

Chapter Eight: Full Recommendations of the Task Force on Alzheimer’s Disease and Related Dementias

The Task Force has identified and listed lead organizations and/or partner organizations responsible for implementing each recommendation. For recommendations with only partner organizations listed, the Task Force intends shared responsibility for implementation.

Recommendation 3.1: Increase awareness and promote education about Alzheimer’s disease and related dementias and available resources through incorporating Alzheimer’s disease and related dementia-specific information in current health promotion and education programs.

In order to increase awareness and promote education about Alzheimer’s disease and related dementias, organizations should establish a partnership (and/or build on existing public/private partnerships) to explore the incorporation of Alzheimer’s disease and related dementias information into current health promotion/education programs and social marketing/health promotion materials. Information should include:

- a) Connection between brain health and other preventable risk factors and health behaviors.
- b) Support for early detection and accurate diagnosis, and information about prevention and clinical trial registries.
- c) Resources/referrals for home- and community-based services, health care providers (including specialists), caregiver support services, home safety, and long-term care.
- d) Financial planning information, including available insurance coverage for different types of care and advanced care planning, legal protections (including information on fraud, guardianship, and Adult Protective Services), care transitions, and employee resources.
- e) Strategies to reduce stigma around Alzheimer’s disease and related dementias.
- f) Resources for underserved populations including individuals with intellectual/developmental disabilities, minority populations, homeless, and rural communities.

Partners: Including, but not limited to, North Carolina Division of Aging and Adult Services, North Carolina Division of Public Health, North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, the state Medicaid agency, North Carolina Department of Public Instruction, Area Agencies on Aging, North Carolina Office of Rural Health, county social and human services agencies, county Departments of Public Health, providers of mental health services, academic programs for professionals in health and human services, philanthropic organizations, North Carolina Chamber of Commerce, businesses/employers, health professional associations, managed care organizations, private payers, faith-based communities, and advocacy organizations.

Recommendation 3.2: Enhance training for health care providers on the benefits and best practices for Alzheimer’s disease and related dementias detection, diagnosis, and services referrals.

Offer pre-service and in-service training in the early detection of Alzheimer’s disease and related dementias. Training should include validated brief assessment and diagnostic tools, and should be tailored to all populations. Training should focus on:

- a) Incorporating specific tools for early detection in all populations, including individuals with limited English proficiency and those with intellectual or developmental disabilities.
- b) How to meet Medicare annual wellness visit requirements for cognitive assessment using validated tools and a functional approach to assessment.
- c) Benefits of early detection for families and caregivers, including family support, advance planning, symptom and care management strategies, non-pharmacological interventions for improving functional and behavioral symptoms, medication options, and need to incorporate family feedback in identifying cognitive impairment.
- d) Referral resources (to include hard copies provided at time of visit, if requested) for additional medical assessment, diagnostic testing, treatment services, and services for caregivers for those with signs of cognitive impairment.
- e) Information about care and available services and supports, including specific additional training or ongoing education for care managers or other staff.

Lead: North Carolina Area Health Education Centers

Partners: Including, but not limited to, the North Carolina Medical Society, the North Carolina Psychiatric Association, the North Carolina Hospital Association, the North Carolina Nurses Association, and academic health science centers.

Recommendation 3.3: Create a collective impact partnership to develop and establish dementia-capable pilot communities.

Using the resources and toolkits available from the Dementia Friendly America and ACT on Alzheimer's projects, partners should develop a collective impact partnership which will work toward the development and establishment of three to four Alzheimer's disease and related dementia-capable pilot communities in North Carolina.

- a) The collective impact partnership should be supported by staff from North Carolina Division of Aging and Adult Services, who will oversee collaboration, establish a statewide advisory committee made up of stakeholders, and facilitate technical assistance.
- b) Philanthropic partners should develop a targeted grant process to identify appropriate communities for initial and/or continuing funding.
- c) The pilot community projects should lead to the development of a sustainable and replicable model that can be disseminated to additional North Carolina communities and serve as a foundation for dementia-capable communities.
- d) The local collective impact pilots will require a full-time staff person to champion and organize local efforts. Resources will be required for facilitation, data planning/analysis, and meeting expenses. The estimated annual budget for each pilot is \$125,000.
- e) Pilots should include evaluation of the costs and benefits of this approach for developing a dementia-capable community.

Lead: North Carolina Division of Aging and Adult Services

Partners: Including, but not limited to, philanthropic organizations, county social and human services agencies, Area Agencies on Aging, Association of County Commissioners, UNC's Jordan Institute for Families, local providers of care (including behavioral health, medical health, and human services), and other academic institutions.

