

# Dementia-Capable North Carolina

## A Strategic Plan for Addressing Alzheimer's Disease and Related Dementias

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# State Plan on Alzheimer's Disease 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 Alzheimer's Association.

# North Carolina Institute of Medicine

- Quasi-state agency chartered in 1983 by the NC General Assembly to:
  - Be concerned with the health of the people of North Carolina
  - Monitor and study health matters
  - Respond authoritatively when found advisable
  - Respond to requests from outside sources for analysis and advice when this will aid in forming a basis for health policy decisions

*NCGS §90-470*



# Task Force on Alzheimer's Disease and Related Dementias

- 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 Face of Alzheimer's Disease & related Dementias today



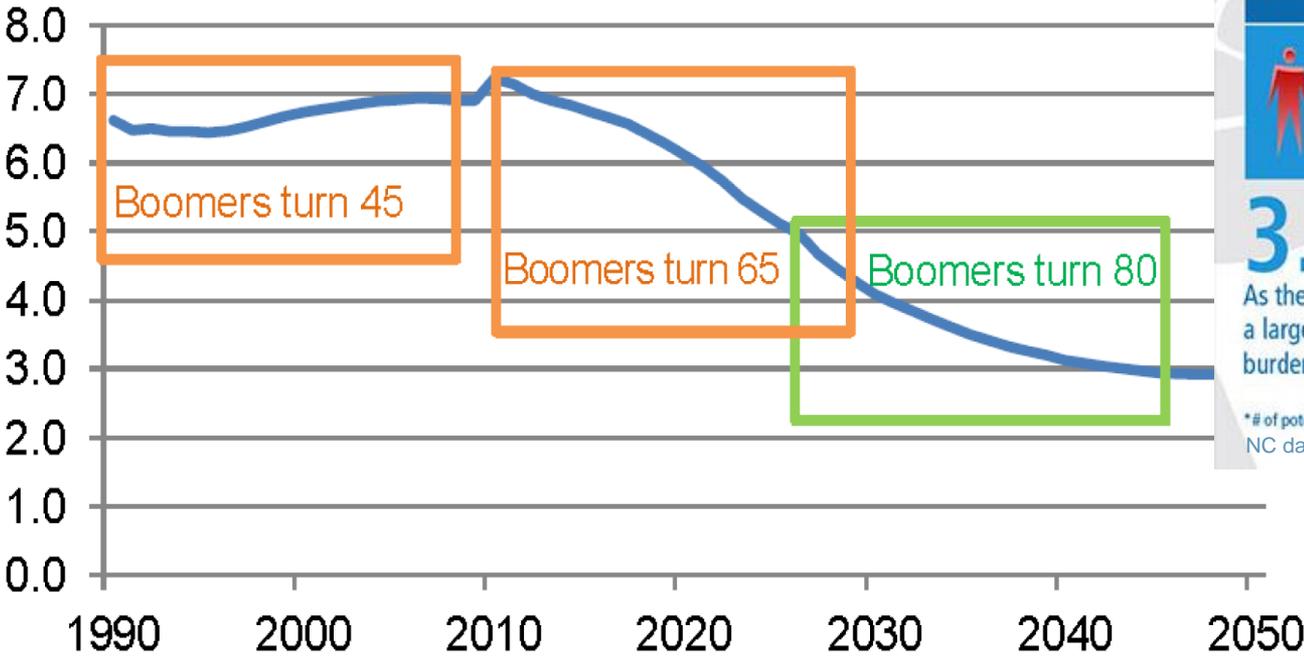
- **Sixth-leading** cause of death, **Fifth-leading** cause of death in NC
- **5.2 million** Americans have Alzheimer's disease
- In the US every **67 seconds** someone develops Alzheimer's
- Currently, NC has over **160,000** older adults with Alzheimer's disease or other types of dementia.
- By **2030**, 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



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

## 8.0 in 2010

TO

## 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  
NC data



# 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. (p...



# 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. (*AHEC*)
- 3.3 Create a collective impact partnership to develop and establish dementia-capable pilot communities. (*DAAS, Philanthropy*)

# Raising awareness about dementia and transforming attitudes

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



# 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. (*providers and payers*)
- 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. (*hospice associations, LTC associations, payers*)

# Having Supportive Options That Foster Quality of Life

- 4.3 Assess health system capacity for people with Alzheimer's disease and related dementias. *(DAAS, LTC Associations)*
- 4.4 Improve telehealth services for people with Alzheimer's disease and related dementias. *(DHHS, LME/MCOs)*
- 4.5 Increase access to medical and community services for people with Alzheimer's disease and related dementia by improving transportation services *(inter-departmental working group-DHHS/DOT)*

