# Chapter Six: Promoting Meaningful Participation in Community Life

Cognitive function decline accompanies the progress of Alzheimer's disease and related dementias. This loss of cognitive capacity and function is devastating for individuals and their families. It also creates a legal problem because the law assumes that an adult has the ability to make rational decisions about their property, health care, financial care, and personal care. As cognitive capacity is lost, individuals are at greater risk for abuse, neglect, and exploitation. In addition, the safety of an individual with Alzheimer's disease and related dementia can be significantly impacted by the disease, both within the home setting and in public. Safety can be limited by changes in cognitive capacity, including a decline in memory, problem solving, and judgment. Depending on other chronic or sensory conditions, people can experience problems with balance, falls, or vision.

**"Guardianship in North Carolina is a legal relationship in which one individual is authorized by the clerk of superior court to have decision-making authority for an adult declared incompetent.**

The Task Force examined the legal protections and safety-related issues for people with Alzheimer's disease or related dementia, and issued recommendations for improvement. Through these recommendations, the Task Force aims to improve community life and promote community engagement for individuals with Alzheimer's disease or related dementia.

### *Legal Protections for People with Alzheimer's Disease or Related Dementia*

*Guardianship*

If an individual's disease has progressed to the point where he or she is no longer able to handle finances, make health care decisions or other important life decisions, and advance directives have not been put in place, then a legal guardian may need to be appointed by the courts to act on behalf of the incapacitated individual. Guardianship in North Carolina is a legal relationship in which one individual is authorized by the clerk of superior court to have decision-making authority for an adult declared incompetent. Guardianship in North Carolina can take one of three forms: guardian of the person, guardian of the estate, or general guardian (both person and estate).[a] Depending on the type of guardianship, decisions may include authorizing medical treatment, managing finances, making decisions about where an individual will live, and consenting to recreational activities. Public and corporate guardians of the person are required to file annual status reports with the clerk of court; all general guardians and guardians of the estate are required to file annual accountings with the clerk of court.

While there is often broad variation in the process of appointing a guardian for an individual, the general process begins with the filing of a petition with the clerk of superior court, alleging that an adult should be declared incompetent. After a petition is filed, the clerk may order medical, psychological, social work, and other evaluations of the individual. Ideally, a multidisciplinary evaluation is an important source of information the clerk uses when determining competency; however, this type of evaluation can be cost prohibitive or time prohibitive, so many courts rely on family members, medical and behavioral health providers, and county social services staff members to provide information in the determination hearing. There is no data regarding the number of guardianship hearings that use a multidisciplinary evaluation to determine competency. If an individual is found incompetent, the clerk then makes a determination of what type of guardianship is needed and who can best serve as guardian.

Identifying willing and able family members to serve as guardian is typically the starting point for naming a guardian. When a guardian is appointed, North Carolina statutes require that individual guardians be considered first, corporations second, and disinterested public agent guardians (county departments of social services) as last resort. In instances where there are no appropriate family members or friends willing to serve in this role, a guardianship corporation or disinterested public agent can be appointed by the clerk of court for the individual. In SFY 2014, local departments of social services served as the guardian for 4,328 adults. It is projected that this number will rise to approximately 7,000 adults by 2017, due to growth in the number of younger adults with disabilities living in community-based settings, retirees settling in North Carolina, increased family mobility, and financial exploitation.[b,c] In addition, it is estimated that approximately 25% of Americans over age 65 are or may become physically

a §NCGS 35A: Incompetency and Guardianship
b Bethel M. Director. North Carolina Coalition on Aging. Written (email) communication. December 12, 2015.
c Warren N. Program Administrator. North Carolina Department of Health and Human Services. Written (email) communication. January 12, 2016.

or socially isolated and lack a close family member or friend to care for them. Known as "elder orphans," these individuals may be especially susceptible to needing public guardianship.[1]

*Elder Financial Abuse*

Elder financial abuse includes both financial exploitation and elder fraud. Financial exploitation is defined in NCGS 108A Articles 6 and 6A as the illegal or improper use of a disabled adult's resources for another's profit or advantage and includes such things as taking money or property by coercion, undue influence, or false pretenses; forging an adult's signature to legal documents such as deeds or wills; and misuse of a power of attorney. Financial exploitation is also a criminal offense defined in NC G.S 14-112.2, "Exploitation of an older adult or a disabled adult."[d] Elder fraud includes targeting older adults with promises of goods, services, financial benefits, or other false pretenses for financial gain. Perpetrators of elder financial abuse can be family members, trusted professionals, fiduciaries, caretakers, predatory individuals, or dishonest businesspeople.[2]

