

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

**DRAFT RECOMMENDATIONS**

Oct. edits

**Discussion Session 1**

**Quality of Care and Care Coordination (possibly integrate with LTC recs)**

1. **Prioritize the incorporation of patient and family engagement into the care planning process, care management, organizational policies, and ongoing care at health care providers and facilities, including hospitals and long term care facilities, and in home health settings. North Carolina Health Care Facilities Association (NCHCFA), North Carolina Assisted Living Association (NCALA), North Carolina Association of Long Term Care Facilities (NCALTCF), North Carolina Hospital Association (NCHA) and other partners should promote policies and processes that support and encourage patient and family engagement within health care facilities and in home health settings , including:**
  - a) Recognition of the role of caregivers as members of the health care team
  - b) Inclusion of residents and families on boards and committees – Facilities should appoint a minimum of two patients, residents, and/or family members to boards and advisory committees within their organizations.
  - c) Appointment of patients and families to boards of directors for governance and operation
  - d) Trained facilitation for health care providers
  - e) Organizational leadership to promote principles of patient and family engagement
  
2. **In order to improve quality of care for people with dementia in health care providers and facilities through performance-based incentives, North Carolina Health Care Facilities Association (NCHCFA), North Carolina Assisted Living Association (NCALA), North Carolina Association of Long Term Care Facilities (NCALTCF), North Carolina Hospital Association (NCHA), in collaboration with the Division of Medical Assistance (DMA or Division of Health Benefits), NC Division of Aging and Adult Services (DAAS), and Division of Health Services Regulation (DHSR), should develop facility-specific standards of care for people with dementia, using Centers for Medicaid and Medicare Services (CMS) standards and/or additional evidence-based indicators as a model. Partners should develop a star rating system (similar to those in fields including early childhood education) and link facility ratings with value-based payments and/or performance based incentives for providers/facilities meeting standardized quality measures specific to dementia care. The rating system should include criteria such as:**
  - a) Provision of approved training at regular intervals for dementia specific and patient and family –centered care for all workers

**Commented [ZAJ1]:** Need to discuss with Sandy Terrell. DMA is an important payer. Also Need to discuss with DHSR to make sure to get this right.

**Commented [RMG2]:** Star ratings exist for some types of facilities, so this should about building on these – building in incentives for quality, and expanding ratings for other types of facilities

- b) Reporting on standardized quality measures and outcome measures (what are current reporting requirements? How do this differ by facility? What is different for Medicare/Medicaid/private pay?). These reports should include consumer input from residents, patients, and families. Data collected should allow comparisons with other states, stratify by county, and
  - c) Achievement of positive outcomes for patients with dementia, tailored to individuals' and families' outcome goals under the principles of patient and family engagement
  - d) Promoting awareness of and use for standardized quality ratings among providers and consumers, including the Quality Ranking System for long-term care facilities and adult care homes
  - e) Implementation best practices in care transition processes, including engaging families in care transition process, assessing capability to care for family members at home, and providing access to community resources and counseling on financial issues (what are requirements under CARE Act – are these only for hospital discharges? What are requirements for other kinds of transitions? Talk to Sarah Roberts at ACT)
  - f) Utilization hospital discharge planners in developing care transition plans, and support additional follow up after discharge
3. **Under Medicaid reform, accountable care organizations (ACOs) and provider led entities (PLEs) should support increased communication between health care providers to enhance care coordination, case management, and medication management for people with dementia. Potential models to use may include team based care, (specific models such as Duke Connected Care – address in text), CCNC models, and additional support for PACE programs at the local level.**

#### **Legal Protections – Elder Fraud and Abuse, Guardianship, APS, Advanced Directives**

1. **The NC Division of Aging and Adult Services should convene a workgroup comprised of representatives of agencies and organizations with experience and expertise in dealing with vulnerable adults, including those with dementia, to examine state statutes for adult protective services and guardianship to ascertain if these statutes provide the needed safeguards and protections for older and disabled North Carolinians. A report from the workgroup, along with recommendations for any changes to state statutes, should be submitted to the NC Department of Health and Human Services, the Joint Legislative Oversight Committee on Health and Human Services, and the Joint Legislative Oversight Committee on Justice and Public Safety by October 1, 2016. Agencies and organizations participating in the workgroup should include: Alzheimer's North Carolina, Disability Rights of North Carolina, the NC Administrative Office of the Courts, the NC Alzheimer's Association, the NC Association of County Directors of Social Services, the NC Bar Association, the NC Coalition on Aging, the NC Conference of Clerks of Superior Court, the NC Council on Developmental Disabilities, the NC Guardianship Association, and the UNC School of Government.**

Commented [RMG3]: Elder Abuse Task Force?

