Long-Term Care in North Carolina

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Much of long-term care is not considered health care, as it is custodial, social, and supportive. But excellent long-term care is also preventive, timely, and accessible, and it provides space for long-term care recipients to find joy and meaning in their lives. This issue of the NCMJ provides a broad overview of long-term care, practical information about programs in our state, and tips for how to make use of these programs. Commentaries and sidebars in this issue also highlight new ideas, innovation, and transformation.

This issue brief sets the stage by describing major events that have shaped the current framework of long-term care services and supports. It also discusses current trends that are influencing long-term care, including the emphasis on quality improvement methods, culture change, health care reform, the influence of geriatrics in primary care, and the desire for home-based care. Although we are not yet where we want to be in North Carolina, we are moving toward a long-term care system that will serve all North Carolinians well.

Long-term care is an important aspect of health care, and the need for long-term care is increasing. The projected growth rate (as a percentage of the 2012 population) for individuals 85 years of age or older in North Carolina is 97% from 2012 to 2032, and 269% from 2032 to 2050; both of these estimates are well above projected national rates, which are 69% and 224%, respectively [1] (see Figure 1). In addition to the frailty and disability that are prevalent among these "oldest old" individuals, other factors that affect the need for long-term care services include living alone and the frailty of family caregivers, many of whom are spouses and who experience high rates of emotional and physical stress. Older people are less likely than children and working-age adults to have household incomes below the federal poverty guidelines, but many of them, especially those aged 85 years or older, have incomes low enough that they qualify for public assistance with respect to long-term care supports and services.

Ideally, long-term care should be defined broadly to include medical and nonmedical care that is provided in the community, in congregate housing, in a residential care facility (eg, assisted living), or in a nursing home. It should include transportation services, congregate and in-home meal services, social supports, and medication support services. Currently, the scope and nature of these services are changing to meet the needs of a diverse older adult population, and services are facing economic, regulatory, and alignment pressures as health care reform continues. Sadly, our medical schools, nursing schools, pharmacy schools, and other health professional training programs provide little exposure, experience, or explanation to prepare graduates to assist patients in navigating and utilizing these services.

The articles in this issue of the NCMJ cover a lot of ground, and much of the content is practical information that can be shared with older adults and their families (see Appendix 1; online version only). Some of the articles also show how North Carolinians are leading the way to a better future by exploring new directions and adopting innovations.

APPENDIX 1.
Online Resources Related to Long-Term Care

This appendix is available in its entirety in the online edition of the NCMJ.

A Historical Perspective

The foundation of long-term care services throughout history has been the family. When family resources fell short, religious organizations often provided both community-based and institutional services to support their members and often the broader community. When all else failed, the last stop for older adults was the poorhouse.

In the United States, nursing homes evolved during the 20th century out of the 19th-century poorhouses. A brief article published in the *Durham Sun* in 1936 [2] described this transition:

> Durham county and thousands of other counties in the United States will find one great solace in the social security machinery being set up in this country. It sounds the knell of that institution which lies over the hill, the poorhouse.
> There will be a need for poorhouses for some years, but the old age relief and old age assistance set-ups . . . inevitably will empty those last hope havens which never achieved the level of respectability.

