

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

Annual Report

20
23

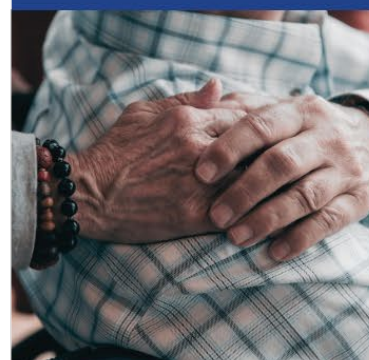
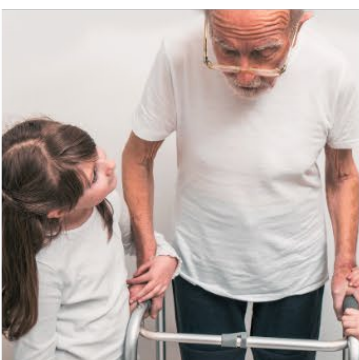
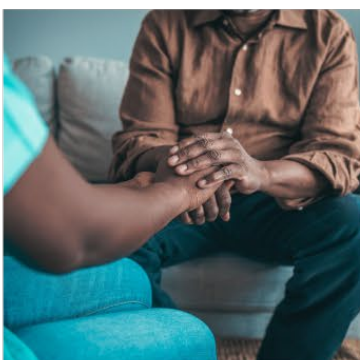


TABLE OF CONTENTS

EXECUTIVE SUMMARY.....	3
<i>A Year in Review and the Year Ahead.....</i>	<i>3</i>
<i>Massachusetts State Plan on Alzheimer’s Disease and Related Dementias: A Living Document.....</i>	<i>6</i>
INTRODUCTION.....	7
<i>Figure 1: The Council’s Goal, Workstreams, and Types of Deliverables.....</i>	<i>7</i>
<i>Figure 2: Key Activities Impacting the Council’s Goal.....</i>	<i>8</i>
IMPLEMENTING EFFECTIVE AND SUSTAINABLE SOLUTIONS.....	11
<i>Progress, Accomplishments, and Next Steps</i>	<i>11</i>
1. Caregiver Support and Public Awareness.....	12
2. Diagnosis and Services Navigation.....	16
3. Equitable Access and Care.....	19
4. Physical Infrastructure.....	22
5. Quality of Care.....	26
6. Research.....	30
7. Risk Reduction and Public Health Infrastructure.....	31
LOOKING TO THE FUTURE.....	34
AMENDMENTS TO THE MASSACHUSETTS STATE PLAN ON ALZHEIMER’S DISEASE AND RELATED DEMENTIAS, 2023.....	35
<i>Caregiver Support and Public Awareness.....</i>	<i>36</i>
<i>Equitable Access and Care.....</i>	<i>37</i>
<i>Quality of Care</i>	<i>38</i>
1. Care Planning	38
2. Interprofessional Dementia Care	39
<i>Research.....</i>	<i>40</i>
APPENDIX A: MEMBERS OF THE MASSACHUSETTS ADVISORY COUNCIL ON ALZHEIMER’S DISEASE AND ALL OTHER DEMENTIAS.....	41
APPENDIX B: IMPLEMENTATION TEAMS & WORKGROUPS.....	43
APPENDIX C: VISION AND PLEDGE TO PROMOTE DIVERSITY, EQUITY, AND INCLUSION.....	48

EXECUTIVE SUMMARY

A Year in Review and the Year Ahead

During calendar year 2023, the Advisory Council on Alzheimer’s Disease and All Other Dementias continued its work to implement the recommendations presented in the [Massachusetts State Plan on Alzheimer’s Disease and Related Dementias \(state plan\)](#). This year’s annual report documents the Council’s progress during 2023 and its next steps for the year ahead. The table below is a high-level summary of the report.

CAREGIVER SUPPORT AND PUBLIC AWARENESS
Implemented activities to improve caregiver awareness of, access to, and experience with the services and support available for Massachusetts residents and families affected by dementia.
<ul style="list-style-type: none">• Began developing a brief public service announcement in three languages (English, Spanish, and Portuguese) to promote the support and services available for people caring for individuals living with dementia (dementia caregivers).• Recruited dementia caregivers to participate in videos where they will discuss the assistance they received and how they received it.• As part of its review and update of the ASAP designation review process, the Executive Office of Elder Affairs (EOEA) began evaluating interactions between Aging Services Access Points and their consumers, including dementia caregivers. EOEA aims to use its findings to implement changes designed to improve those interactions.• EOEA conducted a branding and market research project, which improved EOEA’s understanding of service needs; how residents hear about or engage with services; and barriers that may prevent individuals from accessing services. EOEA attained insights that it intends to use to better serve older adults and their caregivers (including dementia caregivers).
DIAGNOSIS AND SERVICES NAVIGATION ¹
Provided guidance to acute care settings on developing dementia operations plans; and expanded the state’s capacity to provide support after a dementia diagnosis.
<ul style="list-style-type: none">• The Alzheimer’s Association and Massachusetts Hospital Association developed and distributed a toolkit for acute care settings with detailed dementia screening and training options for their dementia operations plans.• Secured \$300,000 in state funding in fiscal year 2024 to expand access to the Alzheimer's Association Dementia Care Coordination program, supporting individuals diagnosed with dementia and their care partners.

¹ Beginning in 2023, to improve linkages across teams, the Council moved its planned efforts associated with innovative approaches in dementia care out of its Diagnosis and Services Navigation workstream into its Interprofessional Dementia Care team and Care Planning team, both of which are part of the Council’s Quality of Care workstream.

- Through a partnership with the Medical and Scientific Advisory Committee of the Alzheimer’s Association, MA/NH Chapter, shared best practice protocols among health care systems to help them deliver new FDA approved anti-amyloid treatments effectively, efficiently, and equitably.
- Developed an approach at EOEA to collaborate with Aging Services Access Points to implement opportunities in the home care program for individuals to advocate for appropriate screening, diagnosis, care, and support. Will revisit this approach in 2025 due to resource constraints and competing priorities in 2024.
- In 2024, the Council will convene discussions about early detection and diagnosis with the objective of devising practical strategies for the Council to undertake as part of its existing work.

EQUITABLE ACCESS AND CARE

Convened inclusive discussions about challenges and cultural barriers experienced by individuals affected by dementia; examined Massachusetts-specific race and geographic health disparities associated with dementia; and began identifying solutions.

- Recruited members and co-leaders for the Council’s Equity and Inclusion team.
- Engaged residents and experts in discussions with the Council about racial and cultural barriers to accessing care.
- Finalized the Council's "Vision and Pledge to Promote Diversity, Equity, and Inclusion."²
- Reviewed and involved the Council in conversations about Massachusetts-specific data on race and geographic health disparities.
- Advised Ariadne Labs on equity considerations related to developing a dementia assessment and care planning tool.
- Will provide advice on building a foundation of equity into recommendations and resources being developed by the Council’s Care Planning team and Interprofessional Dementia Care team.

PHYSICAL INFRASTRUCTURE

Significantly improved stakeholder awareness of age and dementia friendly design for physical infrastructure; and implemented approaches to integrate age and dementia friendly features into physical infrastructure projects seeking state or municipal funding.

- Proactively distributed the Council's guide on age and dementia friendly design, reaching numerous organizations and networks.³
- Delivered impactful presentations to various stakeholders, fostering widespread awareness of the importance of age and dementia friendly design.
- Analyzed state, municipal, and other built environment funding sources to identify opportunities for incorporating age and dementia friendly design standards.
- Identified areas of focus where the Council can have the greatest impact on making the Commonwealth’s built environment age and dementia friendly.
- Actively implemented approaches to integrate age and dementia friendly scoring into physical infrastructure projects seeking state or municipal funding.

² See Appendix C of this report for the Council’s “Vision and Pledge to Promote Diversity, Equity, and Inclusion.”

³ Link to the guide: [Age and Dementia Friendly Design Considerations for Physical Infrastructure](#).

- Received preliminary approval from Boston University to introduce a faculty-led group project in January 2025 for undergraduate students of psychological anthropology.⁴ The project is designed to encourage inclusion of age and dementia friendly design features in state and municipally funded physical infrastructure projects.

QUALITY OF CARE

Made important strides in the direction of identifying gaps in the quality of dementia care in Massachusetts and strategies to close those gaps.

- Identified the essential characteristics of effective person-driven dementia care plans; and reviewed existing care planning models.
- Agreed on the team’s approach and targeted milestones for 2024.
- Provided advice to Ariadne Labs on its development of a person-centered assessment and care plan tool for people living with dementia and their caregivers.
- Formed a team on Interprofessional Dementia Care, which has made significant progress in determining effective dementia care team composition, services, outcomes, and benefits.

