Chapter Four: Having Supportive Options that Foster Quality of Life

For individuals with Alzheimer's disease or related dementia, it is crucial that care be appropriate, tailored to individual needs, and available when needed. As with most people, individuals with Alzheimer's disease or related dementia want to remain in their own homes and communities for as long as possible. As described in Chapter 5, the vast majority of care is provided by untrained and unsupported family caregivers.

The Task Force examined many aspects of care for people with Alzheimer's disease or dementia and issued recommendations for long-term services and supports, improvement of health system capacity, access to treatment, overall quality of care, care coordination, and training for health care professionals.

Long-Term Services and Supports

Among all adults age 65 and over, not just those with Alzheimer's disease or related dementia, there is a 70% chance of needing some type of long-term services and supports, and 20% of adults over 65 will need these services for longer than five years.[1] For people with Alzheimer's or related dementia, nearly all will require long-term care of some kind, and 75% of people with Alzheimer's are admitted to a nursing home by age 80.[2] Annual per-person Medicaid spending for older adults with dementia is 19 times higher than for older adults without dementia, and more than 74% of people with dementia also have other chronic conditions, leading to more complicated and costly long-term care.[2] There are a broad range of long-term services and supports that provide varying levels of medical care and non-medical care, including assistance with activities of daily living. Long-term services and supports can be provided in the home, in a community setting, or in a designated long-term care facility. Due to the range of types and locations of long-term services and supports, there is also a range of payment systems for these different types of care.

Activities of Daily Living

Activities of daily living (ADLs) are every day, personal tasks such as bathing, dressing, eating, toileting, and moving around within the home. Other activities, called instrumental activities of daily living include housework, financial management, medication management, meal preparation, shopping, and responding to emergency alerts.

Source: Administration on Aging. Who will provide your care? US Department of Health and Human Services website. http://longtermcare.gov/the-basics/who-will-provide-your-care/. Accessed February 26, 2016.

Long-term Services and Supports

Long-term services and supports include a wide range of paid and unpaid medical and personal care assistance that people may need – over many weeks, months, or years – when they have difficulty completing self-care tasks as a result of aging, chronic illness, or disability. These services can be provided at home, in a community setting, or in an institutional setting such as a nursing home.

Source: Reaves EL, Musumeci M. Medicaid and long-term services and supports: a primer. Kaiser Family Foundation website. http://kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/. Published December 15, 2015. Accessed January 24, 2016.

Home- and Community-Based Supports

Home-based long-term supports and services from unpaid caregivers constitutes the vast majority of long-term care. Additional care needs such as home health care following surgery or illness; physical, occupational, or speech therapy; or other temporary health needs, are usually provided by paid home health providers. Other paid home-based long-term care may include personal care and assistance with activities of daily living, such as laundry and cooking, as well as instrumental activities of daily living and companion services.[3]

Community-based long-term supports and services consists of services intended to delay or prevent institutionalization and help people remain at home as long as possible. These services often include adult day care services, home delivered meal services, transportation assistance services, senior centers, in-home aide services, and respite care for unpaid caregivers. These services vary by community and are provided by government agencies, such as social services or health and human services, or private organizations.[3] (See Chapter 5 for additional information on home- and community-based services.)

Long-Term Care Facilities

Long-term supports and services are provided within residential facilities. There are a variety of levels of care provided in long-term care facilities. Adult care homes are private facilities, with a broad range in number of residents, who live in private or shared rooms and receive assistance with personal care, but not medical care. While all non-skilled facilities are called adult care homes, those with eight or fewer residents are called family care homes and larger facilities are called assisted living facilities. Within assisted living facilities, more than 7 out of 10 residents have some form of cognitive impairment (29% with mild impairment, 23% with moderate impairment, and 19% with severe impairment).[4] Adult care homes provide a few levels of assistance with activities of daily living, but not as much care as is provided in a skilled nursing facility. Services may include meals, housekeeping, and social activities.

> **“Within assisted living facilities, more than 7 out of 10 residents have some form of cognitive impairment (29% with mild impairment, 23% with moderate impairment, and 19% with severe impairment).**

A skilled nursing facility, also referred to as a nursing home, provides more intensive personal and health care, often including nursing care, supervision, and rehabilitation services. Skilled nursing residents are those who need short-term care following an injury or illness, as well as those who require care for a longer period.[5] Within skilled nursing facilities, there are often special care units, special sections, or programs designated especially for residents with Alzheimer's disease or related dementias.[6] Differences in staffing ratios are critical to differentiate skilled nursing facilities from other residential settings such as adult care homes. Skilled nursing facilities are staffed 24 hours a day, 7 days a week, by nursing staff and must follow federal staffing regulations if they accept Medicare or Medicaid payment for care.[a]

> **“In North Carolina, 12% of hospice patients have dementia as their primary diagnosis and 67% of hospice patients over age 75 have dementia as a secondary diagnosis.**

Continuing Care Retirement Communities

Continuing care retirement communities also provide long-term supports and services. The range of services needed by residents in these communities includes assisted living care, skilled nursing care, and other health care, along with social engagement, recreation, and often independent living arrangements within the same location. These types of living arrangements are private pay only and are not supported by Medicaid or Medicare, thus are often only affordable and accessible for a small proportion of those with Alzheimer's disease or related dementia.

