**Alzheimer’s Advisory Council**

Meeting Minutes

March 19, 2019

3:00-5:00 pm

**Date of meeting:** Tuesday, March 19, 2019

**Start time:** 3:07pm

**End time:** 5:01pm

**Location:** Health Policy Commission Conference Center, 50 Milk Street, 8th Floor, Boston, MA 02110

**Members present:**

* Marylou Sudders – Executive Office of Health and Human Services (Chair)
* Robin Lipson—Executive Officer of Elder Affairs
* Elizabeth Chen—Department of Public Health
* Andrew Budson, MD—VA Boston Healthcare System
* Robin Callahan—MassHealth
* Rep. Ruth Balser—MA House of Representatives
* Sen. Patricia Jehlen—MA Senate
* Hector Montesino, CDP—Alzheimer’s Advocate
* Rhiana Kohl, PhD—Caregiver
* Barbara Meehan—Alzheimer’s Advocate/Former Caregiver
* Bernice Osborne-Pollar—Caregiver
* Heather Sawitsky, JD, MPH—Fox Hill Village Homeowners Corp.
* Linda Pellegrini, NP—UMass Memorial Medical Center
* Jonathan Jackson, PhD—CARE Research Center, Mass. General Hospital
* Susan Antkowiak—Alzheimer’s Association
* James Wessler—Alzheimer’s Association

**Members absent:**

* Maura Brennan, MD—Baystate Medical Center

**Proceedings:**

Secretary Sudders called the meeting to order at 3:07pm.

Secretary Sudders welcomed members to the first meeting of the Alzheimer’s Advisory Council, and invited everyone to briefly introduce themselves. Members went around and shared their professional or personal histories that relate to the work of the Council.

Secretary Sudders thanked the Council members and then briefly summarized the rules of Open Meeting Law, before opening the floor to presentations.

Robert Jones, Deputy Chief of Staff, Executive Office of Health and Human Services (EOHHS), administered the oath of office for special state employees.

David Giannotti, Public Education and Communications Division Chief of the State Ethics Commission, provided the Council with a brief overview of the state’s conflict of interest and ethics regulations. He explained that members of the Council are considered special state employees and should consult the State Ethics Commission with any questions or concerns related to potential conflicts of interest. He highlighted members’ education requirements, which include recertifying each year their receipt of the Open Meeting Law guide, as well as the completion of the state’s online ethics training program every two years.

Lauren Cleary, Associate General Counsel for the Executive Office of Health and Human Services, provided an overview of the Open Meeting Law. She emphasized the importance of transparency and reminded members that documents and minutes from the Council’s meetings are part of the public record.

Secretary Sudders noted any materials that Council members want to circulate should be sent through Amy Kaplan (EOHHS), in order to avoid a violation of the Open Meeting Law.

Secretary Sudders proceeded to introduce the Council’s charge (see meeting materials, posted on the Council’s website: https://www.mass.gov/lists/alzheimers-advisory-council-meeting-materials). Dr. Budson requested a clarification about the language in the charge stating that “the advisory council shall work with the secretary of health and human services to determine the number of persons diagnosed each year with early-onset Alzheimer’s disease regardless of their age”. The Council discussed this language, and Dr. Kohl clarified that this section refers to individuals who developed early-onset Alzheimer’s disease but who are now over 65 years old. Secretary Sudders offered that because the Council is charged with devising a state plan, that these charges may be considered “elements of the plan,” and that one element may be the identification of early-onset Alzheimer’s disease.

Secretary Sudders went on to explain that the statute that created the Council does not designate a Chair. She clarified that EOHHS staff members will staff this Council, if that was of interest. Representative Balser suggested that this may be a result of a drafting error, and Mr. Wessler confirmed that this was the case.

**Vote: Representative Balser introduced a motion to approve Secretary Sudders as the Chair of the Alzheimer’s Advisory Council, which was seconded by Senator Jehlen and unanimously approved.**

Secretary Sudders explained that Dr. Brennan, who was unable to attend this first meeting, had requested that the Council take a vote to allow for remote participation at future meetings.

**Vote: Dr. Kohl introduced a motion to allow remote participation at all subsequent Council meetings, which was seconded by Mr. Wessler and unanimously approved.**

Secretary Sudders expressed that this Council presents a “great opportunity to formalize” a state plan, which has not been done before. She then opened the floor for the Council to discuss how they would like to organize themselves.

Mr. Wessler advocated for an individual living with dementia to be included on the Council, but noted that this may be difficult now that the Council members had been finalized. Ms. Meehan agreed, and noted that it would be an important perspective to have, and that it is important for the Council to “at least hear from some people” who are living with a form of dementia. Dr. Pellegrini agreed and noted that the previously-organized Acute Care Committee hosted speakers. Senator Jehlen suggested that it may be possible to have associate members, who are non-voting. Secretary Sudders offered to look into the possibility of an EOHHS designee position being offered to such an individual.

