State Unit on Aging
Alzheimer's Disease and Other Dementia Advisory Council Meeting
Friday, May 17, 2024

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

Voting Members Present: Nick Faustman, Christopher Kelly, Tracy Lichti, Julie Masters, Kierstin Reed, Corie Sass, Mary Ann Stallings, David Thompson
Voting Members Absent: John Croghan, Julie Kaminski, Lisa Marks
Non-Voting Members Present: Penny Clark, Josie Rodriguez
Non-Voting Members Absent: Kathy Scheele, Timothy Tesmer
Council Staff Present: Joni Dulaney

This meeting was held in person at the Jack J. Huck Continuing Education Center in Lincoln. A link was provided for members of the public to attend virtually. The meeting was called to order at 10:03 a.m. by David Thompson, Council Chair. Roll call was made through member introductions.

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.

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 April 19, 2024, meeting minutes was made by Julie Masters and seconded by Chris Kelly. No corrections were requested to the minutes.

A roll call vote was taken: Yes – 8; No – 0; Abstain – 0.

State Plan

David led the discussion on the List of Topics document he created to guide the writing of the (State Plan) report. This document was based on the outlines distributed previously, the subcommittee reports, the Education subcommittee survey report, the national plan, and state statute. The list includes 20 topics. Before further discussion on the topics, David suggested the following as a timeline for completing the report:

June: David will write his draft introduction and present this at the June meeting.

Council members will collaborate with others as needed as they draft the section of the report specific to their selected topics. The drafts of these sections will be shared at this meeting.

Review the List of Topics to see if there are areas that need additional work or that have not been addressed.

After the meeting, David will pull the subcommittee reports into one draft with his introduction. The draft will be emailed to Council members to read and be prepared to provide feedback at the July meeting.

July: Discuss the draft report and Council member feedback.

Members should bring a list of stakeholders who should review the draft report to provide input.

July-August: Letters will go to stakeholders to let them know to expect a copy of the draft report for review and input.

August: David will combine the section drafts and his introduction to create a draft of the entire report to present at the August meeting.

An additional Council meeting may be added for members to review any revisions made to the draft report before it is sent to stakeholders.

Draft report is sent to stakeholders.

September: Stakeholder input is due.

Council discusses stakeholder feedback and provides recommendations on inclusion of the feedback into the report.

October: The final draft report is submitted to DHHS. DHHS will work through Joni to request any changes to the report before submitting to the Legislature and Governor.

December: DHHS submits the final report to the Legislature and Governor by December 31.

A request was made to create a master rubric, color coded for each subcommittee, to show the information that has been gathered so far to see where there is overlap and what areas still need to be addressed. Joni Dulaney shared the Council shared space webpage to members to determine whether this would provide the information that was asked about in the master rubric. Council and subcommittee members who want access to the shared space must first complete a confidentiality statement. This was emailed out to members and will be sent again after the meeting. These should be completed and returned to Joni as soon as possible.

Council members reviewed the List of Topics and volunteered to write the following sections:

Understanding Dementia – Nick
Impacts on the Healthcare System – Chris
Models of Care – Julie M.
Facility-Based Care – Corie
Caregivers – Julie M.
Reaching Underserved Communities – Tracy
Rural Communities – Tracy & Mary Ann
Families – Julie M.
Home Care – Julie K.
Respite and Adult Day Care – Mary Ann & Tracy
Role of Organizations – Nick & Julie M.
Workforce Development – Chris
Safety – John & David
First Responders – Chris
Behaviors (Out-of-Character Responses) – Corie
Brain Health – Nick
Co-Occurring Disorders – Kierstin
Legal – David
Data – Julie K. & Kierstin
Policy – Kierstin & Nick

Council members will reach out to other Council and/or subcommittee members for additional information while writing their sections. The report will include the overall goals, recommendations, and findings which will be detailed in each section.

Subcommittee Reports

Copies of the subcommittee reports were included in the meeting materials emailed to members prior to the meeting and posted on the Council webpage with the agenda. Due to time constraints, oral reports were not presented.

LB903

LB903, which changed the length of member initial terms, was signed into law by the Governor. Members volunteered to serve either a two-year, three-year, or four-year initial term to meet the statute change to 1/3 of members serving in each of these terms.

2-Year Term: Julie Kaminski, Lisa Marks, Julie Masters, Mary Ann Stallings
3-Year Term: Tracy Lichti, Kierstin Reed, Corie Sass, Vacant Family Caregiver
4-Year Term: John Croghan, Nick Faustman, Chris Kelly, David Thompson

Two-year terms end December 15, 2024. Those members who are interested in applying for reappointment will apply on the Governor's webpage as they did for their original appointment. Three-year term members can apply for reappointment in 2025. Anyone who is reappointed would serve a four-year term after their initial term of two, three, or four years.

Meeting Calendar

Members agreed that the August 16, 2024, meeting will be an in-person meeting instead of virtual. Joni will inquire about using the Jack J. Huck Continuing Education Center. Meeting invitations will be sent to members with the location to make this change on their calendars.

Adjourn

Mary Ann Stallings made a motion to adjourn the meeting. Nick Faustman seconded. The meeting adjourned at 11:58 a.m.

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 – Nick
    a. Different types (Alzheimer’s, Lewy Body, Frontotemporal, 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 – Chris
    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 – Julie M.
    a. Need for more care navigators
    b. Models of care, more cooperation
    c. More individualized care plans, better and more accessible cognitive assessments
    d. Understanding the continuum of care

4. Facility-Based Care – Corie
    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 – Julie M.
    a. Training for unpaid and paid caregivers
    b. Economic impact of caregiving on families
    c. Resources (support groups, etc.)

6. Reaching Underserved Communities – Tracy
    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 – Tracy & Mary Ann
    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 – Julie M.
    a. Role as caregivers
    b. Educational resources
    c. Family dynamics and mediation
    d. Demographic issues such as "sandwich" generation

9. Home Care – Julie K.
    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 – Mary Ann & Tracy
    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 – Nick & Julie M.
    a. Area Agencies 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 – Chris
    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 – John & David
    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 – Chris
    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 ED visits
15. Behaviors (Out-of-Character Responses) – Corie
    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 – Nick
    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 – Kierstin
    a. Mental Illness
    b. Substance abuse
    c. Intellectual disabilities
    d. Finding right model of care depending on combination of disorders

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

19. Data – Julie K. & Kierstin
    a. Current data-gathering
    b. Central repository
    c. Increased tracking

20. Policy – Kierstin & Nick
    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)

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. Project ECHO - 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

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.

A. 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
-

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

   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: Expand Supports for People with Alzheimer’s Disease and Related Dementias and Their Families

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

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:

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.

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.

Role of Government, Quasi-Government Subcommittee

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

Role of Government, Quasi-Government Rubric

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

C. 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

D. 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?

C. 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

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.