

**TASK FORCE ON ALZHEIMER'S DISEASE AND RELATED DEMENTIA**

**NORTH CAROLINA INSTITUTE OF MEDICINE**

**JULY 24, 2015**

**10:00 am - 3:00 pm**

**Meeting Summary**

**INTRODUCTION AND WELCOME TO THE TASK FORCE**

Co-chair Doug Dickerson called the meeting to order and welcomed everyone to the Task Force meeting.

**Task Force members in attendance:** Rep. Marilyn Avila, Sen. Chad Barefoot, Luci Bearon, Alicia Blater, Starr Browning, Melanie Bunn, Chip Cromartie, Linda Darden, Sheila Davies, John Eller, Pam Fox, Steve Freedman, Kalyan Ghosh, Richard Gottlieb, Dan Kaufer, Katherine Lambert, Len Lecci, Eleanor McConnell, Sara Jane Melton, Peggy Noel, Lisa Roberts, Pat Sprigg, Nancy Washington, Debbie Webster, Kathleen Welsh-Bohmer

**Steering Committee members and co-chairs in attendance:** Tom Akins, Mary Bethel, Goldie Byrd, Doug Dickerson, Lisa Gwyther, Mark Hensley, Scott Herrick, Gary Nelson, Peggy Terhune, Alice Watkins

**Speakers/guests in attendance:** Charlotte Yeh, Sharon Wilder, Shannon Kelly, Janine Cacciatore, Matthew Janicki, Genie Komives, Mitchell Heflin, Rose Hoban, Linda Shaw, Meka Sales, Pamela Dillingham, Erin Greene, Jay Worthington, Brian Spillman, Deb Burcombe, Lisa Nguyen, Megan Lamphere

**NCIOM Staff in attendance:** Adam Zolotor, Michelle Ries, Rose Kerber, Diana Dayal, Berkeley Yorkery

**CARE COORDINATION: PERSPECTIVES FROM UNITEDHEALTHCARE**

*The desired outcome of this panel and discussion is a shared understanding of the successes and challenges in care coordination, so that we can develop actionable and feasible recommendations for improvement.*

**Charlotte Yeh, MD**  
Chief Medical Officer  
AARP Services, Inc.

Dr. Yeh talked about AARP's Medicare Pilot Program through United Healthcare which operates in 5 locations, including central North Carolina. High risk case management approaches that involve interdisciplinary in-home care teams have demonstrated substantial cost savings and high patient satisfaction. To transition from a medical to a whole-person model of care, Dr. Yeh recommended care coordination, bundling social and medical supports, and focusing on consumer engagement. Discussion points included: whole person and patient-centered care, patient engagement (found that patients with less at-home support were more engaged in the program), understanding emotional needs and loneliness, and care worker compensation.

## **DEMENTIA-FRIENDLY AMERICA INITIATIVE**

*The desired outcome of this discussion is to identify the ways in which this initiative relates to our Task Force work and recommendations so that we can keep these elements in mind as we move forward.*

Video Presentations:

White House Conference on Aging - July 13, 2015

Dementia-Friendly America – July 2015

### **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 introduced the federal Dementia-Friendly America framework as a potential model to guide future Task Force recommendations. The Dementia-Friendly America Initiative includes 5 thematic areas: Raising awareness, Quality of life, Caregiver support, Community participation, and Reaching underserved populations. The Task Force discussed whether it would be beneficial to adopt this framework as they craft recommendations for the report. There was discussion of the merits of using the phrase “dementia-friendly”. Because this term is established as part of a federal initiative, it may be beneficial to adopt it. Many task force members felt that “dementia-capable” was more appropriate.

## **QUALITY OF CARE**

*The desired outcome of this panel and discussion is a shared understanding of the successes and challenges in quality of care, so that we can develop actionable and feasible recommendations for improvement.*

### **Sharon Wilder**

State Long Term Care Ombudsman

Ms. Wilder emphasized the importance of whole person, patient-centered care in long term care settings. She recommended creating safe homelike environments by using music therapy, improving and increasing staff training requirements, coordinating care with families, consistent staffing, and creating incentives for care workers.

