DRAFT MINUTES
NYS Coordinating Council for Services Related to Alzheimer's Disease
and Other Dementia
Monday, September 14, 2026
11:00 am - 2:00 pm

Council Members and Representatives:

Members Present In Person: Katie Mahar, (Department of Health), John Cochran (Office for the Aging), Elizabeth Smith-Boivin, Dr. David Hart, Catherine James, George Shaw (Office for People With Development Disabilities), Casey Schenk (New York State Education Department), Alana Streifert (Office of Children and Family Services), James Taylor, Dr. Denise Cavanaugh, Dr. Carol Podgorski, David Okrent, Esq., Dr. David Hoffman, Dr. Donna de Levante Raphael

Members Present Virtually: Dr. Louis Belzie, Jed Levine, Maxine Smalling (Office of Mental Health), Theresa Galbier

Members Absent: Dr. William Higgins

New York State Department of Health Staff Present In Person: Tracy Sinnott, Kimberly LaBarge, Susanne Coburn, Rose Gardner, Kim Botto, Jessica Dell'Anno (Division of Legal Affairs), Michael Chittenden

Others Present: Charles Williams (Office for the Aging), Heather O'Connor, Felicia Segelken (Office for the Aging), Dr. Mary Mittelman, Annie Maselli, Bobby White, David Iman, R. Mclaughlin, Lisl Maloney (Office of Children and Family Services)

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

Roll Call:

The meeting was called to order at 11:03 am. Ms. Sinnott conducted roll call of all Council members. It was determined that a quorum of Council members was present. Ms. Alana Streifert (Office of Children and Family Services) and Ms. Casey Schenk (New York State Education Department) were introduced as new designees on the Council.

Welcome, Announcements:

Mr. Cochran reported Governor Hochul's announcement of the first phase of the State University of New York (SUNY) Brain Institute, a $10 million, multi-campus initiative focused on expanding neuroscience research and addressing age-related brain disorders.

Mr. Cochran also provided updates regarding the Prevention Agenda Ad Hoc Committee, including opportunities for greater integration of Building Our Largest Dementia (BOLD) activities and the Master Plan for Aging (MPA).

Ms. Mahar was announced as the new Co-Chair, replacing Mr. Jabonaski. Ms. Mahar requested that as part of the orientation process, Council members provide brief biographies to distribute to current and new Council members.

Approval of Minutes:

The minutes from the June 8, 2026, meeting were approved.

Ethics Review:

Mr. Chittenden reviewed the ethics requirements sent to Council members by email and encouraged members to complete the required ethics course and training by the end of the year. Council members were reminded to send Ms. Sinnott their confirmation of completion for Council records. The training supports the Council's commitment to uphold ethical standards and prevent fraud, waste, and abuse.

Ms. Smith-Boivin noted that the current materials do not specifically address the ethical responsibilities of Council members. The Council discussed adding guidance outlining members' individual ethical responsibilities and expectations.

Neurology and Research Update:

Dr. Hart provided an update from the Alzheimer's Association International Conference (AAIC), a worldwide gathering of dementia scientists and caregivers, which had approximately 13,000 attendees participating in person and online. He highlighted recent research on amyloid-targeting antibodies, including Donanemab and Lecanemab, and the challenges associated with delivering these treatments across the blood-brain barrier, which can deteriorate over time. Dr. Hart discussed ongoing research on Trontinemab, which is designed to improve the delivery of medication across the blood-brain barrier. A Phase Three clinical trial is currently enrolling, with results expected in approximately two to three years.

Dr. Hart also referenced the work of Jeff Cummings and Alzheimer's clinical trials, as well as Genome-Wide Association (GWA) studies, which are being used to better understand genetic factors associated with Alzheimer's disease and related dementias.

Supported Decision Making:

Ms. Diller, Clinical Professor of Law at Benjamin N. Cardozo School of Law, presented on supported decision-making in the context of Alzheimer's disease and other dementias. Supported decision-making helps individuals maintain autonomy and participate in decisions about their lives with assistance from trusted individuals and professionals.

The presentation covered practical strategies, how supported decision-making can be used with advance planning tools, and considerations for protecting individuals from abuse and undue influence. The discussion also addressed supported decision-making as an alternative or complement to guardianship.

Building Our Largest Dementia Infrastructure (BOLD) Update New York State:

Ms. Botto reported that the New York State Department of Health received the Building Our Largest Dementia Infrastructure (BOLD) Notice of Award for Year Four, beginning September

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30, 2026, noting that the award included a 10% funding increase. Ms. Botto provided an update on ongoing public awareness activities, including six focus groups with patients and caregivers that are informing messaging related to early detection, brain health, and dementia. The next phase of the campaign will focus on Washington, Warren, Hamilton, Franklin, Essex, and Clinton counties and will encourage individuals experiencing cognitive concerns to speak with their healthcare provider. Statewide education and outreach activities also continue, including distribution of the Brain Health brochure, which is available in 19 languages. 25,870 copies of this brochure have been ordered to date.

Ms. Botto also reported on continued collaboration with Local Health Departments to incorporate brain health messaging into existing public health initiatives. The Alzheimer's and Dementia Care ECHO® Program for Public Health Professionals is scheduled to launch September 15th, with 35 participants representing 12 Local Health Departments. Planning is underway for early detection training in an underserved region of New York State, and collaboration with the New York City program continues to coordinate future activities and align efforts.

Mr. Taylor noted collaboration with New York State Department of Health Building Our Largest Dementia Infrastructure (BOLD) program to help inform the development of its early detection campaign in Raleigh-Durham, South Carolina.