RESEARCH

Agreed to remove this workstream’s goal of “advancing dementia research in Massachusetts,” recognizing that other organizations are more capable of achieving it.⁵

- The Council agreed to remove this workstream from its scope, recognizing that other organizations are better able to achieve its goal of “advancing dementia research in Massachusetts” and its recommendation to “increase diversity of dementia research and researchers.”
- The Council will; however, continue to use its knowledge about ongoing dementia-related research as it develops its recommendations, policies, programs, and guidance.

RISK REDUCTION AND PUBLIC HEALTH INFRASTRUCTURE

Began implementing activities to reduce the risk of dementia among Massachusetts residents.

- Pursued funding opportunities and received a grant to implement “Springfield’s Healthy Brain Initiative,” a community outreach program to promote better brain health in the city of Springfield.
- Will implement “Springfield’s Healthy Brain Initiative” in 2024 with a goal to reduce the risk of dementia among Springfield’s residents and increase community awareness of the benefits of early detection, screening, and diagnosis.

⁴ For definitions of psychological anthropology, see [*International Encyclopedia of the Social & Behavioral Sciences \(Second Edition\), 2015*](#), Pages 359-365

⁵ [*Amendments to the Massachusetts State Plan on Alzheimer’s Disease and Related Dementias, 2023.*](#)

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

The [Massachusetts State Plan on Alzheimer's Disease and Related Dementias \(state plan\)](#) is part of the state's continuous commitment to support people living with dementia as well as their families and caregivers. It is a living document that the Council continues to update on an ongoing basis. The Council will continue to use the state plan as a guide for achieving meaningful annual progress, while working to enhance the quality of life for Massachusetts residents and families affected by dementia.

As the Council refines or clarifies its recommendations, or adopts new recommendations and strategies, it includes them as amendments to the state plan and documents them in its annual reports. In 2023, the Council adopted five state plan amendments; they are included later in this report in the section entitled, *Amendments to the Massachusetts State Plan on Alzheimer's Disease and Related Dementias, 2023*.

The state plan and its amendments include recommendations and implementation strategies 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. Quality of Care
6. Research⁶
7. Risk Reduction and Public Health Infrastructure

Included among this year's state plan amendments is the removal of the Research workstream from the Council's scope. The Council recognizes that other organizations are more capable of achieving this workstream's goal of “advancing dementia research in Massachusetts” and its recommendation to “increase diversity of dementia research and researchers.”

Ongoing research, innovations, and breakthroughs associated with Alzheimer's Disease and Related Dementias (ADRD) are essential factors affecting every aspect of the Council's workstreams and activities. ADRD research and innovation can take many forms including discoveries around risk reduction, new ways to detect and screen for ADRD; novel treatments; new innovative models of care and support; and more. For that reason, the Council and its workgroups will continue to stay abreast of research in the field; engage in discussions about it; and reflect on it while developing recommendations, policies, programs, and guidance.⁷

⁶ In 2023, the Research workstream's goal of “advancing dementia research in the state of Massachusetts” was removed from the Council's scope.

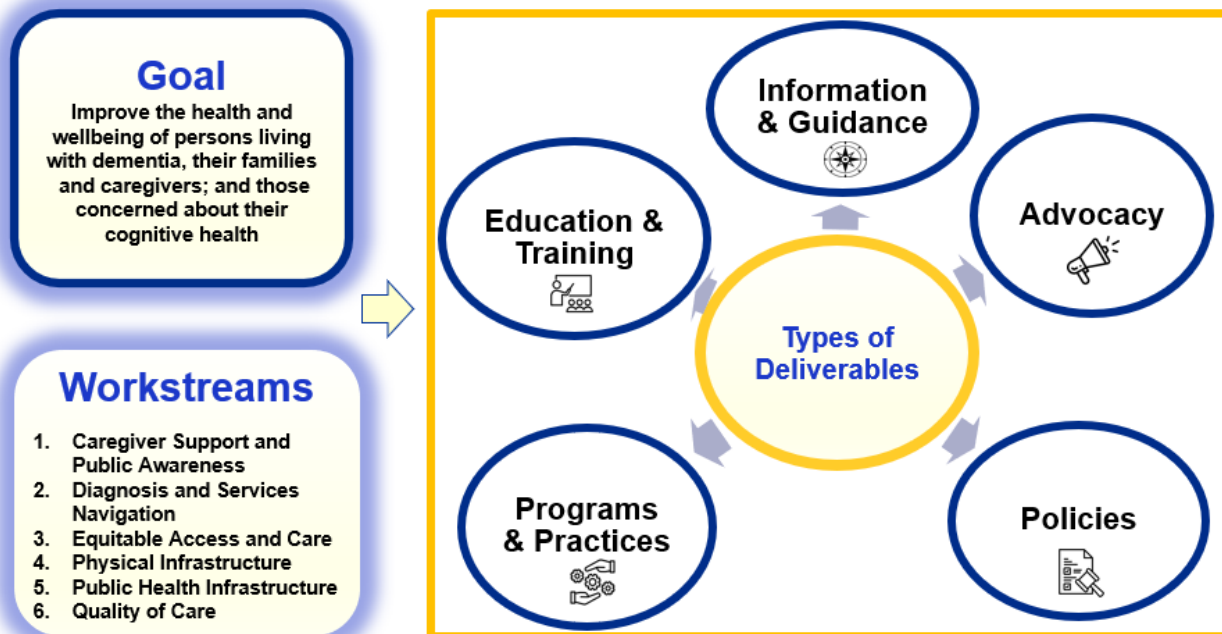
⁷ [Amendments to the Massachusetts State Plan on Alzheimer's Disease and Related Dementias, 2023](#).

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).⁸ 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. The Council currently has one open seat; and it looks forward to recruiting a person living with dementia to fill that seat in 2024.

The Council’s goal is to “improve the health and wellbeing of persons living with dementia, their families, caregivers, and those concerned about their cognitive health.” Teams of volunteers working on behalf of the Council generate deliverables for key stakeholders. Specifically, the Council’s teams examine challenges associated with each of the Council’s workstreams and work to consistently address them with information, guidance, advocacy, policies, programs, practices, education, and training (Figure 1).

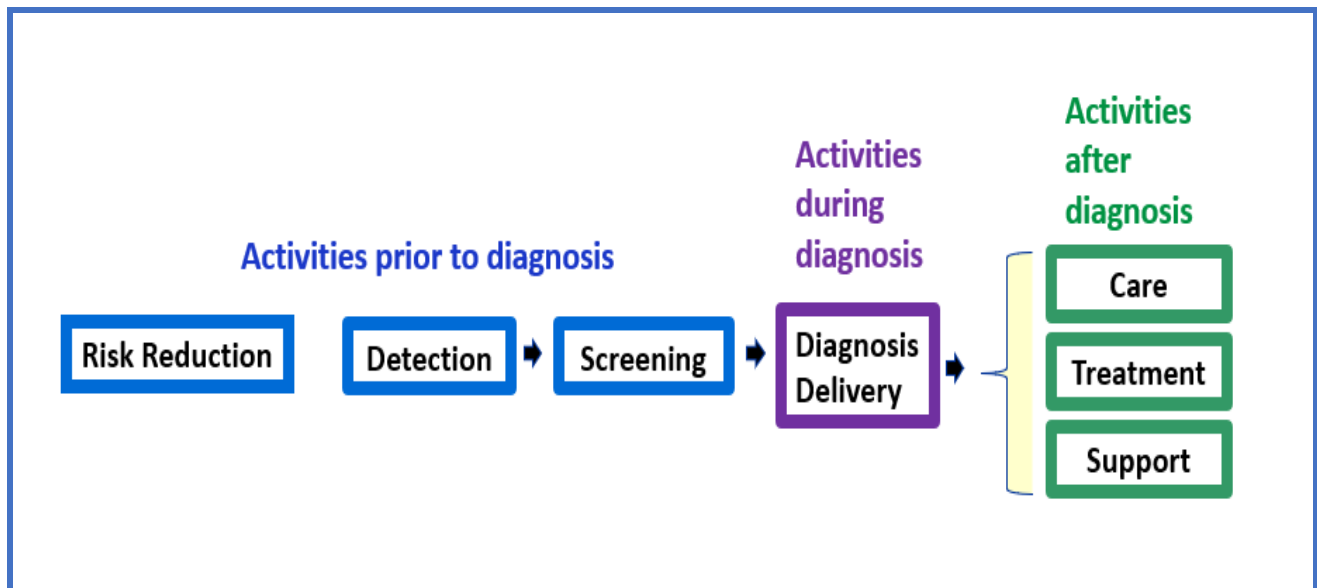
Figure 1: The Council’s Goal, Workstreams, and Types of Deliverables



⁸ The Council was established under Massachusetts General Laws, Chapter 6A, Section 16AA of Chapter 220 of the Acts of 2018.

