



MINUTES

NYS Coordinating Council for Services Related to Alzheimer's Disease
and Other Dementia
Thursday, May 18, 2023
10:00 AM – 12:00 PM

Council Members and Representatives:

Members Present: Andrew Lebwohl (NYSDOH designee for Adam Herbst), John Cochran (NYSOFA designee for Greg Olsen), Teresa Galbier, Catherine James, Jed Levine, Dr. Carl L. Cohen, Maxine Smalling (OMH), Susan Prendergast (OPWDD), Shelly Aubertine-Fiebich (OCFS Designee for Sheila Poole), James Taylor

Members Absent: Dr. Louise Belzie, Elizabeth Smith Boivin, Dr. William Higgins, Suzanne Sullivan (NYSED designee for Shannon Tahoe), Denise Cavanaugh

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

Others Present: Bill Gustafson (Alzheimer's Association), Geri Taylor, Dona Giannotti (PSS-Dementia Friends New York), Rimas Jasin (PSS), Dr. Carol Podgorski, Lisl Maloney (OCFS), Charlie Williams (NYSOFA)

Note: The meeting was conducted via Webex only. The meeting was recorded.

Welcome and Roll Call

Mr. Lebwohl called the meeting to order at 10:05AM. Erin Fay conducted the roll call.

Approval of Minutes from December 5, 2022 and February 16, 2023 Meetings

Mr. Lebwohl addressed the status of the minutes from last two meetings and inquired if they were sent to the Council members for approval. Staff confirmed that the minutes were sent out but could not be approved as there is not a quorum present. Mr. Lebwohl asked for clarification on the update with the Open Meetings Law. Ms. Lawless confirmed that the changes in the law did not affect the current meeting and confirmed there still was not a quorum.

Open Meetings Law and the Extraordinary Circumstances Resolution

Ms. Lawless explained the update in the Open Meetings Law related to ADA compliance. Persons with a disability can attend public meetings virtually and be counted towards the quorum, while others must still attend in person. Mr. Cochran asked if the interpretation included those who have caregiving responsibilities. Ms. Lawless will follow up with the Committee on Open Government and report back. Ms. Lawless explained that the update to the law was just passed so there have not been any training sessions to date. Ms. Lawless explained that the

training sessions on the Open Meetings Law are public and anyone can attend. Ms. Fay requested that Ms. Lawless elaborate on the importance of Council members who are able to, to attend meetings in person. Ms. Lawless explained that since the Council is considered a public body, and the Council provides advice to Department of Health, it is important that the public has a forum where they are heard, in-person, by Council members. Ms. Lawless explained that in order for members that have extraordinary circumstances to vote on a subject remotely, there needs to be an in-person quorum.

Mr. Taylor noted that Council members needed to discuss and devise a plan to assure there would be a quorum to complete official business by the end of 2023. Mr. Lebowhl stated that the next two meetings are on August 17th and November 16th.

Announcements

Mr. Lebowhl announced the retirement of Maribeth Gnozzio, Bureau Director of Community Integration and Alzheimer's Disease. Mr. Lebowhl explained that he, along with Center Leadership, are working hard on filling the position.

Dementia Friends New York

Mr. Lebowhl introduced Mr. Jasin to provide a presentation on Dementia Friends New York (DFNY). Mr. Jasin provided a background of PSS prior to detailing DFNY. Mr. Jasin, along with Ms. Giannotti, explained the importance of DFNY and the goal to expand throughout NYS. Ms. Giannotti detailed the initiative by reviewing a background and history of Dementia Friends USA. Ms. Giannotti explained the difference between Training For Champions and those who want to become a Dementia Friend. Ms. Giannotti explained how to register for the Dementia Friends effort online.

Dr. Cohen asked where the funding comes from and asked for outcome information. Mr. Jasin explained the primary funding comes from NYSDOH and NYC Aging (DIFTA) for PSS Circle of Care along with Foundation funding for the DFNY to cover rollout. Ms. Giannotti explained that about 40% of champions are already conducting their own Dementia Friends informational sessions, with Ms. Giannotti's support.

