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The Nebraska State Plan for Alzheimer's Disease and Other Dementia

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by

The Alzheimer's Disease and
Other Dementia Advisory Council

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Executive Summary

In December 2022, Governor Pete Ricketts signed into law the Alzheimer's Disease and Other Dementia Support Act (Neb Rev. Stat. § 71-561 to 71-567). This important piece of legislation acknowledged that Alzheimer's Disease and other forms of dementia are of "significant concern" to the state of Nebraska, and that "the state would benefit from a more coordinated approach to address Alzheimer's Disease and other dementia." (Please note that while the title of the statute and most discussions among health care providers and others use "Alzheimer's Disease" as an umbrella term and "other dementia" as a catch-all for other types, the advisory council has chosen to use "dementia" as an umbrella term encompassing all forms of dementia, including Alzheimer's.)

The reason for concern and the need for a state-wide coordinated approach are clear. The prevalence of dementia is increasing as the population of people over 65 increases. The population of Americans aged 65 and older is projected to grow from 58 million in 2022 to 82 million by 2050. There are currently approximately 293,000 people in Nebraska over the age of 65, 17.2% of the state's population, and one in ten of them will suffer dementia. There are currently seventeen counties in Nebraska where 12% or more of the population is living with dementia.

The statute also created the Alzheimer's Disease and Other Dementia Advisory Council. The council was tasked with examining (1) our current understanding of the needs of individuals with Alzheimer's Disease and other dementia, (2) the services currently available in the state for those individuals and their caregivers, and (3) the capacity of health care providers, long-term care facilities, the health care system and other stakeholders to meet future needs.

One of the consequences of people living longer is that more people will live to experience some form of dementia. In Nebraska, over 35,000 people are suffering from dementia, 11% of Nebraskans 65 and older. In 2021, the most recent year for which data has been collected, there were 768 deaths from dementia-related causes in Nebraska. Facts and Figures, p.38) The situation is exacerbated by what is happening at the other end of the demographic spectrum. People are having fewer children. Just as more people are experiencing dementia that requires individualized care, there will be fewer adult children to take care of them. A drop in the number of children that people have will continue to contribute to the availability of support in the future. The "brain drain" that has resulted in so many capable young people leaving the state exacerbates the problem.

Dementia poses unique challenges when compared to other chronic health conditions. First, there are numerous varieties of dementia and a wide range of possible symptoms that make diagnosis difficult. Alzheimer's disease is the most familiar type of dementia, accounting for 60-80% of all cases of dementia, but there is also vascular dementia, fronto-temporal dementia, Lewy-Body Syndrome, and Parkinson's, as discussed in more detail below.) Each type of dementia has its own etiology, progression, and symptoms. Older adults often suffer from some form of mixed dementia or have other, co-occurring conditions (physical and psychological) that make diagnosis still more difficult.

Dementia is not treated with medications and procedures alone. Instead, it requires a continuum of care and services that are personalized. The agonizing, often months-long trajectory from the first appearance of symptoms to the correct diagnosis is partly the result of the lack of capacity in our health care system, such as the lack of specialists able to administer cognitive evaluations and lack of geriatricians, neurologists, home health care workers, nurse practitioners and other providers. It can also be difficult, at all levels, be difficult for any professional along the continuum of care to receive best-practices training in dementia care4e. This is a particular problem in less-populated, rural parts of the state, where the average age of a small community may be in the 50s or 60s.

The Alzheimer's Disease and Other Dementia Support Act directed that an advisory council be formed comprised of individuals representing different roles along the continuum of care, from adult day programs to researchers and advocates, along with community members, representatives of state agencies and non-profit organizations such as the Area Agencies on Aging. This plan builds on the work of the first Nebraska State Plan for Alzheimer's Disease and Other Dementia that was presented to the legislature and governor in June 2016 by the Aging Nebraskans Task Force.

The 2016 state plan was part of a national effort that began with the National Alzheimer's Project Act, signed into law by President Barack Obama in January 2011. The legislation led to the formation of the task force in March 2014. A subcommittee of task force members held four town hall meetings in Alliance, Kearney, Pender and Omaha from August to September 2015. Subsequent input from stakeholders and state agencies led to the finalization of the 2016 plan, which served as the roadmap for the state's efforts until now.

One of the chief recommendations of this plan is that Nebraska's educational institutions convene as a group to implement dementia-specific training in diagnosis and treatments that have only recently come into existence. This implementation committee should also formulate strategies to attract more students to choose dementia care as a profession. We need to increase the number of board-certified geriatricians in the state, but also raise awareness of career opportunities at all levels of dementia care. Over half (53%) of Nebraska's population lives in rural areas and, as discussed below, residents of rural communities often have extra difficulty locating resources of all kinds, particularly the memory care facilities that can care for people with dementia once their families find it impossible to do so on their own.

Another aspect of dementia that makes its impact particularly widespread and impactful is that unlike many other diseases, most of the care for individuals with dementia is provided by family members, especially spouses, or other informal and generally unpaid caregivers. Nearly half of all caregivers providing help to adults over 65 are doing so for someone with dementia. That means approximately 40,000 Nebraskans are dementia caregivers. (Working Caregiver Survey Report.)

The essential role that caregivers/care partners play has broad implications for our society. These caregivers are members of our communities and work at the jobs that keep our economy moving and support our quality of life. Twenty percent of caregivers are over 65 themselves and many of them are dealing with health issues of their own, including conditions such as depression that are directly linked to the burdens of caregiving. The relationship between caregiver and person with dementia has been the subject of much recent research, which has shown that what affects caregivers negatively often has negative ramifications for the people they are caring for.

The costs of dementia are significant and often a burden to families and others providing unpaid care. In 2020, the total costs of healthcare, long-term care, and caregiving for a person with dementia in the last five years of life was $287,000. These costs are significantly higher than caring for someone with heart disease or cancer. This burden falls not Just on families, communities and the health care system, but also on the government benefits programs that provide many people with the financial support they need to pay for their care. In 2023, Nebraska Medicaid spent $411 million paying benefits for people with dementia, more than it spends on most other conditions.

One primary reason for these huge costs is the fact that the majority of individuals with dementia will at some point need to enter some type of long-term care facility—assisted living, nursing home or memory care unit. The average cost of assisted living in Nebraska is $3,785 a month, while the average cost of a nursing home is $6,334 a month. After determining what sort of facility is most appropriate for someone with dementia, the next question is whether that type of facility is even available in any particular area of the state. There are currently 283 assisted living facilities with a total of 13,962 beds, and 192 skilled nursing facilities with a total of 14,829 beds. (Leading Age Assisted Living Services in Nebraska.)

The 2016 plan focused on the themes of (i) information about services and their availability in different part of the state; (ii) support such as education and training for law enforcement, first responders, and other public employees to make our state more “dementia-friendly”; and (iii) safety measures such as emergency alert systems, a central registry tracking the prevalence and available services for people with dementia, and programs that address dementia-specific specific issues such as wandering and hoarding.

Created to serve Nebraskans living with dementia as well as their caregivers, the 2016 plan contains 31 recommended action items. While there was a diverse group of stakeholders involved in formulating the plan, there was no broad plan for implementation. As a result, too many of the problems noted in the 2016 plan have not been adequately addressed. There continue to be unnecessary obstacles to care, inefficiencies, exorbitant costs, and missed opportunities that negatively affect our citizens, communities, and health care system.

This plan is structured in terms of the different impacted constituencies and is meant to provide clear, actionable recommendations to those individuals and entities best situated to make change happen. One of the most challenging aspects of being a caregiver is simply knowing what to do and where to go. “Care navigation,” a key term in this plan, is one of the most important services that the state and organizations such the Area Agencies on Aging (AAAs) can provide. Effective care navigation depends on understanding all the different pieces to the dementia care puzzle and how to move seamlessly from one to the other as their loved one’s needs shift. Responding to the dementia crisis and its impact on families, communities, the healthcare system, and the economy will take a comprehensive, multi-pronged approach. Addressing issues one by one will not solve the problem.

It is appropriate that, in 2024, our state develop a new state plan that builds on the lessons of the last eight years. The landscape of diagnosis, treatment, and caregiver support has changed, largely in positive ways. There are needs for infrastructure, capacity, and workforce development that were not addressed previously because these needs were not yet fully recognized. The

Alzheimer's Disease and Other Dementia Support Act requires that the advisory council address 24 different topics that are grouped under three main headings: (1) "trends in the state's Alzheimer's disease and other dementia population and service needs"; (2) "existing strategies, services, and capacity" regarding these populations," and (3) "policies and strategies" addressing issues ranging from public safety and brain health to workforce development, the cost of care facilities and scientific research.

The advisory council elected not to divide the plan into these categories, but rather to discuss each topic separately, covering the trends, existing resources, and strategies related to that particular topic. This is intended to make the plan easier for specialists across the spectrum of aging services to consult in order to understand how their own area of expertise relates to and depends upon the whole. Moreover, we have provided as many cross-references as possible in order to capture the interrelatedness of all these issues and demonstrate how they can be addressed as a system.

The statute establishing the advisory council requires that periodic status reports on the implementation of the plan be submitted to the legislature and the governor every year and that the plan as a whole be revised every four years. It is the fervent hope of the advisory council that when it comes time to submit the first implementation report at the end of 2025, there will have been substantial progress on many of the issues discussed in this plan. To ensure this progress, the recommendations of the plan that appear at the end of each section include the formation of implementation committees composed of specialists who have the experience and knowledge in this specific field necessary to make change happen.

Part I: Dementia and the Continuum of Care

Section A: Understanding Dementia

Dementia is a general term for loss of memory and other mental abilities severe enough to interfere with daily life. It is caused by physical changes in the brain, including the accumulation of proteins such as myeloid and tau. Patients and families are often confused and frustrated. They may feel that the descriptions of different types of dementia provided to them do not adequately describe what they are going through. It will be helpful for the discussion that follows to have a basic understanding of dementia in its various manifestations. Each type of dementia has its own causes and symptoms. All forms of dementia slowly destroy brain function, leading to cognitive decline (e.g., memory loss, language difficulty, poor executive function), behavioral and psychiatric disorders (e.g., depression, delusions, agitation), and declines in functional status, such as the need for assistance with activities of daily living, particularly when it comes to self-care.

