14:5, 733-747, DOI: 10.1517/14740338.2015.1014796. Coupland CAC, Hill T, Dening T, Morriss R, Moore M, Hippisley-Cox J. Anticholinergic Drug Exposure and the Risk of Dementia: A Nested Case-Control Study. *JAMA Intern Med.* 2019;179(8):1084–1093. doi:10.1001/jamainternmed.2019.0677. Shih, H. I., Lin, C. C., Tu, Y. F., Chang, C. M., Hsu, H. C., Chi, C. H., & Kao, C. H. (2015). An increased risk of reversible dementia may occur after zolpidem derivative use in the elderly population: a population-based case-control study. *Medicine*, *94*(17), e809. doi.org/10.1097/MD.0000000000000809. Cheng, Hui-Ting, Lin, Fang-Ju, Erickson, Stephen R., Hong, Jin-Liern , Wu, Chung-Hsuen. The Association Between the Use of Zolpidem and the Risk of Alzheimer's Disease Among Older People. Journal of the American Geriatrics Society. 2017. doi.org/10.1111/jgs.15018.

supplements does not appear to be broadly effective in preventing cognitive decline.[63] Further, memory supplements that are advertised to stave off or restore memory loss do not do so,[64,65] nor do "brain training" programs.[66] Only the nutrition and cognitive engagement recommendations discussed above have been shown to reduce dementia risk.

Identifying Risk Reduction with the Greatest Impact

As stated throughout, several of these risk factors are related to, or directly affect, other risk factors, therefore, an approach which targets multiple risk factors may have the greatest impact. Also important is the consideration of *who* may benefit most from risk factor reduction. Individuals who are the most deprived of institutional and environment support are those who need these interventions most, particularly in Asian, Black, and minority ethnic groups and in vulnerable populations.[67] Societal action that improves the quality of life of these underrepresented groups should be at the fore of any risk reduction approach.

Steps to Consider

1. a. Encourage all students to complete their high school education
   b. Enable all citizens, regardless of economic background, the opportunity to attend college if they wish
2. Working with the Councils on Aging, establish programs to prevent social isolation of elders and all those at risk for such isolation at any age, such as those with physical or mental disabilities
3. Ensure that depression is routinely screened for through annual wellness visits, and that resources are available to treat depression through evidence-based, multi-modal interventions such as exercise and mindfulness, in addition to medications
4. a. Ensure that obesity will be screened for at any age, through schools and annual wellness visits, and that resources are available to reduce obesity, through evidence-based, multi-

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[63] Rahi B, Raji CA, Meysami S, Merrill D. The Role of Nutrition in Cognitive Decline. In: Thomas AK, Gutchess AH, eds. *The Cambridge Handbook of Cognitive Aging*. Cambridge University Press; 2020:612-627. doi:10.1017/9781108552684.038

[64] Federal Trade Commission. Supplement Marketers Will Relinquish $1.4 Million to Settle FTC Deceptive Advertising Charges. Published 2015. Accessed January 4, 2021. https://www.ftc.gov/news-events/press-releases/2015/07/supplement-marketers-will-relinquish-14-million-settle-ftc

[65] Federal Trade Commission., New York State Charge the Marketers of Prevagen With Making Deceptive Memory, Cognitive Improvement Claims. Published 2017. Accessed January 4, 2021. https://www.ftc.gov/news-events/press-releases/2017/01/ftc-new-york-state-charge-marketers-prevagen-making-deceptive

[66] Federal Trade Commission. Lumosity to Pay $2 Million to Settle FTC Deceptive Advertising Charges for Its “Brain Training” Program. Published 2016. Accessed January 4, 2021. https://www.ftc.gov/news-events/press-releases/2016/01/lumosity-pay-2-million-settle-ftc-deceptive-advertising-charges

