CHAPTER 1

DIMENSIONS OF LONG-TERM CARE

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LEARNING OBJECTIVES

After completing this chapter, you should be able to

➤ define long-term care and long-term services and supports;
➤ explain changing patterns of demographics in the United States in terms of growing demand for long-term care services and supports;
➤ understand the history of long-term care service delivery;
➤ describe models for long-term care service delivery;
➤ discuss the providers and payers of long-term services and supports, including informal sources of support such as family caregivers;
➤ apply the theoretical foundations of long-term care service delivery to assess their impact on healthcare policy; and
➤ understand the impact of COVID-19 on health disparities in long-term care service delivery and new directions for long-term services and supports.
What is Long-Term Care?

Long-term care (LTC) consists of a variety of health services, support services, and other assistance provided informally or formally to individuals who are living with a chronic illness or disability and are unable to function independently. Long-term services and supports (LTSS) may be offered in various settings to people at any age who need help performing activities of daily living (ADLs) or instrumental activities of daily living (IADLs). Examples of ADLs include bathing, dressing, eating, toileting, and transferring (e.g., walking). Examples of IADLs include cooking, cleaning, buying groceries and other essentials, administering medication, handling money or finances, and using the telephone. Individuals living with Alzheimer’s disease and other dementias, as well as those living with intellectual or developmental disabilities, may have additional, specialized needs. Long-term care services can be tailored to clients’ physical, mental, emotional, social, spiritual, and financial needs and capacities. Additionally, long-term care services may evolve over time in response to changes in clients’ needs and resources. Long-term care is oriented toward living with and managing chronic illnesses or disabilities, not curing them. As such, it aims to ensure continuity of care rather than deliver episodic interventions (Hooyman and Kiyak 2011).

Consumers of Long-Term Services and Supports in the United States

Two main groups make up the majority of LTSS consumers in the United States: older Americans and adults with disabilities. Each group has specific considerations, but there is some overlap for individuals who are members of both groups. The groups are described further in the two sections that follow; see also the related Current Concept sidebar “Long-Term Care Consumers: Disrupting Ageism and Ableism.”

Older Americans

The United States is experiencing a remarkable demographic transformation characterized by unprecedented growth in both the number of older adults and their share of the country’s total population, as illustrated in exhibit 1.1 (Federal Interagency Forum on Aging-Related Statistics 2016). Compared with previous generations, Americans today are living longer, are more racially and ethnically diverse, and are more prosperous. In 2014, 44.7 million Americans—about 15 percent of the US population—were aged 65 or older, and 6 million were aged 85 or older. By 2060, the number of people aged 65 or older is expected to more than double to 98 million, and the number of people aged 85 or older is expected to triple to 18 million. By 2030, 73 million baby boomers (people born between 1946 and 1964) will all be aged 65 or older (America Counts Staff 2019). Rapid growth in this segment is predicted to continue, as is growth in the “oldest old” segment of adults aged 85 or older.

Americans aged 65 or older are better educated than ever before. In 1965, 24 percent of older adults had a high school diploma and 5 percent had at least a bachelor’s
degree; by 2015, those numbers had risen to 84 percent for a high school diploma, and 27 percent for a bachelor’s degree (Federal Interagency Forum on Aging-Related Statistics 2016). With higher levels of education, older Americans enjoy higher incomes and higher net worth levels. Furthermore, an increasing share of their income comes from earnings as more individuals are working past the age of 65, either from a desire to remain active in the workforce or out of economic necessity. Yet serious income inequalities persist among older Americans, based on differences in gender, social and economic status, education, and race and ethnic background. Older women are more likely to live in poverty than older men, while older Black, Latino, and Asian American men and women are more likely to live in poverty than older white men and women.

General improvements in health have yielded improvements in *life expectancy* (the average number of years remaining to live at a given age) in the twenty-first century, although life expectancy in the United States lags behind many other industrialized nations. Life expectancy varies by gender, race, and socioeconomic status. The impact of COVID-19 on life expectancy is predicted to change these patterns, with a disproportionate impact on Black and Latino populations (Andrasfay and Goldman 2021). *Healthy life expectancy* at the age of 60 (the expected number of years of healthy life after the age of 60) provides insight into the potential quality of life for older adults. Recent research by the World Health Organization (WHO) found that globally from 2000 to 2016, healthy life expectancy was

EXHIBIT 1.1
Population Aged 65 or Older and Aged 85 or Older, Selected Years, 1900–2014, and Projected Years, 2020–2060
about one quarter shorter than life expectancy. Countries with higher income tended to have higher health expectancy, notably Japan and Singapore, while the continent of Africa made greater strides in improvement in life and health expectancy than most world regions did over this period. Women were found to have higher life and health expectancy than men (He and Dupre 2021).

In 2014, the top six causes of death among people aged 65 and older in the United States (heart disease, cancer, chronic lower respiratory diseases, stroke, Alzheimer’s disease, and diabetes) were all chronic health conditions (conditions lasting a year or longer that require ongoing medical care or limit ADLs). Although statistics have shown a decrease in disability and other impairments that restrict the functioning of older adults (Courtney-Long et al. 2015), chronic health conditions contribute significantly to disability and frailty (a condition marked by a lack of resilience to physiological changes and an elevated risk of poor health outcomes). Many, although not all, chronic health conditions are impacted by modifiable health behaviors, including diet, physical activity, and cigarette smoking (Federal Interagency Forum on Aging-Related Statistics 2016). Chronic health conditions are discussed briefly later in this chapter and in greater detail in chapter 7.

