State Unit on Aging
Alzheimer’s Disease and Other Dementia Advisory Council Meeting
Friday, March 15, 2024

St. Mark’s United Methodist Church
8550 Pioneers Blvd.
Lincoln, NE 68520
Upper Fellowship Hall

Voting Members Present In-Person: 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, Kathy Scheele, Timothy Tesmer
Non-Voting Members Absent: NA
Council Staff Present In Person: Joni Dulaney
SUA Staff Present: Erik White

This meeting was held in person at St. Mark’s United Methodist Church in Lincoln. A link was provided for members of the public to attend virtually. The meeting was called to order at 10:08 a.m. 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 door. 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. No comments were shared.

Approval of Minutes

A motion to approve the February 16, 2024, meeting minutes was made by Julie Masters and second by Tracy Lichti. No corrections were requested to the minutes.

A roll call vote was taken: Yes – 11; No – 0; Abstain – 0.

Subcommittee Reports

David reviewed the items in the meeting materials that were emailed prior to the meeting. These included his memo about the subcommittees; a copy of the statute that created the Alzheimer’s Disease and Other Dementia Support Act and the Alzheimer’s Disease and Other Dementia Advisory Council; a roster of subcommittee members by subcommittee; copies of the

2012 Nebraska Legislative Planning Committee Report and the 2014 Aging Nebraskans Task Force Strategic Plan – A Report to the Nebraska Legislature, to be used as references if/as needed; and a chronology of planning going back to 2011 when the Federal Act was passed. Copies of the subcommittee reports from the Government and Quasi-Government Subcommittee, Informal Providers Subcommittee, and Community Subcommittee were handouts at the meeting.

The Role of Government and Quasi-Government Subcommittee

Kierstin Reed reported that the subcommittee members discussed several areas at their first meeting.

Data Collection and Tracking

What are the current numbers of individuals with or self-identifying as having cognitive decline?

Nick Faustman noted that DHHS uses a telephone survey, Behavioral Risk Factor Surveillance Survey (BRFSS), to ask adults in Nebraska a series of health-related questions to gather information and data on health-related risk factors (*https://dhhs.ne.gov/Pages/BRFSS.aspx*). He is in talks with DHHS Public Health to add a cognitive decline module that would ask questions specific to cognitive decline. The purpose is to determine the real numbers and the prevalence of cognitive decline, and the number of people who self-identify as having this decline.

The subcommittee discussed looking at the current number of people with cognitive decline in Nebraska. It was 33,000, what is it now? What are the numbers for other cognitive decline? Look at Area Agencies on Aging (AAA) and AARP data collection. What are other ways DHHS collects data, where is it kept, how is it released, who can receive the data?

Support for Research and Education.

They talked about Building Our Largest Dementia (BOLD) grants for dementia and Alzheimer's infrastructure in Nebraska. A goal is to get one of these grants. They also discussed establishing a Dementia Centers of Excellence, and building community supports in rural Nebraska and strengthening the resources and the ability to find the resources. There are difficulties in providing virtual supports due to technology barriers in rural Nebraska, including knowledge and accessibility. Resources could be provided virtually, however there may be older adults who do not have the knowledge, skills, and abilities to utilize the technology. Rural broadband access may be diminished in many areas. There were questions on what information is being provided by the Coalition Networks and access lines such as 211?

Economic Impacts

The Alzheimer's Association has a lot of data on economic impacts. Look at Medicaid accessibility across the state for memory care services. Are there enough resources in all areas across Nebraska? There is a huge middle area between Medicaid to assist those with very diminished income and those who can afford private pay for memory care services. The economic impact is devastating.

Policy Development and Legislation

Subcommittee members looked at the memory care rates for Medicaid waiver services and the caregiver tax credit bill that is currently a priority bill in the Nebraska legislature. This bill is a start.

The Role of the Community Subcommittee

Mary Ann Stallings and Tracy Lichti reported that the subcommittee met last week. Subcommittee members talked about the importance of becoming one voice. There are many voices saying different things. Is there an opportunity to work through all this to have one voice or one place for people to come to? Ideas included marketing the resources so people are aware of them, making resources available in different languages with English and Spanish at a minimum, providing information in booklets/written format instead of having everything online and making them available at AAAs, doctor's offices, etc., to serve as a one-stop resource that would be updated. The New Horizons newspaper publication was noted as another way to get out information on available resources and provide education.