As shown in Figure 2 below, there are a number of key activities associated with a person’s dementia journey that impact the Council’s efforts to achieve its goal. These activities take place prior to diagnosis, during the delivery of a diagnosis, and post-diagnosis. Each step along the way and throughout the progression of the disease presents its own unique set of challenges and opportunities carefully considered by the Council as it develops recommendations and implements strategies to close critical gaps.

Figure 2: Key Activities Impacting the Council’s Goal



In 2021, when the Council developed the [Massachusetts State Plan on Alzheimer’s Disease and Related Dementias \(state plan\)](#), it identified seven key high-level challenges, which led to the establishment of its focus areas, i.e., workstreams. Those challenges included the following:

- An estimated one-half of residents living with dementia have not been diagnosed.⁹
- Many people living with dementia and their caregivers don’t know where to go for support.
- Access to information and quality dementia care is fragmented and inequitable.
- People living with dementia experience a lack of person-centered dementia care planning and ongoing assessments.
- Caregivers of people living with dementia have inconsistent experiences with the aging services network and health care system.
- Accessibility and safety barriers exist within the state’s physical infrastructure.
- Dementia research lacks diversity in clinical trial participation, researchers, and research methodologies.

In 2023, the Council witnessed promising advances in dementia research; and with those advances came new opportunities as well as new challenges. For example, some of the

⁹ 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>.

challenges around new and upcoming anti-amyloid treatments¹⁰ present barriers for underrepresented communities.¹¹ Some examples include appropriateness of the treatment; eligibility barriers; affordability of the drugs and diagnostics; and barriers to accessing infusion facilities. Compounding the impact of these new barriers are existing challenges that continue to persist such as lack of awareness of dementia symptoms, information, services, and support; stigma; lack of knowledge about brain health and its connection to heart health and other conditions; mistrust of the health care system; and delayed diagnosis if diagnosed at all.

As described in more detail within this report, project teams working on behalf of the Council accomplished the following in 2023:

1. Implemented activities to improve caregiver awareness of, access to, and experience with the services and support available for residents and families affected by dementia.
2. Provided guidance to acute care settings on developing dementia operations plans; and expanded the state's capacity to provide support after a dementia diagnosis.
3. Examined Massachusetts-specific race and geographic health disparities associated with dementia; and began identifying solutions.
4. Significantly improved stakeholder awareness of age and dementia friendly design for physical infrastructure; and implemented approaches to integrate age and dementia friendly features into physical infrastructure projects seeking state or municipal funding.
5. Made important strides in the direction of identifying gaps in the quality of dementia care in Massachusetts and strategies to close those gaps.
6. Began implementing activities to reduce the risk of dementia among residents.

The Council and its teams continue to keep a close eye on influencing factors that may impede a person's ability to benefit from the Council's work. To that end, the Council has established an approach for building a firm foundation of equity in its recommendations and deliverables. The Council will continue to attentively hear from a variety of leaders and experts who have firsthand experience confronting cultural and other obstacles that are specific to their respective groups. Additionally, the Council has established an "Equity and Inclusion" (E&I) team to review and comment on the Council's ongoing work while examining it through a "diversity, equity, and inclusion (DEI) lens." The E&I team will continuously refine its "DEI lens" by challenging itself to identify people representing groups that the Council and E&I team have not yet heard from and actively listen to these community members. This approach will enable the E&I team to reflect on these communities' needs and barriers while offering guidance to the Council and its teams.

As it has been done since inception, the Council plans to continue forming project teams that carefully examine existing challenges as well as new challenges and opportunities as they arise. With the advice of Council members, project teams develop recommendations for the Council's review; identify opportunities; and implement solutions. Upon achieving project goals, the Council consistently initiates new projects, fueling a continuous cycle of innovation and growth.

¹⁰ Cummings J. [Anti-Amyloid Monoclonal Antibodies are Transformative Treatments that Redefine Alzheimer's Disease Therapeutics](#). *Drugs*. 2023 May;83(7):569-576. doi: 10.1007/s40265-023-01858-9. Epub 2023 Apr 15. PMID: 37060386; PMCID: PMC10195708.

¹¹ Center for Disease Control and Prevention: ["Older African Americans are twice more likely to have dementia than whites; Hispanics 1.5 times more likely to have dementia than whites."](#)

This report, which is the Council's fourth annual report,¹² reflects the Council's unwavering commitment to identify and implement approaches to better meet the needs of an estimated 130,000 Massachusetts residents diagnosed with Alzheimer's dementia;¹³ residents living with other dementias¹⁴; an estimated 213,000 family caregivers caring for Massachusetts residents living with dementia;¹⁵ and an estimated 130,000 or more residents currently living with Alzheimer's dementia without a formal diagnosis.¹⁶

As shown in Appendix B, the progress and accomplishments summarized within this report were made possible by volunteers that 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 essential to living healthy and meaningful lives.

¹² The annual reports are posted on the Council's website: <https://www.mass.gov/orgs/alzheimers-advisory-council>.

¹³ 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.org/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.

¹⁴ According to the Centers for Disease Control and Prevention, [Alzheimer's disease is the most common cause of dementia, accounting for 60 to 80 percent of cases](#).

¹⁵ Estimated by the Alzheimer's Association using data from the 2016, 2020 and 2021 Behavioral Risk Factor Surveillance System survey, U.S. Census Bureau, National Alliance for Caregiving, AARP, U.S. Department of Labor and Genworth.

¹⁶ 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>

IMPLEMENTING EFFECTIVE AND SUSTAINABLE SOLUTIONS



Progress, Accomplishments, and Next Steps

This report is the result of an extensive review of the Council’s progress during calendar year 2023 and its continued efforts to implement the strategies included in the [*Massachusetts State Plan on Alzheimer’s Disease and Related Dementias \(state plan\)*](#). The following pages comprise seven sections, one for each of the Council’s original focus areas, or “workstreams.” Each section includes the goals of the workstream; the state plan’s recommendations to advance those goals; and a summary of the Council’s progress during 2023. Additionally, each section concludes with a list of the next steps that the Council plans to begin in 2024 as part of its continued implementation of 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 persons living with dementia**
- **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 (Public Service Announcement and Video Production)

Develop public service announcements and videos in three languages to promote the services and support available for caregivers of people living with dementia

Progress and Accomplishments

- Began developing a brief public service announcement (PSA) in three languages (English, Spanish, and Portuguese). The PSAs will promote the services and support available for people living with dementia (dementia caregivers), including the toll-free phone numbers for the Alzheimer's Association and MassOptions.
- Recruited dementia caregivers and interviewers to participate in two videos - one in Spanish and one in Portuguese. The caregivers will be asked to discuss the assistance they received and how they received it.

Next Steps

- Finalize the caregiver videos and PSAs above. Make them available in the state's website, social media, cable TV stations, and the newsletters, bulletins, and websites of senior centers, aging services agencies, and other stakeholder organizations.

Recommendation #2 (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

(1) Review and Update of the ASAP Designation Review Process

- Completion of First Phase of Review and Update of ASAP Designation Review Process - The Executive Office of Elder Affairs (EOEA) continued its multi-year project to review and update its ASAP designation review process. The intent of this project is to evaluate, assess, and improve the quality of the ASAPs' many services and programs for aging adults and their caregivers; and to improve outcomes including caregiver experience.
 - In 2023, EOEA completed the first phase of this project, referred to as "Test Phase 1" with six of the ASAPs' Information and Referral (I&R) programs participating. The purpose of "Test Phase 1" was to test the methodologies to be implemented throughout this multi-year project.
- Analysis of Consumer Phone Calls - As part of "Test Phase 1" (above); and to continue its efforts to assess consumer experiences with ASAPs, EOEA examined a random sample of phone calls made by 122 consumers to the six participating ASAPs.