Hospice Care

For people who are terminally ill, hospice care is often provided at home or in a nursing or hospice facility. Hospice care teams provide care when a person is expected to live six months or less. Hospice care includes palliative medical care to alleviate pain and symptoms, counseling, respite, and grief support.[7] Patients are referred to hospice care by several sources, including hospitals, physicians, or skilled nursing facilities.[8] In North Carolina, 12% of hospice patients have dementia as their primary diagnosis and 67% of hospice patients over age 75 have dementia as a secondary diagnosis. People with Alzheimer's disease or related dementias must have very advanced disease, be unable to walk or speak, and also have another serious condition to be eligible for hospice care. Because of the unpredictable nature of dementia progression and the requirement that hospice care only be provided for the last six months of life, there are many challenges providing people with Alzheimer's disease and related dementias with appropriate hospice services.[b]

Palliative Care

Palliative care is similar to hospice care, with symptom management as its goal, only it is more broadly applied to people throughout the course of disease, not solely in the last few months of life, and has a team-based approach to in-depth communication with and support of patients and families. Because of the difficulties in terms of accurate prognosis, palliative care may be an appropriate option for people with Alzheimer's disease or related dementia. Research has shown that both hospital-based and community-based palliative care can decrease health care costs for payers and individuals.[9]

In North Carolina, many hospice providers have palliative care specialty programs, with physicians, nurses, physician assistants, and social workers included in care teams. Other models of palliative care include palliative consult teams within hospitals, and home-based palliative care, which can also assist with transitions from acute care settings to home care settings. Throughout the state, access to palliative care specialists varies. Community palliative care services, including outpatient clinics, home-based care, or institutional care, is still the area of greatest need, and rural counties in the east and far west portions of the state have the least access to these services. Large hospitals are most likely to have palliative care consultation and services.

Community Care of North Carolina administers a Palliative Care Initiative throughout its network. This program aims to promote better care at the end of life through enhancing access to and information about palliative care throughout the health care system, increasing communication and person/family autonomy within palliative care, and improving education for health care providers about the clinical and socioemotional tools they can use in discussing and providing palliative care.[10] Community Care of North Carolina's initiative has shown substantial cost savings for participating patients, as well as fewer hospital days and more use of hospice services. Average cost savings were $1,661 per patient, per month, and an estimated total of $2 million in savings among patients receiving the intervention.[11]

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[a] Gwyther L. Duke Family Support Program, Duke University Medical Center. Written (email) communication. January 10, 2016

[b] Fischer J. Physician Consultant. Community Care of North Carolina. Written (email) communication. February 3, 2016

Public Payment Options for Long-Term Services and Supports

For families needing long-term services and supports for family members with Alzheimer's disease or related dementia, the array of options can be extremely difficult to navigate. Adding to this difficulty is the confusion of determining eligibility for services and who pays for the different types of services. Costs for long-term services and supports can be staggeringly high: in 2013, the median annual price for a nursing home in North Carolina was $77,471, much of which is not covered by insurance.[12] Even for less intensive care, the costs for long-term supports and services can be high, and non-medical services provided at home, such as personal care and assistance with activities of daily living, can prove to be a serious financial burden.

> **"In 2013, the median annual price for a nursing home in North Carolina was $77,471.**

Figure 4.1: Medicaid Spending for Long-Term Services and Supports (FY 2013)

Total Institutional: $1,494,718,273

Nursing Facilities: $1,155,379,762

Total Home- and Community-Based Services: $1,910,640,636

1915(c) Waivers (for Home- and Community-Based Services): $922,059,529

Personal Care: $452,127,786

Other Home- and Community-Based Services: $536,453,321

Percent spent on Home- and Community-Based Services: 56.1%

Note: Total institutional excludes nursing facilities; includes institutional care facilities for individuals with intellectual/developmental disabilities and mental health facilities (not listed above). See Chapter 5 for more information.

Source: Eiken S, Sredl K, Burwell B, Saucier P. Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2013: Home and Community-Based Services were a Majority of LTSS Spending. Ann Arbor, MI: Truven Health Analytics; 2015. https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/ltss-expenditures-fy2013.pdf. Accessed January 14, 2016.

Medicare

Many people with Alzheimer's disease or related dementia are over 65, meaning they likely receive health insurance coverage through Medicare. However, Medicare does not provide coverage for services that assist with activities of daily living, and only covers rehabilitation services such as physical therapy for a short period in the home; it does not cover continued assistance needed due to physical or cognitive impairment. Medicare pays for skilled nursing care within a long-term care facility for a maximum of 100 days.[13] Most private insurers pay for similar services as Medicare.

North Carolina Medicaid

In North Carolina, Medicaid provides health care coverage for low-income individuals requiring skilled nursing care. An individual's income must be less than the cost of care in the facility at the Medicaid rate, Medicaid must approve the need for the level of care, and the individual must pay some of the monthly cost of care, called the "patient monthly liability." The rest of the monthly cost is paid directly by Medicaid to the facility.[14] For individuals needing long-term care in a nursing facility who do not qualify for Medicaid and who remain in the facility for longer than the 100-day maximum covered by Medicare, most of the costs must be paid by the individual or their family.