The Role of Informal Providers Subcommittee

Lisa Marks and Julie Masters presented their subcommittee report. Members reviewed and divided the different focus areas and selected areas to work on. There was information sharing and are getting organized. They will be meeting the first Friday of each month through September.

There was discussion among Council members about having one place for all the subcommittees to place documents for all to access. Joni Dulaney talked with the State Unit on Aging IT person. Drop Box was the suggested/recommended platform. A question was asked about creating One Drive. Joni will look into this and report back to the Council.

The Role of Education Subcommittee

Chris Kelly introduced subcommittee member Sarah Wilson, Administrator at Omaha Supported Living, who was attending the meeting virtually. She provided information on a survey that was created after being brought up as an idea at the Nebraska Mental Health Aging Coalition (NeMHAC) Legislative Advocacy Committee meeting. The purpose of the survey is to hear from the people who are working with consumers on a variety of topics. The survey opened two days ago and they have received some responses. It went out to NeMHAC members, Disability Rights Nebraska for distribution to their network, and several facilities.

The 10-question survey is open to the public for anyone to complete. It will collect information on what people want to see happen, what are the gaps in the system, and what training they want to receive to best serve their loved ones or the individuals they serve in their facilities. Joni will get the link to the survey and will send it to Council members after the meeting. Members can forward it to other organizations such as the Area Agencies on Aging for further distribution.

There was discussion on the survey being facility-provider specific. To reach the family caregivers, a separate survey may need to be created. Home care providers and adult day providers can help get the survey out to family caregivers. Kathy Scheele noted that Medicaid and Long-Term Care has an email list of providers and they know who is actively providing services in Home and Community-Based programs through Electronic Visit Verification (EVV). EVV is a federal mandate. Anyone providing services in an individual's home must use EVV if they are providing Medicaid waiver services.

A goal could be for the Council to develop a survey directed to caregivers or use an existing survey. Quarterly care plan meetings would provide an opportunity to families to complete the survey. The survey could also be sent to law enforcement and fire departments.

The Role of Formal Providers

John Croghan shared the names of the subcommittee members. This group will hold their first meeting on April 5.

Copies of the subcommittee reports can be found at the end of these meeting minutes.

State Plan

David revisited the statute that created the Council. He addressed the requirement of having a member 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. This needs to be addressed going forward. Kierstin Reed added that individuals with intellectual and developmental disabilities historically did not live long enough for families to worry about getting dementia. That has changed and is a big concern. She suggested pulling in members of the Olmstead Committee or Developmental Disabilities Advisory Council to the Education Subcommittee could be helpful. Kierstin and Joni can help with providing names.

David asked if there were any questions on his memo regarding the role and purpose of the subcommittees. One question was whether the subcommittees are writing the state plan for their sections. If yes, what is the format? Who will take the lead to ensure the same voice throughout the plan? David noted that he sees each subcommittee writing five to ten pages on their findings and recommendations as noted in the statute. He will pull everything into a draft that will be reviewed by the Council. He suggested that a subgroup group could be formed to focus on preparing the report. The new state plan does not need to follow the 2016 plan; that plan can be used as an example.

There is a lot of information on the DHHS Alzheimer's and Dementia pages. A request was made to get the number of hits that pages receive. This would provide a baseline to show whether there is a difference in the number of people accessing the information going forward. Joni will request this information.

Council members agreed that the subcommittee reports will be completed and submitted by the August 16 Council meeting. David will compile the reports into a single report for distribution to members with the September 20 Council meeting materials. The draft will be finalized at the October 18 meeting with the final draft report being submitted to DHHS by October 31.

David commented that it is possible to bring in guests to make presentations to the Council. For example, police and fire departments or others. This could happen at future meetings.

Announcements

The next meeting will be in-person on April 19 at 10:00 a.m. at St. Mark's United Methodist Church.

Adjourn

Motion to adjourn was made by Julie Kaminski and seconded by Kierstin. Meeting adjourned at 11:54 a.m.