**Adults with Disabilities**

Adults with disabilities occupy a significant position within the population of long-term care service consumers. According for the Centers for Disease Control and Prevention (CDC 2016), in 2016, 1 in 4 adults in the United States, or 61 million people, reported having a disability falling into any of the following six categories: hearing, vision, cognition, mobility, self-care, or independent living. Disabilities were more common for older adults, women, indigenous peoples, adults with income below the poverty line, and adults living in the southern United States. Veterans living with disabilities also represent a significant portion of this group; according to the US Department of Veterans Affairs (2019), more than 4.5 million veterans reported having service-related disabilities in 2018. Exhibit 1.2 shows measures of US disability populations over time.

Non-Hispanic Blacks aged 65 or older were more likely to report living with a disability (26 percent) compared with non-Hispanic whites (21 percent). Hispanics aged 65 or older were more likely to report difficulties with cognition (6 percent) and self-care (5 percent) compared with non-Hispanic whites (5 percent for cognition and 2 percent for self-care)(CDC 2021) Disability increases with age, with 42 percent of people aged 85 or older reporting living with a disability, compared with only 17 percent of people aged 65–74. Adults who had lower education levels, were unemployed, or had lower incomes were also more likely to report living with a disability (Courtney-Long et al. 2015). Annual disability-associated healthcare expenditures were estimated at nearly $868 billion in 2015 (CDC 2021). Such high costs underscore the importance of maintaining the health and functional status of individuals living with disabilities.
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Historically, the needs of older adults and the needs of adults living with disabilities were addressed through separate laws and by various government organizations. The Older Americans Act (OAA), passed in 1965, created the Administration on Aging to provide seven types of services specializing in the needs of older adults. The Developmental Disabilities Assistance and Bill of Rights Act of 2000 established the Administration on Intellectual and Developmental Disabilities with six programs that supported and empowered individuals living with disabilities in the community. The government altered its approach to these areas in 2012, when the US Department of Health and Human Services established the Administration for Community Living (ACL) as an umbrella agency that included the Administration on Aging, the Administration on Intellectual and Developmental Disabilities, and the Office on Disability. The goal for ACL was to reduce the fragmentation of government services for older adults and adults with disabilities and to encourage common solutions for community-living services and supports (ACL 2022b). The chapter 2 section “History of Long-Term Services and Supports” discusses key legislation and historical developments in depth.

EXHIBIT 1.2
Percentage of People Aged 65 or Older Living with a Disability, By Sex and Functional Domain, 2010 and 2014

*Note: Disability* is defined as having a lot of difficulty with or not being able to do at least one of the following activities: vision, hearing, walking or climbing steps, communicating, remembering or concentrating, and self-care.


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Ageism, meaning stereotypes, prejudice, or discrimination against individuals because of their age, is prevalent in modern society and is reflected in popular culture and the media. People older than the age of 65 are frequently grouped together using general labels such as “the elderly” or “senior citizens” and are subjected to positive, negative, and ambivalent stereotyping that has the effect of masking their individuality as unique human beings. Older adults may be stereotyped as being “sweet” or “cute”; research demonstrates that such approaches to elders in long-term care can actually increase their dependence on staff (Coudin and Alexopoulos 2015). Negative stereotypes are even more common and include views that elders are “grumpy” or “stubborn” (Kotter-Grühn and Hess 2012). Ambivalent stereotypes also exist, capturing both positive and negative elements, with the result that elders are often seen as “doddering but dear” (Cuddy and Fiske, 2002, 3).

Stereotyping people into groups, as opposed to seeing them as individuals, can lead to prejudice. Examples of prejudice include believing that older adults are incapable or less valuable than younger people. Discrimination goes one step farther and occurs when someone acts on prejudices about others. However, it is important to note that age discrimination has been noted under federal employment laws. The Age Discrimination in Employment Act of 1967 protects individuals aged 40 or older in the workplace.

It is important to recognize that ageism can be self-directed, as well as other-directed, and many studies have shown that negative attitudes about one’s own aging process can have harmful health consequences, including reduced recovery from serious illness (Levy et al. 2006) and reduced longevity (Levy et al. 2002). It has also been estimated that the cost of ageism is $63 billion, or one of every seven dollars spent on eight prevalent health conditions for older adults, after adjusting for age and sex (Levy et al. 2020). Therefore, it is important for consumers of long-term care and for those working in long-term care to be aware of negative societal attitudes toward aging and how these may affect individuals and their well-being. Ageism can be explicit, or consciously perpetrated, as well as implicit, or unconsciously perpetrated.

Ageism is also associated with ableism, a form of prejudice or discrimination against individuals because of a disability. Ageism and ableism share a common focus on the biomedical aspects of human lives, with a tendency to stigmatize those who do (continued)
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To understand the structure of today’s long-term care delivery system, we must first look at the system’s rich history and heritage in the United States. Some research suggests that the time span that began at the end of the nineteenth century has consisted of a series of cycles and concerns in long-term care, with distinct periods of approximately 20 years each (D. Smith and Feng 2010). These cycles have been extended to include seven periods of disruptive activity that shaped the delivery of long-term services and supports. Each period has focused on a specific concern and a supposed legislative solution, and each has contributed to the inadequate safety net of care that still exists today. Exhibit 1.3 provides a timeline showing the seven periods described in the following sections.