### **Shannon Kelly**

Division of Health Service Regulation

NC Department of Health and Human Services

Ms. Kelly discussed improvements in long term care, including reductions in the use of anti-psychotics and restraints. She drew attention to the need for better patient assessment tools, especially for pain assessment.

### **Janine Cacciatore**

Director of Hospice

Duke Home Care and Hospice

Ms. Cacciatore elaborated on the importance of whole-person care in the home care and hospice

setting. She highlighted the need for caregiver support and called for more information to be available to caregivers and home care providers including falls monitoring, medication management, and other quality indicators.

The quality of care panel was followed by general discussion. Topics included: federal regulations for long term care, standards for whole person care, whether state regulations can add to federal standards, regulations for Assisted Living, and North Carolina's moratorium on new special care units and home care agencies.

## **MENTAL HEALTH AND INTELLECTUAL/DEVELOPMENTAL DISABILITIES**

*The desired outcome of this session is an improved awareness of the lessons to be learned from the mental health and IDD fields regarding care coordination, caregiver support, awareness-raising, and other aspects of care so that we can develop actionable and feasible recommendations for improvement.*

### **Peggy S. Terhune, PhD**

Chief Executive Officer  
Monarch

Dr. Terhune discussed the mental health/ IDD system and possible ways that Alzheimer's care could benefit from the MH/IDD model. North Carolina's mental health system operates as a large managed care system and has a "no wrong door" policy, meaning that individuals are referred to the services they need regardless of where they encounter health services. Discussion points included: different types of services, adults with dementia and mental health problems, suicide and depression, and aging in place.

### **Matthew Janicki, PhD**

Research Associate Professor of Human Development  
Director for Technical Assistance  
Department of Disability and Human Development University of Illinois at Chicago

Dr. Janicki discussed similarities and differences between Alzheimer's patients with and without a developmental or cognitive disability. He stressed the difficulty of properly diagnosing dementia in IDD patients whose baseline is unknown. To accommodate the IDD population, Dr. Janicki suggested that an Alzheimer's plan should emphasize workforce development, caregiver support mechanisms, early diagnosis, long-range planning, and dementia-capable community housing.

Discussion following the MH/IDD panel focused on supports available in MH/IDD system that are not available to dementia patients, as well as problems with MH/IDD system. One problem is regulatory burden, which affects facilities that serve both dementia and IDD populations. MH/IDD population has a different regulatory system and different reimbursement. At the administrative level, there is excess paperwork in MH/IDD system that is required by the state but is never read.

## CARE COORDINATION

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### **Sara Jane Melton**

Administrator  
Southwestern Commission Area Agency  
on Aging

Ms. Melton gave an overview of the Money Follows the Person (MFP) pilot program and process. MFP is available to nursing home residents who wish to live in a community setting and are eligible for the CAP/DA Medicaid waiver. The MFP process can take weeks to over a year and is guided by the recipient with the assistance of the local Area Agency on Aging (AAA). There are currently only two participating AAAs in North Carolina.

### **Genie Komives, MD**

Senior Medical Director  
Duke Connected Care

### **Mitchell Heflin, MD**

Senior Fellow  
Center for the Study of Aging and Human Development  
Duke University

Dr. Komives and Dr. Heflin talked about Duke Connected Care (DCC), an ACO that participates in the Medicare Shared Savings Program. DCC monitors patient data and assigns elderly beneficiaries to different arrays of services depending on their level of independence, amount of caregiver support and their degree of functional impairment. DCC provides interdisciplinary services to patients with the help of integrated care teams. They also have a hospice service. DCC is testing innovative approaches to perioperative care and rehabilitation and has received federal funding for a geriatric workforce enhancement program (GWEP).

Discussion following the Care Coordination panel focused on eligibility for care management, quality reporting, accountability, wait lists and the PACE program. Shared savings programs do not benefit from having wait lists for patient services because that prevents them from realizing cost savings. Quality metrics are limited so far and are mostly based on patient satisfaction. DCC has occasionally had difficulty scheduling time with specialists, but otherwise capacity has not been a problem.

The PACE program is not an ACO, it is an MCO that works on a capitated Medicaid-Medicare plan. 1400 North Carolinians are enrolled in PACE, which operates in 12 locations throughout the state.