



## Department of Health

KATHY HOCHUL  
Governor

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

KRISTIN M. PROUD  
Acting Executive Deputy Commissioner

### MINUTES

NYS Coordinating Council for Services Related to Alzheimer's Disease  
and Other Dementia  
Monday, December 5, 2022  
10:00 AM – 1:00 PM

#### **Council Members and Representatives:**

**Members Present In-Person:** John Cochran (designee for Greg Olsen), Catherine James, Elizabeth Smith-Boivin, James Taylor, Catherine James, Andrew Lebwohl (pending appointment/designee for Adam Herbst), Denise Cavanaugh

**Members Present Virtually:** Dr. Carl Cohen, Shelly Aubertine-Fiebich, Teresa A. Galbier, Jed A. Levine, Dr. Ralph Nixon, Suzanne Sullivan, Dr. William Higgins

**Members Absent:** Dr. Louis Belzie, Susan Prendergast

**NYSDOH Staff Present:** Susanne Coburn, Erin Fay, Maribeth Gnozzio, Susan Lawless Esq. (DLA), Katie Mahar, Tracy Sinnott, Lynn Young

**Others Present:** Bill Gustafson (Alzheimer's Association), Erin Purcell (NYSOFA), Geri Taylor, Emily Palmiero (NYSDOH), Abbey Derepentigny (NYSOFA), Mina Sun (Sun Family Medicine), Alyson Tarek (Executive Chamber)

Note: The meeting was conducted via Webex and in person. The meeting was recorded.

#### ***Welcome, Announcements, and Roll Call***

Mr. Cochran called the meeting to order at 10:15 AM. Ms. Gnozzio requested that Erin Fay conduct the roll call, after which it was determined that a quorum was not present. Mr. Cochran explained that the goal of this Council meeting would be to complete the review of the Goals and Recommendations workplan. No formal action/recommendations would move forward.

#### **Approval of Minutes from September 12, 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. Mr. Cochran noted an error in Recommendation #6 where the reference to funding should be corrected to the John A. Hartford Foundation. Ms. Fay confirmed that this change has already been made.

### **Introduction of Andrew Lebwohl**

Mr. Cochran introduced Andrew Lebwohl, NYSDOH Center Director of the Office of Aging and Long-Term Care (OALTC) Finance and Support Services. Mr. Lebwohl provided an overview of his experience prior to joining the NYSDOH and noted that he is pleased to be part of the Department's team.

### **Update on Council Report**

Ms. Gnozzio noted that the 2020-2021 Council report continues to be under review, awaiting approval. She reported that at this time the report has been cleared through the Division of Legal Affairs and is currently with the Division of Budget. Mr. Taylor asked if there has been feedback on the report as it has gone through the approval process, Ms. Gnozzio confirmed that there have been questions that have been addressed at the time of review. Ms. Gnozzio noted that there have been no questions regarding the contents of the report and Ms. Fay concurred, clarifying that questions were mainly related to the funding. Ms. Gnozzio reinforced the use of the workplan as a working document to guide the development of the 2022-2023 report going forward, and to facilitate a smoother process when finalizing the report.

### **Goals and Recommendation Workplan Review**

Council business moved to the continued discussion of the Goals and Recommendations workplan, starting with Goal 3. Ms. Smith-Boivin voiced that the Goals and Recommendations workplan should prioritize activities that make a difference in communities. Ms. Gnozzio confirmed the objective of the workplan was to ensure activities underway to address Alzheimer's Disease are maintained in a centralized location.

Ms. Gnozzio noted, and Mr. Cochran concurred, that the workplan will inform the NYS Master Plan on Aging as it is developed.

Staff reminded the Council that the framework of the Council report, and its corresponding Goals and Recommendations, are based upon the Healthy Brain Initiative Road Map and matches the priorities promoted on a federal level.

Mr. Cochran suggested that he would announce each goal and solicit discussion, as the Council works through the workplan document. He then requested input for **Goal 3: *Ensure the access to housing and supports that promote living in the least restrictive environment.***

Mr. Taylor asked if there is a Dementia Friendly New York effort underway. Mr. Cochran reviewed ACL funding that provides guidelines to entities interested in establishing dementia friendly communities. A workshop was held for Office For Aging (OFA) staff and contractors to educate on Dementia Friendly Communities. Staff explained that several NYS organizations have taken a lead on establishing dementia friendly environments and suggested that this information could be shared with the Council at a later date.