Money Follows the Person often helps Medicaid recipients navigate the payment transition from nursing facilities to home-based care. Individuals work with their Local Contact Agency, which provides counseling on care options. If the individual has been in a nursing facility for at least three months, receives Medicaid, will require the same level of care received in the nursing facility, and is interested in returning to the community, he/she may apply for Money Follows the Person. If approved, Money Follows the Person will provide the individual with Medicaid waivers for aging in place, covering medical services received in a home setting.[15]

In North Carolina, the Department of Veterans Affairs also provides assistance (known as the Aid and Attendance pension benefit) for older veterans in need of long-term

Figure 4.2: Median Annual Rates for Long-Term Services and Supports in North Carolina (2013)[c]

Homemaker Services (Licensed)	Home Health Aide Services (Licensed)	Adult Day Health Care	Assisted Living Facility (One Bedroom – Single Occupancy)	Nursing Home (Semi-Private Room)	Nursing Home (Private Room)
$38,896	$40,040	$13,000	$34,800	$71,723	$77,741

Source: CareScout. North Carolina State-Specific Data from the Genworth 2013 Cost of Care Survey Richmond, VA: Genworth Financial; 2013. https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/North%20Carolina_gnw.pdf. Accessed December 8, 2015.

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[c] Median Annual Rates* are calculated based on the following:Homemaker Services - hourly rate multiplied by 44 hours per week, multiplied by 52 weeks Home Health Aide Services - hourly rate multiplied by 44 hours per week, multiplied by 52 weeks Adult Day Health Care - daily rate multiplied by 5 days per week, multiplied by 52 weeks Assisted Living Facility - monthly rate multiplied by 12 months Nursing Home - daily rate multiplied by 365 days

services and supports. This assistance can be used to pay for assisted living, skilled nursing facilities, or home-based care, including home-based care provided by a family member.[12]

Community Alternatives Program (CAP-DA)

For home-based long-term supports and services, such as homemaker services or home health aides, median annual prices in North Carolina range from $38,000 to $40,000. Community-based services, such as adult day services, respite care, or meal delivery, are less expensive, but adult day care, for instance, still has a median annual price of $13,000. In North Carolina, home- and community-based long-term services for people at risk of being institutionalized are provided under a Medicaid waiver, called the Community Alternatives Program for Disabled Adults (CAP/DA). This waiver covers services including adult day care, personal care, and caregiver respite services.[16] However, CAP/DA slots are capitated, meaning a specific number of slots are available per county. The current average waiting list for CAP/DA services is two years. CAP/DA is only available for low-income individuals who qualify for Medicaid coverage. Currently families of two must have a monthly income at or below $1,328; households of one must have a monthly income at or below $981 to be eligible for Medicaid.[17] Medicaid will pay for hospice care on a per diem basis for patients who meet eligibility criteria.[d] Under the current North Carolina Medicaid reform plans, services that are defined as optional (including hospice care) are excluded from the program requirements for qualifying provider-led entities and accountable care organizations.[d] Beginning on January 1, 2016, adults who are eligible for Medicaid (and adults who are dually eligible for both Medicaid and Medicare) can receive concurrent hospice care and care under the Personal Care Services program while living at home.[18]

Figure 4.3: Services Covered by CAP/DA Medicaid Waiver

- **Adult day health**
- **Personal care aide**
- **Home accessibility and adaptation**
- **Meal preparation and delivery**
- **Institutional respite services**
- **Non-institutional respite services**
- **Personal emergency response services**
- **Specialized medical equipment and supplies**
- **Participant goods and services**
- **Community transition services**
- **Training, education, and consultative services**
- **Assistive technology**
- **Case management**

Source: North Carolina Division of Medical Assistance. Community Alternative Programs for Disabled Adults. North Carolina Department of Health and Human Services website. https://dma.ncdhhs.gov/medicaid/get-started/find-programs-and-services/community-alternatives-program-for-disabled-adults. Accessed December 12, 2015.

In 2015, the Centers for Medicare and Medicaid Services (CMS) 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, including discussions of hospice and palliative care.[19] Appropriate reimbursement for end-of-life and advance care planning discussions, including those conducted by non-physician professionals, is critical to ensuring that people with dementia and their families understand their options for care.

Long-Term Care Insurance

Long-term care insurance provides some protection for the costs of long-term care. In 2007, the average long-term care insurance policy cost $2,208 per year, covered 4.8 years of long-term care, and covered both home and institutional services. Long-term care insurance also must be purchased individually prior to the onset of disability or impairment. Because of this, families usually pay premiums for several years before needing long-term care, making it cost-prohibitive for most.[20]

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.

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[d] Darden L. President and Chief Executive Officer. Hospice and Palliative Care Center. Written (email) communication. January 25, 2016.

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.

Health System Capacity and Access to Treatment

As their disease progresses, people with Alzheimer's disease or related dementia have an increasing need for health care services. This care is often provided by primary care providers, specialists, and staff in long-term care facilities. The Task Force examined North Carolina's current capacity to serve the growing population of people with dementia, and issued recommendations to address the capacity gaps and improve access to treatment for people with dementia.

> **“In 2011, there were approximately 90 geriatricians in North Carolina.**

Alzheimer's Disease and Related Dementia-Specific Health System Capacity

Within the various types of residential long-term care facilities in North Carolina, there are approximately 8,000 special care unit beds designated for people with Alzheimer's disease and related dementia (as of the end of 2015). This figure includes beds within skilled nursing facilities, as well as 54 special care units in adult care homes.[21] There is currently a moratorium on licensure for new adult care homes, due to increased rates of special care unit beds and a desire to prevent more beds than needed.[21]

North Carolina hospitals have only 66 geriatric psychiatry beds, often needed for people with dementia who exhibit related severe behavioral or psychological symptoms, and who have not yet moved to residential care. Some hospitals also have Acute Care for the Elderly (ACE) units, which aim to provide high quality care to people with dementia while they are hospitalized for other ailments.[22]

There are a limited number of specialists providing medical care to people with Alzheimer's disease or related dementia in North Carolina. Much of this care is provided by primary care physicians or care teams. In 2011, there were approximately 90 geriatricians and 355 neurologists. There were also 2 psychologists per 10,000 residents. It is unclear how many of these specialists focus on dementia care.[23,24]

Because the number of North Carolinians with Alzheimer's disease and related dementias is projected to rise substantially in the coming decades, it is increasingly important that the state and health systems understand the increased need for dementia care, and develop a deeper understanding of current capacity and projected needs.