- 96% of respondents reported getting at least some of the information they needed from their call, and 94% reported positive satisfaction with their call experience.
- One of the findings was that EOEA could not consistently identify essential characteristics of the 122 callers in the sample, including those who may have been dementia caregivers.
 - To address this issue, EOEA began working on a manual that defines call types. The purpose of the manual is to guide ASAPs as they document essential details about each call and caller.
 - Better defined call types will generate uniformity in call documentation among the ASAPs and enable EOEA to identify opportunities for improvement including potential opportunities for improved resource allocation.
- *Consumer Experience Testing* - Another part of “Test Phase 1” (above) employed a different approach to further evaluate interactions between ASAPs and consumers (including dementia caregivers). Specifically, in 2023, EOEA launched a "consumer experience testing" initiative.
 - This testing involved “actors” placing phone calls to the six participating ASAPs. While speaking with I&R call-takers, the actors played the role of a consumer while referring to a script, which included one dementia caregiver scenario.
 - The actors’ scripts intentionally lacked specificity and were written in such a way that a call to any of the ASAPs would end after a brief discussion with the I&R call-taker. The intention was to prevent I&R staff from referring the consumer to other ASAP programs. The scripts were designed this way for the following reasons:
 - Excessive specificity within an actor’s script would potentially lead to confusion within the ASAPs’ official records, intertwining actor-related issues with genuine consumer concerns.
 - As a result, this testing did not generate insights specific to dementia caregiver experiences.
 - To address the above issue, EOEA may consider involving actual dementia caregivers in future efforts to test consumer experiences.

(2) Branding and Market Research Project at the Executive Office of Elder Affairs (EOEA)

- Beginning in the spring of 2022, EOEA conducted a branding and market research project to better understand the service needs of eligible residents, including how residents hear about or engage with services, and what barriers might exist to prevent adults from using/accessing our services.
- Through this research, older adults, caregivers (including caregivers of individuals living with dementia), and aging services network stakeholders were interviewed individually, as well as in focus groups. To ensure perspectives of individuals living with dementia and their caregivers were included in this research, one of the co-leaders of the

Council’s workstream on Caregiver Support and Public Awareness was included in the stakeholder interviews.

- From the caregiver discussions, EOEA learned the following:
 - Caregivers work hard to help their loved ones maintain a high quality of living. However, this often requires large sacrifices from caregivers, who feel as if they have few options for help.
 - While caregivers can often find it challenging to balance their needs with the needs of their loved one, many fear alternative methods of care.
 - Many caregivers believed that the underutilization of EOEA services was primarily due to a lack of awareness.
- EOEA's market research suggests the need for a focused information outreach program that not only offers details about services but also provides guidance on broaching the subject of seeking external assistance for a loved one.

Next Steps

(1) Review and Update of the ASAP Designation Review Process

- Analysis of Consumer Phone Calls - By March 2024, EOEA will complete the next phase of its multi-year project, which is referred to as “Soft Launch 1.” As one part of this phase, EOEA will survey a random sample of callers of all of the Commonwealth’s I&R programs.
- Manual of Call Types - EOEA will continue its efforts to develop a manual that effectively defines the types of consumer phone calls made to ASAPs. The intention is to guide I&R call-takers as they document essential details about each call and caller. This will enable EOEA to glean more detailed insights about consumer experiences in the future.
- Consumer Experience Testing - Within the next two years, EOEA will revisit the methodology that was used in 2023 to test consumer experiences with ASAPs. Specifically, EOEA will determine the feasibility of involving actual dementia caregivers in consumer experience testing.

(2) Branding and Market Research Project at the Executive Office of Elder Affairs (EOEA)

- Market Research - EOEA will use its market research findings to make changes to better serve older adults and their caregivers and improve the aging process in Massachusetts.

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

- To supplement the roadmap released in 2022 for the development of dementia operations plans in acute care settings, the Alzheimer’s Association and Massachusetts Hospital Association developed a toolkit with detailed options for dementia screening and training. Additionally, they disseminated sample dementia operations plans to assist acute care settings in the development of their plans.
- To help implement this recommendation, the Council partnered with the Medical and Scientific (MedSci) Advisory Committee of the Alzheimer’s Association, MA/NH Chapter, which includes top dementia clinicians from health care systems across the Commonwealth. The MedSci Advisory Committee conducted the following activities in 2023:
 - Focused on improving access to diagnosis and developing efficient processes within health care systems to build capacity to provide FDA approved anti-amyloid treatments intended for people living with Mild Cognitive Impairment (MCI) and Mild Alzheimer’s.
 - Shared best practice protocols with each other to help health care systems prepare to deliver the new treatments, including approaches on how to implement diagnostic protocols effectively and efficiently.
 - Engaged in discussions on how to embed equity into health care system protocols, including discussions around involving affiliated community health centers in screening, diagnosis, and treatment plans. Med/Sci Advisory Committee members are also exploring best screening tools for low literacy and non-fluent English speakers.
 - In at least one health care system, began developing a patient workflow with approaches to diagnose and evaluate a patient’s appropriateness for treatment within a single day.
- Staff from the Executive Office of Elder Affairs (EOEA) mapped out an approach to engage with Aging Services Access Points (ASAPs) to identify, examine, and implement opportunities in the home care program to advocate for appropriate dementia screening, diagnosis, care, support, and treatment. Due to resource constraints in 2024 and focused efforts in other competing areas, EOEA will revisit this approach in 2025.

Next Steps

- Convene Council discussions to identify the most important gaps associated with early detection and diagnosis that the Council can realistically help close; and devise practical strategies that can be implemented as part of the Council's existing work.
- Advise the MedSci Advisory Committee as needed as it continues its work to improve access to diagnosis within the Commonwealth's health care systems.
- In 2025, EOEA will reassess the feasibility of convening a team with representatives from EOEA and ASAPs to identify, examine, and implement opportunities in the home care program to advocate for appropriate screening, diagnosis, care, support, and treatment.

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

- Attained \$300,000 in state funding in fiscal year 2024 to expand access to the Alzheimer's Association Dementia Care Coordination program, which is a model for providing support to individuals diagnosed with dementia and their care partners.

Next Steps

- To better take advantage of synergies among the Council's workstreams in 2024 and beyond, issues associated with the "services navigation" portion this workstream will be addressed by the Council's teams on Interprofessional Dementia Care and Care Planning, both of which are within the Council's Quality of Care workstream.

3. Equitable Access & Care



Goal

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

Recommendation #1 (Equity & Inclusion Team)

Form and deploy a team to advise each of the Council’s teams on how to address and close informational gaps and address fragmentation of care access, care planning, and dementia services¹⁷

Progress and Accomplishments

- Recruited co-leaders and a team on Equity and Inclusion (E&I) to implement this recommendation.
- In 2022, the Council invited and listened to individuals from Latino and LGBTQ+ communities to speak about their lived experiences living with or caring for loved ones with dementia. In 2023, the Council continued its practice of convening inclusive discussions by inviting individuals from Black and Asian communities to speak about their lived experiences. They spoke about their challenges and cultural barriers and engaged the Council in discussions about how those challenges affect equitable access to quality dementia care.
- To ensure that the Council addresses inequities as it develops policy recommendations, programs, and resources, finalized the Council’s document entitled, “Vision and Pledge to Promote Diversity, Equity, and Inclusion” (Appendix C).
- Provided advice to Ariadne Labs by participating in a focus group to discuss equity considerations related to developing a dementia assessment and care planning tool.
- Examined Massachusetts-specific data around race and geographic health disparities and discussed findings with the Council.
- Decided on an approach for 2024, which is reflected below in the section entitled, “Next Steps.”

Next Steps

- Develop and continuously refine Diversity, Equity, and Inclusion (DEI) checklists and/or other related tools to help the E&I team effectively review the Council’s work with a “Diversity, Equity, and Inclusion lens.”
- Recommend approaches to eliminate, weaken, or mitigate the impact of barriers that may prevent certain groups from benefiting from the Council’s work. Initially, the E&I team will convene the following activities with two of the Council’s teams where equity considerations are particularly essential:
 - Offer equity-related guidance to the Council’s Care Planning team around its:
 - proposed list of care planning resources;
 - recommended strategies for distributing care planning resources to providers, patients, and families; and
 - proposed strategies for encouraging the use of recommended care planning models.

¹⁷ [Amendments to the Massachusetts State Plan on Alzheimer’s Disease and Related Dementias, 2023.](#)

- Provide equity-related guidance to the Interprofessional Dementia Care team around its:
 - recommendations on effective dementia care teams for the delivery of comprehensive, integrated care and support for patients and families;
 - proposed adjustments to the Age-Friendly Health System initiative to enhance its support for individuals and families at risk of or affected by dementia; and
 - recommended training for interprofessional dementia care teams.
- Identify community access points, i.e., key organizations and individuals; and build and maintain community connections.
- Visit communities exhibiting significant health disparities where the prevalence and risk of developing dementia is high; listen to community members; and reflect on their needs while reviewing recommendations from the Council’s teams.
- Engage community members to review draft strategies around the Council’s work.

Recommendation #2 (Younger-Onset Dementia)

Improve awareness of and access to services, supports, and resources currently available to individuals affected by younger-onset dementia. Improve this awareness among the public as well as the medical community.

Progress and Accomplishments

- Due to resource constraints and focused efforts in other competing areas, this recommendation and its implementation strategies will be revisited in 2025.

