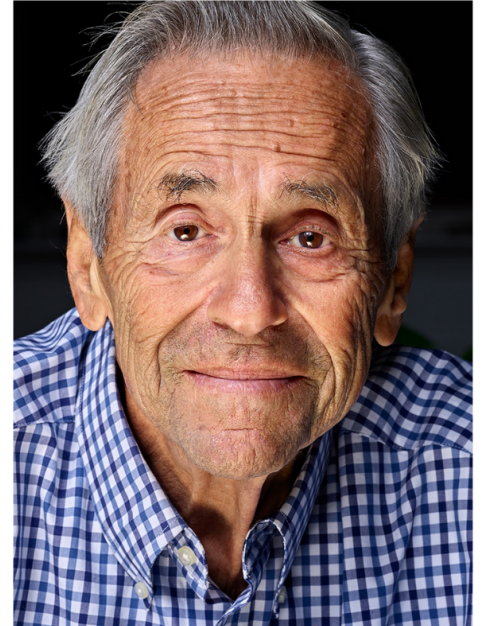




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Massachusetts Advisory Council on Alzheimer's Disease and All Other Dementias Annual Report

April 2022



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EXECUTIVE SUMMARY

A Year in Review and the Year Ahead

In preparing this report, the Advisory Council on Alzheimer's Disease and All Other Dementias took a close look at its achievements since April 2021 when it published the [*Massachusetts State Plan on Alzheimer's Disease and Related Dementias*](#) (state plan). This year's annual report provides a summary of the Council's progress, accomplishments, and next steps in implementing the state plan's recommendations. The table below includes some highlights around the Council's achievements over the past year and next steps for the year ahead.

CAREGIVER SUPPORT AND PUBLIC AWARENESS
Gained significant momentum toward improving public awareness of supports and services available for Massachusetts residents and families affected by dementia.
☑ Produced a video-recorded caregiver interview in English and working to finalize similar videos in Spanish and Portuguese. Plans are underway to distribute the videos widely. ☑ Created a state website on dementia services and resources. Will disseminate widely after incorporating feedback from caregivers and people living with dementia. ☑ Implemented improvements to reinforce cross-referrals as a standard practice between the Aging Services Access Points (ASAPs) and the Alzheimer's Association. ☑ Plans are in place to leverage the MA Executive Office of Elder Affairs' review of its ASAP designation review process to identify opportunities to enhance caregiver experience.
DIAGNOSIS AND SERVICES NAVIGATION
Implemented approaches to promote effective dementia screening and diagnosis; family engagement; and access to information, support, and care after a dementia diagnosis.
☑ Provided primary care clinicians with easy access to helpful resources around dementia screening and diagnosis. Will identify practices to pilot a dementia screening workflow. ☑ Collaborated with the MA Board of Registration in Medicine, resulting in formal guidance for physicians about informing a family of a dementia diagnosis and treatment plan. ☑ Developing a guide around initiating a conversation about a dementia diagnosis. ☑ Plans are in progress to work with key stakeholders to develop a brief user-friendly roadmap on developing and implementing dementia operations plans. ☑ Commenced discussions to identify opportunities within the state's home care program regarding the identification of consumers who may have undiagnosed dementia. ☑ Began assessing information to potentially include in a road map to help Massachusetts residents and families find and access helpful information, services, and support.

EQUITABLE ACCESS AND CARE
Completed important first steps toward advancing the Council’s goal of equitable and inclusive access to dementia information, care planning, health care, support, and services.
☑ Recruited over 20 individuals from a broad range of underserved groups to participate in an Equity and Inclusion Team to advise the Council on issues around equity and inclusion. ☑ Began identifying barriers that are unique to younger adults and their families affected by dementia. ☑ Plans are underway to recommend training courses for Council members on equity, inclusion, and access; expect to deploy members of the Equity and Inclusion Team to the Council’s workgroups and implementation teams later in 2022
PHYSICAL INFRASTRUCTURE
Made significant progress describing the characteristics of dementia-friendly physical infrastructure with a focus on safety, wayfinding, and community engagement.
☑ Developed an initial draft of an extensive guide designed to define the characteristics of dementia-friendly physical infrastructure. ☑ Provided guidance to applicants for funding from MassDOT’s Shared Streets and Spaces Grant program ☑ Spread awareness of age- and dementia-friendly (AF/DF) design among stakeholders and identified programs where AF/DF design characteristics could potentially be included. ☑ Formulating strategies to engage in discussions about AF/DF physical infrastructure with state procurement officials, regional planning agencies, and key stakeholders within AF/DF communities.
PUBLIC HEALTH INFRASTRUCTURE
Established a methodology for assessing the state’s public health infrastructure around dementia with a focus on reducing the risk of dementia among Massachusetts residents.
☑ Developed an assessment framework and populated it with pertinent information to describe the current state of the state’s public health infrastructure around dementia. ☑ Plans are in progress to recruit individuals from the MA Department of Public Health to lead and participate in a team to recommend strategies to address dementia risk factors.
QUALITY OF CARE
Made considerable progress toward addressing the lack of person-directed dementia care planning; and began efforts to promote interprofessional dementia care teams.
☑ Reviewed current resources and collaborated with key stakeholders to begin developing a guide for person-directed care planning for individuals living with dementia. ☑ Plans are in progress to convene focus groups comprised of patients diagnosed with dementia and their caregivers to gain an understanding for what they experience while communicating with physicians. ☑ Convened initial discussions about interprofessional dementia care with the Institute for Healthcare Improvement leadership to leverage the Age-Friendly Health System

movement to help promote interprofessional dementia care; and began developing a list of interprofessional dementia care training tools and resources.

