State Unit on Aging
Alzheimer’s Disease and Other Dementia Advisory Council Meeting
Friday, April 19, 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, Julie Masters, Kierstin Reed, Corie Sass, Mary Ann Stallings, David Thompson
Voting Members Attending Virtually: Julie Paladino-Kaminski
Voting Members Absent: Lisa Marks
Non-Voting Members Present In-Person: Kathy Scheele, Timothy Tesmer
Non-Voting Members Absent: Penny Clark
Guest Present: Sarah Wilson
Council Staff Absent: Joni Dulaney
SUA Staff Present: Ben Stromberg, Erik White

This meeting was held in person at St. Mark’s United Methodist Church in Lincoln with one member attending virtually. 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 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

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 March 15, 2024, meeting minutes was made by Julie Masters and seconded by Tracy Lichti. No corrections were requested to the minutes.

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

State Plan

1. Structure and form of the report.
    a. On issues of overlap and convergence among the work of the subcommittees, David outlined the four main themes that emerged from each subcommittee's meeting notes and from the survey distributed by the Education Subcommittee:
        i. Data
            1. the need for data
            2. how do we gather it
            3. where do we put it so the public can access it
            4. how do we track things going forward
        ii. Caregivers
            1. families
            2. facilities/administrators
        iii. Education
            1. educating on what is Alzheimer's
            2. educating on what is dementia
            3. how Alzheimer's and dementia relate
            4. what are the other types of dementia
            5. what are the different behaviors associated with dementia
                a. how to deal with the behaviors
                b. how to recognize the behaviors
        iv. Reaching Underserved Populations
            1. Rural
            2. Native American communities
            3. Communities of color

    David referenced a story that aired on WOWT News on April 17, 2024, regarding the statistical realities of individuals in the African American and Latino communities being much more likely to be diagnosed with Alzheimer's disease than other groups. See that story here: https://www.wowt.com/2024/04/18/omaha-experts-weigh-findings-new-alzheimers-study/

    Another theme that came from the subcommittees was providing public access to information and having a one-stop-shop to find resources. This could be an online repository. David referenced the 2022 National Plan Updates (https://aspe.hhs.gov/reports/national-plan-2022-update) and the Alzheimer's Association's 2024 Facts and Figures report (https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf). These are just two of many resources that could be included in the repository.

    b. David referenced his Proposed Outline for the Report of the Alzheimer's Disease and Other Dementia Advisory Council document that was emailed to members prior to the meeting. For comparison, he looked closer at the National Plan to Address Alzheimer's Disease: 2022 Update (the table of contents was also emailed prior to the meeting). It is unclear whether the federal agency responsible for writing and updating the national plan is reviewing all state plans. If so, there could be benefit in the state plans following the same structure as the national plan. Anyone should be able to pick up the (Nebraska) report and learn how it deals with key issues.

In the timeline for the 2016 plan, previously sent to Council members, there was a period of time for soliciting the views of stakeholders. It will be up to the Council to determine who, beyond the Council, would be invited to read the rough draft of the report to integrate their input before it is finalized. There are time constraints on how to give stakeholders a chance to be part of the process and to integrate their views, so we need to plan for this going forward.

c. Regarding the specific work product to be produced by each subcommittee, there was discussion on how to address the specific areas of statute. The goals and strategies in the National Plan were reviewed. It was suggested to follow this report flow, with the subcommittee reports tailored toward the national goals. A rubric will be created using the national plan's Table of Contents goals 2 through 6 to create questions for each subcommittee to answer. These would then be used to pull the information into the final report. (Goal 1 of the national plan deals with treatment and prevention. These are medical topics that the subcommittees won't be dealing with in detail.)

   A request was made for Council members to have access to working drafts of the report as it is being put together. The report should not create new levels of regulation or requirements; having several eyes on the end product will help with this.

d. The approach to the bibliography/bibliographies and list(s) of resources to be included in the report was not addressed due to lack of time.

