



TASK FORCE ON ALZHEIMER'S DISEASE AND RELATED DEMENTIA

**NORTH CAROLINA INSTITUTE OF MEDICINE
630 DAVIS DRIVE, SUITE 100
MORRISVILLE, NC 27560**

**APRIL 17, 2015
10:00 am - 3:00 pm**

Members in attendance: Renee Batts, Starr Browning, Sen. Chad Barefoot, Alicia Blater, Melanie Bunn, Chip Cromartie, Kelly Crosbie, Linda Darden, Sheila Davies, Pamela Sarsfield Fox, Kalyan Ghosh, Dan Kaufer, Katherine Lambert, Len Lecci, Eleanor McConnell, Sara Jane Melton, Peggy Noel, Lisa Roberts, Ed Shaw, Pat Sprigg, Nancy Washington, Debbie Webster, Polly Welsh, Kathleen Welsh-Bohmer

Co-chairs in attendance: Goldie Byrd, Doug Dickerson

Steering Committee members in attendance: Tom Akins, Mary Bethel, Mark Hensley, Scott Herrick, Alice Watkins

Guests/speakers in attendance: Carol Meyer

NCIOM staff in attendance: Adam Zolotor, Michelle Ries, Berkeley Yorkery, Kay Downer

INTRODUCTION AND WELCOME TO THE TASK FORCE

Doug Dickerson, MBA
State Director
AARP NC

Goldie S. Byrd, PhD
Dean, College of Arts and Sciences
North Carolina A&T State University

Adam Zolotor, MD, DrPH
Interim President
North Carolina Institute of Medicine

Task Force co-chairs Doug Dickerson and Goldie Byrd brought the meeting to order. Mr. Dickerson facilitated member introductions. Each Task Force member introduced him/herself with name, title, and organization, and gave a brief summary of their work/interest in Alzheimer's disease.

EARLY DETECTION AND DIAGNOSIS

Kathleen Welsh-Bohmer, PhD

Director, Joseph & Kathleen Bryan Alzheimer's Disease Research Center (Bryan ADRC)
Professor, Departments of Psychiatry and Neurology
Chief, Medical Psychology
Duke Medical Center

Dr. Welsh-Bohmer discussed current procedures in early screening for Alzheimer's disease and dementia, including barriers to routine screening and what happens once Alzheimer's is detected. Also discussed was the prevalence of Alzheimer's in North Carolina and the relationship between Alzheimer's and obesity and other chronic diseases. Dr. Welsh-Bohmer discussed the importance of early diagnosis, the differences between Alzheimer's and normal cognitive aging, and steps that can be taken to reduce risk of Alzheimer's disease and slow memory decline and dementia progression. Dr. Welsh-Bohmer's presentation can be viewed [here](#).

Discussion points included:

- Need to get beyond being timid about research – get better at including patients in research
- Duke has AD prevention registry
- Strongest prevention signals we've seen are around exercise, brain health, and social engagement
- Recommendation – access to doctors, work with doctors on increasing physical activity, etc.
- Nih.gov/go4life – good resource
- Need to clarify when we use the word “screener” – tool vs. action?
- 2011 – new diagnostic criteria
- What are practical consequences of improved diagnostic accuracy?
- Need to differentiate normal cognitive aging from dementia from AD, including stages

PANEL DISCUSSION: STATEWIDE AWARENESS AND EDUCATION

Melanie Bunn, RN, MS, GNP

Alzheimer's Training Consultant

Sheila F. Davies, PhD

Director, Public Health Division
Dare County Department of Health & Human Services

Edward G. Shaw, MD, MA, NCC, LPCA

Professor
Department of Counseling
Wake Forest University

Ms. Bunn discussed the importance of education about Alzheimer's disease and dementia and the benefits of reaching out to non-traditional partners to engage in conversations

about early detection. These partners may include crisis intervention teams, law enforcement, emergency management, service professionals, and the faith community. Ms. Bunn discussed how we need to teach how to provide knowledge about Alzheimer's disease in a way that changes behavior – around preventive factors, risk factors, and caregiver support.

