

Governor

JAMES V. McDONALD, M.D., M.P.H.
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JOHANNE E. MORNE, M.S. Executive Deputy Commissioner

DRAFT MINUTES

NYS Coordinating Council for Services Related to Alzheimer's Disease and Other Dementia

Monday March 4, 2024

11:00 AM – 1:00 PM

Council Members and Representatives:

Members Present in Person: John Cochran (NYSOFA), Julie Kelleher (OCFS), George Shaw (OPWDD), Suzanne Sullivan (NYSED), Elizabeth Smith-Boivin, Dr. Denise Cavanaugh, Lisl Maloney (NYSOCFS), George Okrent, Esq

Members Present Virtually: Dr. Louise Belzie, Dr. Carl Cohen, Dr. William Higgins, Maxine Smalling (OMH), Teresa Galbier, Jed Levine, Catherine James, James Taylor, Dr. Carol Podgorski

Members Absent: Andrew Lebwohl (NYSDOH)

NYSDOH Staff Present: Michael Jabonaski, Lynn Young, Katie Mahar, Susanne Coburn, Tyler-Marie Leggett, Cassandra Tysn, Penny Plouffe, Tracy Sinnott, Kim LaBarge, L'eryn Jones, Sue Lawless (DLA)

Others Present: Selvia Sikder, Kristi Dawli, Gail Myers, Vanessa Bongiorno, Filomena Reish

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 11:07AM. Ms. Sinnott conducted the roll call, noting that there was not an in-person quorum present. Mr. Cochran introduced the newest Council member, George Okrent Esq. Ms. LaBarge welcomed Selvia Sikder, introducing her as a fellow Building our Largest Dementia Infrastructure (BOLD) recipient for the New York City Department of Health. Mr. Jabonaski and Mr. Cochran recognized continued difficulty of meeting in-person quorums due to Council member responsibilities, noting that some Council members serve as caregivers.

Approval of Minutes from November 16, 2023:

Mr. Cochran noted that since there is no quorum present, the minutes could not be approved.

Healthy Brain Initiative Road Map: A Public Health Approach to Brain Health-Focus on Risk Reduction Goal:

Mr. Cochran introduced Dr. Hoffman to the Council providing detail on his professional history, including the important roles he has had in the increase of Alzheimer's awareness and services across the United States. Dr. Hoffman presented information on the Healthy Brain Initiative Road Map. Dr. Hoffman provided background information on Alzheimer's disease and related dementias as well as updates from the Lancet Commission Reports. Dr. Hoffman took questions from Council members throughout his presentation. Dr. Hoffman provided detail on risk reduction, discussing ten risk factors, as well as highlighting the importance for quality education beginning as early as pre-school. Dr. Hoffman summarized the presentation noting that public health education is charting the course for a dementia prepared future.

The floor was opened for questions and comment for the presentation. Mr. Taylor noted concern with availability for early detection due to wait times for neurology and primary care physicians comfort level in diagnosing Alzheimer's disease and related dementias. Dr. Hoffman agreed with this concern and explained that increased education in primary care settings continues to be a priority and noted that discussion regarding cognitive decline should begin at the age of 45 as a normal part of adult screening in primary care. Dr. Hoffman highlighted goals for the national plan, including working with accreditors of medical schools on exposure to training on cognition as well as meeting with public health insurers on adding cognitive screenings to cognitive screening.

BOLD Update:

Ms. LaBarge provided an update on the Building Our Largest Dementia Infrastructure (BOLD) and noted the correlation between Dr. Hoffmans presentation on the Healthy Brain Initiative Road Map. Ms. LaBarge provided an overview of Building Our Largest Dementia Infrastructure awardees throughout the country, adding that New York City Department of Health was also awarded the Building our Largest Dementia Infrastructure (BOLD) cooperative agreement, receiving funding under component one. Ms. LaBarge addressed the Year One and Year Two goals education regarding brain health and building capacity for early detection with a focus on the underserved communities.

