

## PART I

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# Introduction to Long-Term Care

As a major component of the health care delivery system, long-term care (LTC) is receiving increasing attention in both developed and developing countries. LTC is closely associated with disabilities emanating from chronic conditions that are mostly related to human aging. Developed countries have seen a steep rise in chronic conditions, and the trend will continue. A rise in chronic conditions and functional limitations will create a growing demand for LTC services in the developing world as well. Thanks to better sanitation, nutrition, and medical care, longevity is increasing in developing countries. The social environment in these countries is also changing. Both men and women are increasingly being drawn into the workforce to improve their standards of living. Their lifestyles are becoming hectic but sedentary.

A broad understanding of long-term care as a distinct segment of the health care delivery system, LTC clients and services, policy perspectives, and industry perspectives lay the foundation for managing any LTC orga-

nization. The three chapters in this section address these areas:

- Chapter 1 explains what long-term care is, why it is needed, what type of health care and social services constitute LTC, who are the clients served by long-term care, and how LTC should interface with the broader health care system.
- Chapter 2 focuses on policy as the driving force behind the evolution of LTC services. Financing, quality, and access to community-based services have shaped some of the recent developments. The future remains challenging and requires a number of policy initiatives to meet the challenges.
- Chapter 3 furnishes details of the long-term industry, which is necessary for the efficient delivery of services. The chapter covers community-based and institutional providers, insurers, LTC professionals, case management agencies, long-term care pharmacies, and seven categories of LTC technology.



# Chapter 1

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## Overview of Long-Term Care

### What You Will Learn

- Long-term care, as a distinct part of the health care delivery system, is best understood through 10 main dimensions that characterize long-term care as a set of varied services. The diverse services fulfill a variety of needs.
- The clients of long-term care are diverse in terms of age and clinical needs. The elderly, however, are the major users of long-term care services.
- Enabling technology reduces the need for long-term care services for many people. But, those who need assistance obtain long-term care services through three systems of care: informal, community based, and institutional.
- Informal care is the largest of the three systems of long-term care. Community-based services have four main objectives and can be classified into two groups: intramural and extramural. The institutional system forms its own continuum of care to accommodate clients whose clinical needs vary from simple to complex.
- Non-long-term care services are often needed by long-term care patients. The long-term care system cannot function without these services. Hence, the long-term care and non-long-term care systems of health care delivery must be rationally linked.

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### The Nature of Long-Term Care

Long-term care (LTC) is often associated with care provided in nursing homes, but that is a narrow view of LTC. Several types of noninstitutional LTC services are provided in a variety of community-based settings.

Family members and surrogates actually provide most of the long-term care that is unseen to outsiders and often unpaid. Another common misconception is that LTC services are meant only for the elderly. Many younger people, and even some children, require LTC services. The elderly, however, are the

predominant users of these services, and most LTC services have been designed with the elderly client in mind.

There is no simple definition that can fully capture the nature of long-term care. This is because a broad range of clients and services are involved. Yet, certain characteristics are common to all LTC services, regardless of whether they are delivered in an institution or in a community-based setting.

**Long-term care** can be defined as a variety of individualized and well-coordinated total care services that promote the maximum possible independence for people with functional limitations and that are provided over an extended period of time, using appropriate current technology and available evidence-based practices, in accordance with a holistic approach while maximizing both the quality of clinical care and the individual's quality of life. This comprehensive definition emphasizes 10 essential dimensions, which apply to both institutional and noninstitutional long-term care. An ideal LTC system will incorporate these 10 characteristics.

1. Variety of services.
2. Individualized services.
3. Well-coordinated total care.
4. Promotion of functional independence.
5. Extended period of care.
6. Use of current technology.
7. Use of evidence-based practices.
8. Holistic approach.
9. Maximizing quality of care.
10. Maximizing quality of life.

### Variety of Services

The delivery of most types of medical services is based on what is called the **medical**

**model**, according to which health is viewed as the absence of disease. When a patient suffers from some disorder, clinical interventions that are widely accepted by the medical profession are used to relieve the patient's symptoms. Prevention of disease and promotion of optimum health are relegated to a secondary status. By contrast, in long-term care, medical interventions are only a part of an individual's overall care. Emphasis is also placed on nonmedical factors such as social support and residential services.

Long-term care encompasses a variety of services for three main reasons: (1) to fit the needs of different individuals, (2) to address changing needs over time, and (3) to suit people's personal preferences. Needs vary greatly from one individual to another. Even the elderly, who are the predominant users of LTC services, are not a homogeneous group. For example, some people just require supportive housing, whereas others require intensive treatments. The type of services an individual requires is determined by the nature and degree of his or her functional disability and the presence of any other medical conditions and emotional needs that the individual may have.

Even for the same individual, the need for the various types of services generally changes over time. The change is not necessarily progressive, from lighter to more intensive levels of care. Depending on the change in condition and functioning, the individual may shift back and forth among the various levels and types of LTC services. For example, after hip surgery, a patient may require extensive rehabilitation therapy in a nursing facility for two or three weeks before returning home, where he or she receives continuing care from a home health care agency. After that, the individual may continue to live independently but require a daily

meal from *Meals On Wheels*, a home-delivered meals service. Later, this same person may suffer a stroke and, after hospitalization, have to stay indefinitely in a LTC facility. Hospice care may become necessary at the end of a person's life.

