

## Executive Summary

**A**lzheimer's disease, the most common form of dementia, affects one in seven North Carolinians over the age of 65. In North Carolina, over 160,000 people are living with Alzheimer's disease, a number projected to increase to more than 210,000 by 2025. Because Alzheimer's disease is underdiagnosed, up to half of the estimated number of people with Alzheimer's may not know they have it. Dementia is a set of symptoms caused by underlying brain malfunction that typically includes memory loss, language difficulty, and impaired judgment. Alzheimer's disease is the most common (and arguably the most well-known) of several brain disorders that cause dementia.

Alzheimer's disease is a terminal illness, the fifth leading cause of death in North Carolina, and the only top 10 cause of death that cannot be cured, prevented, or slowed. Age is the primary known risk factor for dementia. The rates of Alzheimer's disease and related dementias increase as people get older. Genetic predisposition, or family history, is another significant risk factor for developing Alzheimer's disease or related dementia. Other potential risk factors may be modifiable through behavior and lifestyle changes including physical activity, educational attainment, occupation, diabetes, cardiovascular disease, hypertension, obesity, depression, and social and cognitive engagement, among others.

Alzheimer's disease and related dementias have a significant impact on affected families. The Alzheimer's Association estimates that 448,000 North Carolinians provided \$6.2 billion in unpaid care for loved ones with dementia in 2014.

### ***The Task Force on Alzheimer's Disease and Related Dementias***

In March 2015, the North Carolina Institute of Medicine (NCIOM), in partnership with the North Carolina Department of Health and Human Services Division of Aging and Adult Services, convened a statewide, multi-stakeholder Task Force on Alzheimer's Disease and Related Dementias. The Task Force was funded by AARP NC, the Alzheimer's Association, Alzheimer's NC, Carol Woods, Carolina Meadows, the Duke Endowment, LeadingAge NC, the North Carolina Department of Health and Human Services Division of Aging and Adult Services, Southminster, and the Winston-Salem Foundation. Through a mandate from the North Carolina General Assembly, Senate Bill 744 (2014), the Task Force was charged with developing an actionable strategic plan for the state of North Carolina that would address 16 topics as they related to Alzheimer's disease and related dementias. The Task Force recommendations aim to improve statewide awareness and education about Alzheimer's disease and related dementias; support people with dementia and their families; improve and enhance services that support greater quality of life; reach underserved populations; and improve data collection and research around treatment and prevention of Alzheimer's disease and related dementias. In the executive summary, the recommendations are briefly summarized. More detailed recommendations are provided in the chapters of this report. Recommendation numbers correspond to the chapter of the report in which they are listed.

### **Raising Awareness About Alzheimer's Disease and Related Dementias**

Partnering with existing public health promotion efforts is one way to educate the public about Alzheimer's disease and related dementia. Public health messages need to incorporate dementia-specific information including brain health promotion, signs and symptoms of dementia, early detection, available resources, and care planning following diagnosis. **Recommendation 3.1: Increase awareness and promote education about Alzheimer's disease and related dementias and available resources through incorporating Alzheimer's disease and related dementia-specific information in current health promotion and education programs.**

The United States Preventive Services Task Force suggests that health care providers conduct assessments for cognitive impairment whenever there are symptoms that may indicate dementia or mild cognitive impairment. To increase accurate diagnosis, there is a need for enhanced training for health care providers, particularly around detection and assessment tools, benefits of early detection, referrals to services, and the importance of improved care systems for people with dementia. **Recommendation 3.2: Enhance training for health care providers on the benefits and best practices for detection, diagnosis, and services referrals of Alzheimer's disease and related dementias.**

The vision of the Task Force is for North Carolina's communities and systems to be "dementia-capable," meaning that communities and systems will consider the impact of dementia on all aspects of the community, including services eligibility, information distribution and access, caregiver services, safety, workforce training, family decision making and planning, daily interactions for workers and other community members, and community preparedness. **Recommendation 3.3: Create a collective impact partnership to develop and establish dementia-capable pilot communities.**