Mr. Taylor noted working with Indiana and described their efforts to build a Dementia Friendly Organization, particularly as it relates to training workforce. Mr. Cochran added the work of the John A. Harford Foundation toward improving hospitals work with the aging community. He also noted that Age Friendly NY activities are locally driven, and that funding has supported local planning activities and changes to infrastructure.

Ms. Gnozzio noted the NYS Alzheimer's State Plan that was established years ago, stating that this plan would need future updating in conjunction with the Master Plan on Aging.

Mr. Taylor asked about the need for a focus on hospitals becoming age friendly. Staff described efforts underway through the Hospital Association of New York State (HANYS) to transition hospitals using age-friendly guidelines and that the Centers of Excellence for Alzheimer's Disease (CEADs) have taken a lead on these efforts. Ms. Smith-Boivin asked that these activities be added to the workplan. Mr. Cochran also offered to share the list of HANYS Age-Friendly hospitals with Council members.

Ms. Smith-Boivin requested clarification as to the purpose of the workplan being discussed and asked if this would frame the content of the 2022-2023 Council Report. She further asked that new activities be showcased in the next report that gets submitted at the end of 2023, further supporting the funding that NYS provides for Alzheimer's Disease Program (ADP) initiatives. She also asked that data collected from grantees be integrated into the 2023 report.

Mr. Cochran asked if there were activities to be added from other NYS agencies. Staff noted that there is no NYS Division of Housing within the NYSDOH but that there are housing activities under Social Determinants of Health that could be added. Mr. Cochran stated that the Division of Housing and Community Renewal (DHCR) is on the committee for the Master Plan on Aging and noted \$20 billion is part of the Governor's Housing Plan which will include new requirements to support aging in place.

Ms. Smith-Boivin suggested updating any recommendations that reference "Dementia Friendly" communities to read "Age/Dementia Friendly."

Mr. Levine further recommended that all funded ADP initiatives be referenced in the activities, since only the Alzheimer's Disease Community Assistance Program (AlzCAP) was identified in Recommendation 13. Staff agreed to update accordingly. Before moving on, Mr. Cochran shared a definition of Dementia Friendly communities found on Alzheimers.org and Ms. Gnozzio indicated that staff will integrate definitions of both Dementia Friendly and Age Friendly Communities within the report.

Ms. Purcell asked about the process to add updates to Recommendation #16, noting that NYSOFA has trained about 80 Area Agencies on Aging (AAA) Case Managers with Boston University. She and other Council members were advised to share updates with ADP staff between meetings so an updated workplan can be presented at future meetings.

Ms. Smith-Boivin questioned whether a full review and approval of the workplan document is necessary during this meeting. Mr. Cochran noted that the Council asked to review the working document in full and Ms. Gnozzio confirmed that as a baseline document, the workplan would be updated during each upcoming meeting. She reminded the Council that it had previously voted on the Goals and Recommendations and that this review was to ensure that all agree on the activities listed and whether additions were needed. Mr. Taylor noted that the recommended workplan is a good way to inform new members as to what activities are underway to address Alzheimer's Disease and other dementia (AD/D) and to help prioritize activities in 2023. It was also noted by staff that this workplan serves as the Council's internal document to keep staff on point so updates should be sent to staff prior to each meeting to be included.

#### **Goal Four**

Mr. Cochran presented **Goal 4: Supporting Informal Caregivers and Persons Living with AD/D** and summarized the importance of this goal given the role of informal caregivers in avoiding long-term care. He noted NYSOFA's work with the NYS Department of Labor, specific to working caregivers and the need to provide supports to keep them active in the workforce. He

also described work of Judge Deborah Kaplan and the Justice Task Force regarding increases in financial exploitation seen in the court system.

Ms. Gnozzio asked whether Recommendation #24 was too broad in its reference to providing training to “all” long-term care facilities. After discussion, the Council advised to further define the long-term care sites being prioritized for this goal and add reference to acute care.

