



## DRAFT MINUTES

NYS Coordinating Council for Services Related to Alzheimer's Disease  
and Other Dementia  
Thursday, November 16, 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), George Shaw (OPWDD), Susanne Sullivan (NYSED), Elizabeth Smith-Boivin, Dr. Denise Cavanaugh, Teresa Galbier, Jed Levine, Catherine James, James Taylor, Dr. Carol Podgorski

**Members Present Virtually:** Dr. Carl Cohen, Dr. William Higgins

**Members Absent:** Dr. Louis Belzie

**NYSDOH Staff Present:** Amanda Tinaphong, Michael Jabonaski, Lynn Young, Katie Mahar, Susanne Coburn, Tyler-Marie Leggett, Cassandra Tysn, Penny Plouffe, Tracy Sinnott, Kim LaBarge, David Spellman Esq. (DLA)

**Others Present:** Bill Gustafson (Alzheimer's Association), Lisl Maloney (OCFS)

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

### Welcome and Roll Call:

Mr. Cochran called the meeting to order at 10:05AM. Ms. Sinnott conducted the roll call, there was an in-person quorum. Mr. Jabonaski introduced himself as the new Bureau Director for BCIAD. He then reviewed staffing changes and updates, including the departure of Erin Fay, Alzheimer's Unit Supervisor, noting that the department is currently in the process of filling the position. New members to the Council, Dr. Carol Podgorski and George Shaw were welcomed, and they provided brief overview of their experience.

Mr. Jabonaski provided a brief review of how Council members can be reimbursed for travel expenses, as the statute requires Council members to attend meetings in person. A FAQ will be distributed to Council members describing the process for reimbursement.

Ms. Sinnott addressed the schedule for 2024, noting that a later start time was proposed by Council members for travel purposes. Meeting times will be from 11:00AM to 1:00PM and will be scheduled on Mondays in 2024. Mr. Cochran stated that he hopes this adjustment will lead to boosted in-person participation and quorums at every meeting.

Mr. Jabonaski also discussed the addition of members to the Council. While the Council discussed potential nominees, Mr. Jabonaski noted there is a goal for balance and diversity on the Council. He also confirmed that there are currently potential applicants that are going through the review process.

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

A motion was presented to approve the last five meeting minutes as there was an in-person quorum present. It was noted that the minutes are up for approval with requested edits made at the time of review. Copies of the last five meeting minutes, with additions, were provided in folders for review. Ms. Smith-Boivin questioned if the minutes could be approved as a batch or if each individual meeting minutes needed to be approved separately. Mr. Spellman stated that traditionally minutes are approved at each meeting, separately. Mr. Jabonaski described the circumstances surrounding need to approve five sets of meetings at this time, due to the pandemic, noting a quorum being present at this time to approve all minutes. Ms. Smith-Boivin motioned to approve the minutes by date, reading off each date. Council meeting minutes for September 12, 2022, December 5, 2022, February 16, 2023, May 18, 2023, and August 17, 2023. Ms. Sullivan seconded the motion to approve all minutes, all Council members voted in favor to approve minutes. There were no oppositions.

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

Mr. Cochran noted the importance of the Council report and Executive Summary as a road map for conversation going forward on Alzheimer's disease and related dementias, as well as educating government with advocacy work. He also highlighted Ms. Fay's work that was done on report throughout its preparation for review.

Mr. Cochran first reviewed the Executive Summary, describing the summary as detailing great overall insight as to what direction the report is going in, as well as what the current trends are for treatment and progression of the disease. Mr. Cochran then opened it up to the floor for discussion.

Ms. James suggested minor updates to the report. The first recommended update was regarding the section on hearing loss. She suggested there may be a more appropriate place in the report for that brief paragraph, Ms. Sinnott agreed and will update it accordingly. Ms. James also addressed a concern regarding the use of the term 'health behavior' versus 'healthy behavior' in the report. After discussion, it was determined the term 'health behavior' was used appropriately in that context. Ms. James continued the discussion with a concern regarding the Healthy Brain Initiative (HBI) Road Map for 2023-2027. The report stated the Road Map was in process, however, it has now been approved and distributed to the public. Ms. Sinnott agreed and will update report with approved Road Map information.

Ms. James recommended an update regarding information on the SNARL voucher program as it is currently suspended from accepting new applications. Ms. Young explained the SNARL program was initially presented as a demonstration program and is currently paused. Ms. Smith-Boivin described how helpful the program has been, allowing eligible individuals to remain in assisted living facilities, rather than move to skilled nursing facilities due to financial reasons. The Council continues to be in full support of the SNARL program, noting that this program supports the least restrictive environment and is cost-effective.