Mr. Wessler mentioned a previous state plan, which was completed by executive order. He described the plan, which dealt with caregiver issues, access to services, and the training of clinicians. He noted the recommendations from the Acute Care Advisory Committee have not yet been implemented, and that a framework for their implementation could be part of this Council’s work. He also noted that from a public health point of view, there is increasing evidence around numerous risk factors for Alzheimer’s disease and related dementias, and summarized by stating that this Council has “an immense opportunity and tools” at its disposal.

Dr. Budson agreed and noted that the Council should not only report on initiatives to help those currently living with Alzheimer’s, but to provide suggestions to the Commonwealth to reduce the number of individuals developing Alzheimer’s in the future.

Dr. Jackson agreed, but wanted to highlight that “these risk factors are not borne proportionally by the population of Massachusetts.” He explained that the populations that are growing the most quickly are those at highest risk; for example, there is a lack of supportive resources in Spanish. He described the key literacies that inform Alzheimer’s disease treatment: health, medicine, research, and insurance. He reported that in his work, he finds that those with literacy in all four dimensions are successful in finding supportive services and navigating their healthcare, but deficiencies in one area creates significant problems in accessing services. He emphasized that communities that face disproportionate impact of this disease are those that have lower literacy in these domains. He urged the Council to focus on the impact for various ethnic, racial, and rural populations.

Dr. Kohl expressed that “it’s an overwhelming task that [the Council has] been given.” She noted that the concept of navigating a system implies that a system exists; she reported that in her experience, no system exists. She emphasized the piecemeal nature of navigating dementia care, and that any recommended plan should address this. She went on to speak about the importance of increasing public awareness, including the eradication of stigma and myths, which present as barriers to care, and awareness of early-onset Alzheimer’s disease or dementia.

Mr. Montesino seconded what Doctors Jackson and Kohl stated. He went on to note that there are a range of holistic approaches and therapies for dementia, but that these are limited to those with resources, and require a great deal of training. He noted the importance of providing these tools to support caregivers at home.

Ms. Meehan noted that for individuals who are not on MassHealth, but do not have the income level needed to access all services, there is no choice but to engage in long term care, even if this is not preferred. Senator Jehlen expressed interest in understanding this further, to see what services are available or unavailable to individuals at different levels of coverage. Ms. Meehan explained that because she was not married to her partner for whom she was a caregiver, she could technically have served as a Personal Care Attendant (PCA). However, because her partner did not have MassHealth, she was ineligible for PCA services. She noted that the experience of being a caregiver can be very socially isolating, due to the ongoing stigma around Alzheimer’s and dementia. Mr. Wessler noted that outside of MassHealth, most caregiving services are not paid for; Dr. Budson mentioned that the VA does currently provide some services. Secretary Sudders offered to provide a table of existing options, including the federal poverty level and insurer types. She also offered to look back at the Governor’s Council on Aging listening session notes, to see what was heard about the inability to find services/supports for caregivers.

Secretary Sudders summarized what had been brought up so far: a public health approach, through a lens of equity, including economic equity, and including younger-onset individuals.

Mr. Wessler brought up quality of care as another area to examine. He also noted that less than a quarter of individuals with Alzheimer’s disease are diagnosed, and that this presents as a “massive barrier” to medical treatment.

Ms. Osborne-Pollar noted that she would like to hear about respite care providers, and the possibility of providing more of this support, and with extended hours, to home caregivers.

Acting Secretary Lipson added that there needs to be a focus on execution; that she hears stories about providers who are unwilling to treat patients because “they don’t want to deal with it.” She also noted that there is a need to improve how employers support employees who are caregivers. Dr. Pellegrini noted that this relates to dementia-friendly communities.

Dr. Budson mentioned his work on a grant review committee for the state of Pennsylvania, which had specific Alzheimer’s research going towards projects that would not be funded by NIH or pharmaceutical companies, and that a similar grant could be something the Council could consider advocating for. Secretary Sudders requested that he provide more information on this work to her staff; Dr. Budson agreed.

Dr. Jackson brought up the “emergent” issue of those living with dementia who continue to work. He noted that this will be an expanding population. He personally has heard stories about individuals who were either fired, reprimanded, or punished in a work environment because they were acting in a way that people felt was irresponsible and then later diagnosed with Alzheimer’s. He suggested that the Council could “harmonize” its efforts with businesses to put policies or formal courses of action in place for handling these situations. Dr. Kohl agreed, and noted that when these individuals are fired, they are not eligible for long term care. She invoked her personal history, in which her husband accumulated a significant amount of debt before his diagnosis was made, and that while she had evidence that this debt was created while he had a disease, she has been unable to have these debts alleviated. When her husband was let go from his job, he was not eligible for unemployment or social security, resulting in “complete income loss” for her family. She emphasized that this is a “very costly disease, financially, emotionally, and for society.”