The Task Force identified the importance of collaborative work to address dementia in North Carolina, as well as the need for a multi-stakeholder process and leadership to achieve the Task Force goals. **Recommendation 3.4: Establish statewide coordinated leadership to oversee the state plan on Alzheimer's disease and related dementias.**

### Having Supportive Options That Foster Quality Of Life

Nearly all people with Alzheimer's disease or related dementia will require long-term services and supports of some kind. There are a broad range of long-term services and supports, which provide varying levels of medical care and non-medical care, including assistance with activities of daily living. Long-term services and supports can be provided in the home, in a community setting, or in a designated long-term care facility.

For families needing long-term services and supports for family members with Alzheimer's disease or related dementias, the array of options can be extremely difficult to navigate. Adding to this difficulty is the confusion of determining eligibility for services. Costs for long-term services and supports can be staggeringly high: in 2013, the median annual price for a nursing home in North Carolina was \$77,471, much of which is not covered by private insurance. **Recommendation 4.1: Promote appropriate care settings for people with Alzheimer's disease and related dementia, including home- and community-based settings, institutional settings, and hospice and palliative care when appropriate.**

Palliative care and hospice care both aim to manage symptoms, and palliative care is more broadly applied to people throughout the course of disease, not solely in the last few months of life. Models of palliative care include consult teams within hospitals, and home-based palliative care. **Recommendation 4.2: Examine methods of reimbursement and incentives for Alzheimer's disease and related dementia care through new models of care, including care management services and palliative care before people with Alzheimer's disease and related dementia are hospice eligible.**

Because the number of North Carolinians with Alzheimer's disease and related dementia is projected to rise substantially in the coming decades, it is increasingly important that the state and health systems understand the increased need for dementia care, and develop a deeper understanding of current capacity and projected needs. **Recommendation 4.3: Assess health system capacity for people with Alzheimer's disease and related dementias.**

Research has shown that dementia can be reliably diagnosed using detection and assessment tools administered through telehealth. Telehealth services can be especially helpful for these individuals for whom transportation often poses a challenge. Technological solutions can also be helpful for non-health care services, including home monitoring of people with dementia. **Recommendation 4.4: Improve telehealth services for people with Alzheimer's disease and related dementias.**

All 100 counties in North Carolina have transportation services that can provide assistance to those residents needing help getting to health care and other necessary services. However, rules and regulations from the Department of Transportation and the Department of Health and Human Services on who can be transported and how much support is provided can limit accessibility for people with Alzheimer's disease or related dementia. **Recommendation 4.5: Increase access to medical and community services for people with Alzheimer's disease and related dementia through improved transportation services through an inter-departmental working group.**

The Task Force identified strategies of person-centered care as a key component of improving quality of care for people with Alzheimer's disease and related dementias. The core of person-centered care consists of health care and social services professionals at all levels working collaboratively with the individuals who use their services and their families, and affording people dignity, compassion, and respect. **Recommendation 4.6: Apply principles of person-centered care to the care processes and protocols at health care providers and facilities for people with Alzheimer's disease and related dementias.**

Existing measures for evaluating quality of care within health care facilities often do not adequately address many of the issues around quality of care specific to dementia. **Recommendation 4.7: Improve quality of care and care coordination for people with Alzheimer's disease and related dementia through improved ratings systems and dementia-specific indicators.**

The wide variety of care needs for people with Alzheimer's disease and related dementia, the progressive nature of these conditions, and the high rate of co-occurring chronic diseases, mean individuals often receive care from a wide range of providers and in multiple settings. Care coordination, which aims to improve communication among health care and service providers and to connect patients and family with needed

services, can reduce the need for hospitalizations and increase efficiency in care delivery for individuals with dementia. **Recommendation 4.8: Improve care coordination for people with Alzheimer's disease and related dementia through new models of care.**