Next Steps

- To view the Council’s next steps around younger-onset dementia (to be revisited in 2025), please refer to the [Massachusetts State Plan on Alzheimer’s Disease and Related Dementias](#).

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

- Distributed the Council's [guide](#) entitled, *Age and Dementia Friendly Design Considerations* (guide) to numerous organizations who in turn shared it with their networks.
- Worked with the American Planning Association-Massachusetts who included an [article](#) about the guide in their spring 2023 newsletter.
- Delivered presentations about the guide to numerous organizations, for example: Massachusetts Assisted Living Association, Massachusetts Councils on Aging, Leading Age Massachusetts, Massachusetts Library Association, Dementia Friendly Maine, Massachusetts Health and Hospital Association, and the Commonwealth's regional transportation providers.
- Continued to promote the guide's usage among age and dementia friendly communities and local and regional planning agencies.
- Shared the guide while promoting the FY2024 round of grant opportunities from the state's Shared Streets and Spaces Program.
- American Trails, a national organization, included the guide in their [resource library](#).
- Fostered collaborative relationships with design, planning, and public infrastructure procurement sectors to promote a shared vocabulary and comprehension of age and dementia friendly design principles.
- With this team's help, Dementia Friendly Massachusetts and the Massachusetts Healthy Aging Collaborative have successfully operationalized much of this team's work around raising awareness of the importance of age and dementia friendly design.

Next Steps

- As part of their day-to-day operations, Dementia Friendly Massachusetts and the Massachusetts Healthy Aging Collaborative will continue to build partnerships with design, planning, and procurement communities across the state to share the guide and raise awareness of the importance of age and dementia friendly design.

Recommendation #2 (Public Project Scoring)

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

Progress and Accomplishments

- Throughout 2023, the Council's Physical Infrastructure team actively pursued opportunities in line with the Council's directive to "integrate age and dementia friendly scoring into all state-funded physical infrastructure projects."
- To expound on the above directive, the Council endorsed the team's understanding, defining "scoring" as any method that explicitly prioritizes or stipulates requirements for incorporating age and dementia friendly features in physical infrastructure projects seeking state or municipal funding.
- To underscore the explicit prioritization of age and dementia friendly features in infrastructure projects, relevant language around such features was included in a Request for Applications for supportive and social day programs issued by the Massachusetts Executive Office of Elder Affairs.
- Submitted and received preliminary approval from Boston University's [MetroBridge](#) program to launch a project in January 2025 around age and dementia friendly physical space as part of the University's undergraduate psychological anthropology class¹⁸. This faculty-led class project will be designed to encourage inclusion of age and dementia friendly design features in state and municipally funded physical infrastructure projects.
- The Council's Physical Infrastructure team conducted an analysis of state, municipal, and other built environment funding sources to identify opportunities for incorporating age and dementia friendly design standards; and identified areas of focus where the team believes it can have the greatest impact. Those areas are reflected below in the section entitled, "Next Steps."

Next Steps

- As part of Boston University's MetroBridge program, work with faculty to plan the launch of a class project in January 2025 for undergraduate psychological anthropology students. The project involves the development and testing of a layman's assessment tool designed to empower Massachusetts citizens to advocate for publicly-funded spaces that are age and dementia friendly.
- Engage in a discussion with staff at the Massachusetts Executive Office of Housing and Livable Communities about the Physical Infrastructure team's suggested age and dementia friendly enhancements to the agency's design requirements for senior housing (known as "Appendix L").

¹⁸ For definitions of psychological anthropology, see [International Encyclopedia of the Social & Behavioral Sciences \(Second Edition\), 2015](#), Pages 359-365

- Meet with key stakeholders at the Massachusetts Division of Capital Asset Management and Maintenance to discuss potential age and dementia friendly modifications to the agency's *Designer Guidelines and Procedures*, which are for designers working on state and municipally funded physical infrastructure projects.
- Identify additional state-funded physical infrastructure opportunities along with relevant agencies.

5. Quality of Care



Goal

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)

Recommend, distribute, and promote person-centered and person-directed care planning resources; and advise Ariadne Labs in their development of a person-centered assessment and care plan for people living with dementia and their caregivers¹⁹

Progress and Accomplishments

- Began using the Care Planning team’s focus group findings and themes from 2022 to help guide the team’s work in 2023. (During the focus group sessions, patients and caregivers shared their feelings and thoughts about their interactions with health care providers.)
- Added a representative to the Care Planning team from Ariadne Labs, a joint center for health systems innovation at Brigham and Women’s Hospital and the Harvard T.H. Chan School of Public Health.
- Identified, reviewed, and discussed the essential characteristics of effective person-driven dementia care plans; and agreed on the team’s targeted milestones for 2024.
- Began reviewing and assessing existing care planning models.
- Began advising Ariadne Labs in its development of a person-centered assessment and care plan for people living with dementia and their caregivers.
- Agreed to modify the original version of this recommendation, which was to “develop a person-directed care plan framework and template.” The Council agreed that the newly revised recommendation (indicated as “Recommendation #1” above) is more realistic.

Next Steps

- Complete outreach to collect person-driven care planning models.
- Review and recommend person-driven care planning models to add to resource list.
- Identify an approach for distributing care planning resources to families and providers:
 - Research existing approaches
 - Explore distribution opportunities.
 - Decide on a recommended distribution approach.
- Identify approaches for promoting use of recommended care planning model(s) among persons living with dementia, caregivers, and providers.

¹⁹ [Amendments to the Massachusetts State Plan on Alzheimer’s Disease and Related Dementias, 2023.](#)

Recommendation #2 (Interprofessional Dementia Care)

Develop a plan that ensures that staff in primary care across the state receive the training and support needed to build and retain interprofessional dementia care teams²⁰

Progress and Accomplishments

- Recruited co-leaders and a team on Interprofessional Dementia Care to implement this recommendation.
- Discussed this recommendation, which originally focused on several health care settings (primary care, acute care, home care, and long-term care); and agreed to modify it by prioritizing primary care settings as this team's sole focus in 2024.²¹
- Agreed on the following reasons for an initial focus on primary care:
 - Focusing on one setting improves the team's ability to make progress in 2024.
 - The need for coordination and effectiveness is greatest in primary care, which experiences significant resource constraints and involves the greatest number of professional roles.
 - The new Alzheimer's therapies are restricted to MCI and early Alzheimer's, underscoring the urgency of early detection and diagnosis through primary care.
- Began identifying essential primary care services, outcomes, and benefits associated with interprofessional dementia care teams to help determine effective team composition.
- Agreed on the following team approach for 2024:
 - Provide justification for interprofessional dementia care teams in primary care settings.
 - Propose adaptations & approaches to the [Age-Friendly Health System](#) (AFHS) Initiative.
 - Collaborate with the Institute for Healthcare Improvement (IHI).
 - Develop training recommendations and a resource list.

Next Steps

- Determine effective team composition by continuing to identify services, outcomes, benefits, and other essential characteristics of primary care professionals on an interprofessional dementia care team.
- To justify interprofessional dementia care teams in primary care, reflect on identified outcomes and benefits; and clearly articulate the reasons for a collaborative interprofessional dementia care team.
- With the needs of people affected by dementia in mind, examine the Age-Friendly Health System (AFHS) initiative's 4M's (What Matters, Medication, Mentation, Mobility).

²⁰ Ibid

²¹ Ibid

- Suggest adjustments to enhance the AFHS initiative's support for individuals and families at risk of or affected by dementia.
- Work with the Institute for Healthcare Improvement to review and revise the team's suggested dementia-specific adaptations and approaches to the AFHS initiative.
- Identify and articulate key training attributes that would be beneficial for all members of an interprofessional dementia care team in a primary care setting.
- Develop recommendations and a resource list around available and effective training.

6. Research



Goal

Advance dementia research in Massachusetts

Recommendation #1 (Research Diversity)

Increase diversity of dementia research and researchers

Progress and Accomplishments

- The Council agreed to remove this workstream from its scope along with its accompanying goal and recommendation (above).²² Although this workstream's goal and recommendation are of considerable importance, they present a substantial challenge for the Council.
- Compared with the Council, there are other organizations within Massachusetts that are more resourced; better qualified; and currently conducting activities and initiatives designed to achieve this workstream's goal of "advancing dementia research in Massachusetts" as well as its recommendation to "increase diversity of dementia research and researchers."

Next Steps

- Eliminate this workstream from the Council's scope and continue to leverage the Council's knowledge about ongoing dementia-related research, breakthroughs, and innovation to inform its recommendations, policies, programs, and guidance.