Recommendation 3.4: Establish statewide coordinated leadership to oversee the state plan on Alzheimer's disease and related dementias.

Establish a statewide coalition on Alzheimer's disease and related dementias to oversee the implementation of this plan. The coalition should be coordinated by the state Alzheimer's disease specialist. The coalition should be charged with:

- a) Developing the collective impact strategy, including assisting funding agencies in selecting communities for collective impact and convening local collective impact efforts to support shared learning, and, if successful, for scale up of collective impact efforts to other communities.
- b) Coordinating implementation of the plan.
- c) Reporting yearly progress on implementation to the Secretary of Health and Human Services (and/or the Senate and House Committees on Aging).
- d) Support other workgroups charged with implementations of specific recommendations.
- e) Serve in an advisory capacity to the North Carolina Division of Aging and Adult Services to support additional recommendations (i.e., the development of a toolkit).

Lead: The North Carolina Division of Aging and Adult Services

Partners: Including, but not limited to, North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, North Carolina Division of Social Services, the state Medicaid agency, the North Carolina Division of Public Health, the North Carolina Division of Health Services Regulation, Alzheimer's North Carolina, Alzheimer's Association, members of the North Carolina General Assembly, the Governor's Council on Aging, the Duke Endowment, AARP North Carolina, LeadingAge North Carolina, North Carolina Area Health Education Centers, local Area Agencies on Aging, the North Carolina Coalition on Aging, the Geriatrics Workforce Enhancement Program, local providers of care

(including behavioral health, medical health, and human services), media representatives, and caregivers for people with Alzheimer’s disease and related dementia, with special attention to ensure diversity and statewide representation.

Recommendation 4.1: Promote appropriate care settings for people with Alzheimer’s disease or related dementia.

In order to minimize avoidable treatment, increase satisfaction, improve quality of care, and decrease health care costs at the end of life, partners should examine and promote the potential benefits of appropriate care settings, to include:

- a) Information on palliative care through the Palliative Care Initiative, and an examination of the potential cost impact of expanding Medicaid coverage for hospice and palliative care and including it in managed care models.
- b) Review of hospice and palliative care criteria in order to ensure that provided care is appropriate for different types of dementia and/or to provide earlier access to care for people with Alzheimer’s disease or related dementia.
- c) Information on additional options for long-term services and supports and differences between such options.
- d) Use of Medicare codes for advance care planning, Medicaid reimbursement procedures, and expansion of qualified providers within the care team who may participate in the billing of these codes to enable nurses, social workers, and other team members to participate in advance care planning.
- e) Ensuring access to appropriate care settings and long-term services and supports for all populations, including individuals with intellectual/developmental disabilities and/or mental illness.

Partners: Health care providers, vendors, and payers.

Recommendation 4.2: Examine methods of reimbursement and incentives for Alzheimer’s disease and related dementia care through new models of care.

Explore new models of care which use methods of reimbursement to incentivize care for people with Alzheimer’s disease and related dementia and reduce wait lists for specialist care. Models may include:

- a) Leveraging palliative care and end-of-life expertise that resides in community hospice organizations to expand pre-hospice palliative care supports for patients and families.
- b) Incentivizing the expansion of pre-hospice palliative care services through reimbursement for interdisciplinary palliative care services.
- c) Community Care of North Carolina model of expanding services to include skilled nursing facility residents, thereby making these residents eligible for comprehensive care management.

Lead: Association for Home and Hospice Care of North Carolina, the Carolinas Center for Hospice and End of Life Care.

Partners: Health systems, facilities, private and public payers.

Recommendation 4.3: Assess health system capacity for people with Alzheimer’s disease or related dementias.

Conduct an assessment of current health system capacity for caring for patients with Alzheimer’s disease or related dementias. The assessment should include dementia-specific beds in intensive outpatient and psychiatric settings, and also include information on the projected status of moratorium on home care services and on memory care units in adult care homes.

Partners: North Carolina Division of Health Service Regulation, the state Medicaid agency, North Carolina Division of Aging and Adult Services, and health professional trade associations.

Recommendation 4.4: Improve telehealth services for people with Alzheimer’s disease or related dementias.

Examine and identify funding streams for improved telehealth services for people with Alzheimer’s disease or related dementias, with special attention on rural and underserved communities and the impact on health care costs and caregiver well-being. These services should include:

- a) Remote diagnostic capacity and ongoing consultation, medication management, and behavioral management in the context of tele-neurology services when appropriate, and/or at alternate locations (including home locations).
- b) Home monitoring of activities of daily living, with local capacity for follow-up.
- c) Remote resources for caregivers.
- d) Additional non-health care services, such as check in calls, monitoring utilities, falls prevention, and caregiver support services.

