

TASK FORCE ON ALZHEIMER'S DISEASE AND RELATED DEMENTIA

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

**AUGUST 21, 2015
10:00 am - 3:00 pm**

Meeting Summary

In Attendance:

Task Force Members: Renee Batts, Linda Darden, Sheila Davies, Steve Freedman, Michael Lischke, John Eller, Eleanor McConnell, Brian Spillman, Nancy Washington, Kathleen Welsh Boemer, Luci Bearon, Starr Browning, Melanie Bunn, Katherine Lambert, Pat Sprigg
Steering committee and co-chairs: Mary Bethel, Lisa Gwyther, Doug Dickerson, Gary Nelson, Alice Watkins, Mark Hensley
NCIOM staff: Berkeley Yorkery, Adam Zolotor, Michelle Ries
Speakers and guests: Lauren Benbow, David Kirkman, Megan Lamphere, Laura Clark, Julie Tooker, Judson Bodnick, Jay Worthington, Carol Wise, Joyce Massey-Smith

INTRODUCTION AND WELCOME TO THE TASK FORCE

Our Task Force co-chairs brought the meeting to order and facilitated member introductions. Each Task Force member introduced him/herself with name, title, and organization.

LEGAL PROTECTIONS

Panelists discussed various aspects of legal protections related to the needs and vulnerabilities of individuals with Alzheimer's and their caregivers. The desired outcome of this panel and discussion is a shared understanding of legal issues, so that we can develop actionable and feasible recommendations for improvement. The panel was followed by open group discussion and identification of themes around which we can craft recommendations.

John K. Eller

Director
Catawba County Social Services

Mr. Eller provided an overview of the process of determining guardianship for older adults and individuals with dementia, and the role of Adult Protective Services in providing services and care.

Key points included:

- There is no process for providing guardianship guidance to families facing this issue. Guardianship determination can only be made by the courts, under NC GS 35A. Guardianship is not an attempt to control someone's behavior. The purpose of guardianship is to make decisions in the best interest of that individual. It is a last step. They lose some rights.
- Guardian of the Person: health and housing. Guardian of the Estate: financial affairs
- General Guardian: health, housing, and financial affairs
- DSS cannot be a guardian of someone's estate. Usually try to appoint an attorney if no one else is

available.

- Courts have discretion as to what they ask for to determine if someone is competent. This process varies by district. *Room for improvement*
- Question: If a court asks for an evaluation, who pays for it? That is a concern. In theory there is some money at the county level, but it is unclear.
- The number of public guardianship wards has been steadily increasing (3000 in 2007 to 4707 in 2013 and expected to increase)
- DSS has absorbed wardship of individuals coming out of state psychiatric hospitals; this population was not originally part of DSS's caseload.
- Key issues with guardianship in NC: appointment issues, limited family involvement, geography/distance, indigent issues, funding and numbers served
- Key issues with Adult Protective Services: strengthen the statutes in NC, financial exploitation and prosecution, geography, limited family involvement, funding

Lauren Benbow, JD

Investor Education Program

Securities Division

Department of the Secretary of State

Ms. Benbow presented information about legal protections including power of attorney and advanced health directives.

Key points included:

- Legal protection documents include advanced health care directives: health care PoA, Advance directive for a natural death (living will), advance instruction for mental health treatment, organ/tissue donor card
- HC Power of Attorney requires two qualified witnesses and a notary
- Can put in NC Registry; should be easily accessible in the event they are needed.
- Living Will (advance directive for a natural death)
- Advance instruction for mental health treatment: good tool if someone is going through episodic or cyclical mental health problems. CANNOT revoke these forms if you are declared incapable. Recommendation is to do this upon diagnosis.
- Not binding on doctor under certain circumstances

David N. Kirkman, JD

Special Deputy Attorney General

Consumer Protection Division

North Carolina Department of Justice

Mr. Kirkman discussed various types of elder abuse and fraud, focusing on the types of scams to which individuals with dementia are particularly vulnerable.

Key points included:

- Attributes of elder fraud: involves the exploitation of age-related vulnerabilities
- Exploit vulnerabilities of older adults: financial, loneliness/isolation, depression, med cycles, chronic illness, physical impairments, mild cognitive impairment, want to be a "decision maker" again, obsessions
- "Super Victims" those who have lost \$10,000+, often through repeat victimization