²² Ibid

7. Risk Reduction and 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

- ***Building our Largest Dementia Infrastructure*** - A small team from the Massachusetts Executive Office of Elder Affairs and the Alzheimer's Association, MA/NH Chapter convened a brief series of meetings with officials from the Massachusetts Department of Public Health (DPH) to discuss a five-year grant opportunity announced in 2023 by the Centers for Disease Control and Prevention (CDC).
 - Generally speaking, the grant opportunity, referred to as "Building our Largest Dementia (BOLD) Infrastructure" was designed to fund state and local public health departments to:
 - increase their capacity to contribute to the field of Alzheimer's Disease and Related Dementias (ADRD);
 - expand and improve the response to ADRD in their jurisdictions;
 - develop a connected approach to build the dementia infrastructure, including addressing social determinants of health to facilitate health equity; and
 - improve the public health approach to ADRD using the [CDC HBI](#).
 - Due to competing and important demands on staff time at DPH, it was determined that 2023 was not an opportune time to apply for this grant. As an alternative strategy, the emphasis shifted from a statewide approach to a more localized one, with the city of Springfield as the focal point.
- ***Promoting Brain Health in the City of Springfield*** - The city of Springfield was selected as the locality to focus on due to its residents' prevalence of dementia and dementia risk factors.
 - According to data published by UMass Boston's Gerontology Institute in its latest [Massachusetts Healthy Aging Data Report](#) (Data Report), the state average percentage of Medicare beneficiaries age 65+ years ever diagnosed with ADRD was 13.6%. The percentage for most of Springfield's neighborhoods; however, was much higher with one neighborhood reaching as high as 23.71%.²³
 - A number of individuals working on behalf of the Council developed a proposal to implement "Springfield's Healthy Brain Initiative," and identified potential funding sources. In 2023, the Springfield Dementia Friendly Coalition was successful in receiving a small grant to implement the initiative in 2024.

²³ https://mahealthyagingcollaborative.org/wp-content/themes/mhac/pdf/state_maps/MA_Map69_Alzheimer_s.pdf

Next Steps

- *Springfield's Healthy Brain Initiative* - In 2023, after pursuing funding opportunities, a grant was received to implement a community outreach program to promote better brain health in Springfield. The plan is to implement "Springfield's Healthy Brain Initiative" in 2024 in partnership with the Springfield Dementia Friendly Coalition.²⁴ The initiative's goal is to reduce the risk of dementia among Springfield's residents and increase community awareness of the benefits of early detection, screening, and diagnosis.
 - This initiative will strive to accomplish its goal through an event that focuses on brain health. At the event, individuals will view a short video to be produced as part of this initiative. After the screening of the video, participants will have an opportunity to discuss what they learned within facilitated discussion groups.
 - Following the discussions, subject matter experts will be available to answer questions. There will also be manned tables at the event with information on brain health as well as the support and services available in Springfield for people living with dementia and their caregivers.

²⁴ The Springfield Dementia Friendly Coalition consists of representatives from Baystate Health, Springfield Public Health Commission, Public Health Institute of Western Mass, Springfield Department of Elder Affairs, Alzheimer's Association, Greater Springfield Senior Services, and other organizations as necessary.

LOOKING TO THE FUTURE



Over the years, as the Council fully implemented the state plan's strategies within any of its workstreams, it regularly amended the [Massachusetts State Plan on Alzheimer's Disease and Related Dementias \(state plan\)](#) with new recommendations; brought the appropriate stakeholders to the table; and implemented solutions. This year's amendments are included in the next and final section of this annual report.

The Council will continue to use the state plan and its amendments as a guide 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. The Council holds fast to its commitment to ensuring that all Massachusetts residents affected by dementia receive the respect and opportunities they deserve.

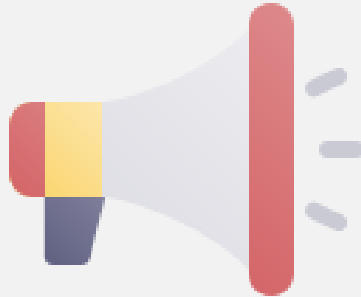
AMENDMENTS TO THE MASSACHUSETTS STATE PLAN ON ALZHEIMER'S DISEASE AND RELATED DEMENTIAS, 2023



The following *Amendments to the Massachusetts State Plan on Alzheimer's Disease and Related Dementias* include information pertaining to recommendations within the Council's:

- Caregiver Support and Public Awareness Workstream;
- Equitable Access and Care Workstream;
- Quality of Care Workstream (Care Planning and Interprofessional Dementia Care); and
- Research Workstream.

Caregiver Support and Public Awareness Workstream
Recommendation #1
(Public Service Announcement and Video Production)



Original Recommendation #1

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

Revised Recommendation #1

Develop public service announcements and videos in three languages to promote the services and support available for caregivers of people living with dementia

Equitable Access and Care Workstream
Recommendation #1 (Equity and Inclusion Team)



Original Recommendation #1

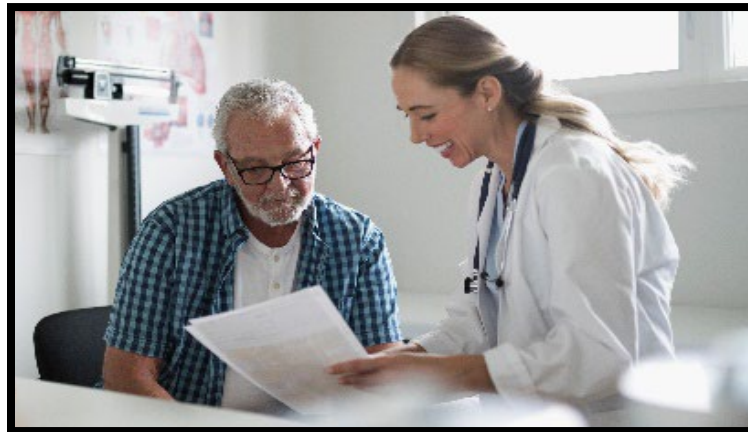
Close informational gaps and address fragmentation of care access, care planning, and dementia services.

Revised Recommendation #1

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

Quality of Care Workstream

Recommendation #1 (Care Planning)



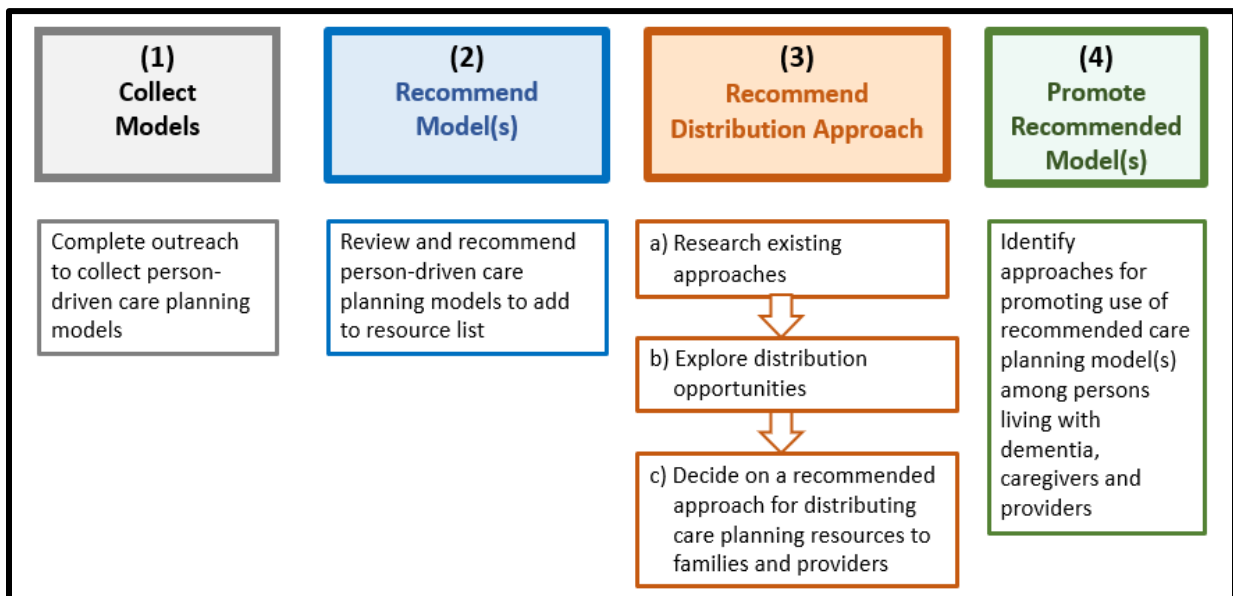
Original Recommendation #1

Develop a person-directed care plan framework and template.

