

TASK FORCE ON ALZHEIMER'S DISEASE AND RELATED DEMENTIA

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

**MAY 15, 2015
10:00 am - 3:00 pm**

Meeting Summary

INTRODUCTION AND WELCOME TO THE TASK FORCE

Co-chair Lisa Gwyther called the meeting to order and welcomed everyone

Task Force members in attendance: Kathy Long, Marilyn Avila, Brian Spillman, Nancy Washington, Polly Welsh, Danny Crawford, Luci Bearon, Michael Lishke, Renee Batts, Pat Sprigg, Alicia Blater, Pamela Sarsfield Fox, , Kathleen Welsh-Bohmer, Lisa Roberts, Debbie Webster, Linda Darden, Sheila Davies, John Eller, Chip Cromartie, Kelly Crosbie, Ginna Templeton, Starr Browning, Ed Shaw, Connie Bishop, Chris Egan, Steve Freedman, Len Lecci, Sara Jane Melton,

Steering Committee members and co-chairs in attendance: Mary Bethel, Lisa Gwyther, Mark Hensley, Scott Herrick, Peggy Terhune, Alice Watkins

Speakers/guests in attendance: Cyndee Crompton, Rosalind Pugh

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

Meeting agenda and background materials can be found [here](#).

SAFETY ISSUES/CAREGIVER ASSISTANCE/HOME AND COMMUNITY-BASED SERVICES

The goal of the panel will be to inform our recommendations on these topic areas. The panel will be followed by open group discussion.

Facilitator:

Lisa Gwyther

Alicia Blater, MS, APR

Family Caregiver Program Consultant

Division of Aging and Adult Services

North Carolina Department of Health and Human Services

Ms. Blater gave remarks about existing caregiver support services, needs of caregivers, and gaps in state services. Discussion points included gaps in awareness (about existing services, about Alzheimer's as a terminal illness, Medicaid qualification criteria); support groups for caregivers;

need for respite and challenges of receiving sufficient respite; and employer/employee issues around caregiver needs.

Rosalind Pugh, MS

Project Care Coordinator
Alzheimers NC

Ms. Pugh discussed public safety issues and home safety issues for individuals with Alzheimer's and their caregivers. Discussion points included assistive technology for use in the home; driving cessation policies and techniques; falls prevention; and community safety issues included wandering and first responder training.

John K. Eller

Director
Catawba County Social Services

Mr. Eller discussed home and community-based services currently available to individuals with Alzheimer's and their family/caregivers. Discussion points included the importance of awareness of available services; range in amount and quality of services by region and county; importance of community flexibility in providing services; dementia-capable training for service providers; need for greater coordination and integration of services.

The presentations were followed by a large group discussion.
Discussion points and questions included:

Discussion and Questions (selected):

- Rep Avila: DHHS is focusing strongly on 0-5 this year. Basically what we have done is take programs that focus on child and maternal health and give them one year of non-recurring funding. They have one year of funding and review to show that they provide a positive return on investment; give us programs that you would like to have reviewed and we can do a similar review—looking for the greatest benefit. Objective- give the right program in the right dose to get a result
- Not about more money; how do we appropriately encourage community-based facilitation of local issues; how do we work better together to deliver services
- North Carolina communities are very faith based : utilize the NC Health Faith Link (right door, right time, ready to be helped, not alone)
- In a case-mix state (like NC) a person that is heavy on ADL support needs (rather than medical) there is a wide-range; nursing homes make money offering acute care, not long-term custodial care as needed by Alzheimer's patients
- In NC, there is no way to get a real respite from care for families. Not just a few hours, but a few days to a week so that the family can get a real break—unless the family can afford to pay privately.
 - Nursing home placement takes time and planning which often families do not have when they hit breaking point
- Might not be more money, but a shift in money. There are HCBS that offer ROI
 - PACE, adult day centers, and others
- Adult day care centers are a great support for individuals and families; there are very few places that are affordable respite
- How can we keep families and caregivers nourished so that the circle of care does not

break

- Families need to have strategic plans. This is a terminal disease. We need everyone involved to do education around end of life planning. Need dementia specialists who can navigate the road ahead with families and explain the system. Educational packet to give families with a newly diagnosed family member.
 - Recent photos of family member
 - ID bracelets
 - Caregiver education is the current big thing out of the federal government
 - NC DAAS did a federal demonstration pilot of a 16-week caregiver education program; we have this program (see DAAS handout)
- Employed caregiver: 60% of caregivers are working; caregiver study from AARP in NC in November; 15% of caregivers give up employment; we need to work more with employers in the state on how we support and accommodate caregivers
- Our rural areas have much more limited resources and getting any of these services is much more difficult
- We need training for family members- assisting with wound care, combativeness; feeding, etc.
 - Need well-trained staff: need to teach caregivers how to occupy individuals with dementia; caregiving without combativeness
- Development of a toolkit for families
- Community process- how do we get counties working together to develop Alzheimer's plans?
- In Orange and Chatham they developed a master aging plan for the the two counties together, including looking at overlapping resources, who could best provide services, etc.

DISCUSSION: PUBLIC SAFETY: DRIVING AND TRANSPORTATION ISSUES FOR PEOPLE LIVING WITH ALZHEIMER'S

Cyndee Crompton, MS, OTR/L, SCDCM CDRS

Occupational Therapist

Driver Rehabilitation Services, PA

Ms. Crompton discussed specific issues on driving and transportation as they relate to people with Alzheimer's Disease and their caregivers. She discussed driver assessment, which includes both clinical and behind-the-wheel assessment. In addition, DMV has a medical review branch – a physician can send a person's name to DMV for medical review in order to get a driver assessment. Families and others can also recommend someone for review (individual can learn who referred them). Ms. Crompton also discussed methods of approaching the topic of driving and stopping driving with caregivers and individuals with Alzheimer's, and the challenges of this conversation.

Discussion and questions (selected):

- Depression often accompanies the loss of a driver's license
- There's anger and often it is directed at the caregiver
 - Maryland study of additional cognitive requirements
 - Need more training for physicians around what is dementia
 - Is there a duty to report at some point?
 - There are some innovative transportation options that we do not have at the table

DISCUSSION OF POTENTIAL RECOMMENDATIONS: STATEWIDE AWARENESS/EDUCATION AND EARLY DETECTION AND DIAGNOSIS

Facilitator:

Michelle Ries, MPH

Ms. Ries facilitated large group discussion about draft recommendations on statewide awareness and education about Alzheimer's and early detection and diagnosis. NCIOM staff and the Steering Committee will revise the draft recommendations following the meeting and present revisions to the Task Force at the next meeting.

Dr. Zolotor and Dr. Gwyther reminded the Task Force members of upcoming meeting dates and brought the meeting to a close.