Dr. Davies spoke about Alzheimer's disease from a public health perspective, focusing on issues around surveillance, prevention, and early detection. Dr. Davies addressed barriers to data collection, including limitations of the BRFSS modules on dementia and caregiving, and emphasized the opportunities in linking public health messaging around obesity, heart disease and other Alzheimer's risk factors. She also discussed the disparities among racial and ethnic groups. Dr. Davies's presentation can be viewed [here](#).

Dr. Shaw spoke about the connection between Alzheimer's disease and mental health, focusing on comorbidities for both individuals with Alzheimer's and their caregivers. Dr. Shaw discussed causative factors for mental health issues in seniors and in individuals with Alzheimer's. He emphasized the importance of screening for depression and other mental illnesses, and of the need for early detection, increased awareness of risk factors and symptoms, and for counselling when a family receives a diagnosis of Alzheimer's. Dr. Shaw's presentation can be viewed [here](#).

Discussion points included:

- Public awareness for what? What are we trying to promote?
- large group of potential caregivers who need to “unlearn” information about Alzheimer's – too many people think that everything is Alzheimer's, there is nothing to be done, etc. This leads to lack of diagnosis, etc. Need to reduce stigma.
- people think everyone has Alzheimer's, don't understand difference between Alzheimer's and dementia
- from a clinical perspective, it's very different, and from perspective of prognosis and treatment. Large movement to do away with term, “dementia,” and use “neurocognitive disorder” instead.
- NAPA, trying to prevent and treat disease by 2025. Increase in prevalence, get plan in place for caregivers, physicians, attempts to escalate treatments and research.
*Awareness of public health crisis.
- silos for public health issues (obesity, diabetes, etc.) – how to break silos with other health issues that are interrelated?
- public health hasn't touched this, aging has focused on supporting caregivers, not seen as mental health issue (dementia is an aging issue). So – is ALZ all 3? Healthy Brain Initiative: national product through CDC, but NC hasn't gotten into it. First responders, public safety, need to be included as potential partners. This is about family and family preparation – be prepared for legal issues, medical decision-making, financial issues. Be proactive rather than reactive.
- workplace issues. Employers not interested in dementia.
- what is driving all of this? Public health, but also cost to state. Project costs to

state, and savings on early detection and diagnosis, prevention.

- caregiver concern is around how to I pay for this? What road am I on? What will this cost me? What resources are available? Lack of awareness particularly for veterans' support
- business community – higher costs due to loss of productivity. Education in workplace, how can we use this to leverage early detection – bank tellers, retail workers, etc.
- economic opportunities, entrepreneurial thinking – what are growth industries around this? Tech solutions, alternate caregiver models, CCRCs, etc.
- what are unintended consequences? Will we have a cure by 2025? What is danger of projecting target of cure and falling short? Overpromising and underdelivering.
- Maybe goal is not cure, but delaying onset – maybe more within our grasp
- not effective to zero in on ALZ or dementia. More to focus on brain health, healthy living, link with obesity, etc.
- remember the part of the population that relies on children for information.
- partnership with Lenoir Community College – psychology as gateway course, students questioned on how many have relative, etc., with Alzheimer's or dementia, and how many of them feel prepared to handle caregiving, etc. – Community college as opportunity area
- what is in our scope, what is not? I.e. healthy brain and lifestyle issues are a whole different issue when it comes to public awareness. Do we want this as part of the TF scope?
- look at Nevada rec on toolkit development
- Getting a handle on cost is going to be a recurring theme. And estimates for 2025, 2050. And who are the costs to? Medicaid, caregiver,
- Where are we going to save money? Who is going to save it?

