

# **Dementia - Capable North Carolina:** A Strategic Plan for Addressing Alzheimer's Disease and Related Dementias



**North Carolina  
Institute of Medicine**  
in Partnership with the  
North Carolina  
Department of Health and  
Human Services; Division of  
Aging and Adult Services

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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 North Carolina; 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's work would not have been possible without their leadership.

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# **DEMENTIA-CAPABLE NORTH CAROLINA: A STRATEGIC PLAN FOR ADDRESSING ALZHEIMER'S DISEASE AND RELATED DEMENTIAS**

## **EXECUTIVE SUMMARY**

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 North Carolina, 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;

**DEVELOPMENT OF STRATEGIC STATE PLAN FOR ALZHEIMER'S DISEASE**

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

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 DEMENTIA 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 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 know 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 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.**

## 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<sup>a</sup>, with approximately 60-80% of dementias classified as Alzheimer's disease.<sup>1</sup> In North Carolina, over 160,000 people are living with Alzheimer's disease, a number projected to increase more than 31% by 2025.<sup>2,3</sup>

Alzheimer's disease is the only cause of death in the top 10 that cannot be cured, prevented, or slowed.<sup>4</sup>

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.<sup>5</sup> 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.<sup>6</sup> 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.<sup>7</sup>

#### *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 North Carolina, the Alzheimer's Association, 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))<sup>8</sup>, 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.)

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<sup>a</sup> "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

**Figure 1.1: DEVELOPMENT OF STRATEGIC STATE PLAN FOR ALZHEIMER'S DISEASE<sup>8</sup>**

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 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.

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.

### ***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:

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.

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

Chapter Six: Promoting Meaningful Participation in Community Life

Legal Protections

Safety-Related Issues for People with Alzheimer's Disease or Related Dementias

Chapter Seven: Reaching Those Who Are Underserved

Underserved Populations

Data Collection

Research

Chapter Eight: Listing of Full Recommendations

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## CHAPTER TWO: OVERVIEW OF ALZHEIMER’S DISEASE AND RELATED DEMENTIAS

### *What is Alzheimer’s Disease and Related Dementia?*

Dementia is a set of symptoms caused by underlying brain malfunction that typically includes memory loss, language difficulty, and impaired judgment.<sup>1</sup> Alzheimer’s disease is the most common (and arguably the most well-known) of several brain disorders that cause dementia. According to the Alzheimer’s Association, 60-80% of dementia cases are attributable to Alzheimer’s disease.<sup>2</sup> Alzheimer’s disease can be confirmed only upon autopsy by the presence of amyloid plaque and neurofibrillary tangles of tau protein in the brain. In life, Alzheimer’s is diagnosed through cognitive testing, but the diagnosis is not definitive.<sup>3</sup> Alzheimer’s disease is a terminal illness, and the only top 10 cause of death that cannot be cured, prevented, or slowed.<sup>4</sup>

For the purposes of this report, both “Alzheimer’s disease” and “dementia” will be used, as well as “Alzheimer’s disease and related dementias.” These phrases can be understood to encompass Alzheimer’s disease as well as forms of dementia that present symptoms similar to those of Alzheimer’s disease.

**Figure 2.1. Most Common Types and Symptoms of Dementia<sup>2,5</sup>**

<b>Type of Dementia</b>	<b>Description</b>	<b>Symptoms</b>
Alzheimer’s Disease	Alzheimer’s disease damages nerve cells in the brain, and symptoms worsen over time as more cells are damaged. It is characterized by the presence of amyloid plaques and tau tangles in the brain. Both early- and late-onset Alzheimer’s have a genetic component.	Severe forgetfulness Changes in mood Confusion Difficulty concentrating or multitasking Getting lost in familiar places
Cerebrovascular/ Vascular Dementia	Cerebrovascular dementia happens when clots block blood flow to the brain and kill brain cells. People with this type of dementia may also have high blood pressure, heart disease, high cholesterol, and/or diabetes. It is considered the second most common type of dementia.	Memory loss Difficulty focusing/concentrating Confusion Symptoms often occur suddenly, then stabilize before occurring again
Mixed Dementia	Experts estimate that up to 45% of people with dementia have both Alzheimer’s disease and vascular dementia.	Same as above
Lewy Body Disease/Dementia with Lewy Bodies (DLB)	DLB occurs when abnormal proteins called Lewy Bodies form in nerve cells in the brain.	Memory loss Confusion Difficulty with movement Excessive sleepiness Hallucinations
Frontotemporal Lobar	This rare type of dementia occurs in the front and sides of the brain, and tends to occur in	Personality changes

Degeneration/ Frontotemporal Dementia (FTD)	younger people and progress more quickly than Alzheimer's disease.	Difficulty with judgment and social skills Poor financial or personal decisions Feelings of disconnectedness
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Source: Alzheimer's Association. Aging, Memory Loss, and Dementia: What's the Difference? Chicago, IL: Alzheimer's Association. [http://www.alz.org/mnnd/documents/aging\\_memory\\_loss\\_and\\_dementia\\_what\\_is\\_the\\_difference.pdf](http://www.alz.org/mnnd/documents/aging_memory_loss_and_dementia_what_is_the_difference.pdf). Accessed July 27, 2015.

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Often, early symptoms of Alzheimer's disease or related dementias are confused with symptoms of normal aging. Symptoms of normal aging include occasional confusion or forgetfulness, such as forgetting someone's name or the day of the week (and remembering later), or losing an item every now and then. Alzheimer's disease, by contrast, is progressive and degenerative, meaning symptoms get worse over time.

Unlike in normal aging, Alzheimer's disease and related dementias are accompanied by physiological changes in the brain that result in severe mental deterioration that far exceeds normal cognitive decline.<sup>2</sup> Early signs and symptoms of Alzheimer's disease include: memory loss that disrupts daily life, changes or challenges in ability to solve problems, difficulty with familiar tasks, confusion about familiar places or time, vision problems, problems with vocabulary and conversation, frequently losing items, poor decision-making or judgment, withdrawal from professional and leisure activities, and personality and mood changes.<sup>6,7</sup>

There is growing evidence that Alzheimer's disease begins with structural changes in the brain that occur years before symptoms arise.<sup>8</sup> Symptoms begin during the phase of Mild Cognitive Impairment (MCI) or early Alzheimer's disease. Daily functioning is unaffected in people with MCI, but higher-level cognitive skills begin to erode. Some people that develop MCI never develop Alzheimer's disease.<sup>8</sup> For those that do develop Alzheimer's, the disease progresses through stages as symptoms develop and worsen, resulting in the loss of cognitive ability and increased dependence on caregivers. The middle stage of the disease is often characterized by a loss of ability to perform an increasing number of tasks including driving, grocery shopping, and paying bills. In the terminal stages of Alzheimer's disease or related dementias, a person may lose all ability to learn, speak, eat, use the toilet, and recognize their loved ones.<sup>8</sup>

### ***Prevalence of Alzheimer's Disease and Related Dementias***

While it is difficult to estimate overall prevalence of dementia, the U.S. Preventive Services Task Force estimates that up to 5.5 million Americans have dementia (including Alzheimer's disease), with rates increasing with age. Five percent of people ages 71 to 79 years have dementia. This number jumps to 24% for those ages 80 to 89 years, and 37% for those older than 90 years.<sup>9</sup>

It is estimated that 5.3 million Americans have Alzheimer's disease, and Alzheimer's disease is the sixth leading cause of death nationally.<sup>10</sup> In North Carolina, over 160,000 people are estimated to be living with Alzheimer's disease.<sup>10</sup> Alzheimer's disease is the fifth leading cause of death in North Carolina, and was responsible for 2,872 deaths in 2012.<sup>11</sup> Americans are now living longer than ever before, and particularly as the baby boomer generation ages, the United States will have to contend with a rapidly growing population of people with Alzheimer's disease or related dementias. For people over the age of 65, the rate of Alzheimer's doubles every five years.<sup>8</sup> One in three people over 85 has Alzheimer's disease.<sup>12</sup> The Alzheimer's Association projects that by 2025, 7.1 million Americans will have Alzheimer's. North Carolina is projected to have 210,000 residents over the age of 65 living with Alzheimer's disease in 2025, an increase of 31.3%.<sup>10</sup> This figure will represent nearly 1 in 10 of the over-65 population. Because Alzheimer's disease is underdiagnosed, up to half of the estimated number of people with Alzheimer's may not know they have it.<sup>13</sup>

### ***Who is at Risk for Alzheimer's Disease and Related Dementias?***

Age is the primary known risk factor for dementia, including late onset Alzheimer's disease.<sup>14</sup> As noted above, 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, and there is evidence to suggest that gene expression – the process by which genes are “switched” on or off due to environmental or behavioral factors – may also play a role in the development of Alzheimer's.

There are other potential risk factors for Alzheimer's disease and related dementias that may be modifiable through behavior and lifestyle changes. Modifiable risk factors that have been linked to Alzheimer's disease include physical activity, educational attainment, occupation, diabetes, cardiovascular disease, hypertension, obesity, depression, and social and cognitive engagement, among others.<sup>15</sup>

A small percentage (approximately 200,000) of the 5.3 million Americans with Alzheimer's disease have young onset Alzheimer's disease. This disease is diagnosed before age 65 and individuals may get it as young as 30 or 40 years old. The symptoms are the same and preparation needs to be made for long-term care. The young onset form of Alzheimer's disease occurs as a result of mutations in one of three specific and rare genes – the gene for the amyloid precursor protein (APP), and the genes for the presenilin1 and presenilin 2 proteins. Individuals who inherit a mutation to any of these are guaranteed to develop Alzheimer's disease well before age 65. This type of Alzheimer's is called familial Alzheimer's and many family members in multiple generations can be affected.<sup>b</sup>

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<sup>b</sup> Byrd G. Professor of Biology and Dean. College of Arts and Sciences, North Carolina A&T State University. Written (email) communication. February 4, 2016. Feb. 4, 2016

History of traumatic brain injury is another risk factor for dementia. Studies have shown that a moderate or severe traumatic brain injury can result in a two- to four-fold increase in dementia risk. While it is unclear if mild traumatic brain injuries result in an increased risk of dementia, there is some evidence that individuals who experience multiple mild traumatic brain injuries, such as repeated minor concussions of the sort often experienced by boxers and football players, may be at increased risk for dementia later in life.<sup>16</sup> Traumatic brain injury among older adults, even when seemingly mild, can contribute to cognitive decline.<sup>c</sup>

Compared to non-Latino whites, Latinos and African Americans are at a higher risk for developing Alzheimer's disease.<sup>17</sup> In the 65-74 age group, African Americans have the highest prevalence of Alzheimer's disease at 9.1%, compared to 7.5% for Latinos and 2.9% for non-Latino whites. For individuals over 85, Latinos have a prevalence rate of 62.9%, compared to 58.6% among African Americans, and 30.2% among non-Latino whites.<sup>18</sup> Women are twice as likely to develop Alzheimer's as men.<sup>17</sup> While the full reasons for the gender disparity are unknown, experts agree that the primary reason is that women tend to live longer than men; age-specific incidence estimates of Alzheimer's and dementia (i.e. new cases) show no significant difference between rates for men and rates for women.<sup>13</sup>

Individuals with Down's syndrome also have a three- to five-times higher risk for Alzheimer's disease than the general population. Alzheimer's tends to develop at a younger age (40s or 50s) for people with Down's syndrome than for other adults. Autopsy results have shown that nearly all people with Down's syndrome have markers in the brain that are associated with Alzheimer's disease.<sup>19</sup>

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.

Bill Smutny, Hendersonville, NC

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<sup>c</sup> Byrd G. Professor of Biology and Dean. College of Arts and Sciences, North Carolina A&T State University. Written (email) communication. February 4, 2016. Feb. 4, 2016

## *Caring for People with Alzheimer’s Disease or Related Dementias*

People with Alzheimer’s disease or related dementias require increasingly intensive care as their disease progresses. Children and spouses are often the primary caregivers for people with Alzheimer’s or related dementias. In 2014, roughly 448,000 North Carolinians provided \$6.2 billion in unpaid care for loved ones with dementia (approximately 2-3 unpaid caregivers for each person with dementia).<sup>11</sup> During the early stages of Alzheimer’s, caregivers often assist with financial planning and major decision-making, but as the disease progresses they may also need to monitor wandering, behavioral problems, and be increasingly involved in activities of daily living. The intensive care needs associated with Alzheimer’s often require that caregivers take time off of work, hire additional help, and sometimes seek a care setting that offers around-the-clock skilled care. Caregivers experience high incidences of stress, anxiety, and depression and are more likely to incur higher medical costs themselves.<sup>21</sup>

**Figure 2.2. Caregiver Costs in North Carolina: Number of Alzheimer’s and dementia caregivers, hours of unpaid care, and costs of caregiving<sup>11</sup>**

<b>Year</b>	<b>Number of Caregivers</b>	<b>Total Hours of Unpaid Care</b>	<b>Total Value of Unpaid Care</b>	<b>Higher Health Costs of Caregivers</b>
<b>2012</b>	437,000	497,000,000	\$6,132,000,000	\$245,000,000
<b>2013</b>	442,000	504,000,000	\$6,272,000,000	\$252,000,000
<b>2014</b>	448,000	510,000,000	\$6,208,000,000	\$263,000,000

Source: Alzheimer’s Association. North Carolina Alzheimer’s statistics. Chicago, IL: Alzheimer’s Association: 2015. [http://www.alz.org/documents\\_custom/facts\\_2015/alz\\_ff\\_northcarolina.pdf?type=interior\\_map&facts=undefined&facts=facts](http://www.alz.org/documents_custom/facts_2015/alz_ff_northcarolina.pdf?type=interior_map&facts=undefined&facts=facts). Accessed September 21, 2015.

There are a variety of home- and community-based support services available to people caring for people with Alzheimer’s disease or related dementias. Meal services, adult day care, senior centers, caregiver support groups, and respite services are available in certain areas to assist caregivers.<sup>8</sup> Access to community services can alleviate caregiver stress and help prolong community living for individuals with Alzheimer’s or related dementias. Unfortunately, caregivers are not always aware of home- and community-based care options, and many communities have long waiting lists for such services. Certain caregiver interventions have demonstrated that connecting caregivers with community resources can extend the amount of time that caregivers are able to care for their loved one in the home rather than in a more costly care facility.<sup>22</sup> In some states, low-income caregivers can access a Medicaid waiver that will pay for these services. North Carolina’s Community Alternatives Program for Disabled Adults (CAP/DA) waiver covers home- and community-based services, but long waiting lists and limited availability (by county) make the waivers difficult to access for thousands of North Carolinians.<sup>22</sup>

Currently in North Carolina, the ratio of potential caregivers (people aged 45-64) to those who need care (over the age of 80) is 8:1. By 2030, there will only be four potential caregivers for every older adult in the state.<sup>24</sup> For a disease that requires intensive caregiving, the declining ratio of potential caregivers to potential dementia patients may mean that nursing homes and residential facilities will play an increasingly large role in caring for those with Alzheimer's disease and related dementia.

### ***Economic Impact of Alzheimer's Disease and Related Dementias***

The combination of formal and informal care that Alzheimer's disease and related dementias require makes it an extraordinarily costly disease. The total annual cost of Alzheimer's disease in the United States was between \$157 and \$215 billion in 2014. By 2040, if no vaccine, treatment, or cure is developed, Alzheimer's disease is projected to cost the nation between \$1.2 and \$1.6 trillion annually.<sup>8</sup>

Because they primarily afflict individuals over the age of 65, Alzheimer's disease and related dementias are especially costly to state budgets. Medicare, which is federally financed, pays for much of the medical care for those over 65. In North Carolina, for those who are eligible, Medicaid pays for most long-term services and supports in an institutional setting—a service that three-quarters of individuals with dementia rely on at some point. Because the average annual cost of care in a skilled nursing facility (commonly known as a nursing home) in North Carolina exceeds \$75,000,<sup>25</sup> many families cannot afford this care. Often, individuals of family members of those with Alzheimer's disease or related dementia will “spend down” assets to become eligible for Medicaid. In fact, Medicaid is the primary payer for two-thirds of nursing home residents.<sup>8</sup> Delaying placement in nursing homes or other long-term care facilities can have a great impact on Medicaid spending. (See Chapter 4 for additional information on long-term services, supports, and payment for medical and non-medical services.)

Individuals with Alzheimer's disease or related dementias also incur higher medical costs than their peers—costs that are largely borne by Medicare or Medicaid. The cognitive decline associated with the disease creates difficulty for patients managing multiple health conditions. People with Alzheimer's are hospitalized two to three times more frequently than their peers without Alzheimer's disease.<sup>8</sup> In particular, people with Alzheimer's are more likely to experience potentially avoidable hospitalizations related to a comorbid condition such as diabetes or heart disease.<sup>26,27</sup> The combined likelihood of hospitalization and institutionalization means that people with Alzheimer's are more costly to both Medicare and Medicaid than other older adults. Individuals with Alzheimer's that are eligible for both Medicare and Medicaid (known as “dual-eligibles,” see Chapter 5) are 3 times as costly to Medicare and 19 times as costly to Medicaid as their peers who do not have dementia.<sup>26</sup>

Recent research has shown that the average total cost of dementia (including out of pocket costs, Medicare and Medicaid costs, private insurance, and costs of informal care) during an

individual's last five years of life is \$287,038. Heart disease is the next most costly condition, at \$175,136. Out-of-pocket spending was 81% higher for people with dementia than for people without dementia: \$61,522 vs. \$34,068.<sup>27</sup> The spending burden also disproportionately affects certain demographic groups. While out-of-pocket spending for all people with dementia was 32% of assets compared with 11% for people without dementia, for African Americans, the proportion of assets was 84%, and for people with less than a high school education it was 48%. Unmarried or widowed women spent 58% of their assets on out-of-pocket costs for dementia.<sup>27</sup>

### ***National and State Action on Alzheimer's Disease and Related Dementia***

In December 2010, Congress unanimously passed the National Alzheimer's Project Act (NAPA), which President Obama signed into law in January 2011 (42 U.S.C. § 11201). NAPA establishes a National Alzheimer's Project housed in the Department of Health and Human Services that is charged with coordinating national efforts for research, treatment, and caregiving. NAPA requires an annual update to the national plan, an annual set of national recommendations, an annual evaluation of all federally-funded Alzheimer's initiatives, and the creation of an Advisory Council on Alzheimer's Research, Care, and Services composed of 22 experts and stakeholders at the federal and state level. NAPA aims to effectively treat or prevent Alzheimer's by 2025; optimize care quality and efficiency; expand supports for people with Alzheimer's and their families; enhance public awareness and engagement; and track progress and drive improvement.<sup>28</sup>

In 2013, the National Institutes of Health (NIH) launched an Alzheimer's disease research plan, with the intended goal being the fulfillment of the NAPA recommendation to prevent and treat Alzheimer's disease by 2025.<sup>29</sup> The primary steps of the research plan included meeting milestones for research on nonpharmacological interventions, biomarkers, public health surveillance, infrastructure, and treatment and prevention study participation and recruitment.<sup>29</sup> While an initial \$50 million outlay in 2012, followed by an additional \$40 million in 2013 and \$100 million in 2014, was allotted by Congress for Alzheimer's funding, experts estimate that such funding increases must continue in order for research goals to be met by 2025.<sup>29</sup> In late 2015, increased attention to Alzheimer's disease and dementia and their impact on individuals and families resulted in a proposed increase of \$350 million for fiscal year 2016 (a 59.7% increase over FY2015) for NIH's Alzheimer's disease and related dementia research funding.<sup>30</sup>

The 2015 NAPA update includes several new initiatives. As part of the 2015 update, the federal Department of Health and Human Services is working to design curricula for workforce training and family caregivers, and has launched a \$4 million brain health awareness campaign. In addition, the Dementia Friendly America Initiative, modeled on Minnesota's ACT on Alzheimer's Program, announced that it will begin pilot programs in 15 communities throughout the country by 2016.<sup>31</sup> (See Chapter 3 for additional information.)

While very few states had comprehensive Alzheimer's plans prior to NAPA, 39 states and Washington, DC, had published Alzheimer's state plans as of July 2015. Including North Carolina, seven more states have convened task forces or working groups that are working to develop Alzheimer's disease and related dementia state plans.<sup>32</sup> North Carolina's statewide Task Force on Alzheimer's and Related Dementia included 45 stakeholders and experts from throughout the state that met monthly over the course of one year. The efforts of the Task Force have culminated in the recommendations detailed in this report.

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## **CHAPTER THREE: RAISING AWARENESS ABOUT ALZHEIMER’S DISEASE AND RELATED DEMENTIAS**

Crucial to helping state stakeholders and individuals address the growing problem of Alzheimer’s disease and related dementias in our state are accurate information about symptoms, diagnosis, disease progression, and relationships to other aspects of preventive health care, as well as guidance and resources for the logistical aspects of dementia, such as caregiver concerns, financial planning, legal protections, and options for long-term care.

The Task Force envisions a collective, statewide effort toward raising awareness and supporting North Carolinians with Alzheimer’s disease or related dementias and their families and caregivers. This effort should also build upon the existing work of the many state stakeholders currently working to promote messages around Alzheimer’s disease and related dementias and ensure that North Carolinians have the information needed to face the challenges of these conditions. The Task Force sought to develop actionable recommendations around raising awareness of many important aspects of Alzheimer’s disease and related dementias for individuals, families, and policymakers, including promoting brain health, early detection and diagnosis of dementia, and collective efforts toward developing dementia-capable North Carolina communities.

### ***Promoting Awareness and Education about Alzheimer’s Disease and Related Dementias***

While the term “Alzheimer’s disease” and some related symptoms and disease characteristics are generally known, many misperceptions remain. These misperceptions include that memory loss or other cognitive symptoms are always a normal part of aging; that only older individuals develop Alzheimer’s; or that there are no effective treatments for Alzheimer’s disease. Also, because Alzheimer’s and related dementias are poorly understood and often feared, there is often stigma surrounding individuals and families who are coping with Alzheimer’s.<sup>1</sup> Studies have shown that the effects of stigma have a negative influence on both individuals with Alzheimer’s or related dementias and their caregivers, including discrimination and rejection for the person with the disease. This stigma can also contribute to caregiver burden.<sup>2,3</sup> Decreasing this stigma can help families better prepare for the emotional, physical, and financial costs of Alzheimer’s disease or related dementias, as well as benefit from community support and medical research.<sup>4</sup>

Many advocacy and research organizations support general messaging around the importance of healthy behaviors and lifestyle choices that can improve brain health and potentially have an impact on the likelihood of developing Alzheimer’s disease or related dementias. Other behavior messages focus on the importance of social engagement and participating in cognitive activities such as reading and completing puzzles.<sup>5,6</sup> Many organizations encourage integrating these messages into broader state and local public health promotion efforts, ensuring that messages are culturally sensitive and relevant to diverse groups, and incorporating appropriate partnerships and collaborations in order to increase awareness of Alzheimer’s disease and related dementias as a public health challenge.<sup>7</sup>

Promotion of available resources and information for families dealing with Alzheimer's disease or related dementias must also be incorporated into awareness and education campaigns. There is a wealth of information and resources in North Carolina (see Chapters 4 and 5), however families often face difficulty in accessing this information when they need it and also in understanding eligibility for services. Families need information about health care providers, long-term care, home- and community-based services, insurance coverage, financial assistance and planning, legal protections, family communication, caregiving roles and tasks, caregiver coping, respite, day-to-day symptom management, and self-care. As health and service providers develop materials for public outreach and education, they should ensure the inclusion of dementia-specific information and resources.

The Task Force examined many examples of the important work currently being done to promote public health messages related to heart and brain health. The Task Force recognized the opportunity to incorporate dementia-specific information into this health promotion work and emphasized the value of collaboration, partnerships, and a shared commitment to raising awareness about Alzheimer's disease and related dementias.

### **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.**

**In order to increase awareness and promote education about Alzheimer's disease and related dementias, organizations should establish a partnership (and/or build on existing public/private partnerships) to explore the incorporation of Alzheimer's disease and related dementias information into current health promotion/education programs and social marketing/health promotion materials. Information should include:**

- a) Connection between brain health and other preventable risk factors and health behaviors.**
- b) Support for early detection and accurate diagnosis, and information about prevention and clinical trial registries.**
- c) Resources/referrals for home- and community-based services, health care providers (including specialists), caregiver support services, home safety, and long-term care.**
- d) Financial planning information, including available insurance coverage for different types of care and advanced care planning, legal protections (including information on fraud, guardianship, and Adult Protective Services), care transitions, and employee resources.**
- e) Strategies to reduce stigma around Alzheimer's disease and related dementias.**
- f) Resources for underserved populations including individuals with intellectual/developmental disabilities, minority populations, homeless, and rural communities.**

**Partners: Including, but not limited to, North Carolina Division of Aging and Adult Services, North Carolina Division of Public Health, North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, the state Medicaid**

agency, North Carolina Department of Public Instruction, Area Agencies on Aging, North Carolina Office of Rural Health, county social and human services agencies, county Departments of Public Health, providers of mental health services, academic programs for professionals in health and human services, philanthropic organizations, North Carolina Chamber of Commerce, businesses/employers, health professional associations, managed care organizations, private payers, faith-based communities, and advocacy organizations.

### *Early Detection and Diagnosis*

Less than 50% of people with diagnosed Alzheimer’s disease or related dementia report being told of their diagnosis. When caregivers (instead of diagnosed individuals) were asked about being told if their family member had Alzheimer’s or dementia, only 50-53% reported that they had been informed of the diagnosis. The current health professional consensus is that individuals and families should always be informed when Alzheimer’s disease or related dementia is detected.<sup>8</sup>

**Figure 3.1: Early Signs of Alzheimer’s Disease<sup>30</sup>**

- Memory loss that disrupts daily life
- Changes or challenges in ability to solve problems
- Difficulty with familiar tasks
- Confusion about place or time
- Vision problems such as judging distance or determining colors
- Problems with vocabulary and conversation
- Frequently losing items
- Poor decision-making or judgment
- Withdrawal from professional and leisure activities
- Personality and mood changes

Early recognition of Alzheimer’s and related dementia symptoms and subsequent appropriate diagnosis can be helpful for families facing the challenges of Alzheimer’s disease or related dementias. Normal aging is the most common reason for memory loss, but detection tools can identify whether there are additional behavioral or cognitive markers that indicate Alzheimer’s disease or other forms of dementia.<sup>9</sup>

There are currently a number of tools in use by health care providers to appropriately identify and diagnose Alzheimer’s disease and related dementias.<sup>10</sup> One of the most common tools is the mini mental state examination. This tool consists of a short series of questions and tasks.<sup>10</sup> The Mini-Cog™ test is another brief and validated

screening test for dementia.<sup>11</sup> Cognitive changes identified by these tests should be interpreted in the context of the person’s medical history, medications, mood symptoms, and concurrent medical concerns.

If a test indicates possible Alzheimer’s disease or a related dementia, the health care provider may perform or refer the person for additional evaluation.<sup>9</sup> For individuals over the age of 65 who receive insurance coverage through Medicare, the annual wellness visit must include a

cognitive assessment. Because there is no universally accepted assessment tool, Medicare does not specify which tool providers should use or how to conduct the tests.<sup>12</sup> Instead, they are required to “assess the beneficiary’s cognitive function by direct observation, with due consideration of information obtained via beneficiary reports and concerns raised by family members, friends, caretakers, or others.”<sup>13</sup> This may consist of reviewing a patient’s other health risks, questioning the patient and/or family members about behavior, and/or using standardized cognitive tests.<sup>12</sup> For individuals with Down’s syndrome, assessment is generally recommended at an earlier age and providers use assessment tools to measure baseline cognitive ability as well as new or ongoing behavioral symptoms. For individuals with Down’s syndrome, behavioral changes are more common early symptoms of Alzheimer’s disease than memory loss or forgetfulness.<sup>14,15</sup> (See Chapter 7 for additional information about individuals with intellectual or developmental disabilities.)

The costs and benefits to universal screening for Alzheimer’s disease and related dementias remain unclear. The United States Preventive Services Task Force studied the use of diagnostic tools for dementia and found that, while many tools are useful for identifying dementia, there is inadequate evidence for the benefits of universal dementia screening for adults over 65 with no cognitive symptoms.<sup>16</sup> There are a limited number of medications or therapies that aim to treat dementia by managing symptoms, but clinical outcomes are inconclusive and many patients experience adverse side effects.<sup>17</sup>

Beyond therapeutic approaches, there still may be benefits of early detection and diagnosis of dementia for individuals and families. Early detection may allow families the opportunity to plan – financially, logistically, and legally – for challenges they might face in dealing with the diagnosis. They may be able to receive referrals to home- and community-based services, support groups, and clinical trial registries. Early detection may also be helpful in preventing loss of income or assets from bad decisions, losing or breaking personal property, and other consequences of early Alzheimer’s disease or related dementias.<sup>d</sup> In part because of the potential planning benefits for families, 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.<sup>e</sup>

In order for providers to adequately conduct dementia screening and diagnosis when indicated, there is a strong need for enhanced training in specific assessment tools, the application of those tools in appropriate contexts, and in best practices for connecting patients to needed additional care and resources. Recent research shows that only 47% of primary care physicians in the U.S. believe that their practice is properly trained and prepared to handle the care needs of people with dementia.<sup>18</sup>

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<sup>d</sup> Gwyther, L. Director, Family Support Program, Associate Professor, Department of Psychiatry and Behavioral Sciences, Division of Geriatric Psychiatry, Center for the Study of Aging and Human Development, Duke University Medical Center. Written (email) communication. Jan 10, 2016.