- Sharp increases in the \$ amount of losses reported (and losses are estimated to represent only 5% of the problem)
- In 2014 have seen a decrease that we attribute to changes in SB 140 law
- Financial capacity is the ability to independently manage one's financial affairs consistent with personal self-interest.
 - Need to weigh financial capability more in determining guardianship of estate
 - In the early stages of Alzheimer's (pre-diagnosis) financial capacity is often impaired
- Requires a more holistic approach to prevent; trusted professionals in their lives can help prevent or stop individuals from engaging in financial fraud
- Questions: Power of Attorney forms being used to scam older adults. What can we do to stop this? There is no oversight of handing off PoA.
 - We made a recommendation about 10 years ago that a presumption be created that all expenditures made by the PoA must be made in the interest of the individual who signed the PoA
 - Group that lobbied against it was the lawyers for estate planning
 - We have brought successful civil suits against people abusing PoA

Following the speaker presentations, Task Force members were asked to write themes/topics that emerged from the presentations and discussions, on which we may want to focus recommendations, and group the themes/topics with others' ideas, using post-its and large poster boards. Dr. Zolotor and Ms. Ries reviewed the submissions with the group and pulled out several emerging themes to table for later discussion.

QUALITY OF CARE

Megan Lamphere, MSW

Section Chief, Adult Care Licensure
 Division of Health Service Regulation
 North Carolina Department of Health and Human Services

Ms. Lamphere gave an overview of quality of care in adult care facilities, focusing on challenges in quality, regulation, and measurement of quality outcomes.

Key discussion points included:

- Adult Care= assisted living
- 3 types of adult care: adult care homes (7+ beds), family care homes (2-6 beds), multi-unit assisted housing with services (contract with home health service companies to provide services; facility itself does not provide services; unregulated and unlicensed)
- Adult care is now very much like what you find in a nursing home.
- Dementia care: 54 homes that are special care unit only; 235 SCUs in adult care homes; total of 8,084 SCU beds in NC; there is a moratorium on SCU licenses right now; moratorium b/c of increase in rates for SCU beds and desire to prevent influx of SCU beds
- There are additional requirements for staff, facility security, etc.
- Are these beds providing higher quality of care?
- Does the Division have the ability to meet demands to license new beds? Still have CON.
- Are the beds full? Varies by area
- There could be significant changes in this industry with the legislature

- Percentage of residents with Alz's/dementia is steadily increasing (Could have a recommendation around quality of data and data collection)
- Common quality issues related to dementia care in ACHs: wandering/elopement, falls, behavior management, assessment and care planning, medication management
- Potential Recommendations:
 - No requirements for facilities to train staff on working with individuals with dementia
 - Explore ways to increase involvement of health care professionals in the assessment and care planning process
 - Increase efforts to promote quality improvement using standard quality measures and processes. In nursing homes/hospice CMS drives many quality measures; in NC we do not have sources of payment for these
 - Design incentives for facilities to increase quality of programming and care of residents with dementia
- Question
 - Direct care workforce providing day to day support; need for such supports is going to overwhelm the workforce soon.
 - One of the things we have talked about is the importance of serving patients with Alz's in their communities, but clearly many are receiving care in residential treatment
 - Adult daycare homes
- Pilot running right now looking at taking over some of the night time responsibilities
- Good community resource
- Restrictions to moving these to overnight programs b/c very different requirements for extending into providing nighttime coverage
- Mostly on the state dollar size; private pay is not stepping up to cover this service

COLLECTIVE IMPACT: OVERVIEW AND COMMUNITY PERSPECTIVE

The desired outcome of this panel and discussion is a shared understanding of collective impact so that we can move forward on discussing how this framework may impact our recommendations.

Laura Clark, MA

Executive Director

Renaissance West Community Initiative

Ms. Clark presented an overview of the guiding principles of "collective impact" and their relevance to the Task Force work.

Key points included:

- We under resource the infrastructure needed to make systems change. It's hard to get to collective impact without an organization that focuses on how to move systems change forward every day.
- Conditions for success: influential champions, financial resources for at LEAST 2-3 years, anchor funder who will be there through the duration of the work, some urgency for change
- Phases of collective impact: governance and infrastructure, strategic planning, community involvement, evaluation and improvement
- It is hard to maintain momentum after a plan is created. **MUST** have a champion who will keep things moving and partners engaged

- Key Components: description of the problem informed by research; clear goal; menu of key strategies that will drive large scale change; set of principles that guide group's behavior; evaluation plan that details shared metrics
- It's difficult when a funder is leading a collective impact project because that compels people to participate but then they realize that their funding will be tied to it
- Backbone organization: the one at the 10,000 foot level pulling all the pieces together. There are multiple types of backbone organizations.
 - Have outcomes for the backbone organization
 - Shared Measurement Systems
- Questions?
 - For the public we are trying to help, can you describe to me where they are in this?
 - I think we are not framing it around the public we are trying to serve. We do defer to providers at experts.
 - It is hard to find an authentic way to engage the public we are serving

Julie Tooker

Community Relations Director

GracePointe Crossing

Ms. Tooker discussed her experience as project lead on the ACT on Alzheimer's initiative in her local community in Minnesota.