Potential recommendations to be shaped around:

(keeping in mind scope of problem and potential for savings, awareness of what and who is appropriate partner and audience, opportunity costs)

- Link between body health and brain health
- Difference between ALZ and dementia, differences from normal aging
- Healthy People 2020 goals
- Costs to state
- Workplace issues
- Development of toolkit – for electronic distribution to partners
- Web-based clearinghouse – who to own this, who pays for it, who keeps it up to date?
- Awareness of public health crisis and changing demographics
- Reduce stigma
- Family preparation

PANEL DISCUSSION: EARLY DETECTION AND DIAGNOSIS

Dan Kaufer, MD

Chief, Cognitive & Behavioral Neurology
Director, UNC Memory Disorders Program
Departments of Neurology and Psychiatry
University of North Carolina at Chapel Hill

Len Lecci, PhD

Professor of Psychology
University of North Carolina - Wilmington
Director of Clinical Services
MARS Memory-Health Network

Dr. Kaufer spoke about the different types of dementia and the differentiation from Alzheimer's disease. He discussed the symptoms, definitions of impairment, and the types of screening. Dr. Kaufer also discussed the Carolina Alzheimer's Network, a "train the trainer" model to train physicians in diagnosis and treatment, link providers to community services and resources, and form a statewide network of care providers and researchers. Dr. Kaufer emphasized the lack of evidence to support widespread screening, tiers of care, and the need for integrated models of care to address Alzheimer's and other forms of dementia. Dr. Kaufer's presentation can be viewed [here](#).

Dr. Lecci spoke about age as the primary risk factor for Alzheimer's disease, and emphasized the importance of early detection as a way to delay progression of the disease. Dr. Lecci cited research showing that early intervention can improve quality of life for individuals with Alzheimer's, and failures in early detection, including relying on self-assessments and routine primary care visits. He also recommended guidelines for who should be screened and at what age (anyone over age 60, in order to establish a baseline of cognitive function), with the primary goals of early detection and stopping disease progression. Dr. Lecci's presentation can be viewed [here](#).

Discussion points included:

- deal with neurocognitive issues as routine care – might not stand out, becomes common care for all at a certain age
- what is risk of people being too eager to jump to prescription, treatment, etc., if receiving a positive screen
- evidence base does not support early jump to pharmaceutical treatments with MCI – but there is evidence for delay of AD – so how much is the extra time worth to the individual? Don't want to be presumptuous about what that time is worth.
- what about side effects?
- physician and patient, and caregivers need to have conversation about the cost/benefits tradeoffs, so we need to prepare people to have that conversation.
- Older patients tend to be more readily willing to listen to doctor, etc. Younger people more interested in being more engaged, etc. So there is a demographic shift

in audience, etc.

- many patients don't have Medicare part D for pharmaceutical coverage
- NC removed tax deduction for medical expenses – how is this public policy decision affecting AD?
- significant selection bias in the cited study. Sounds like there is a consistent treatment effect, but we have to look at cohorts.
- issues around doctors not wanting to raise the issue, so how do we start the conversation
- training caregivers to talk to physicians. Training caregivers to write letters to primary care doctors. We can't expect screening tools to work well. How to change culture – speaking to caregivers, issues of privacy. High costs for those with comorbidities – because person with AD can't manage other conditions.
- expertise concentrated for people with resources to access it.
- CCNC model for care management? not medical management, but what are needs for care management – for caregivers also
- care management as cost saving measure
- Maybe we need to look at quality of assessment rather than widespread screening
- PCPs need to be first responders and be able to refer out

Potential recommendations to be shaped around:

- Education of health care providers – including post-graduate. Training in screening and assessment. Who are partners for health care provider training? NC Medical Society, AHEC, etc.
- Public awareness around stigma
- Preparing caregivers to be involved and engaged in assessment, and creating a system where that is welcome. Care management.
- Follow up care – referral assessment centers (regional)
- Screening for all over 60? 65? 75? Annual?
 - baseline during latency period
 - keeping in mind differences between brief assessment and mass screening.
- Quality of assessment, follow up to assessment- focus on quality
 - physicians conducting screen as first responders –
 - PCP toolkit (national)
 - what are waitlists for specialists? What are issues around payment?
 - New models of care
 - Caregivers as most important variable

WRAP UP AND ADJOURN

Dr. Zolotor reminded Task Force members to complete meeting evaluation survey and of upcoming meeting dates, and brought the meeting to a close.