Many health systems are developing approaches to improve quality of care and enhance the ability to care for people with Alzheimer's disease and related dementias in initiatives known as Dementia Friendly Hospitals. **Recommendation 4.9: Expand the Dementia Friendly Hospital initiative.**

It is crucial to improve Alzheimer's disease and related dementia-specific capabilities of the health professional workforce. One important way to improve health professional skill in caring for people with Alzheimer's disease and related dementia is to offer enhanced training and incentives for health professionals. **Recommendation 4.10: Promote Alzheimer's disease and related dementia-specific training for health professionals and community workforce.**

**Recommendation 4.11: Incentivize entry into geriatric and gerontology specialization and additional training in dementia care.**

The Task Force also discussed the important role that frontline staff, such as nursing assistants and paid caregivers, play in providing care to individuals with dementia and the need to enhance their skills (with commensurate enhanced wages) to decrease turnover. **Recommendation 4.12: Increase compensation based on Alzheimer's disease and related dementia-specific training and certification.**

### **Supporting Caregivers And Families Touched By The Disease**

Adult children and spouses often serve as caregivers for people with Alzheimer's disease and related dementias. An estimated 448,000 people, or almost three per individual in North Carolina, provided unpaid care for family members with dementia in 2014. Caregivers often miss work, must handle the logistics of finding additional care, and may experience increased stress, anxiety, and depression, as well as adverse physical effects.

Services such as adult day care, home delivered meal services, transportation, caregiver support groups, and respite care can provide much-needed assistance to caregivers and delay the need for out-of-home placement. Studies show that respite care and other supports, when coupled with education and ongoing support, reduce caregiver stress and burnout. Unfortunately, such resources are limited and caregivers often experience difficulty in learning about available resources, accessing these resources, and/or identifying the resources for which they may be eligible. **Recommendation 5.1: Promote integration and accessibility of dementia-specific resources through a comprehensive caregiver toolkit and virtual resource center.**

**Recommendation 5.2: Ensure adequate funding for family caregiver support services including dementia-specific respite through NC Project C.A.R.E.**

**Recommendation 5.3: Continue No Wrong Door Initiative through a collaboration with NC 2-1-1.**

Many caregivers for people with Alzheimer's disease and related dementia face logistical and financial difficulties in caring for their family members, especially with regards to employment. Caregivers may risk their jobs when caring for family members because they do not have sick leave benefits for caregiving. In the 2015 North Carolina legislative session, AARP NC, in collaboration with a broad array of partners, sought legislation that would allow employees to use existing sick leave benefits for caregiving for family members, and also to allow employees to take short, unpaid leave for family members' illness, injury, or medical needs. The bill, House Bill 816, was rewritten to broadly study the needs of working caregivers. Passed unanimously by the House, this bill is currently in the Senate Rules Committee. **Recommendation 5.4: Enhance employer policies to support family caregivers.**

Home- and community-based services are generally designed to supplement and improve care provided in the home of older adults, to assist unpaid caregivers, and to delay institutionalization. These programs may include services such as in-home care, respite programs, adult day care, transportation services, and nutrition programs such as home-delivered meals. Funding streams for these programs vary, as does eligibility criteria. Many of these services are those that, if provided, could prevent or delay institutionalization.

The North Carolina General Assembly established the Home and Community Care Block Grant in 1992 to provide home- and community-based services to older adults in North Carolina (NCGS § 143B-181.1(a) (11)). These services target non-Medicaid-eligible older adults in the state. Funding for the block grant comes from federal (49%) and state (51%) funds and is administered at the county level. Total aggregate funding has remained flat at \$61 million over the last three years, despite increasing numbers of older

adult North Carolinians and increasing costs of services. In fiscal year 2015, there were approximately 9,700 individuals statewide on the waiting list for services through the Home and Community Care Block Grant. The total cost for providing needed services for those on the waiting list would be approximately \$19.6 million. **Recommendation 5.5: Examine outcomes and impact of home- and community-based services programs.**