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FIGURE 1.
Projected Growth in the Older Population in North Carolina as a Percentage of 2012 Population, by Age Group
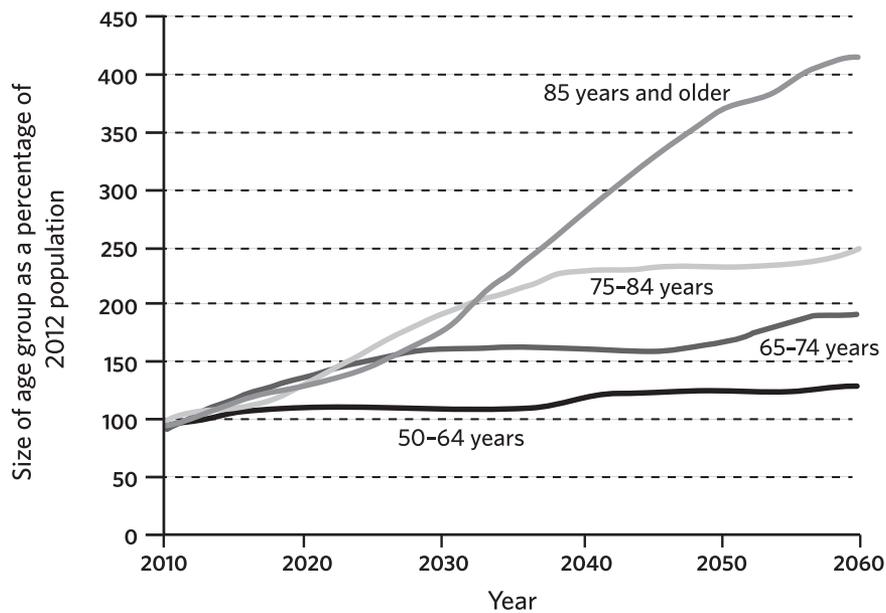
Source: Reproduced with permission from *Across the States: Profiles of Long-Term Services and Supports* [1].

Unfortunately, the poorhouse in Durham—which was located at what is now the site of Duke Regional Hospital—remained in operation until 1969, when the last elderly residents and individuals with disabilities were transferred to rest homes and nursing homes [3].

There were few external pressures to improve or standardize the quality of care provided in nursing homes until 1965, when Medicare and Medicaid were established. It is worth noting that most long-term care services are not covered by Medicare; rather, they are paid for out of pocket, by long-term care insurance, or through state and federal programs for low-income elderly individuals (ie, Medicaid). Although Medicare does cover rehabilitation in skilled nursing facilities after a qualifying hospital stay, as well as periods of home health care and hospice services, it does not cover custodial care in a nursing home or residential care.

The 1970s was a decade of growth in the nursing home industry, mostly in the for-profit sector. Scandals in the industry resulting from poor quality of care led to an outcry for more stringent standards along with the means to enforce those standards. A highly publicized 1986 report from the Institute of Medicine of the National Academies [4] led to passage of the Nursing Home Reform Act, which was part of the Omnibus Budget Reconciliation Act of 1987 [5]. This legislation brought about minimum staffing requirements for registered nurses and licensed practical nurses, and it established minimum training requirements for nurse aides. Furthermore, it emphasized that use of chemical restraints, physical restraints, and urinary catheters should be minimized, and that the highest possible level of physical,

mental, and psychosocial well-being should be attained and maintained; it also instituted stronger enforcement sanctions [6]. In addition, all nursing homes that receive funding from Medicare or Medicaid must now undergo annual, unannounced, rigorous surveys during which a subset of patients and family members are interviewed and the patients' medical charts are reviewed [6].

A major quality initiative of the Omnibus Budget Reconciliation Act of 1987 was the introduction of a resident assessment instrument that must be completed for individual residents at specified intervals; the act also called for the Secretary of Health and Human Services to specify a minimum data set (MDS) of core elements and definitions that nursing facilities should use in conducting these assessments [6]. The MDS provides a national standard that serves as a tool for care planning, helps to determine reimbursement for Medicare patients, and is used to assess the performance of individual facilities. All MDS data are now transmitted electronically to state and federal regulators and are stored in a national database. Nursing homes are also required by the Patient Protection and Affordable Care Act of 2010 (ACA) to have quality assurance and performance improvement programs [7]; the Centers for Medicare & Medicaid Services (CMS) will soon issue guidance to nursing homes regarding those programs. Additional reportable quality indicators related to readmission rates and adverse events are expected in the near future.

