



MINUTES

NYS Coordinating Council for Services Related to Alzheimer's Disease
and Other Dementia
Friday, December 3, 2021
10 am – 12 pm

Attendance

Council Members and Representatives:

Members Present: John Cochran, Teresa A. Galbier, Shelly Aubertine-Fiebich, Adam Herbst, Catherine James, Jed A. Levine, Dr. Ralph Nixon, Greg Olsen, Susan Prendergast, Elizabeth Smith-Boivin, Susan Sullivan, James Taylor

Absent: Dr. Louis Belzie, Dr. Carl Cohen, Dr. William Higgins, Paula J. Rice

DOH Representatives Present: Greg Bucher, Erin Fay, Maribeth Gnozzio, Thea Griffin, Maura Hurley, Trudy Menard, Susan Montgomery, Laura Palmer, Jennifer Perry, Lynn Young

NYSOFA Representatives Present: Erin Purcell

Other Public Guests: Geri Taylor

Welcome, Announcements, and Roll Call

Mr. Cochran, Deputy Director, NYSOFA and Council Co-Chair called to order the meeting of the NYS Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias (Council) at 10:05 am. He welcomed the Council members and other attendees and requested that Erin Fay complete roll call. At that time, it was determined that a quorum was not present but given the expectation that a quorum was pending, he reordered the agenda to postpone the approval of the minutes from the September 20, 2021 meeting.

Status Update on NYSDOH Caregiver Support Initiative

Erin Fay, Program Manager for the Alzheimer's Disease Program (ADP), provided an update of the NYSDOH Caregiver Support Initiative (CSI), noting that procurements are in process to secure new contractors for 2022-2027. Contract awards are expected to be announced in early Spring 2022. She specified that contracts for the Centers of Excellence for Alzheimer's Disease are slated to begin June 1, 2022, with the Regional Caregiver Support Initiatives to begin July 1, 2022.

Current ADP contractors have been granted extensions in an effort to ensure that there are no gaps in services. Contracts under the Caregiver Support Initiative for Underserved Communities were not extended and deliverables previously provided under that program have been integrated into the future CSI programs.

NYSOFA, DOL, DOH, OCFS Caregiver Initiative

Greg Olsen, Director of NYSOFA, provided an overview of the agency's Caregiver Initiative that is focused on promoting the needs of employed caregivers who need linkages to services. He provided information about the landscape of caregivers in the workplace. This NYSOFA initiative, in collaboration with DOL, DOH, and OCFS, has promoted the need for employers to recognize caregiver needs and to assess caregiving intensity. He described the recent development of a Caregivers in the Workplace Guide that has been distributed to NYS businesses. The initiative is also distributing a "Caregiver Intensity Index" tool that can engage caregivers in determining caregiver burden. Data is supporting the knowledge that a large percentage of the NYS workforce are caregivers, so reaching out to employers is of critical importance. Mr. Olsen indicated that links to the caregiver guide and surveys would be shared with Council members. He asked that members to help distribute messaging to NYS employers.

Adult Protective Services and Self Neglect

Shelly Aubertine-Fiebech, Director of OCFS, presented an overview on her agency's focus on Understanding Self-Neglect and the role of Adult Protective Services (APS). She began her presentation by promoting the availability of family-type homes for adults (FTHAs), as an important care option under the oversight of OCFS. These residential settings can be a valuable option for someone who can no longer care for themselves and are in a position of self-neglect. Ms. Aubertine-Fiebech continued with overview of APS key concepts and the laws defining self-neglect. She described seven pillars of self-care and self-neglecting behavioral factors and how, or when, these are addressed by APS across NYS. She highlighted the partnerships that APS maintains to insure coordination of adult services for those at risk.

Approval of the September 20, 2021 Council Minutes

At this time, the Chair was informed that a quorum was in attendance and the agenda returned to approval of the minutes of the September 20, 2021 meeting. Ms. Sullivan made a motion to approve the minutes, which was seconded. Given that there was no discussion about the draft minutes, a vote was taken and the minutes were approved unanimously.