Alzheimer’s Disease

Alzheimer’s disease is the most common cause of dementia, and accounts for 60-80% of dementia cases. In the earliest stages of Alzheimer’s disease—before symptoms can be detected with current tests—plaques and tangles begin to form in brain areas involved in learning, memory, thinking and planning. For more than 90% of people with Alzheimer’s, symptoms do not appear until after age 60, but research suggests that symptoms of Alzheimer’s disease often occur years before an actual diagnosis is made. In rare cases, known as early-onset or younger-onset Alzheimer’s disease, people develop symptoms in their 30s, 40s, or 50s.

Vascular Dementia

Vascular dementia is a decline in thinking skills caused by conditions that block or reduce blood flow to various regions of the brain, depriving them of oxygen and nutrients. In vascular dementia, changes in thinking skills sometimes occur suddenly after a stroke, which blocks major blood vessels in the brain. Thinking difficulties may also begin as mild changes that gradually worsen as a result of multiple minor strokes or other condition that affect smaller blood vessels, leading to widespread damage.

Dementia with Lewy Bodies

Dementia with Lewy Bodies is a type of progressive dementia with features that may include spontaneous changes in attention and alertness, recurrent visual hallucinations, sleep disorder, or bodily rigidity. Alpha-synuclein protein, the chief component of Lewy bodies, is found widely in the brain, but its normal function isn't yet known.

Frontotemporal Dementia or Degeneration

Frontotemporal dementia refers to a group of disorders caused by progressive nerve cell loss in the brain's frontal lobes. The nerve cell damage caused by frontotemporal dementia leads to loss of function in these brain regions, which variably cause deterioration in behavior, personality and/or difficulty with producing or comprehending language.

Parkinson's Disease

The brain changes caused by Parkinson's disease begin in a region that plays a key role in movement, leading to early symptoms that include tremors, muscle stiffness, stooped posture, and lack of facial expression. As brain changes caused by Parkinson's gradually spread, the person may also experience changes in their ability to pay attention, make sound judgments, and plan the steps needed to complete a task.

Mixed Dementia

Mixed dementia is a condition in which brain changes of more than one kind of dementia occur simultaneously. People over 85 or older are most likely to have mixed dementia. In the most common form of mixed dementia, the abnormal protein deposits associated with Alzheimer's disease coexist with blood vessel problems linked to vascular dementia. Alzheimer's brain changes also often coexist with those caused by Lewy bodies. In some cases, a person may have brain changes linked to all three conditions — Alzheimer's disease, vascular dementia, and dementia with Lewy bodies. There are also conditions such as Down Syndrome that increase the chances of having Alzheimer's at a younger age.

Recommendations:

- Ensure that all print materials distributed by health care providers, schools, etc. include information on all forms of dementia.

- Review all materials currently used in K-12 schools to ensure that explanations of dementia.

- Understand that dementia is characterized by nerve cell death, tissue loss, and damage to the brain that is irreversible.

Part I: Dementia and the Continuum of Care

Section B: The Role of Caregivers/Care Partners

Dementia is different from many other chronic conditions in that the majority of the care for people with dementia is provided by a family member, friend or other person working in an informal, unpaid capacity. In addition to directly health-related services such as medication management and transporting loved ones to doctors' appointments, caregiving includes assistance with "activities of daily living" such as bathing, dressing, feeding, toileting, getting in and out of bed, and ambulating around the home.

Because the need for care is constant and provided in the home, caregivers/care partners for those with dementia can feel isolated from the outside world and on their own when it comes to finding information and support. Caregivers/care partners often have difficulty locating providers and appropriate resources and support systems and need assistance with care navigation. Additionally, families may find it difficult to have consistent communication with health care providers.

Due to these issues, finding the right combination of services can vary from individual to individual. While it is largely agreed that remaining in the home setting for as long as possible, i.e., "aging in place," is optimal in many circumstances, this often places the caregiving burden on family members who can easily experience burnout, loneliness, stress and health conditions of their own. According to the Alzheimer's Association, 57.6% of caregivers in Nebraska suffer from one or more chronic health conditions, and 5.4% suffer from depression. (2024 Alzheimer's Statistics.) The intensive support required for people with dementia can negatively impact the caregiver's emotional and physical health and well-being and their ability to work. Additionally, the income lost when caregivers miss work or leave the workforce entirely makes the real economic impact of dementia clearer.

There are approximately 40,000 people in Nebraska providing care to someone with dementia (Facts and Figures 2024, p. 47). These caregivers provide a staggering 62 million hours of care with a value of $1,188,000,000. Research has yielded a profile of the typical caregiver/care partner in Nebraska. The average Nebraska caregiver has a job and is a white female aged 40-59. She is the primary caregiver/care partner for a parent or child (usually both at the same time). She provides at least twenty hours of care per week outside of work. Most of the time, the person with dementia lives in the caregiver's/care partner's home and has been receiving care for between three and five years.

It is worth noting that men also assume the role of a caregiver/care partner, although not in as great of numbers as their female counterparts. The challenges they face can and are different from those experiences by female caregivers/care partners. Proving support to them is also necessary.

According to AARP, about a third of people 50 and older now live alone and don't have children, are estranged from their children or can't depend on them or other family members for help. These solo agers face many of the same planning issues as older adults with children—figuring out how they will manage their future care if their health falters, where they should live and how to make their money last. But their different circumstances often warrant different solutions. Because the number of American step-families has steadily risen, sociologists and researchers now worry about a “step gap” that could affect elder care. A 2021 study found that almost half of those with biological children received care from them. Among those in stepfamilies, fewer than a quarter did.

Caregiving services are frequently provided on a private pay basis if the individual living with dementia does not qualify for Medicaid. Because of the high cost of care, these services are frequently provided by family members or other natural supporters instead of through a paid caregiver. According to AARP, the average family caregiver in the U.S. spends roughly $7,200 a year on caregiving activities, including hiring home care aides.

Because of these factors, facility-based care often becomes a necessity when and if a facility is available. However, there are other options for care that can also be utilized while the individual with dementia remains in the home, such as adult day services and in-home caregivers, such as certified nursing assistants and other direct care workers. Respite stays can also be beneficial, allowing for the caregiver to take needed time for themselves. But families are often not aware of these resources.

One important source of information for caregivers/care partners includes the Area Agencies on Aging (AAAs). AAAs provide services designed to help older adults live in their home as long as possible. Professional care managers work with older adults, identifying and coordinating available community resources and services. The eight AAAs serve the state of Nebraska based on region. A complete listing of Nebraska’s AAAs is found in the appendices. Also included is a link to the Aging Disability Resource Center (ADRC) for Nebraska, offering additional resource information.

Most AAAs have a Caregiver Support Program, and the caregiver is the client rather than the person living with dementia. Case managers are available to consult with caregivers in the program regarding the stresses and challenges of being a caregiver/care partner. In addition to case management, other services that may be provided are in-home respite, adult day program services, support and educational opportunities as well as some supplemental services. This offering, coupled with care or case management can be helpful to caregivers/care partners and the person living with dementia in allowing them to remain in the home.

Additionally, Aging Partners, the Area Agency on Aging servicing counties around the Lincoln area, offers Trualta (trualta.com). Trualta is a web-based service that offers caregivers support through various resources including educational programming, one-on-one care coaching, and support groups. Bi-lingual materials also available. The state of Iowa recently entered into a partnership with Trualta and now offers free access to all of Trualta’s resources. For persons living with dementia under the age of 60, the League of Human Dignity is an option. The League offers information about housing options and other resources in the community.

Recommendations:

- Provide individual counseling, support groups, and training to assist caregivers in the areas of health, nutrition, and financial literacy. Consider the Empowered

Caregiver program available through the national Alzheimer's Association (https://www.alz/org/help-support/resources) is an option for families, especially those living in rural areas, to access.

- Provide supplemental services to complement the care provided by caregivers. Include self-care in training provided through the Caregiver Support program through a caregiver/care partner's local Area Agency on Aging.
- Explore use of Trualta or other on-line caregiver support platform and make access to its programs and services free for all Nebraska residents.

Part I: Dementia and the Continuum of Care

Section C: The Difficulties of Care Navigation

One of the most difficult aspects of being a caregiver for someone with dementia is trying to learn what services are available and what hoops they have to jump through in order to apply for and receive them. This can require numerous telephone calls and hours of on-line research, making care navigation difficult, especially for those unfamiliar with web-based searches.

The AAAs provide care management services designed to help older adults live in their own home for as long as possible. Professional care managers work with older adults, identifying and coordinating available community resources and services. The eight AAAs serve the state of Nebraska based on region.

For those recently diagnosed with dementia, having a source to turn to for information and next steps becomes paramount. Persons with dementia and their caregivers/care partners, caring for persons a loved one can find support by contacting their local Area Agency on Aging (AAA) information and assistance line. In addition to the AAA, people are also able to access the Aging Disability and Resource Center (ADRC) for additional information about resources available to persons with dementia and their caregivers.

One recommendation of the plan is to establish care navigators in each AAA across Nebraska. important goal in the coordination of care services. An initial pilot study is needed in order to determine the return on investment for the state and family caregivers. "Dementia Friendly America" offers a framework for updating community services to support individuals with dementia and their care partners. This model could be beneficial for Nebraska for future consideration.

The AAAs, along with the senior centers who provide means and in some cases activities and are financially supported by the AAA, are often the first resource accessed by family caregivers seeking information about what to do in managing the challenges of caregiving/care partnering. Senior center staff may also be the first to observe changes in someone who visits the center frequently, particularly centers in more rural areas and those serving diverse populations.

In addition to family members, medical providers also rely on AAAs and Senior Centers as a referral source for people early in the disease process. Having the necessary financial support and personnel in place for AAAs becomes a critical current and future necessity.

Recommendations:

- Create a pilot project within an AAA that serves both urban and rural caregivers/care partners.
- Establish a care navigator position within each Area Agency on Agency.
- Create a template for medical providers to access for making a referral and/or providing information about access to care navigation.

- Engage with local hospitals, nonprofits, and support groups to create a comprehensive directory of services available for individuals with dementia.

- Implement the Dementia Friendly America Model

Part I: Dementia and the Continuum of Care

Section D: Diagnosis and Treatment

One reason why the path to diagnosis is so long is because it has several steps, each one requiring people, training, resources, and infrastructure. Nebraska is short on all of these and therefore ill-equipped to meet the dramatic increase in the dementia population ahead. A coordinated plan to build up these resources would benefit the state's residents, health care system and economy.

