NEBRASKA Good Life. Great Mission. DEPT. OF HEALTH AND HUMAN SERVICES	**State Unit on Aging** **Alzheimer's Disease and Other Dementia Advisory Council Meeting** **Friday, May 17, 2024** **10AM – 12PM** **In-Person Meeting Location:** Jack J Huck Continuing Education Center 301 S. 68th Street Place Lincoln, NE 68510 Conference Room 302 **Meeting Link for Members of the Public to attend:** https://sonvideo.webex.com/sonvideo/j.php?MTID=m088b03d3a3f68fa7365bb9c0823da839

IN-PERSON MEETING
AGENDA

Welcome – David Thompson, Chair

Roll Call and Introductions
Roll will be called; Council members and staff will introduce themselves.
Introduction of new Council member Josie Rodriguez.

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 April 19, 2024, meeting.

State Plan
Further discussion of the structure of the final report and the work product that each subcommittee will be providing.

Issues that were not discussed at the April 19 meeting due to lack of time will be discussed:

- How to handle the bibliographies and resources for the report as a whole.
- The need for a centralized source of information for the public and other constituencies.
- A review of the Alzheimer's Disease and Other Dementia Support Act to ensure that all the issues specified in the report are addressed.

There will also be additional discussion of how to share the draft report to key stakeholders and include their views in the final version.

Subcommittee Reports

Council members will report on their respective subcommittees.

There will be an update on the status of the shared space for subcommittees.

LB903
Member Rotations
LB903, which addresses the initial length of terms for members to serve, was signed by Governor Pillen. Members will need to determine who will serve a two-year, three-year, or four-year term. Reappointments after the initial term will be to a four-year term.
Report to the Legislature and Governor
LB903 also provides that "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 Governor" by no later than December 31, 2024.

Meeting Calendar

We will need to review the meeting calendar and change one virtual meeting to in-person to meet the requirement that no more than one-half of the meetings can be virtual meetings.

Announcements

Adjourn

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)

5/17/24

Alzheimer's Disease and Other Dementia Advisory Council

List of Topics for Final Report
(Three to five pages for each topic)

1. Understanding Dementia
   a. Different types (Alzheimer's, Lewy-Body, Fronto-Temporal, Vascular)
   b. Statistics on prevalence across state and projections for the future
   c. Modes of diagnosis (biomarkers, brain imaging, spinal fluid and blood tests)
   d. Treatments (lecanemab, donanemab, others in pipeline)
   e. Models of Care

2. Impacts on the Healthcare System
   a. Educating providers on diagnosis and treatment
   b. Relationships among providers (when PCP refers to a specialist)
   c. Need for more people to enter field
   d. Creating age-friendly hospitals, increase capacity

3. Models of Care
   a. Need for more care navigators
   b. Models of care, more cooperation
   c. [Add]

4. Facilities
   a. Different types (assisted living, skilled nursing, memory care)
   b. Training of staff
   c. Need for more memory care beds, more facilities
   d. Distribution of facilities across state
   e. Stop facility closures

5. Caregivers
   a. Training for unpaid and paid caregivers
   b. Economic impact of caregiving on families
   c. Resources (support groups, etc.)

6. Reaching Underserved communities
   a. African-American, Latino, Native American, Immigrant communities
   b. Greater likelihood of ADRD in these communities
   c. Need for cultural competence (home care and moving loved ones to facilities)
   d. Need for interpreters and materials in multiple languages
   e. Special issues around being minority in a facility, seeking facilities such as hospice and home care focused on these communities

7. Rural Communities
    a. Prevalence of facilities and home care agencies, geographic distribution
    b. Need for more and better-trained providers
    c. Demographic issues (fewer children means fewer caregivers, aging towns)

8. Families
    a. Role as Caregivers
    b. Educational resources
    c. Family dynamics and mediation
    d. Demographic issues such as "sandwich" generation

9. Home Care
    a. Importance of aging in place,
    b. Number of companies across state, lack in rural communities
    c. Compensation structure (Medicaid reimbursement, private pay)
    d. HCBS (role in Medicaid)

10. Respite and adult day care
    a. Importance of respite for caregivers (burnout)
    b. Different kinds of respite care (during the day, overnight, extended)
    c. Number of programs available (how to spread the word)

11. Role of organizations
    a. Area Offices on Aging, distribution across state
    b. Alzheimer's Association
    c. Partnerships (Collective for Hope, Combined Health Agencies Drive)
    d. Need for more funding to support outreach and training

12. Workforce Development
    a. Growth in need given changing demographics
    b. Relationships with education institutions K-12
    c. Geriatric Workforce Enhancement Program (GWEP)
    d. Encourage more people to enter the field

13. Safety
    a. Harm reduction (falls, driving, etc.)
    b. When is safety a factor in moving into a facility
    c. Elder Abuse, Adult Protective Services

14. First Responders
    a. Role in dealing with ADRD population
    b. Current training available
    c. Special units w/mental health counselors within police departments
    d. Economic impact of ER visits

15. Behaviors
    a. Recognizing those associated with each type of dementia
    b. Specific disorders (sundowners, hoarding, wandering)
    c. Training in de-escalation
    d. Determining right mix of care depending on specific behaviors

16. Brain Health
    a. Understanding its role in preventing ADRD
    b. Develop more resources, make them more accessible
    c. Encouraging providers to make this a consideration in ongoing care

17. Co-Occurring Disorders
    a. Mental Illness
    b. Substance abuse
    c. Intellectual disabilities
    d. Finding right model of care depending on combination of disorders

18. Legal
    a. Powers of Attorney
    b. Advance Directives
    c. Guardianships
    d. Long-term care planning (e.g., special needs trusts)

19. Data
    a. Current data-gathering
    b. Central repository
    c. Increased tracking

20. Policy
    a. Current policies, state and national
    b. Funding (reimbursement rates, tax credits, etc.)
    c. Process for developing policies during implementation phase
    d. Integrating ADRD into all planning conversations (housing, transportation)

2024 Alzheimer's and Related Dementias Survey Report

Education Committee

May 02, 2024

Sarah Wilson, ALA

Regarding Alzheimer's and Related Dementias, what is the most pressing issue relating to your specialty?

1. **Education and Training:** Addressing the training needs of the direct care workforce is crucial, particularly in providing adequate support for caregivers and care partners. Many caregivers lack sufficient information about the progression of illnesses and available resources, leading to inconsistencies in care provision. There's a pressing need for education to dispel the misconception that all problems stem from dementia and highlight the importance of early intervention and treatment. Additionally, there is also a need for more specialized psychiatric support to effectively handle difficult behaviors.

