

Advisory Council on Alzheimer's Disease and All Other Dementias



Executive Office of Aging & Independence

Whitney Moyer, Chair

May 6, 2025

3:30-5:00 pm

Video Conference



Agenda

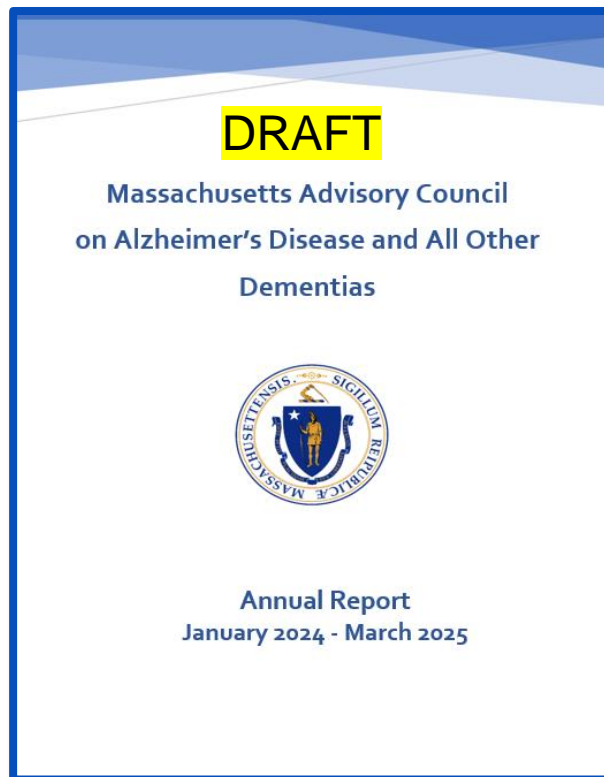


1. Welcome, Logistics, Announcements, Introductions (*15 min*)
2. Annual Report: Present, Discuss, and Plan to Vote (*40 min*)
3. Going Forward: Prioritization Exercise (*32 min*)
4. Next Steps and Vote to Adjourn (*3 min*)

Annual Report Review

January 2024 – March 2025

Present Highlights (20 min)



Annual Report Review

☐ Present Highlights



Activities and Achievements by Workstream



The report includes six sections, one for each of the following workstreams:

- 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



For each recommendation in the state plan, the report includes activities and accomplishments (January 2024 through March 2025); and next steps.

Invaluable volunteers and teams worked on behalf of the Council.

See the report for a list of all team members by team and workstream.



1. Caregiver Support and Public Awareness



Workstream 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

Workstream Leads

Barbara Meehan, Council Member - Dementia Advocate, Former Caregiver

Hector R. Montesino, Council Member - President and CEO, Embrace Home Care and Health Services, Dementia Advocate



1. Caregiver Support and Public Awareness



Public Service Announcements and Video Production

- Produced videos and content for public service announcements for distribution in June.



Caregiver Experience with Aging Services Access Points (ASAPs)

Implemented Changes in Response to Market Research Findings

- Rebranding. Changed name to “Executive Office of Aging & Independence” (AGE), recognizing how adults value independence and self-determination.
- Caregiver Portal. Added concise information to AGE’s caregiver portal (program descriptions, eligibility, costs).



Examined Caregiver Experience with ASAPs

- Surveys & Tests. In 2024, conducted consumer surveys and consumer experience testing in all 24 ASAPs
- Dementia Caregiver Scenario. Twenty completed calls were made by “imitation consumer” using a dementia caregiver scenario - Information & Referral specialists suggested the caller contact the MA Family Caregiver Support Program in only 3 of the calls; and the Alzheimer’s Association in none of the calls.
- Addressing concerns. In January 2025, AGE reflected on findings from the surveys and experience testing to begin addressing concerns and updating ASAP designation tools, processes, and a compliance scoring approach.



2. Diagnosis and Services Navigation



Workstream 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

Workstream Lead

James Wessler, Council Member - President and CEO, Alzheimer's Association, MA/NH Chapter and New England Regional Leader



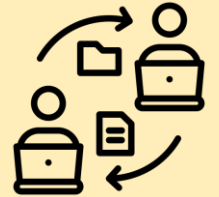
2. Diagnosis and Services Navigation



Diagnosis

Sharing Best Practices

- As reported in last year's annual report, this part of the workstream merged with the efforts of the Medical and Scientific (MedSci) Advisory Committee of the Alzheimer's Association, MA/NH Chapter to examine solutions and share best practices across health care systems.



Dementia Screening in Home Care Program

- In 2025, AGE will follow-up on its promise to reassess the feasibility of convening a team with representatives from AGE and ASAPs to identify opportunities in the home care program to advocate for appropriate screening and diagnosis.



