Alzheimer's Advisory Council

Meeting Minutes December 7, 2021 3:00-5:00 pm

Date of meeting: Tuesday, December 7, 2021

Start time: 3:00 pm End time: 5:00 pm

Location: Virtual Meeting (WebEx)

Members participating remotely		Vote I*
ı	Secretary Elizabeth Chen – Executive Office of Elder Affairs (EOEA) (chair)	×
2	Susan Antkowiak – Alzheimer's Association - MA/NH Chapter	×
3	Michael Belleville – Alzheimer's Advocate	×
4	Andrew Budson – VA Boston Healthcare System	X
5	Jatin Dave – Chief Medical Officer, MassHealth	X
6	Tricia Farley-Bouvier – Mass. House of Representatives	X
7	Jonathan Jackson – Mass General Brigham	-
8	Patricia D. Jehlen – Mass. Senate	X
9	Rhiana Kohl – Caregiver	-
10	James Lavery – Department of Public Health (DPH)	X
П	Barbara Meehan – Alzheimer's Advocate/Former Caregiver	X
12	Hector Montesino – Alzheimer's Advocate	-
13	Linda Pellegrini – UMass Memorial Medical Center	X
14	Heather Sawitsky – Fox Hill Village Homeowners Corp.	X
15	James Wessler – Alzheimer's Association	X
16	Bernice Osborne-Pollard – Caregiver	-
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. Secretary Chen informed the Council that Dr. Maura Brennan has decided to step down from the Council and her vacant Council seat will be filled as soon as possible.

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Vote I to approve the 9/I/2021 minutes: Secretary Chen requested a motion to approve the minutes from the Council's last meeting on September I, 2021. Ms. Meehan introduced the motion, which was seconded by Mr. Belleville and approved by roll-call vote (see detailed record of votes above).

Patty Sullivan, Program Director, Dementia Friendly Mass., Mass. Councils on Aging (MCOA) and James Fuccione, Senior Director, Mass. Healthy Aging Collaborative presented on age and dementia-friendly physical infrastructure and facilitated a discussion on the implementation of the Physical Infrastructure workstream's two recommendations from the Alzheimer's State Plan. The recommendations include: I) raising awareness and developing age and dementia-friendly design criteria; and 2) incorporating age and dementia-friendly scoring into all state-funded physical infrastructure projects. For additional details on the Physical Infrastructure workstream's presentation, refer to the group's slides within the Council's presentation on the Alzheimer's Advisory Council's Meeting Materials webpage.

Molly Purdue, Executive Director, Alzheimer's Family Support Center (AFSC) of Cape Cod, presented on their recent grant from the Administration for Community Living, part of the U.S. Department of Health and Human Services. She explained that the grant will fund the opening of a second AFSC office at the Cape Cod Mall in Hyannis to bring dementia support to residents of the Cape. In addition, she noted that the grant will fund numerous initiatives, including a cognitive health program and the development of memory screenings for use by general practitioners.

Secretary Chen invited workstream leads to report on and discuss the progress of their work with the Council.

Caregiver Support and Public Awareness Workstream

- Molly Evans, Senior Policy Manager with EOEA, provided updates on the efforts of the Caregiver Support and Public Awareness workgroup to embed their work into the office's Aging Services Access Point (ASAP) designation review process and a proposed "agency rebrand" pending CMS approval of an ARPA proposal.
- Ms. Meehan provided an update on the video for family caregivers to raise awareness of available supports. She noted that the English-version has been completed, and the Spanish and Portuguese versions will be finalized in the coming months. She noted that the videos will be distributed to all Mass. cable access stations. She provided additional updates on the development of resource pages within the EOEA website which highlight dementia services, information, and resources for caregivers and people living with dementia.

Quality of Care Workstream

- Lisa Gurgone, Executive Director, Mass Home Care, presented on the American Rescue Plan Act (ARPA) Home and Community based Services (HCBS) recruitment and training initiatives to support direct care workers:

 - o https://www.mass.gov/home-care-aide-training-phcast
- Ms. Pellegrini provided brief updates and led a discussion around the implementation of the Quality
 of Care workstream's recommendations around the development of a person-directed care plan
 framework and template to help guide and empower individuals to communicate their preferences
 to providers.
- Ms. Antkowiak provided an overview of the two virtual focus groups that are being organized for February: one with people living with dementia and another for caregivers of those with dementia.
 She noted that recruitment for the focus groups is ongoing.

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Mr. Belleville proposed that the name of the Council be updated to include a reference to all forms
of dementia in an effort to be inclusive of those with other types of dementia than Alzheimer's. In
response, Dr. Budson noted that the term Alzheimer's Disease and Related Dementias (ADRD) is a
standard term that is commonly understood to include all dementias. Secretary Chen noted that the
proposed name change would be discussed further at a future meeting.

Equitable Access and Care Workstream

- Dr. Kohl provided an update on the work of the Younger-Onset and Equity Analysis workgroup, which met in November to discuss unmet needs and challenges facing this population, which consists of individuals under age 65 who have been diagnosed with dementia, such as limited eligibility for clinical trials and access to aid and support because of the perception of dementia as a geriatric condition. She noted that recommendations and an implementation plan will be shared at a future meeting.
- Dr. Jackson explained that he has organized a workgroup of individuals from across the state to explore issues of equity, access, and inclusion in the Council's work. He stated that his experiences with some organizations associated with the Council have been unfavorable. In response, Secretary Chen stated that she would follow up with Dr. Jackson directly to discuss this issue further and develop a process for addressing his concerns, which may include trainings on diversity, equity, and inclusion for members of the Council.

Research Workstream

• Dr. Budson stated that he has invited Dr. Ron Killiany, Associate Professor of Anatomy and Neurobiology at Boston University School of Medicine, to spearhead the Research workstream beginning in early 2022.

Diagnosis and Services Navigation Workstream

- Mr. Wessler provided various updates on the progress made on the Diagnosis and Services
 Navigation Workstream. He explained that the clinician toolkit with useful links and resources for
 primary care physicians screening individuals for Alzheimer's disease was posted to the Alzheimer's
 Association website. He also noted that Board of Registration in Medicine sent out a communication
 to its members about physicians' responsibilities to inform families of individuals' treatment plans
 and reminding them of their training responsibilities.
- Representative Farley-Bouvier noted that additional efforts are needed to streamline the process for
 case workers from Aging Service Access Points (ASAP) to follow up with clinicians. Secretary Chen
 noted that she would raise this question with the ASAP executive directors to help identify a
 solution.

Secretary Chen noted that the Council's next meeting is scheduled for February 15, 2022.

Secretary Chen adjourned the meeting at 5:00 pm.

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