



TASK FORCE ON ALZHEIMER'S DISEASE AND RELATED DEMENTIA

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

**MARCH 27, 2015
10:00 am - 3:00 pm**

Meeting Summary

Members in attendance: Renee Batts, Starr Browning, Rep. Marilyn Avila, Luci Bearon, Sen. Chad Barefoot, Alicia Blater, Chip Cromartie, Kelly Crosbie, Linda Darden, John Eller, Pamela Sarsfield Fox, Steve Freedman, Kalyan Ghosh, Richard Gottlieb, Dan Kaufer, Katherine Lambert, Len Lecci, Michael Lischke, Eleanor McConnell, Sara Jane Melton, Peggy Noel, Lisa Roberts, Sen. Gladys Robinson, Ed Shaw, Pat Sprigg, Cara Townsend, Nancy Washington, Debbie Webster, Kathleen Welsh-Bohmer

Co-chairs in attendance: Goldie Byrd, Doug Dickerson

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

Guests/speakers in attendance: Dan Israel, Judy Israel, Olivia Mastry, Kathie Smith, Bobbie Matchar, Meka Sales, Rose Kerber, Judson Bodnick, Cammel Hurse, Can Dickerson, Phil Freeman, Carol Wise, Janeli Smith

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 and provided a brief introduction to the Task Force, state legislation, and the scope of Alzheimer’s disease and related dementia in North Carolina. 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.

WELCOME FROM THE NORTH CAROLINA DEPARTMENT OF HEALTH AND HUMAN SERVICES

Sherry Bradsher, MPA

Deputy Secretary for Human Services
North Carolina Department of Health and Human Services

Deputy Secretary for Human Services Sherry Bradsher provided an introduction and welcome from the North Carolina Department of Health and Human Services.

OVERVIEW AND CHARGE OF THE TASK FORCE ON ALZHEIMER’S DISEASE AND DEMENTIA

Adam Zolotor, MD, DrPH

President and CEO
North Carolina Institute of Medicine

Dr. Zolotor outlined the NCIOM Task Force process and lay out the focus and expected product of the Task Force. Dr. Zolotor gave an overview of the work of the NCIOM, recent Task Force work and publications, and the intended trajectory of the work of the Task Force on Alzheimer’s Disease and Related Dementia. Dr. Zolotor also presented statistics and demographics about Alzheimer’s prevalence in North Carolina and nationally, as well as an overview of additional issues/topics on which the Task Force work will focus. Dr. Zolotor’s presentation can be viewed [here](#).

EXPERIENCES WITH ALZHEIMER’S DISEASE

Dan Israel

Caregiver

Judy Israel

Person Living with Alzheimer’s Disease

The Israels are a married couple, and Ms. Israel is a person living with Alzheimer’s Disease. Mr. Israel is her primary caregiver. Mr. and Ms. Israel spoke about their experiences living with Alzheimer’s Disease, including their experience with early

symptoms, the process of testing and diagnosis, and the challenges they are facing in living with Alzheimer's. Mr. Israel spoke about what he is learning to do as Ms. Israel's caregiver, including household chores and driving, following Ms. Israel's changing capabilities, involving adult children in care decisions, and financial concerns around paying for treatment and care.

Discussion questions from the Task Force members included: how/when did you know that the symptoms were something to be concerned about? The Task Force members were very appreciative of the Israels' willingness to share their experiences.

DEVELOPING AND IMPLEMENTING A STATE PLAN FOR ALZHEIMER'S: PERSPECTIVES FROM MINNESOTA

Olivia Mastry
Executive Lead
ACT on Alzheimer's

Ms. Mastry discussed the development process of Minnesota's state plan for Alzheimer's, focusing on clinical and community aspects most applicable to North Carolina. She highlighted successes and challenges in implementing the plan and discussed the collective impact work currently in process. Ms. Mastry gave an overview of ACT on Alzheimer's, including its genesis as the implementation body following the development of Minnesota's state plan on Alzheimer's in 2011, and the collective focus and health equity perspective of the state's work. She discussed the primary topics, curricula, resources, and toolkits available to the organizations participating in the collective impact work, and the convene/assess/analyze/act phases of the work. Ms. Mastry provided specifics on the development and implementation timelines. Ms. Mastry's presentation can be viewed [here](#).

Discussion questions from the Task Force included:

Were there randomized controlled trials on the results from the participating organizations? ACT looked at packaged EBPs for results.

What is the generalizability/applicability of the program for rural areas vs. urban? The tool is applicable to all areas, but implementation is different. Organizations are more effective/faster at convening in rural areas, but there are also more limitations, so the goal is to do more with existing resources.

What is the target of the dementia curriculum? Medical and nursing students, additional medical workforce.

OVERVIEW OF ALZHEIMER'S STATE PLANS IN OTHER STATES

Michelle G. Ries, MPH
Project Director
North Carolina Institute of Medicine

Ms. Ries discussed the origination and features of the National Action Plan on Alzheimer's, and the reasons for states to develop their own plans. Ries discussed several features of Alzheimer's state plans in other states, highlighting common themes and recommendations. Ries identified features of state plans in Indiana and Rhode Island as areas for additional learning for North Carolina stakeholders. Ries' presentation can be viewed [here](#).