Services Navigation

Leveraged Synergies Across the Council's Teams

- To better leverage synergies, the state plan's recommendations on "services navigation" addressed by Council teams working within the "Quality of Care" workstream.





3. Equitable Access and Care



Workstream Goal

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

Workstream Leads

Hugo Aparicio, MD, MPH, Workstream Lead and Council Member - Associate Professor of Neurology, Boston University School of Medicine; Stroke Specialist in the Department of Neurology, Boston Medical Center

Jatin Dave, MD, MBBS, MPH, Workstream Lead and Council Member (until mid-December 2024) - Chief Medical Officer, MassHealth; Director, Office of Clinical Affairs, Commonwealth Medicine, UMass Chan Medical School (until mid-December 2024)



3. Equitable Access and Care



Equity Priorities, DEI Tool, and Listening Session



- Set priorities. Defined equity priorities related to dementia care.
- Developed Tool. Developed a DEI tool designed to help the Council and its teams examine their work with a “diversity, equity, and inclusion (DEI) lens.”
- Initiated Recurring Listening Sessions. Refined the DEI tool based on discussions with people with lived experience - key finding was lack of effective communication with health care providers.

Younger-Onset Dementia – Awareness & Access to Services



- As promised last year, in 2025 AGE will determine the feasibility of implementing the state plan’s recommendations on improving awareness of and access to services available for people affected by younger-onset dementia.



4. Physical Infrastructure



Workstream Goal

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

Workstream Lead

Pam MacLeod, MBA, PMP - Senior Project Director for the Council; Massachusetts Executive Office of Aging & Independence; and UMass Chan Medical School



4. Physical Infrastructure



Designing Age and Dementia Friendly Spaces



Provided Guidance Currently Under Consideration by State Agencies

- Senior Housing Requirements. Recommended changes to the state's guidance on senior housing design to better meet cognitive and physical accessibility needs.
- Guidance for Building Designers. Recommended guidance to add to the state's designer manual used for public infrastructure projects.
- Emergency Shelter Plans. Advised Emergency Management Agency on age and dementia friendly emergency shelter design practices.
- Public Library Construction. Encouraged inclusion of dementia friendly design in public library construction grants.

Developed Assessment Tools

- Partnered with Boston University students to create tools to help “citizen advocates” assess age and dementia friendliness of public spaces including senior centers, libraries, and outdoor parks.



5. Quality of Care



Workstream Goal

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

Workstream Lead

Linda Pellegrini, MS, GNP-BC, Council Member - Geriatric Nurse Practitioner, UMass Memorial Medical Center



5. Quality of Care



Person-Centered Dementia Care Planning



- Developed a Dementia Care Planning Toolkit for individuals living with dementia and their care teams:
 - Includes guidance, sample plans, and a simple worksheet to support meaningful conversations.
 - Promoted the toolkit at two webinars, distributed it widely; will continue to promote it.

Interdisciplinary Dementia Care



- Identified dementia care gaps with input from the Council, its teams, and people with lived experience.
- Analyzed care models; selected Care Ecosystem as best fit for interdisciplinary dementia care.
- Found that effective dementia care requires a focus on dementia care planning, navigation of care and social service systems, and ongoing caregiver support.
- Explored care barriers: e.g., overloaded primary care, system confusion, fragmented services.
- Designing a plan for a pilot with clinical consultants and navigators to streamline, support, and integrate care.



6. Risk Reduction and Public Health Infrastructure



Workstream Goal

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

Workstream Lead(s)

TBD



6. Risk Reduction and Public Health Infrastructure



Springfield's Healthy Brain Initiative

- As reported last year, in 2023, the Springfield Dementia Friendly Coalition partnered with a team working on behalf of the Council to secure a grant for a "Healthy Brain Initiative."
- In 2024, the Coalition launched the initiative with an event to raise dementia awareness and promote brain health, early detection, screening, and diagnosis.
- At the event, participants viewed a brief video, spoke with experts, and visited information tables on local supports and services.





