



MINUTES

NYS Coordinating Council for Services Related to Alzheimer's Disease
and Other Dementia
Monday September 23, 2024
11:00 AM – 1:30 PM

Council Members and Representatives:

Members Present In-Person:

Michael Jabonaski (NYSDOH), Maxine Smalling (NYSOMH), Elizabeth Smith-Boivin, Dr. Denise Cavanaugh, Julie Kelleher (NYSOCFS), David Okrent, Esq, Dr. Carol Podgorski, James Taylor, and Dr. David Hart.

Members Present Virtually:

Suzanne Sullivan (NYSED), Jed Levine, Teresa Galbier, Dr. William Higgins, and Catherine James.

Members Absent:

John Cochran (NYSOFA), Dr. Louis Belzie, and George Shaw (OPWDD).

NYSDOH Staff Present:

Katie Mahar, Susanne Coburn, Tracy Sinnott, Kim LaBarge, Felicia Segelken, Michael Chittenden, Juliana Ryan, and Jessica Dell'Anno (DLA).

Others Present:

Charles Williams (NYSOFA), Lisl Maloney (NYSOCFS), Bill Gustafson (Alzheimer's Association), Lori Novak, and Dean Evan Hart.

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

Welcome and Roll Call:

Mr. Jabonaski called the meeting to order at 11 AM.

Mr. Jabonaski introduced Charles Williams, NYSOFA, who attended in John Cochran's absence.

Mr. Jabonaski discussed in-person quorum requirements and reviewed current open seats in the Council, providing detail on filling vacancies. Ms. Smith-Boivin added that technology inconsistencies are also an issue for those attending virtually. Mr. Okrent requested a notification to the Council ahead of time if a quorum will not be present.

Ms. Sinnott shared details about the vacancies within the Council, including categories of seats. Ms. Mahar informed the Council that potential candidates have reached out to voice interest in joining the Council. Mr. Jabonaski requested that a list of vacant Council seats be provided to the Council members at each meeting. Mr. Taylor suggested having an individual living with

Alzheimer's be considered for a Council seat in the future and Ms. Sinnott informed the Council that this would fall under the seat category of "has expertise in Alzheimer's, other dementia or elder care issues." Ms. Sinnott noted that a list of open Council seats is also available on the Council website.

Mr. Jabonaski provided details about utilizing the Council's recommendations to provide an overview of the New York State priorities. Mr. Jabonaski recommended that the Council document recommendations be completed by June 2025 for the following year's budget proposals. Mr. Jabonaski further discussed using a survey tool (i.e. Survey Monkey) to provide an avenue for the Council members to submit recommendations for Council priorities.

Ms. Sinnott conducted the roll call, noting an in-person quorum was not met.

Ms. Mahar introduced the newest Council member, Dr. David Hart, and provided Dr. Hart an opportunity to introduce himself.

Ms. Mahar also reported that Lynn Young retired from the Alzheimer's Disease Program team.

Approval of Minutes:

Regarding the minutes from the November 16, 2023, March 4, 2024, and June 10, 2024, meetings: a quorum was not present, the minutes could not be approved.

2025 Council Report Update:

Ms. Sinnott updated the Council about the 2025 Council report. She informed the Council that the report is due for submission to the Governor by June 2025. The report will be reviewed for approval by the Council at the December meeting. The Council members were notified that the report draft will be provided to them by the beginning of November. Ms. Sinnott highlighted the planned updates to the report and the expectations of the Council members prior to December's meeting.

Building Our Largest Dementia Infrastructure (BOLD) Update:

Ms. LaBarge provided an update on the Building our Largest Dementia Infrastructure (BOLD) initiative, highlighting the goal to provide education on early detection and diagnosis to a Federally Qualified Health Center (FQHC), or Rural Health Clinic (RHC).

Ms. LaBarge reported a meeting was held with the 10 Centers of Excellence for Alzheimer's Disease (CEAD) on September 12, 2024. During the meeting, Dr. Josh Chodosh provided an overview of strategies for early detection, as well as resources available through NYU Building Our Largest Dementia Infrastructure (BOLD) Public Health Center of Excellence for Early Dementia Detection. The CEADs discussed their current work and identified how BOLD funding could be used to increase education efforts to Federally Qualified Health Centers (FQHCs), Rural Health Clinics (RHCs), or primary care offices in underserved communities on the importance of early detection and diagnosis.