- ☑ Plans are underway to broaden the Council's Interprofessional Training Team to include a wider range of professionals and conduct a review of existing interprofessional dementia care models.
- ☑ Commenced ongoing participation in statewide direct care workforce initiatives to ensure that the needs of individuals and families affected by dementia are effectively addressed.
- ☑ Launched an online version of Alzheimer's Supportive Home Care Aide (SHCA) training for direct care workers.

RESEARCH

Began identifying individuals to implement strategies to increase the diversity of dementia research and researchers.

- ☑ Identified an individual to lead and form a Research Diversity Team.
- ☑ Began identifying individuals to work together to design approaches to achieve specific research diversity objectives.

Massachusetts State Plan on Alzheimer's Disease and Related Dementias: A Living Document

In calendar year 2022, the Council expects to update the current version of the [*Massachusetts State Plan on Alzheimer's Disease and Related Dementias*](#) (state plan). Anticipated changes include recommendations and implementation strategies that address issues around younger-onset dementia, and the dementia risk factors that all Massachusetts residents face. Over the years, as the Council fully implements the state plan's strategies within any of its seven workstreams, it will regularly refresh the state plan with new strategies, bring the appropriate stakeholders to the table, and implement solutions.

The Council is committed to improving the lives of people living with dementia and the people who care about them. It will continue to develop and implement fiscally responsible and sustainable policies and programs; and improve access to dementia information, services, support, care, and treatment. It plans to do so with an unwavering eye toward ensuring that all Massachusetts residents affected by dementia receive the respect and opportunities they deserve.

INTRODUCTION

As required by Massachusetts General Laws, Chapter 220 of the Acts of 2018, the Massachusetts Advisory Council on Alzheimer’s Disease and All Other Dementias (Council) has prepared this report for the Executive Office of Health and Human Services (EOHHS) and Legislature. The Council was established to write a state plan and provide EOHHS and the Legislature with advice on policies around Alzheimer’s Disease and Related Dementias (ADRD).¹ As shown in Appendix A, the 17-member Council is comprised of a diverse group of public health professionals, clinicians, healthcare providers, researchers, legislators, dementia advocates, and caregivers.

This report is the Council’s second annual report and its first since April 2021 when it published the *Massachusetts State Plan on Alzheimer’s Disease and Related Dementias* (state plan).² Since April 2021, the Council has been using the state plan as its roadmap to better meet the needs of the Commonwealth’s 130,000 residents diagnosed with dementia³, supported by over 340,000 family caregivers⁴, and an estimated 130,000 or more residents currently living with dementia without a formal diagnosis.⁵ Specifically, the state plan includes recommendations and implementation plans around seven focus areas, or “workstreams,” which appear 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

¹ The Council was established under Massachusetts General Laws, Chapter 6A, Section 16AA and Chapter 220 of the Acts of 2018.

² The Alzheimer’s State Plan, April 2021 and Annual Report, April 2021 are posted on the Council’s website: <https://www.mass.gov/orgs/alzheimers-advisory-council>.

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 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>

This report summarizes the Commonwealth’s progress, accomplishments, and next steps for each of the state plan’s seven focus areas. As shown in Appendix B, this progress was made possible by volunteers from across the Commonwealth that continue to help the Council implement the state plan’s recommendations. The Council remains grateful for their valuable expertise, insight, resources, time, and commitment to address the challenges of dementia faced by Massachusetts residents, families, and caregivers. This report embodies the state’s continued commitment to ensure that its residents affected by dementia receive the support, services, and care they need to live healthy and meaningful lives.

IMPLEMENTING EFFECTIVE AND SUSTAINABLE SOLUTIONS



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Progress, Accomplishments, and Next Steps

This report is the result of an extensive review of the Council’s progress in implementing the strategies included in the *Massachusetts State Plan on Alzheimer’s Disease and Related Dementias, April 2021 (state plan)*. The following pages comprise seven sections, one for each of the Council’s focus areas, or “workstreams.” Each section begins with the goals of the workstream, lists the state plan’s recommendations to advance those goals, and summarizes the Council’s progress, accomplishments, and next steps for calendar year 2022 around implementing effective and sustainable policies and practices.

1. Caregiver Support & 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**

Recommendation #1 (Video Production)

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

Progress and Accomplishments

- Produced a 30-minute video of a [caregiver interview](#) in English. The video recognizes challenges that caregivers face and the importance of seeking a diagnosis of dementia and assistance early in the process. The video intends to help caregivers realize they are not alone and there are resources available to help.
- Produced and working to finalize 30-minute videos of caregiver interviews in Spanish and Portuguese.

Next Steps

- Finalize 30-minute caregiver videos in Spanish and Portuguese.
- Make the three videos available on the state's website, cable TV stations, and the newsletters, bulletins, and websites of senior centers, aging services agencies, and other stakeholder organizations.
- Develop and implement a plan to produce similar videos in additional languages.
- Produce brief videos ("teasers") to spread awareness and encourage viewing of the full 30-minute videos.

Recommendation #2 (Website Development)

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

Progress and Accomplishments

- Created a state [website](#) on dementia services, information, and resources.
- Gathered valuable feedback about the website from family caregivers of people living with dementia.

Next Steps

- Make improvements to the new website based on feedback provided by caregivers and people living with dementia.