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.

Telehealth and Access to Care

There is opportunity for improved access to quality health care through the expansion of telehealth and other remote-based services for people with Alzheimer's disease or related dementia. Research has shown that dementia can be reliably diagnosed using detection and assessment tools administered through video conferencing technology.[25] In North Carolina, there are nearly 700,000 people over the age of 60 living in rural areas.[e] For these individuals who live in rural areas with fewer available transportation services or for whom distance to health care providers is a challenge, these type of telehealth services for assessment and diagnosis hold promise.

Technological solutions can also be helpful for non-health care services, including home monitoring of people with dementia. People often need a caregiver to monitor whether activities of daily living are completed, and to assist with them if not. However, many people with Alzheimer's disease or related dementia may not have adequate assistance available locally. Systems that remotely monitor home utility use can allow caregivers or service providers to learn about patterns of utility use that may indicate a problem.[26] Other systems may monitor movement within the home to assist caregivers in discerning whether a person has fallen or has become otherwise incapacitated.[27] Many of these technologies can be installed and administered at relatively low cost; however, these services are generally still paid for out of pocket by individuals and families.

There is also potential for care management and caregiver support services for people with Alzheimer's disease or related dementia to be provided remotely, with the caveat that such services should not fully replace in-person assistance so as not to result in social isolation for people with dementia or their caregivers.

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.

Improving Transportation Options to Improve Access to Care

People with Alzheimer's disease or related dementia often have trouble accessing health care and other

services when they are no longer able to drive. In some cases they may have caregivers who are able provide transportation, but many do not. Non-emergency medical transportation services are of particular importance to aging and low-income populations. For people with Alzheimer's disease or related dementia, issues of transportation timing can also be a concern, as it becomes difficult for individuals to navigate long

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[e] Reddy S. Evaluator/Planner. North Carolina Department of Health and Human Services. Written (email) communication. January 25, 2016.

waiting times if they arrive too early for medical appointments or have to wait for a return ride to their homes. The special transportation needs of people with limited informal support systems may include the need for escorts or personal care attendants to assist with the portion of the trip before and after the actual ride.

> **“Person-centered care consists of health care and social services professionals working collaboratively with the individuals who use their services.**

The North Carolina Department of Health and Human Services provides transportation assistance through local providers for many older adults with various needs. If used to access Medicaid services, Medicaid pays for the cost of the non-emergency medical transportation. In some counties, transportation services and aide services, including assistance with transportation to medical or social services appointments, are funded under the Home and Community Care Block Grant. Cost data is not available for the portion of aide services devoted to transportation support, but the average cost for Home and Community Care Block Grant-funded medical transportation is $575 per person annually.[f]

Human services transportation and/or public transportation services are available to some extent in all 100 North Carolina counties. North Carolina has a long history of state-level support for the coordination of transportation services across funding sources. Local community transportation networks have been built with the help of federal and state funding from the North Carolina Department of Transportation Public Transportation Division. Especially in rural communities across the state, the availability of public transportation can be traced directly to the immediate need for human service transportation and access to services. In turn, the Department of Health and Human Services' network of human service agencies has benefited from Department of Transportation investments in local fleets and transportation systems, since the availability of private transportation options is not as robust as it is in more urban areas.[g]

North Carolina can build on the strengths and challenges of expanding current public and private transportation networks to provide greater access for people with Alzheimer's disease or related dementia. One aspect of the solution is to facilitate better communication among state-level agencies that provide or purchase transportation services, especially in terms of understanding the best ways to maximize the resources of each.

For example, due to liability concerns and insurance restrictions on leaving vehicles unattended, most transportation systems are unable to assist riders from home to vehicle, or from vehicle to place of appointment. Department of Health and Human Services agencies are sometimes able to meet this need using personal care attendants when family caregivers are unavailable. However, transportation systems allow personal care attendants to ride without charge when complying with the Americans with Disabilities Act requirements to accommodate riders with disabilities. A formal mechanism for communicating about potential service needs and available resources would allow North Carolina to use available resources in collaborative ways and across funding sources, and to provide greater benefit to families needing long-term services and supports. Because of the many types of medical and non-medical services that people with Alzheimer's disease or related dementias may need and the varying levels of local capacity to provide timely, reliable transportation to these services, the Task Force identified transportation as an area for improvement that would be best addressed through a collaborative state-level effort.

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.

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[f] Reddy S. Evaluator/Planner. North Carolina Department of Health and Human Services. Written (email) communication. January 25, 2016.

[g] Bridgeman, P. Home and Community-Based Services Consultant, Division of Aging & Adult Services, Service Operations Section, North Carolina Department of Health and Human Services. Written (email) communication, February 12, 2016.

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.

Quality of Care and Care Coordination

People with Alzheimer's disease or related dementias and their families often grow increasingly concerned, as the disease progresses, about the type and quality of ongoing care they will need. The Task Force identified several areas where there is a need to improve quality and coordination of care for people with Alzheimer's disease or related dementia.

