Alzheimer’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, AARP North Carolina, Alzheimer’s NC, the Alzheimer’s Association, the Duke Endowment, the Winston-Salem Foundation, and LeadingAge North Carolina, convened a statewide, multi-stakeholder Task Force on Alzheimer’s Disease and Related Dementias. 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 this issue brief, the recommendations are briefly summarized. More detailed recommendations and background information are provided in the chapters of this report. Recommendation numbers correspond to the chapter of the report in which they are listed.

### Raising Awareness And Transforming Attitudes

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 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. 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. **Recommendation 3.3: Create a collective impact**
 Increasing the knowledge and skills of those who work with individuals with Alzheimer’s and their families, including health professionals, community-based providers, and those providing direct care, is crucial to improving overall care. **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.

**Recommendation 4.12:** Increase compensation based on Alzheimer’s disease and related dementia-specific training and certification.

**Supporting Caregivers And Families**

Adult children and spouses often serve as caregivers for people with Alzheimer’s disease and related dementias. An estimated 448,000 North Carolinians, almost three per individual with Alzheimer’s disease, provided unpaid care for family members with dementia in 2014. Caregivers often miss work and may experience increased stress, anxiety, and depression, as well as adverse physical effects. Services such as adult day care, meal delivery services,
Promoting Meaningful Participation In Community Life

Cognitive function decline accompanies the progress of Alzheimer’s disease and related dementias. Planning for long-term care, including payment for these services and dealing with guardianship, is crucial for families facing Alzheimer’s disease. 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.

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 advanced 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. As cognitive capacity is lost, individuals are at greater risk for abuse, neglect, and exploitation. Recommendation 6.1: Increase awareness of legal protections and vulnerabilities of people with Alzheimer's disease and related dementia.

In addition to educating individuals and their families, there is a need to educate health, legal, and financial professionals about the legal protections for people with Alzheimer’s disease or related dementia. Recommendation 6.2: Incorporate legal protection issues specific to people with Alzheimer’s disease and related dementias into health, legal, and financial professional training.

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, which could be built into the North Carolina Accessing Families Through Technology (NC FAST) system. Recommendation 6.4: Integrate elder fraud and abuse data to improve services for people with Alzheimer's disease and related dementia.

The safety of an individual with Alzheimer’s disease or related dementia can be significantly impacted by the disease, both within the home setting and in public. Studies show an annual falls incidence as high as 60% among individuals with dementia. Home environmental safeguards and protections for individuals with Alzheimer’s disease or related dementia 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. As 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 to be trained on symptoms or 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. Compared with 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 with incomes at poverty and 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. In 2011, the North Carolina Behavioral Risk Factor Surveillance Survey (BRFSS) included a module on cognitive impairment. The BRFSS also offers a module consisting of questions about caregiving. Continued periodic inclusion of the cognitive impairment and caregiver modules is critical to 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. North Carolina stakeholders have begun to examine the possibility of creating an APCD or confederated data system to capture data from multiple existing data systems that could be used 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.

A copy of the full report, including background information and complete recommendations, is available on the North Carolina Institute of Medicine website: www.nciom.org

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