Ms. LaBarge provided detail on a recent pilot training presented to the Erie County Department of Health with the Alzheimer's Association. This pilot training had 30 attendees and provided staff with new information that could be implemented in their daily work.

Ms. LaBarge reported on the BOLD public awareness campaign with the Department of Health and the Bureau of Chronic Disease to increase awareness on Brain Health. Ms. LaBarge

shared details of the dissemination process and asked for recommendations from the Council for additional resources for Brain Health.

Master Plan for Aging (MPA) Update:

Mr. Williams (NYSOFA) provided a brief update regarding the Master Plan for Aging Phase 1 and Phase 2. Phase 1 was completed in the summer of 2024, identifying over 100 proposals. Phase 2 includes a stakeholder advisory committee to discuss these proposals and provide a final report, working with the MPA Council, to present to the governor by the end of January 2025. Mr. Jabonaski added that he receives regular updates regarding the Master Plan as well.

Council Top Priorities Discussion:

Mr. Jabonaski discussed the plan to utilize a survey tool such as Survey Monkey to capture priority recommendations from the Council for future opportunities through the Department of Health. Mr. Jabonaski noted that in the future the goal will be to survey community members beyond the Council to determine priorities.

Mr. Taylor requested that the Council identifies overarching priorities to focus and build upon. Ms. Smith-Boivin discussed raising awareness to the public about the warning signs and early diagnosis, as well as increasing diagnosticians at CEADs and medical facilities. Further discussion amongst Council members included the changing landscape of diagnosing Alzheimer's disease, Medicare's impact on diagnosing, and informing physicians of appropriate screening.

Ms. Smith-Boivin and Dr. Podgorski discussed the importance of creating a targeted education plan for the medical community, along with a universal toolkit for CEADs to educate people on the importance of early detection and diagnosis. Ms. Smalling recapped the information shared and agreed the priority goals need to be succinct to create a monetary impact. Ms. Smalling added that the Master Plan for Aging and other overlapping goals should be used to increase the impact for this Council, noting that focusing on relating awareness to Preventative Services outreach has been successful. Mr. Levine added that priorities should include both anticipated costs as well as potential cost to the state if Alzheimer's services are not increased. Ms. Sullivan added the consideration to have Nurse Practitioners and Physician Assistants provide diagnoses to support the Primary Care physicians.

Dr. Podgorski and Ms. Smalling discussed creating incentives for clinicians to care for the aging population and complete cognitive screenings. Further discussion between Council members detailed the changing landscape and awareness of the disease, as well as the need to share the updates in screening and diagnostics with the public--most notably reaching underserved populations.

Ms. Galbier provided information about the new program launched by Centers for Medicare & Medicaid Services (CMS), Guiding an Improved Dementia Experience (GUIDE) model. This model provides reimbursement for wrap-around supportive services for those living with dementia as a nonmedical intervention. Discussion continued among the Council members on how to increase public awareness of the GUIDE model, as well as consideration of the impacts of this 8-year pilot program. Further discussion between Council members evolved around the impact of Medicare Advantage Plans and GUIDE, as GUIDE participants can only have straight Medicare insurance.

Mr. Jabonaski asked the Council to discuss individuals who live alone with Alzheimer's disease and individuals within the developmental disability population impacted by the disease. Ms.

Smith-Boivin, Ms. Kelleher, and Ms. Smalling discussed severe behaviors as a symptom of the disease, the impacts of that on the healthcare system, and identified where support is lacking for the severe behavior.

Dr. Hart provided additional support for identifying incentives for reaching the youth to stay in New York State, as well as the importance of having mid-level staff to help with diagnosis since many times they have more time to spend with a patient than a Primary physician. Dr. Hart provided support for giving doctors across the board tools for educating people on the importance of cognitive screening, as well as proper referrals.

The Council identified three top priorities. The goals of the priorities are Early Diagnosis, Increasing the Direct Care Workforce, and Supporting Formal Caregivers. These priorities will include action steps. Mr. Levine reported that many of these priorities also overlap with the Master Plan for Aging.

Members Announcement and Public Comments:

Ms. Sinnott discussed the upcoming Council meeting dates for 2025, tentatively scheduled for March, June, September, and December.

There were no public comments provided.

Adjournment:

The meeting was adjourned at 1:34 PM.