TASK FORCE ON ALZHEIMER'S DISEASE AND RELATED DEMENTIA

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

OCTOBER 30, 2015
10:00 am - 3:00 pm

Task Force Members in Attendance: Lisa Gwyther, Meka Sales, Kathleen Welsh-Bohmer, Alicia Blater, Lisa Roberts, Steve Freedman, Mark Hensley, Kaylan Ghosh, Kari Barsness, Chip Cromartie, Ellie McConnell, Lucille Bearon, Nacy Washington, Scott Herrick, Ellen Schneider, Laura Marx, Heather Black, Terry Solovioff, Tara Hartman Thorn, Mary Bethel, Peggy Terhune, Doug Dickerson, Goldie Byrd

Phone: John Eller, Peggy Noel, Sheila Davies, Len Lecci, Pam Fox, Renee Batts (Community College System), PJ Dillingham

NCIOM Staff: Michelle Ries, Adam Zolotor, Diana Dayal

INTRODUCTION AND WELCOME TO THE TASK FORCE

Our Task Force co-chairs will bring the meeting to order and facilitate member introductions. Task Force members, speakers, and guests introduced themselves with name, title, and organization.

OPPORTUNITIES FOR IMPROVING CAREGIVER ASSISTANCE AND STATEWIDE AWARENESS WITH AN ENHANCED 211 SYSTEM

Laura Marx
President and CEO
United Way North Carolina

Heather Black
Statewide Strategy Director
United Way North Carolina

Ms. Marx presented an overview of the 2-1-1 call system in North Carolina, and examples of the system in other states. Presentation highlights included information on current call volume and capacity in North Carolina, capacity for data management and evaluation, and a ranking of most common reason for calls to 2-1-1. The Task Force group discussion focused on opportunities to engage state and local stakeholders as partners in developing 2-1-1 as a primary resource for older adults and individuals with dementia and their families. Click here for presentation.

Discussion topics included:

History of 2-1-1 system; it became national movement after terrorist attacks of 9/11/01, as a way to help people find an easy way to connect to services without having many mis-starts -

National call model – evaluated point by point to ensure providing adherence to service to callers, 89% adherence compared to 70% national benchmark

Quality of call is only as good as the data. United Way has made a recent commitment to improving data sets, data blitz next week – updating 20% of resources used the majority 80% of the time

Financial assistance is number one reason for calls – 8000 calls for mental health services

Can provide information to utility companies, food banks, government agencies during time of crisis (Hurricane Sandy example) – potential use of 2-1-1 for driving state action

Washington University in St. Louis – first used it in cancer research project – because of access to vulnerable populations in uniquely high numbers compared to other resources. How else can 2-1-1 be used for population health?

United Way is currently seeking out data partnerships – for example working with North Carolina Coalition to End Homelessness to develop a resource guide for homeless population and working with IBM Watson to combine census and resource information and updates

Potential opportunity to ask about elderly patients or family members in home to drive folks to available resources; could be used for targeting by zipcode

No cost to add messaging for certain resources (for example, adding information on Voter Id Change 2016)

Opportunity for intervention, screening, and prevention through calling mechanism

Little investment in marketing because state has not taken on committed to promoting it – few opportunities besides disaster for governor to remind population. TF feels that marketing is a key component in partnering with 2-1-1 – users need to know it exists and what resources are available.

NC Careline and 2-1-1 have not connected – what is potential here? What are existing resources?

Responders experience 40-hour training and quality assurance process. Task Force feels that dementia-specific training and training in specific resources for people with dementia must be a large part of call center training.

Important to maintain quality and information while respecting existing other call center services by other agencies. How best to connect with existing resources?

RESEARCH AND DATA WORKING GROUP: DISCUSSION OF RECOMMENDATIONS

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

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

Dr. Welsh-Bohmer presented a summary of the Research and Data Working Group meetings and draft recommendations resulting from this group. Click here for draft recommendations and here for presentation.

The presentation was followed by Task Force discussion. There was Task Force consensus around developing a recommendation to improve reporting systems, primarily through the creation of a state all payers claims database. It was also suggested that the recommendation on educating public/families about dementia symptoms, etc., be revised to include the Alzheimer's advocacy community as the primary driver of family engagement, and that this type of targeted education also include information on the connection between improved prevalence data and end of life care and advanced planning – i.e. families should know about death certificate designations, etc., prior to their family members' death.

DISCUSSION OF REVISED RECOMMENDATIONS AND DRAFT CHAPTERS 1-3

Michelle Ries, NCIOM project director, led a large group discussion on the current draft recommendations (revised since September's meeting, based on comments and discussions with Task Force and Steering Committee members). Click here and here for revised recommendations. We will review all revised recommendations (revisions resulting from last month's small group discussion and additional Task Force comments). The desired outcome of this session is to finalize our recommendations, clarifying the "who, what, needed resources" for the recommendations and determine priorities. The Task Force began a discussion of chapters 1-3 of the final Task Force report. The desired outcome of this session is to reach clarity/consensus on appropriate tone, framework, and included data for these chapters. Due to time constraints, Ms. Ries and Dr. Zolotor asked the Task Force to continue the discussion and submit comments and suggested revisions via email.