It is usually a primary care provider who first notices signs of cognitive decline, and they should have the tools needed to conduct cognitive evaluations. These are relatively short tests used to detect cognitive decline and determine whether further test is warranted. The place where most people are likely to encounter a cognitive assessment is during their annual Medicare Wellness Visit, a part of primary care for people over 65 that was introduced in 2011 as part of the Affordable Care Act. When it comes to assessing cognitive function as a required component of the wellness, the Center for Medicaid and Medicare Services (CMS) does not require that any specific testing tool be used. The most common assessment tools used by medical professionals and facility staff are the Montreal Cognitive Assessment (MoCA), the Brief Interview for Mental Status (BIMS) and the Saint Louis University Mental Status (SLUMS) Exam. There are also comprehensive assessments tools like the Mini-Mental State Examination (MMSE) and the Functional Activities Questionnaires.

Nebraska should consider assessing the benefits of taking a more uniform approach to cognitive assessments. If the cognitive impairment section of the wellness visit or some other assessment conducted by a primary care provider indicates the need for more investigation, the next step is a neuropsychological evaluation. These are usually conducted by professionals with a Ph.D. in neuropsychology, as opposed to physicians, and take several hours.

In Nebraska, there are not enough neuropsychologists to keep up with the increasing number of patients requiring assessments and evaluations. For this reason, the waiting list for receiving a neuropsychological assessment can be six months in the best of circumstances and over a year in the worst. One of the best ways to shorten the waiting list is for primary care providers to do some of the diagnostic work on their own before referring to a neurologist. The state needs to do a better job tracking available practitioners and available appointments to enable more people to get the testing they need. If someone gets a low score on the neuropsychological evaluation, the next step is some sort of brain imaging, which requires equipment. If these images suggest cognitive damage, then the next step would be a blood test. There are currently no laboratory facilities in Nebraska capable of processing such tests.

All Nebraskans—people living with dementia and their caregivers—should have access to timely screenings for dementia. A diagnosis of dementia should reflect a standard of practice that is evidence-based and draws on insights from family members and the primary care provider. Educating patients and carers of what the disease progression looks like is critical.

One important reason for improving diagnosis, particularly in the early stages of the disease is because there are now treatments that can slow the progress of some types of dementia. In

January 2023, the Food and Drug Administration gave full approval to Lecanemab (brand name “Leqembi”), a new drug that slows the progress of Alzheimer’s. In July 2024, the FDA approved a second drug, Donanemab (brand name “Kisunla”). Both of these drugs are monoclonal antibodies that attack the proteins that cause Alzheimer’s. They are only effective in slowing early-stage Alzheimer’s and not for late-stage Alzheimer’s or other forms of dementia.

Nebraska Medicine began offering infusion services for administering lecanemab in February 2024 and currently has fifteen patients receiving treatment, which consists of infusions every two weeks. Donenemab is given as a monthly infusion. Both treatments require regular brain scans to detect brain bleeds. CHI Health does not currently offer treatments of either drug.

Many primary care providers are not aware that we have entered what the Alzheimer’s Association calls “the era of treatment.” This lack of knowledge means they might not grasp the importance of conducting regular cognitive assessments of their patients and knowing when to refer them for neuropsychological evaluations, brain scans, and biomarker testing. There is also a lack of the resources and infrastructure needed for testing and treatment to take place.

Recommendations:

- Develop a state-wide roster of neuropsychological assessment and evaluation services to assist families in accessing needed services

- Work with educational institutions on information campaigns and incentives to encourage more students to pursue neuropsychology as a specialty and acquire the training necessary to perform neuropsychological evaluations

- Establish partnerships and funding mechanisms to develop testing capacity in multiple parts of the state

- Establish an implementation committee to develop a state-wide plan on how to increase the availability of imaging, infusion and other services

Part II: Care Settings

Section A: Home Health and Home Care

As we address the home health and home care recommendations, it is important to clarify the difference between the two services. "Home health" refers to skilled medical services, prescribed by a physician and typically comprising skilled nursing, therapy, and provided to individuals who are typically homebound during recovery following hospitalization or a change in medical condition. "Home care" provides nonmedical services such as personal care, companionship, meals, laundry, household assistance, and with activities of daily living such as dressing, personal hygiene, bathing, showering, toileting and transferring, as well as medication assistance.

Home health providers are required under Medicare regulations to be licensed and, in Nebraska, there are 129 licensed home health agencies, which employ licensed health professionals. In contrast, home care providers are not required to be licensed and this lack of regulation makes it difficult to determine how many home care providers operate in Nebraska.

Unfortunately, many older persons in rural areas face challenges due to limited access to home health and home care providers, further complicating aging in place. Nationwide, there is a growing shortage of direct care workers and this is only expected to grow. Another challenge for persons living with dementia is the 24/7 nature of the care and assistance that enable them to live safely at home. For this reason, the cost of home care services for these individuals can become prohibitive. In order for the person living with dementia to remain safely at home, home care alone may be insufficient and other supports (e.g., home modifications, security and monitoring) may become necessary.

When it comes to medical and other services provided outside of an institutional setting, it is important to understand the "Medicaid Waiver" program, discussed in more detail in the "Paying for Long-Term Care" section below. When Medicaid was first established in 1965, the intent for the program was to cover medical services of low-income persons according to a set of uniform regulations covering eligibility, etc. In order to provide for more diverse types of care, however, indicates that a state "may by waiver include as 'medical assistance' . . . home or community-based services."

Home and community-based services are provided "to individuals with respect to whom there has been a determination that but for the provision of such services, the individuals would require the level of care provided in a hospital or a nursing facility." "Home and community-based services" are an important focus of this plan. As the dementia population increases, these services can help fill the gap created by the lack of facility beds while at the same time enable people to stay home when they might otherwise be in a nursing home.

Recommendations:

- Explore tax incentives from state or financial aid to promote home care and home health as specialties.

- Expand Medicaid waiver home and community-based services to include all areas of need. This could include adult day service level of engagement within the home.

- Partner with the entrepreneurial community in Omaha and Chamber of Commerce on pursing home health and home care as viable businesses.

Part II: Care Settings

Section B: Facility-Based Care

Just as arriving at a correct diagnosis for someone with dementia can be difficult, so is finding them the right home care or institutional setting. One of the most difficult questions caregivers and family members have to determine is at what point it becomes necessary to move someone into assisted living, a nursing home, or memory care. Some memory care units are linked to assisted living facilities while others are located within skilled nursing facilities, while still others are stand-alone facilities where the entire resident population has dementia.

The level of care varies based on the setting; independent living communities, which provide little to no physical assistance with activities of daily living, assisted living facilities, which can provide assistance to individuals within a fairly independent home environment, and skilled nursing facilities, which provide continuous medical care and supervision to residents. Some people with dementia have other medical conditions such as diabetes and COPD, while others may only need assistance with activities of daily living—bathing, eating, dressing, toileting, and transferring out of bed.

Memory care units can be found in assisted living or skilled nursing. There are also facilities that are 100% memory care. What differentiates memory care from other levels of care is primarily that it is a secured space, where residents cannot exit the facility without family or staff assistance. For memory care provided in the assisted living and skilled nursing levels of care, facility staff members are required to receive four hours of dementia-specific training on an annual basis.

Besides providing skilled therapy for individuals wishing to rehabilitate and return to other living environments, skilled nursing facilities also provide custodial care for individuals requiring long-term care. Skilled nursing facilities experienced a Medicaid reimbursement increase in the last several years and this has had a positive impact on skilled nursing facilities' ability to accept Medicaid. However, skilled nursing rates could be increased for individuals with dementia, as they typically require a higher level of physical assistance that raises the care rate.

In all types of facilities, there are severe staffing shortages. While the number of healthcare providers has decreased, especially in nursing professions, the Center for Medicaid and Medicare Services has imposed unfunded minimum staffing requirements on skilled nursing facilities. This will present further inequities in income versus cost and this is further compounded by increasing rates of staff turnover.

Eighty-six assisted living facilities (30% of the 283 assisted living facilities in the state) report that they have a dementia or special care unit. There are currently 193 licensed nursing homes in Nebraska. The total number of licensed beds is 14, 916. Forty-five nursing homes (29% of SNFs in the state) report that they have dementia or special care units. However, not all of these facilities are licensed to accept Medicare/Medicaid, and some exist in a hospital-based setting. The lack of memory care beds means that many people who have dementia and need special care live with the general resident population and are cared for by staff who may not have dementia-specific training.

One major factor affecting availability of facility beds is increasing numbers of facility closures. Facility-based care has taken a major hit in the last seven years with thirty-nine nursing home closures and thirty-two assisted living closures since 2017. Many of these closures were facilities in rural portions of the state. There are currently twenty-two counties with zero nursing homes within county lines. Seventeen of these counties also lack an assisted living facility. There are an additional twenty-seven counties that only have one nursing home within county lines. Six of the seven counties with the highest population of people age 65 or older per capita in the state—Sioux, Hooker, Keya Paha, Hayes, Wheeler, Greeley—have zero nursing homes; the exception is Pawnee, which has one nursing home. (Nebraska Health Care Association and Nebraska Hospital Association.)

Current reimbursement for Medicaid Waiver is $3,116 per month (this rate includes residents' room and board portion). This often does not cover the total cost of care, and there can be loss of revenue, which can be between $500-$900 per month for each Medicaid Waiver resident, depending on level of care. The loss of revenue can be even greater for residents with memory care needs. Urban memory care units (licensed under assisted living) report charging between $6,000-$10,000 per month for private pay residents, and again the Medicaid Waiver reimbursement rate for residents at the same rate of $3,116/month.

Current reimbursement does not take these memory support needs into account, and the state should strongly consider an enhanced reimbursement rate for memory care residents to possibly increase the number of assisted living facilities that will accept individuals on Medicaid waiver needing a memory support level of care. At this time, many Nebraskans with dementia are living in long-term care facilities instead of assisted living solely because of their payor source. This phenomenon affects members of underserved communities even more heavily.

Many assisted living facilities are limited in their ability to accept many people on Medicaid Waiver because they would then not be able to meet and sustain operating costs. The state should strongly consider increasing the reimbursement rate for memory care residents. The net effect of this action would allow more facilities to take Medicaid, decrease the amount of facility closures, and allow facilities to hire and retain staff.