[67] Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet*. 2020;396(10248):413-446. doi:10.1016/S0140-6736(20)30367-6

   modal interventions such as exercise programs and whole food, Mediterranean-style menus
   b. Ensure that restaurants and other food-service industries enable citizens to make healthy choices by prominently listing nutritional and other relevant information on all menus and packages
   c. Ensure that restaurants and other food-service industries do not package multi-serving foods and beverages in single-serving containers, such as a wrapped sandwich or soda cup; multiple servings of prepared foods should be packaged separately unless sold for family serving

5. a. Encourage physical activity in students by mandating physical activity at least three times per week. Requirements can be fulfilled through sports and other activities outside school, but opportunities will be provided inside school for those who would not otherwise get it
   b. Encourage physical activity at any age by ensuring that exercise trails for biking, jogging, walking, and other activities (including seasonal activities such as boating, cross-country skiing, ice skating, snow shoeing, and swimming) are available for citizens, including older adults, year-round
   c. Ensure that opportunities are available for physical activity year-round, even during pandemics and other unanticipated events
6. Ensure that annual wellness visits will address alcohol consumption in moderation
7. Ensure that annual wellness visits will address smoking cessation
8. Ensure that citizens and physicians are informed as to the benefits of detecting and treating high blood pressure, and the dire consequences of ignoring or inadequately treating it
9. Encourage a reduction of diabetes in the Commonwealth by targeting the number one diabetes risk factor, obesity, as outlined in Steps 4 and 5 above
10. Working with nonprofit organizations, such as the Concussion Legacy Foundation, encourage citizens of all ages to reduce their risk of head injuries by wearing helmets for relevant sports (such as biking, inline skating, skateboarding, and skiing) and reducing the risks of sports with repetitive head impacts (such as boxing, football, and rugby)
11. Ensure that all citizens have access to earwax removal, hearing aids and hearing screening, regardless of income level
12. Establish measures to reduce air pollution in the Commonwealth
13. Establish programs to specifically target those low-income and underserved populations who are at greatest risk of dementia

Linkages Associated with the Alzheimer's State Plan

Linkages Within the Alzheimer's State Plan

Described below are linkages among the recommendations within this state plan. For each linkage identified, workgroups will work together to align their implementation activities.

Linkages between the Quality of Care Workgroup, and Diagnosis and Services Navigation Workgroup, in 2021 and 2022

As the Quality of Care Workgroup develops a care plan framework, it will ensure that care plans effectively integrate personally meaningful goals with clinical goals, and referrals to non-clinical services and supports are an essential component. There is a direct link between the Quality of Care Workgroup's efforts to establish a care plan framework, and the Diagnosis and Services Navigation Workgroup's strategies to ensure effective access to information and care planning.

As depicted in the diagram below, to ensure alignment, the Quality of Care Workgroup will remain informed of the Diagnosis and Services Navigation Workgroup's efforts, and incorporate some of that Workgroup's outcomes into its activities.

Quality of Care
(Recommendation #1)
Develop a person-directed care plan framework and template

Diagnosis and Services Navigation
(Recommendation #2)
Ensure that after a dementia diagnosis, individuals and their families have access to comprehensive information and care planning services

The **Quality of Care Workgroup** will remain informed of the **Diagnosis and Services Navigation Workgroup's** efforts around establishing:

- a road map to services and supports
- support and strategies for unaccompanied/unsupported individuals
- an expanded Dementia Care Coordination Program of the Alzheimer's Association MA/NH

Linkages Between the Diagnosis and Services Navigation Workgroup, and Caregiver Support and Public Awareness Workgroup, in 2021 and 2022

The Diagnosis and Services Navigation Workgroup will develop a road map to services and supports to disseminate to providers. As it creates this road map, it will access information found within the web-based overview of pathways, services, and supports which was recommended by the Caregiver Support and Public Awareness Workgroup.