The First and Second Periods
The first period lasted from the late 1800s until the 1930s. During this time, the infirm were placed together in almshouses, sometimes referred to as “poor farms” for elderly “inmates.” Residence in these private boardinghouses allowed those with long-term care needs to be eligible for federal Old Age Assistance, which became the hallmark of the second period—the old-age income security solution.

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not meet arbitrary ideals of physical and cognitive ability. This may result in individuals living with disabilities being defined by others based on their physical or cognitive condition, with labels such as “wheelchair bound,” “handicapped,” or “senile.” Like ageism, ableism can be internalized such that individuals living with disabilities absorb negative stereotypes and beliefs about themselves.

Proponents of a social, rather than biomedical, model of both age and disability would argue that individuals are disabled not by their age or their physical or cognitive impairments but by barriers in society. These barriers can be attitudinal, such as assuming older people or people living with disabilities can’t do certain things; physical, such as inaccessible buildings and transportation systems; or enshrined in policies and laws (or the lack of them) that limit the opportunities for older people or people living with disabilities. It is important that long-term care providers and individuals pursuing long-term care careers remove these attitudinal, physical, and policy barriers, which can result in older people and people living with disabilities having more independence, choice, and control over their lives.
The second period began with the Social Security Act, passed in 1935. This law provided pensions to older people, but with the stipulation that anyone housed in a public facility such as an almshouse could not receive one. Although the intent of the legislation was to bring about the end of almshouses, the law helped establish voluntary and proprietary nursing homes that accepted people with physical and mental infirmities (Mara and Olson 2008).

The third period,

By the 1950s, new legislation emerged to establish the next phase of public financing for nursing home facility construction and public payment for long-term care services. This third period, which expanded access to affordable health insurance, lasted until 1970. Changes to the Social Security Act permitted payments to public LTC institutions and direct government payments to LTC facilities, which made the industry appealing to small-business owners. In addition, state licensure programs for nursing homes started to appear. The Hill-Burton Act of 1946, as amended in 1954, provided federal grants (along with construction and design guidelines) to public and not-for-profit companies interested in building nursing homes. However, the amendments stipulated that the nursing homes must be affiliated with hospitals, thereby promoting the medical model of care within the nursing home environment. In the late 1950s, the 1959 Housing Act established Section 202, Supportive Housing for the Elderly, and the newly formed American Association of Nursing Homes successfully lobbied Congress to allow for-profit organizations to obtain...
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nursing home funding from the Small Business Administration and the Federal Housing Administration. The Kerr-Mills Act of 1960 followed and provided federal–state matching funds for the medically needy, including nursing home residents, and federal money for home care services.

The tradition of federal oversight and financing of long-term care carried over into the Great Society legislation of the 1960s. Medicare and Medicaid were signed into law in 1965, and a provision in Medicare covered posthospital “extended care” up to 100 days. The OAA was also passed in the same period, creating the Administration on Aging. Then, in 1967, the Moss amendments to the Social Security Act established new rules and regulations for Medicaid-funded nursing homes to follow.

**The Fourth Period**

The fourth period lasted from the early 1970s through 1989 and further expanded governmental attempts to control provider abuses, while opening the door to providing home and community-based services to long-term care consumers. The Social Security amendments were extended to offer Medicare coverage to individuals living with disabilities; the Supplemental Security Income program was activated in 1974; and, by the late 1970s, certificate-of-need programs and amendments to the Medicare and Medicaid antifraud and abuse provisions were enacted. In 1983, concern about escalating healthcare costs led to the creation of Medicare diagnosis-related groups, which limited payments to hospitals and helped move post-acute care to ambulatory care and nursing home facilities that had few payment limitations. Section 1915 of the Social Security Act was added in 1983 and gave states the option of receiving a waiver from Medicaid to provide funding for home and community-based services. In 1987 with the passage of the Omnibus Budget Reconciliation Act, nursing home reforms were enacted, creating the State Survey and Enforcement System for nursing homes.

**The Fifth Period**

The fifth period extended from 1990 up to 2010. Its early phase in the 1990s was a time of market-based reforms, innovative demonstration programs, and expansion of private insurance for long-term care expenses. The Americans with Disabilities Act, which extended protection to persons with disabilities, was passed by the US Congress in 1990. In 1997, Congress passed the Balanced Budget Act, which established the Prospective Payment System for Medicare-funded posthospital services. In 2004, quality indicators were established for nursing homes that accept Medicare payments.

The US Supreme Court’s 1999 *Olmstead v. L.C.* decision, which prohibited unnecessary institutionalization of persons living with disabilities, provided the impetus for the expansion of home and community-based services. By 2017, nearly 58 percent of Medicaid

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**Medicare**

The federal health insurance program in the United States for individuals aged 65 or older, those on Social Security disability benefits for more than two years, and those living with Lou Gehrig’s disease or end-stage renal (kidney) disease. Medicare covers care provided in skilled nursing facilities for up to 100 days, as well as home care.

**Medicaid**

A means-tested federal insurance program in the United States that pays for medical care and other supportive services for low-income individuals, people living with disabilities, and poor older persons. The states administer their programs under broad federal guidelines.

**Section 1915 of the Social Security Act**

A 1983 amendment to the Social Security Act that allowed states to obtain a waiver from Medicaid to provide home and community-based services.
expenditures were for services provided in noninstitutional settings, as reported by the Medicaid and CHIP Payment and Access Commission (MACPAC 2020). New homelike models of care evolved, such as assisted living, Eden Alternative housing, and Green House Project cottages (discussed further in chapter 4). Despite these innovations, financial challenges remained. The cost of long-term services for all individuals who needed them, regardless of their geographic location or income, continued to strain government and family budgets.