Over the past 2 decades, the hospital-like environment and expense of nursing homes has led to the growth of assisted living facilities (or residential care homes), which

tend to emphasize a more homelike environment. The 2010 National Survey of Residential Care Facilities [8] found that, on any given day in 2010, there were approximately 733,300 residents of assisted living facilities nationwide. Almost 40% of residents received assistance with 3 or more activities of daily living, most commonly bathing and dressing, and almost three-fourths of residents had at least 2 of the 10 most common chronic conditions; high blood pressure and dementias such as Alzheimer disease were the most prevalent of these conditions [8]. Such findings suggest that the residents of residential care facilities are beginning to display a level of frailty comparable to that of long-stay nursing home residents.

Americans generally value personal autonomy and wish to avoid institutional settings, which has contributed to the development of an impressive array of both community-based and institutional long-term care services. Local communities strongly influence the array and quality of long-term care services in a particular area. For example, senior centers and home meal delivery services are usually developed through a combination of funding sources, and they require the concern and cooperation of local citizen groups.

Nevertheless, family caregivers continue to provide the bulk of services; in North Carolina in 2009, the economic value of family caregiving was 3.5 times that of Medicaid spending on long-term services and supports [1]. Thus we should not overlook the role that family members provide in organizing, purchasing, and providing physical support for their loved ones. Unfortunately, the historical process of problem identification followed by either legislative solutions or the development of grassroots, community-based, community-financed services has resulted in an array of services and supports that is complex, fragmented, unevenly available, and difficult for older adults to access.

Current Trends

Quality improvement. As a result of the Omnibus Budget Reconciliation Act of 1987 and various CMS initiatives, quality indicators for nursing homes, home health care agencies, and hospitals are now readily available to researchers, health systems, and consumers. Although the quality of these data may continue to be debated, we now have important tools that can help us gauge the impact of process improvement. Our quality improvement organization in North Carolina provides many resources that support process improvement. In this issue, a commentary by Welsh and Kivisto [9] highlights this work, the adoption of performance improvement methodology by North Carolina nursing homes, and grassroots initiatives that are making a real difference in the state.

Cost containment. The ACA is beginning to have an effect on long-term care providers with its demonstration projects related to bundled payments for episodes of care and its support for CMS's move toward pay for performance [10]. Hospitals now face penalties for high 30-day readmission rates, so skilled nursing facilities, home health agencies, and hospice organizations are looking at their readmission rates and are beginning to partner in substantial ways with hospitals to improve care transitions and to enhance quality of care. Recently, CMS established the Medicare Spending Per Beneficiary metric, which is defined as the average Medicare Part A and Part B spending per patient from 3 days prior to hospital admission to 30 days after discharge [11]. This newly crafted efficiency measure will likely spur hospitals to look even more closely at decisions regarding postacute care. Unfortunately, there is little research to guide the decisions about which type of postacute care to choose for any individual patient. Diagnosis, functional needs, and rehabilitation potential are not the only factors to be considered; the choice of postacute care also depends on availability, patient willingness, proximity, and social supports. As we move into the future, quality, efficiency, and reported outcomes will likely weigh more heavily in this decision.

Culture change. Culture change is a framework in which the voices of older adults and those working with them are considered and respected, and it is often characterized by resident direction of care, a homelike atmosphere, close relationships, staff empowerment, collaborative decision making, and quality improvement processes. The goal of culture change is to attain a person-directed environment that supports each resident's life, dignity, rights, and freedom. Person-directed care occurs when staff and family members support residents in directing their own care; this paradigm stands in contrast to traditional care, which is staff-directed. Involving stakeholders—primarily residents, but also family members and frontline staff—in the process of culture change is imperative. Yet these groups are diverse and may not have congruent priorities. In a 2012 study [12], the aspects of culture change that were important to residents and family members were independence, consistency, autonomy, and community; however, these factors were valued less by staff members, who wanted to prioritize the value of direct-care staff and opportunities for career advancement.