Looking to the Future



Develop an Updated State Plan on ADRD



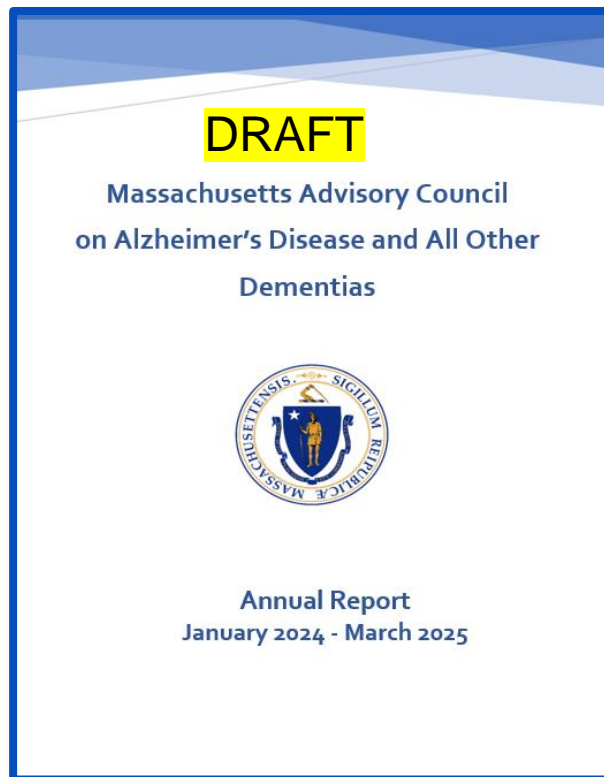
As indicated in the annual report:

- Most of the recommendations in the state plan have been implemented; now is the time to update it.
- We'll spend time in 2025 to identify key priorities to guide a new state plan for release in 2026.
- The Council's work on the plan will require:
 - examining key challenges facing people affected by dementia;
 - exploring potential solutions to those challenges; and
 - determining how the Council can potentially support each solution, e.g., by leading, advising, partnering, advocating, or deferring.

Annual Report Review

January 2024 – March 2025

Provide Comments and Vote (20 min)