2. **Housing:** The lack of memory support units or affordable assisted living facilities (ALFs) for dementia care exacerbates the challenge of finding suitable long-term care, especially for those with unmet needs and behavioral issues. Caregiving support for non-professional family caregivers is essential, including simplifying information on care options, developing caregiving skills, and addressing financial barriers. Additionally, there's a shortage of skilled nursing facility beds, particularly for low-income dementia patients, emphasizing the need for affordable and accessible memory care options.

3. **Funding and Financial Supports:** Lack of funding further compounds the issue, affecting the availability of trained medical and behavioral health providers and quality staff within long-term care facilities. Proper staffing and training are crucial for managing dementia-related behaviors and providing adequate care and treatment options.

4. **Medication Management:** Overprescription of medications and limited access to specialized providers and facilities add to the challenges faced by caregivers and patients alike. There's a stigma surrounding cognitive impairment, leading to misconceptions about patients' decision-making abilities and their involvement in care decisions.

5. **Other Items:** Efforts to combat Alzheimer's disease include developing inexpensive biomarkers for risk assessment and advocating for appropriate Medicaid funding for assisted living and long-term care services. Education and outreach initiatives are essential for raising awareness and providing support to families and caregivers navigating the complexities of dementia care.

What are some additional comments you may have regarding your specialty?

1. **Family Support:** Family caregivers need comprehensive support, including access to advocates, social workers, or support persons who can guide them through the caregiving process. Policies should be developed to provide therapy services to caregivers, along with better coping strategies to manage the challenges of caregiving and prevent burnout.

2. **Education and Communication:** Educating state surveyors on normal and not uncommon behaviors in dementia patients can prevent facilities from being wrongly blamed for unfortunate occurrences. Collaboration and consistency among caregivers is essential, with a focus on understanding and meeting the unique needs of dementia patients, including communication strategies for non-verbal residents and handling aggressive behaviors. Staff training should prioritize best practices for working with dementia and Alzheimer's patients.

3. **Medicaid Reimbursement:** There is a need for increased funding to support dementia patients and their caregivers, stricter regulations and higher reimbursement rates for memory care facilities. More state funded adult day programs are also necessary to provide respite for caregivers and support for individuals with dementia. Adequate Medicaid reimbursement rates for facilities and services catering to dementia patients are essential, along with the inclusion of increased reimbursement rates for memory support in Medicaid coverage. Consistent support and resources should be available for families dealing with a new diagnosis.

4. **Education Related to Other Dementias:** Different types of dementia require tailored approaches, and it's essential to address the unique needs of individuals dealing with various forms of the condition, such as early versus late-onset dementia and specific types including Frontotemporal Dementia, Primary Progressive Aphasia, Lewy-Body Dementia, and Vascular Dementia. Support is needed for individuals with dementia who are justice-involved and their caregivers, as well as couples facing relocation due to dementia.

If caregiver education were available related to Alzheimer's, what topics would you be interested in, and what would be your preferred method of delivery?

Based on the responses provided, caregivers are interested in a variety of topics related to dementia care and management, including diagnosis and early detection, handling aggressive behaviors, effective communication strategies, caregiver burnout, and understanding different types of dementia. They prefer methods of delivery such as online webinars, in-person sessions, self-paced education, and email communication.

Summary of interests and preferred delivery methods:

1. Topics of Interest:

- Diagnosis and early detection
- Handling aggressive behaviors
- Effective communication strategies
- Caregiver burnout
- Understanding different types of dementia
- Resident engagement
- Coping strategies for overwhelmed caregivers
  - Steps to deal with symptoms of Alzheimer's and dementia
- Safety considerations
- Medication management for the elderly

2. Preferred Methods of Delivery:
- Online webinars
- In-person sessions
- Self-paced education
- Email communication
- Video series
- Zoom sessions
- Small group consultations

3. Additional Preferences:
- Respite provided during caregiver groups
- Accessibility for older caregivers, possibly favoring in-person sessions
- Incorporating case scenarios in training sessions
- Offering a mix of in-person and virtual trainings

Overall, caregivers value comprehensive education and support that addresses their needs in caring for individuals with dementia, delivered through flexible and accessible formats.

1. **Caregiver Support:** Caregiver groups that offer respite, whether online or in-person, are valuable resources for individuals caring for loved ones with dementia. These groups provide support, information, and practical training, such as de-escalation techniques and referrals to relevant services. They also offer a space where caregivers can share experiences and learn from one another.

2. **Effective Training:** Training programs for caregivers should focus on practical skills like assessing individual needs to reduce aggression and addressing aggressive behaviors without relying solely on medication. Activities suitable for different levels of dementia, such as music therapy, should be incorporated into training sessions. Additionally, seminars emphasizing the importance of acknowledging one's emotional struggles and seeking help can help reduce caregiver burden and promote self-care.

3. **Education Delivery Methods:** Webinars and online resources are convenient

formats for delivering education on diagnosis, treatment, and caregiving strategies for dementia. These platforms allow for easy access to information, particularly for non-healthcare providers, and can cover topics like sundowning, nutrition, and managing caregiver stress. It's important to offer a variety of learning formats, including in-person sessions, to accommodate different preferences and accessibility needs.

4. **Managing Aggressive Behaviors:** Effective caregiver training should prioritize skills related to anticipating and communicating a person's needs, as well as de-escalating situations of acute distress. This includes understanding the baseline mood and behavior of individuals with dementia and recognizing signs of emotional escalation. Providing caregivers with practical tools and strategies for maintaining calm and supportive communication can enhance their ability to manage challenging behaviors and improve the overall quality of care.

5. **Inclusion of Additional Topics:** In addition to focusing on Alzheimer's disease, education on other types of dementia is essential for caregivers. Additional topics relating to the humanity of the individual such as interpersonal communication, relationships within families, sexuality and sexual health, and anticipatory grief should be addressed to provide comprehensive support to caregivers. Consultation and education sessions tailored to individual or small-group needs can offer personalized guidance and support.

Do you think it would be beneficial to have direct caregivers receive training in nonviolent crisis intervention and harm reduction?

With 90% of respondents indicating a positive response and the remaining 10% showing interest, it suggests that there's strong support for this type of training and approach in managing crises involving individuals with dementia. There were 40 total responses to this inquiry. 36 respondents reported "yes" and 4 reported "maybe". There were no respondents that reported "no".

Do you think it would be beneficial to have direct caregivers receive training in non-violent crisis intervention and harm reduction?