The Sixth Period

The sixth period began with the passage of the Affordable Care Act (ACA) in 2010 and lasted until early 2020. The ACA helped focus attention on the integration and coordination of LTSS, as well as on opportunities to innovate service delivery and reimbursement. The creation of the Administration for Community Living in 2012 provided an opportunity for leaders in aging and disability service provision to deliver programs that benefit both LTSS consumer populations. In addition, a new focus on preventive care service and primary care services delivery, innovative uses of technology for LTSS delivery, and support for informal caregiver services continues to benefit these consumers. The 2015 White House Conference on Aging (WHCOA 2016) commemorated the eightieth anniversary of the Social Security Act and the fiftieth anniversary of the OAA, Medicare, and Medicaid (see related “Did you Know?” sidebar on the WHCOA).

The Seventh Period

The onset of the COVID-19 pandemic in 2020 opened new concerns about long-term service and support delivery. Growing awareness of health as well as racial disparities affecting older adults emerged during the pandemic, as well as the limitations of health care and long-term care providers to adequately address service delivery needs. The American Rescue Plan of 2021 provided $1.43 billion for OAA programs such as nutrition services, family caregiver support, health promotion, and disease prevention, as well as support for resident rights in long-term care communities and programs to combat elder abuse (ACL 2022b).
“The COVID-19 pandemic has exposed and exacerbated long-standing challenges impacting the long term care (LTC) profession,” observed the American Health Care Association and LeadingAge in the introduction of their publication Care for Our Seniors Act: Improving America’s Nursing Homes by Learning from Tragedy and Implementing Bold Solutions for the Future (LeadingAge 2022b). LeadingAge, a consortium of not-for-profit LTSS organizations, concurrently released the Blueprint for a Better Aging Infrastructure, “a series of recommendations that address the economic, social, and racial inequities older Americans face by expanding access to long-term care at home and in our communities; increasing affordable housing for older adults; investing in the physical and technological infrastructure of aging services—including high-speed broadband access; and addressing the fundamental need to better support and grow our nation’s aging workforce” (LeadingAge 2022a). CMS (2022) also released its Framework for Health Equity 2022–2032 to “design, implement, and operationalize policies and programs to support health for all people . . . eliminating avoidable differences in health outcomes experienced by people who are disadvantaged or underserved, and providing the care and support that they need to thrive.”

**Aging, Disability, and Chronic Health Conditions**

To understand the LTC service delivery system, you must first have a foundation of knowledge about the aging process, the components of functioning and disability as defined by the WHO’s International Classification of Functioning, Disability, and Health (ICF); and dominant chronic health conditions. Recall that a chronic health condition is a health condition lasting for a year or longer that requires ongoing medical care, limits an individual’s activities of daily living, or both. Changes in the functions and capabilities of the body are critical determinants of service provision and reimbursement.

**Geriatrics** is the branch of medicine that deals with the health and care of older adults. A physician who specializes in this area is called a geriatrician. Geriatricians are specifically trained to recognize and treat aging-related physiological changes and clinical syndromes, provide team-based care and systems for older adults and their family support systems, take a clinical focus that emphasizes functional status and a holistic approach to health, and use shared decision making that places the older patient’s goals and preferences at the center of care. There is currently a serious shortage of geriatricians in the United States as well as a serious shortage of other healthcare professionals, such as nurses, who have advanced geriatric training. This means that older people are likely to receive treatment from healthcare professionals with limited knowledge and expertise of the aging process.

**Gerontology** is the scientific study of the aging processes from a biological, psychological, social, and spiritual perspective and includes the study of how individuals, populations, and societies age. Gerontology is a multidisciplinary field, with biology, psychology, and sociology forming the core areas of study, with contributions from many other areas of study, including public policy, the humanities, and economics. Specialists in gerontology,
called gerontologists, strive to improve the quality of life and promote the well-being of individuals as they grow older within their families, communities, and society. Gerontologists are involved in many types of work, including research, education, and the application of interdisciplinary knowledge of the aging process and aging populations. Many colleges and universities offer degree programs for students interested in becoming gerontologists.

GENETIC AND ENVIRONMENTAL FACTORS

The way an individual ages depends on a variety of genetic and environmental factors, as well as on access to healthcare services. About 20 percent of a person's health is attributable to genetics, about 20 percent to the medical care received, and the other 60 percent to social, behavioral, and environmental factors, many of which people can and do influence by the choices made throughout life (Jenkins 2016).

PHYSICAL SIGNS OF AGING

As a person ages, the body undergoes a series of gradual changes in most body systems, including the circulatory, nervous, respiratory and digestive systems. Changes in a person's height, skin, and senses (e.g., vision, hearing) are normal parts of the aging process. There is a progressive decrease in the body's physiological capacity and a reduced ability to respond to environmental and other stresses, which leads to an increased susceptibility to disease that ultimately results in an increase in all-cause mortality as individuals grow older. However, it is important to recognize that aging is not synonymous with disease and that declines in health are not inevitable. Instead, we can approach health as a tool for living our best life (Jenkins 2016). The Affordable Care Act’s emphasis on health promotion and wellness complements this idea. It encourages older adults to move away from being dependent patients and toward becoming empowered consumers seeking a partnership with their physicians and other healthcare providers (Jenkins 2016).

