



## Department of Health

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Governor

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Commissioner

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Acting Executive Deputy Commissioner

### MINUTES

NYS Coordinating Council for Services Related to Alzheimer's Disease  
and Other Dementia  
Thursday, August 17, 2023  
10:00 AM – 12:00 PM

#### **Council Members and Representatives:**

**Members Present in Person:** Andrew Lebwohl (NYSDOH), John Cochran (NYSOFA), Maxine Smalling (OMH), Julie Kelleher (OCFS), Elizabeth Smith-Boivin, Denise Cavanaugh

**Members Present Virtually:** Teresa Galbier, Catherine James, Jed Levine, James Taylor

**Members Absent:** Dr. Louis Belzie, Dr. William Higgins, Suzanne Sullivan (NYSED), Dr. Carl L. Cohen, Susan Prendergast (OPWDD)

**NYSDOH Staff Present:** Lynn Young, Katie Mahar, Erin Fay, Susanne Coburn, Tyler-Marie Leggett, Cassandra Tysn, Penny Plouffe, Tracy Sinnott, Susan Lawless Esq. (DLA)

**Others Present:** Bill Gustafson (Alzheimer's Association), Dr. Carol Podgorski, Lisl Maloney (OCFS), Erin Purcell (NYSOFA), Alyson Tarek (Chamber), Geri Taylor

Note: The meeting was conducted in person and via Webex. The meeting was recorded.

#### **Welcome and Roll Call:**

Mr. Lebwohl called the meeting to order at 10:10AM, and Ms. Fay conducted the roll call. Mr. Cochran voiced appreciation for all of the work that has been done on the Master Plan for the Aging, as multiple Council members are involved on work plan groups and sub-committees.

#### **Approval of Minutes from Past Meetings:**

Mr. Lebwohl and Ms. Fay reiterated to the Council members that past minutes cannot be approved as there is not an in-person quorum present for the meeting.

#### **In-Person Quorum and Open Meetings Law and the Extraordinary Circumstances Resolution:**

Mr. Lebwohl reviewed the importance of having an in-person quorum to be able to take official action as a Council. He addressed the concern that the Council has not met the in-person requirement for a quorum for the last several meetings. Mr. Lebwohl explained that leadership has examined the possibility of requesting to a change in statute to decrease the number of representatives on the Council. He also encouraged those who are able to attend in person, to

do so. Ms. Smith-Boivin inquired about the number of seats that are currently open on the Council, and if the Council is aware that they can make recommendations for new Council members. Currently there is a candidate going through the vetting process and will hopefully be appointed by the next meeting, in November. Ms. Smith-Boivin recommended the addition of a neurologist, following Dr. Nixon's departure from the Council. Mr. Cochran requested clarification from Ms. Lawless on in-person regulations. Ms. Lawless provided detail on the ADA (Americans with Disability Act) carve-out and the extraordinary circumstances provision. Ms. Lawless described that the Open Meetings Law is in statute and any requested changes would be a legal matter requiring legislative cooperation, citing that if the Council decided to lobby regarding the matter, they would reach out to the Committee of Open Government.

### **2023 Council Report Status Update and Plan:**

Mr. Taylor requested clarification of the plan for submission of the report, as well as the objective of the report. Ms. Fay reviewed the timeline for submission with a goal to review, complete updates, and approve the draft report at the November Council meeting. Ms. Fay highlighted the importance of having an in-person quorum at the November meeting for an official vote. Ms. Fay explained that once the report was approved by the Council it would go into the internal approval process, including final approval by the Governor's office.

Ms. Smith-Boivin requested clarification on the timeframe covered in the report, Ms. Fay confirmed the report covers 2021 and 2022 and can include updates from 2023 thus far. Ms. Smith-Boivin explained at that the most recent AAIC (Alzheimer's Association International Conference), there was a report released from the researchers at RUSH University Medical Center in Chicago detailing the prevalence of Alzheimer's dementia in the U.S. The report showed that New York State is currently ranked second in the nation for prevalence of Alzheimer's Disease, and five New York counties are among the top ten in the nation for prevalence. Ms. Fay noted that the 2023 information has been included in the report, and Ms. Sinnott noted that she will review the RUSH Report and update the report accordingly.

Ms. Smith-Boivin also stated at the AAIC, studies were presented about blood-based biomarkers and a finger prick diagnostic tool for Alzheimer's disease, which would likely increase diagnosis rates.

Mr. Levine requested that information provided regarding treatments, early detection, and diagnosis also be strengthened. Mr. Taylor noted that the wait list for neurology is growing, with a concern that it could be a two to three year wait, making early detection difficult, and highlighting the importance of advances in technology and diagnostic tools and the need to increase the number of specialists, as well as primary care education. Mr. Leibold highlighted the importance of building infrastructure as a whole, focusing on the importance of early detection, as well as the capacity to evaluate. Ms. Young described the goal of Centers of Excellence for Alzheimer's Disease (CEAD) is to educate primary care and specialty care providers on early detection and assessments. Ms. Smalling inquired about baseline data that is provided by primary care and specialty care.

