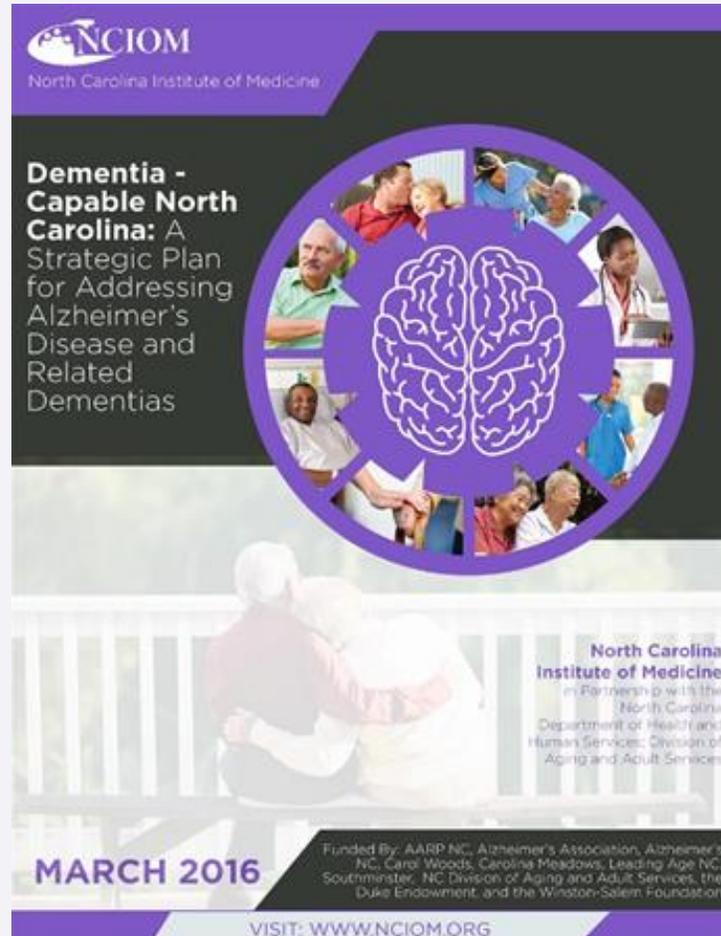


# Dementia-Capable North Carolina



Michelle Ries, MPH  
Project Director

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# Overview

## NCIOM Staff:

- Adam Zolotor, MD, DrPH, President and CEO
- Berkeley Yorkery, MPP, Associate Director
- Michelle Ries, MPH, Project Director

## Co-Chairs:

- Goldie Byrd, NC A&T University
- Lisa Gwyther, Duke Family Support Program
- Doug Dickerson, AARP NC



# Overview

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 developed in partnership of NCIOM and DAAS with funding from The Duke Endowment, Winston Salem Foundation, AARP NC, LeadingAge NC, Alzheimer's NC, and the NC Alzheimer's Association.



# Overview

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

Task Force met 10 times between summer 2015 and spring 2016

Final state plan released in March 2016, and presented to the North Carolina General Assembly



# Background: Alzheimer's Disease and Related Dementias



Sixth-leading cause of death,

Fifth-leading cause of death in NC

5.2 million Americans have Alzheimer's disease

In the US every 67 seconds someone develops Alzheimer's

Currently, NC has over 160,000 older adults with Alzheimer's disease or other types of dementia.

