MINUTES

NYS Coordinating Council for Services Related to Alzheimer’s Disease and Other Dementia
Monday, March 14, 2022
10 am – 1 pm

Council Members and Representatives:

**Members Present:** Adam Herbst, John Cochran, Dr. Carl Cohen, Denise Cavanaugh, Teresa A. Galbier, Dr. William Higgins, Catherine James, Jed A. Levine, Susan Prendergast, Paula J. Rice, Elizabeth Smith-Boivin, Susan Sullivan, James Taylor

**Absent:** Dr. Louis Belzie, Shelly Aubertine-Fiebich, Greg Olsen, Dr. Ralph Nixon

**Others Present:** Amir Bassiri, Cathy Cardillo, Carmella Gaudio-Simmons, Erin Fay, Maribeth Gnozzio, Thea Griffin, Susan Lawless Esq. (DLA), Katie Mahar, Susan Montgomery, Laura Palmer, Caren Mahar, Jennifer Perry, Tracy Sinnott, Charles Williams, Lynn Young, Erin Purcell, Geri Taylor

Welcome, Announcements, and Roll Call

Mr. Cochran, Council Co-Chair, thanked Council members for joining this meeting and 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 and introduced the new Council member, Denise Cavanaugh, who was recently appointed by Governor Hochul. Ms. Cavanaugh is designated as family member caregiver to the Council. Mr. Herbst, Council Co-Chair, joined in welcoming Ms. Cavanaugh.

At this time, Mr. Cochran requested that Erin Fay complete a roll call, which confirmed that a quorum of members was present.

A motion was made by Susan Sullivan and seconded to move the minutes of the December 3, 2021 meeting. The Council voted unanimously to approve the minutes.
Amir Bassiri, Deputy Medicaid Director, NYSDOH, provided an overview of the fiscal year 2023 Medicaid Budget. He described that overall between fiscal year 2022 and fiscal year 2023, Medicaid spending is projected to grow about 10% overall with additional funding being added primarily driven by increases in enrollment. These increases in enrollment are partly due to protections put into place during COVID. Since March of 2020, growth in enrollment is over one million new enrollees, primarily in managed care.

Mr. Bassiri provided an overview of the global cap and plans to change the metrics for determining this global cap as a more accurate reflection of how we measure year to year growth in Medicaid. This will mean an overall increase in Medicaid spending by $3 million over the next three years. Budget proposals will restore previous reductions in Medicaid rates, as well as providing an increase of 1%. Mr. Bassiri also reviewed several programmatic proposals. One proposal will expand the Essential Plan to include community-based long-term care services and supports, including personal care services, for Essential Plan members who are living with long-term chronic illnesses. This initiative will result in a savings in Medicaid spending. The budget also proposes to expand coverage of Medicaid by aligning income eligibility rules and ensure that coverage stays in place as people transition to age 65. Proposals in the budget will also increase fee-for-service private duty nursing services to adult members of Medicaid.

Mr. Bassiri reviewed the budget process timeline leading to an April 1, 2022 enactment, noting that the Legislative One House Bills were submitted on March 13, 2022, and are currently under discussion.

During discussion, Mr. Levine asked about the expansion of supports under the Essential Plan, noting issues related to the availability of home care workers. He mentioned a bill that is currently under discussion to support home care staffing and access to care by increasing pay for home health aides. Mr. Levine shared that half of health care workers are reported to be on public assistance and suggested that a bill to increase pay might actually decrease Medicaid spending overall. Mr. Bassiri confirmed that pay increases are proposed in both House bills, and addressing home care workforce shortages is important to the Governor, so there will be strong discussion on this topic.

Dr. Cohen asked about continued Medicaid coverage for telehealth, emphasizing that this option was critical to reaching patients during the pandemic and continues as a valuable support for his patient populations. Mr. Bassiri assured the Council that Medicaid is intending to continue this coverage and is discussing, at the federal level, the continuation of CMS allowances granted during the public health emergency.
Review, Discussion, and Approval of the 2021 Alzheimer’s Council Report to the NYS Legislature and Priority Recommendations for 2022-2023

Mr. Cochran moved to review the 2021 Alzheimer’s Disease Coordinating Council Annual Report, thanking Ms. Gnozzio and the ADP team for working so closely with members of the Council to complete the report. He and Ms. Gnozzio noted the improvements that have been made in the report since the last meeting, also recognizing the efforts of Ms. Smith-Boivin in drafting the Executive Summary and prioritizing the order of the recommendations.