People's personal preferences also play a role in the determination of where services are received. Experts generally agree that, to the extent possible, people should be able to live and receive services where they want. Almost always, people prefer to live in the community, the first choice being their own home. Home- and community-based services have increasingly become available so that people can age in the community. Severe declines in health, however, may necessitate institutional services, particularly for people who need care around the clock. Again, a variety of long-term care facilities are now available.

LTC services are an amalgam of five distinct types of services:

- Medical care.
- Mental health services.
- Social support.
- Residential amenities.
- Hospice services.

Understanding the distinctive features of these services is important. In actual practice, however, they should be appropriately integrated into the total package of care in accordance with individual needs.

## Medical Care

Medical interventions in long-term care are primarily governed by the presence of two main health conditions that are closely related: chronic illness and comorbidity. First, as opposed to the care for acute conditions, LTC

focuses on chronic ailments, particularly when they have already caused some physical or mental dysfunction. *Acute conditions* are episodic; require short-term but intensive medical interventions; generally respond to medical treatment; and are treated in hospitals, emergency departments, or outpatient clinical settings. *Chronic conditions*, on the other hand, persist over time and are generally irreversible, but must be kept under control. If not controlled, serious complications can develop. In order of their prevalence among the aged population, the most common chronic conditions are hypertension, arthritis, heart disease, cancers, and diabetes (Federal Interagency Forum, 2004). The mere presence of chronic conditions, however, does not indicate a need for long-term care. When chronic conditions are compounded by the presence of *comorbidity*—coexisting multiple health problems—they often become the leading cause of an individual's disability and erode that individual's ability to live without assistance. This is when LTC is needed. The prevalence of comorbidity and disability rise dramatically in aging populations.

Medical care in the LTC environment generally focuses on three main areas:

1. Continuity of care after treatment of acute episodes in hospitals.
2. Clinical management of chronic conditions and prevention of potential complications.
3. Hospitalization when necessary.

## *Continuity of Care after Hospitalization*

Long-term care generally involves continuity of care after discharge from a hospital. Patients are hospitalized for acute episodes. Post-acute LTC often consists of *skilled nursing care*, which is physician-directed care

provided by licensed nurses and therapists. Post-acute care may be provided in a patient's own home through home health care, or in a LTC facility. **Home health care** brings services such as nursing care and rehabilitation therapies to patients in their own homes because such patients do not need to be in an institution and yet are generally unable to leave their homes safely to get the care they need. A **long-term care facility** is an institution, commonly referred to as a nursing home, that is duly licensed to provide long-term care services.

### *Clinical Management and Prevention*

Because chronic conditions cannot be cured, they must be managed. Left unmanaged, chronic conditions often lead to severe medical complications over time. For example, untreated diabetes can lead to heart problems, nerve damage, blindness, and kidney failure. The onset of complications arising from chronic conditions can be prevented or postponed through preventive medicine that includes adequate nutrition, therapeutic diets, hydration (fluid intake), ambulation (moving about), vaccination against pneumonia and influenza, and well-coordinated primary care services. Ongoing monitoring and timely interventions are generally necessary.

### *Hospitalization when Necessary*

Onset of an acute episode requires medical evaluation and treatment in a hospital. Patients in LTC settings may encounter acute episodes, such as pneumonia, bone fracture, or stroke, and require admission to a general hospital. For the same medical conditions, the elderly are more prone to be hospitalized compared with people in younger age groups who may be treated as outpatients.

## **Mental Health Services**

Long-term care patients frequently suffer from mental conditions, most notably depression, anxiety disorders, delirium, and dementia. Approximately two-thirds of nursing home residents suffer from mental disorders (Burns et al., 1993). Mental disorders range in severity from problematic, to disabling, to fatal. Research shows that depression, although common in nursing homes and assisted living facilities, often goes undetected (Smalbrugge et al., 2006; Watson et al., 2006). Under-diagnosis and under-treatment of depression is also a serious problem among community-dwelling older adults. The risk of depression in the elderly increases with other illnesses and when ability to function becomes limited (NIMH, 2007). **Dementia** is another common mental disorder. Characterized by memory loss, patients with dementia find it difficult to do things that they used to do with ease. Patients with dementia are also likely to become aggressive and undergo mood changes.

It is erroneous to believe that mental disorders are normal in older people or that older people cannot change or improve their mental health. But major barriers must be overcome in the delivery of mental health care. Efforts to prevent mental disorders among older adults have been inadequate because present knowledge about effective prevention techniques is not as extensive as our understanding of the diagnosis and treatment of physical disorders. On the other hand, treatment of many elderly people may be inadequate because assessment and diagnosis of mental disorders in older people can be particularly difficult: the elderly often focus on physical ailments rather than psychological problems (DHHS, 1999). Another drawback is that many elder care providers, including

primary care physicians, are often not adequately trained in the diagnosis and treatment of mental health problems.

Mental health services are generally delivered by specialized providers in both outpatient and inpatient facilities. Because LTC facilities are responsible for a patient's total care, nursing home employees must be trained to recognize the need for mental health care, and the facility must arrange to obtain needed services from qualified providers in the community.