Partners: North Carolina Division of Aging and Adult Services, the state Medicaid agency, private payers, medical and behavioral health providers, and LME/MCOs.

Recommendation 4.5: Increase access to medical and community services for people with Alzheimer’s disease and related dementia through improved transportation services.

In the context of a state-level, interdepartmental group of executive branch agencies, establish a workgroup with a mandate to collaborate on human service transportation issues, maximize resources, and address barriers that present challenges to local communities in providing transportation services. Similar to other state transportation committees that have operated in the past, such as the former Human Services Transportation Council, this interagency workgroup should work to assure coordination and communication among state agencies that provide or purchase transportation services, provide a mechanism for collaborative planning efforts across funding sources, be the state-level entity for addressing service gaps identified for special populations such as people with Alzheimer’s disease or related dementia, and periodically make status reports to the Governor as directed.

Lead: North Carolina Department of Health and Human Services and the North Carolina Department of Transportation.

Partners: Statewide Coalition on Alzheimer’s Disease and Related Dementias, county social and human services agencies, local business partners and transportation vendors, and/or lead agencies for public transportation.

Recommendation 4.6: Apply principles of person-centered care to the care processes and protocols at health care providers and facilities for people with Alzheimer’s disease or related dementias.

Prioritize the incorporation of person-centered care 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 care settings. Partners should promote policies and processes that support and encourage person-centered care within health care facilities and in-home and community-based care and services settings, including:

- a) Recognition of the role of unpaid 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 residents and/or family members to boards and advisory committees within their organizations. Family members and caregivers should be included in development of health promotion materials and caregiver resource guides.
- c) Appointment of residents and families to boards of directors for governance and operation, at both the corporate/national and local levels.
- d) Trained facilitation for health care providers in principles of person-centered care.
- e) Organizational leadership to promote principles of person-centered care.

Partners: North Carolina Health Care Facilities Association, North Carolina Assisted Living Association, North Carolina Association of Long-Term Care Facilities, North Carolina Hospital Association, Community Care of North Carolina, LeadingAge North Carolina, Association for Home and Hospice Care of North Carolina, Hospice and Palliative Care Center, and other partners.

Recommendation 4.7: Improve quality of care and care coordination for people with Alzheimer’s disease or related dementia through improved ratings systems and dementia-specific indicators.

Improve the quality of care for people with Alzheimer’s disease or related dementia, convene a working group to determine the feasibility of developing dementia-specific standards of care, using Centers for Medicaid and Medicare Services standards and/or additional evidence-based indicators as a model.

The working group should be overseen by the North Carolina Division of Aging and Adult Services and partners should utilize best practices from existing quality rating systems and dementia-specific reimbursement strategies in order to 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 person- and family-centered care for all workers, regardless of care setting.
- b) Reporting on dementia-specific standardized quality and outcome measures. These reports should include consumer input from residents and families. Data collected should allow comparisons with other states and within North Carolina counties and should evaluate quality ratings systems for effectiveness.
- c) Achievement of positive outcomes for people with Alzheimer’s disease and related dementia, tailored to individuals’ and families’ outcome goals using the principles of person-centered care.
- d) Promoting awareness of and use for standardized quality ratings among providers and consumers, including the Quality Rating System for long-term care facilities and adult care homes.
- e) Implementation of best practices in care transition processes, including engaging families and integrating preferences of the person with dementia in care transition processes, assessing capability to care for family members at home, and providing access to community resources and counseling on financial issues.
- f) Utilization of hospital discharge planners and other professionals involved in transitions who are knowledgeable about person-centered dementia care in developing care transition plans and supporting additional follow up after discharge. This should include education about adult protective services and available home- and community-based services.

Lead: North Carolina Division of Aging and Adult Services.

Partners: North Carolina Health Care Facilities Association, North Carolina Assisted Living Association, North Carolina Association of Long-Term Care Facilities, North Carolina Hospital Association, in collaboration with the state Medicaid agency, the North Carolina Division of Health Services Regulation, Division of Mental Health, Developmental Disabilities and Substance Abuse Services, Departments of Social Services Directors’ Association, county social and human services agencies, Office of the Long-Term Care Ombudsman, Friends of Residents in Long-Term Care, North Carolina’s Coalition on Aging, North Carolina comptroller’s office, academic researchers, and consumer advocacy organizations.

Recommendation 4.8: Improve care coordination for people with Alzheimer’s disease or related dementia through new models of care.