Mr. Levine suggested an update regarding treatment, noting that there have been advances in research that should be clearly noted in the Executive Summary. Ms. Young explained that information in the report should remain inclusive, as possible research and developments are ever changing. The Alzheimer's team (ADP) will review the statement and update it accordingly in the Executive Summary, regarding available treatments, based on updates that were proposed by Council members. Discussion was held with Council members in relation to the amount of dialogue and growth there has been regarding Alzheimer's treatment as research has evolved. The importance of detailing the full approval of Lecanemab in the Executive Summary was discussed, including the name of the medication name as opposed to keeping the summary broader, noting availability of a disease modifying drug. Ms. Young reiterated that this report is a two-year report and should include the most current and up-to-date information. Mr. Levine inquired if there were legal implications to including drug names. Council members are in agreement that there are not as the Council is not endorsing the medication, only providing information on approved treatments.

Mr. Taylor described how much diagnostic procedures are evolving, as well. Ms. Maloney inquired about adding more information regarding early detection and diagnosis into the Executive Summary. The full report provides detail on the importance of early detection and diagnosis.

Mr. Cochran reiterated the goal and importance of using the Council report as a reference through advocacy work, also reiterating that as a document that is updated every two years, recognizing that science is ever changing and growing is important. Ms. Young noted that the goal is to focus on an optimistic outlook regarding lifestyle changes as well as research growth and changes throughout the support system. Ms. Sinnott also addressed the importance of highlighting the programs, including Regional Caregiver Support Initiative (CSI) and Centers of Excellence for Alzheimer's Disease (CEAD), as well as Alzheimer's Community Assistance Program (AlzCAP) throughout the state in the report. Mr. Cochran voiced agreement and explained how much this report will be used while working on the Master Plan for Aging.

Ms. Smith-Boivin revisited the conversation surrounding the Executive Summary's detail on available treatments. She recommended an update to the sentence structure regarding available treatments that the Council members agreed to, with proposed updates to structure of the Executive Summary.

Dr. Podgorski addressed the report's detail on the shortage of neurologists. She noted that there is a shortage of geriatric providers, including but not limited to, geriatric psychiatrists, geriatricians, geriatric NPs, and other physicians who are trained in diagnosing ADRD. The Council agreed on updating the report regarding the shortages to reflect all diagnosing medical providers. Mr. Taylor added that along with the goal to increase the number of geriatric specialists, as the research and development increases in diagnosing ability, the number of Primary Care Physicians (PCP) who can diagnose ADRD needs to increase. Dr. Podgorski explained that neurologists and geriatricians refer to the CEADs for diagnosis rather than diagnosing themselves, agreeing that increased education is key. The Council agreed that there is a shortage of qualified, properly trained medical providers. Ms. Smalling noted there is a broader concern with professions not being interested in working in the geriatric community. Dr. Podgorski feels that as the science evolves and more treatments are available, there may be more interest in entering the field.

Ms. Smalling provided a brief description of a program that is provided in the community to support mental health services. The ECHO program is based out of the University of Rochester and helps support PCPs who may not be familiar with dementia support, as well as other mental health diagnoses, and provides a collaborative effort as an extension of the practice. Ms. Young added that several CEAD providers use ECHO for care consultations.

Ms. Young clarified that there are two areas where the Council recommended updates in the report. Ms. Smith-Boivin volunteered to assist the ADP team in completing updates throughout the report. Ms. Young and Mr. Cochran presented to the Council members that a vote needs to occur to today to approve the Council report as it needs to begin going through the approval process.

Ms. Young provided detail on the history of the Behavioral Work Group that the ADP team, along with Ms. Smalling and Dr. Podgorski, was involved in. The work group identified benefits of the ECHO model that could be transitioned across the state. The work group was disbanded during the pandemic and remains an important conversation for best practices.

Mr. Cochran proposed voting to approve the 2023 Council report. Ms. Smith-Boivin requested clarity from legal counsel on the Council's ability to approve the report with minor edits in process. Mr. Spellman stated that the Council could submit a motion to approve the Executive Summary and the report, with minor edits as discussed and reflected in the minutes, for submission to the legislature. Ms. Sullivan motioned to approve, and Mr. Taylor seconded the motion. The Council voted in favor of approving the Executive Summary and the report, with edits noted.

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

Mr. Lebwohl announced his role change, as he is no longer the Director of the Center for Aging and Long-Term Care Finance and Supports. He is now the Director of the Master Plan for Aging. Mr. Lebwohl briefly described what his new role will entail. He explained that with his position change, Mr. Jabonaski will assume his roll on the Council. Mr. Lebwohl opened the conversation to others on the Council, so they could provide an update on work groups they are assigned to for the Master Plan.