Changing the culture to be more person-centered is not just a matter of focus; it also entails a different approach to solving problems. Some challenges have no obvious single solution, are difficult to identify and describe, and require revising norms and beliefs; these are referred to as adaptive challenges [13]. For example, improving the satisfaction of residents, family members, and staff members with the quality of dining services is an adaptive challenge. This challenge cannot be addressed with new decorations or a new rule or policy; instead, novel solutions must be allowed to emerge from the interactions of people in the organization who face the challenge. In their commentary on adaptive leadership, Corazzini and Anderson provide examples of how this problem-solving technique can be applied [14].

Over the past 2 years, nursing homes have systematically applied culture change to reduce the use of antipsychotic medications in elderly individuals. Prior to this change, a

2011 report from the Office of Inspector General [15] found that 83% of all Medicare claims for atypical antipsychotic drugs prescribed for elderly nursing home residents in the first 6 months of 2007 were for off-label indications. In addition, 88% of the Medicare claims for atypical antipsychotic drugs were for patients who had dementia-related psychosis, even though the US Food and Drug Administration (FDA) requires that these drugs carry a black-box warning stating that elderly patients with dementia-related psychosis are at an increased risk of death when treated with atypical antipsychotic drugs.

As part of the move away from antipsychotic medications, providers have increasingly adopted behavior management techniques as a tool for managing challenging behaviors. With an array of stakeholders working together, nursing facilities in North Carolina have excelled in the institution of behavior management techniques. This approach to dealing with challenging behaviors emphasizes accurate descriptions of behaviors and circumstances, and consideration is given to causes or contributors such as unmet physical needs, environmental or communication issues, and mental health issues. Interventions include adjusting the caregiver's interaction with the patient, modifying the environment, and utilizing behavior-specific interventions. The commentary by McConnell [16] outlines the components of behavioral interventions that can be used to guide implementation of these evidence-based practices.

Home- and community-based services (HCBS). Although the bulk of long-term care spending by the state of North Carolina goes to nursing home care rather than to home-based care or other community-based alternatives, the number of Medicaid-enrolled older people and adults with physical disabilities who are receiving HCBS is increasing at a faster rate than the number who are living in nursing homes. From 2003 to 2008, the number of people receiving Medicaid HCBS in North Carolina increased by 45%, while the number of people using Medicaid nursing home care declined by 2% [1]. On average, the Medicaid dollars needed to support 1 patient in a nursing home are sufficient to provide HCBS for 3 people [1].

Expanding the role of primary care providers. Physicians and others who provide care for older adults play an important role in identifying and describing the long-term care services they need. Beyond diagnosing disease, providers must use tools to identify and measure functional limitations, including deficits in vision and hearing, cognitive deficits, and physical deficits. Providers must help patients and families make decisions about automobile driving abilities and provide information about transportation alternatives. They must recognize when patients need help with their medications and know the pharmacies in town that will provide a filled pillbox or adherence packaging. They must screen for depression and direct families to community services that provide socialization. Asking about falls is particularly important, because patients may not mention such events, yet interventions may help them avoid life-changing injuries and unnecessary self-imposed restrictions that fuel decline. The commentary by Demons and Duncan [17] does an outstanding job of explaining the proven role of exercise in preventing falls and directs readers to resources that promote strength, balance, and aerobic capacity.

Eliciting goals and priorities becomes imperative as older adults and family members attempt to make important decisions about which forms of care will be best. It is important for providers to participate in this process and to help patients adopt a framework of shared decision making. A good resource for people in need of services is the local Area Agency on Aging. These offices, established through the Older Americans Act of 1965, serve to facilitate and support programs in a defined geographic region.

The commentary by Covington [18] does an artful job of describing the community-based services available in North Carolina and how to access them. If and when the need arises, choosing a skilled nursing facility, whether for short-term rehabilitation or long-term care, can be a heart-wrenching decision for many patients and their families. The sidebar by DePorter [19] contains information that can help guide families through the process.