40 responses
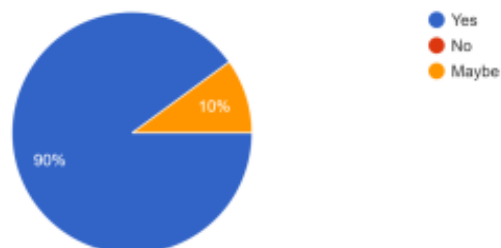
Regarding underserved communities, how would you rate our cultural competence in Nebraska?

This inquiry requested a response on a scale of 1-5, with 1 being satisfied and 5 being very dissatisfied. The majority of respondents were neutral, leading with 35% of responses. Immediately following was dissatisfied, with 30% of responses. 17% of survey participants were very dissatisfied. 6 replies were satisfied, contributing to 15% of received feedback and one individual reported that they were very satisfied, resulting in 2.5% of received replies.
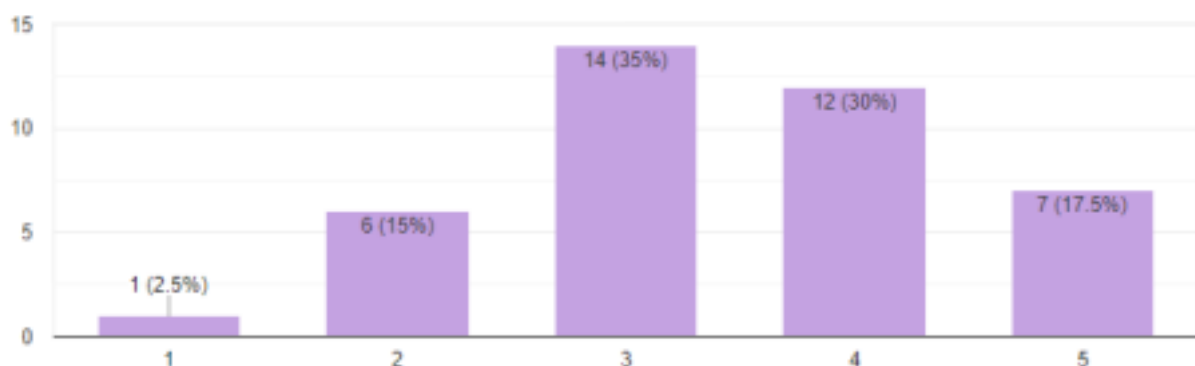
How can Nebraska address underserved communities such as rural and ethnic populations? What can we do to improve?

Based on the responses provided, it's clear that there's a significant need for improved access to dementia care and support services in underserved communities, particularly rural and ethnic populations. Here are some key points and suggested actions:

1. **Multilingual Professionals and Training Materials:** There's a need for professionals and volunteers who can communicate effectively in multiple languages and culturally sensitive training materials. This includes placing professionals and resources in rural and ethnic communities where they can easily access support.
2. **Access to Services:** Increasing access to respite care, support groups, hotlines, and telehealth services can help bridge the gap for individuals and families in underserved communities. Mobile services and community-based education initiatives can also play a crucial role in reaching these populations.
3. **Funding and Reimbursement:** Providing increased funding, higher reimbursement rates, and financial incentives for care facilities and providers in rural areas can help sustain and expand dementia care services. Rethinking the pay model for Medicare and Medicaid to ensure equitable distribution of resources is also essential.
4. **Community Engagement and Research:** Engaging in community-based

participatory research can help identify the specific needs of diverse populations and tailor services accordingly. Pouring more funds into these communities and prioritizing their unique challenges is crucial for addressing disparities in dementia care.

5. **Education and Standardization:** Standardizing dementia care training and establishing clear protocols for identifying and addressing dementia-related issues can improve outcomes for individuals and families. Providing education through senior centers, informal community meetings, and online platforms can empower communities to recognize and respond to dementia-related changes effectively.

6. **Cultural Competency and Support Services:** Increasing access to culturally competent care, behavioral health services, and technology assistance can help meet the unique needs of ethnic and rural populations. Additionally, offering support groups and mobile clinics in underserved areas can enhance access to care and support services.

7. **Addressing Substance Use Issues:** Addressing substance use issues in the workforce and ensuring that employees are trained and capable of providing quality care is essential for maintaining the safety and well-being of individuals with dementia in underserved communities.

By implementing these strategies and prioritizing the needs of underserved populations, we can work towards reducing disparities in dementia care and support services across diverse communities.

How can we improve our performance to benefit the lives of affected persons in Nebraska?

Based on the responses provided, it's evident that there's a pressing need for bridging gaps between providers and improving access to resources, particularly in rural and ethnic communities. Some key points are as follows:

1. **Access to Services:** Placing professionals, buildings, and resources in rural and ethnic communities can greatly improve access to care. This includes ensuring that individuals have access to professionals who speak their language and understand their cultural background. Initiatives such as support groups, hotlines, and outreach clinics can also help bridge the gap and provide much-needed support and information.

2. **Collaboration and Education:** Collaborating with healthcare, mental health, and individual providers is essential for providing comprehensive care. This collaboration can involve sharing resources, coordinating care plans, and ensuring that individuals receive the support they need. Education programs for caregivers and regular checkups from staff can also help improve

outcomes for individuals with dementia.

3. **Funding and Financial Support:** Securing sufficient funding for rural areas, including Medicaid expansion and provisions to pay living wages, is crucial for sustaining and expanding dementia care services. Better pay for providers, increased funding for respite programs, and improved provider rates can help attract and retain qualified caregivers.

4. **Community Engagement and Research:** Engaging in community-based participatory research can help identify the specific needs of underserved populations and inform policy and program development. Including affected persons in policy change and tapping into expertise from academic institutions can lead to more effective and culturally sensitive interventions.

5. **Preventative Care and Education:** Educating individuals about preventative care and providing resources for early intervention can help address dementia-related issues before they escalate. Initiatives such as elder fests, community presentations, and genealogy assessments can raise awareness and identify individuals at risk for dementia.

6. **Centralized Facilities and Outreach:** Establishing centralized facilities for specialty care and conducting outreach to smaller towns and facilities can ensure that individuals receive the care and support they need closer to home. Ambassadors and outreach clinics can provide face-to-face contact and connect individuals with resources and services.

By implementing these strategies and prioritizing the needs of underserved communities, we can work towards reducing disparities in dementia care and support services and improving outcomes for all individuals affected by dementia.

What can we do to serve individuals with Co-occurring diagnoses of mental illness and/or substance abuse and dementia?

