

## Alzheimer's Advisory Council

Meeting Minutes  
December 17, 2019  
3:00-5:00 pm

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**Date of meeting:** Tuesday, December 17, 2019

**Start time:** 3:08pm

**End time:** 4:53pm

**Location:** McCormack Building, One Ashburton Place, 21<sup>st</sup> Floor, Boston, MA

### Members present:

- Elizabeth Chen— Executive Officer of Elder Affairs (Acting Chair)
- Jim Lavery—Department of Public Health
- Andrew Budson, MD—VA Boston Healthcare System
- Robin Callahan—MassHealth
- Rep. Ruth Balser—MA House of Representatives
- Hector Montesino, CDP—Alzheimer's Advocate
- Rhiana Kohl, PhD—Caregiver
- Jonathan Jackson, PhD—CARE Research Center, Mass. General Hospital
- James Wessler—Alzheimer's Association
- Sen. Patricia Jehlen—MA Senate

### Members calling-in:

- Maura Brennan, MD—Baystate Medical Center
- Linda Pellegrini, NP—UMass Memorial Medical Center
- Barbara Meehan—Alzheimer's Advocate/Former Caregiver
- Susan Antkowiak—Alzheimer's Association
- Bernice Osborne-Pollar—Caregiver
- Michael Belleville—Honorary Member
- Heather Sawitsky, JD, MPH—Fox Hill Village Homeowners Corp.

### Members absent:

- Marylou Sudders – Executive Office of Health and Human Services (Chair)

### Proceedings:

Secretary Chen called the meeting to order at 3:08pm.

Secretary Chen announced to the group that she would be chairing this meeting in Secretary Sudders' absence.

**Vote: Rep. Balser introduced a motion to approve the minutes, which was seconded and unanimously approved, by roll call.**

Secretary Chen reminded members of the presentation they had seen at the last meeting by the Alzheimer's Association, and stated her goal to get the group "up to speed on what the Executive Office of Elder Affairs (EOEA)

has been doing for Alzheimer's disease, individuals, their families, and caregivers." She proceeded to deliver her presentation, and members asked technical clarifying questions throughout *[See posted presentation]*.

Dr. Budson noted his surprise that even as a neurologist working in this space, he was relatively unaware of the "depth of [EOEA's] programs," and noted that he was sure there were many other health care providers in the Commonwealth who weren't fully aware. Secretary Chen acknowledged that EOEA had work to do in terms of "communicating [their] work." Dr. Budson added that one contributing problem is that not every physician group providing care for those with Alzheimer's/dementia has a care manager associated with them; it's a lot of private care instead. Secretary Chen noted this as an area for consideration in the annual report.

Dr. Budson inquired whether Continuing Medical Education (CME) trainings include information about EOEA programming. Mr. Wessler replied that CME for physicians requires "certification in dementia care," but does not get more specific beyond that. Rep. Balser inquired whether the CME definition of care includes knowledge about these resources. Mr. Wessler replied that he doesn't believe it's specified. Rep. Balser noted this as an area for consideration in the annual report, to include familiarizing doctors with these resources as part of dementia care certification.

In discussing Memory Cafes, Dr. Kohl noted that their locations can be inaccessible for some communities. Dr. Jackson inquired how many Memory Cafes are run in languages other than English. Secretary Chen agreed to look into this question.

Ms. Callahan asked about how the work of the Governor's Council to Address Aging relates to the work of the Alzheimer's Advisory Council. Secretary Chen noted that these groups should not duplicate one another's work, but rather leverage each other's work.

Ms. Callahan asked about the proportion of individuals receiving home care through ASAPs who are living with Alzheimer's/dementia. Secretary Chen replied that this number is not currently known, as not everyone diagnosed with dementia needs home care immediately. She noted that one potential action item for the Council would be to determine the size of the population. Mr. Wessler and Dr. Budson estimated that two-thirds of the 130k individuals in the Commonwealth with Alzheimer's require some form of homecare.

*Secretary Chen continued her presentation.*

Senator Jehlen entered the meeting at 3:48pm.

Dr. Kohl asked if EOEA runs a hotline or 800-number. Secretary Chen told her about 1-800-AGE-INFO, which EOEA is currently merging with another hotline it operates. Dr. Kohl replied that the semantics of aging, and this hotline being hosted by EOEA is exclusionary to individuals with younger-onset Alzheimer's who are not "elderly." She also asked whether there was another hotline with the capacity to receive "frustration" calls or feedback about services. Secretary Chen replied that this hotline can serve that purpose, as well as the hotline run by the Federal Government, funded by the NIH. She added that EOEA is sensitive to the age implication of the phone number, and that they are considering renaming it.

Secretary Chen concluded her presentation and opened the discussion among the group about its potential recommendations for the Annual Report. She highlighted that this is a "starting point" for the Council, and asked members to consider what can be accomplished in a year. She asked members to look at the 6 "themes" *[slide 19]* and to consider if the items they submitted were "caught" in these "buckets."