**"Adults with Alzheimer's or related dementias may be at risk for physical or emotional abuse, neglect by caregivers, self-neglect, or exploitation.**

Older adults are commonly targeted for financial fraud because they often have significant assets and are often more likely to be vulnerable.[2] Older adults with Alzheimer's or related dementias are particularly at risk for fraud. Research has shown that the ability to manage finances is one of the first instrumental activities of daily living to decline in individuals with Alzheimer's and that these skills worsen rapidly.[3] Thus, individuals who may not need high levels of assistance with other activities of daily living may be at high risk for financial victimization. In 2014, such frauds contributed to losses over $10 million, with the vast majority of elder financial fraud going unreported.[4] Financial fraud is rarely reported and can be quite difficult to prosecute, particularly if the older adult has Alzheimer's and is presumed to be incapable of providing testimony. If the perpetrator is someone who has been granted power of attorney by the defrauded adult, criminal prosecution is very difficult.[e]

*Adult Protective Services*

Adults with Alzheimer's or related dementias may be at risk for physical or emotional abuse, neglect by caregivers, self-neglect, or exploitation (defined as, "illegal or improper use of the disabled adult or his/her resources for another's profit or advantage").[5] In North Carolina, cases of suspected adult maltreatment are referred to the local Department of Social Services (DSS). Local DSS offices investigate reports that meet criteria laid out in NCGS 108A Article 6 (see Figure 6.1). In FYs 2013-2014 and 2014-2015, more than 24,000 cases were reported to North Carolina DSS offices and over half were evaluated. Abuse, neglect, or exploitation were confirmed in 44% of the cases evaluated. [5]

If the need for protective services is substantiated, then Adult Protective Services (APS) is required to provide or arrange for protective services. APS can only take action if the adult is disabled (incapacitated), has been abused, neglected, and/or exploited; is in need of protective services; and is willing to accept services (if she/he has the mental capacity to do so). Alternatively, DSS must be given legal authority when the adult does not have capacity to accept or refuse protective services. In some cases an adult may be the victim of abuse, neglect, or exploitation, but if the adult has the capacity to make decisions on their own behalf, even poor ones, their right to self-determination must be respected by APS. If the adult is willing to accept services, APS can provide protective services, either through consent or court order, including services to improve home care, assistance with long-term care placement, case management, or appointment of a guardian. North Carolina's APS statute requires anyone with reasonable cause to believe that a disabled adult needs protective services to make a report.[f]

**Figure 6.1: North Carolina Adult Protective Services Criteria**

**Disabled-incapacitated by a physical or mental impairment, meaning the consumer cannot complete daily activities or handle his/her affairs or protect interests. (Developmentally or intellectually disabled, cerebral palsy, epilepsy or autism, organic brain damage caused by advanced age or other physical degeneration in connection therewith; or conditions incurred which are the result of accident, mental or physical illness, or continued consumption or absorption of substances.)**

**Abused, neglected, and/or exploited (already occurred).**

**Unable and unwilling to obtain essential services him or herself OR in a situation where no one willing, able and responsible to obtain essential services on their behalf.**

Source: Eller, J. Guardianship and APS in NC http://www.nciom.org/wp-content/uploads/2015/03/IOM-Guardianship-and-APS.pdf

d §NCGS 35A: Incompetency and Guardianship
e Smith T. Special Prosecutor, North Carolina Conference of District Attorneys. Written (email) communication. December 14, 2015.
f §NCGS 108A: Articles 6 and 6A

*Education on Legal Protections and Vulnerabilities*

Individuals with Alzheimer's disease or related dementia and their families must navigate complex legal, medical, and financial issues. These issues are further complicated by the need to address them as early as possible while the affected individual is still capable of engaging in meaningful dialogue about what they hope for in terms of the way they want to live, how they want to be cared for, what sort of medical treatment they prefer, financial planning, and other critical questions that will impact their life.

While there is often insufficient guidance for individuals and families about the need for advanced legal and financial planning for individuals with Alzheimer's, there is also opportunity to improve awareness and education about these issues.

**"Planning for the possibility of needing extensive and/or long-term care is crucial for families facing Alzheimer's disease or related dementia.**

Planning for the possibility of needing extensive and/or long-term care is crucial for families facing Alzheimer's disease or related dementia. Many organizations and programs provide guidance in navigating the types and logistics of available services, but families also need assistance in developing a plan to pay for these services. Clarification on what types of service are paid for by each payer (including Medicare, Medicaid, private health insurers, and long-term care insurance) is particularly important.