> **“78% of nursing homes implementing culture change and engagement initiatives report an improved competitive advantage.**

Principles of Person-Centered Care

People who are actively involved in their health and health care tend to have better outcomes and care experiences, and, in some cases, lower cost.[28,29] The core of person-centered care consists of health care and social services professionals working collaboratively with the individuals who use their services. Person-centered care holds as its principles:

1. Affording people dignity, compassion, and respect.
2. Offering coordinated care, support, or treatment.
3. Offering personalized care, support, or treatment.
4. Supporting people to recognize and develop their own strengths and abilities to enable them to live an independent and fulfilling life.[30]

Within long-term care facilities, in particular, person-centered care focuses on six essential elements: (1) a comprehensive and ongoing process; (2) the transformation of organizational operations and culture; (3) adoption of nurturing and empowering practices; (4) enabling older adults to experience purpose and meaning in their daily lives; (5) a relationship-based culture; and (6) a home environment.[31] Families should also be respected as part of the care team in all types of health care encounters.[32] In addition, health care providers should recognize, acknowledge, and support family members who provide direct care. Health care systems should develop policies that specify families as important members of the health care team and ensure families are welcomed during care appointments.[32]

Creating opportunities and roles for individuals and families to influence the design and governance of health care organizations is also critical to ensure their voices are heard and that health care organizations and systems are responsive to their needs. Representatives serving on governing boards and advisory committees within the health care system can share their perspectives on how policies and processes affect those served by the health care system. Including representatives on the governing board can also help ensure that the health care organization is responsive to the community's health care needs and experiences. Creating opportunities throughout health care organizations for people and family members to influence decisions can help ensure that health care organizations are meeting the needs of the communities they serve.

For nursing homes, there is evidence that a commitment to improving engagement will also give the facility a competitive advantage; 78% of nursing homes implementing culture change and engagement initiatives report an improved competitive advantage in their market area.[33]

The Task Force reviewed strategies for person-centered care for health care systems and facilities, and identified these strategies as a key component of improving quality of care for people with Alzheimer's disease or related dementias. To fully engage individuals and families, health care systems must implement processes to encourage and support person-centered care throughout the health care continuum.

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.

Measuring Quality of Care

Due to the large variety of levels of care that people with dementia may need, there is also a broad variety in the ways that health care facilities' quality and standards of care are evaluated. The Task Force examined several measures and systems for evaluating quality of care within health care facilities and explored ways that these measures can be expanded to be more appropriately and consistently applied to the care for people with Alzheimer's disease and other dementias.

For some types of long-term care facilities, the Centers for Medicare and Medicaid Services (CMS) provides a Quality Rating System that aims to evaluate facilities on measures of quality of care. The rating is on a 1-5 star level, with 5 stars being given to facilities that achieve high scores on quality measures, on measures evaluated through health inspections, and on measures that evaluate optimal staffing levels.[34] Facilities are required by CMS to report on quality measures at specified intervals.[35] The results of these evaluations are available for consumer reference at www.nursinghomecompare.gov.

In North Carolina, Alliant Quality is the state's Medicare quality improvement organization (QIO). QIOs are contracted by CMS and are private, mostly not-for-profit organizations, staffed by health care professionals who work with stakeholders, including long-term care facilities and adult care homes, on quality improvement initiatives of importance to Medicare beneficiaries.

In 2011, CMS launched the National Partnership to Improve Dementia Care in Nursing Homes. This project aimed to reduce the use of antipsychotic medications for people with dementia. North Carolina was a national leader in this initiative; from the start of the program in 2011 through the end of 2013, the rate of antipsychotic medication use for people with dementia fell from 21.1% to 15.6%.[35]

The Task Force acknowledged that these efforts do not adequately address many of the issues around quality of care specific to dementia. Dementia-specific quality concerns include wandering/elopement and other safety concerns, falls, behavior management, mental health, assessment, care planning, and medication management.[36] There was also concern that the measures, while gathering important clinical data, do not address staff training, patient and family experiences, or issues around care transitions and coordination.

In 2011, the Dementia Measures Work Group, an initiative led by the American Academy of Neurology, the American Geriatrics Society, the American Medical Directors Association, the American Psychiatric Association, and the American Medical Association-convened Physician Consortium for Performance Improvement, developed the Dementia Management Quality Measures (see Figure 4.4). These measures were developed in order to improve quality of care for people with dementia, especially with regards to outcomes including preservation of cognitive and functional abilities, reducing behavioral symptoms, reducing safety risks, and improving caregiver well-being and skill in managing their loved ones' symptoms. Several of the measures have been adopted by inclusive quality measurement systems, including the Physician Quality Reporting System and the CMS measures for meaningful use of electronic health records. However, while the Dementia Management Quality Measures provide a feasible guide to improving care for people with dementia, they have yet to be widely adopted.[36]