Mr. Levine asked if training is done in any other languages, he also asked about who the target audience is. Mr. Jasin explained that the target audiences are organizations throughout NYS, has started with DOH and Area Offices on Aging and are expanding. Ms. Giannotti explained they are in the process of translating into Spanish and Mr. Levine offered to assist in translating into Chinese.

Mr. Taylor asked about specialized training for different types of institutions. Mr. Jasin explained that organizations could work with Ms. Giannotti to partner with other organizations for specialized training. Mr. Jasin explained that the goal is to continue working with and training others to continue to expand reach across all types of communities.

Mr. Taylor asked if DFNY has goals and a strategic plan over the next few years. Mr. Jasin explained that the goal is to start the roll out and get a sense of next steps as more communities are reached.

Mr. Cochran thanked Mr. Jasin for the presentation and noted that the concept of DFNY is based on a foundation put forth by the World Health Organization (WHO), in understanding the role of caregivers and stigmas attached for those with cognitive impairment. Mr. Cochran highlighted the importance of having the training and empowerment for those facing the

challenges of caring for those with cognitive impairment, as well as living with cognitive impairment. Mr. Cochran noted the importance of using this type of training with financial institutions, as financial exploitation is an issue. While team members work on the Master Plan on Aging (MPA), this type of programming could become part of the structure in the Informal Caregivers group, along with others. This also addresses the barriers caregivers face due to social isolation. Mr. Taylor encouraged partnerships with the NYS Banking Association, Mr. Cochran agreed.

Ms. Fiebich voiced that she would like to discuss doing a workshop at their annual conference in the fall. Mr. Jasin agreed that would be a beneficial group to network with. Ms. Prendergast noted that there is a similar conference for the NYS Intellectual and Developmentally Disability Nurses Association that would be beneficial to present at as well.

Ms. Maloney asked if the DFNY trainers are only meeting in NYC or if they were able to travel throughout the state. Mr. Jasin explained they could travel, but goal would also be to train champions. He also explained that Champion Training is designed to be online.

2023 Council Report Status Update and Plan

Mr. Lebwohl explained that the 2021 Council Report is still going through the approval process in the executive offices and has not been approved yet. During this time, the team is beginning to prepare the 2023 report. Mr. Lebwohl explained that the 2021 Council Report will be used as a template and updated accordingly with the most up-to-date data and information. Ms. Fay explained that the NYSDOH team will take lead on updating the statistics and information in the report and share with the Council for feedback and content. Staff will send individual sections to state agencies for updates, as well. Ms. Fay explained draft Council Report will be discussed further in August, with the goal to vote on the report in November.

Mr. Taylor asked for clarification on what Report the Council would be working on. Ms. Fay explained that the Council is tasked with completing a report every two years. This report needs to be in for approval by the Fall. Ms. Fay described the difference between the Workplan and the Report. Mr. Taylor voiced importance of updating the Report to reflect disease modifying therapies. Ms. Fay encouraged Mr. Taylor and all Council members to work on a specific section of the report if they had additions or changes. Mr. Taylor asked the Report to be sent out to Council members for review, Ms. Fay agreed.

Member Announcements

Mr. Lebwohl discussed the Master Plan of Aging (MPA) highlighting the Health and Wellness Group as they will likely have a Sub-Committee on Alzheimer's Disease. Mr. Lebwohl explained that there is representation by Council members on the MPA. The MPA is setting long-term goals of two, five, and ten years with the goal of aging in place.

Mr. Taylor explained that he, along with the Voices of Alzheimer's, are advocating for coverage for disease modifying drugs. The Voice of Alzheimer's and Alzheimer's Association will have representation at a rally in Washington D.C., in support of coverage for disease modifying therapies, as well as one in NYC. Mr. Gustafson also spoke about the event.

Adjournment

There are no other public comments. The meeting was adjourned at 11:10 pm without a vote.