The Role of Government and Quasi-Government Sub-Committee Meeting
March 5, 2024
Present: Kierstin Reed, Lara Schiffbauer, Nick Faustman, Julie Kaminski

Items to discuss from the assignment
a. Data collection and tracking

- Currently Nick working with department (public health DHHS) and UNL (administrator) regarding BRFFS survey health related topics to get them to adopt a cognitive decline module – scheduled for later this year for interviews
- AAA assessments completed with caregivers both baseline and reassessment to gather data. Caregiver Stress Survey and SLUMS mental status test
- What data does the department (public health or otherwise) collect regarding this topic, where is it kept and who is it released to
- Registry for dementia- specific type?
- AARP data collection or studies – what information is available
- Landing page on DHHS for data and resources- easier access to the page that contains this information - can we get information on how many page hits these sites have
    - Alzheimer's and Dementia (ne.gov) state landing page
    - https://nadrc.acl.gov/home national landing page
    - Nebraska State Plan for Alzheimer's Disease and Related Dementia infographic

b. Support for research and education

- BOLD Building our largest dementia infrastructure grant – how can Nebraska participate in this project
- Establish dementia centers of excellence
- Community support groups in rural Nebraska
- Virtual support – technology barriers (knowledge and accessibility)
- Caregiver Coalition Networks, access lines such as 2-1-1- what information do they give out?

c. Economic impacts (e.g., Medicaid, Medicare, private insurance, Older Americans Act, Veteran's Affairs, third-party funding, individuals, caregivers, family members, other)

- Alz Association has a lot of data regarding economic impacts
- Medicaid accessibility across the state for memory care services
- Caregiver Stress Survey on economic impacts
- Giant hole in the middle class for access to services

d. Policy development and legislation

- Memory care rate for Medicaid Waiver services
- Caregiver tax credit

Alzheimer Disease and Other Dementia Advisory Council
Role of the Community Subcommittee
Zoom Meeting

Date: March 8, 2024

Sub-Committee Members Attendees:

Traci Lichti
Mary Ann Stallings
Gayleen Bradley
Karla Frese
Carolina Padilla
Deb Marasco
Melanie Haynes-McCurry
Tracy Lichti
Mike Osberg
Absent: Cheryl Brown

Traci reviewed legislation 903 and the letter to extend the time of the Council because of the delay to hire the necessary staff.

The role of the Community was reviewed:

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

Each committee member introduced themselves and the role they have played either professionally or personally with Alzheimer's.

Next steps were discussed:

- Karla Frese offered to set up Google Doc for members to list resources.
- ENOA's website was discussed including the specific Caregivers 5 steps to self-care and first aid.
- How to increase awareness
- Marketing of the ideas and reports of Community subcommittee
- How to grow awareness
- How to be present in many different senior populations
- Language barriers for seniors and families
- How we can have a better start with many different cultures
- How to find support for all of these cultures

- One Voice – Advise state government to share resources
- How would it look with how to be a better caregiver
- Respite times for caregivers and difficulties with different languages
- Central location of services and how and what it would look like
- Veteran recommendations
- Lack of technology and broadband
- Financially unable to afford the technology
- Many want paper to fill out and not have to do it on the Internet
- Grass Roots

What is it we can do to help?

Mike will send a link for ENOA's website to access:

> Bringing Care to the Caregiver" and "Caregiver's 5 Steps to Self-Care First-Aid."
>
> NEW HORIZONS, which is a monthly publication containing resources related to aging, as well as interesting stories.
>
> CAREGIVER TO CAREGIVER, a Handbook for the Journey of Caregiving." This was put together using the direct input from caregivers

It was discussed to have our Zoom meetings on the 1st Friday of the month at 9:00

Informal Providers Subcommittee Report

Report for March 15, 2024, Alzheimer's Disease and other Dementia Advisory Council

The Informal Providers Subcommittee met on March 1, 2024 and will continue to meet the first Friday of each month through September. Subcommittee members agreed to serve as part of the preparation of the state plan.

Each of us is committed to locating information for the following areas listed for our section. Areas and names are below.

The Role of Informal Providers

A, Assess the type, cost and availability of dementia care services (Judy & Diane)

B. Evaluate the capacity of the health care system to deal with ADRD – including FTD (Jean and Julie)

C. Educate providers in early detection and diagnosis (Lakelyn & Diane)

D. Improve Health Care for individuals with ADRD – new name forthcoming from Sarah to include Living Well and Care Partners (Sarah & Lisa)

E. Loss of Income (Lakelyn & Julie)

Our next meeting is scheduled for April 5, 2024 via zoom.