2. Review of the Alzheimer's Disease and Other Dementia Support Act and Outline of Ne. Rev. Statute 71-566 was not addressed due to lack of time, but David suggested that all Council members review these documents.

3. The general issues of data collection, follow-up on centralized source of information, and what additional information or resources would be helpful to the work of subcommittees was included in other agenda item topics but otherwise reserved for future meetings.

Summary of Responses to Alzheimer's Disease and Related Dementias Survey
Chris Kelly introduced Sarah Wilson, a member of the Education Subcommittee. Sarah has coordinated the survey and is compiling the results into a report that will be emailed out to Council members.

Sarah screen-shared the data summarized from the survey. A PDF of the survey responses was emailed to Council members prior to the meeting. A total of 41 individuals responded to the survey. Not all individuals answered all the questions. Responses to areas that stood out included cultural competence, education for caregivers, and the needs of underserved populations/rural populations. Additional data will be compiled and shared with a more detailed report that will be sent to Council members next week.

The survey is currently still open for providers to respond. The survey report can be a living report to include additional responses. It was suggested that future respondents would be able to remain anonymous and could target different audiences, to include the Area Agencies on Aging, people in rural areas, members of the public, and others to make their voices heard.

Additional conversation noted that the report (to the legislature and governor) should include information on what has been done so far and that there is a need for further data to be gathered over the next three years. There should be a systematic, state-wide, multi-category survey that is open to everyone. The Government, Quasi-Government subcommittee is looking at the Parkinson's registry to see what can be gleaned from this or how to add (Alzheimer's and other dementias) to the Parkinson's registry to get information on how caregivers and others are impacted by the disease.

Subcommittee Reports

Members of the subcommittees reported on their respective subcommittees. Copies of the subcommittee reports from the Government, Quasi-Government Subcommittee, the Informal Providers Subcommittee, the Formal Providers Subcommittee, and the Community Subcommittee were emailed prior to the meeting. The Summary of Responses to Alzheimer's Disease and Related Dementias Survey was a report from the Education Subcommittee.

The Role of Government and Quasi-Government Subcommittee

Kierstin noted that the subcommittee membership has grown. They have requested that Jill Krause, the state's Parkinson's Registry coordinator, attend a subcommittee meeting to answer questions and discuss the registry and how it could be expanded. Nick provided additional information on the Behavioral Risk Factor Surveillance System (BRFSS) questionnaire noted in the subcommittee report. They are working with the Department of Health and Human Services to create a module to be included in the next annual statewide telephone survey to include questions about self-identifying whether they are experiencing some level of cognitive impairment. The 2016 State Plan noted a goal of including cognitive impairment and caregiver modules in BRFSS.

The Role of Formal Providers

Corie Sass noted the limited availability of dementia care services in rural areas, and the problem that reimbursement rates for geriatric or dementia-related care through Medicare is much lower. There has been a 60% decrease in the pay rate for geriatric care providers. Providers in rural areas are not able to carry higher caseloads. They looked at the closings of nursing facilities across the state. An early intervention could be to educate CNAs for moving up to become nurses, nurse practitioners, or physicians. Members discussed diagnosing and early detection of Alzheimer's and challenging the perception that dementia does not require medical care. When looking at the statistics, some death certificates list causes of death other than dementia. This makes it more difficult to track dementia-related deaths. David added that there is confusion on what different hospital systems do and how to access services.

Role of Informal Providers Subcommittee

Julie Masters reported that members have collected information from UNMC on information that is available for caregivers. This is being forwarded to Joni Dulaney to be added to the shared resources site. They looked at evaluating the capacity of the healthcare system to deal with Alzheimer's disease and related dementias (ADRD), including frontotemporal dementia (FTD). There is a tremendous cost associated with a FTD diagnosis, which often comes before the age of 65. A diagnosis impacts the individual, the caregiver, and the workforce. There is a need for navigators in the healthcare system.

In the area of educating providers in early detection, UNMC has a Geriatric Workforce Enhancement Program grant (https://www.unmc.edu/NebraskaGWEP/). A new submission or a continuation of this grant would help to educate providers, particularly in the rural areas.