Recommendations:

- Explore providing transition consultant services to focus on Medicaid facilities, i.e., placement services not provided by private transition consultants who focus on private-pay facilities.

- Analyze previous efforts to develop centralized system for locating available beds in facilities across the state to simplify referral system.

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

Part II: Care Settings

Section C: Adult Day and Respite Care

In Nebraska, adult day and respite services offer critical support for individuals who need assistance with activities of daily living and their caregivers. These services provide structured, supervised care which allows individuals to engage in social, recreational, and therapeutic activities while ensuring their safety and well-being. For family caregivers, respite services offer a crucial break from caregiving duties, reducing stress and preventing burnout by providing temporary relief. This support not only enhances the quality of life for those receiving care but also helps maintain the overall health and stability of families throughout the state. Nebraska's commitment to these services reflects a broader effort to support aging adults and individuals with disabilities, ensuring they have access to the resources and care they need.

Respite for caregivers is vital. It has been proven that caregivers providing care for a loved one have a higher chance of passing away from symptoms of stress. These symptoms include anxiety, depression, irritability, feeling tired and run-down, difficulty sleeping, trouble concentrating, new or worsening health problems, and alcohol or drug abuse. These factors can lead a caregiver to isolate themselves, struggle with providing care, and neglect their own needs.

Resources for respite care are limited and often come with time or payor source restrictions. In Nebraska, low-income individuals are eligible to receive adult day services under the Social Services to the Aged and Disabled fund. The reimbursement rates for these services are low, and do not provide an incentive for privately owned facilities to accept this funding, thereby excluding many individuals from necessary services.

Adult day programs also play an important role by providing caregivers with time they can spend stepping back from the daily grind of caregiving, taking care of tasks and errands unrelated to dementia care, spending time with friends, and rejuvenating themselves. In addition to adult day programs, there are other forms of respite to serve the diverse needs of caregivers. Respite can be for a few hours, full days, and even multiple days.

Lifespan Respite Services is a state program that provides funding for eligible unpaid primary family caregivers to purchase respite services The Nebraska Lifespan Respite Network provides support to the family caregiver and care recipient, as well as recruitment and screening of respite providers, assistance with provider matching and sharing of respite resources. The collaboration with the Nebraska Caregiver Coalition, the State Unit on Aging and Lifespan Respite work together to advocate for those in need of respite services.

Many Nebraskans, including professional healthcare providers, are not aware of the respite services that exist. We currently have only two options for adult day services with a dementia focus in our three most populated counties: one in Douglas County and one in Sarpy County. At this time there are no adult day programs currently in Lancaster County. Statewide, there are currently 21 licensed adult day programs in the state, according to DHHS Licensure.

Respite can involve more than just during the day. For example, when an emergency occurs and the primary caregiver has to leave the person with dementia in the home alone, there can be at risk of unsafe living situations. With the current requirements for respite stays in a long-term care or assisted living facility, families and caregivers can be difficult to manage, increasing the risk of an unsafe living situation. If there could be an evaluation of the current regulations to make a modification for respite stays including both private-pay or Medicaid source, many Nebraskans could benefit.

Recommendations:

- Develop a respite admission program for long-term care communities to utilize to reduce the barriers to quick admissions for emergent respite stays.
- Establish a state-wide program that specifically monitors, provides information, and assists people in finding services they need.
- Seek grant funding to long-term care communities and assisted living communities. Also, in rural areas consider including home health agencies and senior centers in establishing adult day care programs within their buildings.
- Establish independent respite centers that service rural communities.
- Explore how currently Nebraskans who are on hospice services are allowed to have five days of respite approved by CMS. This guidance is an effective example of how to offer long-term care communities as an option for emergency respite stays.

Part II: Care Settings

Section D: Special Needs—Co-Occurring Disorders and Behaviors

Caring for people living with dementia is difficult enough in itself, but it can be much more difficult when it comes to older adults with co-occurring disorders such as mental illness, intellectual and developmental disabilities, and substance abuse. Many facilities will not accept these individuals out of fear that they would create disruptions for other residents and the financial implications involved in their care.

The types and severity of dementia-related behaviors can vary based on the individual, the stage of dementia, and any underlying medical conditions or environmental factors. Some types of dementia such as Parkinson's or Lewy-Body, can have symptoms such as delusions and paranoia that resemble mental illness, which delays diagnosis, Mental illnesses such as depression, anxiety, and psychosis commonly coexist with dementia, exacerbating symptoms and complicating care delivery. Studies indicate that up to 40% of dementia patients experience depression, leading to poorer outcomes and increased caregiver burden. Similarly, anxiety disorders are prevalent among dementia patients, contributing to agitation and behavioral disturbances. Psychotic symptoms, including hallucinations and delusions, occur in approximately 20-30% of individuals with dementia, posing significant challenges in treatment and management.

Training staff in de-escalation and communication techniques is vital. While medications are often a first-level approach, especially when being cared for in the home, many psychotropic medications (such as antipsychotics, antidepressants and anticonvulsants) come with serious side effects including increased risk of death. Behaviors are often one of the reasons cited when a facility declines to accept a particular individual into their community. Facility administrators sometimes decide that adding that person to their population would lead to disruptions and disturbances, possibly even conflict between residents. More training in managing resident behavior would enable healthcare professionals to more effectively accommodate residents with serious needs.

These disorders often make care more complicated and stressful for caregivers. Many facilities lack the staff and expertise to deal with this population. There is also a lack of specialized facilities, so finding a facility or getting onto a waiting list can be difficult. Understanding the prevalence, impact, and implications of these co-occurring disorders is essential for developing effective care models tailored to the unique needs of individuals.

Substance abuse represents another significant co-occurring issue in dementia care, though it is often not taken into account. Older adults with dementia may misuse alcohol, prescription medications, or illicit drugs, complicating diagnosis and exacerbating cognitive decline. Substance abuse increases the risk of falls, accidents, and medication interactions, necessitating tailored interventions that address both substance use disorders and dementia.

People with intellectual and developmental disabilities present unique challenges when these conditions occur along with dementia. Individuals with preexisting cognitive deficits may experience accelerated cognitive decline and behavioral disturbances, complicating diagnosis and care management. Down’s syndrome, for instance, predisposes individuals to early-onset dementia due to genetic factors, necessitating specialized care approaches.

Recommendations:

- Coordinate with the Division of Developmental Disabilities to create more facilities focusing on this population

- Develop financial incentives for existing facilities to accept more of this population.

- Provide education for facility-based workers supporting those with dementia that may also have co-occurring conditions such as mental health disorders, substance use disorders and I/DD.

Part III: Access and Education

Section A: Paying for Long-Term Care

Of the $321 billion total amount spent nationally on dementia care, $81 billion (24%) is paid out-of-pocket by families caring for a loved one with dementia. The economic impact of caregiving on families in Nebraska is immense. According to AARP, there are 179,000 caregivers in Nebraska, who account for 168 million hours of care valued at over $2.8 billion. Dementia care makes up almost half of this with $1.1 billion of unpaid care in Nebraska provided by caregivers.

The costs of care for people with dementia are high, in part because many services are private-pay only. This is particularly true of home care. There are other services that are paid for by Medicaid, but locating and accessing these services can be difficult. Most Americans underestimate the risk of disability and the need for long-term care. More than half of older adults turning 65 today will require long-term care, although most will need assistance for less than two years. On average, an American turning 65 today will incur $138,000 in future long-term care costs.

Many families lack the financial resources to pay for long-term care. Dementia exacerbates this problem, because dementia as a cognitive issue often does not require medical assistance and is not funded by original Medicaid, but by waiver.

In April 2024, Governor Pillen signed into law the Caregiver Tax Credit Act, which offers Nebraska family caregivers who meet income requirements a nonrefundable tax credit equal to half of their eligible caregiving expenses. The maximum credit is $2,000 a year or $3,000 per year for caregivers of a veteran or someone with dementia.

The Medicaid Waiver program is extremely important for the families of persons with dementia, who can be generally healthy medically speaking even when their level of cognitive impairment is high. This population does not require a nursing-home level of care. With the extra supervision and security from being in a locked memory care unit, a person with dementia can often function well in an assisted living setting that would be covered under the waiver.

In order for an individual to qualify for Medicaid Long-Term Care Services, or Medicaid Waiver Services, the individual must be evaluated by either the League of Human Dignity or the Area Agency on Aging. This evaluation determines an individual’s level of care and must occur before their stay at the facility (or services in the home) is funded. An individual must require assistance with at least three activities of daily living in order to be eligible for Medicaid/Medicaid Waiver coverage, and this can sometimes present a barrier to acceptance, as residents with dementia do not always report their care requirements accurately. After the level of care determination is completed, Medicaid Waiver provider will also develop a service plan that will address the individual’s needs and determine how and which services are provided.

The state should continue to address the Medicaid Waiver reimbursement rates for providers. Given the increase in the number of participants coming in the next ten years, the demand for these services will continue to rise. Those with dementia have difficulty finding memory care services that will accept Medicaid. This is attributed to the reimbursement rate for these services.

Approximately 60% of nursing home residents rely on Medicaid. Nebraska is slightly under the national averages for the proportion of facility residents on Medicaid and the state has slightly more individuals paying privately than the national average. Facility operating costs have experienced inflation due to supply chain demands, as well as nearly every other factor that largely increases facility costs across the board. In addition, staffing challenges before and after the pandemic have necessitated an increased reliance on staffing companies, which leads to higher labor costs than facilities have previously experienced.

Recommendations:

- Continue to address the Medicaid Waiver reimbursement rates for providers.
- Addressing the middle-income earners with affordable services, tax credits, etc.
- Offer state-sponsored long-term care insurance policies for people with dementia

Part III: Access and Education

Section B: Underserved Communities

When it comes to overall physical health, there are significant disparities among the care and services available to older adults in different communities across the state. Having dementia makes it more challenging, because even where there are health care resources available, there may not be anyone with specialized training in dementia. It is crucial to provide more dementia resources, because members of underserved communities are more likely to develop dementia. National date from the CHAP study indicates that 19% of African American and 14% of Hispanic adults age 65 or older have Alzheimer's dementia compared with 10% of white older adults.