Mr. Levine provided a brief update on the Informal Caregivers, Formal Caregivers, and Long-Term Services and Supports Work Groups. Mr. Levine noted that there has been tremendous consensus and cross reference across the work groups. He provided detail on discussion for supporting working caregivers to protect against discrimination, as well as increasing salary for paid caregivers.

Ms. James provided an update the on Home and Community-Based Partnerships work group, and the critical partnerships and in community work group, describing discussion on care hubs for social care and health care in community settings.

Mr. Gustafson sits on the cognitive health work group. He described recommendations on a public awareness campaign as well as data collection efforts. Mr. Lebwohl praised the work being completed in the Cognitive Health work group in regard to increasing public awareness.

Mr. Lebwohl provided detail on the work being done in the Licensed Profession Group. The group has reached out to geriatrician organizations to engage them further in the conversation to discuss geriatrician training and supplies.

Mr. Lebwohl discussed the importance of prevention and early detection. Prevention and early detection have a goal of healthier aging. This includes medical community education, public education, and infrastructure including medical care providers and non-medical care providers. Mr. Lebwohl explained goal of consolidating plans as goals are developed among work groups. An overall theme amongst work groups has been the importance of advanced care planning for medical and financial needs.

Mr. Lebwohl is currently going through the recommendations and is working on compiling an interim report that will be sent to the Governor by January. The report will likely be released to the public after the budget is completed. The draft final report is due July 2024 and the final MPA is due January 2025.

Ms. Smith-Boivin requested that Mr. Lebwohl provide more detail as to what his new position will entail. Mr. Lebwohl described that he will be able to exclusively focus on the MPA. Ms. Smith-Boivin noted a concern with silos throughout the system, and Mr. Lebwohl explained that cutting down silos will be a primary part of his position, linking committees together and educating people about resources available in the state. Mr. Cochran concurred that working together at a multi-disciplinary level is a key focus of the 32 work groups for the MPA. Mr. Cochran explained that next steps will be to determine where recommendations fall under state agencies, moving forward with a road map for connections in the community to advance a grassroots approach to aging. Ms. Smith-Boivin reiterated the importance of Mr. Lebwohl's new role, which will include dissemination of information throughout the system, and reaching community organizations that work directly with the aging population. Mr. Lebwohl described that the next process will be to pair state agencies with work groups to continue to move forward with recommendations. Ms. Smalling inquired as to what the plan is after the final report is completed. Mr. Lebwohl explained that there is a Center for the Master Plan for Aging to be a champion for the aging population, to put forward legislation, continue to disseminate information across the state, and enacting and tracking recommendations. The recommendations will be organized between two-year, five-year, and ten-year timelines.

**BOLD Update:**

Ms. Young and Ms. LaBarge provided a high-level overview of the BOLD initiative and what process the ADP team is currently in. The NYS ADP team entered a cooperative agreement with the CDC on September 30, 2023. Ms. LaBarge and Mr. Jabonaski detailed their time in the Atlanta, meeting with the Northeast Collaborative, and shared that they received information on what other states goals are within the BOLD initiative. Ms. Young described that as part of the NYS Coalition, the Council will be provided with quarterly updates from the ADP team on progress of the work plan. Currently the work plan and budget are being reviewed to keep goals as realistic as possible for Year One. Ms. Young described that the ADP team plans on collaborating with the NYU BOLD Center of Excellence in distributing their tool kit to the CEADs, to help with early detection and diagnosis. Ms. Young described the three core priorities that the ADP team will be focusing on as part of this initiative. This includes promoting brain health messaging by collaborating with chronic disease messaging in the state, brain health and risk reduction strategies, and working with the CEADs on disseminating the tool kit for early detection and diagnosis. The toolkit will go to Federally Qualified Health Centers (FQHC) and Rural Health Clinics (RHC). Ms. Young explained that the ADP team was granted \$450,000 per year, for a five-year collaborative. There are 43 funded entities, in total. Mr. Taylor requested clarification on the tool kit that will be distributed across the state. Ms. Young explained that the NYU BOLD Center of Excellence has developed a tool kit and the ADP team will be working with the NYS funded CEADs on a distribution.

**Member Announcements**

Ms. Galbier recommended discussing the ECHO model in more detail as a topic for a future Council meeting. Ms. Galbier also asked about the process for nominations for additions to the Council. Ms. Sinnott and Mr. Lebwohl provided an update on recommendations for nominations. Ms. Young described that there is a process that needs to occur for nominations. The 2024 Council meetings will be held on the following dates: March 4, June 10, September 23, and December 9.

**Public Comment:**

Mr. Gustafson reported that he, along with Ms. Fay, attended the Dementia Services Coordinator Summit in Washington DC, where it was noted that New York continues to lead the way in Alzheimer's support and services.

**Adjournment**

Meeting was adjourned at 12:06PM.

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