- Spread awareness of the website by encouraging organizations throughout the Commonwealth’s aging services network to place its link in their websites, newsletters, and bulletins.

Recommendation #3 (Caregiver Experience)

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

Progress and Accomplishments

- Formed a team to reinforce cross-referrals as a standard practice between the Aging Services Access Points (ASAPs) and Alzheimer’s Association.
- Specifically, the team:
 - made improvements to the internal resource database used by the Alzheimer’s Association’s Helpline staff to highlight the role of ASAPs
 - discussed this topic at all regional Aging & Disability Resource Consortia (ADRC) meetings convened in May 2021
 - convened a webinar in July 2021 with the Alzheimer’s Association’s MA/NH staff where representatives from ASAPs and Independent Living Centers showcased their offerings for individuals and families affected by dementia; and
 - distributed talking points about the Alzheimer’s Association’s Helpline to all supervisors of ASAP call-takers.

Next Steps

- The Executive Office of Elder Affairs (EOEA) is conducting a review of its ASAP designation review process. The intent is to review and improve the quality of ASAP outcomes including caregiver experience. This review will continue throughout 2022.
- EOEA has submitted a proposal to the Centers for Medicare and Medicaid (CMS) through the American Rescue Plan Act (ARPA) to undergo an “agency rebrand.” If approved by CMS, this work will result in improved access to aging services and information. Part of this work will involve focus groups with caregivers to identify areas for improvement in caregiver experience.

2. Diagnosis & 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

Recommendation #1 (Diagnosis)

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

Progress and Accomplishments

- Reviewed resources for primary care clinicians around dementia screening and diagnosis, including assessment tools for low-literacy and IDD populations. After the review, the Council posted helpful tools and resources on the Alzheimer's Association's website.
- Collaborated with the MA Department of Public Health to inform acute care settings of the extended deadline (10/1/2022) to develop an operational plan for the recognition and management of patients with dementia or delirium.
- Collaborated with the MA Board of Registration in Medicine (BORIM) to provide [guidance](#) to physicians about informing a family member or legal representative of a dementia diagnosis and treatment plan after securing informed consent.
- As a result of the above efforts, in November 2021, BORIM issued formal guidance and on 12/1/2021, sent an electronic communication about the guidance to all active licensed Massachusetts physicians.
- The above guidance will likely help promote dementia screening and diagnosis and advance caregiver engagement in the treatment of their loved ones. The guidance also reminded physicians of their obligation to secure dementia training as a condition of license renewal.

Next Steps

- Identify primary care practices to pilot a dementia screening workflow, assess its effectiveness, and develop an implementation tool for other practices to replicate.
- In collaboration with the Massachusetts Health and Hospital Association, develop a brief user-friendly roadmap for development and implementation of a dementia operations plan.
- Collaborate with BORIM to develop a draft guide to help physicians initiate a conversation about a dementia diagnosis with their patients. Include specific guidance to obtain informed consent, as well as resources and support for both the patient diagnosed with dementia and the patient's family member or legal representative.
- Examine the processes that Aging Services Access Points (ASAPs) use to identify consumers of the state's home care program who are demonstrating characteristics or behaviors that are consistent with undiagnosed dementia. Identify opportunities to enhance education and advocacy in a manner that supports consumer and family caregiver awareness and generates appropriate healthcare, treatment, and care.

Recommendation #2 (Services Navigation)

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

Progress and Accomplishments

- Began assessing information to potentially include in a road map to direct people diagnosed with dementia and their caregivers to information, services, and support.
- The MA Executive Office of Elder Affairs submitted a proposal to the MA Executive Office of Health and Human Services and Centers for Medicare and Medicaid to attain American Rescue Plan Act (ARPA) funding to expand the availability of dementia care coordination services for caregivers.
- Worked to pass pending legislation that would include dementia care coordination as a required benefit for MA Senior Care Option (SCO) members. (Of the state's six SCO programs, three are already participating in the Alzheimer's Association's DCC program, which currently supports over 2,000 MA families annually across multiple partners.)

Next Steps

- Develop a digital version of a document similar to a [resource](#) available from the National Institute on Aging that includes steps to take after a diagnosis of Alzheimer's disease or other dementia as well as links to local resources.
- Work with primary care providers to determine the most helpful information to include in a road map designed to direct people diagnosed with dementia and their caregivers to comprehensive, easy-to-access information and support.
- Determine the feasibility of including in electronic medical records (EMRs) information and links to services and supports for people living with dementia and their caregivers.
- Develop strategies and an implementation plan for primary care providers on how to interact with unaccompanied and unsupported individuals diagnosed with dementia.
- Continue working to pass pending legislation that would include dementia care coordination as a required benefit for MA Senior Care Option (SCO) members. This requirement would enable expansion of direct referral dementia care coordination (DCC), which is a positive and proven model for providing prompt support to people diagnosed with dementia and their caregivers.
- Explore strategies to expand dementia care coordination services to cover many more MA families in need of this core service.

3. Equitable Access & Care



Goal

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

Recommendation #1 (Equity & Inclusion Consultancy)

Form and deploy a team to advise each of the Council's implementation teams on how to close informational gaps and address fragmentation of care access, care planning, and dementia services

Progress and Accomplishments

- Over 20 individuals have volunteered to participate in the Council's Equity and Inclusion Team in recognition that structural racism, implicit biases, and practical barriers can prevent many of our residents and families affected by dementia from benefiting from the essential health care and community-based services that the Commonwealth has to offer.
 - Individuals who have volunteered to join the team reflect a diversity of interests and are from a broad range of underserved groups, including individuals with lived experience.
 - The team is charged with advising each of the Council's workgroups and implementation teams on issues around equity and inclusion so that all individuals affected by dementia have access to and receive the care, services, and information they need.