Revised Recommendation #1

Recommend, distribute, and promote person-centered and person-directed care planning resources; and advise Ariadne Labs in their development of a person-centered assessment and care plan for people living with dementia and their caregivers.

Updated Implementation Strategies



Quality of Care Workstream

Recommendation #2 (Interprofessional Dementia Care)



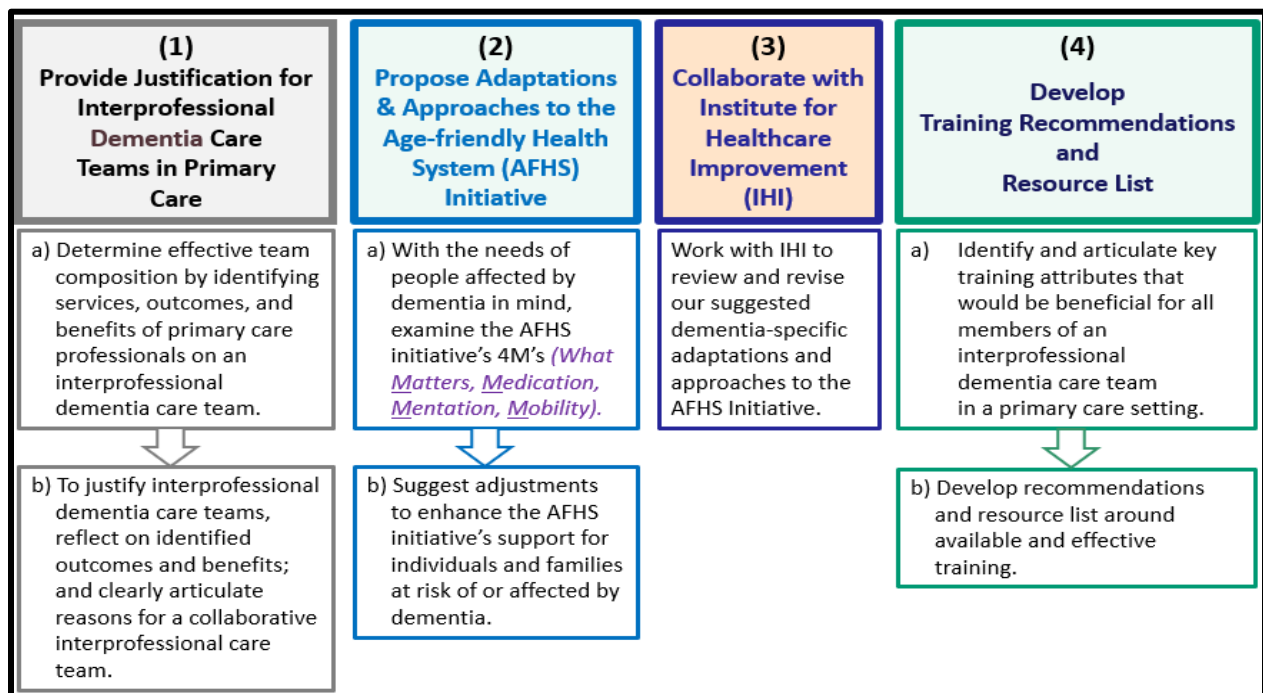
Original Recommendation #2

Develop a plan that ensures that staff in primary care, acute 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.

Revised Recommendation #2

Develop a plan that ensures that staff in primary care across the state receive the training and support needed to build and retain interprofessional dementia care teams.

Updated Implementation Strategies



Research Workstream
Recommendation #1 (Research Diversity)



Original Recommendation #1

Increase Diversity of Dementia Research and Researchers.

Removed Research Workstream from State Plan

Although this workstream's original goal and recommendation (above) are of considerable importance, they present a substantial challenge for the Council. Recognizing that other organizations are better able to achieve the objectives of this workstream, the Council agreed to remove it from its scope. The Council and its workgroups will; however, continue to stay abreast of research in the field; engage in discussions about it; and reflect on it while developing recommendations, policies, programs, and guidance.

APPENDIX A

MEMBERS OF THE MASSACHUSETTS ADVISORY COUNCIL ON ALZHEIMER'S DISEASE AND ALL OTHER DEMENTIAS CALENDAR YEAR 2023

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
Christine Ritchie, MD, MSPH - Kenneth L. Minaker Endowed Chair in Geriatric Medicine; Research Director, MGH Division of Palliative Care and Geriatric Medicine; Director, Mongan Institute Center for Aging and Serious Illness; Director, MGH Dementia Care Collaborative; Professor of Medicine, Harvard Medical School	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
Representative Thomas Stanley - Massachusetts House of Representatives	House Chairman, 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
Hugo Aparicio, MD, MPH - Assistant Professor of Neurology, Boston University School of Medicine; Faculty Lead of the Research and Policy Team Program at the BU Center for Antiracist Research; Stroke Specialists in the Department of Neurology, Boston Medical Center	Alzheimer's Researcher 1

Brent Forester, MD, MSc - Chief, Division of Geriatric Psychiatry & Director, Geriatric Psychiatry Research Program, McLean Hospital; Associate Professor of Psychiatry, Harvard Medical School; Medical Director, Dementia Care and Behavioral & Mental Health Population Health Management, Mass General Brigham	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

TEAMS & WORKGROUPS IN CALENDAR YEAR 2023

Workstream and Council Leads	Members of Teams and Workgroups, Calendar Year 2023 <i>Names appear in alphabetical order with team leads indicated in purple font</i>
<p>1. Caregiver Support & Public Awareness</p> <p>Barbara Meehan, Dementia Advocate/Former Caregiver</p> <p>Hector R. Montesino, President and CEO - Embrace Home Care and Health Services and Alzheimer's Advocate</p>	<p><i>Video Production Team</i> Leonor Buitrago, Diversity Outreach Manager, Alzheimer's Association MA/NH Chapter Jennifer Hoadley, CDP, Regional Manager Southeastern MA - Alzheimer's Association, MA/NH Chapter Barbara Meehan (Co-Lead), Council Member Hector Montesino (Co-Lead), Council Member</p> <p><i>Caregiver Experience – Update of ASAP Designation Review Process</i> Joshua Ferguson (Lead), Director of Data Insights and Program Evaluation, Executive Office of Elder Affairs (EOEA) Elise Tierney, MPH, Aging Services Strategy and Operations Manager, EOEA Karyn B. Wylie, MS, LSW, Massachusetts Aging & Disability Resource Consortia Coordinator, EOEA</p> <p><i>Caregiver Experience - Branding and Market Research</i> Amanda Barnardo (Former Lead), Former Chief of Staff & Chief Strategy Officer, Executive Office of Elder Affairs (EOEA) Ellie Romano (Current Lead), Director of Communications and Outreach Manager, EOEA</p>
<p>2. Diagnosis & Services Navigation</p> <p>James Wessler, President and CEO, Alzheimer's Association, MA/NH Chapter and New England Regional Leader</p>	<p><i>Dementia Operations Plan Toolkit</i> Shirley Conway, MSN, MBA, RN-BC, Director of Geriatric Initiatives, Addison Gilbert Hospital Maura Kennedy, MD, Division Chief of Geriatric Emergency Medicine, Mass General Hospital Liz McCarthy (Lead), Health Systems Director, New England Region, Alzheimer's Association Pat Noga, PhD, RN, VP Clinical Affairs, Mass Health and Hospital Association Arlene Stoller, MSN, Geriatric Nurse Specialist, Lahey Hospital and Medical Center</p> <p><i>Dementia Detection in Home Care</i> Devon Garon, LSW, CCP, Director, Home and Community Programs, Executive Office of Elder Affairs (EOEA)</p>

Workstream and Council Leads	Members of Teams and Workgroups, Calendar Year 2023 <i>Names appear in alphabetical order with team leads indicated in purple font</i>
	Lynn C. Vidler, MBA, BSW, Senior Director, Operations & Policy, Home Care, EOEA
3. Equitable Access & Care Hugo Aparicio, MD, MPH, Assistant Professor of Neurology, Boston University School of Medicine; Faculty Lead of the Research and Policy Team Program at the BU Center for Antiracist Research; Stroke Specialist in the Department of Neurology, Boston Medical Center Jatin Dave, MD, Chief Medical Officer, MassHealth and Director, Office of Clinical Affairs, For Health Consulting, UMass Chan Medical School	<i>Equity and Inclusion Team</i> Hugo Aparicio, MD (Co-Lead), Council Member Jatin Dave, MD (Co-Lead), Council Member Doris Harris, PhD, Consultant, Springfield Dementia Friendly Coalition member, host of <i>Health Matters</i> radio show in Springfield (90.7 FM WTTC) Liana Mendes-Santos, PhD, Researcher, Multicultural Alzheimer's Prevention Program, Massachusetts General Hospital; Visting Researcher, Boston University's Vision & Cognition Laboratory Kevin Reynolds, Diversity, Equity and Inclusion Chair, Alzheimer's Association, MA/NH Chapter Kathy Service, NP, Consultant on aging issues and dementia, often with a special focus on people living with intellectual and developmental disabilities Beth Soltzberg, LICSW, MBA, Director, Alzheimer's/Related Dementias Family Support Program, Jewish Family & Children's Service, Waltham Judith Thermidor, Resident Wellness Director, CSI Support & Development Services, Community Health Educator in Haitian Creole and Spanish