Ms. Callahan agreed that the issue of early-onset Alzheimer’s is important, because there are many community-based services that individuals are only eligible for by virtue of their age. She noted an opportunity to make certain services available for younger populations. She also raised an example regarding Dr. Jackson’s point about individuals with dementia in the work force, in which a worker did not have any family in the area, and her changing behavior was only noticed by her coworkers. She noted the importance of considering individuals without family or caregivers. Mr. Wessler agreed that the issue of people who live alone and without a caregiving unit is persistent. He mentioned that there is currently a bill for an elder disability waiver that would make people with Alzheimer’s eligible for social benefits.

Secretary Sudders, in reference to Dr. Kohl’s anecdote about her husband’s debt, mentioned her own experience in handling a family member’s debt that had accumulated while the family member was suffering from a major mental illness. She described navigating the laws in that state in order to alleviate this debt, and noted that this was only possible through a combination of the Consumer Bill of Rights and the laws around medical guardians for mental health. She noted that some protections for individuals with Alzheimer’s may be sourced from other areas, such as this.

Dr. Kohl mentioned the need for navigators/mentors for caregivers, to help them know how to fill out paperwork, and who to call; “we shouldn’t be living in a vacuum…it was extremely challenging, and I’m extremely resourceful.”

Dr. Jackson asked to clarify the language of the bill, that sometimes it refers to “Alzheimer’s,” and at other times to “Alzheimer’s and related dementias.” He explained that “when we think about Alzheimer’s, we think about symptoms and sometimes we think about the underlying etiology.” He asked to clarify if the Council was thinking about “Alzheimer’s” as an etiology (the formation of amyloid plaques), Alzheimer’s disease symptomology, or broader dementia. He noted that if the Council were to focus on prevention and early intervention, the etiology would need to be considered, but in terms of thinking about public awareness and eradication of stigma, the disease presentation was more important. Mr. Wessler noted that the bill was intended to address both Alzheimer’s disease and other related dementias.

Ms. Sawitsky noted that because of the lack of effective treatment, the identification of a biomarker should be a research priority. Dr. Budson corrected that a biomarker exists, along with an FDA-approved PET scan, but that the scan is not paid for by insurance companies, presenting more of an “economic problem than a scientific problem”. He emphasized that existing treatments can impact symptomology, and can “turn the clock back” to return individuals’ memories to their states 6 or 12 months prior. He agreed that for policy, financial, and technical reasons, there is still a lot to be done. Ms. Antkowiak mentioned that the idea of access to services should include access to clinical trials, and that the Council needs to consider how to make trails accessible. Mr. Wessler added that there is emerging information about lifestyle and its impact on high blood pressure, which correlates with mild cognitive impairment, and agreed that there is a lot of work to be done in this area.

Assistant Commissioner Chen offered that in thinking about “far upstream prevention,” one could look at the “nun study,” which showed that individuals with more “cognitive reserve” had delayed onset of symptoms, even in the presence of post-mortem amyloid plaques. She likened this reserve to physical fitness, and how those with increase fitness are more likely to be able to walk into their older age. She summarized that some upstream public health intervention could focus on “building that cognitive reserve.”

Secretary Sudders referenced the text of the Council’s charge, and noted that it is specific to Alzheimer’s disease until the section pertaining to the Board of Continuing Education, which references related dementias. Representative Balser noted that the Board of Continuing Education and this Council are separate entities, so that in the section pertaining to this Council, it only talks about Alzheimer’s. Mr. Wessler reported that the intent of the language was to include Alzheimer’s and related dementias. Dr. Kohl agreed that the “spirit of the legislature” is intended to include Alzheimer’s and other dementias.

Mr. Wessler noted in reference to Dr. Budson’s grant work in Pennsylvania: the Commonwealth did some funding research with the Mass Biotech Fund.

Secretary Sudders mentioned that when she reviewed the 2012 Massachusetts Alzheimer’s Disease and Related Disorders State Plan document, she did not see it as a formalized state plan, which should be a “living document,” that is “transparent and iterative.” She expressed the need for a comprehensive, actionable plan, which would create a system, to replace the current state of “component parts”. She emphasized that the Council has an opportunity in Massachusetts to have a plan that defines such a system. Dr. Kohl agreed and noted the importance on focusing on a “framework,” that adds treatment, services, supports, and prevention to the literacies that Dr. Jackson had listed. Secretary Sudders agreed, and noted that through a public health approach, the Council would be able to include all of these lenses.

In conclusion, the Secretary announced that the Council would meet at least quarterly. She urged members to consider what information would be helpful to them; she mentioned options to hear from panels of experts, caregivers, or individuals who had been diagnosed.

**Vote: Secretary Sudders introduced a motion for the meeting to adjourn, which was seconded by Acting Secretary Lipson and unanimously approved.**

The meeting was adjourned at 5:01pm.