Chapter One: Introduction: Dementia-Capable North Carolina: A Strategic Plan for Addressing Alzheimer's Disease and Related Dementias

Alzheimer's disease is the most common form of dementia[a], with approximately 60-80% of dementias classified as Alzheimer's disease.[1] In North Carolina, over 160,000 people are living with Alzheimer's disease, a number projected to increase more than 31% by 2025.[2,3] Alzheimer's disease is the only cause of death in the top 10 that cannot be cured, prevented, or slowed.[4]

Alzheimer's disease and related dementias also have a significant impact on caregivers in North Carolina. The Alzheimer's Association estimates that 448,000 North Carolinians provided $6.2 billion in unpaid care for loved ones with dementia in 2014.[5] As their family members require a higher degree of care, caregivers often experience increased stress, anxiety, and depression and incur higher average medical costs themselves.[6] Family caregiving can also have an impact on employee productivity: national employers report a productivity loss of nearly $33.6 billion, with an average cost per full-time employee caregiver (for all conditions) at $2,110.[7]

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, 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. (See Figure 1.1) The Task Force was chaired by Goldie S. Byrd, PhD, Dean, College of Arts and Sciences, North Carolina A&T State University; Doug Dickerson, MBA, State Director, AARP NC; and Lisa Gwyther, MSW, CSW, Associate Professor, Department of Psychiatry and Behavioral Sciences, Center for the Study of Aging and Human Development, Duke University Medical Center. The Task Force was supported by a multidisciplinary Steering Committee comprised of senior program level staff from the North Carolina Department of Health and Human Services Division of Aging and Adult Services, LeadingAge, University of North Carolina, Monarch, the North Carolina Coalition on Aging, Alzheimer's NC, and the Alzheimer's Association (Western North Carolina Chapter). The Steering Committee met on a monthly basis between scheduled Task Force meetings and contributed expert content to the planning of Task Force meetings, clarified issues of relevance for the Task Force, and identified speakers to present expert research at Task Force meetings.

Figure 1.1: Development of Strategic State Plan for Alzheimer's Disease and Related Dementias

1. Statewide awareness and education
2. Early detection and diagnosis
3. Care coordination
4. Quality of care
5. Health care system capacity
6. Training for health care professionals
7. Access to treatment
8. Home- and community-based services
9. Long-term care
10. Caregiver assistance
11. Research
12. Brain health
13. Data collection
14. Public safety and safety-related needs of individuals with Alzheimer's disease
15. Legal protections for individuals living with Alzheimer's disease and their caregivers
16. State policies to assist individuals with Alzheimer's disease and their families

Source: Session law 2014-100 Senate bill 744. Raleigh, NC. 2014; 100:12d. F-12d.F.

The Task Force met 10 times throughout 2015-2016, and developed an actionable, goal-oriented state plan which addresses the topics described by the General Assembly. The state plan provides policymakers, funders, and stakeholder organizations with a common vision and action steps to address Alzheimer's disease and related dementias and their effect on our state. 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.

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[a] "Dementia" is a more general term that is used to describe a range of symptoms related to a decline in cognitive skills or memory, and/or that impair ability to perform daily activities

Organization of This Report

This report examines the scope of the impact of Alzheimer's disease and related dementias in North Carolina, including impact on families, caregivers, and communities. The Task Force emphasizes the importance of working with state, local, and other stakeholders to address the ways in which changing demographics in our state will increase health care costs, reduce the number of caregivers, and increase reliance on state systems for people with dementia and their families. This report outlines a strategic plan for a dementia-capable North Carolina.

The Task Force studied the recent Dementia Friendly America Initiative, a national project currently funding 15 pilot projects for collaborative efforts towards creating dementia-friendly communities (see Chapter 3 for additional information on Dementia Friendly America). The Task Force identified the five Dementia Friendly America work areas as an organizational guideline for the report and recommendations. These areas are:

> **“ 448,000 North Carolinians provided $6.2 billion in unpaid care for loved ones with dementia in 2014.**

1. Raising awareness about dementia and transforming attitudes.
2. Having supportive options that foster quality of life.
3. Supporting caregivers and families touched by the disease.
4. Promoting meaningful participation in community life.
5. Reaching those who are underserved.

The report recommends action steps to enhance work currently being done to address dementia, and builds on this work to ensure adequate preparation for North Carolinians affected by Alzheimer's disease and related dementias. The Task Force has identified and listed lead organizations and/or partner organizations responsible for implementing each recommendation. For recommendations with only partner organizations listed, the Task Force intends shared responsibility for implementation.

This report contains eight chapters and an Executive Summary:

Chapter One: Introduction to the Task Force on Alzheimer's Disease and Related Dementias

Chapter Two: Overview of Alzheimer's Disease and Related Dementias

Chapter Three: Raising Awareness About Alzheimer's Disease and Related Dementias

- Statewide Awareness and Education
- Brain Health
- Early Detection and Diagnosis
- Statewide Policies

Chapter Four: Having Supportive Options That Foster Quality of Life

- Health System Capacity
- Access to Treatment
- Long-Term Services and Supports
- Quality of Care
- Care Coordination
- Health Professional Training

Chapter Five: Supporting Caregivers and Families Touched by the Alzheimer's Disease or Related Dementias

- Caregiver Supports and Services
- Home- and Community-Based Services

CAREGIVER **SPOTLIGHT**

Bill Smutny
Hendersonville, NC

> " Laura, my wife, was an intelligent, vibrant woman in her late 50's when little things started to go awry. To the outside world, Laura appeared to be the same person, but they didn't see her capabilities changing from day to day. Nothing major, nothing extraordinary, just the "little things" that kept adding up. We weren't sure what was happening let alone how to deal with it all. This was more than just memory loss; everything from logic to coordination began to be affected. "

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