

Alzheimer's Disease and Other Dementia Advisory Council Meeting

Friday, March 15, 2024 10AM – 12PM



St. Mark's United Methodist Church 8550 Pioneers Blvd. Lincoln, NE 68520



https://sonvideo.webex.com/sonvideo/j.php?MTID=m509cd6e0058bbc7aeb996bb86c126fc3



IN-PERSON MEETING AGENDA

Welcome – David Thompson, Chair

Roll Call and Introductions

Roll will be called; Council members and staff will introduce themselves.

Notice of Public Meeting

This meeting is being held in compliance with the Nebraska Open Meetings Act.

Public Comment

Members of the public are provided time speak.

Approval of Minutes

Council members will vote to approve the minutes of the February 16, 2024, meeting.

Subcommittee Reports

Council representatives from each subcommittee will report on the first meeting of their respective subcommittees.

State Plan

Review of the statute and outline of the scope of each subcommittee. The Council will discuss the memo provided by Council Chair David Thompson in order to ensure a common understanding of the role and purpose of the subcommittees.

Discussion of the timeframe for completing the report, including the date the plan will need to be provided to DHHS for finalization and approval before it is submitted to the governor and legislature as required by the Alzheimer's Disease and Other Dementia Support Act.

Review of the meeting schedule for the council and subcommittees for all of 2024. Follow-up on request for shared space to house subcommittee notes and related issues.

Announcements

Adjourn

State Unit on Aging Alzheimer's Disease and Other Dementia Advisory Council Meeting Friday, February 16, 2024

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

<u>Voting Members Present In-Person:</u> John Croghan, Christopher Kelly, Nick Faustman, Tracy Lichti, Lisa Marks, Julie Masters, Julie Paladino-Kaminski, Kierstin Reed, Corie Sass, Mary Ann Stallings, David Thompson

Voting Members Absent: NA

Non-Voting Members Present In Person: Penny Clark

Non-Voting Members Absent: Kathy Scheele, Timothy Tesmer

<u>Council Staff Present In Person:</u> Joni Dulaney

SUA Staff Present: Ben Stromberg, Gene Hogan, Erik White

This meeting was held in person at the Jack J. Huck Continuing Education Center in Conference Room 302 in Lincoln. A link was provided for members of the public to attend virtually. The meeting was called to order at 10:04 am by David Thompson, Council Chair. Roll call was conducted and members introduced themselves.

Nebraska Open Meetings Act Announcement

David announced that the Council meetings fall under the Nebraska Open Meetings Act. A copy of the Act was posted on the wall near the sign-in sheet. A link to the Act was provided in the Webex Chat.

Public Comment

David announced that all public meetings must allow time on the agenda for people who are not members of the Council to comment. Jina Ragland with AARP thanked the Council for providing a virtual link for members of the public. Diane Hendricks, Licensed Clinical Social Worker with Nebraska Medicine and contracted to the Alzheimer's Association, thanked the Council for their work on this committee.

Approval of Minutes

A motion to approve the February 9, 2024, meeting minutes was made by Julie Masters and second by Tracy Lichti. A request was made to correct the March meeting date to March 15, 2024.

A roll call vote was taken: Yes -10; No -0; Abstain -0.

State Plan

David asked for a motion to approve the subcommittees as discussed at the February 9, 2024, meeting. A motion was made by Chris Kelly. Nick Faustman seconded. Council members were allotted time to discuss the subcommittees and their focus prior to voting to approve.

David noted that the plan (that the Council is tasked in statute to create) should be comprehensive and actionable and clearly address the different constituencies who would be reading the report. He added his concerns that, in order to fully utilize the resources and expertise of the Council members, the structure of the subcommittees and the focus of each as discussed at the February 9 meeting would not adequately meet this. His proposed alternate subcommittee structure was shared with Council members at the meeting.

Council members reviewed the proposed structure and determined that they were open to further discussion on this proposed structure. Kierstin Reed made a motion to amend the motion on the floor for the proposed subcommittee structure with changes. Tracy seconded. Members reviewed the proposed structure in depth and deliberated on the changes needed. See page 4 of the minutes for the final subcommittee structure. Subcommittees will include a minimum of two Council members on each subcommittee.

A roll call vote was taken: Yes -10; No -0; Abstain -0.

Members announced their subcommittee preferences as noted below.

