



Department of Health

KATHY HOCHUL
Governor

MARY T. BASSETT, M.D., M.P.H.
Commissioner

KRISTIN M. PROUD
Acting Executive Deputy Commissioner

DRAFT MINUTES

NYS Coordinating Council for Services Related to Alzheimer's Disease
and Other Dementia
Monday, September 12, 2022
10:00 AM – 12:00 PM

Council Members and Representatives:

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

Absent: Dr. Louis Belzie, Denise Cavanaugh, Dr. William Higgins, Greg Olsen, Paula J. Rice

Others Present: Erin Fay, Maribeth Gnozzio, Bill Gustafson (Alzheimer's Association), Susan Lawless Esq. (DLA), Marci Goldstein (NYSDOH), Katie Mahar, Tracy Sinnott, Lynn Young, Erin Purcell (NYSOFA), Geri Taylor, Charles Williams (NYSDOH)

Note: The meeting was conducted via Webex in compliance with NYS Open Meeting law and the Governor's Executive Order 11. The meeting was recorded.

Welcome, Announcements, and Roll Call

Ms. Gnozzio welcomed members of the Council and called the meeting to order at 10:03 AM. She requested that Erin Fay conduct the roll call, confirming that a quorum was in attendance.

Ms. Gnozzio also informed the Council that Commissioner Bassett has announced the creation of the Office of Aging and Long Term Care (OALTC), under the leadership of Deputy Commissioner Adam Herbst Esq. With this change, a new Center Director, Andrew Lebwohl, will be joining the Council.

Approval of Minutes from June 13, 2022 Meeting

Mr. Cochran, Council Co-Chair, then asked the Council to approve the minutes of the June 13, 2022 meeting. Ms. Smith-Boivin made a motion to approve the minutes, which was seconded by Susan Sullivan. There was no discussion or changes requested of the minutes and they were approved unanimously as presented.

At this time, Mr. Herbst described the organizational changes underway with the creation of a new Office of Aging and Long-Term Care (OALTC). This office will support Dr. Bassett's strong commitment to aging services and health equity. He shared the vision for this new office to meet the needs of all New Yorkers as they age. The OALTC core mission will be providing opportunities for all New Yorkers to age in place for as long as possible, with access to quality services that promote dignity and independence, in addition to developing policies, programs, and accessible supports that meet the needs of older New Yorkers and people with disabilities.

The Alzheimer's Disease Program will be a critical component of this mission. Mr. Herbst noted the Department's commitment to the Master Plan on Aging, which will focus on aging services and supports for aging in place. In addition to developing policies, programs, and accessible supports that meet the needs of older New Yorkers and people with disabilities, OALTC will focus its efforts on aging and long-term care activities related to licensure, surveillance, data collection and analysis and developing and financing new innovative models of care. Mr. Herbst emphasized the important role that the Council will play in this new future and thanked members for their efforts and collaboration to-date.

Ms. Smith-Boivin noted that she was pleased to hear that there would be efforts to "knock down silos" and asked whether this new Office would include NYSOFA and OPWDD. Mr. Herbst noted that all agencies are working together but are not joining formally at this time. He emphasized that all agencies are working closely on the Master Plan on Aging but that NYSOFA continues to have important initiatives underway that must continue. He again stressed the importance of all agencies working collectively and collaboratively toward addressing aging concerns. The OALTC will work closely with the Office of Health Insurance Programs (OHIP), the Office of Primary Care and Health Systems Management (OPCHSM), the Office of Public Health, the NYS Office for the Aging (NYSOFA), and the new Office of Health Equity & Human Rights.

Mr. Taylor asked whether this new structure would impact the role of the Council. Mr. Herbst noted that there would be no change, adding that the Council was fundamental to the mission and that there was hope that this change would result in more resources. He also noted that Andrew Lebwohl would be joining the Council and should be present for the December meeting.

Ms. Fiebich noted some overlap at OCFS with adult care facilities and expressed hope that there would be a place for different models that don't exist now.

Mr. Cochran reinforced that within such a large organization as the Department of Health that having Mr. Herbst engaged in bringing together all work with long-term care will be valuable; having a leadership position that can maintain a central focus on aging issues and facilitate conversations about important initiatives and systems design.

Council's 2022-2023 Goal Recommendations Discussion (Goals 2-6)

At this time, Mr. Cochran moved the agenda to discussion of the Council's 2022-2023 Goals and Recommendations, starting with Goal 2 to improve clinical care for AD/D, which includes recommendations 4-12. He noted that the workplan includes descriptions of much of the work underway to address individual recommendations and encouraged the Council to add work that might be underway in other state agencies.