Next Steps

- Establish a common baseline of knowledge for Council members on equity, inclusion, and access by recommending specific training courses.
- Begin convening members of the Equity and Inclusion Team to learn from each other while they collaboratively develop information around equity and inclusion for distribution to the Council members and team leaders.
- Deploy members of the Equity and Inclusion Team to provide collaborative advice to each of the Council's workgroups and implementation teams to effectively build a solid foundation of equity and inclusion into their planning and work.
- On an ongoing basis, deploy members of the Equity and Inclusion Team to review the Council's implementation plans, activities, and outcomes, holding Council members and team leaders accountable for doing the work required to develop and sustain policies and programs that are equitable and inclusive.

Recommendation #2 (Younger-Onset & Equity Analysis)

Conduct an analysis of the needs of people affected by younger-onset dementia and provide guidance for other teams on how to apply an equity and inclusion lens by using this population as a case study

Progress and Accomplishments

- The Younger-Onset & Equity Analysis Team has begun conducting an analysis of the needs of people affected by younger-onset dementia.
- As part of its analysis, the team is identifying the challenges faced by people living with younger-onset dementia and their caregivers.
- To inform the team's analysis, staff from the Massachusetts Executive Office of Elder Affairs developed a list of state supported services and supports available to older adults with dementia, and unavailable (or not as easily accessible) to younger adults living with dementia or their caregivers. This is one step toward identifying challenges and gaps that can be characterized as "barriers to equality."

Next Steps

- Apply an equality, equity, and inclusion lens to identify gaps in services, supports, information, and care for individuals and families affected by younger-onset dementia.
- Continue to identify "barriers to equality" and compile a list.
- Identify and develop a list of "barriers to equity," including unmet needs of individuals living with younger-onset dementia or their caregivers that stem from the differing nature of their needs compared with those of older adults.
- Develop and finalize an implementation plan to address unmet needs and close gaps in equality, equity and inclusion for people living with younger-onset dementia and their caregivers.
- Provide guidance to the Council's other workgroups and implementation teams using this workgroup's analysis as a case study on how to apply an equality, equity, and inclusion lens to identify and address gaps in services, supports, care, and information.

4. Physical Infrastructure



Goal

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

Recommendation #1 (Awareness)

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

Progress and Accomplishments

- Developed an initial draft of an extensive guide designed to define the design characteristics of dementia-friendly physical infrastructure.
- Convened discussions with stakeholders to gain consensus about the draft guide.
- Partnered with MassDOT to develop a [one-page guide](#) for municipalities applying for grants from the [Shared Streets and Spaces Grant Program](#). The guide was placed in MassDOT's [Resource Library](#) and distributed to municipalities and regional planning agencies through a variety of communication channels.
- Discussed opportunities with MassDOT to incorporate dementia-friendly design considerations into its Complete Streets Funding Program.
- Delivered a presentation and convened discussions about dementia-friendly design with the Boston Society for Architecture's Design for Aging Subcommittee.
- Delivered a presentation and convened a discussion about potential opportunities for dementia-friendly design with the Massachusetts Pedestrian and Bicycle Advisory Board.
- Convened meeting with the Massachusetts Councils on Aging to raise awareness of dementia-friendly (DF) design among senior center staff. Participants discussed the importance of DF design, which is most often about making minor, not necessarily expensive, adjustments to design elements by looking at physical infrastructure through the eyes of people living with dementia.

Next Steps

- Continue to address comments received from architects, planners, and the aging services community about the draft dementia-friendly design guide.
- Pursue potential opportunities to integrate dementia-friendly elements in a future version of the state's Pedestrian and Bicycle Plans and procurements.
- Pursue potential opportunities to provide the dementia-friendly design guide to communities that apply for funding from MassDOT's Complete Streets Program. This program currently awards extra points for projects that serve older adults.
- After finalizing the guide, encourage age- and dementia-friendly communities to use it as they plan and develop funding proposals for their physical infrastructure projects.

Recommendation #2 (Public Project Scoring)

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

Progress and Accomplishments

- Identified programs to potentially include age- and dementia-friendly (AF/DF) design criteria.
- Continuing to identify state-funded infrastructure projects to incorporate AF/DF scoring into the procurement process.

Next Steps

- Identify funding streams related to the built environment that may be good candidates for the inclusion of age- and dementia-friendly design criteria.
- Present and discuss opportunities with state officials managing procurement processes.
- Work with AF/DF communities and regional planning agencies (RPAs) to plan and build physical infrastructure that incorporates essential elements of AF/DF design. Additionally, gather descriptions and/or images of AF/DF physical infrastructure from AF/DF communities and RPAs and distribute them to others to help illustrate what AF/DF physical infrastructure can look like.

5. Public Health Infrastructure



Goal

Reduce the risk of dementia among Massachusetts residents while enhancing the state's public health infrastructure to address dementia

Recommendation #1 (Risk Reduction & Public Health Infrastructure)

Seek opportunities and implement strategies to reduce the risk of dementia among our residents while enhancing the state's public health infrastructure to address dementia

Progress and Accomplishments

- Began recruiting individuals to participate in a Risk Reduction and Public Health Infrastructure Team.
- To help inform the work of this team, a team from the Massachusetts Executive Office of Elder Affairs (EOEA) and Alzheimer's Association began articulating the current state of the Commonwealth's public health infrastructure around dementia.
 - Specifically, the team developed a framework using the *Healthy Brain Initiative Roadmap* from the Centers for Disease Control and Prevention (CDC) and Alzheimer's Association as a guide. They populated the framework with descriptions of relevant programs, services, and initiatives of EOEA, the aging services network, and Alzheimer's Association.

