

Good Life. Great Mission.

DEPT. OF HEALTH AND HUMAN SERVICES



October 1, 2025

The Honorable Jim Pillen Governor of Nebraska P.O. Box 94848 Lincoln, NE 68509

Mr. Brandon Metzler Clerk of the Legislature P.O. Box 94604 Lincoln, NE 68509

Subject: Annual Report on the Implementation of the State Alzheimer's Plan

Dear Governor Pillen and Mr. Metzler:

On behalf of the Alzheimer's Disease and Other Dementias Advisory Council, I am pleased to submit the Annual Update Report of the Nebraska State Alzheimer's Plan. This year, the Advisory Council has worked diligently to assess the needs of Nebraskans impacted by Alzheimer's disease and other dementias and has developed thoughtful, data-informed actions to enhance services, supports, and care for individuals, families, and caregivers across the state.

This annual update reflects extensive collaboration among stakeholders, including the State Unit on Aging and partners across the Nebraska Department of Health and Human Services. We look forward to working with the Legislature and other key partners to continue implementing strategies that strengthen Nebraska's response to the growing challenges posed by Alzheimer's and other dementias.

Sincerely.

Tony Green

Director, Division of Developmental Disabilities

Annual Update Report of the Nebraska State Alzheimer's Plan

Presented by the Alzheimer's Disease and Other Dementia Advisory Council

October 1, 2025

This update is written to provide insight into the continuing work of the Alzheimer's Disease and Other Dementia Advisory Council.

The Council reviewed the recommendations made in the <u>State Alzheimer's Plan</u>, submitted to the Clerk of the Legislature in March 2025, and narrowed the recommendations to their top five priorities to address in this first update report. Five subcommittees were formed, each focusing on one of the following recommendations:

Increase Support for Caregivers

• Explore the feasibility of implementing Trualta or other on-line caregiver support platforms and make access free to all Nebraska residents. The fiscal cost for this recommendation is \$132,000 to \$180,000 annually.

Provide Care Navigation Through Area Agencies on Aging (AAA)

Create a two-year dementia care navigator pilot project within the Eastern Nebraska
 Office on Aging that serves both urban and rural caregivers/care partners. The projected fiscal expenditure for this recommendation is \$100,000 per year.

Increase Access for Rural and Underserved Communities

Engage with local hospitals, nonprofits, and support groups to create a
comprehensive directory of services available for individuals with dementia.
 Implement targeted outreach by churches, doctor's offices, etc., to raise awareness
about dementia within rural and ethnic communities.

Increase Availability and Quality of Facility-Based Care

 The state should strongly consider increasing the reimbursement rate for memory care, which would increase availability for Alzheimer's Disease and Related Dementias (ADRD) individuals as identified in the "Rate Study for AD Waiver, TBI Waiver and PAS Services" (updated September 2023).

Increase Public Awareness and Education

• Establish partnerships with public health departments and the AAAs to develop awareness and education campaigns focused on brain health for individuals of all ages, with a specific focus on individuals in Nebraska's underserved communities.

Each subcommittee brought together a broad group of dementia experts. This ensured that we were getting the clearest picture of the newest findings, barriers to dementia care and services, and recommendations for next steps to be taken.

Several subcommittees invited guest speakers to inform and educate members on topics that align with the focus of their subcommittees. The Council requested guest speakers to present on their organizations to increase our overall knowledge of the current trends and resources. We appreciate Angel Horton Frank and Sadie Hinkel from the Alzheimer's Association Nebraska Chapter, Karen Houseman from the Nebraska Department of Health and Human Services Division of Developmental Disabilities, and Lindsay Paulson and Karen Heng from United Way of the Midlands 211 for sharing their insights with us.

Each subcommittee has provided an update on their findings and proposed next steps for consideration. These updates are provided on the following pages. A list of Council members follows these reports.

The Alzheimer's Association's Alzheimer's Impact Movement released the statistics for each state for 2025. The one-pager for Nebraska has been added as the last page of this report. These sobering numbers reflect the prevalence of the disease in Nebraska and the caregiving and health care impacts and reinforce the importance of the Council's efforts to further the coordinated approach to addressing Alzheimer's disease and other dementia in Nebraska, as required in state statute.

The Council's next steps will be to continue work on some of the current subcommittees and to prioritize and begin work on additional recommendations from the State Alzheimer's Plan. An updated report on these recommendations will be presented in October 2026.