Mr. Taylor asked staff to explain the use of different color text in the draft. Ms. Fay explained that content written in purple reflects activities underway at NYSDOH, while blue text is specific to NYSOFA, and red notes are points that stem from conversation during the last Council meeting.

Discussion Recommendation #4: Training of primary care providers and the larger medical community in AD/D screening, diagnostics, and clinical care. Mr. Taylor questioned the data available to track physician/provider outreach and training. Staff confirmed that routine reporting was capturing these numbers on a quarterly basis. There was also question as to whether the Department had a set curriculum that the CEADs used. Staff noted that each

CEAD was sensitive to their region's provider community and tailored training to best meet the needs. Staff has also routinely attended and observed provider trainings and found them to be appropriate to the focused topics outlined in this recommendation.

Ms. Smith-Boivin asked whether we have data that measures the impact of training activities on clinical practice. Staff noted that this remains a challenge in terms of evaluating how training information and knowledge are applied in the clinical setting. Ms. Smith-Boivin noted the Association's model for training physicians and the subsequent tracking of referrals to Association services. She suggested it might be useful to monitor the impact of training on referrals.

Mr. Levine described that CaringKind does the same tracking of referrals and noted that the majority of these referrals are not from physicians. Referrals more often come from social workers, physician extenders, and even office staff. Broadening training reach to include office support staff should be considered with this recommendation as well. Ms. Boivin suggested amending the wording to reference physician offices or practices and not just physicians. Mr. Cochran added that case managers in programs supported by NYSOFA play an important role in referring individuals and families to services.

Mr. Taylor noted that this workplan asks a lot of the CEADs, with no change in funding. He asked whether there is any prioritization of what we are asking CEADs to do. He reinforced that this recommendation is of particular importance given that new treatments are on the horizon.

At this point, Ms. Gnozzio summarized the key points made during the discussion of recommendation #4. These include identifying the barriers inherent to developing and measuring best practices for training, quantifying physician outreach, and expanding outreach where possible. Although there is not a common curriculum in place at the CEADs, there are common core goals to that training and each CEAD is responsible to adhere to these priorities. Overall, activities need to explore ways to measure training outcomes, while at the same time expand the array of providers trained.

Discussion Recommendation #5: Increasing public awareness of new treatment options. Ms. James noted that activities under this recommendation are similar to those for #4 and asked whether #5 should be assimilated into other recommendations. It was noted throughout the discussion that there were similarities across several recommendations. Staff noted that CEADs track public awareness and media presence and report quarterly.

Dr. Nixon noted the importance of making people aware of available treatments, but that you can't avoid making them also aware of the risks and barriers to these treatments. He proposed that the recommendations include a website or some other resource link where providers and the public can get information about treatment guidelines for new medications that are coming out. He added the importance of helping the public navigate what has become a confusing landscape as to how to use and prescribe medications as they start to appear on the market, noting the difficult balance of articulating the pros and cons.

Mr. Taylor expressed his concern that recommendation #5 was talking about reaching the public but only focused on the CEADs. He asked whether there was a broader set of resources available to reach the larger audience in NYS. He informed the Council of an upcoming initiative that will be launched on World Alzheimer's Day, September 21, called Voices of Alzheimer's. The goal of this initiative is to create a network of members who will be educated on strategies to advocate for more favorable approval processes and coverage landscapes that

support new medications and diagnostics as they evolve. This new program will include both persons living with dementia and caregivers.

Ms. Galbier noted the Alzheimer's Association's Health Systems Division, which is intended to influence the use of diagnostic criteria by large health care systems and federally qualified health centers and address barriers to implementing appropriate screening and diagnostic protocols.

Ms. Gnozzio suggested that we not eliminate recommendations but instead track the discussion in the outcomes section of the workplan. Once we have completed a review of the entire workplan, the recommendations can be revisited.

After discussion about combining #4 and #5, it was decided that the focus on public awareness in recommendation #5 was targeted toward a larger audience, specific to clinical care and new therapeutics, so it was decided to leave this recommendation as a unique item.

Discussion Recommendation #6: Mr. Cochran noted activity by the Hospital Association, specific to Age Friendly Health Systems. The goal is to identify a number of emergency rooms and hospitals that have established age friendly cultures of care. This has been headed up by the NYSDOH and the Johnny Harper Foundation.

Discussion Recommendation #7: Getting information disseminated about the annual Medicare Wellness Visit. Mr. Cochran noted that NYSOFA operates the health insurance counseling and assistance program designed to provide information to Medicare beneficiaries to ensure they have appropriate Medicare D coverage. This activity can be included in the workplan.