Ms. Smith-Boivin noted that early detection and diagnosis is key, as well as continuing to educate to the community, assuring that they are able to advocate for themselves and get the proper assistance. She also noted that fear is a huge component and there is a need to focus on education. Ms. Smith-Boivin recommended a positive focus in the report for what the future holds for Alzheimer's care. Ms. Smith-Boivin volunteered to update the report based on the discussion for community education. Ms. Smalling voiced agreement that it is essential to combat the fear of the diagnosis of Alzheimer's disease, including psychological and emotional

support needed for the patients and caregivers. The report should highlight the importance of caregiver support initiatives and reiterate the importance of educating primary care and specialty care providers about support services available in the community. Ms. Smith-Boivin expressed how critical it is to stress highlighting the importance of early and accurate diagnosis of Alzheimer's disease and other dementias.

Ms. Smith-Boivin addressed the concern of the potential cost of disease modifying therapies, inquiring if the Council should weigh in on payment concerns. The public is still waiting on follow-up for full coverage of medications, as well as coverage for required services needed.

Ms. Purcell reflected on concerns with lack of reach of services in rural areas. Mr. Levine noted that there are racial disparities in access, as well as trust and support of available services.

Mr. Taylor inquired about reflecting higher level concerns in the executive summary in the report. The executive summary will be included once the report is finalized.

Ms. Smalling asked if funding is allocated based on populations throughout the state that have a higher prevalence of diagnosis and whether there should be more concentrated resources in those areas. Ms. Young explained that the Alzheimer's Disease Program does look at data and prevalence throughout the state, but it can be difficult to be too specific in a two-year report as the data changes regularly. Ms. Smalling noted, and Mr. Leibold voiced agreement and understanding, that prevalence and need of services are not always linked.

Ms. Smith-Boivin announced the Alzheimer's Association is applying for renewal of a grant through the Department of Health and Mr. Taylor asked for more information on the process. Ms. Fay described the request for application (RFA) for the Alzheimer's Disease Community Assistance Program (AlzCAP) funding and explained that the Council does not have any role in determining the award for the RFA. Mr. Levine expressed concern that the funding amounts have not changed over the years, though the needs in the community have. Ms. Smith-Boivin agreed, explaining that the Alzheimer's Association has been advocating for an increase in funding for Alzheimer's disease across the state.

Mr. Cochran addressed the prevention agenda, inquiring if it should be discussed more in depth. Ms. Fay recommended that if there were specific links or information that anyone wanted added to the report related to the discussion, they should be sent to the Alzheimer's Disease Program. Ms. Smith-Boivin also volunteered to work on the prevention agenda and risk reduction section of report. She noted that sex differences should be discussed in the report, since it has been shown that women are at a higher risk for developing Alzheimer's disease than men.

Ms. Smalling addressed the importance of healthy eating and the difficulty for more rural or lower socio-economic areas to have access to healthier food options. Ms. Smalling reviewed that outreach goes beyond education on Alzheimer's disease and early detection but should also be focused on education and availability of healthy eating options.

Ms. Purcell noted that there is a new CMS home and community-based setting regulation for person-centered planning. She also detailed the importance of Dementia Friendly communities and Dementia Specialists educating the public, so that community settings assist and support those with Alzheimer's or related dementia. Ms. Sinnott noted that Dementia Friendly Communities are discussed throughout the report and Ms. Fay added that it is a deliverable under the AlzCAP grant.

Mr. Lebwohl reiterated that Council members should all complete review of the report and send update requests to the Alzheimer's team in order to finalize the report. Once the report is updated, it will be sent out to the Council for a final review prior to approving it during the November meeting. Ms. Smith-Boivin and Mr. Taylor also agreed to work on the executive summary.

Mr. Taylor noted appreciation for the information included regarding the COVID pandemic but asked if more information should be included regarding lessons learned. Ms. Smith-Boivin agreed that it would be beneficial to analyze outcomes of the pandemic regarding long-term care services and acute care services. Mr. Lebwohl noted that while the topic is very important, the scope reaches further than this report. He did note that a call for evaluations to take place is wide-spread and the Council looks forward to those results.

#### **Master Plan for the Aging (MPA) Update:**

Mr. Lebwohl described that a preliminary report was submitted to the Governor over the summer. The report is still under review and has not been released to the public yet. Mr. Lebwohl anticipates it will be available in the next few weeks. Work groups and sub-committees have been meeting regularly since April, including eight sub-committees and 32 work groups, with over 300 people involved. Mr. Lebwohl provided a broad overview of the purpose and goals of the sub-committees and work groups.

Mr. Lebwohl opened the floor up for discussion with those who are on work groups. Mr. Levine is on three work groups including informal caregivers, formal caregivers, and long-term services and supports groups. He noted three major issues that have been highlighted throughout work groups. The first is access to care, the second is the ability to navigate the long-term care system, and the third is the workforce and concerns with fair pay. Ms. Young reiterated that person-centered care is a key component of all groups and noted that Alzheimer's and dementia care crosses over all sub-committees and work groups. Mr. Lebwohl added that there is a specific workgroup that focuses on Alzheimer's disease and dementia care.