Medicaid Home and Community Based Service (HCBS) waivers, including Community Alternatives Program for Disabled Adults (CAP/DA) waiver and the Community Alternative Program for Choice (CAP/Choice), serve a very limited number of low-income individuals with dementia and operate with long wait lists. These waivers cover services including adult day care, personal care, and caregiver respite services. Recent studies have shown that HCBS waiver programs are likely to be cost-effective over time. **Recommendation 5.6: Expand the Medicaid Home and Community Based Services Waiver Program.**

In addition to identifying expanded funding opportunities, particularly those that will result in savings to the state for long-term services and supports, there is also an urgent need to coordinate the variety of home- and community-based services funded at the state level, through Medicaid, Area Agencies on Aging, county agencies, Medicare, and private insurers. **Recommendation 5.7: Implement best practices for the integration and coordination of home- and community-based services.**

### Promoting Meaningful Participation In Community Life

Cognitive function decline accompanies the progress of Alzheimer's disease and related dementias. As cognitive capacity is lost, individuals are at greater risk for abuse, neglect, and exploitation. In addition, the safety of an individual with Alzheimer's disease and related dementia can be significantly impacted by the disease, both within the home setting and in public.

If an individual's disease has progressed to the point where he or she is no longer able to handle finances, make health care decisions or other important life decisions, and advance directives have not been put in place, then a legal guardian may need to be appointed by the courts to act on behalf of the incapacitated individual.

Planning for long-term care, including payment for these services and dealing with guardianship, is crucial for families facing Alzheimer's disease or related dementia. For medical decision making, individuals diagnosed with Alzheimer's disease and related dementias should complete documentation, such as advanced health care directives, early in their illness in order to assist their families once the individual is no longer capable of making health care decisions. **Recommendation 6.1: Increase awareness of legal protections and vulnerabilities of people with Alzheimer's disease and related dementia.**

In addition to educating individuals with Alzheimer's and their families, there is a need to educate health and legal professionals about the legal protections for people with Alzheimer's disease or related dementia. In order to provide the greatest benefit, there should be interdisciplinary commitment to this type of training. **Recommendation 6.2: Incorporate legal protection issues specific to people with Alzheimer's disease and related dementias into health, legal, and financial professional training.**

In the 2014 legislative session, House Bill 817 was introduced and passed the House with a unanimous vote. This bill, the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (often referred to as UAGPPJA), would propose a set of rules for transferring guardianship from one state to another, allow states to recognize other states' guardianship orders, and create a process for establishing guardianship jurisdiction. The bill is currently in the Senate Rules Committee. North Carolina is one of only eight states that has not passed similar legislation. In addition, there is a need for a comprehensive, statewide, collaborative approach to continuing and enhancing work toward legal protections for individuals with Alzheimer's disease or related dementia and their families. **Recommendation 6.3: Examine state statutes to determine adequate legal safeguards and protections for people with Alzheimer's disease and related dementia.**

To provide the necessary tools for counties to view information on vulnerable adults from county to county and to enhance their protection from abuse, neglect, and exploitation, North Carolina needs an integrated Case Management System. Incorporating North Carolina Accessing Families Through Technology (NC FAST), the statewide public assistance and data management and integration system, will allow individuals to more efficiently and effectively receive services. **Recommendation 6.4: Integrate elder fraud and abuse data to improve services for people with Alzheimer's disease and related dementia.**

Studies show an annual falls incidence as high as 60% among individuals with dementia. People with Alzheimer's and related dementias are three times more likely to suffer from hip fractures due to falls

than other older adults, and this may lead to people no longer being able to stay in their homes. Home environmental assessments can be used to develop a care plan to improve mobility and safety of an individual with Alzheimer's disease or related dementia. Other evidence-based practices include training caregivers on dementia care and home safety. Many innovative assistive technological resources also can improve home safety and quality of life for individuals afflicted with Alzheimer's disease or related dementia.