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

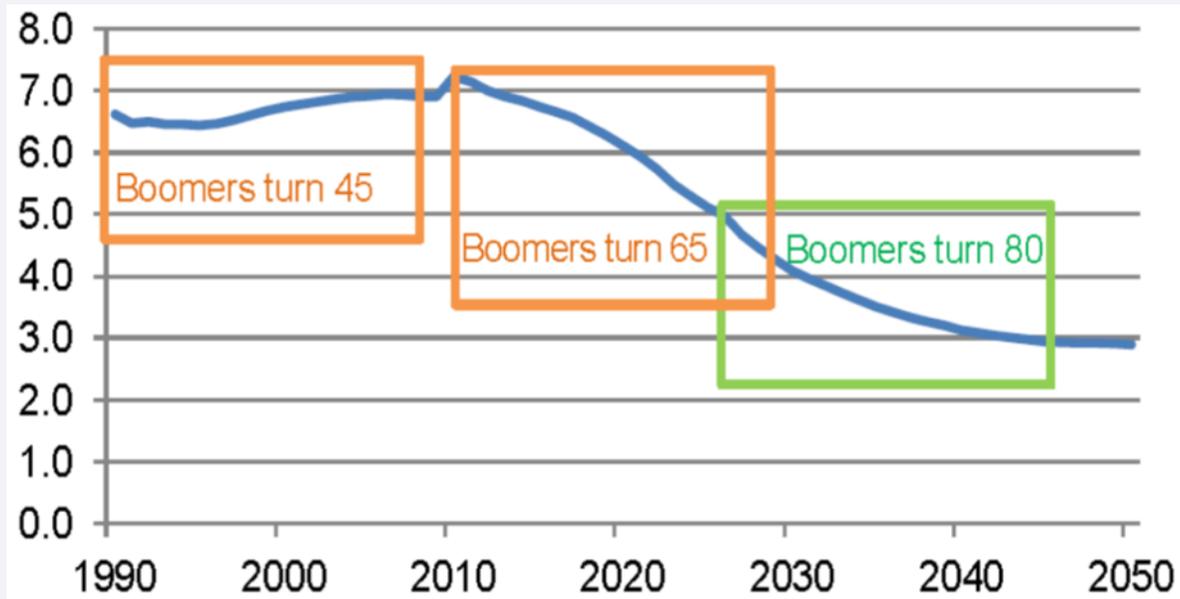


# North Carolina is Aging

- 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.



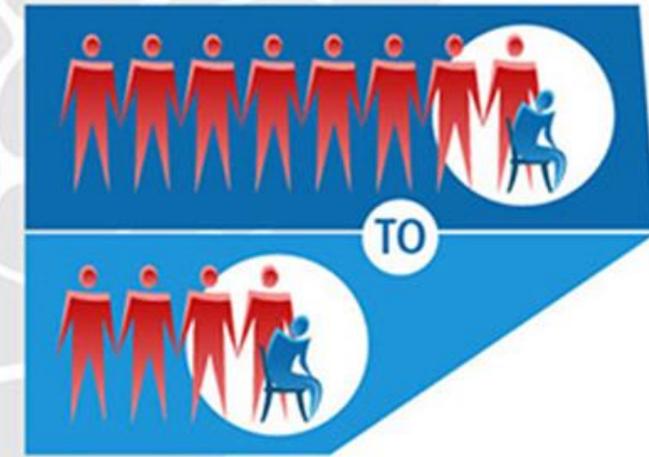
# Caregiver Support Ratio



*AARP Public Policy Institute US Data*

The ratio of potential caregivers for each older adult in the state\* will sharply decline from

**8.0 in 2010**



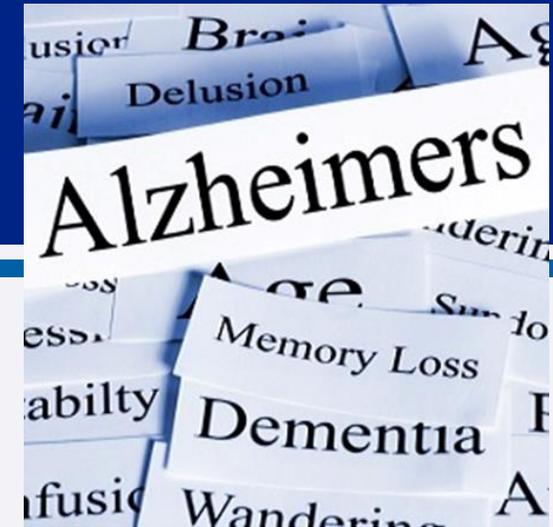
**3.9 in 2030**

As the caregiver ratio declines, there will be a larger financial, emotional, and logistical burden on individuals and families