Increase Support for Caregivers – Trualta Feasibility Subcommittee Report

Subcommittee Status:

The Trualta subcommittee has met three times to discuss Trualta, an online caregiver support platform, along with other products available to help caregivers. Our goal is to find and recommend a product that can support caregivers across Nebraska 24/7/365. We are examining existing products including Trualta and GetSetUp.

New Findings:

The Trualta product was demonstrated for us at our July meeting. The online product is flexible and is available for caregivers supporting people of all ages. In addition to dementia and Alzheimer's, their options cover many topics and life events. This could benefit other agencies across the DHHS landscape. The product is available 24/7/365 online and has options for those who may need support via phone. Training is also available to professional caregivers interested in learning more about managing various behaviors. The program is available in English and Spanish.

GetSetUp is a product currently offered by the Nebraska State Unit on Aging. The focus is to promote healthy living through educational programming that also includes caregiver support. Caregiving programming topics include mindfulness, long-term care, and end-of-life. There is also a program on dementia.

Barriers:

Web-based programming can limit access for people with reduced or no access.

Suggestions for Next Steps:

- The subcommittee continues to identify other products that would be of benefit to caregivers.
- After reviewing the products, identify the top one or two for consideration by the Legislature for supporting Alzheimer's and other dementia caregivers.

Subcommittee Members:

- Jenny Erb, BS, Long Term Care Supervisor, Northeast Nebraska Area Agency on Aging
- Michele Magner, MBA, CDP, Founder & CEO, Inspired Caring
- Cecilia Poon, PhD, ABPP, Licensed Psychologist, Board Certified Geropsychologist, Nebraska Medicine
- Kay Wenzl, MPA, Assistant Director, Aging Partners

- Julie Masters, PhD, Professor UNO Department of Gerontology, Subcommittee Facilitator
- Josie Rodriguez, MSHCA, Administrator II, DHHS Division of Developmental Disabilities

Provide Care Navigation Through Area Agencies on Aging (AAA) – Pilot Care Navigator Subcommittee Report

Subcommittee Status:

The Pilot Care Navigator Subcommittee has met three times to discuss the function of the subcommittee and how this pilot can benefit family caregivers.

New Findings:

Dementia Care Navigator positions exist across the country (e.g., Tennessee). People serve in various roles such as care managers, care navigators, and community navigators. Gaining a better understanding of what each role entails is a priority of this subcommittee.

The definition of the care navigator should be based on a state standard to ensure continuity of the title and role across Nebraska.

The group has identified another population of caregivers not addressed in the State Plan but in need of acknowledgment – the early/young onset caregiver group. These are people under the age of 60 who may still be caring for children at home. Their care needs and the response of the care navigator will be different and require further understanding.

Various assessments are used by Primary Care Providers (PCPs) along with geriatricians. The group is working to identify assessments that can be included as part of the references document being explored by the Centralized Resource Repository subcommittee.

Barriers:

When to contact a care navigator is difficult for the caregiver to determine. A caregiving ladder (flowchart/timeline) might be of use to understand when caregivers can engage with a navigator.

Suggestions for Next Steps:

- Continue to flesh out the role of the care navigator (and even the name) to ensure the efforts are consistent with the needs of caregivers.
- The group noted GUIDE (Guiding an Improved Dementia Experience) Model which is provided to people on original Medicare (not available to people on Medicare Advantage).
- Further review of this offering along with RIPPL (dementia care on demand) to support caregivers in Nebraska.
- Continue to identify groups that would benefit from a care navigator (young-onset, persons from underserved groups).

Subcommittee Members:

- Trish Bergman, Executive Director, Eastern Nebraska Office on Aging
- Melanie Haynes-McCurry, Director, Franciscan Day Center
- Diane Hendricks, LCSW, Nebraska Medicine
- Sadie Hinkel, Program Director, Alzheimer's Association Nebraska Chapter
- Montanna Walling, BS, Case Management Division Director, Eastern Nebraska Office on Aging

- Julie Masters, PhD, Professor UNO Department of Gerontology, Subcommittee Facilitator
- Kierstin Reed, MPA, MSW, President & CEO, LeadingAge Nebraska

Increase Access for Rural and Underserved Communities – Centralized Resource Repository Subcommittee Report

Subcommittee Status:

The Centralized Resource Repository Subcommittee met to discuss creating a comprehensive directory of dementia-related community resources and options for a centralized location to house resources. The goal is to make resources more easily accessible to individuals with dementia and their caregivers.