The Role of Government, Quasi-Government

Nick Faustman Julie Kaminski Kierstin Reed

The Role of Formal Providers

John Croghan Corie Sass

The Role of Informal Providers

Lisa Marks Julie Masters

The Role of Education

Penny Clark Chris Kelly

The Role of the Community

Tracy Lichti

Mary Ann Stallings

Because there are only two to three Council members on each subcommittee, Subcommittee Chairs are not needed. Instead, the Council members will serve as co-chairs.

Members will continue to recruit non-Council members to serve on subcommittees. Joni Dulaney requested that members invite individuals with developmental disabilities and/or their family members to be part of the subcommittees to not miss this underserved population. Names and contact information for non-Council members will be sent to Joni. Subcommittees do not fall under the Nebraska Open Meetings Act so they may begin meeting.

Written reports from each subcommittee will be submitted to Joni prior to the Council meeting for inclusion in the meeting materials. Subcommittees will present an oral report at the monthly Council meetings to apprise the Council on the progress and status of each subcommittee.

Additional comments and questions included a question about what an action plan for each subcommittee would look like, and a request for a repository of some sort to cross-share the work between subcommittees. It was suggested that notes could be housed on the Council's webpage. This will be explored and reported back to the Council.

Announcements

The next meeting will be in-person on March 15 at 10:00 am. Joni will inquire about using the Jack J. Huck Continuing Education Center for the remaining in-person meetings. Meeting invites will be emailed to Council members.

Adjourn

Motion to adjourn was made by Mary Ann Stallings and seconded by Chris. Meeting adjourned at 12:07 pm.

Subcommittees of the Alzheimer's Disease and Other Dementia Advisory Council

I. The Role of Government and Quasi-Government

- a. Data collection and tracking
- b. Support for research and education
- c. Economic impacts (e.g., Medicaid, Medicare, private insurance, Older Americans Act, Veteran's Affairs, third-party funding, individuals, caregivers, family members, other)
- d. Policy development and legislation

II. The Role of Formal Providers

- a. Assess the type, cost, and availability of dementia care services
- b. Evaluate the capacity of the health care system to deal with ADRD
- c. Educate providers in early detection and diagnosis
- d. Improve health care for individuals with Alzheimer's Disease and Related Dementia (ADRD)
- e. Home and Community Based Services (HCBS)
- f. Long-Term Supportive Services (LTSS)
- g. Address the needs of skilled nursing facilities, assisted living, and memory care
- h. Caregivers (families, informal caregivers)
- i. Organizational supports (Area Agencies on Aging, support groups, Alzheimer's Association, care and case management)

III. The Role of Informal Providers

- a. Assess the type, cost, and availability of dementia care services
- b. Evaluate the capacity of the health care system to deal with ADRD
- c. Educate providers in early detection and diagnosis
- d. Improve health care for individuals with ADRD
- e. Loss of income

IV. The Role of Education

- a. Develop and provide best practices dementia training
- b. Disseminate information regarding treatments and other new developments
- c. Increase the number of aging services professionals
- d. Training existing staff continuing education, certification
- e. Increase the knowledge of ADRD (postal workers, police/emergency responders, other)
- f. Encourage brain healthy activities
- g. Develop strategies to address harm reduction and safety needs of those with ADRD

V. The Role of the Community

- a. Increase public awareness of ADRD
- b. Accessible support and education of unpaid caregivers
- c. Develop approaches that address diverse communities
- d. View ADRD in the context of larger conversations about urban planning, transportation, housing, etc.

Date: March 4, 2024

To: Members of the Alzheimer's Disease and Other Dementia Advisory Council

From: David M. Thompson, Council Chair

Re: The Role and Purpose of the Subcommittees

There have been several questions from members of the advisory council regarding the role and purpose of the five subcommittees (governmental and quasi-governmental agencies, formal providers, informal providers, educational organizations, and the community). The Open Meetings Act prevents me from engaging in substantive discussion with individual council members outside of the formal meetings of the council. Given that constraint, I thought it would be helpful to provide this memo addressed to the council as a whole so it can be included with the materials being distributed in advance of the March 15, 2024 meeting and hopefully get us all onto the same page.