DISABLING CONDITIONS

According to the CD (2020), a disability is defined as “any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).” Disability can be a multidimensional experience, and three dimensions of disability recognized by the World Health Organization: (1) impairment, (2) activity restrictions, and (3) participation restrictions (CDC 2020). Disabilities may be acquired at birth or developed later in life. The way people view disabilities has evolved over time. Today, living with a disability is viewed as a social construct that relates to barriers created by society, not as a medical problem or condition.
Disability studies involves interdisciplinary approaches grounded in social science that look at the meaning, nature, and consequences of disability as a social construct. College and university programs have shown a growing interest in this area of LTC training.

**Chronic Health Conditions and wellness**

Chronic health conditions can affect both physical and intellectual functioning and can be medical or psychological in nature. Common chronic health conditions include arthritis, cancer, depression, diabetes, heart disease, hypertension, and respiratory illness. Chronic health conditions are major causes of hospital readmissions in the United States and have received increasing attention in healthcare reform policies. The emergence of a growing number of individuals with multiple chronic health conditions has become an important issue. These individuals require interdisciplinary care coordination to maintain and improve their quality of life (Goodman et al. 2013).

The COVID-19 pandemic raised awareness of the impact of social isolation on the relationships of older adults and the importance of wellness programs, including services to maintain physical and mental health. Having long-term care communities that address wellness of their residents through comfortable, age-friendly features will grow in importance (International Council on Active Aging 2021). Chapter 8 provides a more extensive review of wellness services and chronic health conditions, including their impact on LTC service delivery.

**Models of Long-Term Care Delivery**

As the US population ages, an expansion in the scope and depth of LTC services is driving changes in the provision and delivery of these services. A growing proportion of services are now provided in the home and in other community-based settings, rather than in traditional residential or acute care environments such as nursing homes or hospitals.

To facilitate reimbursement, many providers have organized their activities around a *continuum of long-term care*. This continuum is defined as “a [holistic] system composed of both services and integrating mechanisms that guides and tracks clients over time through a comprehensive array of health, mental health, and social services spanning all levels of intensity of care. . . . It includes mechanisms for organizing those services and operating them as an integrated system” (Evashwick 2005, 4). This continuum helps individuals understand and organize their thinking about the provision of LTSS. However, issues involving treatment and payment for chronic illness and the increasing complexity of the reimbursement system for long-term care (especially services provided on an informal basis) may require different approaches as the baby boomers and generations that follow prefer to live independently in the community.
Since the 1990s, some states have moved to a **single access point (SAP) model** for long-term service delivery. The SAP model is also known by various other names, such as **single entry point** and **aging single-access point**. Regardless of the terminology used, under the SAP model, individuals can obtain all service referrals and service administration through just one provider organization. The SAP concept is discussed further in chapter 2.

In 2012, the ACL, the Center for Medicare & Medicaid Services (CMS), and the Veterans’ Health Administration (VHA) established a **No Wrong Door policy** that enabled all people, regardless of age, income, or disability to obtain long-term services and supports through a single access point. This is a one-stop, coordinated system of care that empowers individuals “to make informed decisions, to exercise control over their long-term care needs, and to achieve their personal goals and preferences” (No Wrong Door 2022). As of 2022, there were 56 states and territories participating in NWD activity, 1,322 access points, and 33 states with legislative/governor support (No Wrong Door 2022).

A similar model for the delivery of LTSS is the **dimensions of care model**, shown in exhibit 1.4. This model includes the services identified in the continuum of care model, allows consumers to have a single point of entry into the LTC delivery system, and emphasizes the option for consumers to use technology and supportive services to assist them in living independently in the community and in maintaining a high quality of life.

The emphasis on technology differentiates the dimensions of care model from other service models. Because this model promotes the use of technology and other supportive services to help older adults and individuals living with disabilities remain independent in their homes and neighborhoods, it may be more flexible than other models if the availability of caregiving supports (especially informal supports) declines. However, the choice of how to use technology in LTSS delivery always belongs with consumers, and the person-centered care process acknowledges and supports their beliefs and traditions. The dimensions of care model is fluid and nonlinear in that it acknowledges that individuals may consume services in acute and long-term care environments as well as in community-based settings, much like an interconnected ecosystem. It also acknowledges the value of care coordination with the assistance of technology throughout these service transitions.

Though no model of LTC service provision is ideal in explaining the consumption of services, the dimensions of long-term care model gives consumers greater flexibility to select services that enable them to live independently in the community, or in their choice of setting, and enjoy greater quality of life. It forms the basis for the organization of this book.
Key Aspects of Long-Term Care

In this final section of the chapter, we briefly examine several key aspects of long-term care: where long-term services and supports are provided; kinds of organizations that provide LTSS; who pays for LTSS; and quality and safety in long-term care services.

Where Long-Term Services and Supports are Provided

Long-term services and supports are typically provided in the following types of settings:

- Acute care
- Ambulatory care
- Home and community
- Residential
- Outreach and linkage
- Technological

Care planning and care coordination services help consumers and their families navigate this range of options for service delivery. The list represents a consolidation and extension of earlier service models and incorporates new developments in
LTSS, in addition to the use of technology to link service providers to consumers. (See the related Current Issue sidebar “Long-Term Care Settings: Rural Versus Urban Communities.”)

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Long-Term Care Settings: Rural Versus Urban Communities

Rural areas present special challenges to the delivery of long-term care services. There are 46.2 million older people in the United States, with 10.6 million in areas designated as rural. More than 20 percent of older Americans live in rural areas, many concentrated in states where more than 50 percent of their older populations are in rural areas (A. Smith and Trevelyan 2019).