Workstream and Council Leads	Members of Teams and Workgroups, Calendar Year 2023 <i>Names appear in alphabetical order with team leads indicated in purple font</i>
<p>4. Physical Infrastructure</p> <p>Elizabeth C. Chen, PhD, MBA, MPH (Council Chair), Secretary - Massachusetts Executive Office of Elder Affairs (EOEA)</p>	<p><i>Age and Dementia Friendly Physical Infrastructure Team</i></p> <p>James Fuccione, MPA, (Co-Lead), Senior Director - MA Healthy Aging Collaborative</p> <p>Elizabeth Giannini, Transportation Program Manager, Franklin Regional Council of Governments</p> <p>Pam MacLeod, MBA, PMP, Senior Project Director, EOEA and University of Massachusetts Chan Medical School</p> <p>Sandra Martin, MEP, MPH, Senior Planner and Health Agent, Berkshire Public Health Alliance, Public Health Program at Berkshire Regional Planning Commission</p> <p>Molly McKenna, MSW LCSW, Programs Development Manager, 2Life Communities</p> <p>Ruth Neeman, AIA, Principal, Director of Senior Environments Studio, LWDA</p> <p>Ithzel Polanco-Cabadas, Real Estate Project Manager, 2Life Communities</p> <p>Philippe Saad, AIA, LEED AP, Principal, Dimella Shaffer</p> <p>Patty Sullivan (Co-Lead), Program Manager, Dementia Friendly MA - MA Councils on Aging</p> <p>Amy Walsh, Project Manager - Institute for Healthcare Improvement</p> <p>Haley Wood, Economic Security and Outreach Manager, MA Councils on Aging</p>
<p>5. Quality of Care</p> <p>Linda Pellegrini, MS, GNP-BC, Geriatric Nurse Practitioner, UMass Memorial Medical Center</p>	<p><i>Care Planning Team</i></p> <p>Susan Antkowiak (Co-Lead), Council Member</p> <p>Rachel Broudy, MD, Faculty Lead on Elder Care Work at Ariadne Labs, Medical Director, Pioneer Valley Hospice and Palliative Care, Board Member, Life Path Aging Services Access Point, Franklin County</p> <p>Deb Dowd-Foley, Caregiver Specialist, Elder Services of Worcester Area, Inc.</p> <p>Laurie Herndon, MSN, GNP, BC, Project Director, Hinda and Arthur Marcus Institute for Aging Research, Hebrew SeniorLife</p> <p>Judy Johanson, Dementia Advocate, Massachusetts Alzheimer's Disease Research Center, Massachusetts General Hospital (MGH)</p> <p>Aaron Madow, Graduate Student (MPH Candidate), University of Massachusetts</p> <p>Gad A. Marshall, MD, Medical Director of Clinical Trials, Center for Alzheimer Research and Treatment, Brigham and Women's Hospital (BWH), Associate Neurologist, BWH, Assistant in Neurology, (MGH), Associate Professor of Neurology, Harvard Medical School</p> <p>Pam Mirick, RN, Former Family Caregiver, Retired Nurse</p> <p>Linda Pellegrini (Co-Lead), Council Member</p>

Workstream and Council Leads	Members of Teams and Workgroups, Calendar Year 2023 <i>Names appear in alphabetical order with team leads indicated in purple font</i>
	<p><i>Interprofessional Dementia Care Team</i></p> <p>Yeimy S. Aleman Miranda, Patient Service Representative, Baystate Memory Assessment and Care Clinic, Department of Medicine, Baystate Medical Center</p> <p>Stephen Bonasera, MD, PhD, Chief, Division of Geriatrics & Palliative Care, Medical Director, Baystate Memory Assessment and Care Clinic, Department of Medicine, Baystate Medical Center</p> <p>Kathryn M. Corelli, MD, Internal Medicine Physician, Chestnut Hill, MA</p> <p>Joe Costello, Organizational Consultant and Dementia Advocate</p> <p>Brent P. Forester, MD, MSc., (Council Member), Dr. Francis S. Arkin Chair of Psychiatry, Tufts University School of Medicine Chief and Chair, Department of Psychiatry, Tufts Medical Center Director of Behavioral Health, Tufts Medicine</p> <p>Lenore Jackson-Pope, RN, BSN, MSM, CCRP, Co-Director of Primary Care Outreach, Center for Alzheimer Research and Treatment (CART) and Massachusetts Alzheimer’s Disease Research Center (MADRC), Mass General Brigham</p> <p>Jayne Kelleher, Home Care Director, Bethany at Home, Framingham, MA, Board Member of Massachusetts Home Care Aide Council</p> <p>Liz McCarthy, Health Systems Director, New England Region, Alzheimer’s Association</p> <p>Pam Mirick, RN, Former Family Caregiver, Retired Nurse</p> <p>Christine Ritchie, MD, MSPH (Council Member), Kenneth L. Minaker Endowed Chair in Geriatric Medicine, Research Director, MGH Division of Palliative Care and Geriatric Medicine, Director, Mongan Institute Center for Aging and Serious Illness, Director, MGH Dementia Care Collaborative, Professor of Medicine, Harvard Medical School</p> <p>Wayne S. Saltsman, MD, PhD, CMD, AGSF, Chief Medical Officer, All Care VNA, Hospice & Private Home Care Services, Lynn, MA</p> <p>Alina Sibley, CNP, (Co-Lead), Team Lead for Geri-Pal Home Care, Baystate Health</p> <p>Amy Walsh, Project Manager, Institute for Health Care Improvement (IHI)</p> <p>Christopher Wight, LICSW (Co-Lead), Clinical Social Worker, Dementia Care Collaborative, Division of Palliative Care and Geriatric Medicine, Massachusetts General Hospital</p>

Workstream and Council Leads	Members of Teams and Workgroups, Calendar Year 2023 <i>Names appear in alphabetical order with team leads indicated in purple font</i>
6. Risk Reduction and Public Health Infrastructure²⁵	<p><i>Springfield's Healthy Brain Initiative - Led by the Springfield Dementia Friendly Coalition:</i></p> <p>Johnetta Baymon, Faith Based Health Alliance Lisa Cardonell, Alzheimer Association, MA/NH Chapter Cynthia Clemons, Safe Harbor Adult & Senior Services Brenda Evans, School of Public Health & Health Sciences, UMass Amherst Samantha Hamilton, Public Health Institute of Western Mass Doris Harris, Consultant Zee Johnson (Lead), Chairperson, Springfield Dementia Friendly Coalition Brenda Labbe, Greater Springfield Senior Services Meghan LeMay, Alzheimer's Association, MA/NH Chapter Luz Lopez, Alzheimer's educator Nina Prenosil, UMass Amherst (intern)</p>

²⁵ In 2024, a team and its lead will conduct a project for this workstream (as indicated in the second column). This project has been designed to align with this workstream's recommendations; however, the workstream itself is currently without a lead from the Council.

APPENDIX C

VISION AND PLEDGE TO PROMOTE DIVERSITY, EQUITY, AND INCLUSION

VISION

The *Massachusetts Advisory Council on Alzheimer's Disease and All Other Dementias* envisions a Commonwealth that reflects the communities we serve and values and benefits all people affected by dementia equally — one that addresses cultural, economic, environmental, and other societal barriers such as racism, ableism, and other forms of discrimination. We recognize and value the lived experience of all Massachusetts residents affected by dementia and strive for equitable outcomes for all.

PLEDGE

As we work to achieve our goals, we pledge to:

- Build and cultivate a culture of diversity, equity, inclusion, and access among all individuals working to advance the Council's goals including the Council, its workgroups, focus groups, and other partners.
- Listen to, learn from, respect, and value diverse life experiences and perspectives including the experiences of those disproportionately affected by societal barriers to dementia research, care, services, support, and decision-making.
- Highlight and address inequities as we develop policy recommendations, programs, and resources for individuals and families affected by dementia and hold ourselves accountable for successes and failures.
- Commit to residents affected by dementia that they will receive the support, services, and care needed to live healthy and meaningful lives.