Key points included:

- Serve 400 older adults and employ about 400 people on their campus
- City of 8300, county 34,000
- Role with Cambridge ACT on Alzheimer's
- Action team has city planner, director of city/county transportation, home health provider, volunteers, EMS, pharmacist, county director, sheriff, chief of policy, social worker, VA service officer, nurse, clergy, etc.
- First step was to invite community leaders to learn about the initiative. ACT is an initiative to make our cities dementia friendly
 - They were interested
 - Surveyed 14 distinct sectors
 - Participants were selected by making a list to coincide with the 14 sectors; made sure our community movers and shakers were involved
- Our ACTION team has been very successful so far
 - Monthly newspaper article (education, resources, etc)
 - Memory screenings through our group (funding from the Alz's foundation)
 - Created Local resource guide
 - Book club
 - Movie I'll Be Me played in local movie theater; mayor greeted everyone;
 - Provide bracelets through the sheriff's department for those who have dementia and may be apt to wander
 - Virtual dementia tour for chief of police and other first responders which helped them develop more empathy
- Sustainability and maintenance are key - A lot of what we are providing is education
- Applied for and received ACT funding of \$18, 000 for one year
- Local senior provider also donated
- Not seen as being in competition with alzheimer's association or other groups

- Challenge has been prioritizing our action steps
- Have not had trouble getting people to the table; take what we can get from those willing to volunteer their time
- Minimal reporting requirements around transforming perceptions, promoting meaningful life, etc.

Additional collective impact discussion:

- There has been some discussion among the steering committee about how collective impact applies to the Alz's work in North Carolina. Are there opportunities for local communities to participate around collective action efforts? Should we make recommendations around this or otherwise encourage communities to engage in this type of process? WE want to figure out where the state needs to get out of the way and let local communities work together around dementia friendly communities and provide some guidance for how to do this.
- Tailoring what you do to the community is critical
- Have to meet a community where they are
- Is there a collective impact toolkit or curriculum?
 - Yes, there are, community tool box and others that I can pass along to help guide the process
 - There are many tools- Adam listed many
- How are a backbone organization and a lead agency different? And collective impact and other means of collaborating as a community? I would say they aren't, but it is important to make sure that people understand what the definitions are and that there is agreement
- One of the other differences is the amount of support that collective impact assigns to a backbone organization
- How did you get interest from business and employers?
 - Small business cards that state on them, please be patient the person with me has Alzheimer's, to be used when out and about in the community. Can be shared discreetly and help everyone involved have a bit more calm and patience.
 - One hour training that helps teach people how to better communicate with those with dementia.
 - Do you have outreach to employers? That is one of our goals, but we have not done this yet.
- Substance expertise in addition to the expertise in the model that you are working in
 - Your organization had this going for them and contributes to real success in finding leadership and purpose
 - Cambridge is one of 34 communities in MN that are ACT communities
 - We get together twice a year; provide support to one another; share ideas, collaborate

Discussion

- Collective impact can be small (2-3 people in a room) or community wide; can create a model for this. Cannot dictate the process without stopping to first decide on a common vision and goals
- We have a number of agencies and organizations working in silos
- If we want people on the bus we need a common vision that ends in a personal goal or vision for people and their families; what resonates with people who are on the bus?
- If we made a pot of \$ available through some means that communities could use to address one of x issues that we highlight in the report but make communities come together. Maybe that gets the ball rolling and communities working together.
- Can do a lot without being prescriptive
- Finding a new pot of money is slim to none. Collective impact process to analyze the services we have at our disposal to meet a common goal. How can we blend these together for the common good? What are we willing to give up? Hard conversation, but worth having b/c we are all duplicating something and there are ways to improve what we are providing to consumers.

- AARP liveable communities initiative
- If we look at Minnesota model, they are not looking at some existing network to put something in; a lot of things are happening in NC; collective impact is an opportunity to bring together efforts that are already happening; need to connect existing efforts and collective impact may be the way to do this
- How much do we need to label this dementia friendly? Does AARP livable communities work or do we need to be dementia-specific? Probably do.
- When have a successful effort, hard to scale up when lots of people want to participate. If we need kits or trainings or whatever, you need the backbone organization and the resources
- Wealthy communities may be able to do this on their own, but if we want to get everyone on board, have to find resources to allow other communities to participate
- People live in communities and systems support communities. If you start pulling the thread then will get to all the issues that we are discussing as a larger group. IF run down any one of these issues alone, then we will wear ourselves out. These issues overlap and impact one another.