Mostly rural counties with high concentrations of elders were located in the eastern half of the United States (with Vermont and Maine having the largest rural populations), while completely rural counties were in the middle of the United States, forming a path from North Dakota to Texas (A. Smith and Trevelyan 2019). Rural elders, on average, are older than their urban counterparts, with many elders belonging in the “oldest old” category (aged 85 or older). Diversity trends seen in the urban US population have also affected rural areas, with immigration of elders from Latin America and Asia (Gurak and Kritz 2013). Among rural elders’ challenges are insufficient transportation options, a limited number of care providers (especially physicians), and inadequate funding for community-based social and health services. In addition, poor older adults in rural areas often face challenging living conditions as well as social isolation.

The mix of residential and community-based providers for LTC services is also different in rural areas. Rural elders are less likely to use a nursing home than an assisted living facility (ALF) because of both income constraints and limited availability. They are more likely to rely on Medicaid than are urban elders, which means rural nursing homes generally have fewer services and higher utilization rates than urban nursing homes do. The same situation exists with rural ALFs: They tend to offer less privacy and fewer services than their urban counterparts. Many LTC services, such as skilled nursing care, are provided in rural institutional settings such as critical access hospitals. Choices for nonresidential care services are also limited in rural areas. Home health care agencies are fewer in number, are more likely to use nursing aides, and offer a smaller variety of services. However, the growth of telehealth services (healthcare services provided via the internet or other telecommunications technologies) has helped spread knowledge and use of community-based services in remote areas.
Kinds of Organizations that Provide LTSS

Healthcare systems, nursing homes, and other residential care organizations such as assisted living facilities (ALFs) provide a large proportion of long-term care services. (ALFs are discussed in chapter 4.) However, a growing number of services are delivered through home and community-based programs. These providers may be privately owned for-profit entities such as Brookdale Senior Living, LCS and Holiday Retirement; not-for-profit organizations such as The Arc, United Cerebral Palsy, or Visiting Nurse Services; governmental entities such as the Area Agencies on Aging, Disabilities Administrations, or Veterans Affairs facilities; or faith-based organizations such as Catholic Charities, Jewish Federations, or the Lutheran Diakon. As the use of assistive technology as an option in the provision of LTSS grows, the list of organizations providing such technology may include small start-up companies as well as established computer, telecommunications, and pharmaceutical firms looking to expand their markets and services.

Who Pays for LTSS

Payment for formal LTSS in the United States comes primarily from government sources such as Medicaid, Medicare, and other public programs. According to the Congressional Research Service, total national spending on LTSS was about $409.3 billion in 2018 (Colello 2020). Medicaid covered 44.1 percent of total expenditures ($180.5 billion), Medicare paid 20.4 percent ($83.7 billion), other public programs paid 6.2 percent ($25.6 billion), consumers’ out-of-pocket funds (i.e., payments for services made directly by individuals) covered 14.9 percent ($61.1 billion), other private programs paid 6.2 percent ($25.0 billion), and private insurance (commercial insurance, managed care plans, and LTC insurance plans) accounted for 8.2 percent ($33.4 billion).

Quality and Safety in Long-Term Care Services

The quality of LTSS has been a growing concern, and the COVID-19 pandemic raised awareness of the problems in ensuring quality and safety for long-term care consumers, especially those living in congregate settings. CMS has attempted to address this issue through regulations affecting the assessment of long-term care needs, new emergency preparedness and infection control requirements, sufficient staffing of LTC services, and the requirement for all long-term care providers covered under the Medicare Conditions of Participation to have a quality assurance and performance improvement plan. (Conditions of Participation are discussed in detail in chapter 14.) States have also increased their regulation of assisted living communities and other residential options for consumers. Additional initiatives will result from ACA provisions, the Medicare Innovation Center’s work to examine new alternatives for providing LTSS, and other private organizations such as the Institute for Healthcare Improvement (IHI), and the Baldrige Excellence Framework. Chapter 16 provides an extended overview of that topic.
A Look Ahead

The outlook for healthcare reform and its impact on LTSS is mixed. The LTC delivery system remains fragmented and patched together, and an increasing number of clients will likely enter the system as America ages. Like many European and Asian countries, the United States is facing the strains of response to the COVID-19 pandemic, declining tax revenues, expensive public health and retirement programs, and rapid growth in the population of people eligible to collect benefits from these programs. The need to address health disparities and health equity in the US healthcare delivery system emerged during this period, with CMS’s new Framework for Health Equity defining the priorities for addressing these issues in all healthcare services, including LTSS (CMS 2022).

However, the passage of the Affordable Care Act, the reauthorization of the Older Americans Act, and proposals by the Biden administration and changes in CMS’s policies to enhance funding for home and community-based services for older adults and persons with disabilities provide a philosophical foundation for wellness and health promotion throughout all stages of our lives. The growth of population health initiatives started under the ACA also raises the importance of addressing chronic health conditions. At the same time, providers are looking at new options for the provision of care and services, such as greater use of technology (especially telehealth services) and shared resources in community settings. These options have spurred growth in new industries and created new job opportunities for individuals interested in providing care to the growing market of LTSS.