Next Steps

- Recruit individuals from the Massachusetts Department of Public Health to lead and participate in a Risk Reduction and Public Health Infrastructure Team.
- Review and prioritize the risk factors and risk reduction approaches listed for consideration in the *Massachusetts State Plan on Alzheimer's Disease and Related Dementias, April 2021*.
- Review potential approaches that promote effective use of community health workers for risk reduction as well as healthcare and service navigation.
- Review the Commonwealth's public health infrastructure around dementia, beginning with a focus on dementia risk reduction.
- Identify strategies and develop an implementation plan to address dementia risk factors while enhancing the state's public health infrastructure to address dementia.

6. Quality of Care



Goals

Identify gaps in quality of care for people living with dementia in Massachusetts, as well as strategies to close those gaps

Recommendation #1 (Care Planning)

Develop a person-directed care plan framework and template

Progress and Accomplishments

- Developed a list of resources on care planning (Appendix C of this document).
- Discussed potential approaches with stakeholders including the Alzheimer's Association, Dementia Friends Massachusetts, and Honoring Choices.
- Based on the above discussions, will likely develop a person-directed care planning guide for individuals living with dementia rather than a template. The goal is to help empower people living with dementia to effectively communicate their values, priorities, preferences, and goals to their caregivers and care providers.

Next Steps

- Recruit individuals to participate in two focus groups, one comprised of people living with dementia, and the other comprised of caregivers.
- Ask focus group participants to describe their experiences communicating with physicians and the most important things they would like their physicians to know.
- Review findings from discussions with focus group participants and other stakeholders.
- Begin developing, testing, and refining a care planning guide.

Recommendation #2 (Staffing & Training)

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

Progress and Accomplishments

- Launched activities around interprofessional dementia care training:
 - Began compiling a list of existing resources to identify gaps and opportunities including for those available at Centers of Excellence, Geriatric Workforce Enhancement Programs (GWEP), Community Based Organizations, the Alzheimer's Association, and the U.S. Health Resources and Services Administration (HRSA).
 - Identified professions on which to focus including, but not limited to, social workers, community health workers, and direct care workers.
 - Convened initial discussions with the Institute for Healthcare Improvement (IHI) leadership to leverage collaboration with the Age-Friendly Health System movement.
- Launched activities around direct care worker training, support, recruitment, and retention:
 - Developed a list of existing direct care workforce initiatives and trainings.
 - While participating in teams addressing the Commonwealth's needs associated with the direct care workforce, began reviewing statewide direct care workforce initiatives

to ensure that the needs of individuals and families affected by dementia are reflected and effectively addressed.

- In the spring of 2021, launched an online version of Alzheimer’s Supportive Home Care Aide (SHCA) training for direct care workers funded by the Massachusetts Executive Office of Elder Affairs.

Next Steps

- Conduct activities associated with interprofessional dementia care training:
 - Broaden the Council’s Interprofessional Training Team to include a wider range of professionals and include key stakeholders in the team’s planning and implementation efforts.
 - Determine how to leverage the expertise of existing teams and/or centers of excellence to support interprofessional dementia care training and ongoing coaching.
 - Examine existing interprofessional dementia care models.
 - Develop a collaborative path with the Institute for Healthcare Improvement’s Age-Friendly Health System movement.
- Conduct activities associated with direct care worker training, support, recruitment, and retention:
 - Continue participating in teams addressing the Commonwealth’s needs associated with the direct care workforce. Continue reviewing statewide direct care workforce initiatives to ensure that the needs of individuals and families affected by dementia are reflected and effectively addressed.

7. Research



Goal

Advance dementia research in Massachusetts

<u>Recommendation #1 (Research Diversity)</u> Increase diversity of dementia research and researchers
Progress and Accomplishments
● Identified a leader to form a Research Diversity Implementation Team to design approaches to achieve specific diversity objectives and secure private funds for small research support grants designed to advance diversity. ● Began identifying individuals to recruit to join the Research Diversity Implementation Team.
Next Steps
● Form a Research Diversity Implementation Team and begin developing approaches to increase diversity of dementia research at for-profit and non-profit organizations in Massachusetts. ● Gather data on dementia research diversity in Massachusetts. ● Seek, secure, and provide private funding for program oversight for a private non-profit organization to: ○ ensure effectiveness of implementation strategies; and ○ award a program management grant to a private non-profit organization to manage a research support grant program, deliver education programs on diversity to research organizations in Massachusetts, inform research organizations of the state's diversity objectives, and compile data. ● Seek and secure private funding for the program management grant. ● Seek private funding for the research support grant program to award small grants intended as seed funding for research organizations to leverage larger grants and research projects to advance diversity in dementia research.

LOOKING TO THE FUTURE

The [Massachusetts State Plan on Alzheimer's Disease and Related Dementias, April 2021](#) (state plan) is part of the state's continuous commitment to support people living with dementia and their families. It is a living document that the Council will update on an ongoing basis as it continues its work.



The Council has made no changes to the state plan since it was published one year ago. Instead, it has been diligently working to implement the state plan's recommendations and, in some cases, build the organizational and team infrastructure necessary for effective implementation.