Underserved communities often lack information and education about brain health, healthier eating habits, and available services. In addition, few residential care facilities, adult day respite programs, home health, home care and hospice providers in Nebraska currently have the knowledge or resources to fully assist individuals from a wide variety of cultures and/or religions. Language barriers are also a significant issue.

Beyond the statistics, there are deep cultural habits that make dementia care more difficult. Many members of underserved communities report being less likely to seek dementia care because they believe they will be discriminated against. When asked how this discrimination manifests itself, the reason most frequently cited is feeling "not listened to" when they express concerns or ask questions of health care providers. This is a serious problem when it comes to caregivers confronting the complexities of care navigation.

Some members of underserved communities believe that treatments and therapies are unlikely to be effective for them because they are based on research that did not involve any members of underserved communities. The lack of diversity in clinical trials is an issue that dementia researchers have been struggling with in recent years. More than half of non-white Americans believe that cognitive impairment is a normal part of aging and thus not a problem needing to be investigated. Twenty percent of African Americans and Hispanics say they would feel insulted if a health care provider asked them to undergo a cognitive assessment.

When we talk about underserved communities, it is important to understand their diversity in Nebraska. In addition to African Americans (108,810), Hispanics (255,210), there are 33,632 Native Americans. The top countries of origin for immigrants were Mexico (34%), Guatemala (7%), India (5%), Myanmar (4%) and Vietnam (4%). In 2023, there were 148,378 foreign-born individuals in our state.

As the U.S. continues to become more diverse, the healthcare industry will also need to look at finding a way to build models of care that could serve a wider variety of cultures. As facilities, home care and home health agencies should employ a more diverse pool of employees—staff members may provide a good way of understanding what would attract people of their culture to live in a facility and what would make them feel welcome. There is a need for interpreters and materials to be in multiple languages. The numbers of non-English speakers in need of services will increase. There is a need for education in sign language, Spanish, and other languages.

Establishing relationships with churches or other faith-based communities is one way of providing information and education about dementia is one way to meet this objective.

Section IV, Part A below recommends establishing regional hubs of dementia resources across the state. Each of these hubs should have at least one staff member from communities representing the makeup of the local population. The state currently participates in the Behavioral Risk Factor Surveillance System, an ongoing telephone survey that covers different topics from year to year depending on funding (discussed below in Section VII, Section A). Another recommendation of this plan is to make the existing modules on cognitive decline and caregiving permanent parts of BRFSS. This survey should also seek information regarding race and ethnicity to be able to allocate care navigation and education resources where they are needed the most.

This plan also recommends establishing a central data registry as called for in § 71-566(1)(d) of the Alzheimer's Disease and Other Dementia Support Act. There needs to be a concerted effort across the industry at all levels to gather information that will enable providers to respectfully accommodate different cultures and religions. It is crucial to educate both caregivers and those receiving care about the importance of cultural sensitivity in ensuring effective and compassionate care.

Recommendations:

- Implement targeted outreach by churches, doctor's offices, etc. to raise awareness about dementia within rural and ethnic communities.

- Create grant opportunities for healthcare staff members to learn a new language or pursue cultural studies focused on the populations they serve.

- Ensure that issues related to underserved communities be integrated into the planning of every implementation committee recommended by this plan.

- Establish programs encouraging more immigrants to enter health care generally but dementia care in particular.

Part III: Education and Access

Section C: Rural Communities

The total population of Nebraska as of 2024 is 1,978,379. Of these, 928,998 live in one of the state's five largest cities (Omaha, Lincoln, Bellevue, Grand Island and Kearney). That means 1,049,381, 52% of the population, live in rural areas or one of the 523 other towns in the state. Due to children moving elsewhere when they become adults means that the average age in some of these towns is in their 50s or 60s.

The size of the aging population and the lack of family caregivers has increased the need for paid caregivers, home health, home care, and above all facility beds. Most facility closures have been in rural areas (as discussed in Part II, Section B). Since 2017, forty skilled nursing facilities and thirty-one assisted living communities have closed across the state of Nebraska. Long-term care communities currently open are usually full or at capacity.

Home care agencies are scarce in western Nebraska. Distance between locations is the main detriment along with travel time and costs for travel. Single rural adults living far from families have more difficulty finding full-time caregivers. The cost of travel time affects the cost per hour. Paid caregivers in metro areas may serve two to three times as many clients as those in rural communities. Incentives to provide services in rural areas may be supplemented by grants to home care businesses. Spouses or children are more likely to keep their loved ones at home longer in rural areas simply because the closest care facility may be an hour's drive away, which would make visitation more difficult.

Broadband and internet availability in rural areas is important for many reasons. Being able to communicate with distant families is important to prevent isolation or depression for aging loved ones. It provides the option for webinars and podcasts for education of dementia and training of caregivers. All education and training should be offered at no cost. Telehealth is an important service for those in rural areas. This may be the only direct line or help they may access or receive quickly on a 24/7 basis. It is imperative to make fiber optics or satellite internet accessibility available for all rural areas This may not be possible due to cost of installation, and also financial need of the individual

Recommendations:

- Develop program for building partnerships between individual facilities and the communities where they are located.
- Provide wage or bonus incentives to home care and home health workers to work in rural areas.
- Provide funding to the Area Agencies on Aging to counsel families on available programs and benefits sch as the Caregiver Tax Credit.

Part III: Access and Education

Section D: Brain Health as Dementia Prevention

Experts believe that in most cases, Alzheimer’s disease, like other common chronic conditions, likely develops from complex interactions among various factors, including age, genetics, environment, lifestyle, and coexisting medical conditions. While certain risk factors, such as age and genetics, are beyond control, others, like high blood pressure and physical inactivity, can often be modified to lower the risk.

Conditions that increase the risk of cardiovascular disease—such as high blood pressure, diabetes, and high cholesterol—are also associated with a higher risk of developing Alzheimer’s disease or other dementias. Per the Alzheimer’s Association, autopsy studies reveal that up to 80% of individuals with Alzheimer’s also have evidence of cardiovascular disease.

Medical providers, educators, and local organizations across the state should collaborate to address the interconnected risks of dementia and vascular health. This entails public awareness campaigns that educate community members on the connectedness of heart health and brain health and state-wide programs that integrate brain and heart health education for individuals of all ages. Special attention should be paid to disseminating this information to populations with high prevalence rates of dementia, members of underserved communities, and students in our K-12 education system. This should also involve incorporating brain health messaging into any existing public health campaigns. As the U.S. population aged 65 and older continues to expand, the number and proportion of individuals experiencing cognitive decline and dementia are expected to rise. Similar to other chronic conditions, the most effective approach to reducing risk, ensuring early detection, and improving safety and quality of care is to take proactive action now.

Brain health has long been a concern of the CDC. In 2005, Congress first appropriated funds for the CDC to focus on brain health and dementia. This action led to the Healthy Brain Initiative (HBI). The overarching vision of the Healthy Brain Initiative (HBI) is that everyone deserves a life with the healthiest brain possible. Across the country, health departments are emerging as leaders and foundational partners in addressing the growing impact of Alzheimer's, cognitive decline, and dementia caregiving. In Nebraska, health departments should use innovative public health approaches to prioritize healthy aging across all communities.

AARP has created a brain health assessment and program called Staying Sharp, which works to educate Americans about how a well-rounded healthy living approach can improve brain health. Comprehensive tools are available for free, allowing public health departments and the State Unit on Aging to collaborate effectively.

The Alzheimer’s Association - Nebraska Chapter offers a free brain health program as well, titled Healthy Living for Your Brain and Body. This program offers science-based recommendations about taking care of our brains and bodies and can be presented to all audiences.

Recommendations:

- 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.

- Create brain health curriculum that can be distributed to public school districts and taught to K-12 students.

- Work with local organizations to implement brain health programming in community centers, churches, and local businesses.

- While Congress has not yet allocated funds for a new round of grants for the Building our Largest Dementia (BOLD) Infrastructure Act, Nebraska should be a viable candidate for this funding and should apply for BOLD funding when possible.

- Ensure local health departments utilize the existing HBI Road Map tools.

Part IV: Building the Dementia Care Workforce

Section A: Educating Health Care Providers

Of all the points in the journey that people with dementia and their caregivers must navigate, among the most impactful is the moment when a patient receives a diagnosis from their physician. Frequently, a diagnosis comes from a specialist, a geriatric neurologist with expertise in dementia and its various types. In fact, however, the initial diagnosis—or at least the first step on the way to a diagnosis—often comes from a primary care provider. This provider is often trained in family medicine, but may not have any specialized training in geriatrics, let alone dementia.

This is often simply a matter of access. Across the state and indeed the nation, there is a shortage of geriatricians. According to the Alzheimer's Association, there are currently 23 board-certified geriatricians in Nebraska. Even if we assumed that only 10% of people over the age of 65 develop dementia, the projected number of geriatricians needed by 2050 is 84. If 30% of the over-65 population develops dementia, the number of geriatricians needed to treat them will be a ten-fold increase. (Facts and Figures 2024.)

Achieving this goal is easier said than done. One might think that from the perspective of a new physician fresh from medical school and residency, this lack of geriatricians translates to many available jobs. This should serve as an incentive for medical students to choose geriatrics as a specialty. The reality, however, is that medical students are disincentivized to specialize in geriatrics. Medicare—the payor for out-of-hospital care—pays less for dementia care than for other specialties.

Family physicians may have difficulty treating an older patient on a regular basis because of the additional time involved. They take more than the fifteen minutes allotted for each patient, in part because the patients have more difficulty responding to doctor's questions and frequently require the presence of a family member or caregiver to make the appointment as informative and useful as it needs to be—particularly for patients who suffer from a tangled set of health conditions.

Cognitive assessments take extra time that doctors often do not have. They may therefore refer patients to specialists because their workload and the lack of necessary facilities prevents them from doing a thorough assessment on their own. But there is a shortage of geriatric neurologists too, so once a referral from a primary care provider to a specialist is made, it can take as long as a year to get an appointment for a thorough cognitive evaluation.