Recommendations:

The subcommittee recommends using 211 Nebraska as the centralized digital repository for dementia-related services, resources, and caregiver support across the state. 211's infrastructure already includes:

- A regularly updated, statewide database of services.
- A 24/7 live call center and accessible website.
- Categorization options that *could* include a dedicated Alzheimer's Disease and Related Dementias (ADRD) section.
- Annual update protocols and partnerships with state agencies and providers.
- An existing program that would avoid the need to build a new system and allows for a living, dynamic platform to serve residents and providers statewide.

Barriers:

- Awareness Gap: Many providers, caregivers, and residents are unaware of 211 as a resource.
- Promotion Strategy: A marketing and outreach plan is needed to elevate 211's visibility statewide, especially in clinical, provider, and discharge settings.
- Customization Needs: Building out an ADRD-specific section on 211 will require collaboration and coordination to ensure content is accurate, helpful, and relevant.
- Submission and Vetting: While 211 has a submission process, not all providers may be comfortable or familiar with how to get listed or maintain their listing.

Suggestions for Next Steps:

- 1. Stakeholder Engagement: Encourage ADRD stakeholders and service providers statewide to explore 211 and consider submitting or updating their information.
- 2. Evaluate Inclusion Policies: Collaborate with 211 to determine the best structure and criteria for listing dementia-specific and caregiver support resources.

3. Develop Promotion Strategy: A future workgroup may focus on increasing 211 visibilities through nonprofit media requirements and partner channels.

Subcommittee Members:

- Dr. Gary Anthone, Chief Medical Officer, Vetter Health Services
- Sawyer Boddy, LNHA, Administrator, Brookefield Park
- Mindy Crouch, LCSW, LIMHP, LISW, Pando Geriatric Counseling
- Diane Hendricks, LCSW, Nebraska Medicine
- Karen Heng, 211 Project Director, United Way of the Midlands
- Dr. Natalie Manley, Associate Professor UNMC Division of Geriatrics, Gerontology and Palliative Medicine

- John Croghan, Vice President, Immanuel Community Operations, Immanuel, Subcommittee Facilitator
- Lisa Marks, Director, Guardian Angels Homecare
- Terri Ridder, PHR, SHRM-CP, Human Resources Director, Franciscan Healthcare
- Corie Sass, LCSW, LMHP, CDP, Director of Social Work, Vetter Health Services
- Mary Ann Stallings, President & CEO, Bridge to Better Living

Increase Availability and Quality of Facility-Based Care – Medicaid Memory Care Rate Subcommittee Report

Subcommittee Status:

The Medicaid Memory Care Rate Subcommittee has met three times to discuss the current availability of Medicaid memory care beds and the current rate for these services across Nebraska.

New Findings:

The group began by discussing the history and current standing of Medicaid rates for assisted living services in Nebraska. In the 109th Legislature First Session, LB261 (2025) was passed to equalize the Medicaid assisted living rate for both urban and rural settings at a rate of \$73.91 per day. This was the previous rate for urban settings and an increase for rural settings. This funding is only allocated for FY25-26. Nebraska currently does not have a differential for memory care services in assisted living. The committee also discussed the CBIZ Optumas Rate Study released in December 2022, as well as the supplemental document indicating a draft rate for memory care under Medicaid waiver at a rate of \$168.90 per day.

The State maintains a roster of assisted living facilities that indicates if they have a Memory Care Endorsement or an Alzheimer's Unit. The roster also indicates the number of beds at the facility and if they accept the Aged and Disabled Medicaid Waiver. Based on the roster, there is a lack of understanding about the actual availability of memory care services for those with memory care who have Medicaid Waiver as a payor source.

The committee completed research by contacting assisted living providers that indicated they have a Memory Care Endorsement or Alzheimer's Care Unit and also accept Medicaid. Of the 45 providers, 34 (78%) responded to our phone survey. They reported a total of 722 memory care beds available across Nebraska. These providers are in 18 cities across Nebraska.