Addressing the intersection of dementia and mental illness presents a complex challenge that requires a multifaceted approach. Here are some suggestions based on the responses provided:

1. **Additional Training for Mental Health Professionals:** Providing specialized training for mental health professionals to work effectively with individuals who have dementia and co-occurring mental health conditions is crucial. This training should focus on person-centered treatment and education rather than illness-focused approaches.

2. **Incentivizing Collaboration with Nursing Homes:** Encouraging psychiatrists to work more closely with nursing homes, possibly through higher reimbursement rates or flexible consultation options, can ensure that residents receive appropriate mental health care in their living environment.

3. **Increased Access to Services:** Making mental health services more accessible and convenient, possibly through alternative hours or telehealth options, can help individuals with dementia and mental illness access the care they need.
4. **Safe and Stable Living Environments:** Ensuring that individuals with dementia and mental illness have access to safe and stable living environments, especially for those who are low-income, is essential for their well-being. This may involve creating specialized housing options or providing additional support services.
5. **Training Across the Healthcare System:** Providing training on dementia and mental illness across the healthcare system, from CNAs to MDs, can help ensure that all providers are equipped to address the unique needs of this population.
6. **Policy and Funding Support**: Advocating for Medicaid payment structures that support services for individuals with dementia and mental illness, as well as addressing regulatory barriers to appropriate medication use, can help improve access to care.
7. **Education and Awareness:** Increasing education and awareness about the intersection of dementia and mental illness among caregivers, families, and the general public can help reduce stigma and ensure that individuals receive appropriate support and understanding.

What gaps in the system would you like to see addressed?

The responses highlight several key gaps and challenges in home and community-based services for individuals with dementia:

1. **Racial and Ethnic Disparities:** There is a need to address racial and ethnic gaps in access to and quality of care. Providing culturally competent services and increasing diversity in the healthcare workforce can help bridge these gaps.
2. **Support for Caregivers:** Caregivers need more support and coping mechanisms to deal with the challenges of caring for someone with dementia. Access to respite care and coping support services is essential to prevent caregiver burnout.
3. **Wage Discrepancies:** There is a discrepancy in wages between direct care workers and administrative staff, which affects the quality of care provided. Addressing wage gaps and ensuring fair compensation for direct care workers is crucial to attract and retain qualified professionals.
4. **Mental Health Services and Early Diagnosis:** Mental health services, including psychiatric services and early diagnosis of dementia, are crucial but often lacking. There is a need for increased funding and resources to improve access to mental health care and facilitate early detection and intervention.
5. **Community Understanding and Stigma:** There is a lack of community understanding of dementia, leading to stigma and reluctance to seek help. Education and awareness programs are needed to educate the public about

dementia, reduce stigma, and encourage early intervention.

6. **Funding and Training:** There are funding gaps at every level, from in-home services to adult day programs. More funding is needed to support dementia care services, as well as training for healthcare providers to ensure they have the skills and knowledge to provide high-quality care.

7. **Transportation and Accessibility:** Access to services, especially in rural areas, is limited due to transportation barriers. Improving transportation options and making services more accessible can help individuals with dementia and their caregivers access the care they need.

8. **Guardianship and Legal Support:** There is a need for more court-appointed guardians to assist individuals with dementia who lack family support. Providing legal support and assistance with healthcare decision-making can ensure that individuals with dementia receive the care they need.

Addressing these gaps requires a comprehensive approach involving policy changes, increased funding, education and training programs, and community outreach efforts. By prioritizing these areas, we can work towards improving the quality of life for individuals with dementia and their caregivers.

Please add any additional comments you may have

These additional perspectives highlight the need for comprehensive and community-driven solutions to support individuals living with dementia and their caregivers:

1. **Common Philosophy and Understanding:** Solutions should be aligned with a common philosophy that promotes independence for individuals living with dementia. This involves recognizing that most individuals with dementia live in the community and receive support from family, friends, and neighbors who may lack understanding of dementia. Education and support programs should empower these informal caregivers to provide effective assistance.

2. **Utilization of Available Resources:** Communities should leverage existing local organizations, systems, and technologies to support individuals with dementia. This includes coordinating services across various sectors such as healthcare, social services, and community organizations to provide comprehensive support.

3. **Education for Healthcare Providers:** There is a need for better dementia education for healthcare providers across various disciplines, including physicians, nurses, CNA's, dentists, and others. This would ensure that individuals with dementia receive appropriate care and support for their specific needs at all levels.

4. **Involvement of Community Leaders:** Church leaders, community organizations, and local business owners can play a pivotal role in supporting individuals with

dementia and their families. By providing resources and support, these community leaders can contribute to creating dementia-friendly communities.

5. **Policy and Funding Considerations:** Policies should prioritize funding for services and support for individuals with dementia. Additionally, innovative ideas such as integrating adult day centers with child care facilities can provide intergenerational and supportive environments for individuals with dementia and their families.

6. **Estate Planning Education:** Families should be educated about the potential challenges of relying solely on Medicaid funding for long-term care services. Estate planning education can help families make informed decisions about asset distribution and long-term care planning.

By addressing these considerations, communities can create more supportive environments for individuals living with dementia and their caregivers, promoting independence, dignity, and quality of life for all.

Education Subcommittee Meeting

10 MAY 2024 / 10:00 AM / ZOOM

Attendees

Sarah Wilson, Penny Clark, Nick Faustman, Chris Kelly, KoriAnne Moslander, Joni Dulaney

Agenda

Last Meeting Follow-up

1. Discuss rubric and outline for revised state plan

New Business

2. Discuss Sadie Hinkel's notes on the rubric

3. Focus on the goals that pertain to education

Notes

I. **Goal 1: Enhance Care Quality and Efficiency**
- A. What specific training programs can be developed or expanded to equip healthcare providers with the skills necessary to offer high-quality care to individuals with dementia?
  1. <u>Project ECHO</u> - clinical education
     a) Alzheimer's Association Alzheimer's and Dementia ECHO Program for Primary Care series will take place on October 10, 2024.
  2. ADAPT Act in DC
     a) Resources for Primary Care providers
     b) Just introduced in the Senate
  3. MANDT and CRT training
     a) Crisis response training
     b) Non-violence crisis intervention training
- B. N/A
- C. What types of educational programs and support systems can be implemented immediately following a diagnosis to help individuals with dementia and their families manage the disease more effectively?