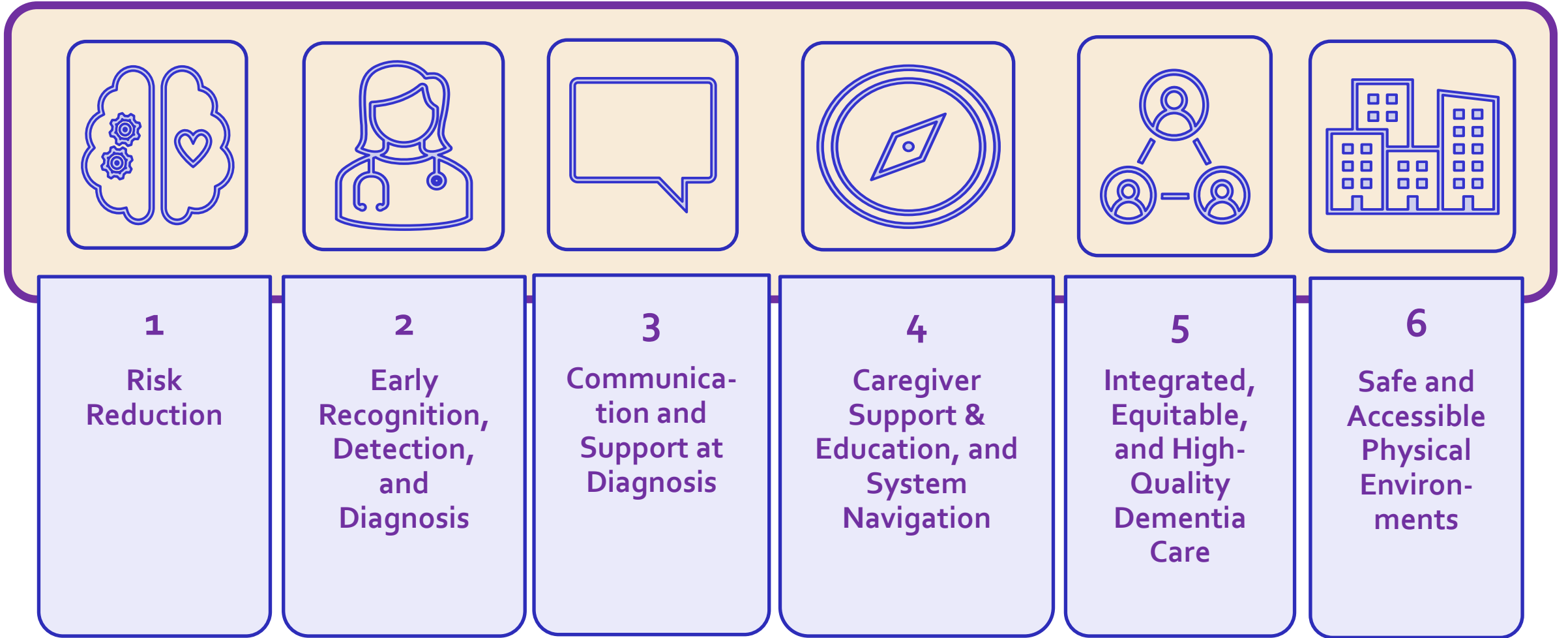


Annual Report Review

- ☐ Provide Comments and Discuss Voting Procedures



4. Going Forward: Prioritization Exercise (32 min)





(a) High-Impact Areas: Survey Results

Challenge Area	# Votes for Rank of 1 or 2	Comments from Council Members
1. Early Recognition, Detection, and Diagnosis	7	<ul style="list-style-type: none">Skills and incentives for early, accurate diagnosis in <u>primary care</u> settings (Susan)Obstacles around screening and diagnosis in <u>primary care</u> (Jim)
2. Caregiver Support & Education, and System Navigation	5	<ul style="list-style-type: none"><u>Screening for caregiver stress</u>, burden, depression, and anxiety so that appropriate referrals can be made (Brent)<u>Awareness</u> and education statewide <u>for all residents</u> via TV, media, buses, trains, radio, etc. (Hector)<u>Financial impact</u> on caregivers (Barb)
3. Integrated, Equitable, and High-Quality Care	4	<ul style="list-style-type: none">Includes communication and support at diagnosis, and caregiver support, education, and system navigation (Linda)
4. Risk Reduction	2	<ul style="list-style-type: none"><u>Engagement of public health</u> to focus on the traditional public health role, i.e., addressing lifestyle and modifiable risk factors (Jim)
5. Communication and Support at Diagnosis	2	<ul style="list-style-type: none">Would be included in “integrated, equitable, and high-quality care” category (Linda)

“Other” Challenge Areas with a rank of 1 or 2

- Gaps for low income and non-English speakers (Jim)
- Recruiting and training the direct care workforce across the continuum (Susan)

Comments in survey related to federal funding cuts/ risks

- Council should identify and articulate local impact of **federal cuts to Medicaid** and potential subsequent gaps in services (Susan)
- Council may want to discuss including **research funding** as a high-impact challenge (Linda)



(b) High-Impact Areas: Insights and Opportunities



For the top two high-impact challenge areas below:

1. What key factors lead you to rank it as high impact?
2. Which critical factors could be addressed next and how?
3. What do you think the Council's role should be in addressing those factors?

Early Recognition, Detection, and Diagnosis

(7 votes for rank of 1 or 2) ^(a)

Critical Factors

- Timely recognition and diagnosis within the healthcare system
- Stigma and fear delaying symptom acknowledgment and diagnosis
- Access to timely and equitable screening and diagnosis
- Culturally sensitive and inclusive assessment approaches
- Other? (e.g., from previous slide: addressing obstacles in primary care settings, e.g., skills and incentives)

(a) Votes from: Hector, Rep. Stanley, Jim, Zee, Susan, Hugo, Linda

Caregiver Support & Education, and System Navigation

(5 votes for rank of 1 or 2) ^(b)

Critical Factors

- Early and ongoing support and education for caregivers
- Awareness of available services among professionals and the public (Also, from previous slide: TV, radio, media, etc.)
- Ongoing support for navigating care and services
- Financial strain on individuals and families
- Other? (e.g., from previous slide: addressing gaps for low income and non-English speakers)

(b) Votes from: Hector, Rep. Stanley, Jim, Randi, Barb



(c) Focusing Our Efforts: What Comes Next?



To Discuss at the Council's Next Meeting (September 18, 2025)

For each high-impact challenge area and factors driving it, describe:

- ☐ **Current State** – Who is currently working on this; and what are they doing?
- ☐ **Future State** - What would meaningful progress look like in the next 2 to 3 years?
- ☐ **Solutions** - What can be done to make meaningful progress; and what should the Council's role be in getting there?

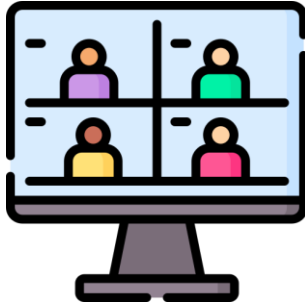
To present at the next meeting, AGE will examine the above from the state's perspective by exploring the extent that high-impact challenges are being addressed within the Executive Office of Health and Human Services (EOHHS).



5. Next Steps & Vote to Adjourn (3 min)



Ad Hoc Meeting to Vote on Annual Report



Next Council Meeting

Thursday, September 18, 2025
3:30 pm to 5:00 pm



Vote to Adjourn

Council Meetings
(3:30 pm to 5:00 pm)

Thursday, September 18, 2025
Tuesday, December 16, 2025