

Dementia Capable North Carolina

**A Strategic Plan Addressing
Alzheimer's Disease and
related dementias**



 Nothing Compares 

State Plan on Alzheimer's and Related Dementias

- A strategic state plan for Alzheimer's disease as required by GS 143B-181.1 of the NC Division of Aging and Adult Services (SB 744).
- State plan has been partnership of NCIOM and DAAS with The Duke Endowment, Winston Salem Foundation, AARP NC, LeadingAge NC, Alzheimer's NC, and the NC Alzheimer's Association.



Task Force on Alzheimer's Disease and Related Dementia

- Co-Chairs:
 - **Goldie Byrd**, NC A&T University;
 - **Lisa Gwyther**, Duke Family Support Program; and
 - **Doug Dickerson**, AARP NC
- 47 Task Force and Steering Committee Members
- Physicians, researchers, gerontologists, service providers, caregivers, staff of executive agencies, and legislators.
- Presentations from content experts, caregivers, and persons with dementia



The Stigma and the Reality





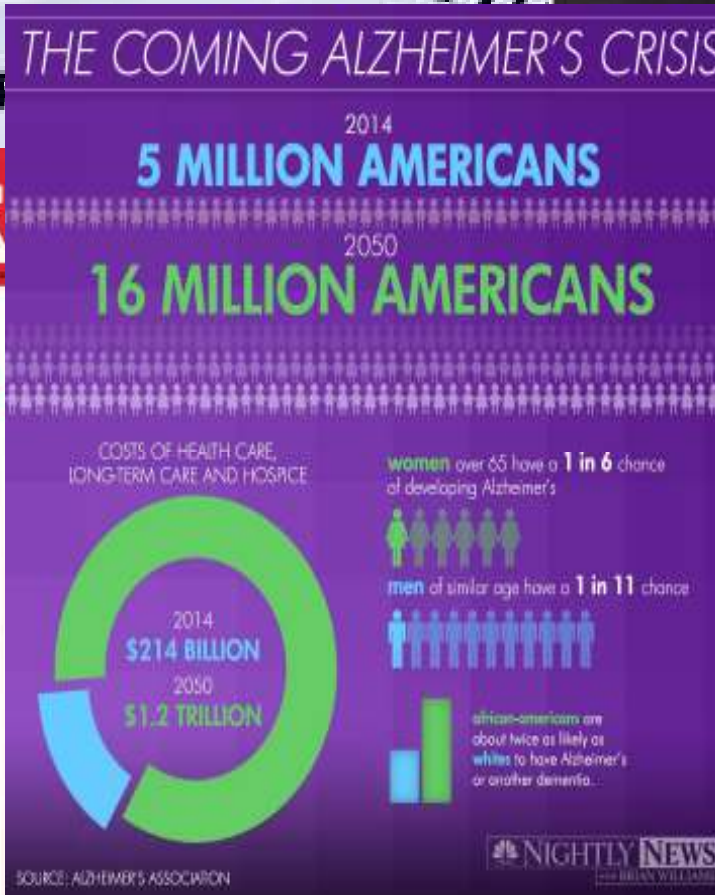
Brain elusion Alzheimers derin

U.S. News & World Report
U.S. News
 The **New Face** of Alzheimer's
 Why more young people than ever are falling prey to this devastating disease
 What you can do
 The push for a cure

Newsweek
 Nov 16 2009 \$5.00

IN A WRENCHING ROLE REVERSAL, ADULT CHILDREN ARE STRUGGLING TO HELP THEIR AILING PARENTS. THE TOLL ON FAMILIES—AND HOW TO COPE.

Caregiving & Alzheimer's



Harry Potter
 HOW GOOD IS THIS ONE?

New Series
Innovators
 The TIME 100 Of the Future

THE NEW SCIENCE OF **ALZHEIMER'S**

- The drugs
- The genetics
- The latest theories
- What you can do now

The Face of Alzheimer's Disease & related Dementias today



- **Sixth-leading** cause of death
- **5.2 million** Americans have Alzheimer's disease
- Currently, NC has over **160,000** older adults with Alzheimer's disease or other types of dementia.
- In the US every **67 seconds** someone develops Alzheimer's
- By **2030**, the total number is projected to rise to over **300,000**
- The only top 10 cause of death that **cannot** be cured, prevented, or slowed