## Social Support

**Social support** refers to a variety of assistive and counseling services to help people cope with situations that may cause stress, conflict, grief, or other emotional imbalances. The goal is to help people make adjustments to changing life events.

Various stressors commonly accompany the aging process itself and create such adverse effects as frailty, pain, increased medical needs, and the inability to do common things for oneself, such as obtaining needed information or running errands. Other stressors are event driven. Events that force an unexpected change in a person's lifestyle or emotional balance—such as moving to an institution, loss of a loved one, or experiencing social conflict—require coping with stress or grief. Even the thought of change brings on anxiety. Many people go through a period of “grieving” when coming to terms with change, which is a normal part of the transition process. Grieving may manifest in reactions such as anger, denial, confusion, fear, despondency, and depression (McLeod, 2002). Social support is needed to help buffer these adverse effects (Feld & George, 1994; Krause & Borawski-Clark, 1994).

Social support includes both concrete and emotional assistance provided by families, friends, neighbors, volunteers, staff members within an institution, organizations such as religious establishments and senior centers, or other private or public professional agencies. Such assistance may also include coordination of simple logistical problems that may otherwise become “hassles” of daily life, providing information, giving reminders, counseling, and offering spiritual guidance. Simply remaining connected with the outside world is an important aspect of social support for many people.

## Residential Amenities

**Supportive housing** is a key component of LTC because certain functional and safety features must be carefully planned to compensate for people's disabilities to the maximum extent possible in order to promote independence. Some simple examples include access ramps that enable people to go outdoors, wide doorways and corridors that allow adequate room to navigate wheelchairs, railings in hallways to promote independent mobility, extra-large bathrooms that facilitate wheelchair negotiation, grab bars in bathrooms to prevent falls and promote unassisted toileting, raised toilets to make it easier to sit down and get up, and pull-cords in the living quarters to summon help in case of an emergency.

Congregate housing—multi-unit housing with support services—is an option for seniors and disabled adults. **Support services** are basic assistive services. They may include meals, transportation, housekeeping, building security, social activities, and outings. However, not all housing arrangements provide all of these services.

In LTC institutions, adequate space, privacy, safety, comfort, and cleanliness are basic residential amenities. In addition, the institutional environment must feel home like, it must encourage social activities, it must promote recreational pursuits, and the décor must be both pleasing and therapeutic.

## Hospice Services

Hospice services, also called end-of-life care, are regarded as a component of long-term care. The focus of hospice, however, differs considerably from other LTC services. *Hospice* incorporates a cluster of special services for the terminally ill with a life expectancy of six months or less. It blends medical, spiritual, legal, financial, and family support services. However, the emphasis is on comfort, palliative care, and social support over medical treatment. *Palliation* refers to medical care that is focused on relieving unpleasant symptoms such as pain, discomfort, and nausea.

The hospice philosophy also regards the patient and family together as one unit of care. The option to use hospice means that temporary measures to prolong life will be suspended. The emphasis is on maintaining the quality of life and letting the patient die with dignity. Psychological services focus on relieving mental anguish. Social and legal services help with arranging final affairs. Counseling and spiritual support are provided to help the patient deal with his or her death. After the patient's death, bereavement counseling is offered to the family or surrogates.

The services are generally brought to the patient, although a patient may choose to go to a freestanding hospice center if one is available. Hospice care can be directed from

a hospital, home health agency, nursing home, or freestanding hospice.

## Individualized Services

Long-term care services are tailored to the needs of the individual patient. Those needs are determined by an assessment of the individual's current physical, mental, and emotional condition. Other factors used for this purpose include past history of the patient's medical and psychosocial conditions; a social history of family relationships, former occupation, community involvement, and leisure activities; and cultural factors such as racial or ethnic background, language, and religion. An individualized plan of care is developed so that each type of need can be appropriately addressed through customized interventions.

## Well-Coordinated Total Care

Long-term care providers are responsible for managing the total health care needs of an individual client. *Total care* means that any health care need is recognized, evaluated, and addressed by appropriate clinical professionals. Coordination of care with various medical providers such as the attending physicians, dentists, optometrists, podiatrists, dermatologists, or audiologists is often necessary to prevent complications or to deal with the onset of impairments at an early stage. The need for total care coordination can also be triggered by changes in basic needs or occurrence of episodes. Transfer to an acute care hospital or treatment for mental or behavioral disorders may become necessary. Hence, long-term care must interface with non-LTC services.



## **Promotion of Functional Independence**

LTC becomes necessary when there is a remarkable decline in an individual's ability to independently perform certain common tasks of daily living. Among children, disabilities can result from birth defects, brain damage, or mental retardation. Younger adults may lose functional capacity as a result of an accident or a crippling disease such as multiple sclerosis.

The goal of LTC is to enable the individual to maintain functional independence to the maximum level practicable. Restoration of function may be possible to some extent through appropriate rehabilitation therapy, but, in most cases, a full restoration of normal function is an unrealistic expectation. The individual must be taught to use adaptive equipment such as wheelchairs, walkers, special eating utensils, or portable oxygen devices. Staff members must render care and assistance whenever the patient is either unable to do things for him- or herself or absolutely refuses to do so.