\*# of potential caregivers age 45-64 for each person 80 or older

# Focus areas required by Senate Bill 744

- 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 those w/ ADRD
- Legal protections for those with ADRD & Caregivers
- State policies to assist those with ADRD & Families



# Dementia Friendly America

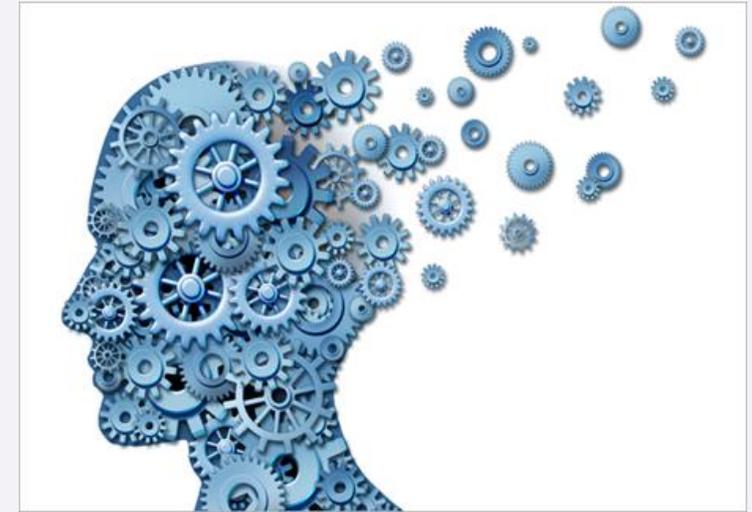
## Framing the Plan

- Raising awareness about dementia and transforming attitudes
  - Education, Awareness, Early Detection and Diagnosis, Brain Health, State Policies
- Having supportive options that foster quality of life
  - Long-Term Care, Access to Treatment, Quality of Care, Care Coordination, Health Care System Capacity, Training for Health Care Professionals
- Supporting caregivers and families touched by the disease
  - Caregiver Assistance, Home and Community Based Services
- 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, Research



# 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.

**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.

**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

- Long-term care is provided in the home, in the community and in long-term care facilities.
- Medicaid costs are 19 times higher for older adults with dementia.
- 75% of people with Alzheimer's are admitted to a nursing home by age 80.
- 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.

**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.



# Having Supportive Options That Foster Quality of Life

- 4.5** Increase access to medical and community services for people with Alzheimer's disease and related dementia by improving transportation services
- 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.
- 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.

AS THE DISEASE PROGRESSES,  
THE EMOTIONAL BURDEN  
INCREASES FOR CAREGIVERS

Caregivers often:

Miss  
Work

Must  
handle logistics  
of finding  
additional  
care

May  
experience  
increased stress,  
anxiety, depression,  
and adverse  
physical effects



# 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.

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



# Supporting Caregivers and Families

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

**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.
- 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.

# Promoting Meaningful Participation in Community Life

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

**6.6** Enhance public safety and law enforcement outreach around Alzheimer's disease and related dementia.

# Reaching Those Who Are Underserved/Data

- 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/Data

- 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.
- 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 and Progress on Recommendations

2016 - Funded \$100k for dementia services coordinator, a dedicated position in Division of Aging

2016 - Funded \$100k for dedicated 2-1-1 coordinator

2016 - Funded \$1.5M for 320 additional CAP-DA slots for HCBS waiver

2016 - Uniform Guardianship enacted

2017 - Legislation on Dementia registry: Provides funding to support the development of an Alzheimer's Registry through the Duke Brain Research Center. \$600,000 in each year

of the biennium. Website and work plan currently under development.

2017 - Legislation on virtual resource center, to be housed at NC A&T

2017 - 3 community events held to launch Dementia-Capable pilot communities, collective impact models

Statewide Alzheimer's Coalition established in March 2017 to oversee implementation. Ongoing work to prioritize recs and identify new partners.



# For More Information

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