For Discussion

1. What is long-term care (LTC), and who are long-term care consumers?
2. What is the difference between formal and informal long-term services and supports (LTSS)?
3. What are ageism and ableism? What is their impact, and why is it important to be aware of them?
4. Describe the process of accessing LTSS, and how it has evolved to a more coordinated, person-centered system of care.
5. What are the periods of care in the history of LTC service delivery, and why are they significant?
6. What are activities of daily living, and why are they used as determinants of need for LTSS?
7. In what settings are LTSS provided, and which settings may become more important in the future?
8. What are some limitations faced by agencies and community organizations that provide LTSS in rural areas?
9. Identify two major payers for LTSS in the United States. What are out-of-pocket expenditures for long-term care, and who pays them?

10. What measures have been taken by CMS and other organizations to monitor the quality and safety of LTSS?

CASE STUDY: COMMUNITY ASSET MAPPING

Jillian Warriner

Sharp HealthCare is one of the dominant health systems serving the county of San Diego, California. It is the only major health system that focuses specifically on health for older adults. Sharp serves San Diego County with four acute care hospitals, three specialty hospitals, three affiliated medical groups, and a commercial health plan (Sharp Health Plan) that provides individual and family plans, employer-sponsored group plans, and Medicare plans, including a Medicare Advantage plan. Further, Sharp is also a leading provider of care for the Medi-Cal (Medicaid) population in San Diego County, and for Covered California (California's state Medicaid program).

Sharp recognizes the importance of providing an effective population health program for older adults, with some services offered directly, some through formal partners, and some through informal referrals. Currently, Sharp operates two Senior Health Centers (SHCs) and two Senior Resource Centers. The SHCs offer clinical services from geriatricians and geriatric nurse practitioners as well as an array of other services tailored specifically for older adults. Each of the SHCs has arrangements with local community providers who offer health-related and social services.

Sharp's Senior Resource Centers are on-site departments at two of its acute care hospitals. They engage primarily in education, outreach, screening, and support for senior patients and community members; they do not offer clinical services.

As the aging population of San Diego County grows, Sharp is considering adding a third SHC to serve the community. This decision would be consistent with the findings of its recent community health needs assessment (Sharp HealthCare 2019). Identifying and evaluating specific community assets are critical components of the program proposal. The staff has begun to gather an array of data to determine the location, service package, and community partners appropriate for the new SHC. The challenge is to determine where the center should be located, what specific programs and services it should offer, and which organizations would be appropriate community partners in building a robust care transitions program for older adults as well as their caregivers. In evaluating the options for a new SHC, Sharp must answer the following three questions:

1. Where in San Diego County should the center be located, based on current and projected demographics?
2. What services should Sharp offer directly on-site?
3. What services should Sharp offer through collaboration with community partners?

**NEEDS OF OLDER ADULTS**

People aged 65 or older require specialized care and often have multiple, complex, chronic health conditions that complicate performing activities of daily living (e.g., eating, bathing, dressing) as well as care delivery and transitions and medication management. Older adults who lack a caregiver at home or who are otherwise socially isolated face increased fall risk, greater behavioral health risks, and more significant cognitive decline, as well as gaps in meeting their social determinants of health, such as transportation to medical appointments and access to nutritious food.

**CARE TRANSITIONS AND CARE COORDINATION**

An array of services is necessary to meet the multiple needs of older adults. Elders might spend five days in a hospital, but for the remaining 360 days of the year they receive care at home and tap into community resources. In considering a new SHC, Sharp must determine what additional age-related services are important to its patients, as well as which community-based organizations (CBOs) offer those services. Moreover, in light of the various payment programs that Sharp offers older adults, the new center’s financial viability is affected by how CBO partnerships are formed, how they are managed for financial efficiency, and what measures used to access the success of the center.

**ASSET MAPPING**

The likely geographic location for Sharp’s next SHC is “South County,” the area in the southern end of San Diego County. To assess potential partners for either formal or informal relationships, Sharp must first identify the agencies that are already serving older adults in this general area as well as partners in other parts of San Diego County that could potentially expand to collaborate with the new SHC if the volume and funding were sufficient to attract their investment. Sharp embarks on asset mapping using hospital discharge disposition data (exhibit 1.5) as well as a model for mapping this discharge information. Sharp’s asset mapping includes the following steps:

1. **Mapping the service area.** Sharp uses internal hospital discharge data to map its service area—that is, the communities (often at the zip code level) where its patients reside and the types of services most commonly used after discharge (as listed in exhibit 1.4).

2. **Identifying potential partners.** The types of agencies or partners sought are based on the need for effective care transitions and care coordination. Sharp
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begins by asking hospital staff—including social workers, case managers, and discharge planners—which agencies currently serve as collaborators to address patients' needs upon discharge. Sharp may also check with 211 San Diego, the San Diego Department of Health and Human Services office serving that region, Aging and Independence Services, and other current partners to obtain contact information for new CBOs with which it might collaborate. Sharp conducts key informant interviews with nurses or administrators of physician practices in the area, and it contacts local churches to ask what social support services might be available. Sharp’s planners also meet with representatives from the county’s Department of Transportation to learn about public transportation routes, dial-a-ride programs, and local proprietary agencies, ranging from taxis to ride-sharing companies.