<sup>e</sup> Gwyther, L. Director, Family Support Program, Associate Professor, Department of Psychiatry and Behavioral Sciences, Division of Geriatric Psychiatry, Center for the Study of Aging and Human Development, Duke University Medical Center. Written (email) communication. Jan 10, 2016.

Researchers from the University of North Carolina at Chapel Hill analyzed a community-based pilot dementia training program conducted with primary care providers. Providers were in family practice and internal medicine, and 21% of participating physicians had a geriatrics subspecialty. The program was a joint project between Carolina Alzheimer's Network (an educational outreach program of the University of North Carolina at Chapel Hill), three North Carolina Area Agencies on Aging, and Project C.A.R.E. (a caregiver resource and support program implemented through the North Carolina Division of Aging and Adult Services). Both physicians and other primary care staff participated in a one-day training program, focused on detection tools, diagnosis, management, and patient and caregiver resources. Participating providers also received post-training follow up.<sup>19</sup>

Physician participants (n=29) completed a baseline interview, a post-training questionnaire, and an additional follow up six months after completing the training program. These tools identified whether and how physician participants' confidence in their practice of dementia detection and diagnosis changed. At the six-month follow up, most participants showed an increase in confidence in dementia detection skills, with the best results evident in distinguishing Alzheimer's from other forms of dementia, patient and caregiver education about dementia, and referring patients and caregivers to community resources. Follow up also showed increased use of dementia assessment tools.

The Task Force examined current protocols for dementia detection, Medicare requirements, and evidence-based recommendations, as well as initiatives to increase primary care providers' capacity and skill in brief standardized assessment tools. Because of the need for improved systems of care for individuals and families who receive a diagnosis of dementia, the Task Force acknowledged potential downsides to families receiving a dementia diagnosis without also having access to quality dementia care and services. Therefore, the Task Force did not recommend universal screening, but instead focused its early detection and diagnosis recommendations on enhanced training for health care providers, particularly around detection and assessment tools, potential 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 Alzheimer's disease and related dementias detection, diagnosis, and services referrals.**

**Offer pre-service and in-service training in the early detection of Alzheimer's disease and related dementias. Training should include validated brief assessment and diagnostic tools, and should be tailored to all populations. Training should focus on:**

- a) Incorporating specific tools for early detection in all populations, including individuals with limited English proficiency and those with intellectual or developmental disabilities.**
- b) How to meet Medicare annual wellness visit requirements for cognitive assessment using validated tools and a functional approach to assessment.**
- c) Benefits of early detection for families and caregivers, including family support, advance planning, symptom and care management strategies, non-pharmacological interventions for improving functional and behavioral symptoms, medication**

**options, and need to incorporate family feedback in identifying cognitive impairment.**

- d) Referral resources (to include hard copies provided at time of visit, if requested) for additional medical assessment, diagnostic testing, treatment services, and services for caregivers for those with signs of cognitive impairment.**
- e) Information about care and available services and supports, including specific additional training or ongoing education for care managers or other staff.**

**Lead: North Carolina Area Health Education Centers (AHEC)**

**Partners: Including, but not limited to, the North Carolina Medical Society, the North Carolina Psychiatric Association, the North Carolina Hospital Association, the North Carolina Nurses Association, and academic health science centers.**

### ***Collective Impact for a Dementia-Capable Community***

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 to achieve the Task Force goals. Collective impact is a method of multi-stakeholder collaboration that meets the following criteria:<sup>20</sup>

- Common agenda
- Shared measurement system
- Mutually reinforcing activities
- Continuous communication
- Backbone support organization

In order to have the greatest success, a collective impact process must have a dedicated organization and staff to serve as infrastructure through the course of the initiative. The backbone organization must commit to handling the logistic and administrative work of the collective impact process, as well as mediate conflicts and oversee technical issues, inter-organization communication, data collection, and analysis/reporting.

Many types of organizations can serve as appropriate backbone organizations. Government agencies, nonprofit organizations (either new or existing), and funder-based organizations can all be effective backbone organizations, and there are pros and cons to each type of entity fulfilling this role, including varying levels of transparency, neutrality/conflicts of interest, sustained funding, and existing infrastructure. Backbone organizations also generally require staff to serve as project director/manager, data manager, and facilitator.<sup>21</sup>

### ***ACT on Alzheimer's: Collective Impact at the State Level***

The state of Minnesota provides a useful example of collective impact in action to address Alzheimer's disease. In 2009, state legislation tasked the Minnesota Board on Aging with establishing the Alzheimer's Disease Working Group and developing recommendations to address the increasing challenges of Alzheimer's in the state. The Working Group recommendations were released in 2011, and ACT on Alzheimer's (originally called Prepare



Minnesota for Alzheimer's 2020) was created to oversee the implementation of the state recommendations.<sup>22</sup> The ACT on Alzheimer's "collective action" initiative now consists of more than 400 individual members and 60 organizations, including private, non-profit, and government groups. Between 2013 and 2015, ACT on Alzheimer's received \$750,000 in state funding and raised an additional \$2 million in funding from philanthropic organizations, advocacy organizations, federal grants, academic institutions, and health care systems.<sup>23</sup>

The goals of ACT on Alzheimer's include:

- Identify and invest in promising approaches that reduce costs and improve care.
- Increase detection of Alzheimer's disease and improve ongoing care and support.
- Sustain caregivers by offering them information, resources, and in-person support.
- Equip communities to be "dementia capable" to support residents who are touched by Alzheimer's disease.
- Raise awareness and reduce stigma by engaging communities.<sup>22</sup>

In working towards these goals, ACT on Alzheimer's emphasizes principles of health equity and aims to include broad community buy-in from those traditionally involved in dementia work and those new to such projects.

ACT on Alzheimer's has used qualitative evaluation methods to assess the initiative's progress in four primary areas: enhanced capacity of providers, organizations, and institutions to provide care and supports for people with Alzheimer's and their families; influence on state guidelines and policies that affect Alzheimer's and dementia within communities; enhanced support to caregivers; and community capacity to engage in the initiative.<sup>24</sup> The evaluation found that the collective action initiative is succeeding in bringing people together to begin planning and ACT on Alzheimer's resources are being used by state and local agencies. There are also many aspects of the initiative that have been identified as needing improvement, including the importance of effective coordinators/leaders at the local level, the need for systematic and consistent communication to stakeholders about the initiative's progress, and the necessity of having people with dementia and their caregivers as active contributing stakeholders.<sup>24</sup>

**Figure 3.2: ACT on Alzheimer’s Dementia-Friendly Community Resources** <sup>25</sup>



Source: ACT on Alzheimer’s. Dementia-friendly resources. ACT on Alzheimer’s website. <http://www.actonalz.org/communities-action-resources>. Accessed October 14, 2016. Reprinted with permission from ACT on Alzheimer’s.

### *Dementia Friendly America and a Model Initiative in Orange County*

Building on the work of Minnesota’s ACT on Alzheimer’s initiative, the Dementia Friendly America Initiative (DFA) announced funding for 15 pilot projects to implement collective impact efforts to address dementia and the creation of dementia-friendly communities. Community partners include local business representatives, faith-based organizations, health care providers, residential facilities, legal and financial services, home- and community-based services providers, and government agencies.

Sponsored and funded by over 50 organizations, including AARP, the Alzheimer’s Association, CVS/Caremark, the International Association of Chiefs of Police, the National League of Cities, and US Against Alzheimer’s, the Dementia Friendly America initiative seeks to leverage community resources and stakeholder partnerships to create communities that “are informed, safe, and respectful of individuals with dementia and their families, provide supportive options, and foster quality of life” for all residents.<sup>26</sup>

In looking at the objectives and anticipated partners for the Dementia Friendly America initiative, the Task Force decided that the term “dementia capable” captured the goals and ideals of DFA, and addressed the needs of a state population dealing with the cognitive, physical, and emotional challenges of residents with dementia and their caregivers. Dementia-capable communities and systems 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.<sup>27</sup>

In 2015, the Orange County Department on Aging received grant funding of \$900,000 from the U.S. Department of Health and Human Services' Administration for Community Living to enhance its community supports and services with the goal of becoming a fully coordinated and effective dementia-capable community. Community, organizational, and individual initiatives will be implemented through the University of North Carolina at Chapel Hill's Center for Aging Research and Educational Services (UNC CARES) program and will include a business and government training program to improve knowledge and understanding about living with or caring for someone with dementia; a skills-based dementia training program for direct care workers in the home; and new or expanded services for individuals with dementia and their caregivers, such as in-home services, support groups, and respite.<sup>28</sup>

The program has also incorporated several measurable outcomes into their planning process, largely focused on caregiver quality of life.<sup>28</sup> The program will also conduct a process evaluation, using a control group of caregivers currently receiving services, and an intervention group of caregivers receiving the UNC CARES' services. The evaluation aims to determine whether the intervention was effectively implemented and to use feedback to improve the interventions and inform similar projects.<sup>28</sup>

In late 2015, UNC's Jordan Institute for Families issued a request for information for communities interested in being considered for the Institute's Adult Network of Care pilot programs. Focused on Alzheimer's disease and related dementias and adult guardianship, these pilot projects will provide technical assistance and guidance to several communities across the state as they engage in collective impact initiatives aimed at improving community life for people with Alzheimer's disease or related dementias, or in improving resources and procedures for adult guardianship.<sup>29</sup>

The Task Force on Alzheimer's Disease and Related Dementias examined the principles of collective impact and their application through ACT on Alzheimer's, Dementia Friendly America, and the Orange County project. The Task Force determined that a collective impact approach to creating dementia-capable communities would be appropriate for our state.

### **Recommendation 3.3:**

**Create a collective impact partnership to develop and establish dementia-capable pilot communities.**

**Using the resources and toolkits available from the Dementia Friendly America and ACT on Alzheimer's projects, partners should develop a collective impact partnership which will work toward the development and establishment of three to four Alzheimer's disease and related dementia-capable pilot communities in North Carolina.**

- a) The collective impact partnership should be supported by staff from North Carolina Division of Aging and Adult Services, who will oversee collaboration, establish a statewide advisory committee made up of stakeholders, and facilitate technical assistance.**
- b) Philanthropic partners should develop a targeted grant process to identify appropriate communities for initial and/or continuing funding.**

- c) **The pilot community projects should lead to the development of a sustainable and replicable model that can be disseminated to additional North Carolina communities and serve as a foundation for dementia-capable communities.**
- d) **The local collective impact pilots will require a full-time staff person to champion and organize local efforts. Resources will be required for facilitation, data planning/analysis, and meeting expenses. The estimated annual budget for each pilot is \$125,000.**
- e) **Pilots should include evaluation of the costs and benefits of this approach for developing a dementia-capable community.**

**Lead: North Carolina Division of Aging and Adult Services**

**Partners: Including, but not limited to, philanthropic organizations, county social and human services agencies, Area Agencies on Aging, Association of County Commissioners, UNC’s Jordan Institute for Families, local providers of care (including behavioral health, medical health, and human services), and other academic institutions.**

**Recommendation 3.4: Establish statewide coordinated leadership to oversee the state plan on Alzheimer’s disease and related dementias.**

**Establish a statewide coalition on Alzheimer’s disease and related dementias to oversee the implementation of this plan. The coalition should be coordinated by the state Alzheimer’s disease specialist. The coalition should be charged with:**

- a) **Developing the collective impact strategy, including assisting funding agencies in selecting communities for collective impact and convening local collective impact efforts to support shared learning, and, if successful, for scale up of collective impact efforts to other communities.**
- b) **Coordinating implementation of the plan.**
- c) **Reporting yearly progress on implementation to the Secretary of Health and Human Services (and/or the Senate and House Committees on Aging).**
- d) **Support other workgroups charged with implementations of specific recommendations.**
- e) **Serve in an advisory capacity to the North Carolina Division of Aging and Adult Services to support additional recommendations (i.e., the development of a toolkit).**

**Lead: The North Carolina Division of Aging and Adult Services**

**Partners: Including, but not limited to, North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, North Carolina Division of Social Services, the state Medicaid agency, the North Carolina Division of Public Health, the North Carolina Division of Health Services Regulation, Alzheimer’s North Carolina, Alzheimer’s Association, members of the North Carolina General Assembly, the Governor’s Council on Aging, the Duke Endowment, AARP North Carolina, LeadingAge North Carolina, North Carolina Area Health Education Centers, local Area Agencies on**

**Aging, the North Carolina Coalition on Aging, the Geriatrics Workforce Enhancement Program, local providers of care (including behavioral health, medical health, and human services), media representatives, and caregivers for people with Alzheimer's disease and related dementia, with special attention to ensure diversity and statewide representation.**

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## CHAPTER FOUR: HAVING SUPPORTIVE OPTIONS THAT FOSTER QUALITY OF LIFE

For individuals with Alzheimer’s disease or related dementia, it is crucial that care be appropriate, tailored to individual needs, and available when needed. As with most people, individuals with Alzheimer’s disease or related dementia want to remain in their own homes and communities for as long as possible. As described in Chapter 5, the vast majority of care is provided by untrained and unsupported family caregivers.

The Task Force examined many aspects of care for people with Alzheimer’s disease or dementia and issued recommendations for long-term services and supports, improvement of health system capacity, access to treatment, overall quality of care, care coordination, and training for health care professionals.

### **Activities of Daily Living<sup>55</sup>**

Activities of daily living (ADLs) are every day, personal tasks such as bathing, dressing, eating, toileting, and moving around within the home. Other activities, called instrumental activities of daily living include housework, financial management, medication management, meal preparation, shopping, and responding to emergency alerts.

### **Long-term Services and Supports<sup>56</sup>**

Long-term services and supports include a wide range of paid and unpaid medical and personal care assistance that people may need – over many weeks, months, or years – when they have difficulty completing self-care tasks as a result of aging, chronic illness, or disability. These services can be provided at home, in a community setting, or in an institutional setting such as a nursing home.

### ***Long-Term Services and Supports***

Among all adults age 65 and over, not just those with Alzheimer’s disease or related dementia, there is a 70% chance of needing some type of long-term services and supports, and 20% of adults over 65 will need these services for longer than five years.<sup>1</sup> For people with Alzheimer’s or related dementia, nearly all will require long-term care of some kind, and 75% of people with Alzheimer’s are admitted to a nursing home by age 80.<sup>2</sup> Annual per-person Medicaid spending for older adults with dementia is 19 times higher than for older adults without dementia, and more than 74% of people with dementia also have other chronic conditions, leading to more complicated and costly long-term care.<sup>2</sup> There are a broad range of long-term services and supports that 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. Due to the range of types and locations of long-term services and supports, there is also a range of payment systems for these different types of care.



### *Home- and Community-Based Supports*

Home-based long-term supports and services from unpaid caregivers constitutes the vast majority of long-term care. Additional care needs such as home health care following surgery or illness; physical, occupational, or speech therapy; or other temporary health needs, are usually provided by paid home health providers. Other paid home-based long-term care may include personal care and assistance with activities of daily living, such as laundry and cooking, as well as instrumental activities of daily living and companion services.<sup>3</sup>

Community-based long-term supports and services consists of services intended to delay or prevent institutionalization and help people remain at home as long as possible. These services often include adult day care services, home delivered meal services, transportation assistance services, senior centers, in-home aide services, and respite care for unpaid caregivers. These services vary by community and are provided by government agencies, such as social services or health and human services, or private organizations.<sup>3</sup> (See Chapter 5 for additional information on home- and community-based services.)

### *Long-Term Care Facilities*

Long-term supports and services are provided within residential facilities. There are a variety of levels of care provided in long-term care facilities. Adult care homes are private facilities, with a broad range in number of residents, who live in private or shared rooms and receive assistance with personal care, but not medical care. While all non-skilled facilities are called adult care homes, those with eight or fewer residents are called family care homes and larger facilities are called assisted living facilities. Within assisted living facilities, more than 7 out of 10 residents have some form of cognitive impairment (29% with mild impairment, 23% with moderate impairment, and 19% with severe impairment).<sup>4</sup> Adult care homes provide a few levels of assistance with activities of daily living, but not as much care as is provided in a skilled nursing facility. Services may include meals, housekeeping, and social activities.

A skilled nursing facility, also referred to as a nursing home, provides more intensive personal and health care, often including nursing care, supervision, and rehabilitation services. Skilled nursing residents are those who need short-term care following an injury or illness, as well as those who require care for a longer period.<sup>5</sup> Within skilled nursing facilities, there are often special care units, special sections, or programs designated especially for residents with Alzheimer's disease or related dementias.<sup>6</sup> Differences in staffing ratios are critical to differentiate skilled nursing facilities from other residential settings such as adult care homes. Skilled nursing facilities are staffed 24 hours a day, 7 days a week, by nursing staff and must follow federal staffing regulations if they accept Medicare or Medicaid payment for care.<sup>f</sup>

### *Continuing Care Retirement Communities*

Continuing care retirement communities also provide long-term supports and services. The range of services needed by residents in these communities includes assisted living care, skilled

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<sup>f</sup>Gwyther L. Duke Family Support Program, Duke University Medical Center. Written (email) communication. January 10, 2016

nursing care, and other health care, along with social engagement, recreation, and often independent living arrangements within the same location.<sup>8</sup> These types of living arrangements are private pay only and are not supported by Medicaid or Medicare, thus are often only affordable and accessible for a small proportion of those with Alzheimer's disease or related dementia.

### *Hospice Care*

For people who are terminally ill, hospice care is often provided at home or in a nursing or hospice facility. Hospice care teams provide care when a person is expected to live six months or less. Hospice care includes palliative medical care to alleviate pain and symptoms, counseling, respite, and grief support.<sup>7</sup> Patients are referred to hospice care by several sources, including hospitals, physicians, or skilled nursing facilities.<sup>8</sup> In North Carolina, 12% of hospice patients have dementia as their primary diagnosis and 67% of hospice patients over age 75 have dementia as a secondary diagnosis. People with Alzheimer's disease or related dementias must have very advanced disease, be unable to walk or speak, and also have another serious condition to be eligible for hospice care. Because of the unpredictable nature of dementia progression and the requirement that hospice care only be provided for the last six months of life, there are many challenges providing people with Alzheimer's disease and related dementias with appropriate hospice services.<sup>8</sup>

### *Palliative Care*

Palliative care is similar to hospice care, with symptom management as its goal, only it is more broadly applied to people throughout the course of disease, not solely in the last few months of life, and has a team-based approach to in-depth communication with and support of patients and families. Because of the difficulties in terms of accurate prognosis, palliative care may be an appropriate option for people with Alzheimer's disease or related dementia. Research has shown that both hospital-based and community-based palliative care can decrease health care costs for payers and individuals.<sup>9</sup>

In North Carolina, many hospice providers have palliative care specialty programs, with physicians, nurses, physician assistants, and social workers included in care teams. Other models of palliative care include palliative consult teams within hospitals, and home-based palliative care, which can also assist with transitions from acute care settings to home care settings. Throughout the state, access to palliative care specialists varies. Community palliative care services, including outpatient clinics, home-based care, or institutional care, is still the area of greatest need, and rural counties in the east and far west portions of the state have the least access to these services. Large hospitals are most likely to have palliative care consultation and services.<sup>h</sup>

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<sup>8</sup> Gwyther L. Duke Family Support Program, Duke University Medical Center. Written (email) communication. January 10, 2016

<sup>h</sup> Fischer J. Physician Consultant. Community Care of North Carolina. Written (email) communication. February 3, 2016

Community Care of North Carolina administers a Palliative Care Initiative throughout its network. This program aims to promote better care at the end of life through enhancing access to and information about palliative care throughout the health care system, increasing communication and person/family autonomy within palliative care, and improving education for health care providers about the clinical and socioemotional tools they can use in discussing and providing palliative care.<sup>10</sup> Community Care of North Carolina's initiative has shown substantial cost savings for participating patients, as well as fewer hospital days and more use of hospice services. Average cost savings were \$1,661 per patient, per month, and an estimated total of \$2 million in savings among patients receiving the intervention.<sup>11</sup>

### ***Public Payment Options for Long-Term Services and Supports***

For families needing long-term services and supports for family members with Alzheimer's disease or related dementia, the array of options can be extremely difficult to navigate. Adding to this difficulty is the confusion of determining eligibility for services and who pays for the different types of 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 insurance.<sup>12</sup> Even for less intensive care, the costs for long-term supports and services can be high, and non-medical services provided at home, such as personal care and assistance with activities of daily living, can prove to be a serious financial burden.

#### *Medicare*

Many people with Alzheimer's disease or related dementia are over 65, meaning they likely receive health insurance coverage through Medicare. However, Medicare does not provide coverage for services that assist with activities of daily living, and only covers rehabilitation services such as physical therapy for a short period in the home; it does not cover continued assistance needed due to physical or cognitive impairment. Medicare pays for skilled nursing care within a long-term care facility for a maximum of 100 days.<sup>13</sup> Most private insurers pay for similar services as Medicare.

#### *North Carolina Medicaid*

In North Carolina, Medicaid provides health care coverage for low-income individuals requiring skilled nursing care. An individual's income must be less than the cost of care in the facility at the Medicaid rate, Medicaid must approve the need for the level of care, and the individual must pay some of the monthly cost of care, called the "patient monthly liability." The rest of the monthly cost is paid directly by Medicaid to the facility.<sup>14</sup> For individuals needing long-term care in a nursing facility who do not qualify for Medicaid and who remain in the facility for longer than the 100-day maximum covered by Medicare, most of the costs must be paid by the individual or their family.

Money Follows the Person often helps Medicaid recipients navigate the payment transition from nursing facilities to home-based care. Individuals work with their Local Contact Agency, which provides counseling on care options. If the individual has been in a nursing facility for at least

three months, receives Medicaid, will require the same level of care received in the nursing facility, and is interested in returning to the community, he/she may apply for Money Follows the Person. If approved, Money Follows the Person will provide the individual with Medicaid waivers for aging in place, covering medical services received in a home setting.<sup>15</sup>

**Figure 4.1: Median Annual Rates for Long-Term Services and Supports in North Carolina (2013)<sup>i,12</sup>**

Homemaker Services (Licensed)	Home Health Aide Services (Licensed)	Adult Day Health Care	Assisted Living Facility (One Bedroom – Single Occupancy)	Nursing Home (Semi-Private Room)	Nursing Home (Private Room)
\$38,896	\$40,040	\$13,000	\$34,800	\$71,723	\$77,741

Source: CareScout. North Carolina State-Specific Data from the Genworth 2013 Cost of Care Survey Richmond, VA: Genworth Financial; 2013.

[https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/North%20Carolina\\_gnw.pdf](https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/North%20Carolina_gnw.pdf). Accessed December 8, 2015.

In North Carolina, the Department of Veterans Affairs also provides assistance (known as the Aid and Attendance pension benefit) for older veterans in need of long-term services and supports. This assistance can be used to pay for assisted living, skilled nursing facilities, or

<sup>i</sup> Median Annual Rates\* are calculated based on the following:

Homemaker Services - hourly rate multiplied by 44 hours per week, multiplied by 52 weeks

Home Health Aide Services - hourly rate multiplied by 44 hours per week, multiplied by 52 weeks

Adult Day Health Care - daily rate multiplied by 5 days per week, multiplied by 52 weeks

Assisted Living Facility - monthly rate multiplied by 12 months

Nursing Home - daily rate multiplied by 365 days

**Figure 4.2:**

**Medicaid Spending for Long-Term Services and Supports (FY 2013)<sup>57</sup>**

Total Institutional: \$1,494,718,273

Nursing Facilities: \$1,155,379,762

Total Home- and Community-Based Services: \$1,910,640,636

1915(c) Waivers (for Home- and Community-Based Services): \$922,059,529

Personal Care: \$452,127,786

Other Home- and Community-Based Services: \$536,453,321

Percent spent on Home- and Community-Based Services: 56.1%<sup>a</sup>

Note: Total institutional includes institutional care facilities for individuals with intellectual/developmental disabilities and mental health facilities (not listed above). See Chapter 5 for more information on home- and community-based services.

Source: Eiken S, Sredl K, Burwell B, Saucier P. Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2013: Home and Community-Based Services were a Majority of LTSS Spending. Ann Arbor, MI: Truven Health Analytics; 2015. <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/ltss-expenditures-fy2013.pdf>. Accessed January 14, 2016.

**Figure 4.3**

**Services Covered by CAP/DA Medicaid Waiver<sup>16</sup>**

Adult day health

Personal care aide

Home accessibility and adaptation

Meal preparation and delivery

Institutional respite services

Non-institutional respite services

Personal emergency response services

Specialized medical equipment and supplies

Participant goods and services

Community transition services

Training, education, and consultative services

Assistive technology

Case management

Source: North Carolina Division of Medical Assistance. Community Alternative Programs for Disabled Adults. North Carolina Department of Health and Human Services website. <https://dma.ncdhhs.gov/medicaid/get-started/find-programs-and-services/community-alternatives-program-for-disabled-adults>. Accessed December 12, 2015.

home-based care, including home-based care provided by a family member.<sup>12</sup>

### *Community Alternatives Program (CAP-DA)*

For home-based long-term supports and services, such as homemaker services or home health aides, median annual prices in North Carolina range from \$38,000 to \$40,000. Community-based services, such as adult day services, respite care, or meal delivery, are less expensive, but adult day care, for instance, still has a median annual price of \$13,000. In North Carolina, home- and community-based long-term services for people at risk of being institutionalized are provided under a Medicaid waiver, called the Community Alternatives Program for Disabled Adults (CAP/DA). This waiver covers services including adult day care, personal care, and caregiver respite services.<sup>16</sup> However, CAP/DA slots are capitated, meaning a specific number of slots are available per county. The current average waiting list for CAP/DA services is two years. CAP/DA is only available for low-income individuals who qualify for Medicaid coverage. Currently families of two must have a monthly income at or below \$1,328; households of one must have a monthly income at or below \$981 to be eligible for Medicaid.<sup>17</sup> Medicaid will pay for hospice care on a per diem basis for patients who meet eligibility criteria.<sup>j</sup> Under the current North Carolina Medicaid reform plans, services that are defined as optional (including hospice care) are excluded from the program requirements for qualifying provider-led entities and accountable care organizations.<sup>k</sup> Beginning on January 1, 2016, adults who are eligible for Medicaid (and adults who are dually eligible for both Medicaid and Medicare) can receive concurrent hospice care and care under the Personal Care Services program while living at home.<sup>18</sup>

In 2015, the Centers for Medicare and Medicaid Services (CMS) issued two new Medicare billing codes, allowing qualified health care professionals to be reimbursed by Medicare for the time spent discussing advance care planning and end-of-life decisions with patients and families, including discussions of hospice and palliative care.<sup>19</sup> Appropriate reimbursement for end-of-life and advance care planning discussions, including those conducted by non-physician professionals, is critical to ensuring that people with dementia and their families understand their options for care.

### *Long-Term Care Insurance*

Long-term care insurance provides some protection for the costs of long-term care. In 2007, the average long-term care insurance policy cost \$2,208 per year, covered 4.8 years of long-term care, and covered both home and institutional services. Long-term care insurance also must be purchased individually prior to the onset of disability or impairment. Because of this, families usually pay premiums for several years before needing long-term care, making it cost-prohibitive for most.<sup>20</sup>

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<sup>j</sup> Darden L. President and Chief Executive Officer. Hospice and Palliative Care Center. Written (email) communication. January 25, 2016.

<sup>k</sup> Darden L. President and Chief Executive Officer. Hospice and Palliative Care Center. Written (email) communication. January 25, 2016.

**Recommendation 4.1: Promote appropriate care settings for people with Alzheimer’s disease or related dementia.**

**In order to minimize avoidable treatment, increase satisfaction, improve quality of care, and decrease health care costs at the end of life, partners should examine and promote the potential benefits of appropriate care settings, to include:**

- a) Information on palliative care through the Palliative Care Initiative, and an examination of the potential cost impact of expanding Medicaid coverage for hospice and palliative care and including it in managed care models.**
- b) Review of hospice and palliative care criteria in order to ensure that provided care is appropriate for different types of dementia and/or to provide earlier access to care for people with Alzheimer’s disease or related dementia.**
- c) Information on additional options for long-term services and supports and differences between such options.**
- d) Use of Medicare codes for advance care planning, Medicaid reimbursement procedures, and expansion of qualified providers within the care team who may participate in the billing of these codes to enable nurses, social workers, and other team members to participate in advance care planning.**
- e) Ensuring access to appropriate care settings and long-term services and supports for all populations, including individuals with intellectual/developmental disabilities and/or mental illness.**

**Partners: Health care providers, vendors, and payers.**

**Recommendation 4.2: Examine methods of reimbursement and incentives for Alzheimer’s disease and related dementia care through new models of care.**

**Explore new models of care which use methods of reimbursement to incentivize care for people with Alzheimer’s disease and related dementia and reduce wait lists for specialist care. Models may include:**

- a) Leveraging palliative care and end-of-life expertise that resides in community hospice organizations to expand pre-hospice palliative care supports for patients and families.**
- b) Incentivizing the expansion of pre-hospice palliative care services through reimbursement for interdisciplinary palliative care services.**
- c) Community Care of North Carolina model of expanding services to include skilled nursing facility residents, thereby making these residents eligible for comprehensive care management.**

**Lead: Association for Home and Hospice Care of North Carolina, the Carolinas Center for Hospice and End of Life Care.**

**Partners: Health systems, facilities, private and public payers.**

### ***Health System Capacity and Access to Treatment***

As their disease progresses, people with Alzheimer's disease or related dementia have an increasing need for health care services. This care is often provided by primary care providers, specialists, and staff in long-term care facilities. The Task Force examined North Carolina's current capacity to serve the growing population of people with dementia, and issued recommendations to address the capacity gaps and improve access to treatment for people with dementia.