Vote and Approve Final Draft 2020-2021 Coordinating Council Report

Mr. Cochran thanked staff and Council members for their efforts to develop and review the draft document and reemphasized that the information provided in this update serves as a road map for the Governor and Legislature regarding best practice and training needs for directing services specific to Alzheimer's care. He requested and received a motion from Ms. Sullivan to approve the submitted report as final, and this motion was seconded. The Council was then asked for discussion.

Discussion ensued around the contents of the draft Council report and issues around the current events of Alzheimer's Disease. A subcommittee was formed with members, Mr. Taylor and Ms. Smith-Boivin. They noted that as subcommittee members they could not identify if their recommendations were included in the report. They presented that it appeared as they were not included. Both members felt that the report needed to provide stronger statements about more recent scientific developments in the treatment of AD/D, advancements in medications, early detection, warning signs, and training of clinical practitioners. In addition,

recommendations need to be prioritized and reorganized for emphasis. Ms. Smith-Boivin indicated that one of recommendations made by the subcommittee was to include a longer executive summary in the report. She also noted that there wasn't enough time allocated at this meeting to discuss the draft Council report. She also indicated that the report lacked data to describe the success of NYS's Healthy Aging Across all Policies initiative. Ms. Griffin was asked to provide a walkthrough of the draft, to outline where Council's comments were integrated. Ms. Griffin noted that the specific wording and locations might be different from the exact recommendations of the subcommittee, but the content and intent was contained within. She indicated that key updates in the 2020-2021 report focus on new FDA approved treatments and the impact of COVID, taking into consideration the feedback of physician members of the Council. She also stated that Council members are encouraged to be part of the discussions around prioritizing recommendations which will occur at the subsequent meeting(s). Ms. Aubertine-Fiebich suggested that it would have been helpful to have received a version of the report with track changes so that it was clear where adjustments were made after the September meeting.

Ms. Menard, NYS DOH Counsel to the Coordinating Council, provided guidance as to the statutory requirements for the Council report, describing that overall, the report should shape state policy regarding services that are crucial to those living with AD/D, and outline the coordination among public and private agencies to meet those needs. The statutory charge of the Council focuses on highlighting best practices, interventions important for caregivers, medical and professional training, assessing strengths in our communities, and identifying gaps, with the global charge of informing state policy. Ms. Menard noted that the statute also dictates the timeline by which each biannual report must be completed and approved, which creates some urgency to finalize this report as soon as possible. She suggested that there could an option to convene another meeting to discuss and approve the report, recognizing that June 30th is the statutory date by which the report must be submitted.

Mr. Levine noted that it was important to recognize the new landscape of dementia care and that the Council has an opportunity to shape state policy going forward, to respond to this new environment. This should include state policy specific to provider education. He asked about the possibility of holding a separate meeting in January to prioritize the recommendations.

Dr. Nixon added his concerns regarding transparency and the importance of knowing where feedback from both the September meeting and the subcommittee was integrated into the report. He reinforced the need to acknowledge new educational needs for providers in a rapidly evolving landscape, as acknowledged by the committee.

At this time, Ms. Gnozzio indicated that staff would move to schedule another subcommittee meeting, preferably in early January, to focus on the report and its content. Staff will use that meeting to walk attendees through the report in detail and ensure that members have the information they need to approve the report at the March Council meeting. At the request of Dr. Nixon, Ms. Menard will provide a copy of the Council bylaws and statutory mandates that should guide Council recommendations.

Ms. Sullivan asked that in addition to seeing a draft report highlighting changes suggested by the committee or Council members, that staff also provide a response to those suggestions so that members have a stronger understanding of how decisions are finalized.

Due to the robust discussion surrounding the draft report, agenda topics: *OMH at the Interface of Mental Health and Dementia* and *Memory Advocate Peers (MAP)* were not presented at this time.

Adjournment

Mr. Cochran noted that no public comments had been brought to the Council. He reminded the members that the 2022 Coordinating Council meetings have been scheduled for March 14, June 13, September 12, and December 5. At that time, he welcomed a motion to adjourn the meeting, made by Mr. Taylor, and seconded. The meeting was adjourned at 12:08 pm.