The most logical way to address this bottleneck is by providing tools to primary care providers that enable them to do the assessments and lab tests in their own office before making a referral. But again, doctors who have little or no training in geriatrics may not know how to use the tools. Geriatrics is not a required rotation for medical residents. It might seem logical to make it one, but many medical school educators have concerns about this idea, because adding geriatrics would mean shrinking or eliminating existing required rotations. Currently, students at the University of Nebraska Medicine, as part of their pre-clinical studies, encounter geriatrics only if they have chosen it as one of the options in their "choice block" of courses. The geriatrics portion of the block is only one week long, and dementia is only one area of focus among the many issues facing older adults. Included in the curriculum are one lecture devoted to geriatrics and one to neurology. Recently a group of faculty recommended making neurology a required rotation.

In addressing the lack of certified geriatricians, it will take more than just imposing additional requirements on medical students. There need to be incentives to encourage more physicians to choose geriatrics as a specialty. This will require action at the federal level, because it is CMS that sets provider reimbursement rates for Medicare. The rates need to be higher, and the set of billing codes related to senior care needs to be expanded to allow physicians to bill for more specific and often time-consuming services related to dementia care.

In addition to encouraging more medical students to pursue geriatrics, there need to be incentives to keep young doctors in Nebraska. It is well-known among our civic leaders and employers that keeping young professionals in the state is crucial to the state's future economic well-being. There are various efforts underway to stop the "brain drain," including Nebraska Medicine' Project Next. According to a 2023 analysis by the Omaha World-Herald, approximately 4,000 young people with bachelor's degrees leave Nebraska annually for other states, many seeking more career opportunities or higher pay.

These efforts should include strategies targeted at the geriatricians we will need to provide the best care to our loved ones with dementia. The lack of geriatricians is, like so many of the issues discussed in this plan, more acute in rural parts of the state. (The particular problems being faced by rural communities is discussed in Part III, Section C.) In addition to educational and economic incentives, there needs to be more infrastructure put in place to accommodate the increased number of health care providers focused on dementia.

Recommendations:

- Support Nebraska Medicine, CHI, Methodist, the VA and other health systems in developing regional hubs across the state providing primary care providers with training in diagnosis and treatment of dementia
- Establish an implementation committee to develop curricular on dementia
- Review requirements for continuing medical education courses and existing courses on geriatrics and dementia

Part IV: Building the Dementia Care Workforce

Section B: Facility Staff Training and Retention

Workforce development is a critical component of Nebraska's strategy to address the challenges posed by dementia. This includes investing in education, training, and support for healthcare professionals, as well as fostering partnerships with educational institutions.

An estimated 1.2 million additional direct care workers will be needed between 2020 and 2030—more new workers than in any other single occupation in the United States. Direct care workers play a vital role in caring for people living with dementia in private homes, adult day services, residential care, skilled nursing homes and other settings. Turnover rates are high in this workforce—estimated at 64% annually for direct care workers providing home care and 99% for nursing assistants in nursing homes.

The CMS State Operations Manual (SOM) requires that all skilled nursing facilities develop, implement, and maintain an effective training program on providing dementia care. Nebraska regulations released in June of 2024 mandate that skilled nursing facilities provide dementia-specific training to *all* employees if they care for individuals with dementia, regardless of the presence of a memory care unit.

State law (NRS §71-516.04) currently requires memory are units (whether in assisted living or nursing facilities) that care for individuals living with dementia to provide four hours of training. However, it does not indicate the specific topics the training should encompass. Given the tremendous demand for quality services, the dementia competency of direct care staff needs to increase.

The most recent update of the Nebraska Nursing Home Regulations (174 NAC 12) approved in May 2024, now requires an initial orientation as well as ongoing training for all employees that includes “Alzheimer’s disease and dementia care if the licensee cares for residents with Alzheimer’s disease or dementia.” These regulations also state that ongoing training must be completed for each employee and must ensure competency and continued compliance with regulations. While the regulations do not state what must be covered in this training, this is a significant expansion on previous regulations which were only required for special care units.

The Behavioral Health Education Center of Nebraska at Nebraska Medicine maintains a dashboard tracking the number of behavioral health providers across the state and their chief characteristics. Perhaps the most important of these characteristics from the perspective of building the dementia care workforce is the average age and proximity to retirement of the providers across our state. There are more therapists leaving the profession than entering it, and over time this will only increase the disparities among different parts of the state when it comes to the availability of care.

Informal caregivers should know that they will have dementia-trained professionals at skilled nursing, assisted living, memory care, hospitals, etc. caring for their loved one. The CDC offers an introductory course, A Public Health Approach to Dementia (www.cdc.gov/aging-programs/php/training/adph-curriculum.html), designed to increase awareness of the impact of dementia and the role of public health in addressing it.

There are also support services from the Department of Education and Nebraska Vocational Rehabilitation, both entities have partnerships with employers. The Department of Education has a program that provides training, upskill and backfilling of positions with individuals/potential employees at no cost to the employer for individuals with disabilities. DHHS has grant opportunities that fund education and training. For example, individual grants are given to individuals wanting to pursue a nursing degree. In 2024 training grants were also given to facilities with the training focus on "leadership." All licensed facilities were able to apply. Grant applications are also available with the Department of Labor. These training opportunities are not limited to nursing staff. For example, a staff member outside of nursing may have interest in being CPR-certified. The goal is to reduce barriers to learning or obtaining a new skill.

In addition to ensuring that they have the most recent training, there also needs to be serious attention paid to issues of burn-out and retention of dementia care workers. The number of therapists specializing in geriatric patients who are retiring exceeds the number of new therapists entering the field, and many therapists move on from exclusively dementia-focused are.

The most common area that is highlighted in employee satisfaction surveys is the desire to receive timely feedback when something is going well or when something is going wrong. The views of staff can be solicited using on-board surveys for new staff and annual engagement surveys. Facilities need to create opportunities for staff to have connections with residents when they are not caring for them. Facilities should build staff-led engagement programs. There should be bonuses not just for new hires but also current staff who are making a difference in the facilities where they work.

Representatives in Congress recently introduced the Building America's Health Care Workforce Act (H.R. 9067), that provides much-needed flexibility for nurse aides in training and gives them the ability to transition to long-term role (to accommodate training and testing capacities to meet demand). The bill includes key provisions that would bolster our nursing workforce and broaden career opportunities. It would allow for time worked as a nurse aid in a nursing home to count towards the 75 hours minimum training to become a CAN so long as the nurse aide is working in an area, identified by the state, as experiencing a nurse aide shortage.

Recommendations:

- Review current regulations for training determine the effect of adopting LB 1221 (it would change 71-516.04).
- Seek grant funding to pay cost of facility staff to received training, e.g., certified Dementia Practitioner training.
- Review training modules currently in use and analyze in terms of best practices in dementia, including developments in diagnosis and treatment.

- Streamline certification processes to reduce barriers to entry for individuals wanting to become nurse aides as recommended by the Building America's Health Care Workforce Act.

Part IV: Building the Dementia Care Workforce

Section C: Outreach to K-12 and Colleges

As noted throughout this plan, one of the issues of greatest concern in facing the growing impact of dementia is the lack of trained dementia care professionals that will be necessary to provide care to a much larger dementia population. This is an issue that has to be faced at the beginning of the career pipeline, in the K-through-12 years when young people are beginning to think about what career path they might want to take in life.

Our educational institutions and partners need to develop initiatives such as career fairs, mentorship programs, and educational outreach that can effectively introduce students to the fulfilling opportunities in this field. By collaborating with schools, Nebraska can inspire the next generation of healthcare professionals to enter dementia care, ensuring a steady pipeline of skilled workers to meet future needs.

It is necessary to have a robust outreach program to connect with the younger generation. This can include people with dementia being pen pals with elementary school students. People with dementia can volunteer at elementary schools. Students can have days of service with schools or organizations. The Nebraska Hospital Association recently launched an initiative aimed at children in third grade or higher to attract them to health care as a profession.

Facilities and other dementia care employers should participate in job fairs, at local colleges and high schools and collect information about interested students. This information is then available for HR specialists to contact regarding the student’s level of interest in applying for a position.

Recommendations:

- Fund internship and apprenticeship programs that offer students hands-on experience in dementia care settings.
- Ensure that the Health Sciences Career Cluster of the Nebraska State Board of Education and other curricula have current content devoted to dementia.
- Work with the Nebraska Association of Teachers of Science to develop dementia-specific conference sessions for teachers.
- Create an implementation committee of educational administrators to review existing training programs and collectively develop strategies for increasing focus on dementia.

Part V: Public Health and Safety

Section A: Harm Reduction

Falls are one of the most serious and prevalent negative occurrences for older persons. The effects of falls—reduced mobility, pain, brain fog, etc.—can trigger a downward spiral that accelerates dementia. Falls among adults 65 and older caused over 38,000 deaths in 2021, making it the leading cause of injury death for that group. In 2021, emergency departments recorded nearly three million visits for older adult falls.

Difficulty with walking and balancing are often among the symptoms of people with Lewy-Body Dementia, Parkinson's and late-stage Alzheimer's. Rushed movements to the bathroom due to incontinence, loss of muscle mass, problems with balance and gait, and changes in blood pressure are all risk factors for falling. Some medications can increase a person's risk of falling due to side effects such as dizziness. Anyone taking four or more medications is at greater risk of falling,

There are numerous tools to assist in improving the safety of home and other environments. The CDC has equipped health care providers with the Stopping Elderly Accidents, Deaths & Injuries (STEADI) initiative. This effort supports providers in making fall prevention a routine part of care. STEADI-Rx also provides guides to pharmacists on how to screen pharmacy patients and assess their medication regime to make changes that will reduce fall risk. The CDC also recommends home modifications such as grab bars in the bathroom, non-slip mats, handrails, and other low-cost interventions.

A key method for determining what safety actions would be most helpful for a particular person in a particular living situation is to do a safety audit. The safety and suitability of the home environment should be thoroughly examined, considering factors such as accessibility, supervision availability, and the presence of hazards. Physical and occupational therapists can provide personalized recommendations.

It should be more widely known that Medicare will pay for home safety inspections under Part B as long as it is ordered by a licensed medical professional. Medicaid Waiver can be used to fund some modification such as ramps, grab bars, widening doorways, and bathroom modifications) for a recently purchased home. Waiver will not cover home modifications considered to be of general utility, standard housing obligations of the participant or homeowner, and which are not of direct medical or remedial benefit.

The National Association of Home Builders has a Certified Aging-in-Place Specialist (CAPS) designation for contractors wanting to specialize in the fastest-growing segment of the housing market. There are currently only fifteen CAPS-certified contractors in the state of Nebraska, nine in Omaha, four in Lincoln, and one each in Grand Island and Arcadia.