#### ***Alzheimer's Disease and Related Dementia-Specific Health System Capacity***

Within the various types of residential long-term care facilities in North Carolina, there are approximately 8,000 special care unit beds designated for people with Alzheimer's disease and related dementia (as of the end of 2015). This figure includes beds within skilled nursing facilities, as well as 54 special care units in adult care homes.<sup>21</sup> There is currently a moratorium on licensure for new adult care homes, due to increased rates of special care unit beds and a desire to prevent more beds than needed.<sup>21</sup>

North Carolina hospitals have only 66 geriatric psychiatry beds, often needed for people with dementia who exhibit related severe behavioral or psychological symptoms, and who have not yet moved to residential care. Some hospitals also have Acute Care for the Elderly (ACE) units, which aim to provide high quality care to people with dementia while they are hospitalized for other ailments.<sup>22</sup>

There are a limited number of specialists providing medical care to people with Alzheimer's disease or related dementia in North Carolina. Much of this care is provided by primary care physicians or care teams. In 2011, there were approximately 90 geriatricians and 355 neurologists. There were also 2 psychologists per 10,000 residents. It is unclear how many of these specialists focus on dementia care.<sup>23,24</sup>

Because the number of North Carolinians with Alzheimer's disease and related dementias 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. Therefore, the Task Force recommends:

#### **Recommendation 4.3: Assess health system capacity for people with Alzheimer's disease or related dementias.**

**Conduct an assessment of current health system capacity for caring for patients with Alzheimer's disease or related dementias. The assessment should include dementia-specific beds in intensive outpatient and psychiatric settings, and also include information on the projected status of moratorium on home care services and on memory care units in adult care homes.**



**Partners: North Carolina Division of Health Service Regulation, the state Medicaid agency, North Carolina Division of Aging and Adult Services, and health professional trade associations.**

### *Telehealth and Access to Care*

There is opportunity for improved access to quality health care through the expansion of telehealth and other remote-based services for people with Alzheimer’s disease or related dementia. Research has shown that dementia can be reliably diagnosed using detection and assessment tools administered through video conferencing technology.<sup>251</sup> In North Carolina, there are nearly 700,000 people over the age of 60 living in rural areas.<sup>m</sup> For these individuals who live in rural areas with fewer available transportation services or for whom distance to health care providers is a challenge, these type of telehealth services for assessment and diagnosis hold promise.

Technological solutions can also be helpful for non-health care services, including home monitoring of people with dementia. People often need a caregiver to monitor whether activities of daily living are completed, and to assist with them if not. However, many people with Alzheimer’s disease or related dementia may not have adequate assistance available locally. Systems that remotely monitor home utility use can allow caregivers or service providers to learn about patterns of utility use that may indicate a problem.<sup>26</sup> Other systems may monitor movement within the home to assist caregivers in discerning whether a person has fallen or has become otherwise incapacitated.<sup>27</sup> Many of these technologies can be installed and administered at relatively low cost; however, these services are generally still paid for out of pocket by individuals and families.

There is also potential for care management and caregiver support services for people with Alzheimer’s disease or related dementia to be provided remotely, with the caveat that such services should not fully replace in-person assistance so as not to result in social isolation for people with dementia or their caregivers.

The Task Force recommends:

#### **Recommendation 4.4: Improve telehealth services for people with Alzheimer’s disease or related dementias.**

**Examine and identify funding streams for improved telehealth services for people with Alzheimer’s disease or related dementias, with special attention on rural and underserved communities and the impact on health care costs and caregiver well-being. These services should include:**

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<sup>m</sup> Reddy S. Evaluator/Planner. North Carolina Department of Health and Human Services. Written (email) communication. January 25, 2016.

- a) **Remote diagnostic capacity and ongoing consultation, medication management, and behavioral management in the context of tele-neurology services when appropriate, and/or at alternate locations (including home locations).**
- b) **Home monitoring of activities of daily living, with local capacity for follow-up.**
- c) **Remote resources for caregivers.**
- d) **Additional non-health care services, such as check in calls, monitoring utilities, falls prevention, and caregiver support services.**

**Partners: North Carolina Division of Aging and Adult Services, the state Medicaid agency, private payers, medical and behavioral health providers, and LME/MCOs.**

### *Improving Transportation Options to Improve Access to Care*

People with Alzheimer’s disease or related dementia often have trouble accessing health care and other services when they are no longer able to drive. In some cases they may have caregivers who are able to provide transportation, but many do not. Non-emergency medical transportation services are of particular importance to aging and low-income populations. For people with Alzheimer’s disease or related dementia, issues of transportation timing can also be a concern, as it becomes difficult for individuals to navigate long waiting times if they arrive too early for medical appointments or have to wait for a return ride to their homes. The special transportation needs of people with limited informal support systems may include the need for escorts or personal care attendants to assist with the portion of the trip before and after the actual ride.

The North Carolina Department of Health and Human Services provides transportation assistance through local providers for many older adults with various needs. If used to access Medicaid services, Medicaid pays for the cost of the non-emergency medical transportation. In some counties, transportation services and aide services, including assistance with transportation to medical or social services appointments, are funded under the Home and Community Care Block Grant. Cost data is not available for the portion of aide services devoted to transportation support, but the average cost for Home and Community Care Block Grant-funded medical transportation is \$575 per person annually.<sup>n</sup>

Human services transportation and/or public transportation services are available to some extent in all 100 North Carolina counties. North Carolina has a long history of state-level support for the coordination of transportation services across funding sources. Local community transportation networks have been built with the help of federal and state funding from the North Carolina Department of Transportation Public Transportation Division. Especially in rural communities across the state, the availability of public transportation can be traced directly to the immediate need for human service transportation and access to services. In turn, the Department of Health and Human Services’ network of human service agencies has benefited from

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<sup>n</sup> Reddy, S. Evaluator/Planner. North Carolina Department of Health and Human Services. Written (email) communication, January 25, 2016.

Department of Transportation investments in local fleets and transportation systems, since the availability of private transportation options is not as robust as it is in more urban areas.<sup>o</sup>

North Carolina can build on the strengths and challenges of expanding current public and private transportation networks to provide greater access for people with Alzheimer's disease or related dementia. One aspect of the solution is to facilitate better communication among state-level agencies that provide or purchase transportation services, especially in terms of understanding the best ways to maximize the resources of each.

For example, due to liability concerns and insurance restrictions on leaving vehicles unattended, most transportation systems are unable to assist riders from home to vehicle, or from vehicle to place of appointment. Department of Health and Human Services agencies are sometimes able to meet this need using personal care attendants when family caregivers are unavailable. However, transportation systems allow personal care attendants to ride without charge when complying with the Americans with Disabilities Act requirements to accommodate riders with disabilities. A formal mechanism for communicating about potential service needs and available resources would allow North Carolina to use available resources in collaborative ways and across funding sources, and to provide greater benefit to families needing long-term services and supports.

Because of the many types of medical and non-medical services that people with Alzheimer's disease or related dementias may need and the varying levels of local capacity to provide timely, reliable transportation to these services, the Task Force identified transportation as an area for improvement that would be best addressed through a collaborative state-level effort.

**Recommendation 4.5: Increase access to medical and community services for people with Alzheimer's disease and related dementia through improved transportation services.**

**In the context of a state-level, interdepartmental group of executive branch agencies, establish a workgroup with a mandate to collaborate on human service transportation issues, maximize resources, and address barriers that present challenges to local communities in providing transportation services. Similar to other state transportation committees that have operated in the past, such as the former Human Services Transportation Council, this interagency workgroup should work to assure coordination and communication among state agencies that provide or purchase transportation services, provide a mechanism for collaborative planning efforts across funding sources, be the state-level entity for addressing service gaps identified for special populations such as people with Alzheimer's disease or related dementia, and periodically make status reports to the Governor as directed.**

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<sup>o</sup> Bridgeman, P. Home and Community-Based Services Consultant, Division of Aging & Adult Services, Service Operations Section, North Carolina Department of Health and Human Services. Written (email) communication, February 12, 2016.

**Lead: North Carolina Department of Health and Human Services and the North Carolina Department of Transportation.**

**Partners: Statewide Coalition on Alzheimer’s Disease and Related Dementias, county social and human services agencies, local business partners and transportation vendors, and/or lead agencies for public transportation.**

### *Quality of Care and Care Coordination*

People with Alzheimer’s disease or related dementias and their families often grow increasingly concerned, as the disease progresses, about the type and quality of ongoing care they will need. The Task Force identified several areas where there is a need to improve quality and coordination of care for people with Alzheimer’s disease or related dementia.

### *Principles of Person-Centered Care*

People who are actively involved in their health and health care tend to have better outcomes and care experiences, and, in some cases, lower cost.<sup>28,29</sup> 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. Person-centered care holds as its principles:

1. Affording people dignity, compassion, and respect.
2. Offering coordinated care, support, or treatment.
3. Offering personalized care, support, or treatment.
4. Supporting people to recognize and develop their own strengths and abilities to enable them to live an independent and fulfilling life.<sup>30</sup>

Within long-term care facilities, in particular, person-centered care focuses on six essential elements: (1) a comprehensive and ongoing process; (2) the transformation of organizational operations and culture; (3) adoption of nurturing and empowering practices; (4) enabling older adults to experience purpose and meaning in their daily lives; (5) a relationship-based culture; and (6) a home environment.<sup>31</sup> Families should also be respected as part of the care team in all types of health care encounters.<sup>32</sup> In addition, health care providers should recognize, acknowledge, and support family members who provide direct care. Health care systems should develop policies that specify families as important members of the health care team and ensure families are welcomed during care appointments.<sup>32</sup>

Creating opportunities and roles for individuals and families to influence the design and governance of health care organizations is also critical to ensure their voices are heard and that health care organizations and systems are responsive to their needs. Representatives serving on governing boards and advisory committees within the health care system can share their perspectives on how policies and processes affect those served by the health care system. Including representatives on the governing board can also help ensure that the health care

organization is responsive to the community's health care needs and experiences. Creating opportunities throughout health care organizations for people and family members to influence decisions can help ensure that health care organizations are meeting the needs of the communities they serve.

For nursing homes, there is evidence that a commitment to improving engagement will also give the facility a competitive advantage; 78% of facilities implementing seven or more initiatives aimed at culture change and increased engagement report an improved competitive advantage in their market area.<sup>33</sup>

The Task Force reviewed strategies for person-centered care for health care systems and facilities, and identified these strategies as a key component of improving quality of care for people with Alzheimer's disease or related dementias. To fully engage individuals and families, health care systems must implement processes to encourage and support person-centered care throughout the health care continuum. Therefore, the Task Force recommends:

**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 or related dementias.**

**Prioritize the incorporation of person-centered care into the care planning process, care management, organizational policies, and ongoing care at health care providers and facilities, including hospitals and long-term care facilities, and in-home care settings. Partners should promote policies and processes that support and encourage person-centered care within health care facilities and in-home and community-based care and services settings, including:**

- a) **Recognition of the role of unpaid caregivers as members of the health care team.**
- b) **Inclusion of residents and families on boards and committees. Facilities should appoint a minimum of two residents and/or family members to boards and advisory committees within their organizations. Family members and caregivers should be included in development of health promotion materials and caregiver resource guides.**
- c) **Appointment of residents and families to boards of directors for governance and operation, at both the corporate/national and local levels.**
- d) **Trained facilitation for health care providers in principles of person-centered care.**
- e) **Organizational leadership to promote principles of person-centered care.**

**Partners: North Carolina Health Care Facilities Association, North Carolina Assisted Living Association, North Carolina Association of Long-Term Care Facilities, North Carolina Hospital Association, Community Care of North Carolina, LeadingAge North Carolina, Association for Home and Hospice Care of North Carolina, Hospice and Palliative Care Center, and other partners.**

## *Measuring Quality of Care*

Due to the large variety of levels of care that people with dementia may need, there is also a broad variety in the ways that health care facilities' quality and standards of care are evaluated. The Task Force examined several measures and systems for evaluating quality of care within health care facilities and explored ways that these measures can be expanded to be more appropriately and consistently applied to the care for people with Alzheimer's disease and other dementias.

For some types of long-term care facilities, the Centers for Medicare and Medicaid Services (CMS) provides a Quality Rating System that aims to evaluate facilities on measures of quality of care. The rating is on a 1-5 star level, with 5 stars being given to facilities that achieve high scores on quality measures, on measures evaluated through health inspections, and on measures that evaluate optimal staffing levels.<sup>34</sup> Facilities are required by CMS to report on quality measures at specified intervals.<sup>35</sup> The results of these evaluations are available for consumer reference at [www.nursinghomecompare.gov](http://www.nursinghomecompare.gov).

In North Carolina, Alliant Quality is the state's Medicare quality improvement organization (QIO). QIOs are contracted by CMS and are private, mostly not-for-profit organizations, staffed by health care professionals who work with stakeholders, including long-term care facilities and adult care homes, on quality improvement initiatives of importance to Medicare beneficiaries.

In 2011, CMS launched the National Partnership to Improve Dementia Care in Nursing Homes. This project aimed to reduce the use of antipsychotic medications for people with dementia. North Carolina was a national leader in this initiative; from the start of the program in 2011 through the end of 2013, the rate of antipsychotic medication use for people with dementia fell from 21.1% to 15.6%.<sup>35</sup>

The Task Force acknowledged that these efforts do not adequately address many of the issues around quality of care specific to dementia. Dementia-specific quality concerns include wandering/elopement and other safety concerns, falls, behavior management, mental health, assessment, care planning, and medication management.<sup>85</sup> There was also concern that the measures, while gathering important clinical data, do not address staff training, patient and family experiences, or issues around care transitions and coordination.

In 2011, the Dementia Measures Work Group, an initiative led by the American Academy of Neurology, the American Geriatrics Society, the American Medical Directors Association, the American Psychiatric Association, and the American Medical Association-convened Physician Consortium for Performance Improvement, developed the Dementia Management Quality Measures (see Figure 4.4). These measures were developed in order to improve quality of care for people with dementia, especially with regards to outcomes including preservation of cognitive and functional abilities, reducing behavioral symptoms, reducing safety risks, and improving caregiver well-being and skill in managing their loved ones' symptoms. Several of the measures have been adopted by inclusive quality measurement systems, including the Physician Quality Reporting System and the CMS measures for meaningful use of electronic health

records. However, while the Dementia Management Quality Measures provide a feasible guide to improving care for people with dementia, they have yet to be widely adopted.<sup>36</sup>

**Figure 4.4: Dementia Management Quality Measures<sup>36</sup>**

<b>Measure Title</b>	<b>Description</b>
No. 1: Staging of dementia	Percentage of patients, regardless of age, with a diagnosis of dementia whose severity of dementia was classified as mild, moderate, or severe at least once within a 12-month period.
No. 2: Cognitive assessment	Percentage of patients, regardless of age, with a diagnosis of dementia for whom an assessment of cognition is performed and the results are reviewed at least once within a 12-month period.
No. 3: Functional status assessment	Percentage of patients, regardless of age, with a diagnosis of dementia for whom an assessment of functional status is performed and the results are reviewed at least once within a 12-month period.
No. 4: Neuropsychiatric symptom assessment	Percentage of patients, regardless of age, with a diagnosis of dementia and for whom an assessment of neuropsychiatric symptoms is performed and the results are reviewed at least once in a 12-month period.
No. 5: Management of neuropsychiatric symptoms	Percentage of patients, regardless of age, with a diagnosis of dementia who have one or more neuropsychiatric symptoms who received or were recommended to receive an intervention for neuropsychiatric symptoms within a 12-month period.
No. 6: Screening for depressive symptoms	Percentage of patients, regardless of age, with a diagnosis of dementia who were screened for depressive symptoms within a 12-month period.
No. 7: Counseling regarding safety concerns	Percentage of patients, regardless of age, with a diagnosis of dementia, or their caregiver(s), who were counseled or referred for counseling regarding safety concerns within a 12-month period.
No. 8: Counseling regarding risks of driving	Percentage of patients, regardless of age, with a diagnosis of dementia, or their caregiver(s), who were counseled regarding the risks of driving and the alternatives to driving at least once within a 12-month period.
No. 9: Palliative care counseling and advance care planning	Percentage of patients, regardless of age, with a diagnosis of dementia, or their caregiver(s), who (1) received comprehensive counseling regarding ongoing palliation, symptom management, and end-of-life decisions and (2) have an advance care plan or surrogate decision-maker in the medical record or documentation in the medical record that the patient did not wish or was not able to name a surrogate decision-maker or provide an advance care plan within two years of initial diagnosis or assumption of care.
No. 10: Caregiver education and support	Percentage of patients, regardless of age, with a diagnosis of dementia whose caregiver(s) were provided with education on dementia disease management.

Source: Odenheimer G, Borson S, Sanders AE, et al. Quality improvement in neurology: dementia management quality measures. *Neurology*. 2013;81(17):1545-1549.

In addition to continuing to develop quality measures, there may be opportunities to use existing measures to improve the quality of care provided in long-term care facilities. The North Carolina Division of Aging and Adult Services administers the state/county Special Assistance Program, which assists low-income older adults in paying for facility-based care. For income-eligible people with Alzheimer's disease or related dementia, the Special Assistance Program may pay for care within a special care unit of a long-term care facility (this does not supplement the cost of skilled nursing facility care, though Medicaid may assist with this care). Special Assistance allows a payment if an individual is in a special care unit and has a diagnosis of Alzheimer's disease or related dementia. This is criteria for licensure of the special care unit as well. The Special Assistance payment amount is determined by the setting of care and the Special Assistance rate set by the General Assembly for licensed special care units. However, while individuals may qualify on the basis of income, care setting, and diagnosis, there are often no available slots and/or no funding for additional slots.<sup>P</sup>

Because the Special Assistance Program has this existing structure to determine payment, there may also be opportunity for the Special Assistance Program to establish a similar mechanism of tiered payment for care provided by facilities that meet dementia-specific indicators of quality. Any change in payment structure for the Special Assistance Program must be in compliance with federal regulations. There may be additional opportunity for expansion of such a payment structure to other types of payers and/or health care facilities.

The Task Force recommends:

**Recommendation 4.7: Improve quality of care and care coordination for people with Alzheimer's disease or related dementia through improved ratings systems and dementia-specific indicators.**

**Improve the quality of care for people with Alzheimer's disease or related dementia, convene a working group to determine the feasibility of developing dementia-specific standards of care, using Centers for Medicaid and Medicare Services standards and/or additional evidence-based indicators as a model. The working group should be overseen by the North Carolina Division of Aging and Adult Services and partners should utilize best practices from existing quality rating systems and dementia-specific reimbursement strategies in order to link facility ratings with value-based payments and/or performance-based incentives for providers/facilities meeting standardized quality measures specific to dementia care. The rating system should include criteria such as:**

- a) **Provision of approved training at regular intervals for person- and family-centered care for all workers, regardless of care setting.**
- b) **Reporting on dementia-specific standardized quality and outcome measures. These reports should include consumer input from residents and families. Data collected should allow comparisons with other states and within North Carolina counties and should evaluate quality ratings systems for effectiveness.**

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<sup>P</sup> Urso C. Special Assistance Program Administrator. Division of Aging and Adult Services, Adult Services Section, North Carolina Department of Health and Human Services. Written (email) communication. January 14, 2016.



- c) **Achievement of positive outcomes for people with Alzheimer’s disease and related dementia, tailored to individuals’ and families’ outcome goals using the principles of person-centered care.**
- d) **Promoting awareness of and use for standardized quality ratings among providers and consumers, including the Quality Rating System for long-term care facilities and adult care homes.**
- e) **Implementation of best practices in care transition processes, including engaging families and integrating preferences of the person with dementia in care transition processes, assessing capability to care for family members at home, and providing access to community resources and counseling on financial issues.**
- f) **Utilization of hospital discharge planners and other professionals involved in transitions who are knowledgeable about person-centered dementia care in developing care transition plans and supporting additional follow up after discharge. This should include education about adult protective services and available home- and community-based services.**

**Lead: North Carolina Division of Aging and Adult Services.**

**Partners: North Carolina Health Care Facilities Association, North Carolina Assisted Living Association, North Carolina Association of Long-Term Care Facilities, North Carolina Hospital Association, in collaboration with the state Medicaid agency, the North Carolina Division of Health Services Regulation, Division of Mental Health, Developmental Disabilities and Substance Abuse Services, Departments of Social Services Directors’ Association, county social and human services agencies, Office of the Long-Term Care Ombudsman, Friends of Residents in Long-Term Care, North Carolina’s Coalition on Aging, North Carolina comptroller’s office, academic researchers, and consumer advocacy organizations.**

*Models of Care to Improve Care Transitions and Care Coordination*

The wide variety of care needs for people with Alzheimer’s disease or related dementias and the progressive nature of these conditions also means individuals often move between types of care, including hospital care, home-based care, and long-term facility-based care such as assisted living or nursing homes. Focusing on improving the transitions between and coordination of the different types of care, while increasing patient-centered care, is key to caring for people with dementia. Care coordination measures have also been estimated to create cost savings through reducing hospitalizations and increasing efficiency in care delivery. The Medicare Coordinated Care Demonstration is estimated to decrease Medicare spending for people with Alzheimer’s disease by \$41 billion over 10 years.<sup>37</sup>

In North Carolina, many health systems and facilities are developing approaches to improve care coordination for people with Alzheimer’s disease or related dementia, through enhanced care management initiatives. Some examples include:

- Community Care of North Carolina, the care management system that provides care management to most of the state’s Medicaid beneficiaries, has developed dementia-specific components of its Care Management Program. This program seeks to improve care coordination and transitions as one of its primary goals, and includes dementia-specific professional training, care coordination needs, and caregiver resources. (See Figure 4.5.)<sup>9</sup>
- MemoryCare, located in Asheville, North Carolina, is a non-profit organization that provides dementia-specific care coordination for its patients. MemoryCare works with patients and caregivers to provide integrated clinical care, caregivers supports, and full care management. Patients must be referred to MemoryCare by a primary care physician or specialist. For non-medical expenses not covered by patients’ insurance, MemoryCare charges an annual cost-sharing fee and covers the remaining expenses through private donations and charitable contributions.<sup>38</sup>
- Duke Connected Care, a care coordination initiative through Duke Medicine, seeks to improve population health through use of multidisciplinary care teams and enhanced care management. The Geriatric Advisory Council of Duke Connected Care focuses on the needs and priorities of older patients and addresses issues including cognitive assessment, falls prevention, and improved care transitions.<sup>39</sup>
- The Caring for Older Adults and Caregivers at Home (COACH) program is a care management program, run through the Veterans’ Administration, for people with moderate to severe dementia. Participants receive care management from teams led by a nurse or social worker who receive additional support as needed from specialists in geriatric medicine, psychiatry, and pharmacy. Measures include alignment with Dementia Management Quality Measures and time to placement in long-term care. Post-pilot results suggest improvements in dementia-specific measures of quality, as well as improved satisfaction with care.<sup>40</sup>
- Programs of All-Inclusive Care for the Elderly (PACE) is a federal- and state-funded model that provides services to older adults in need of extensive care, with the goal of allowing people to remain in their homes and communities for longer. Services include adult day care, nutritional assistance (meals and counseling), social work, medical care, home health care, medications, social services, and respite care.<sup>41</sup> Services are coordinated by an interdisciplinary team, and are paid by either Medicare or Medicaid through a capitated payment system.<sup>42</sup>
- AARP has a partnership with UnitedHealth Group on a pilot program for care management, called Integrated Healthcare Management. The pilots focus on patients with chronic illness/high-risk case management (this is non-dementia specific). Participants receive an integrated care plan and receive care from an interdisciplinary team of health care professionals.<sup>43</sup> The program’s goal is to evaluate whether improved care coordination can achieve cost savings, increased patient satisfaction, and improved health outcomes in a fee-for-service setting. In addition, the total savings from 28,000 total participants in the Integrated Healthcare Management program saved Medicare, Medigap, and program participants \$8.3 million from 2009-2011.

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<sup>9</sup> Barsness K. Manager of Policy and Regulatory Affairs. Community Care of North Carolina. Written (email) communication. November 9, 2015.

**Figure 4.5: Dementia-Specific Components of CCNC Care Management Program<sup>†</sup>**

<b>Dementia-Specific Components of CCNC Care Management Program</b>	
For CCNC primary care practitioners	<ol style="list-style-type: none"> <li>1. Educate primary care practices and care management teams on: <ul style="list-style-type: none"> <li>● Detection and early identification of dementia</li> <li>● Stages of dementia – early, middle, and late and the corresponding best practices for care and treatment</li> <li>● Engagement of caregivers and care giving resources</li> </ul> </li> <li>2. Referrals to CCNC care managers</li> </ol>
For patients living in own home or assisted living	<ol style="list-style-type: none"> <li>1. Perform patient assessments and develop care plans</li> <li>2. Educate patients as well as family and facility caregivers</li> <li>3. Perform patient medication reconciliations and reviews</li> <li>4. Communications with primary care practice</li> <li>5. Provide ongoing monitoring and checking of patient and family caregiver</li> <li>6. Use available home- and community-based resources and continue to work with family based on needs</li> </ol> <p>Assisted living only:</p> <ol style="list-style-type: none"> <li>1. Education on behavioral assessment and management</li> <li>2. Support facility change toward a model of assessment and communication to reduce inappropriate IP/ED utilization</li> </ol>
For patients in the hospital setting	<ol style="list-style-type: none"> <li>1. Transitional care to engage the patient and family prior to discharge, arrange for in-home assessment and care management services</li> <li>2. Educate hospital discharge planners – create awareness of home- and community-based services in the community (work with already existing agencies such as the Council on Aging)</li> </ol>
For patients in a nursing facility setting	<ol style="list-style-type: none"> <li>1. Provide support to the nursing facility staff by making care managers available for consults</li> <li>2. Coordination during transitions both to and from hospital: <ul style="list-style-type: none"> <li>● Assist with medication reconciliation as needed</li> <li>● Follow up on hospital discharge plan</li> <li>● Short term care management</li> </ul> </li> <li>3. Provide transitional care for patients in the nursing facility who are returning home (short stay patients)</li> </ol>

<sup>†</sup> Barsness K. Manager of Policy and Regulatory Affairs. Community Care of North Carolina. Written (email) communication. November 9, 2015.

	<p>4. Communication with the primary care practice on patient’s status</p> <p>5. Provide training and support to skilled nursing facility on processes and resources regarding dementia such as:</p> <ul style="list-style-type: none"> <li>● Cognitive and behavioral assessment and management</li> <li>● Reduction of inappropriate antipsychotic medications</li> <li>● Environmental impact and change</li> <li>● Falls prevention</li> <li>● Palliative care assessment and referral</li> <li>● Family support and education</li> </ul> <p>6. Support facility change toward a model of assessment and communication to reduce inappropriate IP/ED utilization</p>
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**Recommendation 4.8: Improve care coordination for people with Alzheimer’s disease or related dementia through new models of care.**

**Implement new models of care that enhance person-centeredness, care coordination, and integration through communication, care management, and medication management for people with Alzheimer’s disease or related dementia. Potential models to apply may include specific integrated care initiatives and/or enhanced care management programs. The Medicaid agency should include such models in health plan contracts, and the Dual Eligibles Working Group<sup>5</sup> should prioritize recommendations on the application of care coordination models to coverage for the dual eligible population.**

**Lead: Health care systems, facilities, and public and private payers, including accountable care organizations, managed care organizations, and provider-led entities.**

**Partners: North Carolina Department of Insurance, North Carolina Department of Health and Human Services, the state Medicaid agency, and the Dual Eligibles Working Group.**

*Hospital-Based Care for People with Alzheimer’s Disease and Related Dementia*

Between 2008 and 2010, dementia was the 3rd leading mental health reason for visits to the emergency room for North Carolina adults over 65.<sup>44</sup> People with Alzheimer’s disease or related dementia are also hospitalized two to three times more frequently than non-cognitively impaired

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<sup>5</sup> “Dual eligibles” refers to 10.2 million Americans who qualify for coverage under both Medicare and Medicaid. These individuals are among the most disabled, chronically ill, and costly coverage recipients. On average, health care costs for the dual eligible population are 60% more than for non-dual eligible individuals. Approximately half of dual eligible qualify for Medicare because of disability rather than age. Almost one-fifth have three or more chronic conditions. More than 40% use long-term services or supports.<sup>36</sup> In North Carolina, the Dual Eligibles Work Group was mandated by the Medicaid Transformation and Reorganization legislation in 2015 (citation: <http://www.ncleg.net/Sessions/2015/Bills/House/PDF/H372v8.pdf>)

peers.<sup>45</sup> As the population ages, these numbers are expected to rise, and it is imperative that hospitals improve quality of care and care coordination for individuals with Alzheimer’s disease or related dementia in both emergency and non-emergency care settings.