Below are some updates that the Council expects to make to the state plan in calendar year 2022:

- *Younger-Onset Dementia*. The Council's Younger-Onset and Equity Analysis Workgroup plans to bring to the Council a proposed implementation plan to address unmet needs and close gaps in equality, equity, and inclusion for people living with younger-onset dementia and their caregivers. After attaining the Council's feedback and approval, the state plan will be amended to include recommendations and implementation strategies around this topic.
- *Risk Reduction and Public Health Infrastructure*. In 2022, the Council plans to recruit individuals to participate in a Risk Reduction and Public Health Infrastructure Workgroup to propose strategies to the Council. After attaining the Council's feedback and approval, the state plan will be amended to include recommendations and implementation strategies around reducing the risk of dementia while enhancing the state's public health infrastructure around dementia.

Additionally, whenever the Council successfully executes the state plan's strategies within any of its seven workstreams, it will refresh the state plan with new strategies to address the most important challenges encountered by Massachusetts residents and families living with dementia. In doing so, the Council will continue to stay abreast of those challenges, pool its expertise and resources, assess progress, and find and implement sustainable solutions.

The Council, its workgroups, and implementation teams remain keenly focused on the well-being of Massachusetts residents and families living with dementia. This is evidenced by the accomplishments and next steps included in this report. The Council looks forward to continuing to use the state plan as its guide, attaining meaningful progress every year, and enhancing quality of life for each and every Massachusetts resident and family affected by dementia.

APPENDIX A

MEMBERS OF THE MASSACHUSETTS ADVISORY COUNCIL ON ALZHEIMER'S DISEASE AND ALL OTHER DEMENTIAS

Council Member	Seat on Council
Secretary Elizabeth C. Chen, PhD, MBA, MPH - Secretary, Massachusetts Executive Office of Elder Affairs (EOEA)	Secretary, EOHHS and Council Chair
Michael Belleville - Dementia Advocate	Secretary, EOEA
James Lavery - Director, Bureau of Health Professions Licensure, Department of Public Health (DPH)	Commissioner, DPH
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	Secretary, Veterans' Services
Jatin Dave, MD - Chief Medical Officer, MassHealth and Director, Office of Clinical Affairs, Commonwealth Medicine, UMass Chan Medical School	Director, Office of Medicaid
Rep Representative, Tricia Farley-Bouvier - Massachusetts House of Representatives	House Vice Chair, Elder Affairs
Senator Patricia Jehlen - Chairperson, Joint Committee on Elder Affairs & Chairperson, Joint Committee on Labor and Workforce Development, Massachusetts Senate	Senate Vice Chair, Elder Affairs
Hector Montesino, CDP - President and CEO, Embrace Home Care and Health Services and Alzheimer's Advocate	Alzheimer's Patient Advocate 1
Rhiana Kohl, PhD – Caregiver and Alzheimer's Advocate	Alzheimer's Patient Advocate 2
Barbara Meehan - Alzheimer's Advocate & Former Caregiver	Alzheimer's Caregiver 1
Bernice Osborne-Pollar - Caregiver	Alzheimer's Caregiver 2
Heather Sawitsky - General Counsel, Fox Hill Village Homeowners Corp. and White Oak Cottages	Health Care Provider 1
Linda Pellegrini, MS, GNP-BC - Geriatric Nurse Practitioner, UMass Memorial Medical Center	Health Care Provider 2
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	Alzheimer's Researcher 1
Maura Brennan, MD - Program Director, Baystate Health Geriatric Workforce Enhancement Program <i>(Served on this Council through November 2021)</i>	Alzheimer's Researcher 2
Susan Antkowiak - Vice President, Programs & Services, Alzheimer's Association, Massachusetts/New Hampshire Chapter	State Alzheimer's Organization
James Wessler - President and CEO, Alzheimer's Association, Massachusetts/New Hampshire Chapter and New England Regional Leader	State-based Advocacy Organization

APPENDIX B

IMPLEMENTATION TEAMS & WORKGROUPS

Workstream and Council Leads	Members of Implementation Teams and Workgroups
1. Caregiver Support & Public Awareness Barbara Meehan, Dementia Advocate/Former Caregiver Hector R. Montesino, President and CEO - Embrace Home Care and Health Services and Alzheimer's Advocate	<i>Video Production Implementation Team:</i> Barbara Meehan, Council Member (Co-Lead) Hector R. Montesino (Co-Lead) Milagros Abreu, MD, MPH, President/ CEO and Founder - The Latino Health Insurance Program, Inc. Jennifer Hoadley, CDP, Regional Manager Southeastern MA - Alzheimer's Association, MA/NH Chapter Patty Sullivan, Program Director - Dementia Friendly Massachusetts <i>Website Development Implementation Team:</i> Pam MacLeod, MBA, PMP (Lead), Senior Project Director - MA Executive Office of Elder Affairs (EOEA) and University of Massachusetts Chan Medical School Molly Evans, Senior Policy Manager - EOEA Anagha Kumar, Student Intern, Harvard College - EOEA Annette Peele, Director of Community Programs - EOEA <i>Cross Referrals Implementation Team:</i> Pam MacLeod, MBA, PMP (Lead), Senior Project Director – EOEA and University of Massachusetts Chan Medical School Kathy Devine, Prescription Advantage Program Manager - EOEA Carole Malone, Assistant Secretary, EOEA Nicole McGurin, MS, CDP, Family Services Director - Alzheimer's Association, MA/NH Chapter Annette Peele, Director of Community Programs - EOEA Julia Perriello, MA, CDP, Manager of Helpline and Community Referrals - Alzheimer's Association, MA/NH Chapter <i>Caregiver Experience Implementation Team:</i> Amanda Bernardo (Lead), Director of Communications and Strategy – EOEA Kathy Devine, Prescription Advantage Program Manager - EOEA Molly Evans, Senior Policy Manager - EOEA Pam MacLeod, MBA, PMP, Senior Project Director - EOEA and