The workgroup should address and make recommendations about topics including, but not limited to:

- a) Scope of need for adult protective services and guardianship services
- b) Gaps in current state statutes
- c) Implications of the Elder Justice Act on state responsibilities

- d) Resources and training needed to adequately protect vulnerable adults
- e) Reporting of abuse, neglect, or exploitation and penalties for not reporting
- f) Determining competence and the role and process for multi-disciplinary evaluation
- g) Establishing jurisdiction for responsibility

**1. Promote collaboration between the local Area Agencies on Aging, NC Division of Aging and Adult Services (DAAS), the Department of Justice, local Departments of Social Services, State Treasurer, Secretary of State, and community partners on increasing awareness among family caregivers of the available legal protections and relevant vulnerabilities of people with dementia. Awareness and education efforts should be incorporated into local collective impact processes and should include:**

- a) Preparation for cognitive impairment and potential caregiving responsibilities in all financial literacy trainings and counseling, including loss of financial capacity as “early warning” sign of dementia (?)
- b) Promotion of advanced care planning (incl. medical and financial) among family caregivers and people in early stages of dementia, to include information on health care power of attorney signatory requirements and state registry information
- c) Increased information on issues around guardianship, elder abuse, and advanced directives, including legal/logistical requirements, financial responsibilities of guardianship, and limitations regarding APS’s scope of intervention (i.e. unable to intervene for “bad decisions,” respecting self-determination)
- d) Action steps for families and people with dementia to increase use of documentation when needed (i.e. where to put copies of documents, who to inform, etc.)
- e) Promotion of culture change around care planning and financial planning for family members, including caregiver coping strategies such as mediation and family counseling and additional caregiver/family resources
- f) Engaging additional partners (including faith community) in facilitating guardianship and legal protections when family members are reluctant or unable to do so

**2. Incorporate Legal Protection Issues Specific to People with Dementia into Health Professional and Legal Professional Training:**

- a) North Carolina Area Health Education Centers programs, NC Bar Association, financial organizations/banks, DSS/county services, and other organizations including, but not limited to, the North Carolina Medical Society, North Carolina Nurses Association, North Carolina Academy of Physician Assistants, should offer continuing education on the types and unique requirements of various legal protections for people with dementia, including but not limited to guardianship, multidisciplinary evaluations, advanced care directives, financial planning, and health care power of attorney. Training should also incorporate existing best practices in initiating conversations with people with dementia and family caregivers around these issues.
- b) Training should be offered in multiple settings, with opportunities for more intensive trainings for those who will help other staff learn about legal protections, and opportunities for integrating work in different organizations
- c) Trainings should include special considerations and information on identifying and working with people with dementia, including “pre-service” training for APS and court

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Commented [ZAJ4]: Role for state treasurer?

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officials to ensure a minimum level of competency in identifying and serving people with dementia

- d) Incorporate techniques used by law enforcement (classes through NC Justice Academy – identify in text) to identify elder abuse and fraud into health and legal professional training (what are these?)

**4. NC DHHS should pursue county integration of elder fraud and abuse data through NCFAST. This should include:**

- a) Inclusion of APS/guardianship data in county integration (this currently in planning process)
- b) Capacity to cross reference public assistance programs to reduce duplicative efforts and assist with locating vulnerable adults
- c) (what else to enhance? Where would this live? Who would do data collection? Is this around more funding?)

**Home and Community Based Services (definition and types of services to be explained in text)**

- 1. **The Program Evaluation Unit of the North Carolina General Assembly should identify 1-2 evidence-based or evidence-informed home and community based programs that have shown improved outcomes (re: delayed placement in long term care, improved access to care, caregiver wellbeing, etc.) and reduced costs for individuals with dementia, their families, and payers. The Program Evaluation Unit should then provide a full analysis and recommendation to the General Assembly for one-time funding for evidence-based or evidence-informed program pilots within selected communities, with the possibility of recurring funding after additional results and outcomes analysis. As part of this analysis, the Program Evaluation Unit should:**

- a) Include analysis on the impact on overall health care costs, including impact on Medicare and Medicaid costs, and caregiver/family economic and well-being costs, of increasing the number of individuals able to access home and community based services and/or age in place. (Potential programs may include financial provisions for personal care services and missed work days, specialized medical supplies and home safety technologies, and respite care. – identify these in text)
- b) Analyze the ways in which combining dementia services with available I/DD services could utilize economies of scale and contribute to improved outcomes
- c) Include evaluation costs in funding recommendations
- d) Conduct an analysis of modifying the Home and Community Care Block Grant. The analysis should include:
  - i. Estimated benefit to allocating the state ‘over-matching’ funds separate from the existing Home and Community Care Block Grant to counties.