First, I cannot stress enough the importance of taking full advantage of all the resources our community has to offer. The subcommittees should be viewed as an opportunity to include as many additional voices as possible in the work of the council and the final product, namely, a state plan that is comprehensive, beneficial, realistic and actionable. At the same time, however, we all have to be mindful of the pace at which the subcommittees need to move in order for their work to be reflected in the final plan. The final product of each subcommittee should be a draft document that lays out the crucial issues facing the particular constituency comprising each subcommittee and makes recommendations of how to address these issues.

Due to the approval and finalization process that the report will have to undergo *before* it is submitted to the governor and the legislature by the December 31, 2024 deadline, it is essential that the subcommittees move at a brisk pace. While the exact date of submission to DHHS has not been established, it is likely that we will have only seven or eight more meetings of the council in which to prepare the draft report. Given this, all of the subcommittee chairs should have the membership of their respective subcommittee chosen and also have had at least one preliminary discussion as a subcommittee *by the time we convene on March 15*. As of this writing, only one of the five subcommittees is what I would consider fully staffed. I (and probably others as well) have a list of suggested subcommittee members that I would be happy to share so that each subcommittee can have four or so non-council members.

There have also been questions about the role of the subcommittees beyond the 12/31/24 deadline. Under the statute, all members of the advisory council will serve four-year terms. Since the plan has to be completed by the end of year one, that leaves three years to think about how the recommendations of the plan will be implemented. I would say the same of the subcommittees, that they should stay involved. We may as a council want to discuss how long the subcommittees will be in existence, but I see no reason why subcommittee members can't also serve multiple-year terms in order to participate in the work of implementing the plan.

Finally, it is important to remember that anyone can attend meetings of the advisory council as a member of the public. This means that any member of any subcommittee can attend the council meeting and have the opportunity to provide input either during the public comment section of the meeting or if called up by a subcommittee chair. I hope this information is helpful to all subcommittee chairs. I look forward to convening on March 15 and hearing the reports on the activities of each subcommittee.

71-564. Alzheimer's Disease and Other Dementia Advisory Council; members; duties; expenses.

- (1) The Alzheimer's Disease and Other Dementia Advisory Council is created and shall include:
- (a) Twelve voting members appointed by the Governor. The voting members shall consist of: (i) An individual living with Alzheimer's disease or another dementia or a family member of such an individual; (ii) an individual who is the family caregiver of an individual living with Alzheimer's disease or another dementia; (iii) an individual who represents nursing homes; (iv) an individual who represents assisted-living facilities; (v) an individual who represents providers of adult day care services; (vi) an individual who represents home care providers; (vii) a medical professional who has experience diagnosing and treating Alzheimer's disease; (viii) an individual who conducts research regarding Alzheimer's disease or other dementia; (ix) an individual who represents a leading, nationwide organization that advocates on behalf of individuals living with Alzheimer's disease or other dementia; (x) an individual who represents an area agency on aging; (xi) an individual representing an organization that advocates for older adults; and (xii) an individual with experience or expertise in the area of the specific needs of individuals with intellectual and developmental disabilities and Alzheimer's disease or other dementia; and
- (b) Five nonvoting members. The nonvoting members shall consist of: (i) The Director of Public Health or the director's designee; (ii) the Director of Medicaid and Long-Term Care or the director's designee; (iii) a representative of the State Unit on Aging of the Division of Medicaid and Long-Term Care designated by the Director of Medicaid and Long-Term Care; (iv) a representative of the Nebraska Workforce Development Board designated by the board; and (v) the state long-term care ombudsman or the ombudsman's designee.
- (2) The Governor shall make the appointments within ninety days after July 21, 2022. Vacancies shall be filled in the same manner as the original appointments.
- (3) The voting members of the council shall serve for a term of four years. A voting member may be reappointed to one additional term of four years.
- (4) Members of the council shall select the chairperson and vice-chairperson who shall not be employees of the state and may serve in such role for up to four consecutive years. The Director of Public Health or the director's designee shall call and preside over the first meeting until a chairperson is selected. Thereafter, the council shall meet at least quarterly at the call of the chairperson. A majority of the voting members shall constitute a quorum for the conduct of meetings.
- (5) The council shall hold its first meeting not later than thirty days after the appointment of its members and shall hold subsequent meetings at least once every calendar quarter.
- (6) Members shall serve on the council without compensation but shall be compensated for expenses incurred for such service.
- (7) The department shall provide staff and support to the council as necessary to assist the council in the performance of its duties.

Source: Laws 2022, LB752, § 33

71-565. Council; purpose; collaboration.