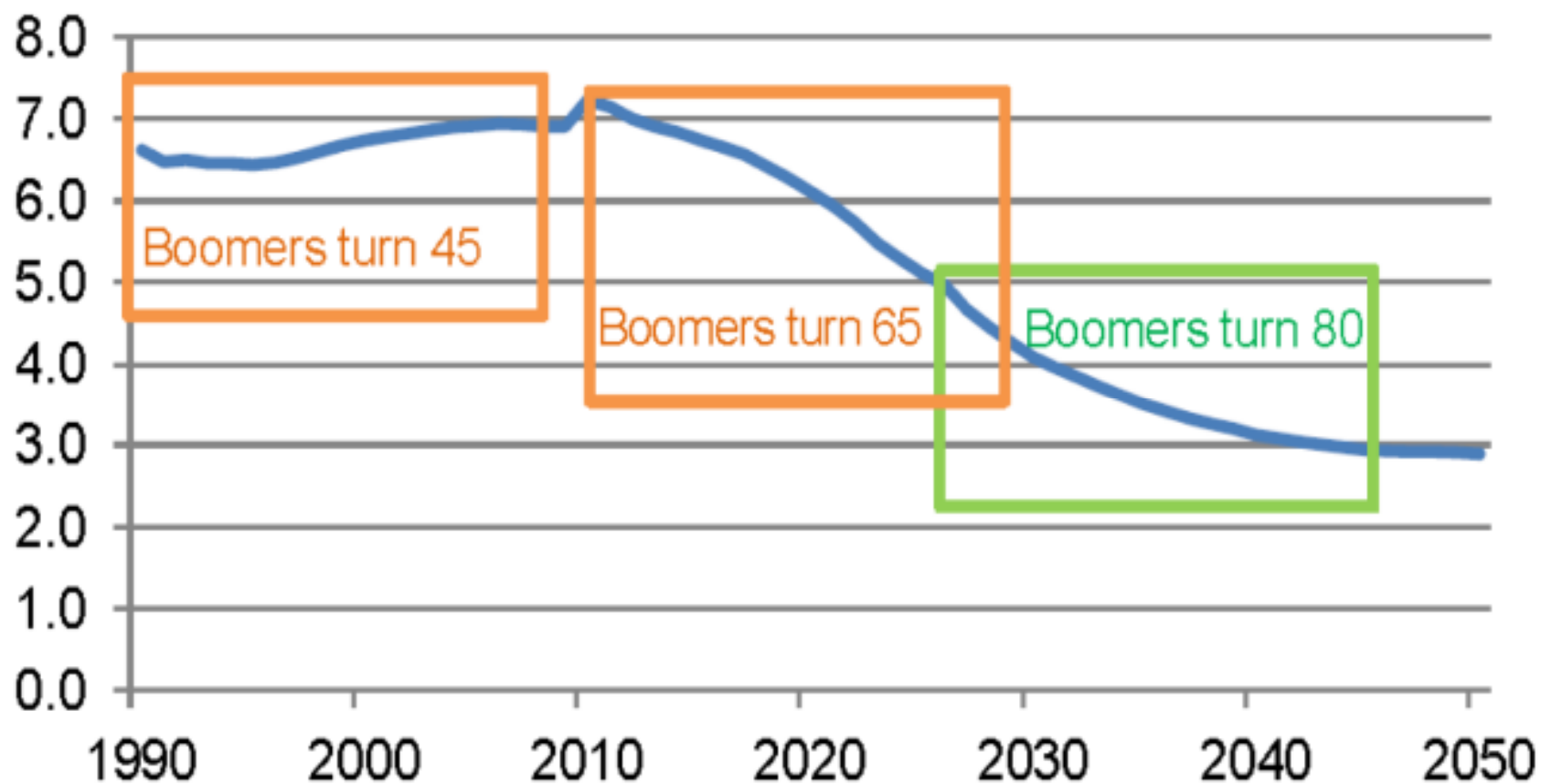
North Carolina is Aging



- The number of adults 65 and older will **increase dramatically** over the next 15 years.
- North Carolina ranks **9th nationally**, both in total population and in the number of people 65 and older.
- In 2025, **one in five North Carolinians will be 65 and older.**
- Our 65 and older population will almost double in the next 20 years from 1.5 to 2.5 million.



Caregiver Support Ratio



16 Focus areas required by Senate Bill 744

- 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 and Data Collection
- Public safety and safety-related needs of those w/ ADRD
- Legal protections for those with ADRD & Caregivers
- State policies to assist those with ADRD & Families



Dementia Friendly America

Framing the Plan

- **Raising awareness about dementia and transforming attitudes**
 - Education, Awareness, Early Detection and Diagnosis
- **Having supportive options that foster quality of life**
 - Quality of Care, Care Coordination, Health Care System Capacity
- **Supporting caregivers and families touched by the disease**
 - Access to Treatment, HCBS, Long-Term Care, Caregiver Assistance
- **Promoting meaningful participation in community life**
 - Public Safety and Safety-Related, Legal Protections
- **Reaching those who are underserved**
 - Rural Communities, IDD population, African-American elders, Data



Raising awareness about dementia and transforming attitudes



- Reducing stigma
- Increasing family education
- Promoting brain health initiatives
 - Early screening diagnosis
- Promote family planning & preparation
 - Community engagement with grassroots organizations

Raising awareness about dementia and transforming attitudes

- 3.1 Increase awareness and promote education about available resources through incorporating Alzheimer's disease and related dementia-specific information in current health promotion and education programs.