The surveyed respondents indicated 102 of their 722 beds (14%) would be available to a resident on Medicaid Waiver. In addition, the majority of those required a period of private pay ranging from one to three years before accepting Medicaid Waiver. A total of 19 beds would accept a Medicaid Waiver recipient on day one of care.

It was also determined that the average monthly cost for memory care in assisted living is \$6,624 per month with the highest being \$8,875 per month. Medicaid Waiver currently reimburses at a rate of \$3,140 monthly, including the room and board portion (\$892) paid by the recipient of services.

Barriers:

The Medicaid reimbursement for memory care services at the assisted living level is severely impacting the ability of providers to accept those on Medicaid Waiver into these services. There is a lack of reputable information regarding the number of available memory care beds in the state based on the roster of services.

Suggestions for Next Steps:

- 1. Implement the recommended rates as determined by the CBIZ Optumas Rate Study, with an inflation factor for the respective years since this study.
- 2. Collaborate with DHHS to determine the number of people who may require memory care in assisted living who are currently on the Medicaid waiver based on data gathered during the Medicaid Waiver intake process. This will assist in determining the number of people needing service in Nebraska.
- 3. Gather stories from those with dementia and their families who are seeking this level of care and support for loved ones about the burden they have experienced in attempting to locate care and the impact it has had on them.
- 4. Continue to evaluate the capacity among assisted living providers to support those with memory care needs as well as evaluate those being served in a higher level of care who could be served at a lower level if there were a memory care rate.

Subcommittee Members:

- Gayleen Bradley, Administrator, Orchard Park
- Alex DeGarmo, Director of Public Policy, Alzheimer's Association Nebraska Chapter
- Jeanette Denson, Executive Director, Custer Care Center
- Karla Freese, Owner, Home Care Partners
- Christi Johnson, Owner, Caring for People Home Care
- Lois Jordan, RN, NHA, President & CEO, Midwest Geriatrics, Inc.
- Cindy Kadavy, Senior Vice President of Policy, Nebraska Health Care Association
- Jami Kampschneider, RN, Director of Nursing, Genoa Medical Center
- Bob Tank, NHA, Administrator, Bethany Home
- Lorie Thomas, LICSW, Manager of Emergency Services, Region 6 Behavioral Health
- DeDe Will, Chief Financial Officer, Douglas County Health Center

- Kierstin Reed, MSW, MPA, President & CEO, LeadingAge Nebraska, Subcommittee Facilitator
- John Croghan, Vice President, Immanuel Community Operations, Immanuel

- Julie Kaminski, MGS, NHA, Chief Operating Officer, Immanuel
- Tracy Lichti, President & CEO, New Cassle Retirement Center
- David M. Thompson, Elder Law Attorney, Burnett Legal Group

Increase Public Awareness and Education – Public Health Subcommittee Report

Subcommittee Status:

The Public Health Subcommittee has met three times to discuss how the Alzheimer's Advisory Council can partner with public health departments across the state (or build upon existing partnerships).

New Findings:

The Alzheimer's Association Nebraska Chapter, partnering with public health departments in the panhandle counties, successfully launched training for people with dementia and their caregivers under the Healthy Brain Initiative. This collaboration led to the establishment of the Panhandle Dementia Coalition.

Next year, an opportunity exists to replicate this model in the tri-cities (Grand Island, Hastings, and Kearney) area. Dr. Cassandra Wehling (UNMC Geriatrics) is organizing a dementia training program for physicians on March 18-19, 2026, at UNK's Regional Engagement Center. As a subcommittee, we discussed partnering with county public health departments and the South Central Area Agency on Aging at this event.

Other scheduled opportunities to engage public health departments include the Alzheimer's Foundation Tour (September 17, 2025 at Bellevue University) and the next meeting of the Panhandle Dementia Coalition in Spring 2026.

Barriers:

While members of the subcommittee and the coalition (individually and collectively) have made inroads in terms of engaging public health departments in Nebraska, there are still many gaps, particularly in underserved areas of Nebraska.

Suggestions for Next Steps:

Our experience, in this and in previous and similar efforts, suggests that it is not enough to offer remote supports, such as trainings. Where we have had success is where we have put "boots on the ground" and met local partners in person. The efforts of the Alzheimer's Association Nebraska Chapter (and Sadie Hinkel, in particular) in the panhandle provides a model for us to use elsewhere.