Diagnosis and Services Navigation

(Recommendation #2)

Ensure that after a dementia diagnosis, individuals and their families have access to comprehensive information and care planning services

Caregiver Support and Public Awareness

(Recommendation #2)

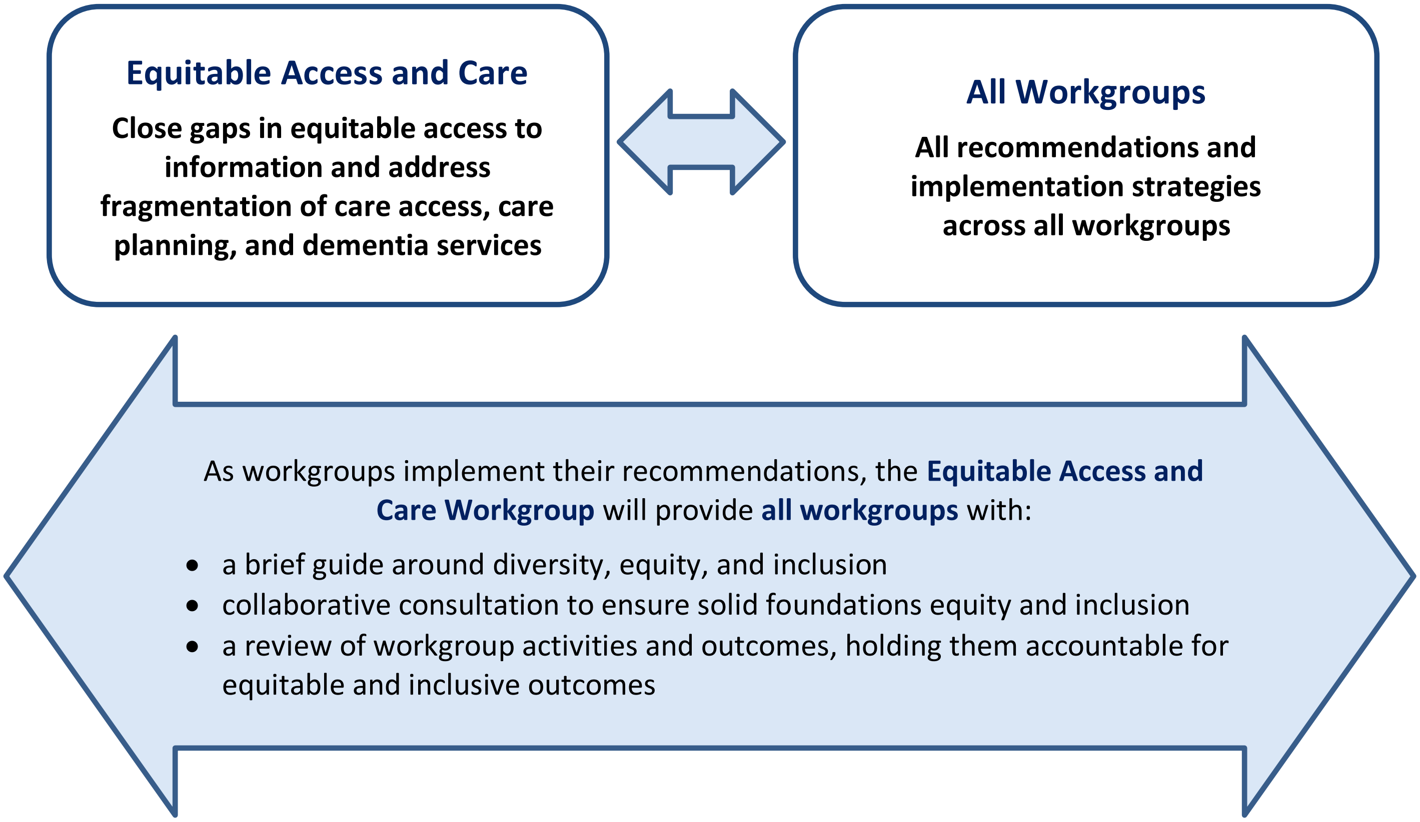
Place on the Massachusetts Executive Office of Elder Affairs (EOEA) website, an overview of statewide pathways, services, and supports for people living with dementia and their caregivers

