

# MA Advisory Council on Alzheimer's Disease and All Other Dementias

## Meeting Minutes

August 16, 2022

3:00-5:00 pm

Date of meeting: Tuesday, August 16, 2022

Start time: 3:02 pm

End time: 4:56 pm

Location: Virtual Meeting (Zoom)

Members participating remotely		Vote I*
1	<b>Secretary Elizabeth Chen</b> – Executive Office of Elder Affairs (EOEA) ( <i>chair</i> )	X
2	<b>Susan Antkowiak</b> – Alzheimer's Association - MA/NH Chapter	X
3	<b>Michael Belleville</b> – Alzheimer's Advocate	X
4	<b>Andrew Budson</b> – VA Boston Healthcare System	X
5	<b>Jatin Dave</b> – Chief Medical Officer, MassHealth	X
6	<b>Rep. Tricia Farley-Bouvier</b> – Mass. House of Representatives	X
7	<b>Sen. Patricia D. Jehlen</b> – Mass. Senate	X
8	<b>Rhiana Kohl</b> – Caregiver and Alzheimer's Advocate	X
9	<b>James Lavery</b> – Department of Public Health (DPH)	X
10	<b>Barbara Meehan</b> – Alzheimer's Advocate/Former Caregiver	X
11	<b>Hector Montesino</b> – Alzheimer's Advocate	X
12	<b>Bernice Osborne-Pollard</b> – Caregiver & Alzheimer's Advocate	X
13	<b>Linda Pellegrini</b> – UMass Memorial Medical Center	X
14	<b>Heather Sawitsky</b> – Fox Hill Village Homeowners Corp.	-
15	<b>James Wessler</b> – Alzheimer's Association	X
16	<b>Vacant Council Seat</b>	-
17	<b>Vacant Council Seat</b>	-

\* (X) Voted in favor; (O) Opposed; (A) Abstained from vote; (-) Absent from meeting or during vote

### Proceedings:

Secretary Chen called the meeting to order at 3:02pm. She welcomed members and noted that all votes taken during the meeting would be conducted via roll call.

### Vote I to Approve the June 21, 2022 Minutes:

Secretary Chen requested a motion to approve the minutes from the Council's June 21, 2022 meeting as amended. A motion made to accept the minutes from the June 21<sup>st</sup>, 2022 meeting by Andrew Budson, it was seconded by Hector Montesino. The minutes were approved by all those present.

### **Updates from the Secretary:**

Secretary Chen announced that funding was secured from the American Rescue Plan Act (ARPA) to support the Council's work. Debra Williams will be joining Pam in coordinating the work of the Council's workgroups, she is a project manager from Commonwealth Medicine of the UMass Chan Medical School.

### **Update on Equitable Access and Care Workstream:**

Secretary Chen announced that Dr. Jatin Dave would be Chairing the Equitable Access and Care Workstream. Jatin reviewed a list of definitions around diversity, equity, and inclusion with the members to level set the conversation. He presented on how the racial and ethnic makeup in Massachusetts has changed over the past decade. He noted the demographics of those being affected are primarily non-English speaking populations: Spanish, Portuguese, and Chinese (including Mandarin and Cantonese). 24.7% of Massachusetts residents are speakers of a non-English language, the national average is 22%. Many organizations have DEI strategies but noted the need for commitment.

Jatin announced the DEI Team will be holding its first meeting soon. One of the team's first goals will be to draft a vision and pledge for the Council to approve. From there, the team's goal will be to build a solid foundation of DEI into the Council's work. Specifically, he hoped that the team can:

- 1) Identify barriers that may prevent certain groups from benefiting from the Council's work.
- 2) Determine reasons for the barriers; identify approaches to eliminate them, weaken them, or mitigate their impact.

He added that the team will also work to refine recommendations already made by the Council to achieve its DEI goals. Once his team is meeting on a regular cadence, members will begin meeting with the other Council's teams to determine the following:

- 1) What challenges have they encountered associated with dementia that are specifically due to a lack of cultural understanding?
- 2) What benefits have they experienced when interacting with people who had a solid understanding of your cultural community?

He noted that those who already face barriers will have an even more difficult time navigating society with dementia.

Michael Belleville felt that it would be important to get feedback from those living with dementia as well. He added that he has friends and colleagues living outside of Massachusetts who could be beneficial as this team begins its work. He also said that a connection should be made with Massachusetts General Hospital to see what they are doing to build relationships with those from diverse backgrounds for their research projects.

Barbara Meehan noted that a major issue to address are the communities that feel "what happens at home, stays at home." She mentioned it would be important to have team members that have the same experiences as those we are seeking to reach; LGBTQ, immigrants, representation of older adults in their 70s/80s, etc. Hector Montesino said he would be interested in providing feedback in any way that he can, especially as it relates to the Hispanic and LGBTQ communities.