Ms. Maloney agreed that the person-centered approach is important, but it is also key to focus on safety concerns, addressing concerns with Family-Type Homes for Adults, specifically.

Ms. James described that five other states currently have Master Plans for the Aging; these plans have been reviewed by work groups and sub-committees. Ms. James serves on the sub-committee for home and community-based services and critical partnerships and adds that there is a crossover in various work groups. Ms. James noted that true social drivers of health have an impact for those who are aging well, incentivizing partnerships in community-based organizations, public and private sectors, as well as business community. Ms. James noted that there is not currently representation from the business community in the critical partnership sub-committee but feels that their voice would be beneficial as caregivers are employed and there are economic and workforce issues for the business community. Mr. Cochran explained that the Office for the Aging completed a study with the Department of Labor. From that, a caregiver guide was created for employers regarding impact of caregiving. The guide went to every business on the Department of Labor's contact list. Mr. Lebwohl stated that he and Mr. Gustafson are on a finance committee that engage with businesses on the relationship between employers and caregivers.

Mr. Lebwohl explained that the Master Plan is also looking at the integration of the prevention agenda with connecting social determinants of health and multidimensional factors that lead to challenges that the Master Plan is trying to address. Mr. Lebwohl noted that early detection and

having access to treatment to allow people to be able to continue engaging with their families and communities is key, and the goal is not just to increase longevity, but to remain healthy throughout the lifespan. Mr. Cochran agreed that the goal is to ensure that older adults are being engaged and are maintaining wellness by addressing environmental factors and lifestyle choices, including factors such as stress and diet.

Ms. Maloney added that cultural differences in accessibility discussions are occurring across the work groups. Mr. Levine added that diversity, equity, and inclusion are considered across the workgroups. Mr. Lebowitz agreed that it is a cross-cutting theme throughout the course of work for the MPA.

### **Member Announcements**

Ms. Kelleher and Ms. Maloney stated that the Adult Abuse Training Institute is scheduled for October 4 and 5, in Albany. Mr. Cochran added that the key theme for this year's conference is the collaboration process to address issues that arise, such as mobile Offices of the Aging and APS working together to protect individuals by creating best practices to help combat elder abuse. Mr. Cochran added that family dynamics can become very complex when working towards resolution, reaffirming that this training opportunity is beneficial in continuing to protect individuals.

Ms. Purcell reported that a brochure can be sent out to Council members, inviting them to attend, as financial exploitation/abuse is the fastest growing type of elder abuse. Ms. Smith-Boivin will be providing a 90-minute research update at the conference and there will be several other informative sessions.

Mr. Levine noted that CaringKind's "To Whom it May Concern" presentation is coming up. The program was launched in 2005 and has been reinvigorated. A group of individuals living with early-stage of Alzheimer's or dementia will discuss their challenges and experiences. It will be a very powerful presentation.

Mr. Taylor provided an update on Voices of Alzheimer's priorities. Currently there are 700 members in the group, which reaches up to 6,000 individuals with information. Updates from Voices of Alzheimer's include medication updates, access to treatments, and the concern with connecting with diagnosing physicians.

Ms. Fay announced that the NYS Department of Health was awarded the BOLD funding, which is a federal funding opportunity granted by CMS. The funding is a five-year cooperative agreement that is set to begin September 30, 2023. The intent is focus on brain health, risk reduction, early detection and diagnosis, with a focus on the underserved. The program will be working with some current partners and anticipates a slow start-up period. Ms. Young added that the NYSDOH has been awarded Component Two, which is awarded to established programs, 43 awards were given in total, including NYC.

Ms. Smalling detailed a Skilled Nursing Facility (SNF) Enhanced Support Program that the Office of Mental Health (OMH) leads. The program provides psychiatric support services in skilled nursing facilities (SNF). The program includes completion of an enhanced Preadmission Screening and Resident Review (PASRR) when needed and offers psychiatric services to patients that OMH has discharged to a SNF. Tele-psychiatry appointments are offered using an Extension for Community Healthcare Outcomes (ECHO) model. Currently 60 SNFs are participating. These tele-ECHO clinics are made up of a robust team, including a gerontologist, a psychiatrist NP, physicians, and a psychiatrist. Ms. Young noted that the University of

Rochester CEAD is involved in this process and lends their support to area SNFs. Ms. Smith-Boivin echoed the importance of these services, as those with behavioral challenges in SNF are having to be transferred out of state for increased support and services.

Mr. Gustafson noted that the Special Needs Assisted Living Voucher Demonstration Program for people with Dementia (SNALR) has been placed on hold by Department of Health due to funding. He added that it is a popular program, and he is hoping that the state budget can increase funding in the next fiscal year.

Ms. Fay noted that beginning in 2024 the meetings will be moved back to Mondays and the meeting time will be changing to 11:00 AM-1:00 PM, to allow time for travel.

### **Adjournment**

Meeting was adjourned at 12:05PM.