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Department of Health

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DRAFT MINUTES

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

Thursday, February 16, 2023
10:00 AM – 12:00 PM

Council Members and Representatives:

Members Present In-Person: Andrew Lebwohl (NYSDOH designee for Adam Herbst), John Cochran (NYSOFA designee for Greg Olsen), Teresa Galbier, Elizabeth Smith-Boivin, Catherine James, Denise Cavanaugh

Members Present Virtually: Dr. Louis Belzie, Jed Levine, Dr. Carl L. Cohen, Dr. William J. Higgins, Susan Prendergast, Shelly Aubertine-Fiebich (OCFS designee for Sheila Poole), James Taylor

Members Absent: Dr. Ralph Nixon, Susanne Sullivan (NYSED designee for Shannon Tahoe)

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

Others Present: Bill Gustafson (Alzheimer's Association), Erin Purcell (NYSOFA), Geri Taylor, Nancy Smith, Sarah McNamara, Dr. Maria Brown (Syracuse University)

Note: The meeting was conducted via Webex and in person. The meeting was recorded. Per Open Public Meetings requirements, a quorum was not present.

Welcome, Announcements, and Roll Call

Mr. Cochran called the meeting to order at 10:12 AM. Ms. Gnozzio requested that Erin Fay conduct the roll call, after which it was determined that a quorum was not present. Ms. Lawless noted that Executive Order 11 was rescinded, and the Open Meetings Law is in effect. Ms. Lawless explained the process Council members were required to complete if they are unable to attend the meeting in-person, as there must be extraordinary circumstances. Dr. Cohen inquired if the Open Meetings Law could be modified due to numerous reasons. Ms. Lawless noted that it could not be changed. Ms. Gnozzio noted the importance of State Representatives attending meetings in person. Ms. Lawless noted that the Council can reimburse members for travel expenses.

Approval of Minutes from December 5, 2022 Meeting

Mr. Cochran and Ms. Gnozzio noted that the minutes could not be approved since there is not a quorum but requested discussion on the minutes as distributed. Ms. Gnozzio noted that the minutes from the prior meeting have also not been approved as of yet. Ms. Fay noted that Catherine James's name was duplicated on the last Council's minutes and that the correction will be made.

Master Plan for Aging Update

Mr. Taylor inquired about the Council's role in the Master Plan for Aging (MPA). Mr. Lebwohl detailed how the process will work for the MPA and explained there will be a subcommittee on health and wellness, which is where Alzheimer's Disease and related Dementia (ADRD) will be represented. Mr. Lebwohl described that the ten-year plan includes creation of a well-established reporting system for all medical providers to have access to resources for Alzheimer's care. Mr. Cochran noted that Ms. Smith-Boivin and Ms. James are involved in the MPA. Ms. Smith-Boivin elaborated on the extent of committee member involvement. Mr. Cochran outlined plans for the MPA that include a survey to the general public for feedback, and engaging with the public through outreach, including stakeholder engagement meetings throughout state. Mr. Cochran also noted engagement with Dementia Friendly Communities to help determine the overall community structures impact on well-being and health, as well as noting the use of the workplan for recommendations. Mr. Taylor inquired about identifying top three priorities from the goals and recommendations and adding them to the MPA. Mr. Cochran noted that since the goals and recommendations are so broad in nature, it would be beneficial to see all reflected in the MPA. Ms. Gnozzio noted that the MPA leadership was provided with the Council's draft legislative report and the current draft of the workplan for their review and consideration.

Early Identification of Cognitive Impairment Among Vulnerable Older Adults Living at Home

Mr. Cochran introduced Dr. Maria Brown to present on the program at Upstate Medical Center, presenting on behalf of Dr. Sharon Brangman. She started her presentation by providing a background of statistics for the ADRD population. Dr. Brown reviewed the clinical benefits of early detection of ADRD and described the early detection project. Dr. Brown voiced that she and Dr. Brangman are hoping to receive support from the Council for future funding of this project. She described the background of the project, which was piloted in early 2018 for engaging trusted community members to conduct brief cognitive screenings in community settings. The Mini-Cog™ tool was used for screening. Dr. Brown noted the need for education on the importance of early detection in the community, and then reviewed the goal to expand the program throughout the Central NY region.

Mr. Levine inquired about the role of the neighborhood advisors and what their educational background is, noting concern over lack of clinical training when speaking to clients. Dr. Brown reviewed training provided by Dr. Brangman. She noted that there would be a training manual that would be provided to future neighborhood advisors/case managers. Ms. Galbier reiterated Mr. Levine's question regarding educational background due to sensitivity of caregivers when discussing cognitive impairment of a loved one. Ms. Smith-Boivin added to the discussion, inquiring about use of Mini-Cog™, voicing concerns which could impede supporting the project as a member of the Council. Dr. Brown discussed the process of dissemination of information from the case manager to the client, noting that they use extreme caution when participating in

these discussions. Ms. Smith-Boivin asked if the screenings could occur at a CEAD site or a primary care physician's office allowing, for increased support and ability to arrange an immediate follow-up appointment. Dr. Brown agreed that the PCP office is the best place to be screened, however, this is often not possible, so in-home evaluations are available as an alternative to ensure screenings will occur as part of the program.