Rep. Balser noted that for her, one of the biggest realizations in this past year of Council work is the prevalence and impact of early-onset Alzheimer's, that while providing access to services to this population may be a recommended goal, it may not be something that can be accomplished in the next year. Dr. Budson agreed, noting that while this is a serious issue requiring attention, only 5% of patients are under 65 years old, and the Council shouldn't "ignore the other 95%."

Dr. Jackson note that his contribution was captured on slide 21, #14, about ensuring equitable distribution of resources. He asserted that this idea should be included as a framework for all of the Council's work. He recommended using Centers for Medicare and Medicaid Services (CMS) data to compare diagnoses across the state with where resources and programs are distributed. Ms. Callahan agreed with Dr. Jackson, and noted that with resources and programs, "Organic growth tends to skew." She agreed that it would be a worthwhile effort for the Council to do some data collection about particular areas of populations who may be underserved.

Mr. Montesino spoke in support of the Public Awareness campaign recommendation. Secretary Chen replied that such campaigns can be costly, so it could make sense to start by targeting a smaller group and making 3-5 year goals.

Mr. Wessler agreed with Dr. Jackson's point, and highlighted that Latino and Black populations face higher risks of developing Alzheimer's/ dementia, and that these communities are underserved and less likely to seek help. He also noted that regarding the public awareness campaign, with the inclusion of modifiable risk factors, the Commonwealth "has a great opportunity to shape this around a public health model."

Secretary Chen asked Dr. Jackson if he could provide the Council with the measures around access, equity, and inclusion that he believes would be good starting points. He agreed to send materials to Council staff (Amy Kaplan). Dr. Budson suggested making Dr. Jackson's recommendation (#14) a 7<sup>th</sup> "area of consensus;" Secretary Chen agreed. Dr. Jackson offered some clarification to the written language, stating that he would frame it around how certain populations are "uniquely vulnerable" at each disease stage, and by "solving for the barriers faced by certain populations, we can address the gaps." He noted that "if we leverage the networks we have, the underserved remain underserved."

Dr. Budson wondered if part of the public awareness campaign could be creating an in-school education day on Alzheimer's in which students do projects and presentations, to get them and their families involved in learning about dementia. Secretary Chen agreed that this could be incorporated as an idea, as a voluntary program for schools to participate in.

Mr. Lavery suggested that one approach in thinking about equity would be to look at communities that are successful in their dementia programming and to examine their "common denominators of success." Secretary Chen replied that one reason why some communities have decided to become age/dementia-friendly is because a large percentage of their populations are over the age of 60, and that becoming age/dementia-friendly is a locally-funded initiative, which goes through the town budget. She agreed that it's important to "get folks in the middle of the state to recognize that this is an important use of their dollars." Kathryn Downes, EOEA, who was seated in the audience, added that in addition to municipal funding, there is a lot of private philanthropy contributing to these efforts.

Dr. Jackson left the meeting at 4:24pm.

Dr. Kohl stated that she didn't submit any recommendations because she thought that what had previously been discussed in meetings would be represented. She went on to state her concerns with keeping accountability for insurance companies to adhere to regulations; she described her experience coordinating her husband's care and

emphasized the “real lack of services and no accountability.” She then spoke about issues with workforce turnover and spoke to her personal issues with the workers that her family received and with confusing paperwork.

Secretary Chen agreed that a central source of information would be very helpful to families, and recognized that “we have a long way to go,” and that the home care workforce turnover is very high. She went on to say that these recommendations can be framed in terms of primary prevention, secondary prevention, and tertiary prevention, explaining all these terms. Dr. Budson noted that these buckets are helpful but that using more descriptive names may be more useful for everyone to understand.

Dr. Brennan added that there are enormous numbers of people with dementia who are not identified, which is a major gap. She argued that this is not primary prevention, and should not be included in the primary prevention bucket. Dr. Brennan emphasized the need to address this gap. Dr. Budson agreed.

Rep. Balser spoke again about early-onset dementia, and considered that it may be useful to frame this population as a minority group in approaching the issue of ensuring that everyone who needs services has access.

Secretary Chen noted that the next scheduled Council meeting is February 25<sup>th</sup>, and that in preparation, the framework would be modified to include Dr. Kohl’s concerns. Mr. Wessler suggested adding the “additional items [slides 20 and 21]” in to the framework as well. Secretary Chen agreed, and added that Council staff will add all of the recommendations into the public health framework and would circulate this among members.

Dr. Budson inquired whether the groups should meet in January in addition to February. Others agreed, with Mr. Montesino added that the group has “spent a lot of time hearing testimony,” and that some additional deliberation time would be helpful. Members agreed to hold an additional meeting in January.

**Vote: Rep. Balser introduced a motion for the meeting to adjourn, which was seconded by Mr. Wessler and unanimously approved, by roll call.**

The meeting was adjourned at 4:53pm.