The Alzheimer’s Association has developed the Dementia Friendly Hospital Initiative to improve quality of care and care coordination within hospitals. This initiative provides a training curriculum and resources for acute care staff in hospitals to better provide person-centered care to people with dementia. Training materials include information about wandering, behavioral management, communication, and eating issues. The initiative also focuses on relationships with caregivers and how hospitals can focus on environmental improvements to improve dementia care.<sup>46</sup> A study of more than 300 hospital staff, including nurses, social workers, and mental health professionals, demonstrated improved confidence in caring for patients with Alzheimer’s disease or related dementia, including in such areas as assessing and recognizing dementia, managing behavioral symptoms such as agitation, and communicating with patients, following participation in the Dementia Friendly Hospital Initiative.<sup>47</sup>

Lake Norman Regional Medical Center in Mooresville, North Carolina, received a Nurses Improving Care for Healthsystem Elders (NICHE) designation in May of 2015. This initiative provides a wide variety of patient/staff tools, family resources, and reports on organizational best practices. While the program focuses on all aspects of elder care, Alzheimer’s disease and related dementia is included in the curriculum. In addition, Lake Norman has also instituted a silver armband to identify patients with cognitive impairments. The armband’s color aligns with the Code Silver theme, and reads “Special Care,” wording that serves to notify staff members, but not expose individuals’ medical status to general public. The armbands alert staff that an individual may not be able to provide a reliable medical history, and should not be questioned without a family member present to verify.<sup>†</sup>

Asheville’s Mission Hospital developed a similar curriculum and organization model to improve care for patients with dementia. Acknowledging the under-diagnosis of dementia in the hospital setting, Mission’s initiative focused on training staff to recognize symptoms of dementia and the ways dementia symptoms may result in adverse health outcomes. The initiative also aimed to reduce or prevent cognitive decline during hospital stays and to improve communication with caregivers. Interventions include multidisciplinary staff training and family/caregiver involvement.<sup>‡</sup> Mission Hospital has served as a national model of a dementia-capable hospital program for the past 10 years.

The Task Force recommends:

**Recommendation 4.9: Expand the Dementia Friendly Hospital initiative.**

**Promote the Dementia Friendly Hospital Initiative in North Carolina’s hospitals, health care providers, and health systems. Facilities should work to include environmental modifications and practices that enhance continuity of care and person-centered care.**

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<sup>†</sup> Whitfield L. Director of Marketing and Public Relations. Lake Norman Regional Medical Center. Written (email) communication. September 15, 2015.

<sup>‡</sup> Hunnicutt NS. Regional Long-Term Care Ombudsman. Land of Sky Area Agency on Aging. Written (email) communication. November 12, 2015.

**Lead: Health care providers and systems.**

**Partners: North Carolina Hospital Association, Alzheimer’s North Carolina, and Alzheimer’s Association.**

### *Training of Health Care Professionals*

While focusing on health system capacity and access to and quality of care, it is also crucial for North Carolina to improve Alzheimer’s disease and related dementia-specific capabilities of the health professional workforce. The training of the health professional workforce to meet the needs of the rapidly growing population of North Carolinians with Alzheimer’s disease or related dementia rests on two basic assumptions. First, only a small portion of health care for people with Alzheimer’s disease or related dementia will be delivered by dementia specialists or geriatric specialists.<sup>48,49</sup> Second, North Carolina is rich in resources for in-service continuing education about caring for people with Alzheimer’s disease or related dementia, but falls short in taking advantage of those opportunities and effectively implementing the highest quality care taught in those settings.

Most health care of people with Alzheimer’s disease or related dementia will be provided by family caregivers (see Chapter 5). A large amount of health care for people with Alzheimer’s disease or related dementia will be delivered by frontline workforce (paid caregivers, certified nursing assistants, physical and occupational therapy technicians, etc.). A small amount of health care will be provided by primary care clinicians.

Dementia and geriatric specialists play a critical role in caring for people with Alzheimer’s disease or related dementia. However, North Carolina has very few of these specialists. Further, these practitioners are clustered in a few geographic locations.

North Carolina has recently been awarded three grants from the Health Research Services Administration (HRSA) for funding of geriatric workforce education programs. These three programs are currently in planning phases, and include programs at Duke University, University of North Carolina at Chapel Hill, and East Carolina University. Each center, as required by supplemental funding, will focus at least a portion of activities on the care of people with Alzheimer’s disease or related dementias.<sup>50-52</sup>

The core common elements of the three geriatric workforce education programs include inter-professional education, quality improvement, development of inter-professional teams in primary care, and enhancement of geriatric skill in primary care. In addition, the Duke and UNC Centers will fund advanced traineeships. All three centers will work with family caregivers and communities to enhance the skill and preparation of the family caregiver and other members of the community. All three geriatric workforce education centers will partner with state Area Health Education Centers (AHEC) to enhance the availability of inter-professional education.<sup>50-52</sup>

The Carolina Geriatric Education Center Consortium is funded by HRSA and the US Department of Health and Human Services. Consortium members include the AHEC program and all regional AHEC partners. The Carolina Geriatric Education Center Consortium trains health professionals including physicians, nurses, social workers, behavioral health providers, dentists, and allied health professionals. Training includes evidence-based falls prevention programs, practitioner core competencies in geriatrics and interdisciplinary practice, health literacy, and advocating for mental health for older adults.<sup>53</sup>

The North Carolina Geriatric Adult Mental Health Specialty Teams also provide training for health providers and community workers in symptoms of mental illness in older adults, and include information about Alzheimer's disease and related dementias in this training. Geriatric Adult Mental Health Specialty Teams aim to improve communication, assessment procedures and techniques, and referral systems for older adults with mental health or dementia symptoms. The Geriatric Adult Mental Health Specialty Teams training is being used in both long-term services and supports settings and in community settings. Geriatric Adult Mental Health Specialty Teams are also used to train health providers in licensed medical entities and managed care organizations.<sup>54</sup> There is opportunity to apply a similar model in other relevant settings.

The Task Force found that there may be adequate professional development opportunities around caring for people with Alzheimer's disease or related dementia, but they are, at times, hard to fill with learners. Perhaps more importantly, in many cases it is the same social worker or nurse getting dementia specific training year after year, and then he or she returns to a usual practice environment where enhanced skills and practices are not supported due to the lack of inter-professional education.

The Task Force supports the need for high quality specialty care, such as that delivered by neurologists specializing in dementia care and geriatricians, but also acknowledges that currently there are only a small handful of these professionals and they are working in a limited number of highly specialized settings. Therefore, one important way to improve health professional skill in caring for people with Alzheimer's disease or related dementia is to offer enhanced training for primary care physicians (family practice and internal medicine), general neurologists, psychiatrists, geriatricians, and generalists, and ideally that training should be in the context of inter-professional education supported by practice, system, or program leadership.

Finally, the Task Force reviewed the important role of frontline staff such as nursing assistants, paid caregivers, and occupational therapy assistants. The bulk of day-to-day care that is not provided by family caregivers is provided by this frontline staff. Frontline workers are often in low skill, low wage, and high turnover occupations. Enhancing skill (with commensurate enhanced wages) is one approach to improve care for people with Alzheimer's disease or related dementia and decrease turnover among caregivers. The Task Force therefore identified the community college system as a critical and underutilized partner in enhancing inter-profession care of people with Alzheimer's disease or related dementia. Some community colleges in North Carolina currently offer geriatric specific course work, and geriatrics are part of the curriculum for certified nursing assistants. There is an available certification as a geriatric aid, but it is not well utilized. The community college system seeks to identify market driven training needs.

Currently few work environments will pay a higher wage for an aid with a geriatric certification, so there is little incentive for an aid to have the higher level of specialized training.

The Task Force recommends:

**Recommendation 4.10: Promote Alzheimer’s disease and related dementia-specific training for health professionals and community workforce.**

**Enhance promotion and dissemination of existing continuing education on Alzheimer’s disease and related dementia-specific training for health care providers and home- and community-based services providers, including but not limited to nurses, certified nursing assistants, outpatient care staff, physicians, social workers, adult day services staff, behavioral health providers, emergency care providers and staff, emergency medical technicians and other first responders, dentists, and clergy and chaplains. Training programs should:**

- a) **Be offered in multiple settings, be provided on an ongoing and recurring basis, include needs of specific vulnerable populations, and include opportunities for more intensive trainings when desired, appropriate, and necessary to achieve minimum proficiency.**
- b) **Be included for all health care professionals in both pre- and in-service training and emphasize inter-professional education and quality improvement.**
- c) **Include information on palliative care, advanced health directives, family care planning resources, and information on Medicare rule on end-of-life planning**
- d) **Emphasize aspects of diagnosis and detection, including information on triage-based and referral-based diagnostic systems (as referenced in Recommendation 3.2).**
- e) **Address needs of people with Alzheimer’s disease or related dementia in the creation of emergency/disaster preparedness plans, and increase awareness of specific needs of this population during emergencies and disasters.**
- f) **Include principles of patient- and family-centered care, as they pertain to people with dementia and their family caregivers**
- g) **Expand behavioral management training for individuals with dementia, using a person-centered approach to care and applying best practices in prioritizing the use of nonpharmacological approaches.**

**Partners: North Carolina Area Health Education Centers programs, the North Carolina Community Colleges System, the three North Carolina based Geriatric Workforce Education Programs, Geriatric Adult Mental Health Specialty Teams, Geriatric Education Center Consortium, colleges and universities, health professional training schools, organizations that provide care management services (including health systems and accountable care organizations), professional associations including, but not limited to, the North Carolina Medical Society, North Carolina Nurses Association, North Carolina Academy of Physician Assistants, North Carolina Academy of Family Physicians, and advocacy organizations including Alzheimer’s North Carolina, and Alzheimer’s Association.**



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

**Identify avenues of entry and provide methods of incentives for health professionals' geriatric/gerontology specialization and additional training in Alzheimer's disease and related dementia care. These methods may include loan forgiveness programs, innovative recruitment models, expansion of areas of concentration eligibility, certificates of added qualifications, and specialty training designations for individual practitioners. These incentives should be tailored for broad application to all health and human services professional designations.**

**Lead: North Carolina academic health education programs supported by North Carolina general funds.**

**Partners: North Carolina Area Health Education Centers and private and public payers.**

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

**Build on existing models for increased compensation upon completion of geriatric and Alzheimer's disease and related dementia-specific training modules/certifications within existing health professional training programs, including physician, nurse, and allied health professionals. This work should include analysis and promotion of the business interest for improved training, such as increased revenue, less employee turnover, and marketing advantages, as well as the benefits to employees and improvement of quality of care.**

**Partners: Health professional employers, consumer advocacy groups, health professional educational/training organizations, and professional associations, including, but not limited to, the North Carolina Home Care Association, North Carolina Long-Term Care Facility Association, Association for Home and Hospice Care of North Carolina, North Carolina Health Care Facilities Association, North Carolina Assisted Living Association, Board of Nursing, Friends of Residents of Long-Term Care, North Carolina Health Care Professional Registry, North Carolina Community College System, and Area Health Education Centers.**

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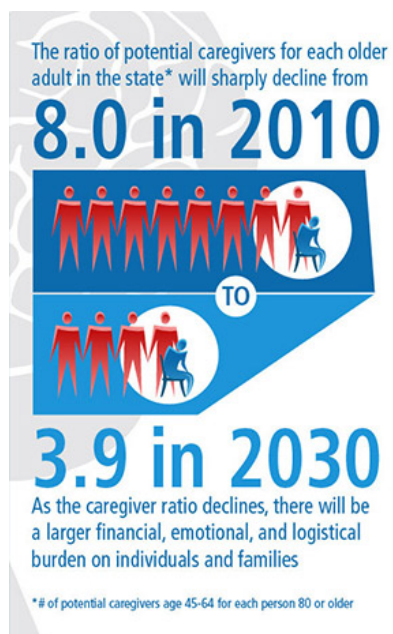
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## CHAPTER FIVE: SUPPORTING CAREGIVERS AND FAMILIES TOUCHED BY ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

As explained in Chapter 4, because of the progressive nature of Alzheimer's disease and related dementias, caring for a person with the disease is often very intensive and can require much of a caregiver's time, financial resources, and emotional and physical commitment. Families also often find themselves unprepared for the many adjustments, decisions, and preparations they have to make when faced with caring for a person with dementia. Adult children and spouses often serve as caregivers for people with Alzheimer's disease or related dementia—approximately 85% of unpaid care is provided by families, and two-thirds of family caregivers for people with dementia are women.<sup>v,1</sup> An estimated 448,000 people in North Carolina provided unpaid care for family members with dementia in 2014, at a value of approximately \$6.2 billion.<sup>1w</sup> As the disease progresses, caregivers often face increasing stress as their loved ones need additional assistance with finances, behavioral problems, wandering, and activities of daily living. Caregivers often miss work and must handle the logistics of finding additional care, and may experience increased stress, anxiety, and depression, as well as adverse physical effects.



In coming years, the burden on caregivers will greatly increase. According to AARP, census data shows that the ratio of individual caregivers (number of potential caregivers age 45-64 for each person age 80 or older) will decrease from 8.0 in 2010 to 3.9 in 2030.<sup>2</sup> As the caregiver ratio declines, there will be a larger financial, emotional, and logistical burden on individuals and families. The Task Force examined the needs of family and other unpaid caregivers and developed actionable recommendations with the goal of providing needed resources and assistance.

### *Caregiver Resources*

Currently in North Carolina, there is a broad system of resources and supports for people providing unpaid care to family members with Alzheimer's disease or related dementia. Services such as adult day care, home delivered meal services, transportation, caregiver support groups, and respite care can provide much needed assistance to caregivers. Studies show that respite care, when coupled with education and ongoing support, reduces caregiver stress and burnout.<sup>3</sup> Unfortunately, caregivers often experience difficulty in learning about available resources,

<sup>v</sup> Bethel Mary. Director. North Carolina Coalition on Aging. Written (email) communication, January 5, 2016.

<sup>w</sup> "Value" is calculated using \$12.17/hour in wages.



accessing these resources, and/or identifying the resources for which they may be eligible. In addition, the availability of resources varies by location, and services remain unaffordable for many North Carolinians.

Many organizations seek to alleviate the difficulties that caregivers face in identifying and accessing appropriate resources. The Duke Family Support Program, within Duke University, provides a broad network of supports for family caregivers. The program was the first in the state to provide family caregiver support groups, and since 1984, has functioned as a clearinghouse/database, crisis hotline, and provider of technical assistance to family caregivers and a resource to providers. The program offers confidential, personalized support in caregiving decisions, current research updates, and assistance with locating appropriate health care and other services.<sup>4</sup>

Alzheimer's and dementia advocacy organizations also provide valuable resources for caregivers, including information about symptoms, diagnosis, and available services. In North Carolina, the Alzheimer's Association and Alzheimer's North Carolina are both statewide nonprofit 501c3 organizations providing information on support groups, caregiver education programs, training of health care professionals, and research. Alzheimer's North Carolina raises private funding to support research efforts and provides limited respite to family caregivers in crisis. Both organizations advocate on behalf of the needs of individuals with Alzheimer's and related dementias and their caregivers. Candlelight Reflections events are held annually across the state to bring awareness to the disease and honor loved ones lost to dementia.

Project CARE (Caregiver Alternatives to Running on Empty), is the only dementia-specific state-funded service through the North Carolina Department of Health and Human Services, Division of Aging and Adult Services providing caregiver support, care management, and referrals to available services. Project CARE partners with local family caregiver support programs within each Area Agencies on Aging and other organizations in order to improve services and increase capacity.<sup>5</sup> Project CARE was designed and tested in North Carolina. It has become a national best practice model for providing respite services to family members who are caring at home for a loved one with Alzheimer's disease or related dementia. Project CARE uses a family consultant model to provide comprehensive support to dementia caregivers. The goal of the program is to increase quality, access, choice, and the use of respite care for low-income (non-Medicaid), rural and

After my diagnosis of Alzheimer's, I have had to re-create myself. Living out of my heart and less out of my head allows me to live in the now. I do not trust my head to remember or to make good decisions as I once did. One day I will not be able to recall the names of the people I love. So, I have told my children, family and friends that I am placing them in my heart where they will always be. Living in the now and placing them in my heart takes away some of the burden of Alzheimer's.

James Hyde, Black Mountain, NC

minority families caring for a person with dementia at home. However, due to a reduction in state funds in 2011 totaling \$500,000, respite care through Project CARE is no longer available to family caregivers.<sup>x</sup>

A similar program is the New York University Caregiver Intervention program. This program combines family and individual counseling, support group referral, and ad hoc consultation. A study of this program applied in Minnesota showed a reduction of almost 50% in placement in a nursing home after two years.<sup>6,7</sup> Other applications of the New York University Caregiver Intervention program showed a delay in placement of 329 days compared to controls.<sup>8</sup> Cost modeling in Minnesota showed that if all caregivers of people with dementia received this program between 2010 and 2015, costs saved in Minnesota would have neared \$1 billion and almost 20% fewer people with Alzheimer's or related dementia would have died in nursing homes.<sup>9</sup>

Research has shown that a formal system of supports for caregivers can greatly alleviate caregiver stress, prevent social withdrawal, and improve well-being. When coupled with respite care, such systems have shown to significantly reduce depression and increase quality of life for family caregivers, of people with Alzheimer's.<sup>7</sup> Because such resources and supports can have a great impact on the well-being of caregivers and, thus, on people with Alzheimer's as well, it is critical that caregivers are easily and quickly able to locate and navigate the services they may need.

The National Family Caregiver Support Program (NFCSP), through Title III E of the Older Americans Act, funds a range of supports that assist caregivers including: 1) information and assistance, 2) individual counseling, organization of support groups, and training to assist caregivers in making decisions and solving problems about their caregiving roles, 3) respite care to provide temporarily relieved from their caregiving responsibilities, and 4) supplemental services, such as incontinence supplies (on a limited basis). Specific services vary by county, however these services work in conjunction with other state- and community-based services to provide a coordinated set of supports. Eligible family caregivers are those either caring for an older adult age 60 or older or providing care for a person with Alzheimer's disease or related dementia or a caregiver (who is not the birth or adoptive parent), age 55 or older, raising a related child age 18 and under or an adult with a disability.<sup>10</sup>

Studies have also indicated that Powerful Tools for Caregivers, a six-week curriculum designed to enhance caregiver self-care, management of emotions, self-efficacy, and use of community resources, results in improvement in all of these domains.<sup>11,12</sup>

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<sup>x</sup> Hensley M, Blater A. Alzheimer's Support Specialist and Family Caregiver Program Consultant. Division of Aging and Adult Services, North Carolina Department of Health and Human Services. Written (email) communication. February 12, 2016.

While there are specific programs in North Carolina currently working to make caregiver supports and resources easier to access and more effective in alleviating caregiver burden, these efforts often remain separate and at times difficult for families to locate, navigate, and pay for. The Task Force identified the need for a comprehensive and integrated resource for accurate, accessible, and practical information for caregivers, and for expanded resources to provide adequate services to families who need them.

**Recommendation 5.1: Promote integration and accessibility of dementia-specific resources through a comprehensive caregiver toolkit and virtual resource center.**

**Develop a comprehensive “virtual resource center” to be maintained on the Department of Health and Human Services website. The virtual resource center will serve as an informational guide for families, professionals, care managers, and navigators including but not limited to NC 2-1-1, stakeholders, and local provider agencies. The virtual resource center will link to an updated Dementia Toolkit available on the Duke Family Support Program website. The virtual resource center and toolkit should include:**

- a) Information about Alzheimer’s disease and related dementia, including definitions/types, prevalence, symptoms, diagnosis, etc.**
- b) Information on financial and logistical preparation for caregiving and end-of-life care, including care goals, decision-making needs, advanced care planning, and ways to avoid elder fraud.**
- c) Resources for services, including employer-based services, adult day care, caregiver respite services, and financial assistance.**
- d) Training resources, including hands-on caregiver training in assistance with activities of daily living.**
- e) Safety resources, including tips on home safety, community safety, and technological innovations (such as Safe Return or other web-based tools).**
- f) Resources and supports for health care providers, including information on available trainings and information on starting conversations with patients and families about financial planning and safety concerns.**
- g) Tools for preliminary assessment of caregiver needs, in order to provide appropriate and effective resources.**
- h) Availability in both web-based and hard copy format, in order to maximize accessibility for all populations.**

**Lead: North Carolina Division of Aging and Adult Services and Duke Family Support Program.**

**Partners: North Carolina Alzheimer’s stakeholder organizations.**

**Recommendation 5.2: Ensure adequate funding for family caregiver support services including dementia-specific respite through Project CARE.**

**Study the needs for adequate funding of Project CARE (Caregiver Alternatives to Running on Empty) as an evidence-based caregiver support service, including ‘episodic’ respite care, education, coaching, and caregiver training. Any initial increases in appropriations should include sufficient resources to evaluate program impacts on program goals, especially with regard to:**

- a) A caregiver’s “intent to institutionalize” care recipients with Alzheimer’s disease or related dementia, real delays in placement, and cost-savings for the Medicaid program and other state programs.**
- b) Show improved outcomes (i.e., delayed placement in long-term care, improved access to care, caregiver well-being, etc.) and reduced costs for individuals with dementia, their families, and payers.**
- c) Provide a full analysis and recommendation to the General Assembly for initial pilot funding for evidence-based programs within selected communities, with the possibility of recurring funding after additional results and outcomes analysis.**

**Lead: North Carolina Division of Aging and Adult Services.**

**Partners: North Carolina General Assembly and Fiscal Research Division.**

*Access to Accurate and Appropriate Long-Term Services and Supports*

North Carolina is working toward making it easier for individuals who need long-term services and supports and their caregivers to learn about the full array of services available and access the help they need. Long-term services and supports help address both the clinical and non-clinical needs of people with chronic illness or disability who need ongoing assistance with daily living. (See Chapter 4 for additional information on long-term services and supports.) These services encompass a wide array of programs, and are provided through private and public agencies. Because of the complicated network of programs, these services are often difficult for individuals or families to access. People trying to access the multitude of services and supports frequently find themselves confronted with a maze of agencies, organizations, and programmatic requirements at a time they may be in crisis. They often require assistance in accessing the appropriate service to meet their current and future needs.<sup>y</sup>

To this end, North Carolina is in the process of developing plans to implement a “No Wrong Door” system of access for long-term services and supports, the primary objective of which is to

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<sup>y</sup> Solovieff T. Project Director. North Carolina Department of Health and Human Services. Written (email) communication, November 9, 2015.

help meet families' needs by providing information, education, and connection to services. No Wrong Door will establish a statewide informational platform to serve as a one-stop connection to information and assistance navigating long-term services and supports, Alzheimer's and dementia related services and supports, and/or other health and human services and supports.<sup>2</sup>

A primary strategy of No Wrong Door is a continued and enhanced partnership with NC 2-1-1. NC 2-1-1 was established and is maintained by United Way of North Carolina and is funded through a combination of public and private investment. United Way partners with state stakeholders to operate the NC 2-1-1 system, which provides access, via telephone and internet, to many services and supports, including health and human services and government programs.<sup>13</sup> Current and potential features of NC 2-1-1 include:

- easy to remember toll-free hotline
- educational website including brief overview of topics, points the reader to relevant service providers and web links to additional details
- 24/7 information and referral services, answered by trained professionals
- multi-language translation services
- comprehensive statewide database of health and human services in the community; to include specific Alzheimer's and dementia related services and supports
- reporting and analytical capabilities to track reasons for calls and referrals made<sup>13</sup>

With a common goal of improving access statewide to appropriate care, resources, and supports for caregivers of individuals with dementia, the Task Force recommends additional state support for North Carolina's No Wrong Door system through a partnership with NC 2-1-1.

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

**Provide an annual investment of \$200,000 for management of state involvement with the No Wrong Door initiative and “virtual front door” access provided through partnership with NC 2-1-1. NC 2-1-1 will provide the infrastructure for the No Wrong Door system, building on the existing information management platform. This funding should support two full-time staff positions to oversee continued No Wrong Door development and implementation, migration of Alzheimer's disease and dementia-related community resources to enhance the existing NC 2-1-1 database, manage Alzheimer's disease and dementia-related stakeholder partnerships, and provide planning for evaluation,**

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<sup>2</sup> Solovieff T. Project Director. North Carolina Department of Health and Human Services. Written (email) communication, November 9, 2015.

**sustainability, and further statewide scaling. As part of this work, the Division of Aging and Adult Services should:**

- a) Develop infrastructure for state and local government involvement with NC 2-1-1 on dementia-specific resources.**
- b) Identify and manage partnerships with organizations including the Area Agencies on Aging, Department of Social Services, aging transition services, Just One Call (Mecklenburg County), caregiver representatives, and other community resource organizations to ensure the integrity of Alzheimer’s disease and dementia-specific information provided to NC 2-1-1 on available services and resources is accurate, up-to-date, and continuously monitored.**
- c) Partner with NC 2-1-1 leadership to identify available outside funding sources to support expansion of information management system, thereby improving access and referral support to older adults and/or people with dementia.**
- d) Work with NC 2-1-1 leadership to expand and enhance systems integration capabilities, develop controlled marketing strategies, website enhancement, training for call center staff, technology opportunities (through mobile apps and others), and development of reporting and quality assurance measurements.**
- e) Partner with aging and dementia advocacy organizations, including the Alzheimer’s Association, Alzheimer’s North Carolina, Area Agencies on Aging, local Departments of Social Services, and AARP North Carolina, to increase awareness of NC 2-1-1 as a primary resource for health care needs, home- and community-based services, and caregiver support and assistance.**
- f) Coordinate training for NC 2-1-1 staff in working with individuals or families with Alzheimer’s disease or related dementias and/or engaging dementia specialists to serve as NC 2-1-1 staff.**

**Lead: General Assembly.**

**Partners: Division of Aging and Adult Services and United Way of North Carolina.**

### ***Caregivers and Employment***

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. Because people with Alzheimer’s disease or related dementias require more care over time, family caregivers often find themselves having to be absent from work or leave the workforce completely in order to attend to their family members’ needs.

Nationwide, the average caregiver is a 49 year-old woman, caring for her 60 year old mother who does not live with her. She is married and employed.<sup>14</sup> In the United States, more than 60% of family caregivers (for all conditions) are employed, and in North Carolina, more than 75% of



Now that my husband is in assisted living, the loss of income has been devastating for me. A guardianship was granted in June 2015. It is hard seeing and accepting the diagnosis. My health deteriorated after a heart attack, I lost my job, and stress is unreal.

Caregiver, Jackson County, NC

family caregivers have had to adjust work schedules to care for family members.<sup>aa,2</sup> Fifteen percent of family caregivers have to give up employment entirely in order to care for a family member. These changes often result in lowered earnings, reduced Social Security benefits, and loss of other employment-related benefits such as health insurance and retirement savings.<sup>2</sup>

Caregiving can also have a negative impact on employers. Nationally, employers report a productivity loss of nearly \$33.6 billion, with an average annual cost per full-time employee caregiver at \$2,110.<sup>15</sup> Employers can contribute to relieving stress on their caregiver employees and also recoup productivity losses through supportive benefits such as enhanced resource referral programs and flexible and accommodating leave policies. While more employers are beginning to offer such policies, there is more work to be done. In the 2015 North Carolina legislative session, AARP North Carolina, 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.<sup>bb</sup>

**Recommendation 5.4: Enhance employer policies to support family caregivers.**

**Partner with employer stakeholders and business interests to develop policies to encourage active employer participation in support for employee caregivers. This should include:**

- a) Education for employers about Alzheimer's disease and related dementia, the role of family caregivers and support for additional promotion of caregiver-friendly policies.**

<sup>aa</sup> This is for all conditions, not just Alzheimer's/dementia-specific.

<sup>bb</sup> House Bill 816 House DRH10314-LR-137A. April 14, 2015.

- b) Policies to support employee caregivers, including options such as flextime, paid and unpaid family leave, non-discrimination against caregivers in workplace, telecommuting, referral programs, respite services, on-site support groups, awareness of available benefits (i.e., Family Medical Leave Act eligibility), expansion of the definition of family for caregiving and leave-related policies, and specialized employee assistance programs.**
- c) Identification of corporate/employer champions to promote benefits of supportive employer policies to economic interests, as well as employee caregivers' interests.**
- d) Encourage passing of House Bill 816 through the North Carolina Senate, in order to study the needs of working family caregivers.**

**Lead: AARP North Carolina, Alzheimer's North Carolina, the Alzheimer's Association, the Association for Home and Hospice Care, and the North Carolina General Assembly.**

**Partners: Employer stakeholders and business interests, including North Carolina Chamber of Commerce and the Society for Human Resources Management.**

### ***Home- and Community-Based Services***

For the purposes of this report, Home and Community-Based Services refer to services funded through state and federal dollars administered at the county level. These services are generally designed to supplement and improve care provided in the home of older adults, to assist unpaid caregivers caring for loved ones in the home, and to delay institutionalization. These programs may include services such as in-home care, nutrition programs such as home-delivered meals, respite programs, adult day care, and transportation services. Funding streams for these programs vary, as does eligibility criteria.