Areas that have been identified include a lack in the number of beds if people need a place to go, the need to expand home and community-based services, and a lack of diversity in choice of research subjects.

The cost is three times higher for caring for someone with dementia than caring for someone with congestive heart failure or other chronic condition.

Members are also looking into the following: refugee population dementia; a caregiver's perspective; the accessibility of resources; dementia-related expenses; how to enhance the 2016 plan; information should be in paper form, not just electronic; ensure that the caregiver can accompany the individual with dementia if they are hospitalized; and reducing the roadblocks for caregivers.

The Role of Education Subcommittee

Chris noted the members had good conversations about the early survey findings that were shared with Council members, the context they have ground the results in, and next steps in gathering more data and including that into the report.

The Role of the Community Subcommittee

Members discussed income/low income individuals. Most individuals in facilities are using Medicaid as their pay source. Their subcommittee membership includes individuals from rural areas as well as the manager of the Intercultural Senior Center in Omaha. The cultural stereotype is for families to not ask for help. The center is piloting a day program specializing in dementia. One subcommittee member runs the home health agency in Gering. There are no other options for home health other than this company; in-home caregivers can charge $200 per hour compared to $25-$30 in the metro area. There is a lack of gerontologists in rural areas. It was noted that the process for transitioning to Medicaid is easier in other states than in Nebraska. Members will be looking further into this.

David recommended that everyone review the report from Sarah Wilson when it is sent next week. He also talked about the people in the "middle area" between the individuals who are eligible for Medicaid and individuals who can afford the care at any cost. He also noted that underserved populations include not just the Spanish speaking community, but the immigrant populations are just as significant if not more so because of the language and cultural barriers. He underscored that home and community-based services need to be talked about because that is one of the best ways to deal with cost issues and help people age in place.

NOTE: There were several references to successful elements of the Washington State Plan. See the plan here:
https://www.dshs.wa.gov/sites/default/files/ALTSA/stakeholders/documents/AD/Washington%20State%20Plan%20to%20Address%20Alzheimer%E2%80%99s%20Disease%20and%20Other%20Dementias%202023-28.pdf

Announcements
The next meeting will be in-person on May 17, 2024, at 10:00 a.m. at the Jack J. Huck Continuing Education Center.

Adjourn
Motion to adjourn was made by Kierstin Reed and seconded by Cori Sass. Meeting adjourned at 12:01 p.m.

Proposed Outline for the Report of the
Alzheimer's Disease and Other Dementia Advisory Council
Due December 31, 2024

I. Introduction
   a. Demographic information about ADRD in Nebraska and U.S. as a whole
   b. Demographic information about aging of population, fewer children and fewer people with support systems
   c. Reasons why this is a propitious moment, new treatments
   d. Description of statute and planning process that led to the report
   e. Summary of the four sections

II. Education
   a. Educating health care providers such as PCPs on how to diagnose and treat ADRD as well as new treatments, develop more available assessment tools
   b. Educating facility staff, first responders, etc. on how to handle people with ADRD, particularly when they present difficult behaviors
   c. Educating caregivers on available resources (training, support groups, respite)
   d. Educating the public on nature of the disease, promoting brain health, benefits of early detection, harm reduction and understanding different levels of ADRD

III. Economic Impact
   a. Cost of memory care and other ADRD services
   b. Loss of income by families, economic value of unpaid caregivers
   c. Burden on Medicaid and Medicaid, effects of this on the finances of facilities
   d. Burden on health care system as a whole, including cost of end-of-life care for those with ADRD compared with those who do not, ER visits, etc.