While developing its road map to services and supports, the **Diagnosis and Services Navigation Workgroup** will remain informed of the **Caregiver Support and Public Awareness Workgroup's** efforts and progress **(via EOEA)** around placing on EOEA's website:

- an overview of statewide pathways, services, and supports for people living with dementia and their caregivers

Linkages Between the Equitable Access and Care Workgroup, and All Workgroups

As depicted in the diagram below, the Equitable Access and Care Workgroup will help to ensure that all workgroups effectively build solid foundations of equity and inclusion into their recommendations and implementation strategies.



Equitable Access and Care

Close gaps in equitable access to information and address fragmentation of care access, care planning, and dementia services

All Workgroups

All recommendations and implementation strategies across all workgroups

As workgroups implement their recommendations, the **Equitable Access and Care Workgroup** will provide **all workgroups** with:

- a brief guide around diversity, equity, and inclusion
- collaborative consultation to ensure solid foundations equity and inclusion
- a review of workgroup activities and outcomes, holding them accountable for equitable and inclusive outcomes

Linkages Between the Alzheimer's State Plan and Other Statewide Efforts

Described below are linkages between the Alzheimer's State Plan and other statewide activities designed to promote the well-being of the Commonwealth's residents. For each linkage identified, the organizations responsible for implementing the recommendations of the Alzheimer's State Plan will work to ensure coordination across state agencies and community partners to align implementation strategies and enhance expected outcomes.

Linkages Between the Massachusetts State Plan on Aging and the Alzheimer's State Plan

Every four years, the Executive Office of Elder Affairs prepares a Massachusetts State Plan on Aging (the Plan) and provides it to the U.S. Administration for Community Living.[68] The Plan serves as the structure for shaping policies and programs designed to advance the empowerment, independence, and well-being of older adults, individuals with disabilities, and their caregivers. The Plan's goals are closely related to the recommendations in the Alzheimer's State Plan. Both plans envision a state where older adults and people of all ages living with dementia will have access to the resources and care they need to live well and thrive in their communities.

The Alzheimer's Advisory Council will work to ensure that the goals, recommendations, and activities stemming from the **Alzheimer's State Plan** are consistently aligned with the goals of the **Massachusetts State Plan on Aging**, which are listed in the table below. The checkmarks represent links to activities associated with the Alzheimer's Advisory Council and Alzheimer's State Plan.

Goals of the Massachusetts State Plan on Aging	**Alzheimer's Advisory Council Workgroups**			
	Caregiver Support and Public Awareness	Diagnosis and Services Navigation	Physical Infra-structure	Quality of Care
Support aging in community	✓	✓	✓	✓
Support caregivers and make Massachusetts dementia capable	✓	✓	✓	✓
Empower healthy aging	✓	✓	✓	✓
Prevent exploitation and injury to, and violence toward, older adults		✓	✓	✓

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[68] View the State Plan on Aging: https://www.mass.gov/doc/ma-state-plan-on-aging-2018-2021/download

Goals of the Massachusetts State Plan on Aging	Alzheimer's Advisory Council Workgroups			
	Caregiver Support and Public Awareness	Diagnosis and Services Navigation	Physical Infra-structure	Quality of Care
Strengthen "no wrong door" access to aging and disability services	✓	✓		
Ensure quality, value, and person-centered community-based care through evidence-informed methods		✓		✓

Linkages Between the Governor's Council to Address Aging in Massachusetts and the Alzheimer's State Plan

The **Governor's Council to Address Aging in Massachusetts** (Governor's Council), formed by an Executive Order in 2017, comprises leaders from academia, advocacy organizations, the business community, caregivers, community organizations and the health care, innovation, municipality, and technology sectors.