Figure 4.4: Dementia Management Quality Measures

Measure Title	Description
No. 1: Staging of dementia	Percentage of patients, regardless of age, with a diagnosis of dementia whose severity of dementia was classified as mild, moderate, or severe at least once within a 12-month period.
No. 2: Cognitive assessment	Percentage of patients, regardless of age, with a diagnosis of dementia for whom an assessment of cognition is performed and the results are reviewed at least once within a 12-month period.
No. 3: Functional status assessment	Percentage of patients, regardless of age, with a diagnosis of dementia for whom an assessment of functional status is performed and the results are reviewed at least once within a 12-month period.
No. 4: Neuropsychiatric symptom assessment	Percentage of patients, regardless of age, with a diagnosis of dementia and for whom an assessment of neuropsychiatric symptoms is performed and the results are reviewed at least once in a 12-month period.
No. 5: Management of neuropsychiatric symptoms	Percentage of patients, regardless of age, with a diagnosis of dementia who have one or more neuropsychiatric symptoms who received or were recommended to receive an intervention for neuropsychiatric symptoms within a 12-month period.
No. 6: Screening for depressive symptoms	Percentage of patients, regardless of age, with a diagnosis of dementia who were screened for depressive symptoms within a 12-month period.
No. 7: Counseling regarding safety concerns	Percentage of patients, regardless of age, with a diagnosis of dementia, or their caregiver(s), who were counseled or referred for counseling regarding safety concerns within a 12-month period.
No. 8: Counseling regarding risks of driving	Percentage of patients, regardless of age, with a diagnosis of dementia, or their caregiver(s), who were counseled regarding the risks of driving and the alternatives to driving at least once within a 12-month period.
No. 9: Palliative care counseling and advance care planning	Percentage of patients, regardless of age, with a diagnosis of dementia, or their caregiver(s), who (1) received comprehensive counseling regarding ongoing palliation, symptom management, and end-of-life decisions and (2) have an advance care plan or surrogate decision-maker in the medical record or documentation in the medical record that the patient did not wish or was not able to name a surrogate decision-maker or provide an advance care plan within two years of initial diagnosis or assumption of care.
No. 10: Caregiver education and support	Percentage of patients, regardless of age, with a diagnosis of dementia whose caregiver(s) were provided with education on dementia disease management.

Source: Odenheimer G, Borson S, Sanders AE, et al. Quality improvement in neurology: dementia management quality measures. *Neurology.* 2013;81(17):1545-1549.

In addition to continuing to develop quality measures, there may be opportunities to use existing measures to improve the quality of care provided in long-term care facilities. The North Carolina Division of Aging and Adult Services administers the state/county Special Assistance Program, which assists low-income older adults in paying for facility-based care. For income-eligible people with Alzheimer's disease or related dementia, the Special Assistance Program may pay for care within a special care unit of a long-term care facility (this does not supplement the cost of skilled nursing facility care, though Medicaid may assist with this care). Special Assistance allows a payment if an individual is in a special care unit and has a diagnosis of Alzheimer's disease or related dementia. This is criteria for licensure of the special care unit as well. The Special Assistance payment amount is determined by the setting of care and the Special Assistance rate set by the General Assembly for licensed special care units. However, while individuals may qualify on the basis of income, care setting, and diagnosis, there are often no available slots and/or no funding for additional slots.[h]

Because the Special Assistance Program has this existing structure to determine payment, there may also be opportunity for the Special Assistance Program to establish a similar mechanism of tiered payment

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[h] Urso C. Special Assistance Program Administrator. Division of Aging and Adult Services, Adult Services Section, North Carolina Department of Health and Human Services. Written (email) communication. January 14, 2016.

for care provided by facilities that meet dementia-specific indicators of quality. Any change in payment structure for the Special Assistance Program must be in compliance with federal regulations. There may be additional opportunity for expansion of such a payment structure to other types of payers and/or health care facilities.

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.

Models of Care to Improve Care Transitions and Care Coordination

The wide variety of care needs for people with Alzheimer's disease or related dementias and the progressive nature of these conditions also means individuals often move between types of care, including hospital care, home-based care, and long-term facility-based care such as assisted living or nursing homes. Focusing on improving the transitions between and coordination of the different types of care, while increasing patient-centered care, is key to caring for people with dementia. Care coordination measures have also been estimated to create cost savings through reducing hospitalizations and increasing efficiency in care delivery. The Medicare Coordinated Care Demonstration is estimated to decrease Medicare spending for people with Alzheimer's disease by $41 billion over 10 years.[37]

In North Carolina, many health systems and facilities are developing approaches to improve care coordination for people with Alzheimer's disease or related dementia, through enhanced care management initiatives. Some examples include:

> **“Improving transitions between and coordination of different types of care, while increasing patient-centered care, is key to caring for people with dementia.**

- Community Care of North Carolina, the care management system that provides care management to most of the state’s Medicaid beneficiaries, has developed dementia-specific components of its Care Management Program. This program seeks to improve care coordination and transitions as one of its primary goals, and includes dementia-specific professional training, care coordination needs, and caregiver resources. (See Figure 4.5.)[i]
- MemoryCare, located in Asheville, North Carolina, is a non-profit organization that provides dementia-specific care coordination for its patients. MemoryCare works with patients and caregivers to provide integrated clinical care, caregivers supports, and full care management. Patients must be referred to MemoryCare by a primary care physician or specialist. For non-medical expenses not covered by patients’ insurance, MemoryCare charges an annual cost-sharing fee and covers the remaining expenses through private donations and charitable contributions.[38]
- Duke Connected Care, a care coordination initiative through Duke Medicine, seeks to improve population health through use of multidisciplinary care teams and enhanced care management. The Geriatric Advisory Council of Duke Connected Care focuses on the needs and priorities of older patients and addresses issues including cognitive assessment, falls prevention, and improved care transitions.[39]
- The Caring for Older Adults and Caregivers at Home (COACH) program is a care management program, run through the Veterans’ Administration, for people with moderate to severe dementia. Participants receive care management from teams led by a nurse or social worker who receive additional support as needed from specialists in geriatric medicine, psychiatry, and pharmacy. Measures include alignment with Dementia Management Quality Measures and time to placement in long-term care. Post-pilot results suggest improvements in dementia-specific measures of quality, as well as improved satisfaction with care.[40]
- Programs of All-Inclusive Care for the Elderly (PACE) is a federal- and state-funded model that provides services to older adults in need of extensive care, with the goal of allowing people to remain in their homes and communities for longer. Services include adult day care, nutritional assistance (meals and counseling), social work, medical care, home health care, medications, social services, and respite care.[41] Services are coordinated by an interdisciplinary team, and are paid by either Medicare or Medicaid through a capitated payment system.[42]
- AARP has a partnership with UnitedHealth Group on a pilot program for care management, called Integrated Healthcare Management. The pilots focus on patients with chronic illness/high-risk case management (this is non-dementia specific). Participants receive an integrated care plan and receive care from an interdisciplinary team of health care professionals.[43] The program’s goal is to evaluate whether improved care coordination can achieve cost savings, increased patient satisfaction, and improved health outcomes in a fee-for-service setting. In addition, the total savings from 28,000 total participants in the Integrated Healthcare Management program saved Medicare, Medigap, and program participants $8.3 million from 2009-2011.