Implement new models of care that enhance person-centeredness, care coordination, and integration through communication, care management, and medication management for people with Alzheimer’s disease or related dementia. Potential models to apply may include specific integrated care initiatives and/or enhanced care management programs. The Medicaid agency should include such models in health plan contracts, and the Dual Eligibles Working Group^a should prioritize recommendations on the application of care coordination models to coverage for the dual eligible population.

Lead: Health care systems, facilities, and public and private payers, including accountable care organizations, managed care organizations, and provider-led entities.

Partners: North Carolina Department of Insurance, North Carolina Department of Health and Human Services, the state Medicaid agency, and the Dual Eligibles Working Group.

Recommendation 4.9: Expand the Dementia Friendly Hospital initiative.

Promote the Dementia Friendly Hospital Initiative in North Carolina’s hospitals, health care providers, and health systems. Facilities should work to include environmental modifications and practices that enhance continuity of care and person-centered care.

^a “Dual eligibles” refers to 10.2 million Americans who qualify for coverage under both Medicare and Medicaid. These individuals are among the most disabled, chronically ill, and costly coverage recipients. On average, health care costs for the dual eligible population are 60% more than for non-dual eligible individuals. Approximately half of dual eligible qualify for Medicare because of disability rather than age. Almost one-fifth have three or more chronic conditions. More than 40% use long-term services or supports.³⁶ In North Carolina, the Dual Eligibles Work Group was mandated by the Medicaid Transformation and Reorganization legislation in 2015.

Lead: Health care providers and systems.

Partners: North Carolina Hospital Association, Alzheimer's North Carolina, and Alzheimer's Association.

Recommendation 4.10: Promote Alzheimer's disease and related dementia-specific training for health professionals and community workforce.

Enhance promotion and dissemination of existing continuing education on Alzheimer's disease and related dementia-specific training for health care providers and home- and community-based services providers, including but not limited to nurses, certified nursing assistants, outpatient care staff, physicians, social workers, adult day services staff, behavioral health providers, emergency care providers and staff, emergency medical technicians and other first responders, dentists, and clergy and chaplains. Training programs should:

- a) Be offered in multiple settings, be provided on an ongoing and recurring basis, include needs of specific vulnerable populations, and include opportunities for more intensive trainings when desired, appropriate, and necessary to achieve minimum proficiency.
- b) Be included for all health care professionals in both pre- and in-service training and emphasize inter-professional education and quality improvement.
- c) Include information on palliative care, advanced health directives, family care planning resources, and information on Medicare rule on end-of-life planning
- d) Emphasize aspects of diagnosis and detection, including information on triage-based and referral-based diagnostic systems (as referenced in Recommendation 3.2).
- e) Address needs of people with Alzheimer's disease or related dementia in the creation of emergency/disaster preparedness plans, and increase awareness of specific needs of this population during emergencies and disasters.
- f) Include principles of patient- and family-centered care, as they pertain to people with dementia and their family caregivers
- g) Expand behavioral management training for individuals with dementia, using a person-centered approach to care and applying best practices in prioritizing the use of nonpharmacological approaches.

Partners: North Carolina Area Health Education Centers programs, the North Carolina Community Colleges System, the three North Carolina based Geriatric Workforce Education Programs, Geriatric Adult Mental Health Specialty Teams, Geriatric Education Center Consortium, colleges and universities, health professional training schools, organizations that provide care management services (including health systems and accountable care organizations), professional associations including, but not limited to, the North Carolina Medical Society, North Carolina Nurses Association, North Carolina Academy of Physician Assistants, North Carolina Academy of Family Physicians, and advocacy organizations including Alzheimer's North Carolina, and Alzheimer's Association.

Recommendation 4.11: Incentivize entry into geriatric and gerontology specialization and additional training in dementia care.

Identify avenues of entry and provide methods of incentives for health professionals' geriatric/gerontology specialization and additional training in Alzheimer's disease and related dementia care. These methods may include loan forgiveness programs, innovative recruitment models, expansion of areas of concentration eligibility, certificates of added qualifications, and specialty training designations for individual practitioners. These incentives should be tailored for broad application to all health and human services professional designations.

Lead: North Carolina academic health education programs supported by North Carolina general funds.

Partners: North Carolina Area Health Education Centers and private and public payers.

Recommendation 4.12: Increase compensation based on Alzheimer's disease and related dementia-specific training and certification.

Build on existing models for increased compensation upon completion of geriatric and Alzheimer's disease and related dementia-specific training modules/certifications within existing health professional training programs, including physician, nurse, and allied health professionals. This work should include

analysis and promotion of the business interest for improved training, such as increased revenue, less employee turnover, and marketing advantages, as well as the benefits to employees and improvement of quality of care.