1. Navigating a Dementia Diagnosis and Empowered Caregiver - Alzheimer's Association programs
2. Statewide Referral System
3. Caregiver support groups - Alzheimer's Association
4. More accessibility in training and programs
   a) Zoom, In-Person, Hybrid
   b) Other circumstances (no internet access)
   c) All Nebraska
   d) Focus on Western Nebraska
5. Need volunteers to have capacity at the Alzheimer's Association

D. How can we identify and disseminate high-quality dementia care guidelines that are applicable across diverse care settings?
   1. Live on DHHS website - links to organizations, ADRC, AAA
      a) One centralized page

II. **Goal 2: Expand Supports for People with Alzheimer's Disease and Related Dementias and Their Families**

A. How can we ensure that all dementia education, training, and support materials are culturally and linguistically appropriate for diverse communities?
   1. Diverse workforce, different languages
   2. Alzheimer's Association has resources for the majority of minority groups
   3. Helpline assistance can be translated

B. What programs or resources can be developed to help family caregivers continue to provide care while also maintaining their own health and well-being?
   1. Caregiver well-being resources - Alzheimer's Association
      a) https://www.alz.org/media/Documents/alzheimers-dementia-caregiver-emotions-ts.pdf
      b) https://www.alz.org/media/Documents/alzheimers-dementia-caregiver-stress-ts.pdf
   2. 24/7 Hotline for caregivers - Alzheimer's Association
   3. Accessibility needed for caregiver resources

C. What tools and resources can be provided to families to assist them in planning for future care needs of their loved ones with dementia?
   1. Empowered Caregiver education program - Alzheimer's Association
   2. Alzheimer's Association resources
      a) https://www.alz.org/help-support/resources
      b) https://www.alz.org/help-support/resources/publications

III. **Goal 3: Enhance Public Awareness and Engagement**

A. What innovative strategies can be employed to educate the public about Alzheimer's disease and related dementias?
    1. Partnerships with UNO and the Alzheimer's Association, the Triple A's and other aging centered organizations
        a) Education and awareness for students
        b) Related events (ex. Advocacy Day)
    2. Churches, Senior centers, community centers
        a) Seek out informal caregivers
    3. Lunches and Learns

B. How can we effectively translate recent research findings on risk reduction into practical, actionable guidelines for clinical practice?
    1. *Question misrepresents clinical care
        a) Involving licensed healthcare providers, home and community based services, direct care workers, family caregivers, CNA and CMA's, etc.

C. N/A

D. N/A

E. N/A

F. What are the most effective ways to engage the public in understanding and implementing lifestyle changes that could reduce their risk of developing Alzheimer's disease and related dementias?
    1. Public Health Campaign - Statewide
        a) Ex. 988 Suicide and Crisis Lifeline and Implementation of Nebraska State Suicide Prevention Plan
    2. Funding and manpower needed
    3. Contact different DHHS members for information for funding and partnerships for delivering information

Subcommittee Meeting: The Role of Formal Providers

5/3/24

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

Items of Discussion:

Goal 1: Enhance Care Quality and Efficiency

A. **What specific training programs can be developed or expanded to equip healthcare providers with the skills necessary to offer high-quality care to individuals with dementia?**
   - Behavioral type plan that focuses on non-pharmacological interventions for challenging behaviors.
   - Comprehensive so that all disciplines (healthcare, law enforcement, etc) are involved.
   - Community Intensive training for Police Officers – 3-4x a year open to anyone in community from professionals to community members.
   - Empathy training for understanding "they are *having* a hard time, they aren't *giving* you a hard time,"
   - Focus on crisis care and crisis management.
   - Concerns about lack of incentives for those going into geriatrics. Not enough providers.

B. **How can we streamline the process for diagnosing Alzheimer's disease to ensure it is both timely and accurate?**
   - Current diagnosis process depends on family members getting their loved ones in timely for assessment.
   - Screening must be simple and direct. Mini-Cog is commonly used.

- Dementia at times can be misdiagnosed in ED settings, and ADRD is a permanent and potentially devastating diagnosis. There is a fine line between QUICK and CORRECT diagnosis.
- Discussion of biomarkers for ADRD – may assist with accurate diagnosis but present financial/economic barriers.
- Could there be routine cognitive screening at primary care appointments? Would need to be very clear algorithms on how to administer the assessments, what to do when there are positive results, etc. Discussion of diagnosis by qualified and trained providers who are familiar with ADRD.

C. **What types of educational programs and support systems can be implemented immediately following a diagnosis to help individuals with dementia and their families manage the disease more effectively?**
- Centralized repository that is easy for families to navigate. A google search will provide a multitude of resources, but how much of that is local? May also include information from non-reputable sources.
- Local Geriatric Resource Center, local website, survey/questionnaire that will direct people appropriately, narrow down the laundry-list.
- Could other organizations, DHHS, Alz Assoc, etc be able to link to this hub of information?
- The state of Washington has an integrated EHR that allows for providers to click a button to make referrals for resources that would then connect with families. Automatically connects to local entities: waclc.org/consite/connect/refer_a_patient.php
- Many people in the community don't even know what Area Agencies on Aging are, where they are, what they do, etc.
- Could a referral system be built into Hospital EHR's, Primary Care EHR's, etc.

D. **How can we identify and disseminate high-quality dementia care guidelines that are applicable across diverse care settings?**
- Ensuring follow up when diagnosis is received.
- Often 1-2 major health systems in a community/geographic region. When other diagnoses are received, there are systems in place to refer to appropriate specialists.
- Must evolve from institutionalization to individualized care policies. The goal of aging in place necessitates this.
- There are more single older adults, childless older adults, older adults living far from family that make it challenging for family-based care.

- Discussion of POA initiatives

E. What are the most promising new models of care for dementia, and how can we test their effectiveness on a larger scale?
- GUIDE Model with CMS – seeking to recruit and provide care navigators to individuals in the community. Proposed release July 2024.
- https://www.cms.gov/priorities/innovation/innovation-models/guide
- UCLA model – ADC program: https://www.uclahealth.org/medical-services/geriatrics/dementia/adc-stories

F. What are the best practices for ensuring safe and effective care transitions for people with dementia between different care settings and systems?
- The concept of Care Navigator is crucial here – a person/organization that would be able to provide education/communication when individuals are moving throughout different levels of care.
- Care Navigation would help reduce the chaos of getting too much input from not-entirely reputable sources. Help make individuals less susceptible to scams.
- Who would pay for and train Care Navigators – families aren't able to afford the $40/hr to pay individuals to this.
- Transition from hospital to facility, and facility to home may be covered, but not in other places.
- PCP's have transitional care ICD 10 code for billing but there are stipulations for using it, many providers do not use it.
- AAA's can assist with resources and Service Coordination but can't provide emergency services.
- Creation of a "fire-escape" plan for crisis intervention
- Utah – proactive dementia care: https://www.uclahealth.org/medical-services/geriatrics/dementia/adc-stories
- 5 wishes document specific to dementia care.