In keeping with the goal of maximizing functional independence for the patient, nursing home staff members should concentrate on maintaining whatever ability to function the patient still has and on preventing further decline of that ability. For example, a patient may be unable to walk independently but may be able to take a few steps with the help of trained staff members. Assistance with mobility helps maintain residual functioning. Progressive functional decline may be slowed by appropriate assistance and ongoing maintenance therapy, such as assisted walking, range of motion exercises, bowel and bladder training, and cognitive reality orientation. However, in spite of these efforts, it is reasonable to expect a gradual decline in an in-

dividual's functional ability over time. As this happens, services must be modified in accordance with the changing condition. In other words, LTC must "fill-in" for all functions that can no longer be carried out independently. For instance, a comatose patient who is totally confined to bed presents an extreme case in which full assistance from employees is required. In most other instances, staff members motivate and help the patient do as much as possible for him- or herself.

## **Extended Period of Care**

For most LTC patients, the delivery of various services extends over a relatively long period because most recipients of care will at least require ongoing monitoring to note any deterioration in their health and to address any emerging needs. Certain types of services—such as professional rehabilitation therapies, post-acute convalescence, or stabilization—may be needed for a relatively short duration, generally less than 90 days. In other instances, LTC may be needed for years, perhaps indefinitely. In either situation, the period during which care is given is much longer than it is for acute care services, which generally last only for a few days. Because patients stay in nursing care facilities over an extended time, holistic care and quality of life (discussed later) must be integrated into every aspect of LTC delivery.

## **Use of Current Technology**

Use of technology varies according to the type of LTC setting. Certain types of safety technologies, such as nonslip footwear and hip protectors that protect the hip from injury during a fall, can be used in almost all

settings. Other technologies, such as call systems to summon assistance, bathing systems, and wander management systems, are designed for specific applications. Chapter 3 covers LTC technology in greater detail.

## Use of Evidence-Based Practices

*Evidence-based care* relies on the use of best practices that have been established through clinical research. Increasingly, clinical processes that have been proven to provide improved therapies are being standardized into *clinical practice guidelines*. These guidelines become evidence-based standardized protocols that are indicated for the treatment of specific health conditions. They have been developed to assist practitioners in delivering appropriate health care for specific clinical circumstances. An increasing number of standard guidelines have been developed for use in nursing homes. Some of these same guidelines can also be used in other LTC settings such as home health and assisted living.

## Holistic Approach

In sharp contrast to the medical model, the *holistic model* of health proposes that health care delivery should focus not merely on a person's physical and mental needs, but should also emphasize well-being in every aspect of what makes a person whole and complete. In this integrated model, a patient's mental, social, and spiritual needs and preferences should be incorporated into medical care delivery and all aspects of daily living.

By its very nature, effective LTC is holistic. Once the need for LTC has been established, a holistic approach must be used in the delivery of care. The following are brief

descriptions of the four aspects of holistic caregiving:

1. *Physical*. This refers to the technical aspects of care, such as medical examination, nursing care, medications, diet, rehabilitation treatments, etc. It also includes comfort factors such as appropriate temperature and cozy furnishings, cleanliness, and safety in home and institutional environments.
2. *Mental*. The emphasis is on the total mental and emotional well-being of each individual. It may include treatment of mental and behavioral problems when necessary.
3. *Social*. Almost everyone enjoys warm friendships and social relationships. Visits from family, friends, or volunteers provide numerous opportunities for socializing. The social aspects of health care include housing, transportation services, information, counseling, and recreation.
4. *Spiritual*. The spiritual dimension operates at an individual level. It includes personal beliefs, values, and commitments in a religious and faith context. Spirituality and spiritual pursuits are very personal matters, but for most people they also require continuing interaction with other members of the faith community.

## Maximizing Quality of Care

*Quality of care* is maximized when desirable clinical- and satisfaction-related outcomes have been achieved. Maximization of quality is an ongoing pursuit, and is never fully achieved. Hence, maximizing quality requires a culture of continuous improvement. It re-

quires a focus on the other nine dimensions encompassing the nature of LTC discussed in this section. It requires emphasis on both clinical and interpersonal aspects of caregiving. To improve quality, standards such as regulatory standards and evidence-based clinical practice guidelines must be implemented. Quality must be evaluated or measured to discover areas needing improvement, and processes should be changed as necessary. This becomes an ongoing effort.

### Maximizing Quality of Life

*Quality of life* refers to the total living experience, which results in overall satisfaction with one's life. Technology that enables people to live independently generally enhances the quality of life. Quality of life is a multifaceted concept that recognizes at least five factors: lifestyle pursuits, living environment, clinical palliation, human factors, and personal choices. Quality of life can be enhanced by integrating these five factors into the delivery of care.