### **Joseph Montminy, Younger Onset and Equity Analysis Presentation:**

Before discussing the work of the Younger Onset and Equity Analysis team, Joe began by discussing his experiences living with Younger Onset Dementia. He shared his diagnosis and how it was presented, and the traumatic affect it had on his family at the time. He said he knows what it is like to live with Alzheimer's and not have resources because of his age and the strain it can cause on one's life; financial, social, etc.

Dr. Andrew Budson thanked and encouraged Joe. He felt that the neurologist that give him his prognosis errored greatly. He noted a 10-year prognosis should never be given because the data does not support it.

Michael Belleville said he had a similar experience, acted immediately after receiving his prognosis and sold his house, but nine years later he is still here. He noted that they could have stayed in their home. Jim Wessler thanked Joe and noted that the Council's efforts should include addressing better ways to diagnose, as well as better ways to communicate prognosis. Linda Pellegrini and Secretary Chen agreed, she added that continuing education in this area is needed.

Joe stated that the goal of the group is to address unmet needs and close gaps in equality, equity, and inclusion for people living with younger-onset dementia and the people who care for them.

The workgroup has identified over 15 unmet needs by those living with early onset. The workgroup believes that some of those are the result of individuals under 60 not being old enough to qualify for some state funded services and supports. Unmet needs fell into 5 categories; Public Awareness, Education and Stigma; Diagnosis; Caregivers; Finances; and Clinical Trials. Joe listed the next steps as the following:

- 1) Prioritize unmet needs and develop recommendations to address them,
- 2) Build approaches to address those recommendations, and
- 3) Provide Council with recommendations around unmet needs falling within the purview of the Council's other workstreams.

Rep. Tricia Farley-Bouvier discussed legislative involvement and what can be done to ensure that those with an early onset diagnosis have access to services that older adults do. Secretary Chen noted that those with an Alzheimer's diagnosis do have access to ASAP services and can access them without MassHealth.

Linda Pellegrini said that she appreciated the thoughtful and deliberative process that the workgroup took and felt their work would help all of the Council's other workgroups. She added that the prognosis discussion was valuable and will inform the work of her Care Planning workgroup going forward. She asked Joe about his experiences around mental health services. He responded that the Alzheimer's Association has several guides that he found helpful, which include how to live well with dementia. He has also attended support groups, and it has been helpful to hear from those with lived experience. However, back in 2017 when he was first diagnosed, those were harder to find.

#### **Council Members Roundtable Discussion:**

Susan Antkowiak noted that Governor Baker signed into law the Massachusetts FY23 budget at the end of July, it included 2 key items affecting families living with Alzheimer's disease and other dementia. 1) \$100k was approved to support the Dementia Care Coordination program; 2) \$150k for a MA public awareness campaign targeted to reach diverse communities. Susan thanked Sen. Jehlen and Rep. Farley-Bouvier for their leadership on these important budget items. She added that Dementia Operational Plans are due in October, a webinar has been scheduled for September 8<sup>th</sup> to assist hospital systems with developing these plans. Secretary Chen mentioned that the FY23 budget also included a grant program of \$75,000 to support training to family caregivers of people living with dementia.

Hector Montesino mentioned that EOEA is finalizing the dementia resources webpage after receiving feedback from those living with dementia and from caregivers. The next step is to ask stakeholders to promote the site, by including the link in their communications such as newsletters.

Jim Wessler shared that he recently attended the Alzheimer's Association International Conference, which brought together over 10,000 scientists. There were presentations on lifestyle, including the value of exercise and the negative impact of processed foods. He also heard presentations on how racism and homelessness are factors that could lead to dementia. He talked briefly about Project ECHO, which brings together PCPs for a series of lunch and learn sessions hosted by the Alzheimer's Association over the

course of 2 months. Jim also mentioned an effort underway by the Joint Commission to adopt the Dementia Care Practice recommendations for the licensure of nursing homes. He felt this could be significant in improving the quality of care.

Barbara Meehan asked about Massachusetts complying with the training requirements in Chapter 220 of the Acts of 2018. Jim Lavery responded that DPH oversees this mandate for nurses, NPs, and LPNs, who have until November 7<sup>th</sup>, 2022 to comply with the training requirement; the vast majority have already done so. Reminder notices will be going out in September. Dr. Andrew Budson pointed out that a one-time training will not cover all needs.

Secretary Chen concluded the roundtable by thanking everyone for sharing their thoughts. She stated that the next meeting will be held on November 1<sup>st</sup>, 2022.

Secretary Chen adjourned the meeting at 4:56 pm.