Governor Charlie Baker charged the Governor's Council to think differently and innovatively about aging in Massachusetts. In 28 recommendations will improve the lives of people living with dementia and their caregivers. Woven throughout the recommendations are concepts that are closely related to the goals of the **Alzheimer's State Plan**. The Alzheimer's Advisory Council will remain informed of the strategies behind those recommendations, check for linkages with the Alzheimer's State Plan, ensure alignment, and strive to enhance, rather than duplicate, implementation activities and outcomes.

The table below lists concepts woven throughout the Governor's Council's recommendations that are closely related to recommendations in the Alzheimer's State Plan. The checkmarks represent links to activities associated with the Alzheimer's Advisory Council and the Alzheimer's State Plan.

Concepts Embedded within Recommendations of the Governor's Council to Address Aging	Alzheimer's Advisory Council Workgroups			
	Caregiver Support and Public Awareness	Diagnosis and Services Navigation	Physical Infra-structure	Quality of Care
Support both caregivers and individuals living with dementia in the workplace	✓			
Ensure programs and resources are affordable, inclusive, and known	✓	✓	✓	✓
Develop accessible and supportive housing and transportation options			✓	
Promote dementia-friendly communities, and connection and engagement to decrease isolation and loneliness	✓	✓	✓	✓
Increase access to healthcare and trained direct care workforce		✓		✓
Address stigma and reframe aging	✓			

Linkages Between the Age-Friendly Massachusetts Action Plan and the Alzheimer's State Plan

"Age-friendly" describes a movement to make communities more welcoming and livable for people of all ages. Age-friendly efforts create places where people can grow up and grow older together in a thriving environment. A critical partner to the age-friendly movement is the effort to become dementia friendly. The aim of dementia friendly is to make communities more welcoming, inclusive, and supportive of people living with dementia, as well as their families and care partners. A dementia-friendly community is informed, respectful of, and safe for people living with dementia, and enables them and those who care about them to live engaged, full lives. In Massachusetts, the age- and dementia-friendly movements are intertwined with partners such as Dementia Friendly Massachusetts playing a critical role in steering the statewide work.

The **Age-Friendly Massachusetts Action Plan** serves as the Commonwealth's multiyear plan to make the state, as a whole, more age- and dementia-friendly.[69] It includes goals and strategies

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[69] View the Age-Friendly Massachusetts Action Plan: *Reimagine Aging: Planning Together to Create an Age-Friendly Future for MA*, January 2019: https://www.mass.gov/doc/age-friendly-ma-draft-action-plan-january-2019/download

designed to advance Massachusetts' efforts to become an age-friendly state. The Alzheimer's Advisory Council will remain informed of the strategies in the Age-Friendly State Plan, check for linkages with the **Alzheimer's State Plan**, and ensure alignment. The table below lists the goals of the Age-Friendly Massachusetts Action Plan. The checkmarks represent links to activities associated with the Alzheimer's Advisory Council and the Alzheimer's State Plan.

Goals of the Age-Friendly Massachusetts Action Plan	**Alzheimer's Advisory Council Workgroups**			
	Caregiver Support and Public Awareness	Diagnosis and Services Navigation	Physical Infra-structure	Quality of Care
Deepen and strengthen age- and dementia-friendly efforts to be inclusive of all communities and populations	✓		✓	✓
Communicate information in an accessible and user-friendly manner to residents, organizations, and municipalities	✓	✓		
Change the conversation about aging from a "challenge" to an "asset", increase literacy about issues related to aging, and eliminate ageist images and expressions in language across print, social, and other media	✓	✓		✓
Encourage the adoption of age-friendly policies and practices in all sectors			✓	✓
Take specific actions to improve economic security of older adults and caregivers				
Leverage existing structures to sustainably guide and support the work of Age-Friendly Massachusetts and partner initiatives			✓	✓