1. Lifestyle factors are associated with personal enrichment and making one's life meaningful through activities one enjoys. For example, almost everyone enjoys warm friendships and social relationships. Elderly people's faces often light up when they see children. Many residents in institutional settings may still enjoy pursuing their former leisure activities, such as woodworking, crocheting, knitting, gardening, and fishing. Many residents would like to engage in spiritual pursuits or spend some time alone. Even patients whose functioning has decreased to a vegetative or comatose state can be creatively engaged in something that promotes sensory awakening through visual, auditory, and tactile stimulation.
2. The living environment must be comfortable, safe, and appealing to the senses. Cleanliness, décor, furnishings, and other aesthetic features are critical.
3. Palliation should be available for relief from unpleasant symptoms such as pain or nausea.
4. Human factors refer to caregiver attitudes and practices that emphasize caring, compassion, and preservation of human dignity in the delivery of care. Institutionalized patients generally find it disconcerting to have lost their autonomy and independence. Quality of life is enhanced when residents have some latitude to govern their own lives. Residents also desire an environment that promotes privacy. For example, one field study of nursing home residents found that dignity and privacy issues were foremost in residents' minds, overshadowing concerns for clinical quality (Health Care Financing Administration, 1996).
5. As pointed out earlier, people overwhelmingly choose to be independent. However, even institutions should make every effort to accommodate patients' personal choices. For example, food is often the primary area of discontentment, which can be addressed by offering a selective menu. Many elderly resent being awakened early in the morning when nursing home staff begin their responsibilities to care for patients' hygiene, bathing, and grooming. Patient privacy is compromised when a facility can offer

only semi-private accommodations. But, in that case, the facility can at least give the patients some choice in deciding who their roommates would be.

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## Clients of Long-Term Care

More than 10 million Americans are estimated to need LTC services. The majority (58%) are elderly, but a significant proportion (42%) are under the age of 65. Among those who need LTC, 14% are in nursing homes and 86% reside in the community (Kaiser, 2007).

LTC clients can be classified into five main categories:

1. Older adults.
2. Children and adolescents.
3. Young adults.
4. People with HIV/AIDS.
5. People needing subacute or high-tech care.

### Older Adults

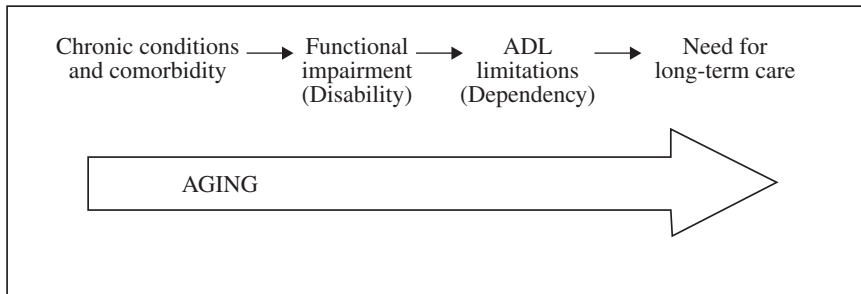
The elderly, people 65 years of age or older, are the primary clients of long-term care. Most of the elderly, however, are in good health. According to household interviews of the elderly civilian noninstitutionalized population, only 25% described their health as fair or poor (DHHS, 2008a). It is reasonable to assume that the segment of the elderly population in fair-to-poor overall health is likely to require LTC at some point. Even for those in good or excellent health, short-term LTC (needed for 90 days or less) may become necessary after an accident, surgery, or acute illness. Also, important differences in health exist according to population characteristics. Those in fair or poor health are more likely

to be black, Hispanic, or American Indian rather than white or Asian; financially poor or near poor; and rural rather than urban residents.

A person's age, or the presence of chronic conditions, by itself does not predict the need for long-term care. However, as a person ages, chronic ailments, comorbidity, disability, and dependency tend to follow each other. This progression is associated with increased probability that a person would need long-term care (Figure 1–1). In 2007, approximately 7% of civilian, noninstitutionalized elderly in the United States needed help with personal care from other individuals (DHHS, 2008b).

Disability is commonly assessed in terms of a person's ability to perform certain key everyday activities. Although chronic mental impairments are often assumed to eventually manifest in physical dysfunction, that is not always the case. Individuals with certain chronic mental illnesses may be able to perform most everyday activities but may require supervision and monitoring. Severe dementias, on the other hand, which are mostly confined to older people, are commonly accompanied by physical functional limitations.

Two standard measures are available to determine a person's level of dependency. The first, the *activities of daily living (ADL)* scale, is used to determine whether an individual needs assistance in performing six basic activities: eating, bathing, dressing, using the toilet, maintaining continence, and transferring into or out of a bed or chair. Grooming and walking a distance of eight feet are sometimes added to evaluate self-care and mobility. The ADL scale is the most relevant measure for determining the need for assistance in a long-term care facility. Therefore, ADLs are a key input in determining a facil-

**Figure 1–1** Progressive Steps Toward the Need for Long-Term Care Among the Elderly

ity's aggregate patient acuity level. *Acuity* is a term used to denote the level of severity of a patient's condition and, consequently, the amount of care the patient would require.

The second commonly used measure is called *instrumental activities of daily living (IADL)*. This measure focuses on a variety of activities that are necessary for independent living. Examples of IADLs include doing housework, cooking, doing laundry, grocery shopping, taking medication, using the telephone, managing money, and moving around outside the home (Lawton & Brody, 1969). The measure is most helpful when a nursing home patient is being discharged for community-based LTC or independent liv-

ing. It helps in assessing how well the individual is likely to adapt to living independently and what type of support services may be most appropriate to ensure that the person can live independently.