3. **Evaluating partners.** Armed with a list of potential community assets, Sharp’s planning staff begin the process of evaluating each of the potential partners

<table>
<thead>
<tr>
<th>Discharge Disposition</th>
<th>Aged 64–74</th>
<th>Aged 75–84</th>
<th>Aged 85+</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home/self-care (routine)</td>
<td>55.89%</td>
<td>44.24%</td>
<td>29.24%</td>
<td>44.79%</td>
</tr>
<tr>
<td>Skilled nursing</td>
<td>17.44%</td>
<td>24.22%</td>
<td>31.63%</td>
<td>23.53%</td>
</tr>
<tr>
<td>Home health service</td>
<td>14.96%</td>
<td>18.84%</td>
<td>21.29%</td>
<td>17.94%</td>
</tr>
<tr>
<td>All other</td>
<td>6.55%</td>
<td>8.00%</td>
<td>12.56%</td>
<td>8.69%</td>
</tr>
<tr>
<td>Short-term acute</td>
<td>2.25%</td>
<td>2.12%</td>
<td>1.98%</td>
<td>2.13%</td>
</tr>
<tr>
<td>Board/care residential</td>
<td>0.74%</td>
<td>0.40%</td>
<td>0.37%</td>
<td>0.53%</td>
</tr>
<tr>
<td>Rehab</td>
<td>0.69%</td>
<td>0.74%</td>
<td>0.66%</td>
<td>0.70%</td>
</tr>
<tr>
<td>Long-term acute</td>
<td>0.62%</td>
<td>0.64%</td>
<td>0.32%</td>
<td>0.54%</td>
</tr>
<tr>
<td>Psychiatric hospital</td>
<td>0.49%</td>
<td>0.20%</td>
<td>0.06%</td>
<td>0.28%</td>
</tr>
<tr>
<td>Assisted living</td>
<td>0.37%</td>
<td>0.60%</td>
<td>1.89%</td>
<td>0.87%</td>
</tr>
</tbody>
</table>

*Source: Sharp HealthCare (2019).*

**EXHIBIT 1.5**

Sharp Hospital Discharge Dispositions for Patients Aged 64 or Older, 2017

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for quality indicators, reputation, financial stability, service area, and capacity of staff to provide services, as well as power within the community. For most services, accreditation or licensing bodies provide information and metrics on select criteria. However, each service has distinct accreditation or quality measures, so a separate assessment is done for quality. In addition, potential partners must meet criteria for risk and financial performance.

Sharp must project the approximate demand for each service based on the total client pool expected at the SHC, as well as the health and social needs (i.e., the social determinants of health) likely to be observed. The selection of CBO partners must have the capacity to meet the needs of the projected patient volume. Additionally, the CBOs must have their own incentives to participate in a collaborative effort with Sharp.

**Financial Arrangements**

The proportion of payments for Sharp’s two existing SHCs is shown in exhibit 1.6. The new center is expected to be financed primarily through managed care health plans, including Medicare, Medicare Advantage, Medi-Cal (Medicaid), and other government programs. The financial composition is anticipated to be in relation to the demographics of the area.

In addition to the incentives associated with payment through Medicare Advantage, Sharp has a financial interest in improving care transition and care coordination as a way to reduce avoidable costs. For instance, significant cost savings can be achieved when CBO programs and support serve as a supplement to patients’ medical care, helping to meet the

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**EXHIBIT 1.6**

Payment Arrangements for Sharp’s Existing Senior Health Centers

<table>
<thead>
<tr>
<th>Category</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare (traditional)</td>
<td>88.14%</td>
</tr>
<tr>
<td>Medicare Advantage</td>
<td>6.76%</td>
</tr>
<tr>
<td>Dual Medicare &amp; Medi-Cal</td>
<td>4.90%</td>
</tr>
<tr>
<td>Other government</td>
<td>0.11%</td>
</tr>
<tr>
<td>HMO</td>
<td>0.05%</td>
</tr>
<tr>
<td>Self-pay</td>
<td>0.03%</td>
</tr>
<tr>
<td>PPO</td>
<td>0.02%</td>
</tr>
</tbody>
</table>

*continued*
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Sharp Senior Health Center: Downtown

<table>
<thead>
<tr>
<th>Category</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare (traditional)</td>
<td>36.89%*</td>
</tr>
<tr>
<td>Dual Medicare &amp; Medi-Cal</td>
<td>49.12%</td>
</tr>
<tr>
<td>Medicare Advantage</td>
<td>12.88%</td>
</tr>
<tr>
<td>Self-pay</td>
<td>1.04%</td>
</tr>
<tr>
<td>PPO</td>
<td>0.07%</td>
</tr>
</tbody>
</table>

*In 2017, nearly 18 percent of this category was aligned with Sharp HealthCare’s NextGen accountable care organization.

HMO: health maintenance organization; PPO: preferred provider organization.

Source: Data from Sharp Healthcare (2019).

Social determinants of health of patients after discharge from the hospital. Such services not only can help patients avoid inpatient readmissions and emergency room visits; they can also enable older adults to thrive in the management of their health outside the hospital walls, thus greatly improving quality of life.

Sharp’s SHC team has compiled a wealth of data related to the location, services, partners, and expected financial performance of the new center, but decisions about each of these areas remain to be made. The staff submit their report and recommendations to the leadership team of Sharp HealthCare and await the results.

Case Study Questions

1. What is asset mapping? Why is it important in facilitating care transitions and care coordination?
2. What are social determinants of health, and how can addressing these patient needs improve their coordination of care?
3. How many organizations should Sharp identify as potential partners for its Senior Health Center? Which ones should be the highest priority? What criteria should they use to decide?
4. Once Sharp establishes relationships with partners and starts operation of its new SHC, what criteria and methods will it use to evaluate the success of those partnerships?

Source: Case study adapted from Evashwick and Turner (2020).
REFERENCES


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