Ms. Smith-Boivin commented on the importance of conducting focus groups with individuals who are not personally connected to dementia to better understand public awareness and perceptions. Dr. Hoffman noted that the National Association of Chronic Disease Directors (NACDD) has focused on dementia risk-reduction strategies for many years.

Mr. Taylor requested clarification on the target age group for the upcoming public awareness campaign. Ms. LaBarge explained that the campaign is intended to promote awareness earlier, and also detection of cognitive concerns. Ms. LaBarge acknowledged the importance of reaching individuals who qualify for Medicare Annual Wellness Visits beginning at age 65 and the continued gap in cognitive assessment, while emphasizing the importance of encouraging individuals to recognize concerns and seek information or care before age 65.

Building Our Largest Dementia Infrastructure (BOLD) Update National:

Dr. Hoffman discussed his work at the United States Department of Health and Human Services (HHS) through the National Alzheimer's Project Act (NAPA), including national planning initiatives and related efforts. Dr. Hoffman emphasized the importance of promoting brain health from a public health perspective and ensuring that elected officials are aware of ongoing Alzheimer's disease and brain health initiatives. Dr. Hoffman noted that he has been advocating with two senators and members of Congress, who have expressed interest in these issues.

Dr. Hoffman also highlighted resources from the National Association of Chronic Disease Directors (NACDD), including the Healthy Aging and Healthy Brain Resource Hub, developed in partnership with the Alzheimer's Association and other organizations. He emphasized the value of the Lancet Commission reports in informing dementia prevention and risk-reduction efforts. He also shared information on a new episode of the *Let's Not Forget (State University of New York Plattsburgh)* podcast, in which he discusses brain health, recognizing misinformation, and the importance of credible information for families affected by Alzheimer's disease. The discussion also highlights the impact of caregiver stress, sleep, and overall well-being,

emphasizing that caregiver health should remain an important part of Alzheimer's disease support.

New York State Alzheimer's Disease Caregiver Support Initiative Overview:

Alzheimer's Disease Community Assistance Program (AlzCAP)

Ms. Mahar provided an overview of the Alzheimer's Disease Community Assistance Program (AlzCAP), which supports people living with Alzheimer's disease and related dementias and their caregivers throughout New York State. Established in the early 2000s, it is the only Alzheimer's disease grant program established in New York State Public Health Law. The program is in its third year and funds the Coalition of New York State Alzheimer's Association Chapters, which oversees seven statewide subcontractors. Services include care planning and consultation, caregiver training, support groups, a 24-hour helpline, community awareness, training for key groups, and, newly this contract cycle, outreach and engagement with underserved communities.

Center of Excellence for Alzheimer's Disease

Ms. Gardner provided an overview of the ten Centers of Excellence for Alzheimer's Disease, which receive $4.7 million annually in New York State funding. The Centers provide regional access to comprehensive and coordinated diagnostic services and expertise for people living with Alzheimer's disease and related dementias and their caregivers. Services include early detection, diagnosis and treatment, care planning, professional training, clinical trial education, and referrals to community resources. The Centers also work with primary care providers and community partners to promote coordinated care and educate the public about early detection, annual wellness visits, and addressing cognitive changes with a health care provider.

Regional Caregiver Support Initiative

Ms. Coburn provided an overview of the eleven Regional Caregiver Support Initiative programs across New York State, which receive $16.5 million annually to promote the health and well-being of caregivers. Over five years, the initiative aims to support caregivers through individual and group activities, expand services for underserved communities, improve coordination and access to supportive services, increase access to respite care, and reduce unnecessary transitions. The initiative also promotes collaboration among organizations and community partners in every county across New York State.

Alzheimer's Coordinating Council Priority Goals (2027-2028):

Ms. Mahar reviewed the Alzheimer's Coordinating Council's 2025-2026 priority goals as a foundation for developing future priorities for 2027-2028. Council members discussed broadening the goals and considering how funding, early detection and risk reduction, the direct care workforce, and support for caregivers can inform future priorities. Dr. Podgorski proposed establishing a subcommittee to consider revisions to the report so that it more accurately reflects the goals and priorities identified and agreed upon by the Council.

2027 Council Report:

Ms. Sinnott reviewed the requirements for the 2027 Council Report and noted that the report needs to be submitted for approvals no later than March 2027. The report will address state

dementia policy; services coordinated by public and private agencies; cognitive impairment screening tools used across the health care continuum; provider best practices for early identification and referral; available interventions and services; and gaps in identification, intervention, and public education, including recommendations to address identified needs. Dr. Podgorski proposed that the report focus on new developments in science, technology, and services as well as available supports.

Ms. Sinnott cited Missouri's State Dementia Plan as an example for consideration when developing the 2027 Council Report. Mr. Cochran reported that he had been contacted by Services and Advocacy for Gay, Lesbian, Bisexual, and Transgender Elders (SAGE) regarding information that may be relevant to the Report. Ms. Smith-Boivin recommended including lessons learned from the COVID-19 pandemic, including the use of virtual learning and other remote approaches to education and service delivery.

Member Announcements, Public Comments:

Mr. Taylor reported that Massachusetts recently passed legislation requiring dementia training for First Responders including fire, police, and emergency medical services personnel. He also discussed a federal Request for Information regarding the physician fee schedule and a proposed code for clinical trials, sponsored by the oncology community.

Ms. Smith- Boivin discussed mandated training for the New York State Police through the Understanding the Emotionally Distressed Person Program, which focuses on individuals with medical disabilities and includes 16 hours of training.

Dr. de Levante Raphael presented information on a national study she is conducting on the biopsychosocial impact of dementia. Dr. de Levante Raphael also announced to the Council that she has published a book on what to expect after receiving a diagnosis of Alzheimer's disease.

Adjournment: The meeting was adjourned at 2:03 pm.

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