G. How can we better coordinate and integrate health and long-term services to support individuals living with dementia?
- Crucial to educate Acute care providers to be well informed and skilled in providing dementia-specific care.
- Proper dementia care results in fewer re-hospitalizations, and faster placement when individuals with ADRD in post-acute settings.
- Cancer initiatives have great wrap-around models that might help dementia step away from linear care.

H. What targeted interventions can be developed to improve care for populations disproportionately affected by Alzheimer's and related dementias?

- Must focus on rural provision of care, and increase telehealth options to improve access to services for those residing far from Urban healthcare systems
- VA system has a robust telehealth system that may be examined:
- https://www.uclahealth.org/medical-services/geriatrics/dementia/adc-stories
- Focus on Information-based support groups rather than emotional support groups, as it tends to attract more individuals.
- Senior center enrollment is down due to people not wanting to be called "seniors", but senior centers already have monthly educational topics.
- Discussion at Senior Centers to consider renaming to be more approachable and adopt a name that translates to a younger population.

Goal 2: Expand Supports for People with Alzheimer's Disease and Related Dementias and Their Families

A. How can we ensure that all dementia education, training, and support materials are culturally and linguistically appropriate for diverse communities?

- Tailoring assessments to all cultures. There are some cultures that we miss the mark entirely because our assessments aren't asking the right questions, or are asking questions in a way that are offensive/not related to that culture.
- Work with Intercultural Senior Center
- Many cultures view aging differently. Some value keeping their loved ones at home with family. US culture tends to focus on very individualized concepts of care.
- How does culture/language impact access to care.

B. What programs or resources can be developed to help family caregivers continue to provide care while also maintaining their own health and well-being?

- Majority of individuals with ADRD live at home with families.
- Lack of knowledge about caregiver resources/respite resources for ADRD individuals living in the home.
- Facility-based care providers are not always aware of what resources can be provided in the home in order to educate individuals/families about in-home care.
- Crucial for medical community to recognize the burden of caregiving, and normalize asking for help, asking for respite.
- Emphasizes need for automatic referral system to provide umbrella of services to individuals and families with ADRD

5/14/24 Meeting Discussion
Attended:
Unable to attend: Cindy Kadavy, Tasia Theoharis, Lara Schiffbauer, Jina Ragland,

The following topics have been discussed by the Alzheimer's and Other Dementia Governmental Sub-committee. Please indicate the areas below that you feel we need to continue to focus on and add any other areas that you feel need to be added to our discussion. During our meeting on May 14th, we will discuss the rubric for the report, how these areas play into the questions in the rubric as well as any other questions you feel need to be included.

The webpage devoted to ADRD on the DHHS website redesigned to be a "one stop shop."

A strategic communication plan from DHHS including the coordination of social media that is relevant to ADRD, across all relevant divisions

The state plans of other states

Nebraska DHHS applying for the BOLD Grant

Could HCBS services be expanded to include things that would be useful to those with dementia and caregivers to provide relief.

The number of AL's providing memory care accepting Medicaid.

Deficits on the SNF side for those in need of rehab services--Many SNF will not accept them, or they have to bring in additional private duty caregivers to address their needs.
- Comment from Cindy K- Deficits on the SNF side for those in need of rehab services--Many SNF will not accept them, or they have to bring in additional private duty caregivers to address their need - I have many questions about this topic. I've not heard of this and it's puzzling since Medicare pays a higher rate for rehab care than Medicaid pays for ongoing care. Is there any data that indicates this is happening or how often it happens?

Need to review the cost of care for those paying privately for in home and out of home care to find average costs. How are they paying for services?

What services are funded under the older Americans act?

Care management services/care and the increasing demand.
- Comment from Cindy K-

-
- Care management services/care and the increasing demand. I like the suggestion of a focus on the Care Management services provided through the Area Agencies on Aging. This seems like it would be a great resource for family caregivers trying to navigate the system and find options for in-home and out-of-home resources. I realize additional funding may be needed, but this service has the potential to be really helpful to families in need.

The increasing prevalence of early-onset

Training for formal caregivers

Public data – how gathered and stored (BRFFS, AAA assessments, Parkinson's/ALZ registry, data DHHS currently has, etc)

Support for research

Economic impacts (Medicaid, Medicare, private insurance, etc)

Establishment of a memory care rate for Medicaid waiver services

Rubric for Subcommittees

Goal 1: Enhance Care Quality and Efficiency

A. What specific training programs can be developed or expanded to equip healthcare providers with the skills necessary to offer high-quality care to individuals with dementia?
    - Project ECHO- improving access to diagnosis and receiving high quality dementia care through tele-monitoring with primary care physicians (Alz Asso)
    - House and Senate bill Accelerating Access to Alz & Other Dementia Care Act
    - Access to specialist with tele-health
    - Age Friendly expansion to community-based health programs- education on how to identify and get people to the correct resources
    - Best practices for Alzheimer's special care units on education for direct care staff in long term care providers- consistency across settings with best practices

B. How can we streamline the process for diagnosing Alzheimer's disease to ensure it is both timely and accurate?
    - Introduction of federal regulations to provide education to health care providers on criteria for diagnosis
    - Identification of symptoms for providers of long-term care services

C. What types of educational programs and support systems can be implemented immediately following a diagnosis to help individuals with dementia and their families manage the disease more effectively?
    - Care Management – AAA's – increased funding for this program
    - Care Navigators- to assist and support families in early diagnosis- Alternative to care management to explore- who could do this and how would it be funded?
    - Alz Association- Navigating the dementia diagnosis- free service
    - Caregiver videos and tutorials for informal caregivers to support them with the diagnosis- Empowered Caregiver?

D. How can we identify and disseminate high-quality dementia care guidelines that are applicable across diverse care settings?
    - LB1221- training on best practice required by LTC specialized providers
    - Other information listed above
    - Updated website with "one stop shop" for information on symptoms, diagnostics, medical care, family care, long term care options. Also broken down by region- for

available services in that area. examples of good websites include: Virginia Alz Commission, Wisconsin, Illinois, Washington

- Collection of Data through a registry for the state

E. What are the most promising new models of care for dementia, and how can we test their effectiveness on a larger scale?