Mr. Taylor inquired as to how people in the community are made aware of resources in the community. Council members and staff described initiatives in place through the ADP funded initiatives, such as the National 800 “hot line” with the Alzheimer’s Association that links callers to information about resources but funds follow-up calls from their local Chapters. Mr. Levine noted references to public awareness in this goal and staff added the requirement for all NYS funded initiatives to participate in public awareness efforts.

Ms. Smith-Boivin reinforced the importance of this report in supporting ongoing, as well as additional funding for AD/D initiatives, as service delivery costs increase. Mr. Taylor added concern over the need for increased public awareness for early detection. Ms. Smith-Boivin voiced concern regarding significant wait times at CEADs, and impact on an individual’s ability to get a diagnosis so they can participate in clinical trials.

Ms. Gnozzio noted the importance of coordinating public awareness messaging across agencies. Mr. Cochran added that the level of awareness has increased globally, further enhancing the need for staff to provide access to early diagnosis. Staff informed the Council that many of the CEADs have formed partnerships with primary care practices and Federally Qualified Health Centers in their respective regions, as a way to build capacity. Ms. Gnozzio addressed the importance of the continuum of care post diagnosis as well, while staff pointed out that with the continuum of care in place through the Alzheimer’s Disease Caregiver Support Initiative (ADCSI), the CEADs can refer to a local CSI or AlzCAP program post diagnosis.

Mr. Taylor discussed conversations at a federal level for the use of blood panels for diagnosis, suggesting this could improve access to diagnosis. Council members added that this procedure is not currently FDA approved or reimbursed and Ms. Smith-Boivin noted that educating primary care physicians (PCPs) about these types of advancements to diagnosis and treatment of AD/D is addressed in Goal #1. She also outlined the availability under Medicare for providers to bill under G-Codes, which reimburse for additional assessment time and care planning. Mr. Taylor also added the availability of the annual wellness visit under Medicare that is not routinely offered by physicians, as required.

Ms. Smith-Boivin reiterated concerns about public awareness as it relates to research, and suggested use of this activity in the next Council report to request increased funding.

Ms. Gnozzio explained that updated *At-A-Glance* documents, used by the ADCSI programs, show the growth all of initiatives. Mr. Taylor inquired as to where to get those documents and staff stated that, once approved, the documents would be provided to the Council.

Ms. Aubertine-Fiebich noted that several facilities under Office of Children and Family Services (OCFS) fall under long-term care, such as the Family Type Homes, and asked what training might be appropriate under Recommendation #24. Ms. Smith-Boivin noted the Association’s EssentiALZ® training program, which is evidence-based, appropriate for assisted living and family care homes. She added that local Chapters receive funding from the ADCSI to offer this

training, Ms. Aubertine-Fiebich added information about current work with Association staff to train Adult Protective Services workers about AD/D in 2023.

Ms. Gnozzio informed the Council that the ADP is increasing data collection efforts through the BRFSS using Tax Check-off Funds.

Ms. Aubertine-Fiebich inquired whether they should state the Goal and Recommendation number when sending updates to the ADP. Ms. Gnozzio agreed that would be best practice.

### **Goal Five**

Mr. Cochran introduced **Goal 5, Address Disparities and Improve Health Equity**, noting that this would be a large focal point for the Master Plan on Aging and summarizing that impact. Ms. Smith-Boivin recommended adding information about the CEAD's work with Federally Qualified Health Centers to Recommendations #27 and #28. She also noted the goals under AlzCAP are to reach diverse populations, and convening six community forums in individual regions. They are also providing information and programs in Spanish. Ms. Gnozzio noted that rural populations are assumed to be included in the group of "underserved" communities but should be clearly identified. Discussion followed regarding issues pertinent to rural communities and how access to care is impacted.

Mr. Cochran explained a new initiative to place case managers in physician offices to assist with services. He described increased requests for health insurance counseling, further noting the effectiveness of the State's Health Insurance Information and Counseling Assistance Program (HIICAP) for accessing Medicare and other types of benefits.

Ms. Gnozzio asked whether Recommendation #30 was more appropriate elsewhere in the workplan. Staff explained that this recommendation is specific to the ID/DD population in this Goal and that a similar statement is found in Goal #1, Recommendation #1, for the overall population. Ms. Galbier informed the Council of training developed by the Rochester Chapter specific to the ID/DD population that could be added to this recommendation. She will forward this information to the ADP team via [alz@health.ny.gov](mailto:alz@health.ny.gov).

