State Unit on Aging
Alzheimer's Disease and Other Dementia Advisory Council Meeting
Friday, October 18, 2024

Jack J Huck Continuing Education Center
301 S. 68th Street Place
Lincoln, NE 68510
Conference Room 302

Voting Members Present: Nick Faustman, Christopher Kelly, Tracy Lichti, Julie Masters, Kierstin Reed, Corie Sass, David Thompson
Voting Members Absent: John Croghan, Julie Kaminski, Lisa Marks, Mary Ann Stallings
Non-Voting Members Present: Josie Rodriguez
Non-Voting Members Absent: Lisa McGuire, Timothy Tesmer
Council Staff Present: Joni Dulaney
State Unit on Aging Staff Present: Ben Stromberg

This meeting was held in person at the Jack J. Huck Continuing Education Center in Lincoln. A link was provided for members of the public to attend virtually. The meeting was called to order at 10:11 a.m. by David Thompson, Council Chair, after enough voting members were present to create a quorum. Roll was taken and Council members introduced themselves.

Nebraska Open Meetings Act Announcement

David announced that Council meetings fall under the Nebraska Open Meetings Act. A copy of the Act was posted on the wall near the door and on the Council webpage.

Public Comment

All public meetings must allow time on the agenda for people who are not members of the Council to comment. No public comments were made.

Approval of Minutes

A motion to approve the September 20, 2024, meeting minutes was made by Nick Faustman and seconded by Chris Kelly. No corrections were requested to the minutes.

A roll call vote was taken: Yes – 7; No – 0; Abstain – 0.

State Plan

Update on the Status of the State Alzheimer's Plan and Estimated Completion Date.

David reported that Chris Kelly and subcommittee member Sarah Wilson are working on cleaning up the State Alzheimer's Plan draft, focusing on removing repetitive language, looking at the data, and completing the bibliography. David is adding information to fill in gaps where needed and reviewing the recommendations to ensure they are specific and informed as they will be the roadmap going forward and the basis for the implementation committees.

The Plan was to be ready for final review at the October 18 Council meeting; that date has been pushed back. David opened a discussion to address the delay. During their reviews, it was discovered that some specific language was not cited and some cited references were not correct or were non-existent. These are being researched and added/corrected with the assistance of Julie Masters and subcommittee member Anna Fisher. Further, it appears that artificial intelligence may have been used to write some of the Plan. These areas are being rewritten. Once these areas are corrected and the Plan is complete, it will be emailed to Council members for a final review. The Council will vote at the November meeting to approve the Plan for submission to the Legislature and Governor. If the Plan is not ready to submit to DHHS for their internal review processes and submission to the Legislature and Governor by December 31, 2024, Tony Green, Director of the Division of Developmental Disabilities, will send a letter to the Legislature and Governor letting them know the Plan is in process and will be submitted as soon as possible.

Review of Issues Raised at the September 20 Meeting on Revisions to Home Health and Home Care and the Role of Area Agencies on Aging and

Review Commitments from Council and Subcommittee Members to Provide Specific Content and Appendices.

Additional information is being written for the section on paying for services such as respite, home care, and facility care. All other additional information that needed to be written or provided as discussed at the September meeting has been submitted.

Julie M. stated that the Area Agencies on Aging (AAA) want to be the first point of contact for individuals and their families. Ben Stromberg with the State Unit on Aging noted this might be a better fit as Aging and Disability Resource Centers (ADRCs) focus more on those age 60 or older and/or those who experience a disability, but that it could go either way. ADRCs include the AAAs, Brain Injury Alliance, 2-1-1, Munroe-Meyer Institute, Easterseals Nebraska, and the League of Human Dignity. Both the AAAs and ADRCs can track the individuals and provide information and guidance. Julie M. offered to write a piece for the Care Navigators section of the Plan that talks about the role of the AAAs and the ADRCs and the point of entry for individuals and families.

The topic of the registry was brought up. It was suggested that while the information tracked by AAAs would not be part of the registry, the AAAs could provide information on the registry to individuals and families to bring awareness and encourage participation.

David has meet with several individuals in different professional roles since the September Council meeting. He has incorporated some of what he has learned into the Plan.

More Discussion of the Healthy Brain Initiative Data for Action Project and the BOLD Grant.

The Healthy Brain Initiative (HBI) is a collaboration between states working together to develop best practices and developing public health strategies. The three focuses of HBI are dementia, caregiving, and brain health. Nebraska was invited to participate in the 2025 cohort for HBI Data for Action Project. This project utilizes the Behavioral Risk Factor Surveillance System (BRFSS) data collected from a survey conducted annually. The survey encompasses different modules or areas to gather information. There is a cognitive decline module and a caregiving module, though these modules are not always included in the survey. The cognitive decline module is being utilized in the current survey. There are efforts to have the caregiving module included in the next survey. Because each module must be funded to be included, the Council would recommend that there is funding to include both modules permanently in the BRFSS survey.