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[i] Barsness K. Manager of Policy and Regulatory Affairs. Community Care of North Carolina. Written (email) communication. November 9, 2015.

Figure 4.5: Dementia-Specific Components of CCNC Care Management Program

Dementia-Specific Components of CCNC Care Management Program	
For CCNC primary care practitioners	1. Educate primary care practices and care management teams on: ● Detection and early identification of dementia ● Stages of dementia – early, middle, and late and the corresponding best practices for care and treatment ● Engagement of caregivers and care giving resources 2. Referrals to CCNC care managers
For patients living in own home or assisted living	1. Perform patient assessments and develop care plans 2. Educate patients as well as family and facility caregivers 3. Perform patient medication reconciliations and reviews 4. Communications with primary care practice 5. Provide ongoing monitoring and checking of patient and family caregiver 6. Use available home- and community-based resources and continue to work with family based on needs Assisted living only: 1. Education on behavioral assessment and management 2. Support facility change toward a model of assessment and communication to reduce inappropriate IP/ED utilization
For patients in the hospital setting	1. Transitional care to engage the patient and family prior to discharge, arrange for in-home assessment and care management services 2. Educate hospital discharge planners – create awareness of home- and community- based services in the community (work with already existing agencies such as the Council on Aging)
For patients in a nursing facility setting	1. Provide support to the nursing facility staff by making care managers available for consults 2. Coordination during transitions both to and from hospital: ● Assist with medication reconciliation as needed ● Follow up on hospital discharge plan ● Short term care management 3. Provide transitional care for patients in the nursing facility who are returning home (short stay patients) 4. Communication with the primacy care practice on patient's status 5. Provide training and support to skilled nursing facility on processes and resources regarding dementia such as: ● Cognitive and behavioral assessment and management ● Reduction of inappropriate antipsychotic medications ● Environmental impact and change ● Falls prevention ● Palliative care assessment and referral ● Family support and education 6. Support facility change toward a model of assessment and communication to reduce inappropriate IP/ED utilization

Source: Barsness K. Manager of Policy and Regulatory Affairs. Community Care of North Carolina. Written (email) communication. November 9, 2015.

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[j] 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.

Hospital-Based Care for People with Alzheimer's Disease and Related Dementia

Between 2008 and 2010, dementia was the 3rd leading mental health reason for visits to the emergency room for North Carolina adults over 65.[44] People with Alzheimer's disease or related dementia are also hospitalized two to three times more frequently than non-cognitively impaired peers.[45] As the population ages, these numbers are expected to rise, and it is imperative that hospitals improve quality of care and care coordination for individuals with Alzheimer's disease or related dementia in both emergency and non-emergency care settings.

The Alzheimer's Association has developed the Dementia Friendly Hospital Initiative to improve quality of care and care coordination within hospitals. This initiative provides a training curriculum and resources for acute care staff in hospitals to better provide person-centered care to people with dementia. Training materials include information about wandering, behavioral management, communication, and eating issues. The initiative also focuses on relationships with caregivers and how hospitals can focus on environmental improvements to improve dementia care.[46] A study of more than 300 hospital staff, including nurses, social workers, and mental health professionals, demonstrated improved confidence in caring for patients with Alzheimer's disease or related dementia, including in such areas as assessing and recognizing dementia, managing behavioral symptoms such as agitation, and communicating with patients, following participation in the Dementia Friendly Hospital Initiative.[47]

Lake Norman Regional Medical Center in Mooresville, North Carolina, received a Nurses Improving Care for Healthsystem Elders (NICHE) designation in May of 2015. This initiative provides a wide variety of patient/staff tools, family resources, and reports on organizational best practices. While the program focuses on all aspects of elder care, Alzheimer's disease and related dementia is included in the curriculum. In addition, Lake Norman has also instituted a silver armband to identify patients with cognitive impairments. The armband's color aligns with the Code Silver theme, and reads "Special Care," wording that serves to notify staff members, but not expose individuals' medical status to general public. The armbands alert staff that an individual may not be able to provide a reliable medical history, and should not be questioned without a family member present to verify.[k]

Asheville's Mission Hospital developed a similar curriculum and organization model to improve care for patients with dementia. Acknowledging the under-diagnosis of dementia in the hospital setting, Mission's initiative focused on training staff to recognize symptoms of dementia and the ways dementia symptoms may result in adverse health outcomes. The initiative also aimed to reduce or prevent cognitive decline during hospital stays and to improve communication with caregivers. Interventions include multidisciplinary staff training and family/caregiver involvement. Mission Hospital served as a national model of a dementia-capable hospital program for over 10 years.[l]

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.