IV. Availability of Resources
   a. Need to make accessing resources easier, provide one-stop shop, links on websites, care planning checklist, make materials generally available (doctor's office, etc.)
   b. Focus on underserved communities, particularly rural areas, non-English speaking communities, individuals with mental illness, and individuals with intellectual disabilities.
   c. Look at number of facilities at different levels of care, harm of facility closures
   d. Home and community-based services and home care as alternatives to facilities

V. Growing the ADRD Workforce
   a. Produce more health care providers specializing in gerontology and ADRD
   b. Train and adequately compensate professional caregivers

   c. Strengthen relations with educational institutions to encourage more students to consider entering the ADRD workforce

VI. Conclusion
   a. Accepting the challenges before us
   b. Roadmap for implementation

The Role of Government and Quasi-Government Sub-Committee Meeting

Meeting notes from April 2, 2024

Present: Lara Schiffbauer, Michelle Manger, KoriAnn Moslander, Nick Faustman, Cindy Kadavy, Tasia Theoharis, Joni Dulaney, Megan Novell, Kierstin Reed, Jina Ragland

Lara provided an overview of the case management and care management services provided by AAA's

Review of the hits from the state website that were sent to members of the committee. The group discussed that the page needs to be user friendly on what is available and need to increase information on how to locate the information. Strategic communication plan should include organization of information and a plan to communicate it. This should include social media.

Information from the state should be a one stop shop for connecting to actual resources, factual information and clearly defined for all users:

- Prevention
- Detection
- Resources for those experiencing dementia
- Resources for caregivers
- Resources available to each region

Discussion about Parkinson's Registry and how this came about. Potentially adding on to the reporting mechanism for this site that already exists. Need to find more information on this registry. Joni will talk to Jill about presenting to the group.

Discussion about prevention work for the public

Discussion about the number of Assisted Living Memory Care placements available in the state. Cindy stated that 71% of AL's accept waiver, 30% have an Alzheimer's unit, and 30% of nursing homes have an Alzheimer's unit. The group further discussed that although they accept waiver, there may not be waiver availability for the services needed at the time they are needed. It is difficult to gage from the state list of providers what the true picture is of available services. There is a legislative resolution that will be heard on assisted living that may give us additional information on services available across the state.

Action Steps:

- Combine all the topics that have been sent out for feedback and all the discussions into categories for further review on the task of the group
- Begin discussions about the requirements of this group for the state plan- What is the factual information to share in the report? What are our recommendations and why?
    a. Data Collection and Tracking

b. Support for Research and Education
c. Economic Impacts (e.g., Medicaid, Medicare, Private Insurance, Older Americans Act, VA, Third-Party Funding, Individuals, Caregivers, Family Members, Other)
d. Policy Development and Legislation

Subcommittee Meeting: The Role of Formal Providers

4/5/24

Present:
John Croghan
Corie Sass
Dr. Gary Anthone
Jenny Erb
Amy Bracht
Erin Nelson
Mindy Crouch
Dr. Natalie Manley

Other attendees:
David Thompson
Joni Dulaney

Absent: None
Introductions

John reviewed the previously constructed State Alzheimer's Plan, made the group aware of the other subcommittees, and discussed the goals of the Formal Providers Subcommittee which includes final report to be given to the ARDC by September 2024.

Items of Discussion:

Assess the type, cost, and availability of dementia care services

- Limited beds throughout the state for facility-based care of individuals with ADRD
- Limited understanding of the cost of LTC, and being housed in acute care while figuring that out.
- NEMAC – 60% decrease in pay rate for geriatric care providers – not just mental health providers but also geriatric primary care. Leads to shortage of providers.
- Significant gaps in availability and affordability - Nebraska is a resource desert, most services are in Omaha/Lincoln. Committee members know of individuals living in North-Central Nebraska are faced with having to drive 200+ miles
- Individuals living in Memory Care on Hospice – many are forced to move at end of life due to memory care not being able to meet their care needs.
- Facility based care can cost upwards of $10-$12k/month (Skilled care) $8-10k/month (ALF)
- General public (and even any providers) doesn't understand the different levels of care (skilled vs. ALF vs. ILF) can provide, and experiences sticker-shock when they are made aware of the costs.