### Children and Adolescents

In children, functional impairments are often birth related, such as brain damage that can occur before or during childbirth (Figure 1–2). Examples of birth-related disorders include cerebral palsy, autism, spina bifida, and epilepsy. These children grow up with physical disability and need help with ADLs. The term *developmental disability* describes the

**Figure 1–2** Common Conditions Creating the Need for Long-Term Care Among the Nonelderly

Children/adolescents (ages birth to 17):	Birth defects Brain damage Mental retardation
Young adults (ages 18–64):	Major injury Serious illness AIDS Complications from surgery

general physical incapacity such children may face at a very early age. Those who acquire such dysfunctions are referred to as developmentally disabled, or DD for short. **Mental retardation**, that is, below-average intellectual functioning, also leads to developmental disability in most cases. The close association between the two is reflected in the term MR/DD, which is short for mentally retarded/developmentally disabled. Thus, some children and adolescents can have the need for LTC services that are generally available in special pediatric long-term care and MR/DD facilities.

### Young Adults

Permanent disability among young adults commonly stems from neurological malfunctions, degenerative conditions, traumatic injury, or surgical complications. For example, multiple sclerosis is potentially the most common cause of neurological disability in young adults (Compston & Coles, 2002). Severe injury to the head, spinal cord, or limbs can occur in victims of vehicle crashes, sports mishaps, or industrial accidents. Other serious diseases, injuries, and respiratory or heart problems following surgery can make it difficult, or even impossible, for a patient to breathe naturally. Such individuals, who cannot breathe (or ventilate) on their own, require a ventilator. A **ventilator** is a small machine that takes over the breathing function by automatically moving air into and out of the patient's lungs. Ventilator-dependent patients also require total assistance with their ADLs.

Many MR/DD victims are entering adulthood. The aging process begins earlier in people with mental retardation, and the age of 50 has been suggested to demarcate the elderly segment in this population (Altman, 1995). An increasing number of people with

MR/DD are now living beyond the age of 50. Hence, this population will manifest not only severe mental and physical impairments but also the effects of chronic conditions and comorbidity.

Evidence suggests that MR/DD patients may function better in community-based residential settings than in traditional nursing homes. Studies of patients who had moved out of nursing homes to community settings demonstrated that these patients had higher levels of adaptive behavior, lifestyle satisfaction, and community integration than residents who remained in nursing homes (Heller et al., 1998; Spreat et al., 1998). Opportunity to make choices, small facility size, attractive physical environment, and family involvement were associated with higher levels of adaptive behavior and community integration (Heller et al., 1999; Heller et al., 2002).

### People with HIV/AIDS

When it first gained national attention in the early 1980s, AIDS was a fatal disease that resulted in a relatively painful death shortly after HIV infection. Since then, the introduction of protease inhibitors, antiretroviral therapy, and antibiotics for the treatment of AIDS-related infections has vastly improved the health condition of HIV/AIDS patients. Consequently, AIDS has evolved from an end-stage terminal illness into a chronic condition. With reduced mortality, the prevalence of HIV in the population has actually increased, including among the elderly.

Over a period of time, people with AIDS are subject to a number of debilitating conditions, which create the need for assistance. Hence, the demand for LTC services is increasing, particularly because at least 25% of all known people with HIV/AIDS are age 50 and older (New York City Department of

Health and Mental Hygiene, 2004) and mortality rates from HIV/AIDS have decreased.

Care of HIV/AIDS patients presents special challenges, especially because this population has characteristics that are quite dissimilar to the rest of the LTC population. HIV/AIDS patients have a significantly higher prevalence of depression, other psychiatric disorders, and dementia associated with AIDS. HIV/AIDS patients also have a significantly higher prevalence of weight loss and incontinence of bladder and bowel (Shin et al., 2002).

### People Requiring Subacute or High-Tech Care

A growing number of nursing facilities have developed subacute and technology-intensive services. The term *subacute care* applies to post-acute services for people who require convalescence from acute illnesses or surgical episodes. These patients may be recovering but are still subject to complications while in recovery. They require more nursing intervention than what is typically included in skilled nursing care. The patients are transferred from the hospital to a nursing home after the acute condition has been treated, or after surgery. Some common orthopedic episodes include hip and knee replacement. Other subacute and high-tech services are needed for patients who require ventilator care, head trauma victims, comatose patients, and those with progressive Alzheimer's disease.

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## The Long-Term Care Delivery System

The LTC system is sometimes referred to as the *continuum of long-term care*, which means the full range of long-term care ser-

vices that increase in the level of acuity and complexity from one end to the other—from informal and community-based services at one end of the continuum to the institutional system at the other end.