In addition to helping patients access appropriate resources, providers should facilitate discussions and shared decision making related to advance directives. In North Carolina, we are fortunate that state law supports several mechanisms for documenting and sharing patient wishes related to end-of-life planning. These options are described in a commentary by Lee [20] and in an accompanying sidebar by Caprio [21].

Primary care providers must become more adept at recognizing cognitive impairment and must work to protect and enhance cognitive function. For example, they must help patients avoid the array of drugs that put cognitive function at risk, including nonprescription drugs and alcoholic beverages. They must also recognize the effects that depression and/or anxiety can have on cognition and help older adults accept the effective treatments now available for these conditions. Patients with dementia and their family members will likely require help with difficult behaviors, decisions regarding level and place of care, and decisions about managing other illnesses appropriately. Fortunately, North Carolina has a statewide resource specifically aimed at supporting caregivers of those with Alzheimer disease or other memory disorders. The Duke Family Support Program, described in a sidebar by Matchar and Gwyther [22], is a service that family members and professionals can contact when problems arise and they need someone to listen and provide direction.

Future Directions

Long-term care specialists. Over the past 10 years, many physicians, nurse practitioners, and physician assistants have begun to see the benefits of working exclusively with

patients receiving long-term care. There are now both solo and large group practices that make home visits, provide care to residents of nursing homes and/or assisted living facilities, or have some combination of these venues as their practice site. In a sidebar in this issue, Kronhaus [23] explains the rationale for providing home-based primary care to frail, elderly patients. This type of site-based care allows the practitioner to interact effectively with caregivers; to thoroughly understand the capabilities, regulatory constraints, and limitations of the care setting; and to limit overhead to ensure financial viability. This type of practice is proving to be financially viable and allows practitioners trained in geriatric medicine to apply their skill set. Practitioners also value the clear endpoints for patients who are undergoing rehabilitation and the long-term relationships they can develop with patients who require custodial care.

Seamless care. At present, electronic health records are being rapidly adopted throughout large and small hospitals in North Carolina, and nursing homes also face a mandate to adopt electronic health records. Ideally these systems will be able to share information and will enhance transitions of care between sites. The current trend of site-specific care providers has also fueled the growth of transitional care programs and educational initiatives that highlight communication and documentation, which have led to successful transitions from one site of care to another.

Insurers and health systems are also making use of various case management models to control costs and to improve care for older adults who are high utilizers of care and who frequently transition between sites of care. The Program of All-Inclusive Care for the Elderly (PACE), which is described in the sidebar by Shaw [24], has a focus on strong community-based care and is designed both to control costs and to improve quality by coordinating care between sites.

Innovation. We do not yet have all of the solutions to North Carolina's long-term care needs, and we still must work to make long-term care services in the state as affordable, accessible, and diverse as citizens expect them to be. AARP (formerly the American Association of Retired Persons) and other advocacy groups are helping states to take a broad view of long-term care services and supports. For example, AARP recently published a "scorecard," titled *Raising Expectations 2014* [25], which is the basis for the Running the Numbers column in this issue. The column by Kassner [26] interprets data from this scorecard in a way that allows readers to recognize both North Carolina's strengths and its weaknesses.

Finally, the commentary in this issue by Sloane and colleagues [27] describes the most innovative current programs in North Carolina and potential future trends. The concept of aging in community, along with a tsunami of baby boomers, will likely stimulate innovation and opportunities for care that will bring aging out of the shadows and into the mainstream of society.

In summary, North Carolina has much of which to be proud. The articles in this issue provide a wealth of infor-mation that I hope will stimulate discussions among health care providers in clinics, hospitals, nursing homes, pharmacies, senior centers, and other health care venues about ways of enhancing current efforts. I especially hope that this issue will stimulate conversations in educational institutions about how to incorporate both knowledge and experience related to long-term care into the curriculum, so that the state's future workforce will be well prepared to serve [28-30]. NCMJ

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