**Commented [ZAJ5]:** I like where this is going. I wonder if we can be more specific about suggesting 1 or 2 models and ask Program Eval Unit of the NCGA to evaluate those potential opportunities in NC, and if analysis is favorable in NC, ask the NCGA or funders generically which could include ACOs to invest in pilots of those programs.

**Commented [ZAJ6]:** Do we want a goal statement in this rec? Like reduction of wait list. Can we get more information about wait list? Ask mark?

**Commented [RMG7]:** Text: Ohio program of home health aides, NYU caregiver program, hospice-based care management? Project CARE, Powerful Tools for Caregivers, Memory Care

**Commented [RMG8]:** Address “right Servicing” approach in text

- ii. Evaluate the benefit of implementing a sliding fee cost sharing model of recipients receiving community based services provided by over-matching state funds.
- iii. Detailed analysis of the process by which the modifications would be made to existing state statutes (NCGA approval, etc.)
- iv. Estimated potential expansion of services from revenue generated from instituting a sliding fee for service (income based) and return on investment analysis

**2. The Division of Medical Assistance (DMA), within the Department of Health and Human Services, should work with the House Subcommittee on Aging to provide additional funding for the existing Medicaid Home and Community Based Services waiver program (including CAP/DA and CAP/Choice) to include additional services for individuals with Alzheimer's Disease and their families. Expansion should:**

- a) Have the ultimate goals of reducing the wait list for receipt of services (at a rate of X% per year) and delaying placement in long term care.
- b) Allow greater flexibility to cover adult day care services and group respite.
- c) Include provisions for local community work on increasing awareness and navigation of available services for people with dementia and their caregivers, including limitations and provisions of Caregiver Directed Vouchers
- d) Include provisions to address barriers faced by local Departments of Social Services in providing immediate services
- e) Include additional funding for evaluation of impact of expansion on wait list, outcomes, and health care costs

**Commented [ZAJ9]:** Need to refer back to Rose's research and ask Sandy Terrell or someone from DMA to help with this. Will Medicaid reform change the waiver programs, fold them into ACOs?

**Commented [RMG10]:** Discuss SeniorLink in text as potential program

**3. DAAS should work with DMA and local Departments of Social Services to identify best practices for the integration and coordination of home and community based services, and work statewide to implement these practices and improve awareness of available services. Potential strategies may include using new models of care (such as the Transformation Innovations Center under Medicaid reform) to deliver improved services, expansion of online resources (i.e. dementia toolkit, online training programs, etc.), implementing a statewide version of Just One Call and connecting DHHS services with 211, and expanding training for health care providers and options counselors on existing services, waiver programs, and financial assistance.**

**Caregiver Support and Assistance**

- 1. The NC Division of Aging and Adult Services (DAAS) and philanthropic partners should expand the existing collaboration with Duke Family Center to update the comprehensive online dementia "toolkit" for placement on the DAAS website, Duke Family Center website, and other partner organizations' websites, ensuring statewide availability and access. The toolkit should compile materials and contain practical tips, health professional and caregiver training materials, and links to educational programs for use by caregivers, home

**and community based services staff, and others. DAAS should seek funding for the toolkit (incl. updating, maintenance, promotion) through foundation and other partner support.**

**This toolkit should include:**

- a) Information about dementia, including definitions/types, prevalence, symptoms, diagnosis, etc. (more info in text about what already exists, how to build on it, etc.)
- b) Information on financial and logistical preparation for caregiving and end of life care, including care goals and decision-making needs
- c) Resources for services, including employer/based services, adult day care, caregiver respite services, and financial assistance
- d) Training resources, including continuing education programs, etc.
- e) Safety resources, including tips on home safety, community safety, and technological innovations (such as Safe Return or other web-based tools)
- f) Resources and supports for health care providers, including information on available trainings and information on starting conversations with patients and families about financial planning and safety concerns
- g) Working with 211 (see recommendation XXX) to ensure both online and offline access to full resources

2. **AARP NC, Alzheimer's NC, and the Alzheimer's Association should partner with employer stakeholders such as the Chamber of Commerce, the Society for Human Resources Management, and other business interests to develop policies to encourage active employer participation in support for employee caregivers. This should include:**

- a) Education for employers about dementia and role of family caregivers and support for additional promotion
- b) Exploration of policies to support employee caregivers, including flextime, paid family leave, non-discrimination against caregivers in workplace, telecommuting, referral programs, respite services, on-site support services, awareness of available benefits (i.e. FMLA eligibility), and enhanced Employee Assistance Programs

**Commented [RMG11]:** Doug, can you clarify what's already happening here?