The DHHS Division of Public Health does not have the capacity to take on this project. Per the CDC, this is the only office in the state that can take the lead on the HBI Data for Action Project. States that have participated in this project have created informative, colorful infographics using their BRFSS data. Nebraska could replicate this outside of the Data for Action Project by making this the focus of an implementation committee and inviting the Public Policy Center, University College of Public Health, and other groups to be part of this effort. The next BOLD grant would begin in 2027.

It was suggested that someone who works with the BRFSS survey could present to the Council so there is a better understanding of BRFSS. It was also suggested that the person responsible for Nebraska’s Parkinson’s Disease Registry present at a meeting to learn more about this registry to give an idea of how to move forward on a dementia registry.

Conversation turned to membership on the Council, what role has not been filled, and where there are gaps in representation. There were thoughts shared that increasing the number of voting members in specific professional areas would be helpful. Nick commented that a bill (LB1417) was introduced in the 2024 legislative session that eliminates some advisory councils and boards. He is concerned about whether the Alzheimer’s Council will be among those that could be eliminated. (This bill was indefinitely postponed by the end of the session; it would need to be reintroduced in another legislative session to be considered.)

A comment was made about visiting with senators about the Plan and the recommendations after the State Alzheimer’s Plan is submitted. Council members were reminded that encouraging senators to introduce legislation or vote a specific way on a legislative bill is lobbying and not something Council members can do on behalf of the Council. They may visit with their senators on their own behalf or as a representative of their non-State agency. They may identify that they are members of the Council but are not to speak on behalf of or represent the Council.

Discussion of the Implementation Phase, Formation of Implementation Committees.

David reiterated that the annual reports to the Legislature should be reports on things that have actually happened. Implementation committees will be more targeted and encompass professionals and subject matter experts with one or two Council members on each committee. Examples of implementation committees were discussed at the meeting. This draft list can be found at the end of these minutes and will be emailed out to Council members. It was suggested that the focus of the implementation committees should follow the recommendations in the State Plan. Different committees would meet at different points based on the state plan priorities – some might start in January 2025; others may not start until 2026. Council members should create a list of their thoughts on the number of committees needed, the names and focus for the implementation committees and names of potential committee members, and prioritization of when the committees would begin to meet. Send these to Joni Dulaney so she can put all the ideas together and distribute the revised list with the next version of the State Alzheimer's Plan by no later than November 8, 2024, for discussion at the November 15, 2024, meeting. Formal letters will be sent to individuals requesting that they serve on a specific implementation committee.

Julie Masters suggested that a one-page document be created to go with the State Plan to show senators the top three to five priority areas, the number of their constituents across the state who have some form of dementia, and who/how they could benefit from the activities taking place under the Council's State Alzheimer's Plan. Data can be gathered from CDC, DHHS, and other sources to create an infographic to let people know what is happening in Nebraska.

The recommendations made by John Croghan were shared with the Council. There was verbal agreement that these were strong recommendations.

- Develop a dementia care workforce through partnerships with educational institutions and healthcare organizations.
- Create dementia care navigators at Area Agencies on Aging to assist families with care planning (Trualta).
- Expand public education on brain health and dementia prevention.
- Increase support for caregivers, including tax credits and respite care programs.
- Assure access to dementia services in rural areas through grants and infrastructure development (Medicaid reimbursement/access).

A request was made to create a repository for saving documents created by other organizations that provide numbers of dementia diagnoses, workforce development, and other information that can be used as reference for the Council's one-pager flyer. This flyer would emphasize the priority areas along with the estimates for Trualta and the care navigator pilot project. SharePoint was set up for all Council members to have access to documents such as these; however, Council members had difficulty setting up their accounts. It was suggested to use

Google Docs, which is not an option based on a response from the State Office of the Chief Information Office that the Council cannot use Google Docs.

Council Meetings Schedule for 2025

This topic has been tabled for discussion at the November meeting.

Announcements

The next Council meeting will be held virtually on November 15, 2024.

Adjourn

The meeting adjourned at 12:00 p.m.

<u>Proposed Implementation Committees</u>

Workforce Development

Facilities

Underserved Communities

Health Care Providers

Caregivers – Formal, Informal, Professional, Family

Education – K-12, Higher Ed

Education – Professional

Brain Health

Data & Information Infrastructure

Home Care – Private Duty Paid Caregivers, Hospice, Services Provided In-Home

Home Health and Hospice

Service Agencies – AAAs, ADRCs, Alzheimer's Association, AARP, Transition Consultants

Research – Current/Ongoing Social Sciences, Clinical

Legal – APS, Guardianships, Advance Directives

Technology