F. What are the best practices for ensuring safe and effective care transitions for people with dementia between different care settings and systems?
- Age Friendly
- Finding the right setting and building the services in a person centered way
-

G. How can we better coordinate and integrate health and long-term services to support individuals living with dementia?
- Age Friendly
- Finding the right setting and building the services in a person centered way
-

H. What targeted interventions can be developed to improve care for populations disproportionately affected by Alzheimer's and related dementias?
- Socioeconomic and race indicators for impacts that can be more severe
- Data collection on a registry at the state level to examine areas or populations that may have more impacts than others.

Goal 2: Expand Supports for People with Alzheimer's Disease and Related Dementias and Their Families

A. How can we ensure that all dementia education, training, and support materials are culturally and linguistically appropriate for diverse communities?
- Redesign of website to be more effective to retrieve information for families
- Assure resources are available in other languages and assure cultural sensitivity on the topic of Alz and other dementias for the primary resources- Spanish, Vietnamese, and many other languages used in the area.
- Alz Helpline- can be translated into different languages

Rubric for Subcommittees

B. What programs or resources can be developed to help family caregivers continue to provide care while also maintaining their own health and well-being?
- Caregiver support services- mental health services for caregiver
- Caregiver Tax Credit implementation
- Respite Network expansion to include Alz and other dementias
- Care Management – AAA
- Tele-health & helpline services for caregivers
- Support groups across Nebraska and virtually, or online groups
- Expansion of PACE Services across the state
- Expansion of Day Services specializing in alz and other dementias

C. What tools and resources can be provided to families to assist them in planning for future care needs of their loved ones with dementia?
- Alz Associations resource and helpline
- Resources available in regional areas in Nebraska – listing on website
- Videos and information on service options available
- Forms and resources on what they need to do for advanced care planning- available at AAA, law offices, clinics, doctors, hospitals, etc.
- Red File- all resources in one place on wishes for care

D. How can we ensure that the dignity, safety, and rights of people with dementia are maintained in all settings and circumstances?
- Education about what a POA/Guardians is and what they are responsible for and what the limitations of that are
- Education program for POA's- similar to what guardians do
- Dementia training for public guardians office and ombudsmen on dementia and alz.

E. What mechanisms can be put in place to assess and address the long-term services and supports needs of people with Alzheimer's and related dementias?
- Tracking of the availability of specialized services for Alz
- Make it easier to identify what beds are available and what options may exist for a caregiver to call- using the list is not a positive experience
- Information for caregivers on how the operations work to receive services

Goal 3: Enhance Public Awareness and Engagement

A. What innovative strategies can be employed to educate the public about Alzheimer's disease and related dementias?

B. How can we improve coordination between state, tribal, and local governments to advance awareness and readiness for Alzheimer's disease and related dementias?

C. In what ways can the United States coordinate its efforts with the global community to address Alzheimer's disease and related dementias?

Goal 4: Improve Data to Track Progress

A. How can the federal government enhance its capabilities to track and report progress on Alzheimer's disease and related dementias?

B. What metrics should be monitored to evaluate the effectiveness of the National Plan on Alzheimer's disease and related dementias?

Goal 5: Accelerate Action to Promote Healthy Aging and Reduce Risk Factors for Alzheimer's Disease and Related Dementias

A. What are the emerging research priorities that need to be explored to better understand the risk factors for Alzheimer's and related dementias, and how can funding be directed to support these priorities?

B. How can we effectively translate recent research findings on risk reduction into practical, actionable guidelines for clinical practice?

C. What specific public health actions can be accelerated to address known risk factors for Alzheimer's disease and related dementias?

D. How can the aging network be expanded to include interventions that reduce risk factors, manage chronic conditions, and enhance overall well-being among the elderly?

E. What steps can be taken to identify and address the inequities in risk factors for Alzheimer's disease and related dementias among marginalized populations?

F. What are the most effective ways to engage the public in understanding and implementing lifestyle changes that could reduce their risk of developing Alzheimer's disease and related dementias?

Additional Areas from the Statute to be Addressed:

Trends in Service Needs
- The state's policies regarding individuals with ADRD?
- The fiscal impacts of ADRD on publicly funded health care programs?

Existing Resources for Diagnosing and Caring for Individuals with ADRD
- State-supported research on ADRD at state universities.

Policies and Strategies
- Evaluate the capacity of the health care system to deal with ADRD.
- Address legal barriers and protections for individuals with ADRD.
- Improve the ways government formulates policies for people with ADRD.

Summary of meeting and Rubric for Subcommittees
Informal Providers Subcommittee

The informal providers subcommittee met on May 3rd. We discussed the rubric and added text for consideration by the advisory council. Our contributions are listed below.

Attending: Dr. Lakelyn Eichenberger, Jean Holt, Diane Hendricks, and Julie Masters. David Thompson attended for the larger council.

Our next meeting will be June 7, 11 am, via Zoom.

Goal 1: Enhance Care Quality and Efficiency

A. What specific training programs can be developed or expanded to equip healthcare providers with the skills necessary to offer high-quality care to individuals with dementia?

B. How can we streamline the process for diagnosing Alzheimer's disease to ensure it is both timely and accurate? Public health component to encourage people to seek a diagnosis. Starting with PCP – initial questions. Who to refer to – Does the PCP provider know/understand the diagnosis? Can they ask for assistance in locating a provider to assist with diagnosis. Mini-Cog. Under 65 would present to his or her provider. Public Education – the benefits of diagnosis and to R/O other causes.

C. What types of educational programs and support systems can be implemented immediately following a diagnosis to help individuals with dementia and their families manage the disease more effectively?

   Health care systems – statewide – do they have a person who is educated on the disease and resources – what education/information/resources do they have available. Does the health system have a pchm – Public Health and health systems – AAAs and behavioral network – AAAs host the ADRCs. Brain Injury Alliance.

   Does there need to be a person with advanced training in dementia within each AAA? Community Resource Navigator.

   Caregiver education for families. How can we elevate programming? Techniques to better care.

Personal/hands-on care – training on care, providing ADLs, safety, how to provide a bath to someone who has a few of water – mechanics of how to do this for someone with dementia.

D. How can we identify and disseminate high-quality dementia care guidelines that are applicable across diverse care settings?

Personal/hands-on care – training on care, providing ADLs, safety, how to provide a bath to someone who has a few of water – mechanics of how to do this for someone with dementia.

E. What are the most promising new models of care for dementia, and how can we test their effectiveness on a larger scale?