Workstream and Council Leads	Members of Implementation Teams and Workgroups
	University of Massachusetts Chan Medical School Annette Peele , Director of Community Programs - EOE Lynn C. Vidler , Director of Home Care - EOE
2. Diagnosis & Services Navigation Rep. Tricia Farley-Bouvier , Massachusetts House of Representatives James Wessler , President and CEO, Alzheimer's Association, MA/NH Chapter and New England Regional Leader	Diagnosis Implementation Team: James Wessler, Council Member (Lead) Kathryn C. Burns, MHA , Chief Executive Officer - Greater Lynn Senior Services, Inc. Hollis D. Day, MD, MS , Chief of Geriatric Medicine - Boston Medical Center and Associate Professor of Medicine, Boston University School of Medicine James Lavery (Council Member), Director, Bureau of Health Professions Licensure - Massachusetts Department of Public Health Liz McCarthy , Health Systems Director - Alzheimer's Association, New England Region Rebecca Starr, MD, AGSF , Medical Director, Geriatrics - Cooley Dickinson HealthCare Hagen Yang, MD , Neurologist - Atrius Health, Braintree - Harvard Vanguard Services Navigation Implementation Team: Rep. Tricia-Farley Bouvier, Council Member (Lead) Ellen M. McDonough , Former Director of Clinical Services - Elder Services of Cape Cod & the Islands Nicole McGurin, MS, CDP , Family Services Director - Alzheimer's Association, MA/NH Chapter Molly Purdue, PhD , Executive Director - Cape Cod Alzheimer's Family Support Center Caitlin Roy , Options Counselor - Aging Services of North Central Massachusetts Karyn B. Wylie , Community Care Ombudsman - EOE
3. Equitable Access & Care Jonathan Jackson., PhD , Founder and Executive	Equity and Inclusion Team: Jonathan Jackson, PhD. Council Member (Lead) <i>Note: Twenty-six individuals have agreed to participate in this team beginning in Calendar Year 2022.</i>

Workstream and Council Leads	Members of Implementation Teams and Workgroups
Director, Community Access, Recruitment, and Engagement (CARE) Research Center at Massachusetts General Hospital; Instructor in Neurology at Harvard Medical School	<i>Younger-Onset & Equity Analysis Workgroup:</i> Rhiana Kohl, PhD, Council Member (Lead) Chris Anne Banks, Former Caregiver Mike Belleville, Council Member & Dementia Advocate Kathy Devine, Prescription Advantage Program Manager - EOE Liz Gross, Caregiver Judy Johanson, Dementia Advocate - Mass. Alzheimer's Disease Research Center, MGH Tracy Lungelow, Caregiver MacKenzie Nicholson, Public Policy Manager - Alzheimer's Association, MA/NH Chapter Paul Mathew, MD, Caregiver Barbara Meehan, Council Member & Dementia Advocate/Former Caregiver
4. Physical Infrastructure Elizabeth C. Chen, PhD, MBA, MPH (Council Chair), Secretary - Massachusetts Executive Office of Elder Affairs (EOEA)	<i>Age- and Dementia-Friendly Physical Infrastructure Implementation Team:</i> James Fuccione, MPA (Co-Lead), Senior Director - MA Healthy Aging Collaborative Patty Sullivan (Co-Lead), Program Manager, Dementia Friendly MA - MA Councils on Aging Laura Brelsford, Assistant General Manager, Department of System-Wide Accessibility - MBTA Pam MacLeod, MBA, PMP, Senior Project Director - EOE and University of Massachusetts Chan Medical School Sandra Martin, MEP, MPH, Senior Planner and Health Agent - Berkshire Public Health Alliance, Public Health Program at Berkshire Regional Planning Commission Molly McKenna, MSW LCSW, Programs Development Manager - 2Life Communities Maureen Mullaney, MA, Transportation and GIS Program Manager II - Franklin Regional Council of Governments Ruth Neeman, AIA, Principal, Director of Senior Environments Studio - LWDA Philippe Saad, AIA, LEED AP, Principal - Dimella Shaffer Sanja Stegich, Intern Amy Walsh, Project Manager - Institute for Healthcare Improvement