Appendix A

Members of the Alzheimer's Advisory Council and Workgroups

Alzheimer Advisory Council
Secretary Elizabeth C. Chen, PhD, MBA, MPH – Massachusetts (MA) Secretary, Executive Office of Elder Affairs and Chair of Alzheimer's Advisory Council
Susan Antkowiak – Vice President of Programs & Services, Alzheimer's Association MA/NH
Michael Belleville – Dementia Advocate
Maura Brennan, MD – Program Director, Baystate Health Geriatric Workforce Enhancement Program
Andrew Budson, MD – Chief of Cognitive & Behavioral Neurology, Associate Chief of Staff for Education and Director of the Center for Translational Cognitive Neuroscience at Veterans Affairs (VA) Boston Healthcare System; Associate Director for Research at Boston University Alzheimer's Disease Center; Lecturer in Neurology at Harvard Medical School; Medical Director of the Boston Center for Memory
Robin Callahan – MassHealth (Retired)
Representative Tricia Farley-Bouvier – Vice Chair, Joint Committee on Elder Affairs
Jonathan Jackson, PhD – Founder and Executive Director, Community Access, Recruitment, and Engagement (CARE) Research Center at Massachusetts General Hospital; Instructor in Neurology at Harvard Medical School
Senator Patricia Jehlen – Co-chair, Joint Committee on Elder Affairs
Rhiana Kohl – Caregiver
James Lavery – Director, Bureau of Health Professions Licensure, MA Department of Public Health
Barbara Meehan – Alzheimer's Advocate/Former Caregiver
Hector Montesino – President, Embrace Home Care Services
Bernice Osborne-Pollar – Caregiver
Linda Pellegrini, MS, GNP-BC – Geriatric Nurse Practitioner, UMass Memorial Medical Center
Heather Sawitsky – Fox Hill Village Homeowners Corporation
James Wessler – Chief Executive Officer, Alzheimer's Association MA/NH and New England Regional Leader

Caregiver Support and Public Awareness Workgroup		
Barbara Meehan ***Workgroup Co-lead and Council Member*** Alzheimer's Advocate/Former Caregiver	**Hector R. Montesino** ***Workgroup Co-lead and Council Member*** President, Embrace Home Care Services	**Katie Brandt, MM** Director of Caregiver Support Services and Public Relations, Massachusetts General Hospital; Co-Chair, National Alzheimer's Project Act (NAPA) Council
Jennifer Hoadley, CDP Regional Manager, Southeastern MA Alzheimer's Association	**Senator Patricia Jehlen** ***Council Member*** Co-chair, Joint Committee on Elder Affairs	**Rhiana Kohl** ***Council Member*** Caregiver
Kathryn Perrella, LSW, CIRS A/D Options Program Manager, Elder Services of the Merrimack Valley and North Shore	**Patty Sullivan** Program Director, Dementia Friendly Massachusetts, Massachusetts Councils on Aging	

Diagnosis and Services Navigation Workgroup		
Representative Tricia Farley-Bouvier ***Workgroup Co-lead and Council Member*** Vice Chair, Joint Committee on Elder Affairs	**James Wessler** ***Workgroup Co-lead and Council Member*** Chief Executive Officer, Alzheimer's Association MA/NH, and New England Regional Leader	**Kathryn C. Burns, MHA** Chief Executive Officer, Greater Lynn Senior Services, Inc.
Robin Callahan ***Council Member*** MassHealth (Retired)	**Ellen M. McDonough** Former Director, Clinical Services, Elder Services of Cape Cod & the Islands	**Nicole McGurin, MS, CDP** Family Services Director, Alzheimer's Association MA/NH
Caitlin Roy Options Counselor, Montachusett Home Care Corporation	**Rebecca Starr, MD, AGSF** Medical Director, Geriatrics, Cooley Dickinson HealthCare	