The long-term care delivery system has three major components:

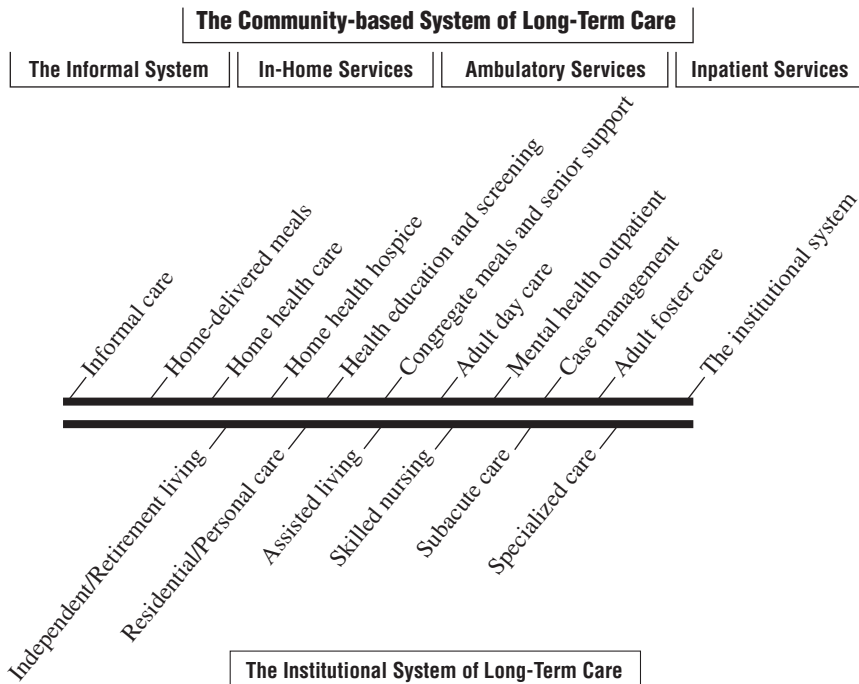
- The informal system.
- The community-based system.
- The institutional system.

The first component, informal care, is the largest, but it generally goes unrecognized. For the most part, it is not financed by insurance and public programs, but it includes private-duty nursing arrangements between private individuals. The other two components have formalized payment mechanisms to pay for services, but payment is not available for every type of community-based and institutional service. In many situations, people receiving these services must pay for them out of their personal resources.

Although institutional management is the focus of this book, the other two components, informal care and community-based service, also have important implications for administrators who manage LTC institutions. The community-based services and informal systems compete with the institutional system in some ways, but are also complementary.

The three subsystems that form the LTC continuum are illustrated in Figure 1–3. The patients' levels of acuity and the complexity of services they need increase from one end of the continuum to the other, for the most part. Informal care provided mainly by family members or friends involves basic assistance and is at one extreme of the continuum. Next on the continuum are the various community-based in-home services and

Figure 1–3 The Continuum of Long-Term Care



ambulatory services. Finally, there are different levels of institutional settings.

Given the complexity of the LTC system, case management (also called care management) fills in a key role. **Case management** is a centralized coordinating function in which the special needs of older adults are identified and a trained professional determines which services would be most appropriate, determines eligibility for those services, makes referrals, arranges for financing, and coordinates and monitors delivery of care to ensure that clients are receiving the prescribed services. Case management helps link, manage, and coordinate services to meet the varied and changing health care needs of elderly clients. Case management provides a single entry point for obtaining information about and accessing services. The extent of disability and personal needs primarily determine

which services on the continuum may be best suited for an individual. However, client preferences, availability of community-based services, and ability to pay for services also play a significant role.

In recent years, numerous public and private health care organizations have proliferated—organizations that offer information to consumers on how to care for someone at home, how to find and pay for community-based services, and how to find an appropriate institutional setting.

## The Informal System

The informal long-term care system is very large. An accurate estimate of its size is difficult, mainly because the system is not formally organized and it cannot even be called a system in the true sense. However, there



are perhaps more than 7 million Americans who provide care to more than 4 million elderly persons with functional limitations. The economic value of such care may be as high as \$96 billion a year (O’Keeffe & Siebenaler, 2006). For the most part, services rendered are believed to be basic, such as general supervision and monitoring, running errands, dispensing medications, cooking meals, assistance with eating, grooming and dressing, and, to a lesser extent, assistance with mobility and transfer.

The extent of informal care that an individual receives is highly dependent on the extent of the social support network the individual has. People with close family, friends, neighbors, or surrogates (such as members of a religious community) can often continue to live independently much longer than those who have little or no social support. For those who do not have an adequate informal support network, community-based services can become an important resource for allowing an individual to continue to live independently.

## The Community-Based System

Community-based LTC consists of formal services provided by various health care agencies. These services can be categorized as intramural and extramural. Community-based LTC services have a fourfold objective:

1. To deliver LTC in the most economical and least restrictive setting whenever appropriate for the patient’s health care needs.
2. To supplement informal caregiving when more advanced skills are needed than what family members or surrogates can provide to address the patients’ needs.

3. To provide temporary respite to family members from caregiving stress.
4. To delay or prevent institutionalization.

## Intramural Services

*Intramural services* are taken to patients who live in their own homes, either alone or with family. The most common intramural services include home health care and Meals On Wheels. Limited support programs that provide services such as homemaker, chores and errands, and handyman assistance also exist, but the funding to pay for such services is not well established and varies from community to community.

## Extramural Services

*Extramural services* are community-based services that are delivered outside a patient’s home. They require that patients come and receive the services at a community-based location. This category mainly includes ambulatory services, such as adult day care, mental health outpatient clinics, and congregate meals provided at senior centers. Respite care is another type of service that can be classified as extramural.