Many of these services are those that, if provided, could prevent or delay institutionalization. An AARP analysis of home- and community-based services provided in 25 states between 2005 and 2012 showed overwhelming evidence that investment in expanded home- and community-based services contains costs and slows cost growth, largely due to savings from delayed or prevented institutionalization.<sup>16</sup> For respite care specifically, research has shown that an increase of \$100 toward respite care produced approximately a one-week delay in institutionalization.<sup>17</sup>



### *Home and Community Care Block Grant*

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.<sup>cc</sup> These services target non-Medicaid eligible older adults in the state. The North Carolina Division of Aging and Adult Services administers the block grant and the Area Agencies on Aging disburse funding to counties. Funding is combined with several federal sources including Title III-B funding for supportive services, Title III-C-1 funds for congregate meals, Title-III-C-2 funding for home-delivered meals, Title III-D funds for frail elderly services, Older Americans Act funds for older adult services, and state appropriations for older adult services. The Federal Older Americans Act provides about 49% of North Carolina's Home and Community Care Block Grant funds with the remaining 51% provided in recurring state appropriations.<sup>dd</sup> 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.<sup>18</sup>

In North Carolina 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.<sup>ee</sup>

North Carolina has combined a variety of state and federal funds to provide services through the Home and Community Care Block Grant. Combining funds results in greater administrative efficiency. However, it also means that all provided services must comply with the Older Americans Act, which requires that states do not allow cost-sharing or charge for services paid for with Home and Community Care Block Grant funds. Programs are allowed only to offer the opportunity for service recipients to make voluntary contributions. One option to increase the number of individuals served would be to unbundle some state funding from this program to offer services on an income-based sliding scale to individuals with varying levels of ability to pay.<sup>ff</sup>

The Task Force recommends:

#### **Recommendation 5.5: Examine outcomes and impact of home- and community-based services programs.**

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<sup>cc</sup> NCGS § 143B-181.1(a) (11).

<sup>dd</sup> Hensley M. Alzheimer's Support Specialist. Division of Aging and Adult Services, North Carolina Department of Health and Human Services. Written (email) communication. September 28, 2015.

<sup>ee</sup> Reddy S, Hayden L. Planner/Evaluator. Division of Aging and Adult Services, North Carolina Department of Health and Human Services. Written (email) communication. February 8, 2016.

<sup>ff</sup> Hensley M. Alzheimer's Support Specialist. Division on Aging and Adult Services, North Carolina Department of Health and Human Services. Written (email) communication. September 28, 2015.

**In order to maximize state resources, the lead agency should examine home and community based programs that have shown improved outcomes (such as delayed placement in long term care, improved access to care, and improved caregiver wellbeing) and reduced costs for individuals with Alzheimer’s disease or related dementias, their families, and payers. Lead agency should:**

- a) Analyze the impact of home- and community-based services on overall health care costs, including impact on Medicare and Medicaid costs, and caregiver/family economic and well-being costs, of increasing the number of individuals able to access home- and community-based services, and/or age in place. (Potential programs may include financial provisions for personal care services and missed work days, specialized medical supplies and home safety technologies, and respite care.)**
- b) Include evaluation costs in funding recommendations to determine whether service providers met outcome goals, including waiting lists for services.**
- c) Conduct an analysis of modifying the Home and Community Care Block Grant configuration. The analysis should include:**
  - i. Review of current allocation methodology and payment to allow for consumer cost-sharing.**
  - ii. Detailed analysis of the process by which the modifications would be made to existing state statutes (i.e., North Carolina General Assembly approval).**
  - iii. Estimated potential expansion of services from revenue generated from instituting a sliding fee for service (income-based) and return on investment analysis.**

**Lead: North Carolina Department of Health and Human Services.**

### *Medicaid Coverage of Home- and Community-Based Services*

Established in 1981 under section 1915 (c) of the Social Security Act, Medicaid Home- and Community-Based Service (HCBS) waivers—including North Carolina’s Community Alternatives Program for Disabled Adults (CAP/DA) and CAP/Choice waivers—have become increasingly popular as states look to reduce Medicaid spending on long-term services and supports delivered in institutional settings. The CAP/DA waiver and the Community Alternatives Program for Choice (CAP/Choice) covers services including adult day care, personal care, and caregiver respite services.<sup>19</sup> CAP/Choice allows individuals to pay family members for providing home-based care.<sup>20</sup> (See Chapter 4 for additional information on Medicaid waivers.)

In December 2013, North Carolina had 11,214 approved CAP/DA slots across the state, with a waitlist of over 8,000 individuals. As of early 2014, CAP/DA lead agencies are required to utilize at least 95% of their available CAP/DA slots and this utilization rate is reviewed quarterly.<sup>21</sup> Many counties or service providers may, technically, have “open” slots for

individuals seeking services through waivers, but the slots cannot be filled due to lack of local funding.

Medicaid-funded HCBS programs operate under two conditions:

1. To receive an HCBS waiver a person must meet the eligibility criteria for institutional care under Medicaid (see Chapter 4).
2. An HCBS program must be cost-neutral, meaning that for people meeting the same level of institutional eligibility, the average per-person HCBS payment must not exceed the average per-person institutional payment.

Recent studies have shown that HCBS programs are likely to be cost-effective over time. On the individual level, an HCBS waiver costs Medicaid far less than institutional care—a difference of about \$44,000 in 2006.<sup>22</sup> Evidence shows that while states are in the process of expanding HCBS programs, Medicaid spending on long-term care will increase more rapidly than in states with small HCBS services. However, once large HCBS programs are established, Medicaid long-term care spending increases at a slower rate than in states with small HCBS programs. States with large HCBS programs experienced an inflation-adjusted net reduction in Medicaid expenditures on nursing homes of about 15% between 1995 and 2005.<sup>23</sup> HCBS program expansion can help save Medicaid money over time by slowing the growth of long-term care expenditures.

States have begun to look beyond HCBS waivers to different models for delivering community-based services, including consumer-directed care and capitated payment models. The evidence on Medicaid costs for these models is mixed. On the whole, these alternative programs have elevated patient and caregiver satisfaction above institutional care satisfaction. Some have demonstrated improved health outcomes—most notably the Program of All-Inclusive Care for the Elderly (PACE), which uses capitated Medicaid and Medicare payments to provide community-based integrated care. Some studies have found that Medicaid costs increased as a result of these programs, while others have found cost reductions.<sup>24</sup> Individuals on the waitlists for services through CAP/DA may be referred to PACE programs if they are locally available.<sup>21</sup>

PACE, Cash and Counseling, Wisconsin Family Care, Minnesota Senior Health Options, S/HMO II, and Medicare Alzheimer's Demonstrations are among the community-based programs that have demonstrated higher Medicaid costs than traditional institutional care. Arizona's Long-Term Care System, a statewide mandatory managed care program that incentivizes HCBS, and Texas STAR+PLUS have produced cost savings to Medicaid. Figure 5.1 shows additional data on cost savings from state programs that aim to reduce long-term care costs through delaying institutionalization.

**Figure 5.1: State Data on Impact of Delays in Institutionalization through Expanded Home- and Community-Based Services**

State	Program Description	Evidence of Impact on Cost and Delays in Institutionalization
Arkansas <sup>25</sup>	Arkansas Community Connector is a three-year Medicaid demonstration program. The program identified individuals at risk for entering nursing homes (using Medicaid criteria) and linked them with community-based services and supports. Medicaid spending for individuals receiving care coordination services was compared with a control group who did not receive the services.	The intervention resulted in a 23.8% average reduction in annual Medicaid spending per participant. Savings equaled \$2.619 million for the 919 individuals included in the study's intervention group, a \$3 return on investment per \$1 invested.
Connecticut <sup>26</sup>	Connecticut Home Care Program for Elders includes a Medicaid waiver program that provides home- and community-based services to individuals who would otherwise require full-time nursing facility care.	A cost-effectiveness model that estimated annual savings of nearly \$107 million compared with serving participants in a nursing facility. 19,932 individuals received services through the Medicaid waiver program.
Georgia <sup>27</sup>	SOURCE (Service Options Using Resources in a Community Environment) is a Medicaid waiver program that provides care management and home- and community-based services to participants who would otherwise require nursing facility care.	In fiscal year 2007, the average monthly per-participant cost was \$1,538; the average monthly per-recipient cost of nursing facility placement in Georgia was \$4,369. Cost effectiveness was demonstrated across different levels of care needs. There was a reduction in percentage of total Medicaid expenditures for institutional care versus community-based care (73% institutional care in FY 2005; 64% institutional care in FY 2008).
Maryland <sup>28</sup>	Money Follows the Person helps Medicaid recipients navigate the payment transition from nursing facilities to home-based care and provides Medicaid waivers for aging in place, covering long-term services and supports received in a home setting.	Comparing spending for pre and post Money Follows the Person (MFP) transitions, Medicaid costs declined following transitions to the community. Pre-transition costs for FY 2008–FY 2010 were \$9,114 per-member per-month, compared with \$5,957 per month following MFP transition. More MFP-transitioned individuals reported higher quality of life.

West Virginia <sup>29</sup>	West Virginia implemented Money Follows the Person in 2011.	Projected savings between \$57 million and \$62 million over a 10-year period from transitioning between 75 and 150 individuals from nursing facilities to home and community-based services.
Rhode Island <sup>30</sup>	Rhode Island’s Global Waiver program provides Medicaid-eligible recipients with home- and community-based services, and attempts to shift spending on long-term services and supports to home- and community-based services and decrease or delay institutionalization.	The Global Waiver program resulted in Medicaid savings on long-term services and supports of \$35.7 million over the three-year study period (for an average of 8,681 beneficiaries per year). For those enrolled in care management services, data showed improved access to physicians and decreased emergency department utilization, resulting in estimated savings of about \$5 million in FY 2010.

Structured Family Caregiving is a model of care administered through a private company called Caregiver Homes. This model is made available through Medicaid waiver programs and provides professional and financial support to family and other caregivers, such as neighbors or friends, who are providing full-time care. Caregivers receive individualized support from nurses and social workers, including coaching on how to perform personal care and manage challenging behaviors. Caregivers are required to complete daily health and welfare status updates to inform the care team of the status of the person under his or her care. The stipend is non-taxable income and is less than half the cost of skilled nursing facility services. In the first year that Rhode Island offered this program, 115 people signed up and the state reported saving over \$1.5 million. Structured Family Caregiving is currently available as a Medicaid service in seven states.<sup>gg,31</sup>

Overall, the evidence is mixed on the cost-effectiveness of HCBS and other community-based care models. Some populations are unequivocally more cost-effective to serve in the home or community. For example, state HCBS funding significantly decreases the likelihood of institutionalization for childless seniors.<sup>32</sup> Increased state spending on HCBS waivers also reduces the number of low-income individuals in nursing homes.<sup>33</sup>

The Patient Protection and Affordable Care Act (ACA) also includes several provisions designed to shift long-term services away from institutional care. Currently, North Carolina only participates in one of the ACA rebalancing initiatives, the Money Follows the Person Grant.<sup>34</sup> This initiative allows for Medicaid eligible people who wish to leave institutional care for community care to do so with HCBS funding from PACE or CAP.<sup>35</sup> Data from the North Carolina Department of Health and Human Services, Division of Medical Assistance shows a

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<sup>gg</sup> Hendley R. Alzheimer’s Support Specialist. Caregiver Homes. Written (email) communication. February 8, 2016.

reduction of 32% in Medicaid spending for individuals who transitioned to community-based care from an institutional setting through Money Follows the Person.<sup>hh,ii</sup>

The Task Force recommends:

**Recommendation 5.6: Expand the Medicaid Home- and Community-Based Services Waiver Program.**

**Provide additional funding for the existing Medicaid Home- and Community-Based Services waiver program (including CAP/DA and CAP/Choice) to include additional services for individuals with Alzheimer’s disease and their families. Expansion should:**

- a) Have the ultimate goals of reducing the waitlist for receipt of services and delaying placement in institutional long-term care. The Dual Eligibles Work Group<sup>jj</sup> should also examine root causes of waitlists and identify ways to reduce them.**
- b) Allow greater flexibility to cover adult day care services and group respite.**
- c) Under reform, allow managed care organizations and provider-led entities to contract for community-based services using a flexible waiver.**
- d) Include provisions for local community work on increasing awareness and navigation of available services for people with dementia and their caregivers, including limitations and provisions of Caregiver Directed Vouchers.**
- e) Include provisions to address barriers faced by county Departments of Social Services in providing immediate services.**
- f) Include additional funding for evaluation of impact of expansion on waitlist, outcomes, and health care costs (including impact on Medicaid costs).**

**Lead: North Carolina General Assembly.**

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 home- and community-based services funded at the state level through Medicaid, Area Agencies on Aging, county agencies, Medicare, and private insurers. As the aging population grows, the number of people with Alzheimer’s disease or related dementias increases, and the number of

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<sup>hh</sup> Hensley M. Alzheimer’s Support Specialist. Division of Aging and Adult Services, North Carolina Department of Health and Human Services. Written (email) communication. February 18, 2016.

<sup>ii</sup> NOTE: Figure include individuals who qualify under aging/physical disability only (not those who qualify with intellectual/developmental disability).

<sup>jj</sup> “Dual eligibles” refers to 10.2 million Americans who qualify for coverage under both Medicare and Medicaid. These individuals are among the most disabled, chronically ill, and costly coverage recipients. On average, health care costs for the dual eligible population are 60% more than for non-dual eligible individuals. Approximately half of dual eligible qualify for Medicare because of disability rather than age. Almost one-fifth have three or more chronic conditions. More than 40% use long-term services or supports.<sup>151</sup> In North Carolina, the Dual Eligibles Work Group was mandated by the Medicaid Transformation and Reorganization legislation in 2015 (citation: <http://www.ncleg.net/Sessions/2015/Bills/House/PDF/H372v8.pdf>)

available caregivers declines, North Carolina state agencies must look forward in order to avoid a crisis. Services are available to some individuals and families depending on household income, insurance coverage, and geography, but state stakeholders must develop a comprehensive understanding of available services, service gaps, and the most efficient, equitable, and affordable way to connect individuals to services.

**Recommendation 5.7: Implement best practices for the integration and coordination of home- and community-based services.**

**Identify best practices for the integration and coordination of home- and community-based services, and work statewide to implement these practices and improve awareness of available services. Potential strategies may include using new models of care such as the Transformation Innovations Center under Medicaid reform to identify best practices and deliver improved services; expanding of online resources (i.e., dementia toolkit, online training programs, etc.); connecting services with NC 2-1-1, (see Recommendation 5.3); integration of health services and community-based services; and expanding training for health care providers, care managers, and options counselors on existing services, waiver programs, and financial assistance.**

**Lead: North Carolina Division of Aging and Adult Services.**

**Partners: State Medicaid Agency and county Departments of Social Services.**

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## CHAPTER SIX: PROMOTING MEANINGFUL PARTICIPATION IN COMMUNITY LIFE

Cognitive function decline accompanies the progress of Alzheimer’s disease and related dementias. This loss of cognitive capacity and function is devastating for individuals and their families. It also creates a legal problem because the law assumes that an adult has the ability to make rational decisions about their property, health care, financial care, and personal care. 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. Safety can be limited by changes in cognitive capacity, including a decline in memory, problem solving, and judgment. Depending on other chronic or sensory conditions, people can experience problems with balance, falls, or vision.

The Task Force examined the legal protections and safety-related issues for people with Alzheimer’s disease or related dementia, and issued recommendations for improvement. Through these recommendations, the Task Force aims to improve community life and promote community engagement for individuals with Alzheimer’s disease or related dementia.

### *Legal Protections for People with Alzheimer’s Disease or Related Dementia*

#### *Guardianship*

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. Guardianship in North Carolina is a legal relationship in which one individual is authorized by the clerk of superior court to have decision-making authority for an incompetent adult. Guardianship in North Carolina can take one of three forms: guardian of the person, guardian of the estate, or general guardian (both person and estate).<sup>kk</sup> Depending on the type of guardianship, decisions may include authorizing medical treatment, managing finances, making decisions about where an individual will live, and consenting to recreational activities. Public and corporate guardians of the person are required to file annual status reports with the clerk of court; all general guardians and guardians of the estate are required to file annual accountings with the clerk of court.

While there is often broad variation in the process of appointing a guardian for an individual, the general process begins with the filing of a petition with the clerk of superior court, alleging that an adult should be declared incompetent. After a petition is filed, the clerk may order medical, psychological, social work, and other evaluations of the individual. Ideally, a multidisciplinary evaluation is an important source of information the clerk uses when determining competency; however, this type of evaluation can be cost prohibitive or time prohibitive, so many courts rely

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<sup>kk</sup> §NCGS 35A: Incompetency and Guardianship

on family members, medical and behavioral health providers, and county social services staff members to provide information in the determination hearing. There is no data regarding the number of guardianship hearings that use a multidisciplinary evaluation to determine competency. If an individual is found incompetent, the clerk then makes a determination of what type of guardianship is needed and who can best serve as guardian.

Identifying willing and able family members to serve as guardian is typically the starting point for naming a guardian. When a guardian is appointed, North Carolina statutes require that individual guardians be considered first, corporations second, and disinterested public agent guardians (county departments of social services) as last resort. In instances where there are no appropriate family members or friends willing to serve in this role, a guardianship corporation or disinterested public agent can be appointed by the clerk of court for the individual. In SFY 2014, local departments of social services served as the guardian for 4,328 adults. It is projected that this number will rise to approximately 7,000 adults by 2017, due to growth in the number of younger adults with disabilities living in community-based settings, retirees settling in North Carolina, increased family mobility, and financial exploitation.<sup>ll,mmm</sup> In addition, it is estimated that approximately 25% of Americans over age 65 are or may become physically or socially isolated and lack a close family member or friend to care for them. Known as “elder orphans,” these individuals may be especially susceptible to needing public guardianship.<sup>1</sup>

### *Elder Financial Abuse*

Elder financial abuse includes both financial exploitation and elder fraud. Financial exploitation is defined in NCGS 108A Articles 6 and 6A as the illegal or improper use of a disabled adult’s resources for another’s profit or advantage and includes such things as taking money or property by coercion, undue influence, or false pretenses; forging an adult’s signature to legal documents such as deeds or wills; and misuse of a power of attorney. Financial exploitation is also a criminal offense defined in NC G.S 14-112.2, “Exploitation of an older adult or a disabled adult.”<sup>nn</sup> Elder fraud includes targeting older adults with promises of goods, services, financial benefits, or other false pretenses for financial gain. Perpetrators of elder financial abuse can be family members, trusted professionals, fiduciaries, caretakers, predatory individuals, or dishonest businesspeople.<sup>2</sup>

Older adults are commonly targeted for financial fraud because they often have significant assets and are often more likely to be vulnerable.<sup>2</sup> Older adults with Alzheimer’s or related dementias are particularly at risk for fraud. Research has shown that the ability to manage finances is one of the first instrumental activities of daily living to decline in individuals with Alzheimer’s and that these skills worsen rapidly.<sup>3</sup> Thus, individuals who may not need high levels of assistance with other activities of daily living may be at high risk for financial victimization. In 2014, such frauds contributed to losses over \$10 million, with the vast majority of elder financial fraud going unreported.<sup>4</sup> Financial fraud is rarely reported and can be quite difficult to prosecute,

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<sup>ll</sup> Bethel M. Director. North Carolina Coalition on Aging. Written (email) communication. December 12, 2015.

<sup>mmm</sup> Warren N. Program Administrator. North Carolina Department of Health and Human Services. Written (email) communication. January 12, 2016.

<sup>nn</sup> §NC GS 14-112.2

particularly if the older adult has Alzheimer's and is presumed to be incapable of providing testimony. If the perpetrator is someone who has been granted power of attorney by the defrauded adult, criminal prosecution is very difficult.<sup>oo</sup>

**Figure 6.1**

**North Carolina Adult Protective Services Criteria**

- Disabled-incapacitated by a physical or mental impairment, meaning the consumer cannot complete daily activities or handle his/her affairs or protect interests. (Developmentally or intellectually disabled, cerebral palsy, epilepsy or autism, organic brain damage caused by advanced age or other physical degeneration in connection therewith; or conditions incurred which are the result of accident, mental or physical illness, or continued consumption or absorption of substances.)
  - Abused, neglected, and/or exploited (already occurred).
  - Unable and unwilling to obtain essential services him or herself OR in a situation where no one willing, able and responsible to obtain essential services on their behalf.

Source: Eller, J. Guardianship and APS in NC <http://www.nciom.org/wp-content/uploads/2015/03/IOM-Guardianship-and-APS.pdf>

*Adult Protective Services*

Adults with Alzheimer's or related dementias may also be at risk for physical or emotional abuse, neglect by caregivers, self-neglect, or exploitation (defined as, "illegal or improper use of the disabled adult or his/her resources for another's profit or advantage").<sup>5</sup> In North Carolina, cases of suspected adult maltreatment are referred to the local Department of Social Services (DSS). Local DSS offices investigate reports that meet criteria laid out in NCGS 108A Article 6 (see Figure 6.1). In FYs 2013-2014 and 2014-2015, more than 24,000 cases were reported to North Carolina DSS offices and over half were evaluated. Abuse, neglect, or exploitation were confirmed in 44% of the cases evaluated.<sup>5</sup>

If the need for protective services is substantiated, then Adult Protective Services (APS) is required to provide or arrange for protective services. APS can only take action if the adult is disabled (incapacitated), has been abused, neglected, and/or exploited; is in need of protective services; and is willing to accept services (if she/he has the mental capacity to do so). Alternatively, DSS must be given legal authority when the adult does not have capacity to accept or refuse protective services. In some cases an adult may be the victim of abuse, neglect, or exploitation, but if the adult has the capacity

to make decisions on their own behalf, even poor ones, their right to self-determination must be respected by APS. If the adult is willing to accept services, APS can provide protective services, either through consent or court order, including services to improve home care, assistance with long-term care placement, case management, or appointment of a guardian. North Carolina's APS statute requires anyone with reasonable cause to believe that a disabled adult needs protective services to make a report.<sup>pp</sup>

<sup>oo</sup> Smith T. Special Prosecutor, North Carolina Conference of District Attorneys. Written (email) communication. December 14, 2015.

<sup>pp</sup> §NCGS 108 A Articles 6 and 6A.

### *Education on Legal Protections and Vulnerabilities*

Individuals with Alzheimer’s disease or related dementia and their families must navigate complex legal, medical, and financial issues. These issues are further complicated by the need to address them as early as possible while the affected individual is still capable of engaging in meaningful dialogue about what they hope for in terms of the way they want to live, how they want to be cared for, what sort of medical treatment they prefer, financial planning, and other critical questions that will impact their life.

While there is often insufficient guidance for individuals and families about the need for advanced legal and financial planning for individuals with Alzheimer’s, there is also opportunity to improve awareness and education about these issues.

Planning for the possibility of needing extensive and/or long-term care is crucial for families facing Alzheimer’s disease or related dementia. Many organizations and programs provide guidance in navigating the types and logistics of available services, but families also need assistance in developing a plan to pay for these services. Clarification on what types of service are paid for by each payer (including Medicare, Medicaid, private health insurers, and long-term care insurance) is particularly important.

In 2015, the Centers for Medicare and Medicaid Services issued two new Medicare billing codes, allowing qualified health care professionals to be reimbursed by Medicare for the time spent discussing advance care planning and end-of-life decisions with patients and families. The advance care planning discussions covered by Medicare aim to incentivize health care professionals to assist families in determining the types and extent of long-term care they wish to receive at the end of life, and to share these decisions with family members, friends, and health care professionals.<sup>6</sup>

It is also important for families to understand state regulations on advanced health care directives. Ideally, individuals with Alzheimer’s disease and related dementias are diagnosed early enough in the progression of the disease that they have time to make advanced health care directives, including advanced directives for a natural death (also known as a living will), preferences for mental health treatment, and organ donation. Individuals may also appoint, in advance, a substitute decision-maker who they know and trust to make health and care decisions for them—a health care power of attorney. Once appointed health care power of attorney, this person is then able to consent to medical treatment, withhold or withdraw life prolonging treatment, and make other treatment decisions as described above.<sup>7</sup> Individuals diagnosed with Alzheimer’s disease or related dementias should complete such directives early in their illness, if possible, in order to assist their families in medical decision-making once the individual is no longer capable of making health care decisions.

Therefore, the Task Force Recommends:

**Recommendation 6.1: Increase awareness of legal protections and vulnerabilities of people with Alzheimer’s disease or related dementia.**

**Promote collaboration between partners on increasing awareness among family caregivers of the available legal protections and relevant vulnerabilities of people with Alzheimer’s disease or related dementia. Awareness and education efforts should be incorporated into local collective impact processes and should include:**

- a) Planning for the possibility of cognitive impairment and potential caregiving responsibilities in all financial literacy trainings and counseling, including loss of financial capacity as an early warning sign of Alzheimer’s disease and related dementia.**
- b) Promotion of advanced care planning (including medical and financial) among family caregivers and people in early stages of Alzheimer’s disease or related dementia, to include information on health care power of attorney signatory requirements and state registry information.**
- c) Increased information on issues around guardianship, elder abuse, and advanced directives, including legal/logistical requirements, financial responsibilities of guardianship, recognition and reporting of abuse, and limitations regarding Adult Protective Service’s scope of intervention.**
- d) Action steps for families and people with Alzheimer’s disease or related dementia to enhance use of documentation when needed (i.e., where to put copies of documents, who to inform, etc.).**
- e) Promotion of culture change around care planning and financial planning for family members, including caregiver coping strategies such as mediation and family counseling and additional caregiver/family resources.**
- f) Engaging additional partners (including faith community) in facilitating guardianship and legal protections when family members are reluctant or unable to do so.**

**Partners: Local Area Agencies on Aging, North Carolina Division of Aging and Adult Services, the Department of Justice, local Departments of Social Services, State Treasurer, Secretary of State, North Carolina Attorney General, AARP North Carolina, North Carolina Bankers Association, savings and loan associations, Carolinas Credit Union League, North Carolina Bar Association (Elder and Special Needs and Estate Planning and Fiduciary Sections), North Carolina Partnership to Address Adult Abuse, North Carolina Guardianship Association, Rethinking Guardianship statewide stakeholders workgroup, family and caregiver representatives, and other community partners.**

In addition to educating individuals with Alzheimer’s disease and related dementia and their families, there is a need to educate health and legal professionals about the various legal protections for these individuals. It is important that education and discussions about end-of-life care planning, elder fraud and abuse, and other legal issues facing individuals with dementia and their families be discussed as early in the disease progression as possible. Currently the North Carolina Department of Justice offers training classes for law enforcement on identifying



financial fraud, insurance fraud, and crimes in long-term care facilities. In addition, the Area Health Education Centers and various university and college training programs offer courses in legal protections for health care professionals. In order to provide the greatest benefit for people with Alzheimer's disease or related dementia, there should be interdisciplinary commitment to the intersection and collaboration of these various types of trainings and intended professional audiences.

Therefore the Task Force recommends:

**Recommendation 6.2: Incorporate legal protection issues specific to people with Alzheimer's disease or related dementias into health, legal, and financial professional training.**

**Offer continuing education on the types and unique requirements of various legal protections for people with Alzheimer's disease or related dementia, including but not limited to guardianship, multidisciplinary evaluations, advanced care directives, financial planning, and health care power of attorney. Training should also incorporate existing best practices in initiating conversations with people with dementia and family caregivers around these issues.**

- a) Trainings should be offered in multiple settings, with opportunities for more intensive trainings for those who will help other staff learn about legal protections and opportunities for integrating work in different organizations and building collaborations between sectors.**
- b) Trainings should include special considerations and information on identifying and working with people with Alzheimer's disease and related dementia, including training for Adult Protective Service workers, court officials, and others, to ensure a minimum level of competency in identifying and serving people with dementia, including identifying people with reduced decision-making capacity.**
- c) Incorporate techniques used by law enforcement to recognize elder abuse and fraud into health and legal professional training.**

**Partners: North Carolina Area Health Education Centers programs, North Carolina Bar Association, financial organizations/banks, Departments of Social Services/county services, and other organizations including, but not limited to, the North Carolina Medical Society, North Carolina Nurses Association, North Carolina Academy of Physician Assistants, North Carolina Academy of Family Physicians, North Carolina chapter of the American College of Physicians, Office of the Attorney General, the Senior Consumer Fraud Task Force, North Carolina Partnership to Address Adult Abuse, the Department of Justice, and other law enforcement entities.**

*Statewide Effort Toward Enhancing Legal Protections*

In recent years, North Carolina state agencies and advocacy organizations have examined the adequacy of state statutes and regulations around the vulnerabilities of elder adults. In January 2012, the Task Force on Fraud on Older Adults was convened; the Task Force met through 2013.

Co-chaired by Senator Bingham and Representative Blackwell, the goals of the Task Force included:

- (1) Identifying, clarifying, and strengthening laws to provide older adults a broader system of protection against abuse and fraud.
- (2) Establishing a statewide system to enable reporting on incidents of fraud and mistreatment of older adults.
- (3) Identifying opportunities for partnership among the State Banking Commission, the financial management industry, and law enforcement agencies to prevent fraud against older adults.
- (4) Granting the Attorney General authority to initiate prosecutions for fraud against older adults.

The work of the task force resulted in passage of Session Law (hereinafter S.L.) 2013-337; S.L. 2013-203; S.L. 2014-115, § 44. This includes NCGS 108A Article 6A. This law aims to make it easier for departments of social services to access financial records when investigating reports of financial abuse.<sup>8</sup>

In addition, the Public Guardianship Subcommittee was a short-term legislative subcommittee appointed for the 2013-2014 General Assembly session with the intent of studying the adequacy of state adult protective services and guardianship regulations. While the Subcommittee's membership was solely comprised of legislators, they also consulted with many public and private individuals when crafting their recommendations. Recommendations included: maintain the state's publicly funded guardianship model; provide adequate resources for public guardianship services; implement standardized procedures to ensure appointment of a publicly funded guardian when there is no other appropriate individual to serve; and continue the study of other methods of improving the state guardianship system.<sup>9</sup> The subcommittee terminated when its report was issued in 2014, and limited action has been taken to date on the recommendations.<sup>9q</sup>

Convened by the Jordan Institute for Families at the University of North Carolina at Chapel Hill, the Rethinking Guardianship working group completed the first of three years of work in late 2015. This group seeks to build upon the work of the other guardianship initiatives and apply a collaborative approach and focused inclusion of family and community members to the issue of guardianship protections. The Rethinking Guardianship group has identified gaps in existing data on guardianship statutes, eligibility, and capacity.<sup>rr</sup>

In the 2014 legislative session, House Bill 817 was introduced and passed the House with a unanimous vote. This bill, called 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.<sup>ss,10</sup> Following passage in

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<sup>9q</sup> Bethel M. Director. North Carolina Coalition on Aging. Written (email) communication. December 12, 2015.

