



MINUTES

NYS Coordinating Council for Services Related to Alzheimer's Disease
and Other Dementia
Monday, December 9, 2024
11:00 AM – 1:00 PM

Council Members and Representatives:

Members Present in Person: Michael Jabonaski (NYSDOH), John Cochran (NYSOFA), Dr. Denise Cavanaugh, Elizabeth Smith-Boivin, Catherine James, Maxine Smalling (NYSOMH), Suzanne Sullivan (NYSED), Julie Kelleher (NYSOCFS), James Taylor, Dr. David Hart

Members Present Virtually: David Okrent, Esq, Teresa Galbier, Jed Levine, George Shaw (OPWDD), Dr. Carol Podgorski

Members Absent: Dr. Louis Belzie, Dr. William Higgins

NYSDOH Staff Present: Katie Mahar, Tracy Sinnott, Kim LaBarge, Felicia Segelken, Cassandra Tsyn, Susanne Coburn, Michael Chittenden, Juliana Ryan, Jessica Dell'Anno (DLA)

Others Present: Charles Williams (NYSOFA), Lisl Maloney (NYSOCFS), Donna de Levante Raphael

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

Welcome, Announcements, and Roll Call:

Mr. Jabonaski called the meeting to order at 11:21 am.

Mr. Jabonaski requested that state agencies appoint an alternate designee to represent the agency on the Council in the event the primary designee is unavailable for meeting. This would help ensure the Council reaches a quorum for meetings.

Ms. Sinnott conducted the roll call, noting an in-person quorum was not met. Ms. Sinnott reported there are currently four vacant Council seats, providing detail on status of open seats.

Approval of Minutes from November 16, 2023, March 4, 2024, June 10, 2024, and September 23, 2024:

A quorum was not met, the minutes could not be approved.

2025 Council Report Review/Update:

Ms. Sinnott reviewed individual sections of the 2025 Council report draft. Mr. Taylor inquired about an executive summary of the report, Ms. Sinnott reported the Executive Summary will be updated after the report is completed. Ms. Smith-Boivin recommended report years (2023-2024) be added to the introduction section of the report. Feedback was provided by the Council members to move the Council's 2025 top three priority goals to the beginning of the report.

Mr. Taylor addressed private insurance coverage for testing and treatment options for persons with Alzheimer's disease or related dementia. Council members shared knowledge of private insurance coverages based on their experiences and identified questions to direct next steps for advocacy. Ms. Smalling identified the Council's responsibility to have a deeper awareness of research across the state. Mr. Cochran shared information about Age Friendly Health Systems that addresses the ability of hospitals interactions with older adults (including those with dementia).

Mr. Taylor and Dr. Hart shared information about clinical trials currently being conducted that focus on those diagnosed with moderate stage dementia. Ms. Galbier identified caregiver skills training that is now billable under Medicare that should also be included in the Council report, including the Physician Fee Schedule and the Guiding Our Largest Improved Dementia Experience (GUIDE) model. Ms. Mahar noted that information of the GUIDE model has been added to the report and will be reviewed for additional information, per Council's recommendations.

Dr. Podgorski asked about efforts being made around the state to ensure synergistic services. Alzheimer's Disease Program (ADP) staff will explore this. Ms. James requested that the years the data were collected be included in report, to qualify the timeline of the data from the Alzheimer's Disease Caregiver Support Initiative (ADCSI) grants. Ms. Smith-Boivin expressed the need to highlight that, though data shows an extensive reach, there are still many caregivers not receiving these vital services. Ms. Smalling asked the Council to continue to consider the barriers and why caregivers are not accessing the caregiver support services.

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 provided detail on the recently completed pilot training on Brain Health and Risk Reduction in Erie County to the Local Department of Health. The goal for Year Two is to expand this training to two additional local health departments, in partnership with the Alzheimer's Association.

Ms. LaBarge shared information about a recent webinar that was held with local health departments in partnership with the Bureau of Chronic Disease, to discuss the importance brain health and risk of Alzheimer's disease or relation dementia in connection with chronic disease. The webinar was presented by Erica Salamida, Alzheimer's Association, Dr. Dave Hoffman, and Kimberly LaBarge.

Ms. LaBarge reported BOLD will also be collaborating with specific Centers of Excellence for Alzheimer's Disease (CEADs) to create a training curriculum on early detection and diagnosis to pilot in either a Federally Qualified Health Center or Rural Health Clinic.

Ms. LaBarge shared information about the upcoming Public Awareness Campaign focusing on brain health and risk reduction strategies. The Public Awareness Campaign will link to a landing page, providing information on brain health and links directly to the New York State Department of Health's Alzheimer's Disease Programs website.

Master Plan on Aging Update:

Mr. Cochran provided an update regarding the Master Plan for Aging. The Master Plan on Aging is expected to be finalized in early 2025, once approved it will be released to the public.

Member Announcements, Public Comments:

There were no public comments provided.

Mr. Taylor shared information about work being done by Voices of Alzheimer's to address young onset Alzheimer's and the wait time to receive Social Security disability. Mr. Taylor informed the Council that Voices of Alzheimer's is working with The American Academy of Family Physicians (AAFP) to train physicians on screening for cognitive changes.

Ms. Sinnott provided the 2025 Council meeting dates: March 17, June 2, September 8 and December 1. The Council members were asked to send any additional suggested report revisions to Alzheimer's Disease Program staff using the BML (alz@health.ny.gov). Ms. Mahar expressed the importance of reaching a quorum March's Council meeting to ensure approval of the Council Report.

Adjournment:

The meeting was adjourned at 12:57 PM.