**MA Advisory Council on Alzheimer’s Disease and All Other Dementias**

Meeting Minutes

June 21, 2022

3:00-5:00 pm

Date of meeting: Tuesday, June 21, 2022

Start time: 3:00 pm

End time: 5:00 pm

Location: Virtual Meeting (Zoom)

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

**\*** (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 3:00 pm. She welcomed members and noted that all votes taken during the meeting would be conducted via roll call.

**Vote 1 to approve the February 15, 2022 minutes:** Secretary Chen requested a motion to approve the minutes from the Council’s last meeting on February 15, 2022. Ms. Meehan introduced the motion, which was seconded by Mr. Montesino and approved by roll-call vote (see detailed record of votes above).

**Presentation by the Care Planning Team**

Linda Pellegrini and Susan Antkowiak provided an update on the Care Planning team’s efforts. The team developed fliers to recruit individuals for focus groups and conducted phone screenings of potential participants. To date, the team has convened 2 focus groups over Zoom with a total of 5 participants. All have consented to having the sessions recorded. The sessions were led by staff from the Alzheimer’s Association and were made up of individuals living with dementia, caregivers, and care providers.

Some next steps include recruiting additional caregivers of people living with dementia to participate in focus groups this fall. Ensuring a diverse representation of participants has been a challenge. Through caregiver participation in the focus groups, the goal is that their thoughts and ideas will help the team create a guide for individuals as they communicate their values and preferences to their doctors. Linda Pellegrini added that she and members of the team will be meeting with the Worcester Senior Center. Jim Wessler suggested coordinating with community health centers. Barb Meehannoted that she facilitates an LGBTQ support group and said caregivers would be more than willing to participate. She also suggested identifying very specific populations, e.g., Portuguese speakers. It was noted that the conveners should try to be as flexible as possible when scheduling these focus groups. The Dementia Friendly Coalition in Springfield was also brought up as a potential resource.

**Update on Equitable Access and Care Workstream**

Secretary Chen announced that Dr. Jonathon Jackson resigned from the Council and that now both researcher seats on the Council are open. Council members are invited to put forward recommendations for the administration to consider. The Secretary announced Dr. Jatin Dave will chair the Equitable Access and Care workstream and will present and lead a discussion at the Council’s August meeting. Secretary Chen then asked for feedback from council members who attended the training hosted by the Racial Equity Institute (REI).

Linda Pellegrinitalked about the lake analogy used during the training. Circumstances in a lake can be changed, but it might still not change the lake because the groundwater feeding the lake is the same. She added that certain populations have difficulty getting a diagnosis due to socioeconomic issues. Jim Wessler felt it was a good reminder that good policies can have unintended consequences when not viewed through an equity lens. Barb Meehannoted that she was taken back by how little she knew. The two-day training was incredibly moving. She said there needs to be more understanding of history to understand cultural differences. Hector Montesinofelt we need to focusonhow to reach participants. We need to meet people where they are and be willing to pay them for their time, to incentivize them. Susan Antkowiak found the lack of understanding bewildering; school systems need to make the invisible visible. Mike Belleville said trust is an issue and more people need to take the training to understand where mistrust is coming from. He added that it is easy to take privilege for granted.

**Why Diversity, Equity and Inclusion (DEI) Matter – *Panel of Individuals with Lived Experience***

Everyone on the panel has been affected by dementia. They shared their stories around cultural understanding (or lack thereof) experienced, for example, among healthcare professionals, dementia care professionals, elder service agencies.

1. **Clint Kershaw**, a gay person living with dementia was 56 years old when first diagnosed and is now 61. He was referred to a neurologist to “get better.” However, because of his young age people who do not know him do not see what his caregiver sees. Clint’s partner and caregiver, Jeff, said it is difficult for gay and lesbian people as they do not always have family. They rely on friends or “chosen family” for support. Client said he does not have trouble accessing services as a gay man; however, he does have trouble accessing them as a person who is younger with dementia. He added that an early diagnosis has enabled him to plan out how he wants to live better. Massachusetts has a tremendous amount of services and it is a matter of knowing how to access them.
2. **Pastor Tirsa Ramirez’s** mother was diagnosed with dementia. At that time, Pastor Ramirez did not know what dementia was; this is not uncommon for those in the Latino community. Pastor Ramirez said she received education and training from Caregiver Homes. She went on to become her mother’s caregiver until she passed away. Pastor Ramirez expressed the need for community leaders in the Latino community that can encourage people to access resources. People do not understand what Alzheimer’s is; individuals protect their families and there is a stigma around it. In her culture, some people even think it is funny when people forget things. She hopes to continue to spread awareness and educate people about Alzheimer’s; this is a topic she talks to her congregation about. The universal language of education is incredibly important to break down barriers and bring people together.
3. **Valderez Oliveria** expressed how happy she was that there was so much interest in hearing her story. Ms. Oliveria immigrated from Brazil in 1996. Her husband was diagnosed in 2013 in Brazil. The biggest challenge they faced was not having a lot of support from their doctors; she was dismayed by the lack of “warmth”, and they seemed to not care about their family’s situation. Often her son had to translate for her and her husband. She had to research what services were available to him and then went on to care for him full time. She would have liked for her husband’s doctors to have done follow-up wellness calls to see how he was doing. She added that there should be mental health services available for caregivers to help them care for their loved ones. Her husband passed away in 2021 after having dementia for 8 years.

Secretary Chen adjourned the meeting at 5:01 pm.