Partners: Health professional employers, consumer advocacy groups, health professional educational/training organizations, and professional associations, including, but not limited to, the North Carolina Home Care Association, North Carolina Long-Term Care Facility Association, Association for Home and Hospice Care of North Carolina, North Carolina Health Care Facilities Association, North Carolina Assisted Living Association, Board of Nursing, Friends of Residents of Long-Term Care, North Carolina Health Care Professional Registry, North Carolina Community College System, and Area Health Education Centers.

Recommendation 5.1: Promote integration and accessibility of dementia-specific resources through a comprehensive caregiver toolkit and a virtual resource center.

Develop a comprehensive “virtual resource center” to be maintained on the Department of Health and Human Services website. The virtual resource center will serve as an informational guide for families, professionals, care managers, and navigators including but not limited to NC 2-1-1, stakeholders, and local provider agencies. The virtual resource center will link to an updated Dementia Toolkit available on the Duke Family Support Program website. The virtual resource center and toolkit should include:

- a) Information about Alzheimer’s disease and related dementia, including definitions/types, prevalence, symptoms, diagnosis, etc.
- b) Information on financial and logistical preparation for caregiving and end-of-life care, including care goals, decision-making needs, advanced care planning, and ways to avoid elder fraud.
- c) Resources for services, including employer-based services, adult day care, caregiver respite services, and financial assistance.
- d) Training resources, including hands-on caregiver training in assistance with activities of daily living.
- 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) Tools for preliminary assessment of caregiver needs, in order to provide appropriate and effective resources.
- h) Availability in both web-based and hard copy format, in order to maximize accessibility for all populations.

Lead: North Carolina Division of Aging and Adult Services and Duke Family Support Program.

Partners: North Carolina Alzheimer’s stakeholder organizations.

Recommendation 5.2: Provide adequate funding for family caregiver support services including dementia-specific respite through Project CARE.

Study the needs for adequate funding of Project CARE (Caregiver Alternatives to Running on Empty) as an evidence-based caregiver support service, including ‘episodic’ respite care, education, coaching, and caregiver training. Any initial increases in appropriations should include sufficient resources to evaluate program impacts on program goals, especially with regard to:

- a) A caregiver’s “intent to institutionalize” care recipients with Alzheimer’s disease or related dementia, real delays in placement, and cost-savings for the Medicaid program and other state programs.
- b) Show improved outcomes (i.e., delayed placement in long-term care, improved access to care, caregiver well-being, etc.) and reduced costs for individuals with dementia, their families, and payers.
- c) Provide a full analysis and recommendation to the General Assembly for initial pilot funding for evidence-based programs within selected communities, with the possibility of recurring funding after additional results and outcomes analysis.

Lead: North Carolina Division of Aging and Adult Services.

Partners: North Carolina General Assembly and Fiscal Research Division.

Recommendation 5.3: Continue No Wrong Door Initiative through a collaboration with NC 2-1-1.

Provide an annual investment of \$200,000 for management of state involvement with the No Wrong Door initiative and “virtual front door” access provided through partnership with NC 2-1-1. NC 2-1-1 will provide the infrastructure for the No Wrong Door system, building on the existing information management platform. This funding should support two full-time staff positions to oversee continued No Wrong Door development and implementation, migration of Alzheimer’s disease and dementia-related community resources to enhance the existing NC 2-1-1 database, manage Alzheimer’s disease and dementia-related stakeholder partnerships, and provide planning for evaluation, sustainability, and further statewide scaling. As part of this work, the Division of Aging and Adult Services should:

- a) Develop infrastructure for state and local government involvement with NC 2-1-1 on dementia-specific resources.
- b) Identify and manage partnerships with organizations including the Area Agencies on Aging, Department of Social Services, aging transition services, Just One Call (Mecklenburg County), caregiver representatives, and other community resource organizations to ensure the integrity of Alzheimer’s disease and dementia-specific information provided to NC 2-1-1 on available services and resources is accurate, up-to-date, and continuously monitored.
- c) Partner with NC 2-1-1 leadership to identify available outside funding sources to support expansion of information management system, thereby improving access and referral support to older adults and/or people with dementia.
- d) Work with NC 2-1-1 leadership to expand and enhance systems integration capabilities, develop controlled marketing strategies, website enhancement, training for call center staff, technology opportunities (through mobile apps and others), and development of reporting and quality assurance measurements.
- e) Partner with aging and dementia advocacy organizations, including the Alzheimer’s Association, Alzheimer’s North Carolina, Area Agencies on Aging, local Departments of Social Services, and AARP North Carolina, to increase awareness of NC 2-1-1 as a primary resource for health care needs, home- and community-based services, and caregiver support and assistance.
- f) Coordinate training for NC 2-1-1 staff in working with individuals or families with Alzheimer’s disease or related dementias and/or engaging dementia specialists to serve as NC 2-1-1 staff.