- (1) The purpose of the council shall be to examine (a) the needs of individuals living with Alzheimer's disease or other dementia, (b) the services available in the state for those individuals and their family caregivers, and (c) the ability of health care providers and facilities to meet the current and future needs of such individuals.
- (2) The council shall collaborate with the department and other state departments as needed to gather input on issues and strategies that pertain to Alzheimer's disease and other dementia and identify proactive approaches on public health, workforce, caregiver support, and care delivery. The council shall monitor analysis, policy development, and program implementation related to Alzheimer's disease and other dementia.

Source: Laws 2022, LB752, § 34.

71-566. Council; considerations; findings and recommendations.

The council shall consider and make findings and recommendations on the following topics:

- (1) Trends in the state's Alzheimer's disease and other dementia populations and service needs, including:
- (a) The state's role in providing or facilitating long-term care, family caregiver support, and assistance to those with early-stage or early-onset Alzheimer's disease or other dementia;
 - (b) The state's policies regarding individuals with Alzheimer's disease or other dementia;
- (c) The fiscal impact of Alzheimer's disease and other dementia on publicly funded health care programs; and
- (d) The establishment of a surveillance system to better determine the number of individuals diagnosed with Alzheimer's disease or other dementia and to monitor changes to such numbers;
- (2) Existing resources, services, and capacity relating to the diagnosis and care of individuals living with Alzheimer's disease or other dementia, including:
 - (a) The type, cost, and availability of dementia care services;
- (b) The availability of health care workers who can serve people with dementia, including, but not limited to, neurologists, geriatricians, and direct care workers;
- (c) Dementia-specific training requirements for public and private employees who interact with people living with Alzheimer's disease or other dementia which shall include, but not be limited to, long-term care workers, case managers, adult protective services, law enforcement, and first responders;
- (d) Home and community-based services, including respite care for individuals exhibiting symptoms of Alzheimer's disease or other dementia and their families;
 - (e) Quality care measures for home and community-based services and residential care facilities; and

- (f) State-supported Alzheimer's disease and other dementia research conducted at universities located in this state; and
 - (3) Policies and strategies that address the following:
 - (a) Increasing public awareness of Alzheimer's disease and other dementia;
- (b) Educating providers to increase early detection and diagnosis of Alzheimer's disease and other dementia;
- (c) Improving the health care received by individuals diagnosed with Alzheimer's disease or other dementia:
- (d) Evaluating the capacity of the health care system in meeting the growing number and needs of those with Alzheimer's disease and other dementia;
- (e) Increasing the number of health care professionals necessary to treat the growing aging and Alzheimer's disease and dementia populations;
- (f) Improving services provided in the home and community to delay and decrease the need for institutionalized care for individuals with Alzheimer's disease or other dementia;
- (g) Improving long-term care, including assisted living, for those with Alzheimer's disease or other dementia;
 - (h) Assisting unpaid Alzheimer's disease or dementia caregivers;
 - (i) Increasing and improving research on Alzheimer's disease and other dementia;
 - (j) Promoting activities to maintain and improve brain health;
- (k) Improving the collection of data and information related to Alzheimer's disease and other dementia and the resulting public health burdens;
- (l) Improving public safety and addressing the safety-related needs of those with Alzheimer's disease or other dementia:
- (m) Addressing legal protections for, and legal issues faced by, individuals with Alzheimer's disease or other dementia; and
- (n) Improving the ways in which the government evaluates and adopts policies to assist individuals diagnosed with Alzheimer's disease or other dementia and their families.

Source: Laws 2022, LB752, § 35.

71-567. State Alzheimer's Plan.

- (1)(a) No later than eighteen months after July 21, 2022, the council shall compile the findings and recommendations under the Alzheimer's Disease and Other Dementia Support Act and submit them as a State Alzheimer's Plan to the Legislature and the Governor.
- (b) Every four years thereafter, the council shall issue an updated State Alzheimer's Plan addressing the items in sections 71-565 and 71-566 and any other issues the council deems necessary and relevant toward addressing Alzheimer's disease and dementia in Nebraska.
- (2) By October 1 of each year after the creation of the State Alzheimer's Plan, the council shall electronically submit to the Legislature and the Governor an annual report on the status of implementation of the State Alzheimer's Plan recommendations and any barriers to implementation.

Source: Laws 2022, LB752, § 36.