In 2015, the Centers for Medicare and Medicaid Services issued two new Medicare billing codes, allowing qualified health care professionals to be reimbursed by Medicare for the time spent discussing advance care planning and end-of-life decisions with patients and families. The advance care planning discussions covered by Medicare aim to incentivize health care professionals to assist families in determining the types and extent of long-term care they wish to receive at the end of life, and to share these decisions with family members, friends, and health care professionals.[6]

It is also important for families to understand state regulations on advanced health care directives. Ideally, individuals with Alzheimer's disease and related dementias are diagnosed early enough in the progression of the disease that they have time to make advanced health care directives, including advanced directives for a natural death (also known as a living will), preferences for mental health treatment, and organ donation. Individuals may also appoint, in advance, a substitute decision-maker who they know and trust to make health and care decisions for them—a health care power of attorney. Once appointed health care power of attorney, this person is then able to consent to medical treatment, withhold or withdraw life prolonging treatment, and make other treatment decisions as described above.[7] Individuals diagnosed with Alzheimer's disease or related dementias should complete such directives early in their illness, if possible, in order to assist their families in medical decision-making once the individual is no longer capable of making health care decisions.

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**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.

In addition to educating individuals with Alzheimer's disease and related dementia and their families, there is a need to educate health and legal professionals about the various legal protections for these individuals. It is important that education and discussions about end-of-life care planning, elder fraud and abuse, and other legal issues facing individuals with dementia and their families be discussed as early in the disease progression as possible. Currently the North Carolina Department of Justice offers training classes for law enforcement on identifying financial fraud, insurance fraud, and crimes in long-term care facilities. In addition, the Area Health Education Centers and various university and college training programs offer courses in legal protections for health care professionals. In order to provide the greatest benefit for people with Alzheimer's disease or related dementia, there should be interdisciplinary commitment to the intersection and collaboration of these various types of trainings and intended professional audiences.

**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 Area Health Education Centers programs, North Carolina Bar Association, financial organizations/banks, Departments of Social Services/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, 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.

*Statewide Effort Toward Enhancing Legal Protections*

In recent years, North Carolina state agencies and advocacy organizations have examined the adequacy of state statutes and regulations around the vulnerabilities of elder adults. In January 2012, the Task Force on Fraud on Older Adults was convened; the Task Force met through 2013. Co-chaired by Senator Bingham and Representative Blackwell, the goals of the Task Force included:

(1) Identifying, clarifying, and strengthening laws to provide older adults a broader system of protection against abuse and fraud.

(2) Establishing a statewide system to enable reporting on incidents of fraud and mistreatment of older adults.

(3) Identifying opportunities for partnership among the State Banking Commission, the financial management industry, and law enforcement agencies to prevent fraud against older adults.

(4) Granting the Attorney General authority to initiate prosecutions for fraud against older adults.

The work of the task force resulted in passage of Session Law (hereinafter S.L.) 2013-337; S.L. 2013-203; S.L. 2014-115, § 44. This includes NCGS 108A Article 6A. This law aims to make it easier for departments of social services to access financial records when investigating reports of financial abuse.[8]

In addition, the Public Guardianship Subcommittee was a short-term legislative subcommittee appointed for the 2013-2014 General Assembly session with the intent of studying the adequacy of state adult protective services and guardianship regulations. While the Subcommittee's membership was solely comprised of legislators, they also consulted with many public and private individuals when crafting their recommendations. Recommendations included: maintain the state's publicly funded guardianship model; provide adequate resources for public guardianship services; implement standardized procedures to ensure appointment of a publicly funded guardian when there is no other appropriate individual to serve; and continue the study of other methods of improving the state guardianship system.[9] The subcommittee terminated when its report was issued in 2014, and limited action has been taken to date on the recommendations.[g]

Convened by the Jordan Institute for Families at the University of North Carolina at Chapel Hill, the Rethinking Guardianship working group completed the first of three years of work in late 2015. This group seeks to build upon the work of the other guardianship initiatives and apply a collaborative approach and focused inclusion of family and community members to the issue of guardianship protections. The Rethinking Guardianship group has identified gaps in existing data on guardianship statutes, eligibility, and capacity.[h]

In the 2014 legislative session, House Bill 817 was introduced and passed the House with a unanimous vote. This bill, called the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (often referred to as UAGPPJA), would propose a set of rules for transferring guardianship from one state to another, allow states to recognize other states' guardianship orders, and create a process for establishing guardianship jurisdiction.[i, 10] Following passage in the House, the bill is currently in the Senate Rules Committee. Currently, North Carolina is one of only eight states that has not passed the UAGPPJA.[10]

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**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 statues 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.