Equitable Access and Care Workgroup		
Jonathan Jackson, PhD ***Workgroup Lead and Council Member*** Founder and Executive Director, Community Access, Recruitment, and Engagement (CARE) Research Center, Massachusetts General Hospital; Instructor in Neurology at Harvard Medical School	**Patty Blake** President of Senior Products, Tufts Health Plan	**Leonor Buitrago** Diversity Outreach Manager, Alzheimer's Association MA/NH
Michael P. Kincade Communications and Outreach Coordinator, Center for Alzheimer's Research and Treatment, Brigham & Women's Hospital, Massachusetts Alzheimer's Disease Research Center, Massachusetts General Hospital	**Beth Soltzberg, LICSW, MBA** Director, ADRD Family Support Program, Jewish Family & Children's Service	

Physical Infrastructure Workgroup		
Elizabeth Chen, PhD, MBA, MPH ***Workgroup Lead and Council Chair*** Secretary, MA Executive Office of Elder Affairs; Chair, Alzheimer's Advisory Council	**Laura Brelsford** Assistant General Manager, Department of System-Wide Accessibility, MBTA	**Elana Brochin** Program Director of Health Equity, MA Assoc. of Community Development Corporations (MACDC)
Angela Cleveland, AICP President, American Planning Association, Massachusetts Chapter (APA-MA), Director of Community and Economic Development, City of Amesbury	**Jackie DeWolfe** Director of Sustainable Mobility, Office of the Secretary, Massachusetts Department of Transportation	**Linda Dunlavy** Executive Director, Franklin Regional Council of Governments
James Fuccione, MPA Senior Director, Mass. Healthy Aging Collaborative	**Jeffrey R. Parenti, PE, PTOE, PTP, ENV SP** Deputy Chief Engineer, Division of Design and Engineering,	**Kathryn Quigley** Deputy Director of Strategic Planning, Department of System-Wide Accessibility, MBTA

Physical Infrastructure Workgroup		
	MA Department of Conservation and Recreation (DCR)	
Patty Sullivan Program Manager, Dementia Friendly Massachusetts, Massachusetts Councils on Aging	**Jeffrey Walker, AICP** Executive Director, Southeastern Regional Planning & Economic Development District	**Amy Walsh, MSc, CDP** Dementia Friendly Boston, Age Strong Commission, City of Boston
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Public Health Infrastructure Workgroup		
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Appendix B

Resources on Care Planning and Training Programs

Care Planning Resources

- https://www.honoringchoicesmass.com
- https://respectcaregivers.org/wp-content/uploads/2016/04/Alzheimers-Patient-Navigation-Model1.pdf
- https://daanow.org/day-papers-summits
- https://www.alz.org/professionals/health-systems-clinicians/care-planning
- https://www.alzheimersnavigator.org
- https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-StarterKit-Alzheimers-English.pdf
- https://www.alzheimers.org.uk/get-support/publications-factsheets-full-list

Training Resources

Primary Care

- Training Programs for Providers and Staff could include any of following:
  - Massachusetts Medical Society’s five-part Continuing Medical Education course: *Diagnosis Treatment and Care of Alzheimer's Disease and Related Dementias*
  - *Geri Pal (Geriatrics and Palliative Care) Immersion Training*, Baystate Geriatrics Workforce Enhancement Program (GWEP)
  - U.S. Health Resources and Services Administration (HRSA) training for interprofessional clinicians and caregivers: *ADRD training curriculum*
  - *Road Map to Diagnosis – Physician edition*, Center for Alzheimer Research and Treatment (CART), Brigham and Women’s Hospital; and Massachusetts Alzheimer’s Disease Research Center (MADRC), Massachusetts General Hospital.
- Following initial basic training, clinicians will need ongoing coaching and support. Options include:
  - UCLA Alzheimer's and Dementia Care Program: several systems are utilizing this program or have Memory Loss Program's Center of Excellence
  - Baystate GWEP Echo Program can provide ongoing didactics and case-based coaching virtually