# 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. (*LTC associations*)
- 4.7 Improve quality of care and care coordination for people with dementia through improved ratings systems and dementia-specific indicators. (*DAAS*)



# 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. *(Health systems, facilities, payers)*
- 4.9 Expand the Dementia Friendly Hospital initiative. *(Health systems)*
- 4.10 Promote Alzheimer's disease and related dementia-specific training for health professionals and community workforce. *(AHEC, NC CCS)*

# Having Supportive Options That Foster Quality of Life



- 4.11 Incentivize entry into geriatric and gerontology specialization and additional training in dementia care. (*Academic Health Centers*)
- 4.12 Increase compensation based on Alzheimer's disease and related dementia-specific training and certification. (*LTC Associations*)

# 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. *(DAAS)*



# Supporting Caregivers and Families

- 5.2 Ensure adequate funding for family caregiver support services including dementia-specific respite through NC Project C.A.R.E. (*DAAS, NCGA*)
- Reduction in state funds 2011 \$500,000, no longer able to provide respite services.
- Respite services have been shown to delay institutionalization.
- Every \$100 spent on respite care delays nursing home placement by one week. A similar model delayed placement by 329 days and could save Minnesota \$1 billion (over 5 years), resulting in 20% fewer people dying in nursing homes.

# Supporting Caregivers and Families

- 5.3 Continue No Wrong Door Initiative through a collaboration with NC 2-1-1. (*DAAS, NCGA*)
- Virtual front door for health and human services.
- NC system is not yet comprehensive.
- System built by United Way in Partnership with public and private agencies.
- Additional training and promotion of 211 system.
- Recommendation for \$200,000 in appropriations. 2 staff (1 call center, 1 DAAS, responsible for curation).

# Supporting Caregivers and Families

- 5.4 Enhance employer policies to support family caregivers. *(AARP, NCGA, CoC)*
- This recommendation largely a partnership between AARP, Alzheimer's advocacy organizations, and business community.
- Recommendation supports HB 816 to study the needs of working family caregivers. Passed unanimously in the house in 2015. Is now in the Senate Rules Committee.

# Supporting Caregivers and Families

- 5.5 Examine outcomes and impact of home and community-based services programs. *(DHHS)*
- \$61 million total (49% federal, 51% state).
- Funding flat for 3 years
- Services include: nutrition, transportation, respite, home care
- Waitlist 9,700 (would cost \$19.6 million per year to eliminate current waitlist).

# Supporting Caregivers and Families

- 5.6 Expand the Medicaid Home and Community-Based Services Waiver Program.  
(NCGA)
- CAP/DA (adult day care, respite care, personal care). CAP Choice allows more caregiver flexibility. In 2013, NC had 11,214 slots and a waitlist of 8,000. Other waiver programs include PACE, Money Follows the Person, and Structured Family Caregiving (aka SeniorLink).

# Supporting Caregivers and Families

- Expansion of waivers typically increases short term costs and decreases 2 and 5 year costs.
- Several examples in report:
  - Arkansas saved \$2.6 million for 919 people (ROI 3:1).
  - Connecticut estimated saving \$107 million serving 19,932 individuals.
  - West VA projected ~60 million over 10 years serving ~110 people.

# Supporting Caregivers and Families

- 5.7 Implement best practices for the integration and coordination of home and community-based services. *(DAAS)*

# 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. (*Partnership, DAAS, AAA, DOJ, DSS*)
- 6.2 Incorporate legal protection issues specific to people with Alzheimer's and related dementias into health, legal, and financial professional training. (*AHEC and partners*).



# 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. (*DAAS, NCGA*)
- NCGA should consider HB 817 - passed unanimously by House in 2015, now in Senate Rules Committee. Uniform guardianship (UAGPPJA). Currently enacted in 42 states.

# Promoting Meaningful Participation in Community Life

- 6.4 Integrate elder fraud and abuse data to improve services for people with Alzheimer's disease and related dementia. *(DHHS)*



# 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. (*Academic Health Centers*)
- 7.2 Continue periodic inclusion of cognitive impairment and caregiver modules of the Behavioral Risk Factor Surveillance System. (*NCSCHS*)

# Reaching Those Who Are Underserved/Data



- 7.3 Improve prevalence data through accurate death certificate completion. *(NC OCME)*

# Reaching Those Who Are Underserved/Data

- 7.4 Improve data on Alzheimer's disease and related dementia prevalence through implementing a statewide data reporting system.  
(NCGA)

# Next Steps:

- Report release today
- Printing and mailing report and issue brief over next two weeks. Print issue brief in *North Carolina Medical Journal*
- Awareness, Advocacy, and Outreach activities to Communities and Stakeholders
- A Living Document for the Division of Aging and Adult Services.

# For More Information

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