<sup>rr</sup> Massey-Smith J. Social Services Adult Program Representative. North Carolina Department of Health and Human Services. Written (email) communication. December 15, 2015.

<sup>ss</sup> House Bill 817.

the House, the bill is currently in the Senate Rules Committee. Currently, North Carolina is one of only eight states that has not passed the UAGPPJA.<sup>10</sup>

**Recommendation 6.3: Examine state statutes to determine adequate legal safeguards and protections for people with Alzheimer’s disease or related dementia.**

**Convene a workgroup comprised of representatives of agencies and organizations with experience and expertise in dealing with vulnerable adults, including those with dementia, to examine state statutes and ongoing initiatives for Adult Protective Services and guardianship to determine if the state is adequately providing the needed protections for older and disabled North Carolinians. A preliminary/interim report from the workgroup, along with recommendations for any changes to state statutes, should be submitted to the North Carolina Department of Health and Human Services, the Joint Legislative Oversight Committee on Health and Human Services, and the Joint Legislative Oversight Committee on Justice and Public Safety by December 15, 2016, with a final report by April 1, 2017.**

**The workgroup should address and make recommendations about topics including, but not limited to:**

- a) Scope of need for Adult Protective Services and guardianship services, including the passage of House Bill 817 from 2015 (Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act).**
- b) Gaps in current state statutes.**
- c) Implications of the federal Elder Justice Act on state responsibilities.**
- d) Adequacy of existing resources and training needed to protect vulnerable adults, and what expansion is needed.**
- e) Reporting of abuse, neglect, or exploitation and penalties for not reporting.**
- f) Determining competence and the role, process, and frequency of use of multidisciplinary evaluation.**
- g) Establishing jurisdiction for responsibility.**
- h) Data assessment of increase in need for services, and strategies to address this growth.**
- i) Assessment of legal proceedings to prosecute exploitation and alternatives to strengthen process.**

**Lead: North Carolina Division of Aging and Adult Services.**

**Partners: Agencies and organizations participating in the workgroup should include: Alzheimer’s North Carolina, Disability Rights North Carolina, the North Carolina Administrative Office of the Courts, Alzheimer’s North Carolina, the North Carolina Association of County Directors of Social Services, the North Carolina Bar Association, the North Carolina Coalition on Aging, the North Carolina Conference of Clerks of Superior Court, the North Carolina Council on Developmental Disabilities, the North Carolina Guardianship Association, Rethinking Guardianship statewide stakeholder workgroup, North Carolina Partnership to Address Adult Abuse, the North Carolina Department of**

**Justice, the North Carolina Office of the Attorney General, North Carolina Conference of District Attorneys, the North Carolina Administrative Office of the Courts, the UNC School of Government, state legislators, and consumer and family representatives.**

*Data Systems to Improve Legal Protections*

North Carolina Families Accessing Services through Technology (NC FAST) serves as the statewide public assistance and data management and integration system. NC FAST aims to provide a quick and efficient system for county departments of social services to access case management tools and to evaluate case management and integration outcomes. 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. This would provide more accountability and the ability to track persons across counties who may have a history of abuse, neglect, or exploitation against a vulnerable adult. An integrated system allows the state to focus on improving outcomes for vulnerable individuals. Using one common data model results in a more comprehensive view of individuals and can be used to drive improvement of the data systems.

While NC FAST is currently in the active implementation phase for several intended services, including child nutrition programs, child care, child protective services, and Medicaid, the integration of data from the Division of Aging and Adult Services (including Adult Protective Services) is not scheduled to be completed until June 30, 2018 at the earliest (possibly later and contingent upon funding).

Therefore, the Task Force recommends:

**Recommendation 6.4: Integrate elder fraud and abuse data to improve services for people with Alzheimer’s disease or related dementia.**

**In order to improve case management operations and allow individuals to more efficiently and effectively receive services from several organizations/agencies, the lead organization should pursue county integration of elder fraud and abuse data through North Carolina Families Accessing Services through Technology (NCFAST). This should include:**

- a) Inclusion of Adult Protective Service/guardianship data in county integration.**
- b) Capacity to cross reference public assistance programs to reduce duplicative efforts and assist with locating vulnerable adults.**
- c) Examination of existing case management operations and how data can be used at the population level to improve services and abuse/fraud protection.**

**Lead: North Carolina Department of Health and Human Services.**

## *Individual and Home Safety Resources*

While older adults overall tend to be the most vulnerable age group for injuries and falls, those with Alzheimer's disease or related dementias are at an especially high risk. Studies show an annual falls incidence as high as 60% among individuals with dementia; seniors with Alzheimer's or related dementias in particular are three times more likely to suffer from hip fractures due to falls than other older adults.<sup>11</sup> Injuries due to falls often require surgery and long-term hospitalization, further worsening disability for an afflicted individual. Research shows that injuries such as a broken hip can increase the likelihood for a person with Alzheimer's disease or related dementia to no longer be able to be cared for in the home.<sup>12</sup>

The American Geriatrics Society has developed a clinical practice guideline for falls prevention, recommending that all older adults should be questioned annually regarding falls, frequency of falling, and difficulties with gait or balance.<sup>13</sup> Evidence-based guidelines according to the Alzheimer's Association and Centers for Disease Control and Prevention also recommend regular assessments to determine a person's fall risks.<sup>14</sup> These recommendations include consultations with a physical therapist for mobility issues and an occupational therapist for assistance with activities of daily living.<sup>15</sup>

The Alzheimer's Association also suggests an environmental assessment in the home for arrangement of furniture and safety of the layout of the space. Providers can use these assessments to develop a care plan to improve mobility and safety of an individual with Alzheimer's to prevent injury in the home. Other evidence-based practices include training caregivers on dementia care and ways to reduce falls risk.<sup>166</sup> The North Carolina Falls Prevention Coalition goals are in line with the recommendations of the Alzheimer's Association, with an emphasis on evidence-based practices supported by research including risk assessments, care plan formation, and home safety monitoring.<sup>16</sup>

There are many innovative technological resources to improve caregiving and quality of life for individuals afflicted with Alzheimer's disease or related dementia. Comfort Zone, developed by the Alzheimer's Association, is a comprehensive web-based location management service. This tool allows families to remotely monitor a person with Alzheimer's by receiving automated alerts throughout the day and night when a person has travelled beyond a preset zone.<sup>17</sup> The check-in service allows for an on-demand "find me" function to alert caregivers of the location of an individual.

Assistive technology products have also been designed to support patients with cognitive impairment. Some electronic products assist with tracking misplaced items using an electronic tag. Some telephones offer speed dialing capabilities for people who cannot remember phone numbers or are unable to look them up. Other technological tools include automated pill organization systems and medication reminders, as well as medication dispensers to prevent drug

misuse or overdose.<sup>18</sup> While these tools range in price, private insurance can cover certain assistive technology if prescribed by a physician. The cost of Alzheimer's products and services beyond in-home care are not covered by Medicare or Medicaid but can be supported by state-funded Family Respite Care Grants and funding from the Alzheimer's Foundation of America.<sup>19</sup>

Medication-related problems also pose a risk to people with Alzheimer's who may be on multiple prescriptions for other conditions as well. Safety can be compromised due to potential drug interactions or accidental misuse, leading to drug overdose or other health conditions. Key recommendations for caregivers include assessing the home for hazardous areas or items; ensuring the home is equipped with working safety devices; installing locks out of sight; adding additional lights to walkways; removing, locking, or disabling guns and other weapons; and removing tripping hazards. The Caregiver Center of the Alzheimer's Association offers an Alzheimer's navigator tool to provide free, customized home safety checklists. In North Carolina, the Alzheimer's Association of Eastern North Carolina, Alzheimer's Association of Western North Carolina, and Alzheimer's North Carolina also provide resources for support groups and education programs to ensure necessary guidance for caregivers.

With a common goal of ensuring home safety for people with Alzheimer's disease and improving access to statewide resources, the Task Force recommends additional work on the part of North Carolina organizations and agencies for improved resources and expanding awareness of evidence-based practices to improve home safety.

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

**In order to ensure home safety for people with Alzheimer's disease or related dementia, organizations/agencies should work to:**

- a) Enhance and promote falls and injury prevention programs for both people with Alzheimer's disease or related dementia and their caregivers, as aligned with the goals of the North Carolina Falls Prevention Coalition.**
- b) Promote awareness of available home safety assessment services through physical therapy and occupational therapy providers and available financial assistance/reimbursement.**
- c) Address home safety assessment workforce, reimbursement, and incentives.**
- d) Explore use of innovative technology in home safety, including web-based monitoring devices, and promotion of existing low-tech solution, innovative technologies to address home safety, and potential return on investment for such technologies.**
- e) Utilize training resources on initiating conversations with people with Alzheimer's disease or related dementia and families about proactive preventive steps to reduce fall risk.**

**Partners: Departments of Social Services, Area Agencies on Aging, primary care providers, adult residential facilities, hospice providers, home care agencies, and other relevant agencies.**

## ***Public Safety for Individuals with Alzheimer's Disease or Related Dementia***

As Alzheimer's disease and related dementia progresses, individuals increasingly face behavioral symptoms that may pose a safety threat to themselves or to others in the community. Wandering and/or getting lost is a significant problem for people with dementia, even in early stages of the disease; six in ten people with dementia will wander from home or other familiar places.<sup>20</sup> These individuals may experience difficulty remembering their name and home address and experience confusion and disorientation.<sup>20</sup>

The North Carolina Silver Alert program is administered by state and local law enforcement and the North Carolina Center for Missing Persons to protect individuals that suffer from dementia or other cognitive impairment.<sup>21</sup> Designed to quickly disseminate descriptive information about missing persons, the system is activated when a family or caregiver reports a missing person to law enforcement, and identifies the person as having dementia. Law enforcement agencies then determine if the criteria warrant a Silver Alert and, if initiated, all law enforcement agencies are notified via a statewide bulletin. The North Carolina Center for Missing Persons updates this information on its website and notifies local media, including radio and television, on description information regarding the missing person. The North Carolina Department of Transportation is also requested to activate highway message signs.<sup>21</sup> There is currently no system in place to involve social media or mobile technology.

Law enforcement personnel and first responders are not currently required by law in North Carolina to be trained on dementia. According to a nationwide survey in 2015, only 10 states were found to have laws requiring dementia training on symptoms and behavioral management for law enforcement personnel, including Colorado, Florida, Indiana, Maryland, New Hampshire, New Jersey, Oklahoma, Oregon, South Carolina, and Virginia.<sup>22</sup> Dementia training standards tend to be general surrounding the dangers of wandering or getting lost, the course of Alzheimer's disease, and how law enforcement can best handle difficult situations safely.<sup>22</sup> The National Council of Certified Dementia Practitioners has developed a training module for first responders, called the Certified First Responder Dementia Trainer. This module includes an overview of dementia symptoms, stages, common behaviors (including wandering, getting lost, and other safety concerns), communication strategies, and multicultural considerations. The US Department of Justice and Alzheimer's advocacy organizations have also developed toolkits and training resources for first responders.

Mental and behavioral health training programs law enforcement and first responders may apply to people with Alzheimer's and related dementias. The Crisis Intervention Team of the National Alliance on Mental Illness offers support and training to law enforcement to identify and respond to situations involving individuals with mental illness.<sup>23</sup> The North Carolina Geriatric/Adult Specialty Teams (GAST) also provides training for health providers and community workers in symptoms of mental illness in older adults. GAST aims to improve communication, assessment procedures and techniques, and referral systems for older adults with mental health symptoms.<sup>24</sup>

In order to promote safe driving, the North Carolina Division of Motor Vehicles administers the Driver Medical Evaluation program to review individuals with medical problems that may increase risk for motor vehicle accidents.<sup>25</sup> The Division of Motor Vehicles and the Department of Health and Human Services require persons to disclose if they are experiencing medical conditions that affect cognitive ability, including dementia. Driver licenses can be restricted or revoked if an individual exhibits risk of driving impairment on the basis of a medical condition.<sup>25</sup>

Unfortunately, regulatory efforts to address safe driving are not sufficient. Often the conversation about when is the appropriate time for a person with dementia to stop driving must start within the family, as family members are often the first to notice when cognitive symptoms begin to impact driving skills. Health care providers can also provide guidance on resources for families about safe driving, discussions on driving, and alternative transportation options.<sup>26</sup>

**Recommendation 6.6: Enhance public safety and law enforcement outreach for Alzheimer’s disease and related dementia.**

**To increase safety in the community for people with Alzheimer’s disease or related dementia, partners should work within the guidelines of the Dementia Friendly America Initiative to:**

- a) Expand the utilization of locator devices and promote programs such as Silver Alert.**
- b) Increase and promote professional training opportunities and explore setting a minimum standard of training for emergency workers (including fire and emergency medical services), law enforcement officers, and other first responders on dementia symptoms, common behaviors (such as wandering), and individual/community safety concerns.**
- c) Collaborate with the North Carolina Department of Motor Vehicles Medical Evaluation Program on outreach work with physician and health professional training groups to promote existing tools that measure cognitive ability and impairment; promote resources for health care providers about safe driving and starting conversations about safe driving with individuals with Alzheimer’s disease or related dementia and their families; and develop protocols for referring individuals with revoked driver’s licenses to community resources and transportation options.**

**Partners: North Carolina Department of Public Safety, the North Carolina Department of Justice, consumer advocacy groups, and the North Carolina Division of Aging and Adult Services.**



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## CHAPTER SEVEN: REACHING THOSE WHO ARE UNDERSERVED

Throughout the development of the state plan for Alzheimer's disease and related dementias, the Task Force worked to keep in mind the needs of all North Carolina populations, with a special consideration for those who are disproportionately affected by these conditions, as well as those who have also been historically underserved within health care and health research. The Task Force examined the needs of these populations and developed recommendations to improve research, data collection capacity, and health care quality for all North Carolinians.

As discussed in Chapter 2, there are several populations that are disproportionately affected by Alzheimer's disease and related dementias, including people with intellectual and/or developmental disabilities and a number of minority populations. In addition, in North Carolina, there are geographical disparities in access to care due to the large rural areas of the state.

Individuals with Down's syndrome also have a three- to five-times higher risk for Alzheimer's disease than the general population. Alzheimer's tends to develop at a younger age (40s or 50s) for people with Down's syndrome than for other adults. Autopsy results have shown that nearly all people with Down's syndrome have markers in the brain that are associated with Alzheimer's disease.<sup>1</sup> Caregivers for people with Down's syndrome may also experience their own type of "sandwich generation" dilemma, as they themselves and/or their spouses may be at risk of developing dementia around the same time as their children. At the same time, there is opportunity for communities to learn from the experiences of individuals with intellectual and developmental disabilities and their families. Having navigated a similarly complex array of services and facilities, such families and service providers may offer many appropriate lessons for those wishing to develop dementia-capable communities.

Compared to non-Latino whites, Latinos and African Americans are at a higher risk for developing Alzheimer's disease.<sup>2</sup> In the 65-74 age group, African Americans have the highest prevalence of Alzheimer's disease at 9.1%, compared to 7.5% for Latinos and 2.9% for non-Latino whites. For individuals over 85, Latinos have a prevalence rate of 62.9%, compared to 58.6% among African Americans, and 30.2% among non-Latino whites.<sup>2</sup> Women are twice as likely to develop Alzheimer's as men,<sup>3</sup> primarily because women tend to live longer than men.<sup>4</sup>

Disparities in Alzheimer's care reflect disparities in health care more generally for North Carolinians. People in rural areas are about equally as likely to be uninsured as are those in urban areas (16.5% versus 15.7% respectively).<sup>5,6</sup> Many rural communities also experience shortages of key health professionals, including primary care, specialty care, mental health care, and allied health care. Overall there is increased demand on the primary care workforce due to aging baby boomers, population growth, and increased rates of insured people.<sup>7</sup> North Carolina has 66 counties (or parts of counties) that are designated as primary care shortage areas, 22 counties (or parts thereof) that are designated as behavioral health shortage areas, and 69 counties (or parts

thereof) that are designated as dental shortage areas.<sup>tt</sup> Of those designated communities, 48 of the primary care health professional shortage areas (HPSAs) are in rural counties. As discussed in Chapter 4, properly assessing health system capacity, including rural disparities in the health care workforce, is an important step in improving care for people with Alzheimer’s disease or related dementia.

As communities focus resources and efforts on addressing disparities in rates of Alzheimer’s disease and related dementia, they must also keep cultural competency in mind. Cultural competency is defined as understanding different groups’ history, diversity, and culture. As is the case in emphasizing person-centered care within health care settings (see Chapter 4), a culturally competent approach will value others’ experiences, respect their viewpoints, and refrain from judgement.<sup>8</sup> The following recommendations are directly related to underserved populations but have been included in chapters reflecting the broader constructs:

- 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.
- Recommendation 4.1: Promote appropriate care settings for people with Alzheimer’s disease and related dementia.
- Recommendation 4.3: Assess health system capacity for people with Alzheimer’s disease and related dementias.
- Recommendation 4.4: Improve telehealth services for people with Alzheimer’s disease and related dementias.
- Recommendation 4.5: Increase access to medical and community services for people with Alzheimer’s disease and related dementia.
- Recommendation 4.8: Improve care coordination for people with Alzheimer’s disease and related dementia through new models of care.
- 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 Project CARE.
- Recommendation 5.5: Examine outcomes and impact of home- and community-based programs.
- Recommendation 5.6: Expand the Medicaid Home- and Community-Based Services Waiver Program.
- Recommendation 6.1: Increase awareness of legal protections and vulnerabilities of people with Alzheimer’s disease or related dementia.
- Recommendation 6.3: Examine state statutes to determine adequate legal safeguards and protections for people with Alzheimer’s disease or related dementia.
- Recommendation 6.4: Integrate elder fraud and abuse data to improve services for people with Alzheimer’s disease or related dementia.
- Recommendation 7.1: Support research through the establishment of a statewide collaborative registry.

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<sup>tt</sup> The HPSAs designated as Single County, Geographical Area, and Population Group were counted on August 15, 2013.

- Recommendation 7.2: Continue inclusion of cognitive impairment and caregiver modules of the Behavioral Risk Factor Surveillance System.
- Recommendation 7.3. Improve prevalence data through accurate death certificate completion.
- Recommendation 7.4: Improve data on Alzheimer’s disease and related dementia prevalence through implementing a statewide data reporting system.

In addition, 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, 10% of North Carolinians over the age of 65 had incomes below the federal poverty level (\$20,090), and an additional 24% had incomes between 100% and 199% of the federal poverty level. The median income for North Carolinians over 65 years of age was \$35,204.<sup>9</sup> 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. There is only a small subset of families who can afford to pay privately for services or for long-term care insurance (see Chapter 4 for additional information on payment for long-term services and supports).

### ***Research***

Although Alzheimer’s disease affects approximately 5.3 million Americans and costs the federal government up to \$215 billion annually<sup>11</sup>, federal funding for research on Alzheimer’s lags behind other major diseases. For FY 2016, the federal government allocated \$638 million to research for Alzheimer’s disease. In the same year, the federal government allocated \$5.5 billion for cancer and \$2 billion for cardiovascular disease. In late 2015, however, increased attention to Alzheimer’s disease and dementia and their impact on individuals and families resulted in a proposed increase of \$350 million for fiscal year 2016 (a 59.7% increase over FY 2015) for the National Institute of Health’s Alzheimer’s disease and related dementia research funding.<sup>12</sup>

While increased federal funding for research is crucial, there is much that can be done at the state level to increase the body of knowledge on Alzheimer’s and related dementia. Researchers at academic research institutions and private businesses across our state are studying Alzheimer’s and related dementia. In 2014, Duke University and the University of North Carolina at Chapel Hill, along with other academic research institutions, received a \$130,000 grant from Alzheimer’s North Carolina to launch the North Carolina Regional Consortium for Brain Health in Aging. The mission of the consortium is to “draw together the state’s major academic institutions that are engaged in Alzheimer’s disease research, along with potential partners in industry, primary care, and other stakeholders, into a collaborative network to spur research and innovation” towards better prevention, treatment, and cure for Alzheimer’s disease.<sup>13</sup> By combining efforts and sharing knowledge, the Consortium aims to speed up the pace of discovery and improve collaborative efforts toward prevention and treatment. Starting in 2016, the Consortium is known as the Memory and Brain Aging Research Coalition (MBARC).

One of the goals of the consortium is to develop a statewide registry of healthy individuals and diagnosed dementia patients, cross-referenced with a current database of clinical trials, to facilitate a shared network and inform research regarding dementia treatment and prevention.

Finding individuals to participate in research studies can significantly slow down the research process. An optional Alzheimer's and related dementia registry would be a place for people with Alzheimer's disease and related dementias and healthy individuals to indicate their interest in participating in research and clinical trials. Academic researchers could use the registry to share information about their research and identify studies that need participants. A registry can also be used to share the latest news and research findings on Alzheimer's and related dementias.

A key priority for the statewide registry would be to expand outreach to underserved populations in North Carolina, for the purpose of participation in clinical trials and research studies, as well as to promote awareness of and resources for those dealing with dementia. As discussed above, there are disparities in rates of Alzheimer's disease and related dementia between many racial and ethnic groups. There is also a disparity among research participants, with fewer minorities participating in clinical trials and other research studies. While the reasons for this vary, contributing factors include higher levels of additional health problems, language barriers, mistrust of clinical research, under-diagnosis, and higher caregiver burdens.<sup>14</sup>

African Americans are twice as likely to have Alzheimer's disease as non-Hispanic whites, are most burdened by the disease, are most likely to get a late (or no) diagnosis, and have the worst health and caregiving outcomes of the disease. In addition, persons in rural and underserved counties have poorer outcomes than those in urban areas, especially those close to universities and health care systems. North Carolina A&T University's Center for Outreach in Alzheimer's Aging and Community Health (known as COAACH) aims to understand genetic factors that predispose African Americans to Alzheimer's disease. The Center was founded as a result of lower literacy and engagement among African Americans in research, clinical trials, interventions, and care management skills. Researchers began conducting Alzheimer's genetics work among African Americans in 2002 with investigators at Duke University. The Center was a major contributor to publishing the largest Alzheimer's genome-wide association study (with 6,000 participants) in African Americans in 2013. In finding a cure, intervention, or therapy for Alzheimer's, it will be important to include all populations, including underrepresented groups, to reduce generalizability of research results.<sup>uu</sup>

In order to foster Alzheimer's disease and related dementias research across the state, the Task Force recommends:

**Recommendation 7.1: Support research through the establishment of a statewide collaborative registry.**

**Establish a statewide registry/clinical trials network of people diagnosed with Alzheimer's disease and related dementia and healthy individuals, in order to better inform research into Alzheimer's disease and related dementia treatment and prevention. The collaborative network should:**

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<sup>uu</sup> Byrd G. Professor of Biology and Dean. College of Arts and Sciences, North Carolina A&T State University. Written (email) communication. February 4, 2016.

- a) **Build on the existing work of the Memory and Brain Aging Research Coalition (MBARC) to expand partnerships, establish continued funding, and determine appropriate methods of sustainability.**
- b) **Focus on inclusion of underserved and underrepresented populations in Alzheimer’s disease and related dementia treatment, prevention, and clinical trial participation.**
- c) **Work to apply research findings to education/awareness campaigns on Alzheimer’s disease and related dementia prevalence, symptoms, and opportunity for participation in clinical trial research.**
- d) **Promote the ways in which a statewide registry may have a positive economic impact on North Carolina.**

**Lead: Academic institutions, including Duke University, University of North Carolina at Chapel Hill, Wake Forest University, North Carolina A&T University, North Carolina State University, Appalachian State University, Western Carolina University, University of North Carolina at Asheville, and University of North Carolina at Wilmington.**

**Partners: Philanthropic organizations, Alzheimer’s North Carolina, and the Alzheimer’s Association.**

### ***Data Collection***

Informed action requires data. 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 also by measuring progress towards improved services, care, and potential treatments for Alzheimer’s disease and related dementia.

Rates of Alzheimer’s disease are estimated through the use of US Census data and from large population-based studies of affected populations. The Alzheimer’s Association also uses data from the Chicago Health and Aging Project, which studies chronic diseases in older adults, to estimate Alzheimer’s prevalence. For other forms of dementia, the Aging, Demographics, and Memory Study provides useful prevalence data.<sup>15</sup> However, while these studies provide a population-based estimate of prevalence, because Alzheimer’s and other dementias are significantly underdiagnosed in the community, the Alzheimer’s Association estimates that about half of individuals with Alzheimer’s have never been given a diagnosis by a health care provider.<sup>15</sup> In addition, because Alzheimer’s disease is progressive, it is difficult to get an accurate estimate of the number of individuals in any given stage of the disease. Remaining stigma and lack of awareness around Alzheimer’s disease also result in reduced accuracy of prevalence data, as families either may not recognize symptoms as distinct from normal cognitive aging, or may be hesitant to seek a formal diagnosis. Improved data collection may also be helpful in identifying potential environmental risks by geographical area that impact the development of Alzheimer’s disease and related dementia.



**Figure 7.1**  
**BRFSS Cognitive Impairment**  
**Module<sup>16</sup>**

1. During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?
2. During the past 12 months, as a result of confusion or memory loss, how often have you given up day-to-day household activities or chores you used to do, such as cooking, cleaning, taking medications, driving, or paying bills?
3. As a result of confusion or memory loss, how often do you need assistance with these day-to-day activities?
4. When you need help with these day-to-day activities, how often are you able to get the help that you need?
5. During the past 12 months, how often has confusion or memory loss interfered with your ability to work, volunteer, or engage in social activities outside the home?
6. Have you or anyone else discussed your confusion or memory loss with a health care professional?

Source: Centers for Disease Control and Prevention. Behavioral Risk Factor Surveillance System (BRFSS) cognitive decline module. Centers for Disease Control and Prevention website. <http://www.cdc.gov/aging/healthybrain/brfss-faq-cognitive.htm>. Published July 1, 2015. Accessed February 12, 2016.

In order to fully evaluate the problem and impact of Alzheimer’s disease and related dementia, as well as to determine if other Task Force goals and recommendations are reached, more robust methods of data collection are needed, in addition to greater coordination and linked analysis of data.

*Behavioral Risk Factor Surveillance System (BRFSS)*

In North Carolina, the State Center for Health Statistics, conducts an annual population-based survey of North Carolina residents aged 18 and older. The survey was created in the late 1980s by the Centers of Disease Control and Prevention (CDC) and is conducted in all 50 states via household telephones.

In 2011, the North Carolina BRFSS included, for the first time, a CDC Healthy Aging Program-developed module on cognitive impairment.<sup>16</sup> The 2011 cognitive impairment module consisted of one question: “During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?” For 2016, North Carolina plans to include the cognitive impairment module again.

In addition to the cognitive impairment module, BRFSS also offers a module consisting of questions about caregiving. While not specific to dementia, this module captures data on caregiving such as caregivers’ relationship to the person being cared for, the condition/illness for which the person is receiving care, caregivers’ experiences, and the impact of caregiving on caregivers’ health and well-being.<sup>17</sup> North Carolina last included the caregiving module in 2011. States that have implemented the caregiver module have learned

that caregivers for people with Alzheimer’s or related dementias provide care for a longer period of time and were more likely to report health problems related to caregiving than caregivers for other conditions.<sup>18</sup>

While the BRFSS data provides helpful information about rates of cognitive impairment and aspects of caregiver experiences, there are limitations to this data. Estimates of cognitive impairment collected by BRFSS are meant to be used on a population level within states and communities, and not be compared with (or replace) other measures of cognitive impairment. Because the data is self-reported, it is also not intended to be used as an estimate of prevalence. The data is also limited, given that BRFSS is conducted via single family households, and does

not include people living in nursing homes or other residential facilities. By survey design, BRFSS only includes people who are able to verbally respond to the full survey and thus also would not capture data on individuals who are too severely impaired to participate.<sup>17</sup> Despite limitations to the BRFSS data, 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 inclusion of cognitive impairment and caregiver modules of the Behavioral Risk Factor Surveillance System.**

**In order to better track the demographic and economic impact of Alzheimer’s disease and related dementia on the state of North Carolina, dementia advocacy groups should continue to fund the cognitive impairment module of the Behavioral Risk Factor Surveillance System on a five-year interval, measuring self-reported cognitive decline, and consider continued inclusion of the caregiver module at an appropriate interval. Resulting data should be used to inform public awareness campaigns and data dissemination efforts by state policymakers, state agencies, and advocacy organizations. Data should also be analyzed for potential connection with other behavioral and lifestyle risk factors tracked by the statewide survey.**

**Lead: State Center for Health Statistics and dementia advocacy organizations.**

*Dementia and Death Certificate Completion*

When a person dies, a physician is required to provide information on cause of death for the death certificate. This information consists of an immediate cause of death, as well as opportunity for the physician to provide an underlying cause of death, defined as “disease or injury that initiated the events resulting in death,” and other significant conditions contributing to death (but not resulting in the underlying cause or immediate cause of death).<sup>19</sup>

Because of uncertainty around dementia diagnosis or identification of dementia as immediate/underlying cause of death or as contributing to death (i.e., Alzheimer’s cannot be definitively diagnosed except through autopsy, physicians may lack information on dementia background of an individual, etc.), it is difficult to assess the accuracy of death certificate data when it is used to estimate prevalence, identify population health needs, or other research needs. Research has shown that Alzheimer’s disease in particular is underreported as cause of death on death certificates, and that attempts to capture a single immediate cause of death do not always capture the reality of individuals’ deaths resulting from dementia.<sup>20</sup>

Families may also have concerns about the classification of death resulting from dementia. For some families, it may be important to have an official classification of Alzheimer’s disease or dementia as a cause of death. These families may seek to increase awareness of the severity of Alzheimer’s and want to honor their loved ones through an accurate representation of their illness and resulting death. Other families may feel differently—they may feel that identifying

Alzheimer's or dementia as a cause of death will further stigmatize their loved one and family, and may prefer to not acknowledge dementia as a cause of death. Conversations about death certificate completion and families' wishes around the identification of dementia as a cause of death would be appropriate to include in broader conversations about end-of-life care and advanced care planning.