Raising awareness about dementia and transforming attitudes



- 3.2 Enhance training for health care providers on the benefits and best practices for detection, diagnosis, and the services referrals of Alzheimer's disease and related dementias.
- 3.3 Create a collective impact partnership to develop and establish dementia-capable pilot communities.

Raising awareness about dementia and transforming attitudes

- 3.4 Establish a statewide coordinated leadership to oversee the state plan on Alzheimer's disease and related dementias.



Having Supportive Options That Foster Quality of Life

- 75% of people with Alzheimer's are admitted to a nursing home by age 80.
- Medicaid costs are 19 times higher for older adults with dementia.
- Long-term care is provided in the home, in the community and in long-term care facilities.
- The median annual cost for nursing home care was in NC \$77,471 in 2013.
- Access to care is often difficult to navigate.

Having Supportive Options That Foster Quality of Life

- 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.
- 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.

Having Supportive Options That Foster Quality of Life

- 4.3 Assess health system capacity for people with Alzheimer's disease and related dementias.
- 4.4 Improve telehealth services for people with Alzheimer's disease and related dementias.
- 4.5 Increase access to medical and community services for people with Alzheimer's disease and related dementia by improving transportation services through an inter-departmental working group.

Having Supportive Options That Foster Quality of Life

- 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 dementia.
- 4.7 Improve quality of care and care coordination for people with dementia through improved ratings systems and dementia-specific indicators.



Having Supportive Options That Foster Quality of Life



- 4.8 Improve care coordination for people with Alzheimer's disease and related dementia through new models of care.
- 4.9 Expand the Dementia Friendly Hospital initiative.
- 4.10 Promote Alzheimer's disease and related dementia-specific training for health professionals and community workforce.

Having Supportive Options That Foster Quality of Life



- 4.11 Incentivize entry into geriatric and gerontology specialization and additional training in dementia care.
- 4.12 Increase compensation based on Alzheimer's disease and related dementia-specific training and certification.

Supporting Caregivers and Families

- Caregiver ratios will change from 8/1 in 2010 to 3.9/1 in 2030.
- Community-based supports, including respite, delay institutionalization.
- Extensive waiting lists for HCBS limit caregiver options for care.
- Employed caregivers face logistical and financial difficulties when providing care.
- Caregivers are at risk for stress, depression and declining personal health.

Supporting Caregivers and Families

- 5.1 Promote integration and accessibility of dementia-specific resources through a comprehensive caregiver toolkit and a virtual resource center.
- 5.2 Ensure adequate funding for family caregiver support services including dementia-specific respite through NC Project C.A.R.E.
- 5.3 Continue No Wrong Door Initiative through a collaboration with NC 2-1-1.



Supporting Caregivers and Families

- 5.4 Enhance employer policies to support family caregivers.
- 5.5 Examine outcomes and impact of home and community-based services programs. (CAP)
- 5.6 Expand the Medicaid Home and Community-Based Services Waiver Program.
- 5.7 Implement best practices for the integration and coordination of home and community-based services.



Promoting Meaningful Participation in Community Life

- Individuals with dementia are at risk for fraud, abuse, financial exploitation, self neglect and the need for guardianship.
- Families need awareness of advanced directives, including Powers of Attorney, long-term care planning and financing.
- Wandering, falls and driving are safety risks for persons with Alzheimer's and related dementias.

Promoting Meaningful Participation in Community Life

- 6.1 Increase awareness of legal protections and vulnerabilities of people with Alzheimer's disease and related dementia.
- 6.2 Incorporate legal protection issues specific to people with Alzheimer's and related dementias into health, legal, and financial professional training.



Promoting Meaningful Participation in Community Life



- 6.3 Examine state statutes to determine adequate legal safeguards and protections for people with Alzheimer's disease and related dementias.
- 6.4 Integrate elder fraud and abuse data to improve services for people with Alzheimer's disease and related dementia.

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Reaching Those Who Are Underserved



- The prevalence of dementia is significantly higher for persons with African Americans, Latinos, and those with Intellectual and Developmental Disabilities (IDD)
- Deaths related to dementia are highly underreported.
- Participation in clinical trials is key to successful research.
- Prevalence data is currently estimated

Reaching Those Who Are Underserved



- 7.1 Support Alzheimer's disease and related dementia research through the establishment of a statewide collaborative registry.
- 7.2 Continue periodic inclusion of cognitive impairment and caregiver modules of the Behavioral Risk Factor Surveillance System (BRFSS)

Reaching Those Who Are Underserved



- 7.3 Improve prevalence data through accurate death certificate completion.
- 7.4 Improve data on Alzheimer's disease and related dementia prevalence through implementing a statewide data reporting system.

Next Steps:

- A Living Document for the Division of Aging and Adult Services and NC DHHS.
- NC Alzheimer's Coalition
- Priority setting and new initiatives
- Dementia Friendly America Workshop on October 18 Wake Forest, NC



For More Information

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