Lead: General Assembly.

Partners: Division of Aging and Adult Services and United Way of North Carolina.

Recommendation 5.4: Enhance employer policies to support family caregivers.

Partner with employer stakeholders and business interests to develop policies to encourage active employer participation in support for employee caregivers. This should include:

- a) Education for employers about Alzheimer’s disease and related dementia, the role of family caregivers and support for additional promotion of caregiver-friendly policies.
- b) Policies to support employee caregivers, including options such as flextime, paid and unpaid family leave, non-discrimination against caregivers in workplace, telecommuting, referral programs, respite services, on-site support groups, awareness of available benefits (i.e., Family Medical Leave Act eligibility), expansion of the definition of family for caregiving and leave-related policies, and specialized employee assistance programs.
- c) Identification of corporate/employer champions to promote benefits of supportive employer policies to economic interests, as well as employee caregivers’ interests.
- d) Encourage passing of House Bill 816 through the North Carolina Senate, in order to study the needs of working family caregivers.

Lead: AARP North Carolina, Alzheimer’s North Carolina, the Alzheimer’s Association, the Association for Home and Hospice Care, and the North Carolina General Assembly.

Partners: Employer stakeholders and business interests, including North Carolina Chamber of Commerce and the Society for Human Resources Management.

Recommendation 5.5: Examine outcomes and impact of home- and community-based services programs.

In order to maximize state resources, the lead agency should examine home and community based programs that have shown improved outcomes (such as delayed placement in long term care, improved access to care, and improved caregiver wellbeing) and reduced costs for individuals with Alzheimer's disease or related dementias, their families, and payers. Lead agency should:

- a) Analyze the impact of home- and community-based services 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.)
- b) Include evaluation costs in funding recommendations to determine whether service providers met outcome goals, including waiting lists for services.
- c) Conduct an analysis of modifying the Home and Community Care Block Grant configuration. The analysis should include:
 - i. Review of current allocation methodology and payment to allow for consumer cost-sharing.
 - ii. Detailed analysis of the process by which the modifications would be made to existing state statutes (i.e., North Carolina General Assembly approval).
 - iii. Estimated potential expansion of services from revenue generated from instituting a sliding fee for service (income-based) and return on investment analysis.

Lead: North Carolina Department of Health and Human Services.

Recommendation 5.6: Expand the Medicaid Home- and Community-Based Services Waiver Program.

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 waitlist for receipt of services and delaying placement in institutional long-term care. The Dual Eligibles Work Group should also examine root causes of waitlists and identify ways to reduce them.
- b) Allow greater flexibility to cover adult day care services and group respite.
- c) Under reform, allow managed care organizations and provider-led entities to contract for community-based services using a flexible waiver.
- d) 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.
- e) Include provisions to address barriers faced by county Departments of Social Services in providing immediate services.
- f) Include additional funding for evaluation of impact of expansion on waitlist, outcomes, and health care costs (including impact on Medicaid costs).

Lead: North Carolina General Assembly.

Recommendation 5.7: Implement best practices for the integration and coordination of home- and community-based services.

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 identify best practices and deliver improved services; expanding of online resources (i.e., dementia toolkit, online training programs, etc.); connecting services with NC 2-1-1, (see Recommendation 5.3); integration of health services and community-based services; and expanding training for health care providers, care managers, and options counselors on existing services, waiver programs, and financial assistance.

Lead: North Carolina Division of Aging and Adult Services.

Partners: State Medicaid Agency and county Departments of Social Services.

Recommendation 6.1: Increase awareness of legal protections and vulnerabilities of people with Alzheimer’s disease or related dementia.

Promote collaboration between partners on increasing awareness among family caregivers of the available legal protections and relevant vulnerabilities of people with Alzheimer’s disease or related dementia. Awareness and education efforts should be incorporated into local collective impact processes and should include:

- a) Planning for the possibility of cognitive impairment and potential caregiving responsibilities in all financial literacy trainings and counseling, including loss of financial capacity as an early warning sign of Alzheimer’s disease and related dementia.
- b) Promotion of advanced care planning (including medical and financial) among family caregivers and people in early stages of Alzheimer’s disease or related 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, recognition and reporting of abuse, and limitations regarding Adult Protective Service’s scope of intervention.
- d) Action steps for families and people with Alzheimer’s disease or related dementia to enhance 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.