**Recommendation 6.5: Improve home safety resources and workforce capacity.**

As Alzheimer's disease and related dementias progress, individuals increasingly face behavioral symptoms, such as wandering or getting lost, that may pose a safety threat to themselves or to others in the community. North Carolina's Silver Alert program helps protect individuals that suffer from dementia or other cognitive impairment. Decline in cognitive function also affects individuals' ability to drive safely. Law enforcement and first responders are often called on when an individual goes missing or exhibits behavioral symptoms that pose a threat to others; however, they are not currently required by law in North Carolina to be trained on symptoms or management of dementia. Existing training modules could be used to increase law enforcement personnel and first responders' understanding of dementia and how to interact with individuals with dementia and their caregivers. **Recommendation 6.6: Enhance public safety and law enforcement outreach around Alzheimer's disease and related dementia.**

### Reaching Those Who Are Underserved

Several populations are disproportionately affected by Alzheimer's disease and related dementia, including people with intellectual and/or developmental disabilities (particularly those with Down's syndrome) and a number of minority populations. Compared to non-Latino whites, Latinos and African Americans are at a higher risk for developing Alzheimer's disease.

There are also wide discrepancies in the ability of individuals with Alzheimer's disease or related dementia to pay for care and services. In 2014, the median income for North Carolinians over 65 was \$35,204. People and families with incomes at the poverty level, as well as middle class families, do not qualify for Medicaid and often face difficulty in paying for any care not covered by Medicare or private insurance. **Recommendations that are important to reaching underserved populations and addressing disparities in diagnosis, care, and outcomes include: 3.1, 4.1, 4.3, 4.4, 4.5, 4.8, 5.1, 5.2, 5.5, 5.6, 6.1, 6.3, 6.4, 7.1, 7.2, 7.3, 7.4.**

Although Alzheimer's disease affects approximately 5.3 million Americans and costs the federal government up to \$215 billion annually, federal funding for research on Alzheimer's lags behind other major diseases. In 2014, Duke University and the University of North Carolina at Chapel Hill, along with other academic research institutions, launched the North Carolina Regional Consortium for Brain Health in Aging. The consortium aims to create a statewide registry of healthy individuals and diagnosed dementia patients to inform research into dementia treatment and prevention, and to promote opportunities for participation in clinical trials with a focus on underserved populations. **Recommendation 7.1: Support Alzheimer's disease and related dementia research through the establishment of a statewide collaborative registry.**

Data plays a critical role in achieving the goals of the Task Force by both raising awareness of the scope of Alzheimer's disease in our state, and measuring progress towards improved services, care, and potential treatments for Alzheimer's disease and related dementias. While census data and large population-based studies provide an estimate of prevalence, Alzheimer's and other dementias are significantly underdiagnosed.

In 2011, the North Carolina Behavioral Risk Factor Surveillance Survey (BRFSS) included a Centers for Disease Control and Prevention Healthy Aging Program-developed module on cognitive impairment. The BRFSS also offers a module consisting of questions about caregiving that captures data including the impact of caregiving on caregivers' health and well-being. The Task Force identified continued inclusion of the cognitive impairment and caregiver modules as a necessary component of improving data and understanding of the impact of dementia and resulting caregiving on North Carolina. **Recommendation 7.2: Continue periodic inclusion of cognitive impairment and caregiver modules of the Behavioral Risk Factor Surveillance System.**

Death certificates are an important source of data on the prevalence of dementia. However, research has shown that Alzheimer's disease in particular is underreported as cause of death on death certificates. **Recommendation 7.3: Improve prevalence data through accurate death certificate completion.**

Several states have created all-payer claims data (APCD) systems to help provide state-level data that can improve accuracy of prevalence data for all conditions, including dementia. The data included in APCD systems generally consists of claims data from health care providers and insurers. North Carolina stakeholders have begun to examine the possibility of creating a similar APCD or confederated data system to capture

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data from multiple existing data systems that could be used in North Carolina to study population health, cost, and quality issues across the state. **Recommendation 7.4: Improve data on Alzheimer’s disease and related dementia prevalence through implementing a statewide data reporting system.**