Workstream and Council Leads	Members of Implementation Teams and Workgroups
5. Public Health Infrastructure <i>Note: In 2022, the Council will seek a leader for this workstream and its associated workgroup.</i>	<i>Risk Reduction & Public Health Infrastructure Workgroup:</i> <i>Note: Although some preliminary work for this workstream has been conducted, this workgroup will begin its work in earnest after recruiting additional members in 2022.</i> Steven Joubert, LMHC, LNHA, Executive Director, Board of Certification of Community Health Workers - MA Department of Public Health Pam MacLeod, MBA, PMP, Senior Project Director - EOE and University of Massachusetts Chan Medical School Liz McCarthy, Health Systems Director - Alzheimer’s Association, New England Region
6. Quality of Care Maura Brennan, MD, Program Director, Baystate Health Geriatric Workforce Enhancement Program Linda Pellegrini, MS, GNP-BC, Geriatric Nurse Practitioner, UMass Memorial Medical Center	<i>Care Planning Implementation Team:</i> Susan Antkowiak, Council Member (Co-Lead), Vice President of Programs & Services, Alzheimer’s Association, MA/NH Chapter Linda Pellegrini, Council Member (Co-Lead) Mike Belleville, Council Member & Dementia Advocate Deb Dowd-Foley, Caregiver Specialist - Elder Services of Worcester Area, Inc. Laurie Herndon, MSN, GNP, BC, Project Director - Hinda and Arthur Marcus Institute for Aging Research, Hebrew SeniorLife Judy Johanson, Dementia Advocate - Mass. Alzheimer’s Disease Research Center, MGH Gad A. Marshall, MD, Medical Director of Clinical Trials at Center for Alzheimer Research and Treatment, Brigham and Women’s Hospital (BWH); Associate Neurologist at BWH; Assistant in Neurology at Massachusetts General Hospital; Associate Professor of Neurology at Harvard Medical School Victoria Martischnig, Graduate Student (MPH candidate) Southern New Hampshire University Pam Mirick, RN, Former caregiver, and nurse <i>Interprofessional Training Implementation Team:</i> Maura Brennan, MD, Council Member (Co-Lead) Robert Schreiber, MD (Co-Lead), Vice President and Medical Director, Program of All-inclusive Care for the Elderly (PACE) - Fallon Health

Workstream and Council Leads	Members of Implementation Teams and Workgroups
	Pam Mirick, RN, Former caregiver, and nurse Nina M. Silverstein, PhD, Professor of Gerontology - University of Massachusetts Boston <i>Direct Care Worker Recruitment & Retention Implementation Team:</i> Tara Gregorio (Co-Lead), President, Massachusetts Senior Care Association Lisa Gurgone, MS (Co-lead), CEO, Mystic Valley Elder Services
7. Research 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	<i>Research Diversity Implementation Team:</i> <i>Note: This team will begin its work after recruiting individuals to join the team in 2022.</i> Ronald Killiany, PhD (Lead), Professor, Neurology - Boston University School of Medicine; Associate Professor, Environmental Health - Boston University School of Public Health

APPENDIX C

CARE PLANNING RESOURCES

Resources	Languages
Alzheimer's Association Care Planning	Main page is available in English Alzheimer's Association resources are available in: • English • Arabic • Chinese • Finnish • French • German • Hindi • Italian • Polish • Portuguese • Korean • Russian • Japanese • European Spanish • Mexican Spanish • Rioplatense Spanish • Vietnamese
Alzheimer's Navigator	• English Only
Alzheimer's Society, UK (Publications)	The Dementia Guide (the society's main post-diagnostic book) • English • Arabic • Bengali • Gujarati • Hindi • Punjabi • Traditional Chinese • Urdu (online only) • Welsh • British Sign Language (online only) Living with Dementia, My Life, My Goals • English only

Resources	Languages
	Additional Resources/Information: • “Easy Read” fact sheets are available with images and “plain” language for those with learning disabilities. • “The dementia guide: Living well after diagnosis” is available in braille (2017 version). • All factsheets can be printed in large print for those with sight loss. • “The dementia guide: Living well after diagnosis” and 15 of the most popular factsheets are free online to listen to or they can be ordered in CD format for those who are blind or who have sight loss. • Five fact sheets are subtitled and available in British Sign Language on alzheimers.org.uk/bsl-factsheets for those who are deaf or who have hearing loss.
The Conversation Project	What Matters to Me Workbook • English • Spanish • Chinese Most resources are available in: • English • Spanish • Chinese Except “Being Prepared in the Time of COVID-19” which is only available in: • English • Spanish Alternate options for each resource: Conversation Starter Guide (Older Versions) • French • German

Resources	Languages
	• Haitian Creole • Hebrew • Russian • Vietnamese • Hindi • Japanese • Korean • Portuguese <u>Your Guide to Choosing a Health Care Proxy (Older Versions)</u> • Haitian Creole • Portuguese <u>Your Guide for Talking with a Health Care Team (Older Versions)</u> • French • Korean <u>For Caregivers of People with Alzheimer’s or Other Forms of Dementia--Additional Resources (Older Version)</u> • French Only
Dementia Action Alliance	• English Only
Dementia Engagement and Empowerment Project (DEEP), UK	Making Things More Accessible Guides • English • Welsh Involving People with Dementia Guides • English • Welsh
Honoring Choices Massachusetts	Health Care Proxy (HCP) • English • Spanish • Portuguese • Vietnamese • Haitian • Russian • Traditional Chinese

Resources	Languages
	• Arabic • Khmer • Albanian Personal Directive/Living Will • English • Spanish • Portuguese • Russian • Traditional Chinese “Who’s Your Agent?” Flyer/Poster • English • Spanish • Portuguese “5 Things to Talk About With Care Providers Discussion Guide” • English • Russian
Institute for Healthcare Improvement	What Matters • English Only
LiveWell Institute	• English Only
Patient Priorities Care	• English Only
Research Institute for Aging, Canada	By Us For Us Guides • English Only
Stanford Letter Project	Letter Template • English • Tagalog • Spanish • Mandarin Who Matters Most Letter (for those in good health and those with chronic illness): • English • Hindi • Spanish • Tagalog

Resources	Languages
	• French • Vietnamese • Urdu • Chinese <i>More languages are coming soon.</i> <u>Advanced Directives</u> • English Only <u>Patient Videos</u> • English • Chinese