Partners: Local Area Agencies on Aging, North Carolina Division of Aging and Adult Services, the Department of Justice, local Departments of Social Services, State Treasurer, Secretary of State, North Carolina Attorney General, AARP North Carolina, North Carolina Bankers Association, savings and loan associations, Carolinas Credit Union League, North Carolina Bar Association (Elder and Special Needs and Estate Planning and Fiduciary Sections), North Carolina Partnership to Address Adult Abuse, North Carolina Guardianship Association, Rethinking Guardianship statewide stakeholders workgroup, family and caregiver representatives, and other community partners.

Recommendation 6.2: Incorporate legal protection issues specific to people with Alzheimer’s disease or related dementias into health, legal, and financial professional training.

Offer continuing education on the types and unique requirements of various legal protections for people with Alzheimer’s disease or related 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.

- a) Trainings 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 and building collaborations between sectors.
- b) Trainings should include special considerations and information on identifying and working with people with Alzheimer’s disease and related dementia, including training for Adult Protective Service workers, court officials, and others, to ensure a minimum level of competency in identifying and serving people with dementia, including identifying people with reduced decision-making capacity.
- c) Incorporate techniques used by law enforcement to recognize elder abuse and fraud into health and legal professional training.

Partners: North Carolina Academy of Physician Assistants, North Carolina Academy of Family Physicians, North Carolina chapter of the American College of Physicians, Office of the Attorney General, the Senior Consumer Fraud Task Force, North Carolina Partnership to Address Adult Abuse, the Department of Justice, and other law enforcement entities.

Recommendation 6.3: Examine state statutes to determine adequate legal safeguards and protections for people with Alzheimer's disease or related dementia.

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 and ongoing initiatives for Adult Protective Services and guardianship to determine if the state is adequately providing the needed protections for older and disabled North Carolinians. A preliminary/interim report from the workgroup, along with recommendations for any changes to state statutes, should be submitted to the North Carolina 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 December 15, 2016, with a final report by April 1, 2017.

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, including the passage of House Bill 817 from 2015 (Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act).
- b) Gaps in current state statutes.
- c) Implications of the federal Elder Justice Act on state responsibilities.
- d) Adequacy of existing resources and training needed to protect vulnerable adults, and what expansion is needed.
- e) Reporting of abuse, neglect, or exploitation and penalties for not reporting.
- f) Determining competence and the role, process, and frequency of use of multidisciplinary evaluation.
- g) Establishing jurisdiction for responsibility.
- h) Data assessment of increase in need for services, and strategies to address this growth.
- i) Assessment of legal proceedings to prosecute exploitation and alternatives to strengthen process.

Lead: North Carolina Division of Aging and Adult Services.

Partners: Agencies and organizations participating in the workgroup should include: Alzheimer's North Carolina, Disability Rights North Carolina, the North Carolina Administrative Office of the Courts, Alzheimer's North Carolina, the North Carolina Association of County Directors of Social Services, the North Carolina Bar Association, the North Carolina Coalition on Aging, the North Carolina Conference of Clerks of Superior Court, the North Carolina Council on Developmental Disabilities, the North Carolina Guardianship Association, Rethinking Guardianship statewide stakeholder workgroup, North Carolina Partnership to Address Adult Abuse, the North Carolina Department of Justice, the North Carolina Office of the Attorney General, North Carolina Conference of District Attorneys, the North Carolina Administrative Office of the Courts, the UNC School of Government, state legislators, and consumer and family representatives.

Recommendation 6.4: Integrate elder fraud and abuse data to improve services for people with Alzheimer's disease or related dementia.

In order to improve case management operations and allow individuals to more efficiently and effectively receive services from several organizations/agencies, the lead organization should pursue county integration of elder fraud and abuse data through North Carolina Families Accessing Services through Technology (NCFAST). This should include:

- a) Inclusion of Adult Protective Service/guardianship data in county integration.
- b) Capacity to cross reference public assistance programs to reduce duplicative efforts and assist with locating vulnerable adults.
- c) Examination of existing case management operations and how data can be used at the population level to improve services and abuse/fraud protection.

Lead: North Carolina Department of Health and Human Services.

Recommendation 6.5: Improve home safety resources and workforce capacity.

In order to ensure home safety for people with Alzheimer’s disease or related dementia, organizations/agencies should work to:

- a) Enhance and promote falls and injury prevention programs for both people with Alzheimer’s disease or related dementia and their caregivers, as aligned with the goals of the North Carolina Falls Prevention Coalition.
- b) Promote awareness of available home safety assessment services through physical therapy and occupational therapy providers and available financial assistance/reimbursement.
- c) Address home safety assessment workforce, reimbursement, and incentives.
- d) Explore use of innovative technology in home safety, including web-based monitoring devices, and promotion of existing low-tech solution, innovative technologies to address home safety, and potential return on investment for such technologies.
- e) Utilize training resources on initiating conversations with people with Alzheimer’s disease or related dementia and families about proactive preventive steps to reduce fall risk.