In addition to the tri-cities, which have great potential for success due to well-developed healthcare infrastructure, we also need to consider areas in Nebraska with greater need, because the shortage of care providers and workers is growing. One example is the area

served by the Northeast Nebraska Area Agency on Aging, a service area that stretches from the Missouri River to Cherry County.

Subcommittee Members:

- Dr. Anna Fisher, CADDCT, CDP, CMDCP, CDSGD, QCP, Bellevue University
- Sadie Hinkel, Program Director, Alzheimer's Association Nebraska Chapter
- KoriAnne Moslander, Doctoral Student, UNO Department of Gerontology
- Dr. Cassandra Wehling, Internal Medicine Geriatrics, Nebraska Medicine
- Sarah Wilson, Administrator, Omaha Supportive Living

- Dr. Christopher Kelly, Professor & Chair UNO Department of Gerontology, Subcommittee Facilitator
- Julie Kaminski, Chief Operating Officer, Immanuel
- Tracy Lichti, President & CEO, New Cassel Retirement Center

Alzheimer's Disease and Other Dementia Advisory Council Members

John Croghan

Voting member representing: Assisted living facilities

Dr. Christopher (Chris) M. Kelly

Voting member representing:

An individual who conducts research regarding Alzheimer's disease or other dementia

Tracy Lichti

Voting member representing: Provider of adult day care services

Lisa Marks

Voting member representing: Home care providers

Dr. Julie Masters

Voting member representing: Area Agency on Aging

Julie Paladino-Kaminski

Voting member representing: Nursing homes

Kierstin Reed

Voting member representing:
Organization that advocates for older adults

Terri Ridder

Nonvoting member representing: Nebraska Workforce Development Board

Josie Rodriguez

Nonvoting member representing: State Unit on Aging

Corie Sass

Voting member representing: Medical professional with experience diagnosing and treating Alzheimer's disease

Odessa Schoneberg

Nonvoting member representing: State Long-Term Care Ombudsman

Mary Ann Stallings

Voting member representing: Individual with experience/expertise in the needs of individuals with intellectual/ developmental disabilities and Alzheimer's

Dr. Timothy Tesmer

Nonvoting member representing: DHHS Division of Public Health

David M. Thompson

Voting member representing: Individual living with or family member of individual living with Alzheimer's disease or other dementia

VACANT

Voting member representing: Family caregiver

VACANT

Voting member representing: Leading, nationwide organization that advocates for individuals living with Alzheimer's/dementia

VACANT

Nonvoting member representing: Medicaid & Long-Term Care

Joni S. Dulaney

Council Staff, DHHS Division of Developmental Disabilities

2025 NEBRASKA

ALZHEIMER'S STATISTICS



PREVALENCE

Number of People Aged 65 and Older with Alzheimer's (2020)

35,100

% of Adults Over 65 with Alzheimer's

11.0%

WORKFORCE

of Geriatricians in 2021

27

Increase Needed to Meet 2050 Demand

137.0%

of Home Health and Personal Care Aides in 2022

10,120

Increase Needed to Meet 2032 Demand

22.1%

CAREGIVING

of Caregivers

41,000

Total Hours of Unpaid Care

63M

Total Value of Unpaid Care

\$1.5B

Caregivers with Chronic Health Conditions

57.6%

Caregivers with Depression

25.4%

Caregivers in Poor Physical Health

13.2%

HEALTH CARE

of People in Hospice (2017) with a Primary Diagnosis of Dementia

1,648

Hospice Residents with a Primary Diagnosis of Dementia

18%

of Emergency Department Visits per 1,000 People with Dementia (2018)

1,154

Dementia Patient Hospital Readmission Rate (2018)

18.7%

Medicaid Costs of Caring for People with Alzheimer's (2025)

\$446M

Per Capita Medicare Spending on People with Dementia in 2024 Dollars

\$26,251

More than 7 million

Americans are living
with Alzheimer's,
and nearly 12 million
provide their unpaid
care. The cost of
caring for those
with Alzheimer's
and other dementias
is estimated to total
\$384 billion in 2025,
increasing to nearly

(in today's dollars)
by mid-century.
For more
information, view
the 2025 Alzheimer's
Disease Facts and
Figures report at
alz.org/facts.

\$1 trillion



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MORTALITY

of Deaths from Alzheimer's Disease (2022) Alzheimer's Disease as Cause of Death Rank

746

7th