- In rural areas, availability of home-care providers limited, let alone finding a SNF or Memory Care Facility that will take on the care of the individual with ADRD.
- Providers can't carry as high of caseloads in rural areas as distance between patients is higher.
- Most providers are requiring 2 years private pay due to reimbursement rate from Medicaid being so low.
- Strength: Payment differences were eliminated between telehealth an in-person visits during Covid. (previously, telemedicine was only being reimbursed at 50% of in-person visit) Also legislation passed that mandated coverage of mental health.
- Strength: Reimbursement increased for Medicaid waiver in rural areas. (Can we confirm this? Talk to Courtney Reif) – it is either up for approval or has been approved.

Potential Recommendations for State Intervention:

- Closures of nursing facilities has significantly impacted care available. Funding and staffing have been the two major contributors to closures. 38 (16%) SNFs and 28 (9%) ALFs in NE closed in last 5 years.
- In-home care providers limited – Education to the public that education and funding is available to care for loved ones in the home.
- Education on Advocacy strategies for care providers to address staffing issues across the board
- State prepared and EASILY ACCESSIBLE Education on ADRD for healthcare but also other disciplines (Police and other Emergency Responders)
- Process for physicians to be able to make referrals for residents with ADRD – "push a button" during a visit and ADRD providers reach out to the individual/caregiver
- Target Certified Nursing Assistants, how to care for ADRD – because they are direct caregivers but also often use this as a springboard into other careers. Facility-based care requires dementia education already, so would need to educate at an certification level or original training level. Incorporate experiential learning and mentorship in the field during initial training/certifications.
- Compensation for providers who must drive further to see patients in rural areas.
- Education about telehealth/telemonitoring options for providers to be able to see rural patients.
- Increase internet access for individuals to be able to utilize telehealth/telemonitoring options
- Continued evaluation of Medicaid reimbursement rates to be appropriate to cost of care.

Evaluate the capacity of the health care system to deal with ADRD

- Levels of care not taught in med school or residency training, so healthcare providers don't typically understand services available to seniors.

Educate providers in early detection and diagnosis

- This isn't just about frontline caregivers providing care to ADRC, this is also about providers diagnosing individuals with dementia.
- Perception with current students is that dementia doesn't require medical care. Pull anecdotal evidence from Dr. Manley about residents surveyed about primary health condition needing treated in facility-based care (and how they said no dementia does not need care)
- Education needed about how confusion or altered mental status is often mistaken for dementia when there is an alternate acute medical condition.
- Barrier – some providers don't want to "deal with" dementia because there is no treatment. Dr. Anthone said the same was with bariatric care. Until there is good treatments for a disease, Drs. tend to stay away.
- Wait list is 9+ months long for geriatric evaluation to DX
- Fear – many individuals fear the "label" of dementia. People say "why do I need this diagnosis if it's not going to change anything". It's viewed as a "feet-first" disease – the only way I'm going out this door is feet-first to the hearse. Suicide is high amongst older adults.
- Do we de-value other treatments because there is no magic pill to cure dementia. Those treatments that are early-stage are not as accessible (behavior, diet, sleep) and not as glamourous
- Statistics are a challenge in the state – accuracy of death certificate DX for those who die from complications r/t dementia – when other things get put on Death Cert, then it looks like more services are needed for heart disease, etc, because there are so many "deaths" related to those other things. But it's really related to ADRC. These numbers drive funding for national research and other interventions. When it's underreported, it's underfunded.

Potential Recommendations for State Intervention:

- Education – Early detection DOES matter - Intervention is easier if caught earlier. Rather than waiting until moment of crisis to intervene.

Improve health care for individuals with Alzheimer's Disease and Related Dementia (ADRD)

- "An adult doesn't learn what they have to know, until it hurts them NOT to know"
- There are only 23 certified geriatricians in the state of NE
- When Med School curriculum gets built, all providers clamor over their information being included. We may want to propose that ADRC education needs to be included in medical training and gather evidence for WHY this needs to be included.
- Getting people interested in elder care. By the time people get to residency, they have already figured out what they want to do. Rotations in geriatric is one thing, but we need to look at pilot programs in pre-med programs. Start in High School

- Barrier - Lack of respect in our society for seniors – retire and get out of the way. Other cultures have different ways of looking at this.