Partners: Departments of Social Services, Area Agencies on Aging, primary care providers, adult residential facilities, hospice providers, home care agencies, and other relevant agencies.

Recommendation 6.6: Enhance public safety and law enforcement outreach for Alzheimer’s disease and related dementia.

To increase safety in the community for people with Alzheimer’s disease or related dementia, partners should work within the guidelines of the Dementia Friendly America Initiative to:

- a) Expand the utilization of locator devices and promote programs such as Silver Alert.
- b) Increase and promote professional training opportunities and explore setting a minimum standard of training for emergency workers (including fire and emergency medical services), law enforcement officers, and other first responders on dementia symptoms, common behaviors (such as wandering), and individual/community safety concerns.
- c) Collaborate with the North Carolina Department of Motor Vehicles Medical Evaluation Program on outreach work with physician and health professional training groups to promote existing tools that measure cognitive ability and impairment; promote resources for health care providers about safe driving and starting conversations about safe driving with individuals with Alzheimer’s disease or related dementia and their families; and develop protocols for referring individuals with revoked driver’s licenses to community resources and transportation options.

Partners: North Carolina Department of Public Safety, the North Carolina Department of Justice, consumer advocacy groups, and the North Carolina Division of Aging and Adult Services.

Recommendation 7.1: Support research through the establishment of a statewide collaborative registry.

Establish a statewide registry/clinical trials network of people diagnosed with Alzheimer’s disease and related dementia and healthy individuals, in order to better inform research into Alzheimer’s disease and related dementia treatment and prevention. The collaborative network should:

- a) Build on the existing work of the Memory and Brain Aging Research Coalition (MBARC) to expand partnerships, establish continued funding, and determine appropriate methods of sustainability.
- b) Focus on inclusion of underserved and underrepresented populations in Alzheimer’s disease and related dementia treatment, prevention, and clinical trial participation.
- c) Work to apply research findings to education/awareness campaigns on Alzheimer’s disease and related dementia prevalence, symptoms, and opportunity for participation in clinical trial research.
- d) Promote the ways in which a statewide registry may have a positive economic impact on North Carolina.

Lead: Academic institutions, including Duke University, University of North Carolina at Chapel Hill, Wake Forest University, North Carolina A&T University, North Carolina State University, Appalachian State

University, Western Carolina University, University of North Carolina at Asheville, and University of North Carolina at Wilmington.

Partners: Philanthropic organizations, Alzheimer’s North Carolina, and the Alzheimer’s Association.

Recommendation 7.2: Continue inclusion of cognitive impairment and caregiver modules of the Behavioral Risk Factor Surveillance System.

In order to better track the demographic and economic impact of Alzheimer’s disease and related dementia on the state of North Carolina, dementia advocacy groups should continue to fund the cognitive impairment module of the Behavioral Risk Factor Surveillance System on a five-year interval, measuring self-reported cognitive decline, and consider continued inclusion of the caregiver module at an appropriate interval. Resulting data should be used to inform public awareness campaigns and data dissemination efforts by state policymakers, state agencies, and advocacy organizations. Data should also be analyzed for potential connection with other behavioral and lifestyle risk factors tracked by the statewide survey.

Lead: State Center for Health Statistics and dementia advocacy organizations.

Recommendation 7.3. Improve prevalence data through accurate death certificate completion.

In order to improve data collection on rates of death from Alzheimer’s disease and related dementia, the lead agency and partners should offer continued medical education training on the identification of Alzheimer’s disease and related dementia as cause of death and the importance of accurate identification of Alzheimer’s disease and related dementia. Medical schools and residency programs should also offer education and training in this area.

Lead: North Carolina Office of the Chief Medical Examiner.

Partners: North Carolina Area Health Education Centers programs and the Office of Vital Records.

Recommendation 7.4: Improve data on Alzheimer’s disease and related dementia prevalence through implementing a statewide data reporting system.

Collaborate to create a statewide, mandatory data reporting system to enhance claims transparency for medical care and health care services and improve prevalence and diagnosis data for Alzheimer’s disease and related dementia. This collaborative effort should include input from additional stakeholders on database use and access, and participating stakeholders should include employers, provider professional associations, private and public payers, community members, consumer advocates, academic and clinical researchers, and the pharmaceutical and data management industry.

Lead: North Carolina General Assembly.

Partners: North Carolina Department of Insurance, the North Carolina Department of Health and Human Services, health care systems, and insurers.