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g Bethel M. Director. North Carolina Coalition on Aging. Written (email) communication. December 12, 2015.
h Massey-Smith J. Social Services Adult Program Representative. North Carolina Department of Health and Human Services. Written (email) communication. December 15, 2015.
i North Carolina General Assembly. Enact Uniform Law on Guardianship. House Bill 817. Session 2015. April 30, 2015.

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.

*Data Systems to Improve Legal Protections*

North Carolina Families Accessing Services through Technology (NC FAST) serves as the statewide public assistance and data management and integration system. NC FAST aims to provide a quick and efficient system for county departments of social services to access case management tools and to evaluate case management and integration outcomes. To provide the necessary tools for counties to view information on vulnerable adults from county to county and to enhance their protection from abuse, neglect and, exploitation, North Carolina needs an integrated case management system. This would provide more accountability and the ability to track persons across counties who may have a history of abuse, neglect, or exploitation against a vulnerable adult. An integrated system allows the state to focus on improving outcomes for vulnerable individuals. Using one common data model results in a more comprehensive view of individuals and can be used to drive improvement of the data systems.

While NC FAST is currently in the active implementation phase for several intended services, including child nutrition programs, child care, child protective services, and Medicaid, the integration of data from the Division of Aging and Adult Services (including Adult Protective Services) is not scheduled to be completed until June 30, 2018 at the earliest (possibly later and contingent upon funding).

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**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.

***Individual and Home Safety Resources***

While older adults overall tend to be the most vulnerable age group for injuries and falls, those with Alzheimer's disease or related dementias are at an especially high risk. Studies show an annual falls incidence as high as 60% among individuals with dementia; seniors with Alzheimer's or related dementias in particular are three times more likely to suffer from hip fractures due to falls than other older adults.[11] Injuries due to falls often require surgery and long-term hospitalization, further worsening disability for an afflicted individual. Research shows that injuries such as a broken hip can increase the likelihood for a person with Alzheimer's disease or related dementia to no longer be able to be cared for in the home.[12]

**"People with Alzheimer's disease or related dementias are at an especially high risk for injuries and falls.**

The American Geriatrics Society has developed a clinical practice guideline for falls prevention, recommending that all older adults should be questioned annually regarding falls, frequency of falling, and difficulties with gait or balance.[13] Evidence-based guidelines according to the Alzheimer's Association and Centers for Disease Control and Prevention also recommend regular assessments to determine a person's fall risks.[14] These recommendations include consultations with a physical therapist for mobility issues and an occupational therapist for assistance with activities of daily living.[15]

The Alzheimer's Association also suggests an environmental assessment in the home for arrangement of furniture and safety of the layout of the space. Providers can use these assessments to develop a care plan to improve mobility and safety of an individual with Alzheimer's to prevent injury in the home. Other evidence-based practices include training caregivers on dementia care and ways to reduce falls risk.[166] The North Carolina Falls Prevention Coalition goals are in line with the recommendations of the Alzheimer's Association, with an emphasis on evidence-based practices supported by research including risk assessments, care plan formation, and home safety monitoring.[16]

There are many innovative technological resources to improve caregiving and quality of life for individuals afflicted with Alzheimer's disease or related dementia. Comfort Zone, developed by the Alzheimer's Association, is a comprehensive web-based location management service. This tool allows families to remotely monitor a person with Alzheimer's by receiving automated alerts throughout the day and night when a person has travelled beyond a preset zone.[17] The check-in service allows for an on-demand "find me" function to alert caregivers of the location of an individual.