Next steps:

Does the AAA have a document that lists providers (SNF, ALF, Memory care) in each region of the state (Jenny)

Does Washington State have a system in place for physician referral to Alzheimer’s “hub” of resources (Dr. Manley)

Gather other State Plans/Guides for state workers (eg Police Dept) to work with ADRD (Joni)

What are other states doing to collaborate information for individuals/caregivers (Amy)

Next meeting: May 3, 2024 10-11:30am (Meetings will fall on First Friday of each month)

ADRC Council Meeting May 17, all subcommittee members are welcome to attend as member of the public.

Respectfully submitted by John Croghan and Corie Sass (co-chairs)

Informal Providers Subcommittee Report

Report for April 19 2024, Alzheimer's Disease and other Dementia Advisory Council

Subcommittee Members: Diane Hendricks, Dr. Lakelyn Eichenberger, Dr. Judy Dierkhising, Dr. Sarah Teten Kanter, Jean Holt, Co-Chairs – Lisa Marks and Julie Masters

Adjunct members attending meetings – Joni Dulaney and David Thompson

The Informal Providers Subcommittee met on April 5, 2024.

Subcommittee members discussed findings related to their areas of research interest listed below. Links to relevant articles and websites were provided to Joni for cataloging for the state plan.

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)

As a group we are committed to engaging in further research on the following new topics.

Jean Holt – refugee population and dementia

Judy Dierkhising – a caregiver's perspective on navigating through available resources in the community

Lakelyn Eichenberger – expenses of ADRD faced by persons of diverse backgrounds.

Sarah Teten – what items from the 2016 plan could be used for this new plan? Julie Masters will assist Sarah in locating updated data.

Our next meeting will be held May 3 at 11 am via Zoom.

Respectfully submitted by Lisa Marks and Julie Masters (co-chairs)

Alzheimer Disease and Other Dementia Advisory Council Community Subcommittee

Zoom Meeting

Date: April 5, 2024

Sub-Committee Members Attendees:

Tracy Lichti
Mary Ann Stallings
Gayleen Bradley
Karla Frese
Deb Marasco
Melanie Haynes-McCurry
Mike Osberg
Tyson Gould

Absent: Cheryl Brown, Carolina Padilla

Tracy shared the following as a working path for the subcommittee:

1)Trends in the state's Alzheimer's disease and other dementia populations and service needs and the 4 bullets included

2) Existing resources, services and capacity relating to the diagnosis and care of individuals living with Alzheimer's disease or other dementia, including the 5 bullets.

Answering the questions included in the above points will give the subcommittee direction and the means to meet the legislative bill.

Discussion included the following trends:

1. Increase Public Awareness of ADRD
   Tracy shared the Assisted Living: A Growing Aspect of Long-Term Care information
2. Low Income:
   a. No means to get to Doctor appointments, Daycare etc.
   b. Lack of Social Worker assistance
   c. Families have a disconnect from services available.
3. The process to get Medicaid is longer and more difficult.
4. Not receiving valuable information to navigate through the Medicaid process.
5. Hospitals sending people home earlier; patients not receiving information on available resources or education.
6. No education on how to manage diagnosis of Dementia/Alzheimer's or next steps.
7. Lack of neurologists to help navigate through the next steps and lack of follow-up, especially outside of urban areas of Nebraska.
8. Not enough monies budgeted through the State for memory loss Medicaid/Waiver.

9. Lack of Geriatricians.
10. Lack of services and resources in rural areas.
11. Nebraskans with Dementia and their caregivers are not aware of all the resources and education available or do not know who to reach out to.

Next Steps:

Members of the committee research resources available to meet these trends.

Research what other states have in place for resources or process for Medicaid applications.

Please put in the Google Doc Karla Frese set up for us:

https://docs.google.com/document/d/1L4ED1Yq_EeN9HRWB8rc7zo59wmm7GVvLpzkl7nh0RsE/edit

Next Meeting: Friday, May 3rd at 9:00 on Zoom (invite has been sent)