During discussion, Task Force members asked about federal funding and identified Wisconsin and Texas as additional states to study.

OVERVIEW OF ALZHEIMER'S SERVICES IN NORTH CAROLINA

Mark Hensley, MA

Project C.A.R.E. Director and Alzheimer's Support Specialist
Division of Aging and Adult Services
North Carolina Department of Health and Human Services

Mr. Hensley provided an overview of the services currently available in North Carolina for persons living with Alzheimer's, their families, and caregivers. Hensley identified the Duke Family Support Program, Project C.A.R.E., Just One Call, Alzheimer's Association, Alzheimer's NC, and the NC Area Agencies on Aging as primary resources for services. Hensley's presentation can be viewed [here](#).

Task Force members discussed how the Alzheimer's care system is frequently playing catch-up, and needs to increasingly engage private partners and county commissioners, and identify additional funding sources, with an end game of serving more people. There was discussion of the business model for service providers, and it was asked how services can be sold to hospitals and employers. Task Force members discussed the need for an improved system for documenting and managing waitlists for services, and the problem of how people on the waitlists are those who are aware of available services, but there are still many people not aware of them.

SMALL GROUP DISCUSSION AND REPORT-BACK

Task force members broke into 4 groups, each led by a member of the Steering Committee. Each group was given 3-4 topic areas (from those identified in the state legislation mandating the Task Force process) and asked to discuss strengths and weaknesses in North Carolina's services/infrastructure in each area, and also to identify priorities, necessary resources, and relevant organizations to address each topic area.

Topics:

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 individuals with Alzheimer's disease and their caregivers
State policies to assist individuals with Alzheimer's disease and their families

Discussion notes:

Group 1

Statewide awareness and education:

Strengths: Area Agencies on Aging has infrastructure to reach all counties. Programs such as Just One Call, Community Resource Connection. Strong collaboration between programs.

Weaknesses: lack of awareness of services, no single point of access (people don't know what they don't know), lack of coordination. Not enough funding, no widespread funding. Lack of sustainability. State cuts in funding – worst fiscal year last year. Who is not here at our TF? – technology sector employers (SAS, Quintiles) – we need information management and to look at how to make money on this to get them on board. Remaining stigma, lack of understanding of disease and symptoms

Priorities: optimizing infrastructure; increasing funding opportunities; creating central point of access, then put infrastructure in place; reimbursement. To the extent you increase awareness, this will also impact care coordination and early detection.

Early detection and diagnosis:

Strengths: increased screening and early, reliable diagnosis – but are these tests being applied wisely? What happens if people receive a diagnosis but don't ever experience symptoms?
Telemedicine innovations

Weaknesses: lack of treatment options; lack of specialists

Priorities: training for PCPs to work with patients beyond initial diagnosis

Group 2

Health system capacity and access:

Strengths: collaboration, engaged stakeholders, increased coordination; community services

Weaknesses: access, ability to get there. 10% of Alzheimer's families access services. People falling in donut hole. Ageism, stigma, belief that this is "lot in life."

Priorities: increase rural outreach, minority outreach. Telemedicine access (but what is cost to provider?). Shift focus to early diagnosis, stop progression, accurate diagnosis, allay costs, keep out of ERs. Funding map. Increasing geriatric training (NPs, PAs, CNAs)

Resources: technology to keep people at home; future tech diagnosis; streamlined, cost-effective diagnosis. Coordination of faith-based resources and community care.

Orgs: TF members in this room, major university systems

Group 3:

Long term care:

Strengths: urban areas have more options than rural areas. Private pay only. Paying with Medicaid dollars creates obstacles.

Weaknesses: limited number of beds. LTC is not evidence-based.

Priorities: alternatives to bricks and mortar facilities. Increasing Pace program – relieving caregivers, allowing them to work. Community Alternative Program (CAP) – address waitlist (currently at 18 mos.). Think outside the box – pilots of different treatment options in long term care. Look at Medicaid payment structure – what is impact on Medicaid reform?

Caregiver assistance:

Strengths: Good models (ie. Project CARE),

Weaknesses: Project CARE is underfunded. Moratorium on home care agencies – no expansion, no new licensing. Lack of awareness of available services and payment options.

Priorities: More money. Alternate models – workforce training, flex account funding for paying for respite care, think more broadly about how to address this need. Faith based community training to provide respite care.

Research and brain health:

Is there a research clearinghouse? Support all efforts, channeling money from federal streams.

Evidence based wellness programs - expanding mission to brain health.

Group 4:

Data collection:

Strengths: What is role of public policy? A lot of data elements out there.

Weaknesses: lack of connection/integration – data is in pockets

Priorities: registry, improved integration and collection

Resources: depth of knowledge (SAS, IBM, universities) – collaboration. Then – what is necessary funding? Awareness of what different systems are doing, and where are the pockets of money?

Collective impact – backbone organization.

Public safety

Hard to focus on these issues without better data – do we know how big these issues are?