F. What are the best practices for ensuring safe and effective care transitions for people with dementia between different care settings and systems?

Caregiver is acknowledged as an important stakeholder in the transition process. Voice of the caregiver is valued at each step of the journey – special colored lanyard for person with dementia in health system – and also to identify caregiver.

Age (dementia) Friendly Health Systems – who are aware of the issues with dementia – emergency room, inpatient care. How to create the environment.

G. How can we better coordinate and integrate health and long-term services to support individuals living with dementia?

Caregiver is acknowledged as an important stakeholder in the transition process. Voice of the caregiver is valued at each step of the journey – special colored lanyard for person with dementia in health system – and also to identify caregiver.

H. <mark>What targeted interventions can be developed to improve care for populations disproportionately affected by Alzheimer's and related dementias?</mark>

Refugees who are 40 to 60. The need for services that might be language specific. Karen population. Intercultural Senior Center -Color Room. Trusted resources – for Latino/Latina and Black communities. Church/Faith communities. Parish nurses.

Materials are at least bi-lingual.

Is there an opportunity to partner with packing plants, etc. Working with Human Resources.

What did we learn during COVID and the vaccines.

Goal 2: <mark>Expand Supports for People with Alzheimer's Disease and Related Dementias and Their Families</mark>

A. How can we ensure that all dementia education, training, and support materials are culturally and linguistically appropriate for diverse communities?

    Refugees who are 40 to 60. The need for services that might be language specific. Karen population. Intercultural Senior Center -Color Room. Trusted resources – for Latino/Latina and Black communities. Church/Faith communities. Parish nurses.

    Materials are at least bi-lingual.

B. What programs or resources can be developed to help family caregivers continue to provide care while also maintaining their own health and well-being?

Health care systems – statewide – do they have a person who is educated on the disease and resources – what education/information/resources do they have available. Does the health system have a pchm – Public Health and health systems – AAAs and behavioral network – AAAs host the ADRCs. Brain Injury Alliance

Caregiver education for families. How can we elevate programming? Techniques to better care.   Supporting people at the PCP level

Personal/hands-on care – training on care, providing ADLs, safety, how to provide a bath to someone who has a few of water – mechanics of how to do this for someone with dementia.

Need to understand more about AFHS across the state.

C. What tools and resources can be provided to families to assist them in planning for future care needs of their loved ones with dementia?

Community Resource Navigators incorporated into the AAAs. Checklists, printed materials for family caregivers.

Tax credit for caregivers https://states.aarp.org/nebraska/nebraska-governor-signs-caregiver-tax-credit-act-into-law

Trualta – free online caregiver support portal – covers all kinds of caregiving. Also offers one on one coaching. Modules are brief. Subscription based.

D. How can we ensure that the dignity, safety, and rights of people with dementia are maintained in all settings and circumstances?

Are there ways that families can inform others of a diagnosis? Years ago, a caregiver created a business card to hand to wait staff at restaurants asking them to be patient with his wife. Are there other ways to be supportive?

E. What mechanisms can be put in place to assess and address the long-term services and supports needs of people with Alzheimer's and related dementias?

How is the LTC Ombudsman's office involved in this plan? Especially for memory support units?

Goal 3: Enhance Public Awareness and Engagement

A. <mark>What innovative strategies can be employed to educate the public about Alzheimer's disease and related dementias?</mark> Examine all opportunities for informal care givers and share these with the public (many health systems use a variety of platforms to get their information and education. -We cannot endorse any program or entity offering education but should provide a listing (The offered program Trualta via Aging Partners is very good) which in my opinion is quite robust!

B. How can we improve coordination between state, tribal, and local governments to advance awareness and readiness for Alzheimer's disease and related dementias?

C. In what ways can the United States coordinate its efforts with the global community to address Alzheimer's disease and related dementias?

Goal 4: Improve Data to Track Progress

A. How can the federal government enhance its capabilities to track and report progress on Alzheimer's disease and related dementias?

B. What metrics should be monitored to evaluate the effectiveness of the National Plan on Alzheimer's disease and related dementias?

Goal 5: Accelerate Action to Promote Healthy Aging and Reduce Risk Factors for Alzheimer's Disease and Related Dementias

A. What are the emerging research priorities that need to be explored to better understand the risk factors for Alzheimer's and related dementias, and how can funding be directed to support these priorities?

B. How can we effectively translate recent research findings on risk reduction into practical, actionable guidelines for clinical practice?

C. What specific public health actions can be accelerated to address known risk factors for Alzheimer's disease and related dementias?

D. How can the aging network be expanded to include interventions that reduce risk factors, manage chronic conditions, and enhance overall well-being among the elderly? Consider the efforts of programs such as the GWEP that is National, Age Friendly health systems, etc. working on the 4-5 M's, training the work force to meet the needs of older adults.

E. What steps can be taken to identify and address the inequities in risk factors for Alzheimer's disease and related dementias among marginalized populations?

F. <mark>What are the most effective ways to engage the public in understanding and implementing lifestyle changes that could reduce their risk of developing Alzheimer's disease and related dementias?</mark>
State Public Health initiatives offered throughout the State i.e. Public Health Dept, BHECN, Regions for MH, and AAA all working together.

Additional Areas from the Statute to be Addressed:

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- The state's policies regarding individuals with ADRD?
- The fiscal impacts of ADRD on publicly funded health care programs?

Existing Resources for Diagnosing and Caring for Individuals with ADRD
- State-supported research on ADRD at state universities.

Policies and Strategies
- Evaluate the capacity of the health care system to deal with ADRD.
- Address legal barriers and protections for individuals with ADRD.
- Improve the ways government formulates policies for people with ADRD.

Alzheimer Disease and Other Dementia advisory Council Community Subcommittee

Zoom Meeting

Date: May 3, 2024

Subcommittee members Attendees:

Mary Ann Stallings
Gayleen Bradley
Karla Frese
Mike Osberg
Cheryl Brown
Caroline Padilla
David Thompson joined at the end of the meeting

Rubric was discussed.

1A. Specific training program developed or expanded…
    a) Types of certifications were noted.
    b) Teepa Snow's programs in both Spanish & English.
    c) Possible to give employees CEU's for taking different programs?
    d) Best Friends Approach
    e) Alzheimer's Society detailed s a model

1C. Educational programs and support
    a) Rooms of Color
    b) Renaming Alzheimer's/Dementia to Type 3 Diabetes
    c) Educational health care on all levels

The committee discussed the Rubric but felt most of the Goals were over their pay grade and level of expertise.