Acute Care

- Guidance for Developing an Operational Plan to Address Diagnosis and Care for Patients with Alzheimer's Disease and Related Dementias in Hospital Settings – Implementation to be reviewed and assessed in terms of:
    1. the need to provide culturally sensitive training on dementia and/or delirium to a broad range of caregivers;
    2. the necessity of learning the patient's prior history by working with the patient, family, caregivers, and EMS personnel, among others;
    3. management of treatment once the patient is in the care of providers in the hospital
    4. improving communication in care transfers and in discharges; and
    5. incorporating advanced-care planning into the general information provided to patients and caregivers, to ensure that patients with Alzheimer's and related dementias have the full range of resources available to them.

Home Care

- Alzheimer's Association's Person-Centered Dementia Care (Train-the-Trainer model for long-term care and community-based settings)
- ASAPs have dementia specialist experts to work with families/clients with diagnosis and to help consumers find maximal community-based and home-care supports
- Direct training of caregivers should be supported and compensated in conjunction with regular communication with ASAP or other specialists to ensure feedback on unmet needs
- Age-friendly home-care systems must link with primary-care system (in Age-Friendly Health system) to assess and support patients at times of changes in status

Long-Term Care

- Develop and identify mandatory training modules to support identification of needs and appropriate responses; all staff must be trained including dining staff, front office, and housekeeping
    - Alzheimer's Association's Person-Centered Dementia Care (Train-the-Trainer model for long-term care and community-based settings)
    - Alzheimer's Association's Alzheimer's and Dementia Care ECHO Program or participation in a broader AFHS ECHO (GWEP supported) since ongoing support and coaching will be needed to develop a core team of local experts to impact culture over time

Acronyms Used in this Report

4Ms, Matters, Medication, Mentation, Mobility

ACL, Administration for Community Living

ADEAR, Alzheimer’s Disease Education and Referral

ADRD, Alzheimer's disease and related dementias

AF, age-friendly

ASAPs, Aging Services Access Points

BOLD, Building Our Largest Dementia Infrastructure

BORIM, Massachusetts Board of Registration in Medicine

CART, Center for Alzheimer Research and Treatment

CDC, Centers for Disease Control and Prevention

Commonwealth, Commonwealth of Massachusetts

CWM, Commonwealth Medicine

DCC program, Dementia Care Coordination program

DCR, Massachusetts Department of Conservation and Recreation

DF, dementia-friendly

DFM, Dementia Friendly Massachusetts

DPH, Massachusetts Department of Public Health

ECHO model, Extension for Community Healthcare Outcomes

ED, Emergency Department

EOEA, Massachusetts Executive Office of Elder Affairs

EOHHS, Massachusetts Executive Office of Health and Human Services

GWEP, Baystate Geriatrics Workforce Enhancement Program

HRSA, Health Resources and Services Administration

I/DD, intellectual and developmental disabilities

IHI, Institute for Healthcare Improvement

MA, Massachusetts

MACDC, Massachusetts Association of Community Development Corporations

MADRC, Massachusetts Alzheimer’s Disease Research Center

MBTA, Massachusetts Bay Transportation Authority

MD, Medical Doctor

NAPA, National Alzheimer's Project Act

NH, New Hampshire

NIA, National Institute on Aging

NIH, National Institutes of Health

NOFO, Notice of Funding Opportunity

PA, Physician Assistants

PACE, Program of All-inclusive Care for the Elderly

PCP, Primary Care Provider

PHO, Physician Health Organization

UMMS, University of Massachusetts Medical School

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- **Dan Zotos**, Director of Public Policy & Advocacy, Alzheimer's Association MA/NH, who assisted in recruiting individuals to join workgroups, and contributed to the writing of this plan's section entitled, *Overview of Alzheimer's Disease and Related Dementias*

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[70] See Appendix A for a list of Council and workgroup members