In addition to falls and other injuries in the home, persons with dementia are at high risk of eloping or wandering outside of the home. The 2016 plan recommended the "analysis of a Silver Alert system implementation to coincide with the state's Amber Alert system to aid in finding lost seniors." The result was the Nebraska State Patrol's Endangered Missing Advisory, which provides information to the public that may help locate a vulnerable missing person. The system is voluntary, mainly relying upon the public to proactively sign up for, and forward, its email blasts. This differs from the Amber Alert, which is statewide and activated automatically through the Emergency Alert System. For the safety of individuals living with dementia, the state should look to improve the Endangered Missing Advisory system so that alerts reach more people and that missing individuals are found before it is too late.

Recommendations:

- Launch a public awareness campaign about home safety and the availability of Medicare and Medicaid funds for safety audits.
- Fund home safety assessments for elements that are not covered, such as new construction and homes purchased after waiver enrollment.
- Work with labor unions, businesses and educational institutions with construction programs to incentivize pursuing the CAPS designation.
- Include home safety as a priority for the housing implementation committee

Part V: Public Health and Safety

Section B: Elder Abuse and the Role of Adult Protective Services

One unfortunate consequence of the growing number of older adults living at home—often alone and without any supervision beyond visiting caregivers—is that cases of elder abuse are on the rise. Elder abuse is the mistreatment or harming of an adult considered vulnerable due to cognitive impairment, including dementia. Abuse can be physical, emotional, or sexual, and it includes unreasonable confinement and alienation from family members along with neglect and financial exploitation. Many social factors, often a lack of support services, can make conditions ripe for elder abuse.

Reports of abuse are handled by Adult Protective Services (APS), a unit within DHHS that operates pursuant to the Adult Protective Services Act (Neb. Rev. Stat. § 28-348 to 28-387). Not surprisingly, older adults with dementia are at far greater risk of abuse and neglect than those without dementia. Individuals with dementia are frequently too impaired to understand what others are communicating to them or what their own needs are. Failure to perform "self-care" is considered to be a form of neglect. Of the shockingly high number of 18,274 total calls made to APS in 2023, 4,272 (23%) of those calls involved self-neglect—poor hygiene, lack of healthy food, inability to perform activities of daily living, etc. Sometimes "hoarding" disorder or lack of attention to plumbing, etc. can make a living situation dangerous.

APS does not currently track whether dementia is a factor in the calls it receives. A common scenario is for a neighbor or caregiver to call the APS hotline to express concern that a senior is living in substandard, often dangerous conditions. It is often a hospital emergency department that makes the call when an individual arriving at the hospital shows signs of neglect by caregivers or themselves. Neglect by caregivers or self-neglect by older adults themselves constitute 73% of the total number of abuse allegations in 2023 (Adult Protective Services Registry Statistics). Various professionals, including physicians and other health care providers, are mandated to report suspicions of abuse. Willful failure by a mandatory reporter to make a report to APS is a Class III misdemeanor in Nebraska.

APS has identified the lack of appropriate and affordable housing as the biggest challenge to vulnerable adults in Nebraska. Many vulnerable persons with dementia have been living alone in unsafe situations, and their disease has often progressed beyond their capability to recognize their own safety. Many people with cognitive decline are living unhoused due to being evicted from their residences or simply because they no longer have the ability to secure and maintain appropriate housing. Individuals with mental illness often lose their housing due to behavior issues, and once they are kicked out of housing situation, they are flagged and cannot rent elsewhere. Individuals with personality disorders that cannot be treated are evicted, and frequently APS is the only party available to find housing options for them. Individuals experiencing cognitive decline and/or mental illness are often not accepting of their diagnoses or treatment.

Access to a neuropsychologist or mental health professional who can perform a cognitive evaluation is extremely difficult, so APS specialists must often make quick preliminary assessments themselves. (The need for more neuropsychologists is discussed above in the "Educating Health Care Providers" section.) There is a new assessment tool developed at Cornell

Weiill Medical School called the Interview for Decisionable Abilities. APS has explored adopting this tool, but Weill-Cornell does not currently have the capacity to train. This tool addresses decisional ability as it pertains to specific types of decisions, including medical decisions and financial decisions. APS Specialists currently employ several screening tools for assessing clients' capacity.

APS specialists cannot diagnose dementia or decide that an individual lacks capacity. The tools are utilized to screen for potential cognitive impairment when the client has not already been diagnosed. If the result of the screening indicates possible deficit, the client is referred to a physician for an evaluation. Standardized screening tools can assist APS specialists in determining if a client needs further assistance from a physician, psychiatrist or attorney. Capacity assessment scales and tools should not be used alone but as a "package" of observations, interviewing, and assessments.

Pre-Covid, Nebraska APS had a budget of only $100,000, provided by the Social Services Block Grant. That funding has increased and is currently at $250,000 annually. These state funds were temporarily supplemented, significantly, by federal legislation: the Coronavirus Response and Relief Supplemental Appropriations Act and American Rescue Plan Act, both from 2021. Totaling $2.8 million, most of these funds were used to purchase goods and services for APS clients, a lesser-known aspect of APS's role. They were also used on a public outreach campaign, on upgrading training, technology and even transportation (by buying vehicles) for staff to use in visiting clients.

These pandemic-era funds will be spent by September 2025. But even given the increase in capacity over the last few years, APS is still not sufficiently equipped to deal with the coming increase in elder abuse cases—many characterized by the self-harm that often occurs when an older person with dementia tries to live at home. There should also be funding to support a much broader public awareness campaign, so that more citizens of our state understand where to go when they suspect cases of abuse.

Recommendations:

- Include dementia among factors routinely tracked by APS.
- Establish a network of ongoing relationships between APS and cognitive neuropsychologists and other mental health professionals across the state
- Fund training for all APS specialists in the Interview for Decisional Abilities and capacity assessments in general.
- Establish a network of nursing homes with beds available to APS clients on a short-term basis while staff seek permanent placement in long-term care.

Part V: Public Health and Safety

Section C: The Role of First Responders

[need data re: ED visits]

First responders, including law enforcement, fire departments and emergency medical technicians (EMTs), are often among the first to be contacted to provide assistance during emergencies. As the number of Nebraskans living with dementia continues to grow, these workers will face several obstacles during these encounters.

Basic dementia training for this group of professionals was recommended by the 2016 plan. Since then, many have undergone some form of dementia training, but requiring this training for all first responders would be most beneficial to the state.

Individuals with dementia are at a higher risk of wandering and getting lost. First responders play a critical role in locating and safely returning these individuals to their homes or care facilities.

Training programs aimed at equipping first responders with the necessary knowledge and skills to effectively interact with individuals with dementia are available in Nebraska. These programs cover various topics, including (1) information about the symptoms and behaviors to help first responders recognize and appropriately respond to individuals with cognitive impairments. (2) specialized communication techniques for effectively interacting with individuals with dementia. (3) De-escalation Strategies: Given the potential for agitation or aggression in some dementia patients, de-escalation strategies are crucial for ensuring the safety of both the individual and the responders.

Some police departments in Nebraska have established special units equipped with mental health counselors to respond to incidents involving individuals with dementia or other mental health conditions. These units collaborate closely with other first responders to provide on-site assessment and intervention, reducing the likelihood of escalation and ensuring appropriate care and support for individuals with dementia.

These special units offer mental health counselors to accompany first responders to incidents involving individuals with dementia, conducting on-site assessments to determine the most appropriate course of action. In situations where individuals with dementia exhibit behavioral challenges or agitation, mental health counselors provide crisis intervention and support, helping to de-escalate the situation and connect the individual with appropriate resources.

Emergency Department visits related to dementia have significant economic implications for Nebraska's healthcare system. These visits often result from complications such as falls, injuries, or acute exacerbations of underlying medical conditions associated with dementia.

Resource Utilization: ED visits related to dementia contribute to the utilization of emergency medical services, hospital beds, and diagnostic resources, impacting the overall capacity and efficiency of the healthcare system.

The Dementia Friendly First Responder Training Program helps law enforcement and other first responders create a dementia-friendly culture that embraces, supports, and properly responds to residents with dementia and their caregivers. This program helps law enforcement and other first responders create a dementia-friendly culture that embraces, supports, and properly responds to residents with dementia and their caregivers. This training will teach you how to become Dementia knowledgeable, Dementia Sensitive, and Dementia Responsive. The Dementia Friendly First Responder Training program is also available as an onsite training event. Contact your local area agency on aging to schedule a training event on site at your local department.

Recommendations:

- Provide funding to increase the number of behavioral health teams within police departments.
- [Discuss possible changes to regulations for EMTs regarding do-not-resuscitate orders]

Part V: Public Health and Safety

Section D: Creating a Dementia Registry

As the number of people diagnosed with dementia increases, so will the need for information that the state and the health care system can use to understand the prevalence of dementia and how allocating resources to deal with it. One of the essential tools in gathering this information is a dementia registry. While national surveys are helpful, state-level tracking offers a more granular understanding of regional variations and facilitates targeted interventions depending on the resources currently available or needing to be built in particular areas.

Nebraska already has models that would be useful in creating a dementia registry. One such model is the Parkinson's Registry, established pursuant to the Parkinson's Disease Registry Act pass by the legislature in 1996. This legislation requires physicians and pharmacists to report anyone diagnosed with Parkinson's or being provided with Parkinson's Disease medications.

The dementia registry would be voluntary and assure protection of the identity of anyone who wishes to be included. Those eligible to be placed on the registry would have the ability to opt out of the reporting. Data collected on the registry would be utilized to inform policy that will identify regional disparities, allocate resources based on prevalence, provide early intervention and prevention, enhance support to caregivers and make informed policy decisions.

The dementia registry would have numerous benefits. The expectation would be that any Nebraskan newly diagnosed with dementia would be entered into the database, with a responsible party listed in case an emergency situation arises. Certain demographic information would be collected, such as location, family size, demographic profile and other factors. State-level tracking would enable Nebraska to identify regional disparities, allocate resources based on prevalence, provide early intervention and prevention, enhance support to caregivers and make informed policy decisions.