Mr. Cochran requested a motion that the Council approve this 2021 Council Report and the Executive Summary. Ms. Smith-Boivin submitted a motion to approve the report and the Executive Summary as presented, with Mr. Taylor seconding that motion. The Council voted unanimously to approve the report.

There was discussion regarding how to effectively use the report and how the Council will address goals and recommendations on a regular basis. Also, it was suggested by several members that recommendations for 2022-2023 be prioritized by the Council. Members, including state agency Council members, will then report on progress, strategies, and barriers on the related recommendations as appropriate to the requirements of their programs/membership designation.

Mr. Taylor raised concerns that time was not being allowed during this meeting to prioritize the recommendations that would be focused on over the next year and waiting until the June meeting is too late in the year to identify them. It was suggested that a subgroup of the Council be formed to start prioritizing recommendations prior to the June meeting. ADP staff will develop a template that serves as an ongoing scorecard of activities, accomplishments, and barriers specific to addressing the recommendations.

Memory Advocate Peers (MAP) Presentation

Jed Levine, President Emeritus, Director External Relations, CaringKind, and Jim Taylor, Council member and Care Partner, presented on a new pilot program called Memory Advocate Peers or the MAP Program. This program recognizes the devastating impact of receiving a diagnosis of Alzheimer’s disease or other dementia on the individual and their respective support partner. The goal of this program is to connect the newly diagnosed dyad (person with disease and a care partner) with a mentor who is a caregiver of someone living with dementia. Each mentor is able to provide support and minimize isolation around the diagnosis. There is also an objective to increase awareness about, and promote participation in, clinical trials, given the limited participation, especially among minorities. For caregivers, this allows them to “give back” and help others who are going through the post-diagnostic experience. This program is a person-centered, post-diagnosis peer support for those with dementia and their care partners, focusing on underserved communities and populations. The MAP pilot program, and initial funding, will target 50 dyads and provide support for 12 months. The program will seek to
recruit 25 or more mentors, representing culturally diverse populations. Mentors will also give personal support to locating, and participating in, clinical trials.

Following the presentation, Ms. Smith-Boivin asked about those not interested or able to participate in clinical trials, and Mr. Taylor confirmed that willingness to participate in clinical trials was not a prerequisite for participation in MAP.

Susan Sullivan asked for a clarification of “care partner.” Mr. Levine described that a care or support partner can be any combination of family or friend, but will not include professional care partners.

Dr. Cohen noted that his program at SUNY Downstate has difficulty getting individuals to travel into Manhattan for clinical trial participation, and stressed the need for programs to come to the patients where they live. He further noted that SUNY Downstate serves a large minority population and encouraged options for satellite clinical trial locations. Ms. Rice informed Council members that Columbia University currently has studies available to African-Americans where researcher physicians are sent out to the client.

**Adjournment**

Mr. Cochran noted that no public comments had been brought before the Council for this meeting. He then solicited member announcements at this time.

Mr. Levine announced that CaringKind will be hosting a webinar for 10th Annual Palliative Care Project, called “Finding Comfort” on April 5, 2022, in the evening.

Ms. Fay announced the completion of a recent procurement seeking new grantees for the NYS Centers of Excellence for Alzheimer's Disease. Ten awardees have been announced for a new 5-year grant cycle. All current Centers will be continuing, with one change at the University of Buffalo, where a new team will be coordinating this effort in Western New York.

Mr. Cochran asked the Council to submit topic suggestions for further meetings, reminding the remaining 2022 Coordinating Council meetings scheduled for June 13, September 12, and December 5. Mr. Taylor asked to include a discussion during the June meeting specific to prioritizing goals and objectives for 2022, and describing the accomplishments year-to-date. Mr. Levine also suggested that CaringKind has several new programs under development with funding from an ACL grant and these might be of interest to the Council.

At that time, Mr. Cochran welcomed a motion to adjourn the meeting, which was made by Susan Sullivan, and seconded by Mr. Levine. The meeting was adjourned at 12:10 pm.