Mr. Cochran described the comprehensive process that the NYSOFA case managers complete for a certification through Boston College that includes clinical components. He also detailed the assessments that the case managers complete to identify services and assistance needed both in and out of the home. Dr. Cohen noted that the annual Medicare visit requires cognitive screenings to be completed by a PCP and encouraged that work be done to increase the occurrence of those screenings in the most appropriate setting. Dr. Cohen also noted a concern with the Mini-Cog™ secondary to educational and cultural differences. Ms. Smith-Boivin added that Dr. Nixon, who was unable to attend the meeting today, has requested she share his thoughts on the process. Dr. Nixon also noted concerns with educational background and training of the case managers who are completing the screenings.

Mr. Taylor commended the project as he presented there is a significant need for early diagnosis and access to therapies. He also emphasized that he understands the concerns presented. Mr. Taylor inquired about the use of the screening tool with the Hispanic population and encouraged that more statewide data be evaluated prior to expanding the program. Dr. Brown recognized the concerns and questions presented by Council members. ADP staff noted that there is guidance from DOH that ADCSI contractors are unable to complete community screenings unless there is a clear path to a medical provider, resulting in a timely assessment. ADP staff also noted the barrier in the limited number of CEADs in the state and subsequent wait-times for further assessments, noting that capacity building is a continued concern. Ms. Gnozzio noted the barriers with PCP annual assessments, due to the number of topics that are discussed in an appointment and concern that there may not be enough time to complete these annual assessments. Ms. Smith-Boivin took the opportunity to discuss the option of adding a social worker into PCP offices and inquired if OFA case workers could go into PCP settings, noting that modifying the setting could be more beneficial than the screen occurring in the home. Mr. Cochran reiterated that the cognitive screen is a piece of the larger assessment that is completed, with the goal for clients to remain in their homes, aging in place with appropriate services and with potential of an earlier diagnosis.

Mr. Taylor presented a question to the Council about what level of training the group felt would suffice to complete the cognitive screenings. Dr. Brown explained the pilot program was developed by Dr. Brangman, and she felt that the training that was provided was sufficient. Dr. Brown indicated that the initial training was three hours, and Dr. Brangman was available at any time should the case managers have questions or concerns. Ms. Smith-Boivin inquired about support from the DOH, Ms. Gnozzio noted that the DOH was not involved in the proposal for the project at this time.

Mr. Cochran concluded the discussion by summarizing the thoughts from the Council as well as Dr. Brown, reiterating that the goal remains to provide the best care and treatment to those living with, and at risk for, ADRD. Ms. Gnozzio encouraged Council members to e-mail the Alzheimer's BML and a list of follow-up questions would be sent to Dr. Brown and Dr. Brangman.

Goals and Recommendation Workplan Review

Mr. Cochran requested that Council members review the Goals and Recommendations in the workplan again and provide potential resources that could be useful in supporting the goals. Mr. Cochran noted that NYSDOH and NYSOFA have started to add resources into the document. He asks that if Council members have additional resources to add, to send them to the Alzheimer's BML. Ms. Gnozzio noted that the goal is to create a resource library to post on the website. Mr. Taylor recommended that the request be sent out in an e-mail. Ms. Gnozzio confirmed that an email will be sent out with the request and the workplan will be attached for viewing. Mr. Taylor noted that he appreciated hearing that the Goals and Recommendations of the workplan will be viewed by others, and he feels encouraged there will be continued use of information.

Member Announcements

Ms. Galbier presented her observation that there is a lack of diversity on the Council. She inquired about the status of open seats and the process for appointing new members. Ms. Fay explained that there is currently someone going through vetting process to join the Council and that there is one Governor's appointment open. There are also several Legislative Leadership appointees open at this time. Ms. Gnozzio reviewed the process for filling the available seats. Ms. Lawless noted that the Council members should recommend someone, particularly if they have someone in mind from an under-represented group.

Ms. Fay explained that there was a Notice of Funding Opportunity (NOFO) released by the Centers for Disease Control (CDC) on January 19, for Building Our Largest Infrastructure Alzheimer's Act (BOLD.) It is DOH's intent to apply. Ms. Fay noted that the application is due on March 23, 2023. The application will present a plan to leverage the current statewide network to build capacity for early detection and diagnosis capabilities and enhance brain health and risk reduction awareness. Ms. Fay detailed the current plan is to work with the NYU BOLD Center of Excellence for early detection, as well as the Alzheimer's Association BOLD Center of Excellence for Risk Reduction, noting that the proposed project closely aligns with both the Healthy Brain Initiative (HBI) roadmap and the Council's Report and Recommendations. Ms. Fay and ADP staff requested support and asked for a formal Letter of Support from the Council for the NOFO application. Ms. Fay further detailed the goals of the proposed application to work with healthcare settings on early detection through work with the Centers of Excellence in Alzheimer's Disease (CEADs), Federally Qualified Health Centers (FQHC), Rural Health Centers (RHC), and primary care physician practices. In addition, proposed work will be done with the Alzheimer's Association on educational messaging on brain health messaging. ADP staff noted that it will be a highly competitive process.

Mr. Taylor noted that there is a new Alzheimer's disease modifying therapy approved by the FDA on January 6, however, this most recent therapy has not been approved by CMS. Ms. Smith-Boivin noted that the Alzheimer's Association will be in Washington DC during the end of March to advocate for approval of the new drug therapy. Mr. Lebwohl inquired about which electeds are going to Washington to advocate. Ms. Smith-Boivin stated that Rep. Paul Tonko is the lead sponsor for the reversal of decision.

Adjournment

There are no other public comments. The meeting was adjourned at 12:01 pm without a vote.