### **Goal Six**

Mr. Cochran reviewed **Goal 6: Promote Research, Prevention and Risk Reduction Strategies**. Ms. Smith-Boivin asked to amend the wording of Recommendation #31, adding "Utilizing public health data" to the beginning of the statement. She noted the importance of public health data in the promotion of lifestyle change. She also noted the Healthy Living Through the Body Program and TrialMatch, and asked that these programs be added to Recommendations # 31 and #32. Dr. Nixon concurred regarding the addition of TrialMatch but also suggested adding ClinicalTrials.gov. Mr. Taylor mentioned that TrialMatch may not be the most user-friendly resource and described an additional website, "Being Patient" ([www.beingpatient.com](http://www.beingpatient.com)). He also noted "Site Match" which is being developed to help consumers locate research by location and site of that research.

Regarding Recommendations #31 and #32, Ms. Smith-Boivin suggested wording that expands the promotion of lifestyle changes beyond those living with AD/D to include the general public, given what we now know about risk reduction. Dr. Nixon was in agreement.

Mr. Taylor noted the importance of recruiting "healthy" volunteers to clinical trials and having these individuals available to guide others interested in participating in research. This activity

should be added to wording in Recommendation #32. Ms. Gnozzio added that these “healthy” volunteers help create the baseline.

Ms. Gnozzio highlighted next steps to expand wording throughout the workplan, integrating references to reaching the public where pertinent, to risk reduction and lifestyle modification. Ms. Smith-Boivin reiterated the importance of using this document to draft future Council reports. Mr. Taylor suggested that the workplan could inform agendas and topics of discussion in the future. Mr. Cochran recommended adding a 15-minute standing agenda item to touch base on the workplan.

### **Member Announcements**

Mr. Taylor reported on his recent attendance at the CTAD (Clinical Trials Alzheimer’s Disease) conference where information was shared about new medications and treatments that are on the horizon, and pending approvals. He highlighted potential uses of combination therapies, as well as off-label use of known medications and excitement of evolving use of blood panels for diagnosis. Ms. Smith-Boivin added discussion about the benefits of both Tau and Amyloid acting medications approved so that combination studies are enhanced.

Mr. Taylor described his involvement with the development of Voices of Alzheimer’s ([www.voicesofad.com/](http://www.voicesofad.com/)), a new advocacy group.

As a member of the public, Mr. Gustafson expressed concerns regarding the lack of funding increases for ADP initiatives at a time when operational costs are increasing. He asked what could be done internally by the Council and the Department. Discussion followed outlining that the Department is aware of this concern, noting that advocacy for our program has changed with the last election and that the Association’s legislative strategy remained important.

Mr. Levine posed a question as to the possibility of Executive Order (EO) 11 being reinstated given the rise in COVID numbers. Ms. Lawless explained that this decision is made by the Governor. Ms. Gnozzio explained that there is a process for the Council to request a change in meeting requirements, but this process would take time. Ms. Lawless did not anticipate that the EO would be reissued and noted that the Governor’s authority to issue such orders has changed. Staff acknowledged that the Council had a quorum for this meeting, but the issue was having a quorum “in-person” and asked about amending meeting schedules to reduce the number of times that members needed to attend in person. This might result in one in-person meeting each year to conduct business that requires a vote.

Ms. Lawless outlined that this Council must obey open meeting laws, recognizing that this interpretation has changed over time. She noted that the Council report is required in statute and that the legislation must consider the recommendations of that report. Per statute, the Council must meet quarterly. Ms. Lawless committed to exploring the law further to determine if scheduling could be restructured to allow for a combination of in-person meetings with a quorum to conduct business and others virtual when only information is being shared.

### **2023 Meeting Dates**

Ms. Gnozzio asked if there were any conflicts for the meeting schedule presented for 2023. Mr. Taylor asked that the August meeting be moved to September. Staff indicated that they would revisit the 2023 dates.

### **Adjournment**

There are no other public comments. The meeting was adjourned at 12:25 pm without a vote.