Discussion Recommendation #8: Increase number and funding of CEADs. Mr. Taylor asked what the Council and concerned individuals in the public can do to advocate for additional funding of the CEADs. Discussion about the realities of the state budget process followed, but the Council was encouraged to speak up about specifics for funding and address ideas to the Chamber and Legislature.

Mr. Taylor expressed concern about being able to get through all the recommendations and asked whether we could convene a separate meeting specific to getting through the agenda. Ms. Gnozzio noted that a workgroup could be assembled but it couldn't be an official action by the Council. The recommendations of the workgroup could then be brought to the full Council. Mr. Taylor was more interested in having feedback of the full group. Staff noted that the December meeting could be focused entirely on completing the discussion of the recommendations. It was decided that Council members will be surveyed via email as to their preference for convening an additional meeting versus convening a workgroup.

Before ending the discussion, a question was raised about the difference between recommendation #5 and #10. Staff will look at combining these 2 recommendations prior to the next meeting.

Update on NYS Open Meetings Law

Susan Lawless, NYSDOH Division of Legal Affairs and Counsel to the Coordinating Council, provided an update to the Open Meetings Law. The Executive Order (EO) #11, allowing remote participation in meetings, was extended after the last meeting but that extension ends

September 12. A provision of the law requires the adoption of a resolution that would allow members to videoconference into meetings under certain “extraordinary circumstances.” The definition of extraordinary includes, but is not limited to, temporary or permanent disability, illness, caregiving responsibilities, or any other significant or unexpected factor or event which precludes the member’s physical attendance at such meeting.

Ms. Lawless outlined that the Council can adopt a resolution defining “extraordinary circumstances” and the terms under which the Council will do business. This will allow those members not physically present at the meeting to vote on Council actions, with the requirement that a quorum is physically present at the meeting location.

Members attending virtually are required to be on camera, be heard, seen, and identified, while the meeting is being conducted.

After discussion, Mr. Taylor made a motion to adopt the model resolution. The motion was seconded by Ms. Sullivan and approved unanimously by the Council. Staff will finalize the wording of the model resolution for specific use by the Council. In addition, staff will draft instructions for implementing extraordinary circumstance provisions and present this information at the December meeting for consideration of the Council.

Ms. Lawless discussed the uncertainty as to whether EO #11 will be extended. If it is not extended members of the Council are to anticipate attending the December meeting in person. Mr. Herbst asked that staff message the Council by email to keep them informed of the status of EO #11.

Healthy Brain Initiative (HBI) Consumer Education Campaign

Marci Goldstein, Director, Division of Communications, NYSDOH, presented the outcome of the “Healthy Brain” public awareness campaign that was funded by the Alzheimer’s tax check-off program. The campaign ran from February 9 through March 20, 2022. The targeted demographic was underserved populations aged 45-65 in Bronx and Kings counties. The budget for the project was \$226,000 and the focus was to get as much impact as possible with the available funds. The formats used included digital media, “out-of-home” ads (bus shelters and convenience stores) and print advertisements.

Ms. Goldstein provided the Council with performance data from the campaign and explained how the project successfully reached the targeted audiences.

Mr. Taylor asked how to access the videos and Ms. Goldstein directed him to the NYSDOH Facebook page and the Alzheimer’s Disease Program website. Staff will send the links to the videos out to the Council. He also inquired as to the source of the funding and how we could ensure that funding is available to all parts of NYS. Staff explained that funds for this project were derived from the tax check-off. It was also noted that contractors under the Caregiver Support Initiative use funding to support Public Awareness activities across the state.

Ms. Fiebich asked about the methods of measuring “impressions” and Ms. Goldstein offered to verify the exact methods with the vendor while noting the use of QR coding with the State of Health campaign.

Ms. Gnozzio thanked Ms. Goldstein for her presentation and asked the Council if there were any announcements. Ms. Fiebich noted that their upcoming annual meeting will have staff in

attendance from Adult Protective Services and all Area Agencies of Aging. She requested literature about ADP funded programs and helpful links to important information. Ms. Gnozzio indicated that ADP staff will provide those resources in advance of the conference.

Ms. Smith-Boivin reported that the Alzheimer's Association was convening its first Federal Affairs Meeting in Washington, DC. Representatives have been invited from states that have been successful in developing an array of services for those living with AD/D. New York State has been recognized for its efforts in this area and Ms. Gnozzio has been invited to represent NYS during this event.

There were no public comments submitted for this meeting.

The Council was reminded that at this time, the December 5, 2022 meeting will be an in-person meeting at One Commerce Plaza, Albany unless the Governor's Executive Order is extended again. Ms. Gnozzio outlined that 2023 meeting dates will be drafted soon.

A motion was then made by Ms. Sullivan to adjourn the meeting. This motion was seconded by Ms. James and the meeting was adjourned at 12:06 PM.