Because of the importance of identifying dementia as an underlying cause of death and/or contributing condition, the Task Force identified the need for additional physician and medical examiner training in dementia identification and accurate completion of death certificates.

**Recommendation 7.3. Improve prevalence data through accurate death certificate completion.**

**In order to improve data collection on rates of death from Alzheimer's disease and related dementia, the lead agency and partners should offer continued medical education training on the identification of Alzheimer's disease and related dementia as cause of death and the importance of accurate identification of Alzheimer's disease and related dementia. Medical schools and residency programs should also offer education and training in this area.**

**Lead: North Carolina Office of the Chief Medical Examiner.**

**Partners: North Carolina Area Health Education Centers programs and the Office of Vital Records.**

*Diagnostic Coding and Claims Data*

In 2012, researchers at the University of North Carolina at Chapel Hill School of Medicine, in collaboration with Carolinas HealthCare System in Charlotte, began a project aimed at improving prevalence and diagnostic data for dementia. This project, through the Carolina Data Warehouse for Health, consisted of analyzing coding practice data from the two participating organizations' electronic medical records and provider charts, in order to produce an accurate estimate of number of patients with dementia and the diagnosis and treatment practices for these patients.<sup>21</sup> Experts hope that new diagnostic codes released under the 2014 revision of the International Statistical Classification of Diseases and Related Health Problems (ICD) 10th Revision, known as ICD-10, will provide additional clarification on the diagnosis and coding of dementia. The ICD-10 codes categorize diseases, symptoms, and other health circumstances and causes, as classified by the World Health Organization.<sup>22</sup>

Prescription claims also provide potentially useful data about the prevalence and distribution of dementia. Prescriptions of Aricept or other clinical treatments for dementia can provide information in the absence of formal diagnosis of Alzheimer's or other forms of dementia.

However, both diagnostic coding data and prescription claims data have limitations, most notably being that this data is currently accessible only to policymakers and researchers and is therefore of limited use. Several states have created all-payer claims data (APCD) systems to help provide state-level data that can improve accuracy of prevalence data for dementia. These

claims data systems also support quality improvement activities, compare prevalence or utilization patterns across the state, identify successful cost containment measures, and evaluate health care reform efforts on costs, quality, and access. The data included in APCD systems generally consists of claims data from hospitals, physicians, pharmacists, and dental care claims from public and private insurers, and may include payment information such as plan charges and member liabilities (e.g., co-pay, deductible payments, and co-insurance).<sup>23</sup>

As of late 2015, 18 states had fully functional APCD systems or were considering building APCD systems.<sup>24</sup> In 2012, the North Carolina Department of Health and Human Services created a workgroup to examine the possibility of creating a similar APCD or confederated data system to capture data from multiple existing data systems that could be used in North Carolina to examine population health, cost, and quality issues across the state. Such a system could provide important data on health care costs, including those for specific procedures, providers, or health systems. However, North Carolina's efforts are currently on hold while the state is implementing other major health information technology efforts, with several groups continuing to hold interest meetings regarding whether to move forward on APCD or a united data system.

**Recommendation 7.4: Improve data on Alzheimer's disease and related dementia prevalence through implementing a statewide data reporting system.**

**Collaborate to create a statewide, mandatory data reporting system to enhance claims transparency for medical care and health care services and improve prevalence and diagnosis data for Alzheimer's disease and related dementia. This collaborative effort should include input from additional stakeholders on database use and access, and participating stakeholders should include employers, provider professional associations, private and public payers, community members, consumer advocates, academic and clinical researchers, and the pharmaceutical and data management industry.**

**Lead: North Carolina General Assembly.**

**Partners: North Carolina Department of Insurance, the North Carolina Department of Health and Human Services, health care systems, and insurers.**

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**CHAPTER EIGHT: FULL RECOMMENDATIONS OF THE TASK FORCE ON  
ALZHEIMER’S DISEASE AND RELATED DEMENTIAS**

**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.**

In order to increase awareness and promote education about Alzheimer’s disease and related dementias, organizations should establish a partnership (and/or build on existing public/private partnerships) to explore the incorporation of Alzheimer’s disease and related dementias information into current health promotion/education programs and social marketing/health promotion materials. Information should include:

- a) Connection between brain health and other preventable risk factors and health behaviors.
- b) Support for early detection and accurate diagnosis, and information about prevention and clinical trial registries.
- c) Resources/referrals for home- and community-based services, health care providers (including specialists), caregiver support services, home safety, and long-term care.
- d) Financial planning information, including available insurance coverage for different types of care and advanced care planning, legal protections (including information on fraud, guardianship, and Adult Protective Services), care transitions, and employee resources.
- e) Strategies to reduce stigma around Alzheimer’s disease and related dementias.
- f) Resources for underserved populations including individuals with intellectual/developmental disabilities, minority populations, homeless, and rural communities.

Partners: Including, but not limited to, North Carolina Division of Aging and Adult Services, North Carolina Division of Public Health, North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, the state Medicaid agency, North Carolina Department of Public Instruction, Area Agencies on Aging, North Carolina Office of Rural Health, county social and human services agencies, county Departments of Public Health, providers of mental health services, academic programs for professionals in health and human services, philanthropic organizations, North Carolina Chamber of Commerce, businesses/employers, health professional associations, managed care organizations, private payers, faith-based communities, and advocacy organizations.



**Recommendation 3.2: Enhance training for health care providers on the benefits and best practices for Alzheimer’s disease and related dementias detection, diagnosis, and services referrals.**

Offer pre-service and in-service training in the early detection of Alzheimer’s disease and related dementias. Training should include validated brief assessment and diagnostic tools, and should be tailored to all populations. Training should focus on:

- a) Incorporating specific tools for early detection in all populations, including individuals with limited English proficiency and those with intellectual or developmental disabilities.
- b) How to meet Medicare annual wellness visit requirements for cognitive assessment using validated tools and a functional approach to assessment.
- c) Benefits of early detection for families and caregivers, including family support, advance planning, symptom and care management strategies, non-pharmacological interventions for improving functional and behavioral symptoms, medication options, and need to incorporate family feedback in identifying cognitive impairment.
- d) Referral resources (to include hard copies provided at time of visit, if requested) for additional medical assessment, diagnostic testing, treatment services, and services for caregivers for those with signs of cognitive impairment.
- e) Information about care and available services and supports, including specific additional training or ongoing education for care managers or other staff.

Lead: North Carolina Area Health Education Centers

Partners: Including, but not limited to, the North Carolina Medical Society, the North Carolina Psychiatric Association, the North Carolina Hospital Association, the North Carolina Nurses Association, and academic health science centers.

**Recommendation 3.3: Create a collective impact partnership to develop and establish dementia-capable pilot communities.**

Using the resources and toolkits available from the Dementia Friendly America and ACT on Alzheimer’s projects, partners should develop a collective impact partnership which will work toward the development and establishment of three to four Alzheimer’s disease and related dementia-capable pilot communities in North Carolina.

- a) The collective impact partnership should be supported by staff from North Carolina Division of Aging and Adult Services, who will oversee collaboration, establish a statewide advisory committee made up of stakeholders, and facilitate technical assistance.
- b) Philanthropic partners should develop a targeted grant process to identify appropriate communities for initial and/or continuing funding.
- c) The pilot community projects should lead to the development of a sustainable and replicable model that can be disseminated to additional North Carolina communities and serve as a foundation for dementia-capable communities.

- d) The local collective impact pilots will require a full-time staff person to champion and organize local efforts. Resources will be required for facilitation, data planning/analysis, and meeting expenses. The estimated annual budget for each pilot is \$125,000.
- e) Pilots should include evaluation of the costs and benefits of this approach for developing a dementia-capable community.

Lead: North Carolina Division of Aging and Adult Services

Partners: Including, but not limited to, philanthropic organizations, county social and human services agencies, Area Agencies on Aging, Association of County Commissioners, UNC's Jordan Institute for Families, local providers of care (including behavioral health, medical health, and human services), and other academic institutions.

**Recommendation 3.4: Establish statewide coordinated leadership to oversee the state plan on Alzheimer's disease and related dementias.**

Establish a statewide coalition on Alzheimer's disease and related dementias to oversee the implementation of this plan. The coalition should be coordinated by the state Alzheimer's disease specialist. The coalition should be charged with:

- a) Developing the collective impact strategy, including assisting funding agencies in selecting communities for collective impact and convening local collective impact efforts to support shared learning, and, if successful, for scale up of collective impact efforts to other communities.
- b) Coordinating implementation of the plan.
- c) Reporting yearly progress on implementation to the Secretary of Health and Human Services (and/or the Senate and House Committees on Aging).
- d) Support other workgroups charged with implementations of specific recommendations.
- e) Serve in an advisory capacity to the North Carolina Division of Aging and Adult Services to support additional recommendations (i.e., the development of a toolkit).

Lead: The North Carolina Division of Aging and Adult Services

Partners: Including, but not limited to, North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, North Carolina Division of Social Services, the state Medicaid agency, the North Carolina Division of Public Health, the North Carolina Division of Health Services Regulation, Alzheimer's North Carolina, Alzheimer's Association, members of the North Carolina General Assembly, the Governor's Council on Aging, the Duke Endowment, AARP North Carolina, LeadingAge North Carolina, North Carolina Area Health Education Centers, local Area Agencies on Aging, the North Carolina Coalition on Aging, the Geriatrics Workforce Enhancement Program, local providers of care (including behavioral health, medical health, and human services), media representatives, and caregivers for people with Alzheimer's disease and related dementia, with special attention to ensure diversity and statewide representation.

**Recommendation 4.1: Promote appropriate care settings for people with Alzheimer’s disease or related dementia.**

In order to minimize avoidable treatment, increase satisfaction, improve quality of care, and decrease health care costs at the end of life, partners should examine and promote the potential benefits of appropriate care settings, to include:

- a) Information on palliative care through the Palliative Care Initiative, and an examination of the potential cost impact of expanding Medicaid coverage for hospice and palliative care and including it in managed care models.
- b) Review of hospice and palliative care criteria in order to ensure that provided care is appropriate for different types of dementia and/or to provide earlier access to care for people with Alzheimer’s disease or related dementia.
- c) Information on additional options for long-term services and supports and differences between such options.
- d) Use of Medicare codes for advance care planning, Medicaid reimbursement procedures, and expansion of qualified providers within the care team who may participate in the billing of these codes to enable nurses, social workers, and other team members to participate in advance care planning.
- e) Ensuring access to appropriate care settings and long-term services and supports for all populations, including individuals with intellectual/developmental disabilities and/or mental illness.

Partners: Health care providers, vendors, and payers.

**Recommendation 4.2: Examine methods of reimbursement and incentives for Alzheimer’s disease and related dementia care through new models of care.**

Explore new models of care which use methods of reimbursement to incentivize care for people with Alzheimer’s disease and related dementia and reduce wait lists for specialist care. Models may include:

- a) Leveraging palliative care and end-of-life expertise that resides in community hospice organizations to expand pre-hospice palliative care supports for patients and families.
- b) Incentivizing the expansion of pre-hospice palliative care services through reimbursement for interdisciplinary palliative care services.
- c) Community Care of North Carolina model of expanding services to include skilled nursing facility residents, thereby making these residents eligible for comprehensive care management.

Lead: Association for Home and Hospice Care of North Carolina, the Carolinas Center for Hospice and End of Life Care.

Partners: Health systems, facilities, private and public payers.

**Recommendation 4.3: Assess health system capacity for people with Alzheimer’s disease or related dementias.**

Conduct an assessment of current health system capacity for caring for patients with Alzheimer’s disease or related dementias. The assessment should include dementia-specific beds in intensive outpatient and psychiatric settings, and also include information on the projected status of moratorium on home care services and on memory care units in adult care homes.

Partners: North Carolina Division of Health Service Regulation, the state Medicaid agency, North Carolina Division of Aging and Adult Services, and health professional trade associations.

**Recommendation 4.4: Improve telehealth services for people with Alzheimer’s disease or related dementias.**

Examine and identify funding streams for improved telehealth services for people with Alzheimer’s disease or related dementias, with special attention on rural and underserved communities and the impact on health care costs and caregiver well-being. These services should include:

- a) Remote diagnostic capacity and ongoing consultation, medication management, and behavioral management in the context of tele-neurology services when appropriate, and/or at alternate locations (including home locations).
- b) Home monitoring of activities of daily living, with local capacity for follow-up.
- c) Remote resources for caregivers.
- d) Additional non-health care services, such as check in calls, monitoring utilities, falls prevention, and caregiver support services.

Partners: North Carolina Division of Aging and Adult Services, the state Medicaid agency, private payers, medical and behavioral health providers, and LME/MCOs.

**Recommendation 4.5: Increase access to medical and community services for people with Alzheimer’s disease and related dementia through improved transportation services.**

In the context of a state-level, interdepartmental group of executive branch agencies, establish a workgroup with a mandate to collaborate on human service transportation issues, maximize resources, and address barriers that present challenges to local communities in providing transportation services. Similar to other state transportation committees that have operated in the past, such as the former Human Services Transportation Council, this interagency workgroup should work to assure coordination and communication among state agencies that provide or purchase transportation services, provide a mechanism for collaborative planning efforts across funding sources, be the state-level entity for addressing service gaps identified for special populations such as people with Alzheimer’s disease or related dementia, and periodically make status reports to the Governor as directed.

Lead: North Carolina Department of Health and Human Services and the North Carolina Department of Transportation.

Partners: Statewide Coalition on Alzheimer’s Disease and Related Dementias, county social and human services agencies, local business partners and transportation vendors, and/or lead agencies for public transportation.

**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 or related dementias.**

Prioritize the incorporation of person-centered care into the care planning process, care management, organizational policies, and ongoing care at health care providers and facilities, including hospitals and long-term care facilities, and in-home care settings. Partners should promote policies and processes that support and encourage person-centered care within health care facilities and in-home and community-based care and services settings, including:

- a) Recognition of the role of unpaid caregivers as members of the health care team.
- b) Inclusion of residents and families on boards and committees. Facilities should appoint a minimum of two residents and/or family members to boards and advisory committees within their organizations. Family members and caregivers should be included in development of health promotion materials and caregiver resource guides.
- c) Appointment of residents and families to boards of directors for governance and operation, at both the corporate/national and local levels.
- d) Trained facilitation for health care providers in principles of person-centered care.
- e) Organizational leadership to promote principles of person-centered care.

Partners: North Carolina Health Care Facilities Association, North Carolina Assisted Living Association, North Carolina Association of Long-Term Care Facilities, North Carolina Hospital Association, Community Care of North Carolina, LeadingAge North Carolina, Association for Home and Hospice Care of North Carolina, Hospice and Palliative Care Center, and other partners.

**Recommendation 4.7: Improve quality of care and care coordination for people with Alzheimer’s disease or related dementia through improved ratings systems and dementia-specific indicators.**

Improve the quality of care for people with Alzheimer’s disease or related dementia, convene a working group to determine the feasibility of developing dementia-specific standards of care, using Centers for Medicaid and Medicare Services standards and/or additional evidence-based indicators as a model. The working group should be overseen by the North Carolina Division of Aging and Adult Services and partners should utilize best practices from existing quality rating systems and dementia-specific reimbursement strategies in order to link facility ratings with value-based payments and/or performance-based incentives for providers/facilities meeting

standardized quality measures specific to dementia care. The rating system should include criteria such as:

- a) Provision of approved training at regular intervals for person- and family-centered care for all workers, regardless of care setting.
- b) Reporting on dementia-specific standardized quality and outcome measures. These reports should include consumer input from residents and families. Data collected should allow comparisons with other states and within North Carolina counties and should evaluate quality ratings systems for effectiveness.
- c) Achievement of positive outcomes for people with Alzheimer's disease and related dementia, tailored to individuals' and families' outcome goals using the principles of person-centered care.
- d) Promoting awareness of and use for standardized quality ratings among providers and consumers, including the Quality Rating System for long-term care facilities and adult care homes.
- e) Implementation of best practices in care transition processes, including engaging families and integrating preferences of the person with dementia in care transition processes, assessing capability to care for family members at home, and providing access to community resources and counseling on financial issues.
- f) Utilization of hospital discharge planners and other professionals involved in transitions who are knowledgeable about person-centered dementia care in developing care transition plans and supporting additional follow up after discharge. This should include education about adult protective services and available home- and community-based services.

Lead: North Carolina Division of Aging and Adult Services.

Partners: North Carolina Health Care Facilities Association, North Carolina Assisted Living Association, North Carolina Association of Long-Term Care Facilities, North Carolina Hospital Association, in collaboration with the state Medicaid agency, the North Carolina Division of Health Services Regulation, Division of Mental Health, Developmental Disabilities and Substance Abuse Services, Departments of Social Services Directors' Association, county social and human services agencies, Office of the Long-Term Care Ombudsman, Friends of Residents in Long-Term Care, North Carolina's Coalition on Aging, North Carolina comptroller's office, academic researchers, and consumer advocacy organizations.

**Recommendation 4.8: Improve care coordination for people with Alzheimer's disease or related dementia through new models of care.**

Implement new models of care that enhance person-centeredness, care coordination, and integration through communication, care management, and medication management for people with Alzheimer's disease or related dementia. Potential models to apply may include specific integrated care initiatives and/or enhanced care management programs. The Medicaid agency

should include such models in health plan contracts, and the Dual Eligibles Working Group<sup>vv</sup> should prioritize recommendations on the application of care coordination models to coverage for the dual eligible population.

Lead: Health care systems, facilities, and public and private payers, including accountable care organizations, managed care organizations, and provider-led entities.

Partners: North Carolina Department of Insurance, North Carolina Department of Health and Human Services, the state Medicaid agency, and the Dual Eligibles Working Group.

#### **Recommendation 4.9: Expand the Dementia Friendly Hospital initiative.**

Promote the Dementia Friendly Hospital Initiative in North Carolina’s hospitals, health care providers, and health systems. Facilities should work to include environmental modifications and practices that enhance continuity of care and person-centered care.

Lead: Health care providers and systems.

Partners: North Carolina Hospital Association, Alzheimer’s North Carolina, and Alzheimer’s Association.

#### **Recommendation 4.10: Promote Alzheimer’s disease and related dementia-specific training for health professionals and community workforce.**

Enhance promotion and dissemination of existing continuing education on Alzheimer’s disease and related dementia-specific training for health care providers and home- and community-based services providers, including but not limited to nurses, certified nursing assistants, outpatient care staff, physicians, social workers, adult day services staff, behavioral health providers, emergency care providers and staff, emergency medical technicians and other first responders, dentists, and clergy and chaplains. Training programs should:

- a) Be offered in multiple settings, be provided on an ongoing and recurring basis, include needs of specific vulnerable populations, and include opportunities for more intensive trainings when desired, appropriate, and necessary to achieve minimum proficiency.
- b) Be included for all health care professionals in both pre- and in-service training and emphasize inter-professional education and quality improvement.

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<sup>vv</sup> “Dual eligibles” refers to 10.2 million Americans who qualify for coverage under both Medicare and Medicaid. These individuals are among the most disabled, chronically ill, and costly coverage recipients. On average, health care costs for the dual eligible population are 60% more than for non-dual eligible individuals. Approximately half of dual eligible qualify for Medicare because of disability rather than age. Almost one-fifth have three or more chronic conditions. More than 40% use long-term services or supports.<sup>36</sup> In North Carolina, the Dual Eligibles Work Group was mandated by the Medicaid Transformation and Reorganization legislation in 2015 (citation: <http://www.ncleg.net/Sessions/2015/Bills/House/PDF/H372v8.pdf>)

- c) Include information on palliative care, advanced health directives, family care planning resources, and information on Medicare rule on end-of-life planning
- d) Emphasize aspects of diagnosis and detection, including information on triage-based and referral-based diagnostic systems (as referenced in Recommendation 3.2).
- e) Address needs of people with Alzheimer’s disease or related dementia in the creation of emergency/disaster preparedness plans, and increase awareness of specific needs of this population during emergencies and disasters.
- f) Include principles of patient- and family-centered care, as they pertain to people with dementia and their family caregivers
- g) Expand behavioral management training for individuals with dementia, using a person-centered approach to care and applying best practices in prioritizing the use of nonpharmacological approaches.

Partners: North Carolina Area Health Education Centers programs, the North Carolina Community Colleges System, the three North Carolina based Geriatric Workforce Education Programs, Geriatric Adult Mental Health Specialty Teams, Geriatric Education Center Consortium, colleges and universities, health professional training schools, organizations that provide care management services (including health systems and accountable care organizations), professional associations including, but not limited to, the North Carolina Medical Society, North Carolina Nurses Association, North Carolina Academy of Physician Assistants, North Carolina Academy of Family Physicians, and advocacy organizations including Alzheimer’s North Carolina, and Alzheimer’s Association.

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

Identify avenues of entry and provide methods of incentives for health professionals’ geriatric/gerontology specialization and additional training in Alzheimer’s disease and related dementia care. These methods may include loan forgiveness programs, innovative recruitment models, expansion of areas of concentration eligibility, certificates of added qualifications, and specialty training designations for individual practitioners. These incentives should be tailored for broad application to all health and human services professional designations.

Lead: North Carolina academic health education programs supported by North Carolina general funds.

Partners: North Carolina Area Health Education Centers and private and public payers.

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

Build on existing models for increased compensation upon completion of geriatric and Alzheimer’s disease and related dementia-specific training modules/certifications within existing



health professional training programs, including physician, nurse, and allied health professionals. This work should include analysis and promotion of the business interest for improved training, such as increased revenue, less employee turnover, and marketing advantages, as well as the benefits to employees and improvement of quality of care.

Partners: Health professional employers, consumer advocacy groups, health professional educational/training organizations, and professional associations, including, but not limited to, the North Carolina Home Care Association, North Carolina Long-Term Care Facility Association, Association for Home and Hospice Care of North Carolina, North Carolina Health Care Facilities Association, North Carolina Assisted Living Association, Board of Nursing, Friends of Residents of Long-Term Care, North Carolina Health Care Professional Registry, North Carolina Community College System, and Area Health Education Centers.

**Recommendation 5.1: Promote integration and accessibility of dementia-specific resources through a comprehensive caregiver toolkit and a virtual resource center.**

Develop a comprehensive “virtual resource center” to be maintained on the Department of Health and Human Services website. The virtual resource center will serve as an informational guide for families, professionals, care managers, and navigators including but not limited to NC 2-1-1, stakeholders, and local provider agencies. The virtual resource center will link to an updated Dementia Toolkit available on the Duke Family Support Program website. The virtual resource center and toolkit should include:

- a) Information about Alzheimer’s disease and related dementia, including definitions/types, prevalence, symptoms, diagnosis, etc.
- b) Information on financial and logistical preparation for caregiving and end-of-life care, including care goals, decision-making needs, advanced care planning, and ways to avoid elder fraud.
- c) Resources for services, including employer-based services, adult day care, caregiver respite services, and financial assistance.
- d) Training resources, including hands-on caregiver training in assistance with activities of daily living.
- e) Safety resources, including tips on home safety, community safety, and technological innovations (such as Safe Return or other web-based tools).
- f) Resources and supports for health care providers, including information on available trainings and information on starting conversations with patients and families about financial planning and safety concerns.
- g) Tools for preliminary assessment of caregiver needs, in order to provide appropriate and effective resources.
- h) Availability in both web-based and hard copy format, in order to maximize accessibility for all populations.

Lead: North Carolina Division of Aging and Adult Services and Duke Family Support Program.

Partners: North Carolina Alzheimer’s stakeholder organizations.

**Recommendation 5.2: Provide adequate funding for family caregiver support services including dementia-specific respite through Project CARE.**

Study the needs for adequate funding of Project CARE (Caregiver Alternatives to Running on Empty) as an evidence-based caregiver support service, including ‘episodic’ respite care, education, coaching, and caregiver training. Any initial increases in appropriations should include sufficient resources to evaluate program impacts on program goals, especially with regard to:

- a) A caregiver’s “intent to institutionalize” care recipients with Alzheimer’s disease or related dementia, real delays in placement, and cost-savings for the Medicaid program and other state programs.
- b) Show improved outcomes (i.e., delayed placement in long-term care, improved access to care, caregiver well-being, etc.) and reduced costs for individuals with dementia, their families, and payers.
- c) Provide a full analysis and recommendation to the General Assembly for initial pilot funding for evidence-based programs within selected communities, with the possibility of recurring funding after additional results and outcomes analysis.

Lead: North Carolina Division of Aging and Adult Services.

Partners: North Carolina General Assembly and Fiscal Research Division.

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

Provide an annual investment of \$200,000 for management of state involvement with the No Wrong Door initiative and “virtual front door” access provided through partnership with NC 2-1-1. NC 2-1-1 will provide the infrastructure for the No Wrong Door system, building on the existing information management platform. This funding should support two full-time staff positions to oversee continued No Wrong Door development and implementation, migration of Alzheimer’s disease and dementia-related community resources to enhance the existing NC 2-1-1 database, manage Alzheimer’s disease and dementia-related stakeholder partnerships, and provide planning for evaluation, sustainability, and further statewide scaling. As part of this work, the Division of Aging and Adult Services should:

- a) Develop infrastructure for state and local government involvement with NC 2-1-1 on dementia-specific resources.
- b) Identify and manage partnerships with organizations including the Area Agencies on Aging, Department of Social Services, aging transition services, Just One Call (Mecklenburg County), caregiver representatives, and other community resource

organizations to ensure the integrity of Alzheimer's disease and dementia-specific information provided to NC 2-1-1 on available services and resources is accurate, up-to-date, and continuously monitored.

- c) Partner with NC 2-1-1 leadership to identify available outside funding sources to support expansion of information management system, thereby improving access and referral support to older adults and/or people with dementia.
- d) Work with NC 2-1-1 leadership to expand and enhance systems integration capabilities, develop controlled marketing strategies, website enhancement, training for call center staff, technology opportunities (through mobile apps and others), and development of reporting and quality assurance measurements.
- e) Partner with aging and dementia advocacy organizations, including the Alzheimer's Association, Alzheimer's North Carolina, Area Agencies on Aging, local Departments of Social Services, and AARP North Carolina, to increase awareness of NC 2-1-1 as a primary resource for health care needs, home- and community-based services, and caregiver support and assistance.
- f) Coordinate training for NC 2-1-1 staff in working with individuals or families with Alzheimer's disease or related dementias and/or engaging dementia specialists to serve as NC 2-1-1 staff.

Lead: General Assembly.

Partners: Division of Aging and Adult Services and United Way of North Carolina.

#### **Recommendation 5.4: Enhance employer policies to support family caregivers.**

Partner with employer stakeholders and business interests to develop policies to encourage active employer participation in support for employee caregivers. This should include:

- a) Education for employers about Alzheimer's disease and related dementia, the role of family caregivers and support for additional promotion of caregiver-friendly policies.
- b) Policies to support employee caregivers, including options such as flextime, paid and unpaid family leave, non-discrimination against caregivers in workplace, telecommuting, referral programs, respite services, on-site support groups, awareness of available benefits (i.e., Family Medical Leave Act eligibility), expansion of the definition of family for caregiving and leave-related policies, and specialized employee assistance programs.
- c) Identification of corporate/employer champions to promote benefits of supportive employer policies to economic interests, as well as employee caregivers' interests.
- d) Encourage passing of House Bill 816 through the North Carolina Senate, in order to study the needs of working family caregivers.

Lead: AARP North Carolina, Alzheimer's North Carolina, the Alzheimer's Association, the Association for Home and Hospice Care, and the North Carolina General Assembly.

Partners: Employer stakeholders and business interests, including North Carolina Chamber of Commerce and the Society for Human Resources Management.