Assistive technology products have also been designed to support patients with cognitive impairment. Some electronic products assist with tracking misplaced items using an electronic tag. Some telephones offer speed dialing capabilities for people who cannot remember phone numbers or are unable to look them up. Other technological tools include automated pill organization systems and medication reminders, as well as medication dispensers to prevent drug misuse or overdose.[18] While these tools range in price, private insurance can cover certain assistive technology if prescribed by a physician. The cost of Alzheimer's products and services beyond in-home care are not covered by Medicare or Medicaid but can be supported by state-funded Family Respite Care Grants and funding from the Alzheimer's Foundation of America.[19]

Medication-related problems also pose a risk to people with Alzheimer's who may be on multiple prescriptions for other conditions as well. Safety can be compromised due to potential drug interactions or accidental misuse, leading to drug overdose or other health conditions. Key recommendations for caregivers include assessing the home for hazardous areas or items; ensuring the home is equipped with working safety devices; installing locks out of sight; adding additional lights to walkways; removing, locking, or disabling guns and other weapons; and removing tripping hazards. The Caregiver Center of the Alzheimer's Association offers an Alzheimer's navigator tool to provide free, customized home safety checklists. In North Carolina, the Alzheimer's Association of Eastern North Carolina, Alzheimer's Association of Western North Carolina, and Alzheimer's North Carolina also provide resources for support groups and education programs to ensure necessary guidance for caregivers.

With a common goal of ensuring home safety for people with Alzheimer's disease and improving access to statewide resources, the Task Force recommends additional work on the part of North Carolina organizations and agencies for improved resources and expanding awareness of evidence-based practices to improve home safety.

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**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.

***Public Safety for Individuals with Alzheimer's Disease or Related Dementia***

As Alzheimer's disease and related dementia progresses, individuals increasingly face behavioral symptoms that may pose a safety threat to themselves or to others in the community. Wandering and/or getting lost is a significant problem for people with dementia, even in early stages of the disease; six in ten people with dementia will wander from home or other familiar places.[20] These individuals may experience difficulty remembering their name and home address and experience confusion and disorientation.[20]

**"Often the conversation about when is the appropriate time for a person with dementia to stop driving must start within the family.**

The North Carolina Silver Alert program is administered by state and local law enforcement and the North Carolina Center for Missing Persons to protect individuals that suffer from dementia or other cognitive impairment.[21] Designed to quickly disseminate descriptive information about missing persons, the system is activated when a family or caregiver reports a missing person to law enforcement, and identifies the person as having dementia. Law enforcement agencies then determine if the criteria warrant a Silver Alert and, if initiated, all law enforcement agencies are notified via a statewide bulletin. The North Carolina Center for Missing Persons updates this information on its website and notifies local media, including radio and television, on description information regarding the missing person. The North Carolina Department of Transportation is also requested to activate highway message signs.[21] There is currently no system in place to involve social media or mobile technology.

Law enforcement personnel and first responders are not currently required by law in North Carolina to be trained on dementia. According to a nationwide survey in 2015, only 10 states were found to have laws requiring dementia training on symptoms and behavioral management for law enforcement personnel, including Colorado, Florida, Indiana, Maryland, New Hampshire, New Jersey, Oklahoma, Oregon, South Carolina, and Virginia.[22] Dementia training standards tend to be general surrounding the dangers of wandering or getting lost, the course of Alzheimer's disease, and how law enforcement can best handle difficult situations safely.[22] The National Council of Certified Dementia Practitioners has developed a training module for first responders, called the Certified First Responder Dementia Trainer. This module includes an overview of dementia symptoms, stages, common behaviors (including wandering, getting lost, and other safety concerns), communication strategies, and multicultural considerations. The US Department of Justice and Alzheimer's advocacy organizations have also developed toolkits and training resources for first responders.

Mental and behavioral health training programs law enforcement and first responders may apply to people with Alzheimer's and related dementias. The Crisis Intervention Team of the National Alliance on Mental Illness offers support and training to law enforcement to identify and respond to situations involving individuals with mental illness.[23] The North Carolina Geriatric/Adult Specialty Teams (GAST) also provides training for health providers and community workers in symptoms of mental illness in older adults. GAST aims to improve communication, assessment procedures and techniques, and referral systems for older adults with mental health symptoms.[24]

In order to promote safe driving, the North Carolina Division of Motor Vehicles administers the Driver Medical Evaluation program to review individuals with medical problems that may increase risk for motor vehicle accidents.[25] The Division of Motor Vehicles and the Department of Health and Human Services require persons to disclose if they are experiencing medical conditions that affect cognitive ability, including dementia. Driver licenses can be restricted or revoked if an individual exhibits risk of driving impairment on the basis of a medical condition.[25]

Unfortunately, regulatory efforts to address safe driving are not sufficient. Often the conversation about when is the appropriate time for a person with dementia to stop driving must start within the family, as family members are often the first to notice when cognitive symptoms begin to impact driving skills. Health

care providers can also provide guidance on resources for families about safe driving, discussions on driving, and alternative transportation options.[26]

**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.

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