

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 NC 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



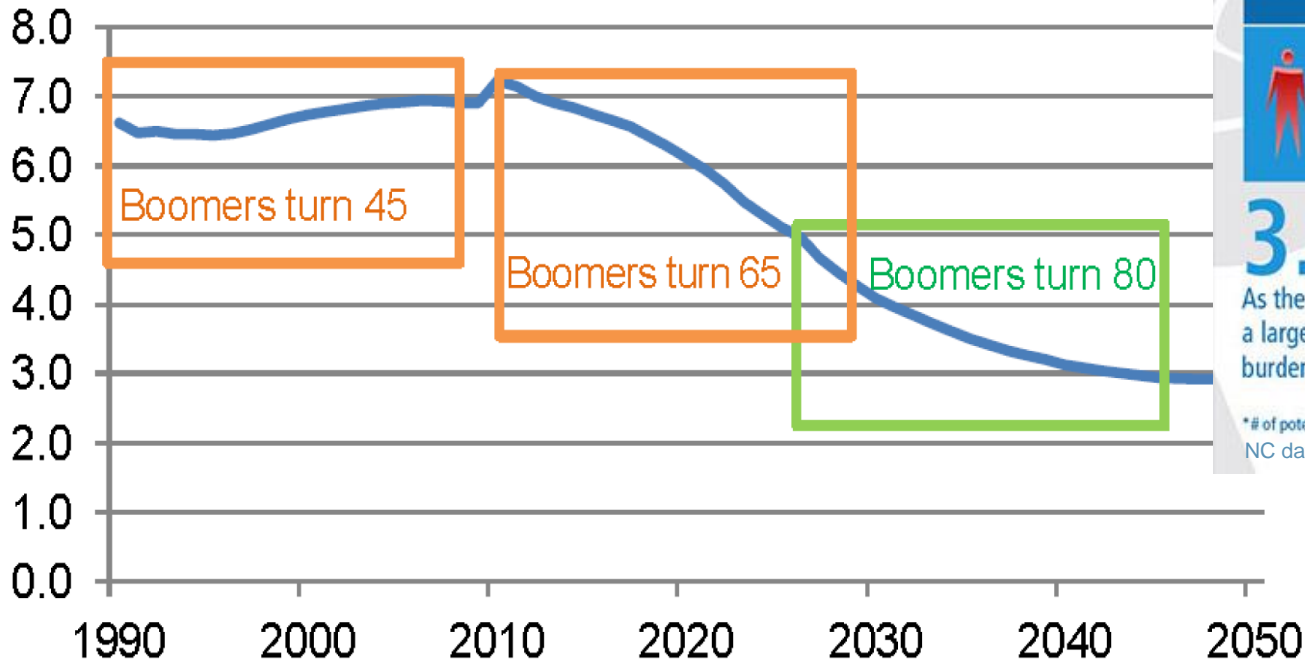
- **Sixth-leading** cause of death, **Fifth-leading** cause of death in NC
- **5.2 million** Americans have Alzheimer's disease
- In the US every **67 seconds** someone develops Alzheimer's
- Currently, NC has over **160,000** older adults with Alzheimer's disease or other types of dementia.
- By **2030**,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

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 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, 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.
(*partnership*)



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)*

Promoting Meaningful Participation in Community Life



- 6.5 Improve home safety resources and workforce capacity. *(DSS, AAA)*
- 6.6 Enhance public safety and law enforcement outreach around Alzheimer's disease and related dementia. *(DPS, DOJ)*

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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