**Recommendation 5.5: Examine outcomes and impact of home- and community-based services programs.**

In order to maximize state resources, the lead agency should examine home and community based programs that have shown improved outcomes (such as delayed placement in long term care, improved access to care, and improved caregiver wellbeing) and reduced costs for individuals with Alzheimer’s disease or related dementias, their families, and payers. Lead agency should:

- a) Analyze the impact of home- and community-based services on overall health care costs, including impact on Medicare and Medicaid costs, and caregiver/family economic and well-being costs, of increasing the number of individuals able to access home- and community-based services, and/or age in place. (Potential programs may include financial provisions for personal care services and missed work days, specialized medical supplies and home safety technologies, and respite care.)
- b) Include evaluation costs in funding recommendations to determine whether service providers met outcome goals, including waiting lists for services.
- c) Conduct an analysis of modifying the Home and Community Care Block Grant configuration. The analysis should include:
  - i. Review of current allocation methodology and payment to allow for consumer cost-sharing.
  - ii. Detailed analysis of the process by which the modifications would be made to existing state statutes (i.e., North Carolina General Assembly approval).
  - iii. Estimated potential expansion of services from revenue generated from instituting a sliding fee for service (income-based) and return on investment analysis.

Lead: North Carolina Department of Health and Human Services.

**Recommendation 5.6: Expand the Medicaid Home- and Community-Based Services Waiver Program.**

Provide additional funding for the existing Medicaid Home- and Community-Based Services waiver program (including CAP/DA and CAP/Choice) to include additional services for individuals with Alzheimer’s disease and their families. Expansion should:

- a) Have the ultimate goals of reducing the waitlist for receipt of services and delaying placement in institutional long-term care. The Dual Eligibles Work Group should also examine root causes of waitlists and identify ways to reduce them.
- b) Allow greater flexibility to cover adult day care services and group respite.

- c) Under reform, allow managed care organizations and provider-led entities to contract for community-based services using a flexible waiver.
- d) Include provisions for local community work on increasing awareness and navigation of available services for people with dementia and their caregivers, including limitations and provisions of Caregiver Directed Vouchers.
- e) Include provisions to address barriers faced by county Departments of Social Services in providing immediate services.
- f) Include additional funding for evaluation of impact of expansion on waitlist, outcomes, and health care costs (including impact on Medicaid costs).

Lead: North Carolina General Assembly.

**Recommendation 5.7: Implement best practices for the integration and coordination of home- and community-based services.**

Identify best practices for the integration and coordination of home- and community-based services, and work statewide to implement these practices and improve awareness of available services. Potential strategies may include using new models of care such as the Transformation Innovations Center under Medicaid reform to identify best practices and deliver improved services; expanding of online resources (i.e., dementia toolkit, online training programs, etc.); connecting services with NC 2-1-1, (see Recommendation 5.3); integration of health services and community-based services; and expanding training for health care providers, care managers, and options counselors on existing services, waiver programs, and financial assistance.

Lead: North Carolina Division of Aging and Adult Services.

Partners: State Medicaid Agency and county Departments of Social Services.

**Recommendation 6.1: Increase awareness of legal protections and vulnerabilities of people with Alzheimer’s disease or related dementia.**

Promote collaboration between partners on increasing awareness among family caregivers of the available legal protections and relevant vulnerabilities of people with Alzheimer’s disease or related dementia. Awareness and education efforts should be incorporated into local collective impact processes and should include:

- a) Planning for the possibility of cognitive impairment and potential caregiving responsibilities in all financial literacy trainings and counseling, including loss of financial capacity as an early warning sign of Alzheimer’s disease and related dementia.
- b) Promotion of advanced care planning (including medical and financial) among family caregivers and people in early stages of Alzheimer’s disease or related dementia, to include information on health care power of attorney signatory requirements and state registry information.

- c) Increased information on issues around guardianship, elder abuse, and advanced directives, including legal/logistical requirements, financial responsibilities of guardianship, recognition and reporting of abuse, and limitations regarding Adult Protective Service's scope of intervention.
- d) Action steps for families and people with Alzheimer's disease or related dementia to enhance use of documentation when needed (i.e., where to put copies of documents, who to inform, etc.).
- e) Promotion of culture change around care planning and financial planning for family members, including caregiver coping strategies such as mediation and family counseling and additional caregiver/family resources.
- f) Engaging additional partners (including faith community) in facilitating guardianship and legal protections when family members are reluctant or unable to do so.

Partners: Local Area Agencies on Aging, North Carolina Division of Aging and Adult Services, the Department of Justice, local Departments of Social Services, State Treasurer, Secretary of State, North Carolina Attorney General, AARP North Carolina, North Carolina Bankers Association, savings and loan associations, Carolinas Credit Union League, North Carolina Bar Association (Elder and Special Needs and Estate Planning and Fiduciary Sections), North Carolina Partnership to Address Adult Abuse, North Carolina Guardianship Association, Rethinking Guardianship statewide stakeholders workgroup, family and caregiver representatives, and other community partners.

**Recommendation 6.2: Incorporate legal protection issues specific to people with Alzheimer's disease or related dementias into health, legal, and financial professional training.**

Offer continuing education on the types and unique requirements of various legal protections for people with Alzheimer's disease or related dementia, including but not limited to guardianship, multidisciplinary evaluations, advanced care directives, financial planning, and health care power of attorney. Training should also incorporate existing best practices in initiating conversations with people with dementia and family caregivers around these issues.

- a) Trainings should be offered in multiple settings, with opportunities for more intensive trainings for those who will help other staff learn about legal protections and opportunities for integrating work in different organizations and building collaborations between sectors.
- b) Trainings should include special considerations and information on identifying and working with people with Alzheimer's disease and related dementia, including training for Adult Protective Service workers, court officials, and others, to ensure a minimum level of competency in identifying and serving people with dementia, including identifying people with reduced decision-making capacity.
- c) Incorporate techniques used by law enforcement to recognize elder abuse and fraud into health and legal professional training.

Partners: North Carolina Area Health Education Centers programs, North Carolina Bar Association, financial organizations/banks, Departments of Social Services/county services, and other organizations including, but not limited to, the North Carolina Medical Society, North Carolina Nurses Association, North Carolina Academy of Physician Assistants, North Carolina Academy of Family Physicians, North Carolina chapter of the American College of Physicians, Office of the Attorney General, the Senior Consumer Fraud Task Force, North Carolina Partnership to Address Adult Abuse, the Department of Justice, and other law enforcement entities.

**Recommendation 6.3: Examine state statutes to determine adequate legal safeguards and protections for people with Alzheimer’s disease or related dementia.**

Convene a workgroup comprised of representatives of agencies and organizations with experience and expertise in dealing with vulnerable adults, including those with dementia, to examine state statutes and ongoing initiatives for Adult Protective Services and guardianship to determine if the state is adequately providing the needed protections for older and disabled North Carolinians. A preliminary/interim report from the workgroup, along with recommendations for any changes to state statutes, should be submitted to the North Carolina Department of Health and Human Services, the Joint Legislative Oversight Committee on Health and Human Services, and the Joint Legislative Oversight Committee on Justice and Public Safety by December 15, 2016, with a final report by April 1, 2017.

The workgroup should address and make recommendations about topics including, but not limited to:

- a) Scope of need for Adult Protective Services and guardianship services, including the passage of House Bill 817 from 2015 (Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act).
- b) Gaps in current state statutes.
- c) Implications of the federal Elder Justice Act on state responsibilities.
- d) Adequacy of existing resources and training needed to protect vulnerable adults, and what expansion is needed.
- e) Reporting of abuse, neglect, or exploitation and penalties for not reporting.
- f) Determining competence and the role, process, and frequency of use of multidisciplinary evaluation.
- g) Establishing jurisdiction for responsibility.
- h) Data assessment of increase in need for services, and strategies to address this growth.
- i) Assessment of legal proceedings to prosecute exploitation and alternatives to strengthen process.

Lead: North Carolina Division of Aging and Adult Services.

Partners: Agencies and organizations participating in the workgroup should include: Alzheimer’s North Carolina, Disability Rights North Carolina, the North Carolina Administrative Office of the Courts, Alzheimer’s North Carolina, the North Carolina Association of County Directors of Social Services, the North Carolina Bar Association, the North Carolina Coalition on Aging, the

North Carolina Conference of Clerks of Superior Court, the North Carolina Council on Developmental Disabilities, the North Carolina Guardianship Association, Rethinking Guardianship statewide stakeholder workgroup, North Carolina Partnership to Address Adult Abuse, the North Carolina Department of Justice, the North Carolina Office of the Attorney General, North Carolina Conference of District Attorneys, the North Carolina Administrative Office of the Courts, the UNC School of Government, state legislators, and consumer and family representatives.

**Recommendation 6.4: Integrate elder fraud and abuse data to improve services for people with Alzheimer’s disease or related dementia.**

In order to improve case management operations and allow individuals to more efficiently and effectively receive services from several organizations/agencies, the lead organization should pursue county integration of elder fraud and abuse data through North Carolina Families Accessing Services through Technology (NCFAST). This should include:

- a) Inclusion of Adult Protective Service/guardianship data in county integration.
- b) Capacity to cross reference public assistance programs to reduce duplicative efforts and assist with locating vulnerable adults.
- c) Examination of existing case management operations and how data can be used at the population level to improve services and abuse/fraud protection.

Lead: North Carolina Department of Health and Human Services.

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

In order to ensure home safety for people with Alzheimer’s disease or related dementia, organizations/agencies should work to:

- a) Enhance and promote falls and injury prevention programs for both people with Alzheimer’s disease or related dementia and their caregivers, as aligned with the goals of the North Carolina Falls Prevention Coalition.
- b) Promote awareness of available home safety assessment services through physical therapy and occupational therapy providers and available financial assistance/reimbursement.
- c) Address home safety assessment workforce, reimbursement, and incentives.
- d) Explore use of innovative technology in home safety, including web-based monitoring devices, and promotion of existing low-tech solution, innovative technologies to address home safety, and potential return on investment for such technologies.
- e) Utilize training resources on initiating conversations with people with Alzheimer’s disease or related dementia and families about proactive preventive steps to reduce fall risk.

Partners: Departments of Social Services, Area Agencies on Aging, primary care providers, adult residential facilities, hospice providers, home care agencies, and other relevant agencies.



**Recommendation 6.6: Enhance public safety and law enforcement outreach for Alzheimer’s disease and related dementia.**

To increase safety in the community for people with Alzheimer’s disease or related dementia, partners should work within the guidelines of the Dementia Friendly America Initiative to:

- a) Expand the utilization of locator devices and promote programs such as Silver Alert.
- b) Increase and promote professional training opportunities and explore setting a minimum standard of training for emergency workers (including fire and emergency medical services), law enforcement officers, and other first responders on dementia symptoms, common behaviors (such as wandering), and individual/community safety concerns.
- c) Collaborate with the North Carolina Department of Motor Vehicles Medical Evaluation Program on outreach work with physician and health professional training groups to promote existing tools that measure cognitive ability and impairment; promote resources for health care providers about safe driving and starting conversations about safe driving with individuals with Alzheimer’s disease or related dementia and their families; and develop protocols for referring individuals with revoked driver’s licenses to community resources and transportation options.

Partners: North Carolina Department of Public Safety, the North Carolina Department of Justice, consumer advocacy groups, and the North Carolina Division of Aging and Adult Services.

**Recommendation 7.1: Support research through the establishment of a statewide collaborative registry.**

Establish a statewide registry/clinical trials network of people diagnosed with Alzheimer’s disease and related dementia and healthy individuals, in order to better inform research into Alzheimer’s disease and related dementia treatment and prevention. The collaborative network should:

- a) Build on the existing work of the Memory and Brain Aging Research Coalition (MBARC) to expand partnerships, establish continued funding, and determine appropriate methods of sustainability.
- b) Focus on inclusion of underserved and underrepresented populations in Alzheimer’s disease and related dementia treatment, prevention, and clinical trial participation.
- c) Work to apply research findings to education/awareness campaigns on Alzheimer’s disease and related dementia prevalence, symptoms, and opportunity for participation in clinical trial research.
- d) Promote the ways in which a statewide registry may have a positive economic impact on North Carolina.

Lead: Academic institutions, including Duke University, University of North Carolina at Chapel Hill, Wake Forest University, North Carolina A&T University, North Carolina State University, Appalachian State University, Western Carolina University, University of North Carolina at Asheville, and University of North Carolina at Wilmington.

Partners: Philanthropic organizations, Alzheimer's North Carolina, and the Alzheimer's Association.

**Recommendation 7.2: Continue inclusion of cognitive impairment and caregiver modules of the Behavioral Risk Factor Surveillance System.**

In order to better track the demographic and economic impact of Alzheimer's disease and related dementia on the state of North Carolina, dementia advocacy groups should continue to fund the cognitive impairment module of the Behavioral Risk Factor Surveillance System on a five-year interval, measuring self-reported cognitive decline, and consider continued inclusion of the caregiver module at an appropriate interval. Resulting data should be used to inform public awareness campaigns and data dissemination efforts by state policymakers, state agencies, and advocacy organizations. Data should also be analyzed for potential connection with other behavioral and lifestyle risk factors tracked by the statewide survey.

Lead: State Center for Health Statistics and dementia advocacy organizations.

**Recommendation 7.3. Improve prevalence data through accurate death certificate completion.**

In order to improve data collection on rates of death from Alzheimer's disease and related dementia, the lead agency and partners should offer continued medical education training on the identification of Alzheimer's disease and related dementia as cause of death and the importance of accurate identification of Alzheimer's disease and related dementia. Medical schools and residency programs should also offer education and training in this area.

Lead: North Carolina Office of the Chief Medical Examiner.

Partners: North Carolina Area Health Education Centers programs and the Office of Vital Records.

**Recommendation 7.4: Improve data on Alzheimer's disease and related dementia prevalence through implementing a statewide data reporting system.**

Collaborate to create a statewide, mandatory data reporting system to enhance claims transparency for medical care and health care services and improve prevalence and diagnosis data for Alzheimer's disease and related dementia. This collaborative effort should include input

from additional stakeholders on database use and access, and participating stakeholders should include employers, provider professional associations, private and public payers, community members, consumer advocates, academic and clinical researchers, and the pharmaceutical and data management industry.

Lead: North Carolina General Assembly.

Partners: North Carolina Department of Insurance, the North Carolina Department of Health and Human Services, health care systems, and insurers.



**APPENDIX A  
TASK FORCE ON ALZHEIMER'S DISEASE AND RELATED DEMENTIAS  
RECOMMENDATIONS BY RESPONSIBLE AGENCY/ORGANIZATION**

Recommendation	Responsible Agency/Organization																			
	DHHS Divisions										Responsible Agency/Organization									
	DHHS (overall)	DAAS	DPH	DMH/DD/SAS	State Medicaid Agency	DHSR	Office of Rural Health	DFS	NCGA	Area Agencies on Aging community concerns	human services agencies	Providers	Academic programs for institutions	Philanthropy	Business and employers	Advocacy organization	Health professional/trade organizations	AHEC	Other	
<b>CHAPTER 3: RAISING AWARENESS</b>																				
Rec. 3.1: Increase awareness and promote education and available resources through incorporating Alzheimer's disease and related dementia -specific information in current health promotion and education programs.		X	X	X	X					X	X	X	X							NC Department of Instruction, county Departments of Public Health, NC Chamber of Commerce, MCOs, private payers, faith-based communities
Rec. 3.2: Enhance training for health care providers on the benefits and best practices for Alzheimer's disease and related dementia detection, diagnosis, and services referrals.												X						NCMS, NCPA, NCHA, NCNA	X	
Rec. 3.3: Create a collective impact partnership to develop and establish dementia-capable pilot communities.		X							X	X	X	X	X							Association of County Commissioners, UNC's Jordan Institute for Families
Rec. 3.4: Establish statewide coordinated leadership to oversee the state plan on Alzheimer's disease and related dementia		X	X	X	X	X		X	X	X	X	X		Duke Endowment		Alzheimer's NC, Alzheimer's Association, AARP NC, LeadingAge NC				Governor's Council on Aging, NC Coalition on Aging, GWEPs, media representatives, caregiver representatives
<b>CHAPTER 4: HAVING SUPPORTIVE OPTIONS THAT FOSTER QUALITY OF LIFE</b>																				
Rec. 4.1: Promote appropriate care settings for people with Alzheimer's disease and related dementia												X								Vendors and payers
Rec. 4.2: Examine methods of reimbursement and incentives for Alzheimer's disease and related dementia care through new models of care																	Association for Home and Hospice Care of NC, the Carolinas Center for Hospice and End of Life Care			Health systems, facilities, private and public payers
Rec. 4.3: Assess health system capacity for people with Alzheimer's disease and related dementias		X			X	X											X			
Rec. 4.4: Improve telehealth services for people with Alzheimer's disease and related dementias		X			X							X								Private payers, LMEs, MCOs
Rec. 4.5: Increase access to medical and community services for people with Alzheimer's disease and related dementia through improved transportation services	X	X									X				X					NC Department of Transportation, Statewide Coalition on Alzheimer's Disease and Related Dementias, local business partners and transportation vendors, and/or lead agencies for public transportation
Rec. 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.																	NCHCFA, NCALA, NCALTCF, NCHA, AHHC NC, LeadingAge NC			Community Care of NC, Hospice and Palliative Care Center
Rec. 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		X		X	X	X					X	X					NCHCFA, NCALA, NCALTCF, NCHA			Departments of Social Services Directors' Association, Office of the Long-Term Care Ombudsmen, Friends of Residents of Long-Term Care, Governor's Coalition on Aging, NC comptroller's office
Rec. 4.8: Improve care coordination for people with Alzheimer's disease and related dementia through new models of care	X			X																Health care systems, facilities, public/private payers, ACOs, MCOs, PLEs, NC Department of Insurance
Rec. 4.9: Expand the Dementia Friendly Hospital initiative											X				Alzheimer's NC, Alzheimer's Association	NCHA				Health care systems

**APPENDIX A  
TASK FORCE ON ALZHEIMER'S DISEASE AND RELATED DEMENTIAS  
RECOMMENDATIONS BY RESPONSIBLE AGENCY/ORGANIZATION**

Recommendation	Responsible Agency/Organization																		
	DHHS Divisions																		
	DHHS (overall)	DAAS	DPH	DMH/DD/SAS	State Medicaid Agency	DHSR	Office of Rural Health	DSS	NCCA	Area Agencies on Aging	County social and human services agencies	Providers	Academic programs or institutions	Philanthropy	Business and employers	Advocacy organization	Health professional/trade organizations	AHEC	Other
Rec. 4.10: Promote Alzheimer's disease and related dementia-specific training for health professionals and community workforce													x			Alzheimer's NC, Alzheimer's Association	NCMS, NCNA, NCAPA, NCAFP	x	NC Community College System, GWEPs, GAST, organizations that provide care management services
Rec. 4.11: Incentivize entry into geriatric and gerontology specialization and additional training in dementia care													x					x	Private and public payers
Rec. 4.12: Increase compensation based on Alzheimer's disease and related dementia-specific training and certification													x		x	Friends of Residents	NCALTCF, AHHC NC, NCHCFA, NCALA, Board of Nursing, NC Health Care Professional Registry	x	NCCCS
<b>CHAPTER 5: SUPPORTING CAREGIVERS AND FAMILIES TOUCHED BY ALZHEIMER'S DISEASE AND RELATED DEMENTIAS</b>																			
Rec. 5.1: Promote integration and accessibility of dementia-specific resources through a comprehensive caregiver toolkit and virtual resource center		x																	Duke Family Support Program, NC Alzheimer's disease stakeholders
Rec. 5.2: Ensure adequate funding for family caregiver support services including dementia-specific respite through North Carolina Project C.A.R.E.		x								x									Fiscal Research Division
Rec. 5.3: Continue No Wrong Door Initiative through a collaboration with NC 2-1-1.		x																	United Way of NC
Rec. 5.4: Enhance employer policies to support family caregivers														x		AARP NC, Alzheimer's NC, Alzheimer's Association	AHHC NC		NC Chamber of Commerce, SHRM
Rec. 5.5: Examine outcomes and impact of home and community based programs	x																		
Rec. 5.6: Expand the Medicaid Home and Community Based Services Waiver Program																			
Rec. 5.7: Implement best practices for the integration and coordination of home and community based services		x			x														
<b>CHAPTER 6: PROMOTING MEANINGFUL PARTICIPATION IN COMMUNITY LIFE</b>																			
Rec. 6.1: Increase awareness of legal protections and vulnerabilities of people with dementia		x								x	x					AARP NC			Department of Justice, State Treasurer, Secretary of State, NC Attorney General, NC Bankers' Association, Savings and Loan Associations, Carolinas Credit Union League, NC Bar Association (Elder and Special Needs and Estate Planning and Fiduciary Sections), NC Partnership to Address Adult Abuse, NC Guardianship Association, and Rethinking Guardianship statewide stakeholders workgroup, family and caregiver representatives
Rec. 6.2: Incorporate legal protection issues specific to people with Alzheimer's disease and related dementias into health, legal, and financial professional training																	NCMS, NCNA, NCAPA, NCAFP, NC Chapter of the American College of Physicians	x	NC Bar Association, financial organizations/banks, Office of the Attorney General, the Senior Fraud Task Force, NC Partnership to Address Adult Abuse the Department of Justice, and other law enforcement entities

**APPENDIX A  
TASK FORCE ON ALZHEIMER'S DISEASE AND RELATED DEMENTIAS  
RECOMMENDATIONS BY RESPONSIBLE AGENCY/ORGANIZATION**

Recommendation	Responsible Agency/Organization																			
	DHHS Divisions										Other									
	DHHS (overall)	DAAS	DPH	DMH/DD/SAS	State Medicaid Agency	DHSR	Office of Rural Health	DSS	NCGA	Area Agencies on Aging	County social and human services agencies	Providers	Academic programs or institutions	Philanthropy	Business and employers	Advocacy organizations	Health professional/trade organizations	AHEC	Other	
Rec. 6.3: Examine state statutes to determine adequate legal safeguards and protections for people with Alzheimer's disease and related dementia		x							x				UNC School of Government							NC Administrative Office of the Courts, NC Association of County Directors of Social Services, NC Bar Association, NC Coalition on Aging, NC Conference of Clerks of Superior Court, NC Council on Developmental Disabilities, NC Guardianship Association, Rethinking Guardianship statewide stakeholder workgroup, NC Partnership to Address Adult Abuse, NC Department of Justice, NC Office of the Attorney General, NC Conference of District Attorneys, NC Administrative Office of the Courts, and consumer and family representatives.
Rec. 6.4: Integrate elder fraud and abuse data to improve services for people with Alzheimer's disease and related dementia	x																			
Rec. 6.5: Improve home safety resources and workforce capacity									x	x	x									Adult residential facilities, hospice providers, home care agencies
Rec. 6.6: Enhance public safety and law enforcement outreach for Alzheimer's disease and related dementia		x													x					NC Department of Public Safety, NC Department of Justice
<b>CHAPTER 7: REACHING THOSE WHO ARE UNDERSERVED</b>																				
Rec. 7.1: Support research through the establishment of a state-wide collaborative registry													Duke University, UNC Chapel Hill, Wake Forest University, NCA&T University, NCSU, Appalachian State University, Western Carolina University, UNC Asheville, and UNC Wilmington							
Rec. 7.2: Continue inclusion of cognitive impairment and caregiver modules of the Behavioral Risk Factor Surveillance System															x					State Center for Health Statistics
Rec. 7.3: Improve prevalence data through accurate death certificate completion																				Office of the Chief Medical Examiner, Office of Vital Records
Rec. 7.4: Improve data on Alzheimer's disease and related dementia prevalence through implementing a statewide data reporting system	x								x											NC Department of Insurance, health care systems, insurers

**APPENDIX B  
TASK FORCE ON ALZHEIMER'S DISEASE AND RELATED DEMENTIAS  
RECOMMENDATIONS BY LEGISLATIVE TOPIC**

Recommendation	Legislated Topic															
	Statewide awareness and education	Early detection and diagnosis	Care coordination	Quality of care	Health care system capacity	Training for health care professionals	Access to treatment	Home- and community-based services	Long-term care	Caregiver assistance	Research	Brain health	Data collection	Public safety and safety-related needs of individuals with Alzheimer's disease or related dementia	Legal protections for individuals living with Alzheimer's disease/related dementia and their caregivers	State policies to assist individuals with Alzheimer's disease and their families
<b>CHAPTER 3: RAISING AWARENESS</b>																
Rec. 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.	X											X				X
Rec. 3.2: Enhance training for health care providers on the benefits and best practices for Alzheimer's disease and related dementia detection, diagnosis, and services referrals.		X			X				X							
Rec. 3.3: Create a collective impact partnership to develop and establish dementia-capable pilot communities.	X		X	X	X		X	X	X				X	X		X
Rec. 3.4: Establish statewide coordinated leadership to oversee the state plan on Alzheimer's disease and related dementia																X
<b>CHAPTER 4: HAVING SUPPORTIVE OPTIONS THAT FOSTER QUALITY OF LIFE</b>																
Rec. 4.1: Promote appropriate care settings for people with Alzheimer's disease and related dementia			X	X	X		X	X	X							
Rec. 4.2: Examine methods of reimbursement and incentives for Alzheimer's disease and related dementia care through new models of care			X	X	X											
Rec. 4.3: Assess health system capacity for people with Alzheimer's disease and related dementias			X	X	X											
Rec. 4.4: Improve telehealth services for people with Alzheimer's disease and related dementias	X	X	X	X			X									
Rec. 4.5: Increase access to medical and community services for people with Alzheimer's disease and related dementia through improved transportation services			X				X	X					X			



**APPENDIX B  
TASK FORCE ON ALZHEIMER'S DISEASE AND RELATED DEMENTIAS  
RECOMMENDATIONS BY LEGISLATIVE TOPIC**

Recommendation	Legislated Topic															
	Statewide awareness and education	Early detection and diagnosis	Care coordination	Quality of care	Health care system capacity	Training for health care professionals	Access to treatment	Home- and community-based services	Long-term care	Caregiver assistance	Research	Brain health	Data collection	Public safety and safety-related needs of individuals with Alzheimer's disease or related dementia	Legal protections for individuals living with Alzheimer's disease/related dementia and their caregivers	State policies to assist individuals with Alzheimer's disease and their families
Rec. 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.			X		X				X							
Rec. 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		X	X		X			X	X							
Rec. 4.8: Improve care coordination for people with Alzheimer's disease and related dementia through new models of care		X	X	X												
Rec. 4.9: Expand the Dementia Friendly Hospital initiative	X	X	X	X	X	X										
Rec. 4.10: Promote Alzheimer's disease and related dementia-specific training for health professionals and community workforce	X		X	X	X	X	X	X					X			
Rec. 4.11: Incentivize entry into geriatric and gerontology specialization and additional training in dementia care			X	X	X	X										
Rec. 4.12: Increase compensation based on Alzheimer's disease and related dementia-specific training and certification			X	X	X	X		X								
<b>CHAPTER 5: SUPPORTING CAREGIVERS AND FAMILIES TOUCHED BY ALZHEIMER'S DISEASE AND RELATED DEMENTIAS</b>																
Rec. 5.1: Promote integration and accessibility of dementia-specific resources through a comprehensive caregiver toolkit and virtual resource center	X							X	X	X		X	X	X		X
Rec. 5.2: Ensure adequate funding for family caregiver support services including dementia-specific respite through North Carolina Project C.A.R.E.								X	X	X						X
Rec. 5.3: Continue No Wrong Door Initiative through a collaboration with NC 2-1-1.	X	X				X	X	X	X							X

**APPENDIX B  
TASK FORCE ON ALZHEIMER'S DISEASE AND RELATED DEMENTIAS  
RECOMMENDATIONS BY LEGISLATIVE TOPIC**

Recommendation	Legislated Topic															
	Statewide awareness and education	Early detection and diagnosis	Care coordination	Quality of care	Health care system capacity	Training for health care professionals	Access to treatment	Home- and community-based services	Long-term care	Caregiver assistance	Research	Brain health	Data collection	Public safety and safety-related needs of individuals with Alzheimer's disease or related dementia	Legal protections for individuals living with Alzheimer's disease/related dementia and their caregivers	State policies to assist individuals with Alzheimer's disease and their families
Rec. 5.4: Enhance employer policies to support family caregivers									X							
Rec. 5.5: Examine outcomes and impact of home and community based programs						X	X	X	X							X
Rec. 5.6: Expand the Medicaid Home and Community Based Services Waiver Program						X	X	X	X							X
Rec. 5.7: Implement best practices for the integration and coordination of home and community based services			X			X	X	X								
<b>CHAPTER 6: PROMOTING MEANINGFUL PARTICIPATION IN COMMUNITY LIFE</b>																
Rec. 6.1: Increase awareness of legal protections and vulnerabilities of people with dementia	X								X						X	
Rec. 6.2: Incorporate legal protection issues specific to people with Alzheimer's disease and related dementias into health, legal, and financial professional training	X				X				X						X	
Rec. 6.3: Examine state statutes to determine adequate legal safeguards and protections for people with Alzheimer's disease and related dementia	X														X	X
Rec. 6.4: Integrate elder fraud and abuse data to improve services for people with Alzheimer's disease and related dementia													X	X		X
Rec. 6.5: Improve home safety resources and workforce capacity									X				X			
Rec. 6.6: Enhance public safety and law enforcement outreach for Alzheimer's disease and related dementia	X												X	X		X
<b>CHAPTER 7: REACHING THOSE WHO ARE UNDERSERVED</b>																
Rec. 7.1: Support research through the establishment of a state-wide collaborative registry	X	X								X	X	X				
Rec. 7.2: Continue inclusion of cognitive impairment and caregiver modules of the Behavioral Risk Factor Surveillance System									X	X		X				X
Rec. 7.3: Improve prevalence data through accurate death certificate completion												X				
Rec. 7.4: Improve data on Alzheimer's disease and related dementia prevalence through implementing a statewide data reporting system												X				X