Lead: Health care providers and systems.

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

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[j] "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. In North Carolina, the Dual Eligibles Work Group was mandated by the Medicaid Transformation and Reorganization legislation in 2015

[k] Whitfield L. Director of Marketing and Public Relations. Lake Norman Regional Medical Center. Written (email) communication. September 15, 2015.

[l] Hunnicutt NS. Regional Long-Term Care Ombudsman. Land of Sky Area Agency on Aging. Written (email) communication. November 12, 2015.

Training of Health Care Professionals

While focusing on health system capacity and access to and quality of care, it is also crucial for North Carolina to improve Alzheimer's disease and related dementia-specific capabilities of the health professional workforce. The training of the health professional workforce to meet the needs of the rapidly growing population of North Carolinians with Alzheimer's disease or related dementia rests on two basic assumptions. First, only a small portion of health care for people with Alzheimer's disease or related dementia will be delivered by dementia specialists or geriatric specialists.[48,49] Second, North Carolina is rich in resources for in-service continuing education about caring for people with Alzheimer's disease or related dementia, but falls short in taking advantage of those opportunities and effectively implementing the highest quality care taught in those settings.

> **“Only a small portion of health care for people with Alzheimer's disease or related dementia will be delivered by dementia specialists or geriatric specialists.**

Most health care of people with Alzheimer's disease or related dementia will be provided by family caregivers (see Chapter 5). A large amount of health care for people with Alzheimer's disease or related dementia will be delivered by frontline workforce (paid caregivers, certified nursing assistants, physical and occupational therapy technicians, etc.). A small amount of health care will be provided by primary care clinicians. Dementia and geriatric specialists play a critical role in caring for people with Alzheimer's disease or related dementia. However, North Carolina has very few of these specialists. Further, these practitioners are clustered in a few geographic locations.

North Carolina has recently been awarded three grants from the Health Research Services Administration (HRSA) for funding of geriatric workforce education programs. These three programs are currently in planning phases, and include programs at Duke University, University of North Carolina at Chapel Hill, and East Carolina University. Each center, as required by supplemental funding, will focus at least a portion of activities on the care of people with Alzheimer's disease or related dementias.[50-52]

The core common elements of the three geriatric workforce education programs include inter-professional education, quality improvement, development of inter-professional teams in primary care, and enhancement of geriatric skill in primary care. In addition, the Duke and UNC Centers will fund advanced traineeships. All three centers will work with family caregivers and communities to enhance the skill and preparation of the family caregiver and other members of the community. All three geriatric workforce education centers will partner with state Area Health Education Centers (AHEC) to enhance the availability of inter-professional education.[50-52]

The Carolina Geriatric Education Center Consortium is funded by HRSA and the US Department of Health and Human Services. Consortium members include the AHEC program and all regional AHEC partners. The Carolina Geriatric Education Center Consortium trains health professionals including physicians, nurses, social workers, behavioral health providers, dentists, and allied health professionals. Training includes evidence-based falls prevention programs, practitioner core competencies in geriatrics and interdisciplinary practice, health literacy, and advocating for mental health for older adults.[53]

The North Carolina Geriatric Adult Mental Health Specialty Teams also provide training for health providers and community workers in symptoms of mental illness in older adults, and include information about Alzheimer's disease and related dementias in this training. Geriatric Adult Mental Health Specialty Teams aim to improve communication, assessment procedures and techniques, and referral systems for older adults with mental health or dementia symptoms. The Geriatric Adult Mental Health Specialty Teams training is being used in both long-term services and supports settings and in community settings. Geriatric Adult Mental Health Specialty Teams are also used to train health providers in licensed medical entities and managed care organizations.[54] There is opportunity to apply a similar model in other relevant settings.

The Task Force found that there may be adequate professional development opportunities around caring for people with Alzheimer's disease or related dementia, but they are, at times, hard to fill with learners. Perhaps more importantly, in many cases it is the same social worker or nurse getting dementia specific training year after year, and then he or she returns to a usual practice environment where enhanced skills and practices are not supported due to the lack of inter-professional education.

The Task Force supports the need for high quality specialty care, such as that delivered by neurologists specializing in dementia care and geriatricians, but also acknowledges that currently there are only a small handful of these professionals and they are working in a limited number of highly specialized settings. Therefore, one important way to improve health professional skill in caring for people with Alzheimer's disease or related dementia is to offer enhanced training for primary care physicians (family practice and internal medicine), general neurologists, psychiatrists, geriatricians, and generalists, and ideally that training should be in the context of inter-professional education supported by practice, system, or program leadership.

Finally, the Task Force reviewed the important role of frontline staff such as nursing assistants, paid caregivers, and occupational therapy assistants. The bulk of day-to-day care that is not provided by family caregivers is provided by this frontline staff. Frontline workers are often in low skill, low wage, and high turnover occupations. Enhancing skill (with commensurate enhanced wages) is one approach to improve care for people with Alzheimer's disease or related dementia and decrease turnover among caregivers. The Task Force therefore identified the community college system as a critical and underutilized partner in enhancing inter-profession care of people with Alzheimer's disease or related dementia. Some community colleges in North Carolina currently offer geriatric specific course work, and geriatrics are part of the curriculum for certified nursing assistants. There is an available certification as a geriatric aid, but it is not well utilized. The community college system seeks to identify market driven training needs. Currently few work environments will pay a higher wage for an aid with a geriatric certification, so there is little incentive for an aid to have the higher level of specialized training.

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.

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