In addition to a central registry, another important means of gathering information is the Behavioral Risk Factor Surveillance System. BRFSS is the nation's leading system of health-related telephone surveys that collect data regarding health-related risk behaviors, chronic health conditions, use of preventive services and other issues. Nebraska currently participates in the BRFSS system by way of UNL's Bureau of Sociological Research, which has been conducting surveys annually since 1986. The system is based on a research design developed by the CDC and used in all fifty states. Questions are standardized to ensure comparability of data across states and over time.

BRFFS is comprised of a set of modules that are included for limited periods of time among the modules utilized by survey-takers at any given point in the ongoing survey. A module has to be funded in order to be included in the BRFSS survey. There are two existing modules related to dementia, one focused on cognitive decline and another on caregiving. These modules have been in Nebraska's annual BRFSS survey in the past—both in 2015, the cognitive decline module in 2019, and the caregiving module in 2021—when funded by a combination of CDC grant funding and private donor funding. The state should make necessary investments in the future to ensure that the cognitive decline and caregiving modules are permanently part of the annual survey.

Recommendations:

- Establish a state-wide tracking system for dementia overseen by DHHS or a contracted entity such as UNL's Bureau of Sociological Research.
- Reintroduce the dementia registry legislation introduced in 106th Congress, Second Session 2020 9 (LB 1138).
- Seek permanent funding for inclusion of Cognitive Decline and Caregiving Modules in the annual BRFSS survey

Part VI: Legal Protections

Section A: Cognitive Capacity and Powers of Attorney

When it comes to providing appropriate legal protections for someone with dementia, the most important documents are the Powers of Attorney (one for finances and one for health care). In most situations but particularly in situations involving dementia, the powers of attorney are the most impactful components of a standard estate plan. These are documents in which the “principal” (the person needing assistance) designates an “agent,” often a child or other family member, to make legal and financial decisions on the principal’s behalf.

The most common practice today is for a power of attorney to be durable, meaning it becomes valid upon signing and continues to be in effect even after the principle becomes incapacitated by dementia or some other impairment. This contrasts with a “springing” power of attorney, which goes into effect only after a person becomes incapacitated as attested to by one or more doctors.

As the various types of dementia progress over the months and years, it can be difficult to determine the precise moment when someone reaches the point when they clearly cannot make appropriate decisions regarding their health care. In general, there is no such moment; certain mental and physical abilities slowly fade, some appear and disappear sporadically. Someone with dementia can have “good days” when they do have basic recollection, or “bad days,” when they are not oriented to time or place and exhibit behaviors such as repeating the same sentence incessantly.

It is often up to the attorney meeting with a client to make a capacity determination to decide if the person can discuss legal issues at all, much less sign documents. It is generally accepted by attorneys that the capacity threshold is lower when it comes to health care than with finances. We accept that someone with mild cognitive impairment can say “I want my daughter to take care of me” and have that request be honored, whereas saying “I want to put my daughter on my bank account” often raises suspicions on the part of the attorney.

Attorneys are more accustomed to bright-line tests and may not know how to assess cognitive impairment appropriately. Attorneys may also lack knowledge of “supported decision-making,” a methodology built around the idea that individuals should be involved in decisions regarding their care to the extent their level of impairment allows. Supported decision-making is more frequently discussed when it comes to persons with intellectual or developmental disabilities, but it is equally relevant to persons with dementia.

There is no clear test utilized across the legal profession for assessing cognitive capacity. There is also no training for attorneys to learn about and cognitive assessments. This year’s annual meeting of the Nebraska State Bar Association included a session devoted to [add]. The NSBA should explore the pros and cons of implementing such a test and within the state and analyze how that test might harmonize with the quick assessments often used in medical settings. There is an assessment tool currently under consideration for regular use by Adult Protective Services caseworkers. Called the Interview for Decisional Abilities, the test assesses capacity as it pertains to medical, financial and other types of decisions.

Recommendations:

- The Supreme Court and the NSBA should convene a working group to improve the use of capacity determinations in a legal context.

- Nebraska should require that every attorney take a course on dealing with capacity issues as part of its annual ethics requirement.

- The NSBA should offer seminars in supported decision-making.

Part VI: Legal Protections

Section B: Guardianships

Sometimes a power of attorney is not sufficient to protect someone who is impaired because they need assistance that is not reliant on input from the impaired person themselves. The next level of protection is a guardianship, a legal arrangement in which a county court judge—after notice is sent to all interested parties and a hearing is held at which objections can be made—appoints a guardian when it is clear that the person falls into the category of “protected persons.” Often this person needing protection is someone who neglected to sign a power of attorney before they lost capacity and is no longer in a person to appoint one. The judge may also appoint a “conservator” to handle financial decisions.

This can be confusing to some people, who often assume that a guardianship can be imposed on anyone, particularly a parent or other family member, who requires assistance managing their affairs. On the contrary, state law requires that courts seek the “least restrictive alternative” when they are being asked to curtail the rights of an older or disabled person. Children are often surprised to learn that a guardianship over a parent would even be necessary.

One scenario that is becoming more common is when someone, usually a child, persuades their loved one to sign a power of attorney when they do not have the capacity to do so—and sometimes when there is an existing power of attorney that the individual signed before dementia overcame them. One child may be convinced that the other child does not have the parent’s best interests in mind, or that they are making decisions contrary to a parent’s true wishes. This can be especially concerning in situations involving dementia, because children can take advantage of their parent’s desire to stay home.

Sometimes it is clear that a guardianship is necessary, but there is no one able or willing to play that role. The Office of Public Guardian (OPG) may have to be asked step in. OPG is designed to serve as the guardian or conservator for an individual when no other alternative is available. In addition to providing the means of last resort as guardians or conservators for those situations where no family member or suitable individual is available, the OPG provides education, training, and support for volunteer and family guardians and conservators, and recruits individuals to serve as guardians and conservators for Nebraska’s vulnerable individuals.

Recommendations

- Increase funding for the Office of Public Guardian to hire additional caseworkers, particularly in less populated areas of the state.
- Require law students or attorneys fulfilling their CLE requirements to be trained in mediation in the elder law context
- Develop training programs for social workers, health care providers, facility staff on guardianships.

Part VI: Legal Protections

Section C: Advance Directives and End-of-Life Planning

In addition to powers of attorney, another component of the standard estate plan that is crucial when it comes to counseling families facing dementia is the "Advance Directive." A broad term that covers a variety of different documents, an advance directive is a document in which a person expresses their wishes about the health care they wish to receive in an end-of-life situation. The most common type of advance directive is the "living will." Most living wills prepared by Nebraska attorneys follow the Rights of the Terminally Act (Neb. Rev. Stat, § 20-401 to 416), which allows people to make "a declaration governing the withholding or withdrawal of life-sustaining treatment."

Such a declaration only becomes operative, however, when a physician determines that someone either has a "terminal condition"—i.e., "an incurable and irreversible condition that, without the administration of life-sustaining treatment, will, in the opinion of the attending physician, result in death within a relatively short time"—or is in a "persistent vegetative state"—i.e., a medical condition "characterized by a total and irreversible loss of consciousness and capacity for cognitive interaction with the environment and no reasonable hope of improvement."

Neither "terminal condition" nor "persistent vegetative state" quite suffices to describe dementia and the end-of-life scenarios to which it leads. With dementia, it can be hard to determine whether death will occur "within a relatively short time," or whether the "capacity for cognitive interaction" has disappeared forever, and therefore it can be difficult to determine when an advance directive is activated. The Nebraska legislature should evaluate the Rights of the Terminally Ill Act and determine whether its language should be expanded to take situations involving dementia into account.

Another area where there is widespread confusion is "do not resuscitate" (DNR) orders, a confusion that often leads to outcomes contrary to the patient's wishes. Unlike a a Living Will, which is a legal documents that is not part of someone's official medical record, a DNR is part of the medical record and therefore should be known to all treatment providers. The admission paperwork that has to be signed when someone moves into a facility always asks whether there is an existing advance directive and if so whether it has been provided to facility staff, or it asks the person signing the paperwork (often the POA) whether they want the person to be considered a "DNR" or full code.

[Delete or move to first responders section?] Because the living will is not a medical document containing a physician's order, EMTs cannot follow it [add on this]. Studies have shown that many medical personnel assume that if a living will is in place, it is treated as if it were a DNR, which means it might be used to justify stopping treatment of someone nowhere near death. The Rights of the Terminally Ill Act is also not particularly well-suited for emergency situations, in which EMTs are the individuals providing medical care in the first instance.

Medicare will pay for advance care planning as part of the primary care provided during the annual Medicare Wellness Visit. Medicare has billing codes (99497 and 99498) to cover advance care planning. DHHS should work with hospitals and other providers to research the frequency and effectiveness of such planning in Nebraska.

Recommendations:

- Work with the NSBA and other organizations to develop education programs regarding end-of-life planning for people with dementia.

- Ensure that staff of facilities have a clear understanding of Do Not Resuscitate orders and the facility's practices.

- Review legislation in other states creating a Uniform Dementia Directive.

Conclusion

There are numerous issues that are beyond the scope of this plan but which will need to be addressed if we are to truly succeed at improving the care and resources we provide to people living with dementia and their families across our state. The most significant of these issues is housing. As the population of people with dementia increases, more families will find it helpful—and less costly than a facility—to move their loved ones into their own home. States such as California have changed zoning laws and other regulations to facilitate the construction of “accessory dwelling units,” sometimes referred to as “Granny flats.”

There are initiatives in our state to deal with the growing problem of senior housing. The city of Grand Island announced in September 2024 that it would be working with a private developer to convert two buildings on the campus of the former Veterans Home, was closed in 2019 when the new Veterans Home in Kearney was opened. The forty-six one- and two-bedroom apartments will be designated for older adults and veterans. In addition to housing, our transportation system and public spaces must be reconceived from the perspective of someone with cognitive impairment.

The Alzheimer’s Disease and Other Dementia Support Act requires the advisory council to submit an annual report on the status of implementing the recommendations contained in this plan. In addition, the plan as a whole will be revised every four years, meaning that the next iteration of the plan will be submitted to the legislature and governor at the end of 2025. The advisory council has done its best to break down the twenty-four topics listed in the statute into a series of projects, each with its own action plan to be carried out by an implementation committee with expertise in that particular area. In this midst of all these projects, however, it is important to remember that our best chance of succeeding in implementing Nebraska’s State Alzheimer’s Plan comes when each implementation committee does its work with the activities of the other implementation committees in mind.