Ms. LaBarge described the partnership with the Coalition of New York State Alzheimer's Association chapters, utilizing partnership for brain health messaging and training at a local level, including working with the Office for the Aging and local health departments.

Ms. LaBarge then described the partnership with the New York State Centers of Excellence for Alzheimer's Disease (CEAD). Ms. LaBarge provided detail on goals for the Centers of Excellence for Alzheimer's Disease (CEAD) to meet in-person in the fall to compile a training and curriculum on early detection and diagnosis to implement in a Federally Qualified Health Center (FQHC), Rural Health Clinic (RHC), or a primary care office.

Ms. LaBarge described the partnership with the New York State Chronic Disease Bureau on integrating brain health and risk reduction messaging with messaging about chronic disease. Ms. LaBarge also described partnership with SUNY Albany School of Public Health for evaluation efforts. Under Building our Largest Dementia Infrastructure (BOLD), the program will be using the Behavioral Risk Factor Surveillance System (BRFSS) as a data source, as well as developing new data sources in regards activities occurring under Building our Largest Dementia Infrastructure (BOLD).

Master Plan for Aging (MPA) Update:

Mr. Cochran provided an update that the final set of recommendations from the Master Plan for Aging (MPA) work groups and sub-committees are due March 20, 2024. Mr. Cochran explained that the goal will be engaging in continued conversations with sub-committees, including conversations and suggestions that didn't make it into the initial recommendations.

Ms. Young explained that Council recommendations have been brought up as a source of guidance for content areas in some work groups, including recommendations with funding attached.

Ms. James inquired about the effect that work plan recommendations for the Master Plan for Aging (MPA) may have on this year's state budget. Mr. Cochran explained that the recommendations put forward will help guide discussions in the future for growth and Mr. Jabonaski added that this Master Plan for Aging (MPA) work is part of a multi-year execution plan.

Ms. Smith-Boivin asked Dr. Hoffman if he was aware of any efforts to complete a risk benefit analysis on what could be saved nationwide with a robust public awareness campaign, noting the importance of consumers being aware of the relevance of risk factors and risk reduction strategies for Alzheimer's disease and related dementias (ADRD). Dr. Hoffman explained that the CDC did request funding for a public awareness campaign for the White House budget this year, Dr. Hoffman was not aware of if the request had made it into the Congressional Budget.

Member Announcements and Public Comment:

Ms. Galbier asked if there were any updates for the Alzheimer's Community Assistance Program (AlzCAP) Request for Application (RFA). Ms. Tsyn stated the application approval process is still ongoing, and applicants will be made aware of award status when the process is complete.

Ms. Myers inquired about the Councils' thoughts on proposed change in the Governor's budget in the Consumer Directed Personal Assistance Program (CDPAP), the budget proposes that consumers will not be able to participate in the program if they are not self-directed. Mr. Okrent noted that many consumers would lose their services if this change were approved, Ms. Smith-Boivin agreed with the concerns with potential changes. Mr. Jabonaski proposed that this concern be discussed further as an official agenda item in the future.

Mr. Taylor asked if New York State was involved in the Guiding an Improved Dementia Experience (GUIDE) model through the Center for Medicare and Medicaid Services (CMS). Ms. Mahar explained that some of the Centers of Excellence for Alzheimer's Disease (CEAD) as well as the Alzheimer's Association did intend on applying for the Guiding an Improved Dementia Experience (GUIDE) model. Mr. Taylor inquired if Guiding an Improved Dementia Experience (GUIDE) will be a model for achieving goals in the Council, Ms. Mahar noted that at this time the effect of Guiding an Improved Dementia Experience (GUIDE) is undetermined. Ms. Young added that the New York State Department of Health did not apply for the funding.

A discussion was held regarding difficulty in convening a quorum for quarterly Alzheimer's Coordinating Council meetings and Mr. Jabonaski voiced plans to continue discussing the Open Meetings Law and goal to investigate options for virtual quorums in the future. Ms. Lawless will draft an analysis and a summary of the Open Meetings Law to share with the Council to discuss