*Adult day care* enables a person to live with family but receive professional services in a daytime program in which nursing care, rehabilitation therapies, supervision, and social activities are available. Adult day care centers generally operate programs during normal business hours five days a week. Some programs also offer services in the evenings and on weekends. *Senior centers* are local community centers where seniors can congregate and socialize. Many centers offer a daily meal. Others sponsor wellness programs, health education, counseling services,

information and referral, and some limited health care services. *Respite care* can include any kind of LTC service (adult day care, home health, or temporary institutionalization) when it allows family caregivers to take time off while the patient's care is taken over by the respite care provider. It allows family members to get away for a vacation or deal with other personal situations without neglecting the patient.

## The Institutional System

A variety of LTC institutions form the institutional continuum, with facilities ranging from independent living facilities or retirement centers at one extreme to subacute care and specialized care facilities at the other extreme (see the lower section of Figure 1–3). On the basis of the level of services they provide, institutional LTC facilities may be classified under six distinct categories:

- Independent or retirement living.
- Residential or personal care.
- Assisted living.
- Skilled nursing.
- Subacute care.
- Specialized care.

For most people, the array of facilities that often go by different names can be remarkably confusing. This is particularly true because distinctions between some of them can be blurry. For example, what is defined as board-and-care (i.e., residential and personal care) in one state may be called assisted living in another. This is because services provided by these facilities can overlap. Brief descriptions of these facilities follow. Additional details are found in Chapter 3.

## Independent or Retirement Housing

Independent housing units and retirement living centers are not LTC institutions in the true sense because they are meant for people who can manage their own care. These residences do not deliver clinical care but emphasize privacy, security, and independence. Their special features and amenities are designed to create a physically supportive environment to promote an independent lifestyle. For example, the living quarters are equipped with emergency call systems. Bathrooms have safety grab bars. Rooms are furnished with kitchenettes. Congregate housing units have handrails in the hallways for stability while walking. Other housing units offer detached cottages with individual garages that allow residents to come and go as they please. *Hotel services* such as meals, housekeeping, and laundry may or may not be available.

## Residential or Personal Care Homes

Facilities in this category go by different names such as domiciliary care facilities, adult care facilities, board-and-care homes, and foster care homes. In addition to providing a physically supportive environment, these facilities generally provide light assistive care such as medication use management and assistance with bathing and grooming. Other basic services such as meals, housekeeping, laundry, and social and recreational activities are also generally included. Because personal care homes are located in residential neighborhoods, they are sometimes regarded as a community-based rather than an institutional service.

## Assisted Living Facilities

An *assisted living facility* can be described as a residential setting that provides personal

care services, 24-hour supervision, scheduled and unscheduled assistance, social activities, and some nursing care services (Citro & Hermanson, 1999). The services are specially designed for people who cannot function without assistance and therefore cannot be accommodated in a retirement living or residential care facility.

The range of services in assisted living facilities is similar to that in personal care homes, except that the level of frailty among the residents is generally higher. Hence, assistance with some ADLs is often furnished. Common types of ADL help include assistance with eating, bathing, dressing, toileting, and ambulation. Most residents also require help with medications.

### **Skilled Nursing Facilities**

These are the typical nursing homes at the higher end of the institutional continuum. Compared with the types of residences discussed earlier, the environment in skilled nursing facilities is more institutionalized and clinical. Yet, many facilities have implemented creative ideas in layout and design to make their living environments as pleasant and homelike as practicable. Some of these innovations are discussed in Chapter 8.

These facilities employ full-time administrators who must understand the varied concepts of clinical and social care and have been trained in management and leadership skills. The facility must be adequately equipped to care for patients who require a high level of nursing services and medical oversight, yet the quality of life must be maximized. A variety of disabilities—including problems with ambulation, incontinence, and behavioral episodes—often coexist among a relatively large number of patients. Compared with other types of facilities, nursing homes have a

significant number of patients who are cognitively impaired, suffer from other mental ailments such as depression, and have physical disabilities and conditions that often require professional intervention. The social functioning of many of these patients has also severely declined. Hence, the nursing home setting presents quite a challenge to administrators in the integration of the four service domains discussed earlier—medical care, mental health services, social support, and residential amenities.

### **Subacute Care Facilities**

Subacute care, defined earlier, has become a substitute for services that were previously provided in acute care hospitals. It has grown because it is a cheaper alternative to hospital stay. Early discharge from acute care hospitals has resulted in a population that has greater medical needs than what skilled care facilities were earlier able to provide.

### **Specialized Care Facilities**

By their very nature, both subacute care and specialized care place high emphasis on medical and professional nursing services. Some nursing homes have opened specialized care units for patients requiring ventilator care, treatment of Alzheimer's disease, intensive rehabilitation, or closed head trauma care. Other specialized facilities include intermediate care facilities for the mentally retarded (ICF/MR). The key distinguishing feature of the latter institutions is specialized programming and care modules for patients suffering from mental retardation and associated disabilities. Another type of specialized facility provides pediatric LTC to children with developmental disabilities.

## The Non-Long-Term Health Care System

Health care services described in this section are complementary to long-term care. Even though these services fall outside the LTC domain, they are often needed by long-term care patients. Hence, ideally, the two systems—long-term care and non-long-term care—should be rationally linked. The following are the main non-LTC services that are complementary to long-term care:

- **Primary care**, which is defined as medical care that is basic, routine, coordinated, and continuous over time. It is delivered mainly by community-based physicians. It can also be rendered by mid-level providers such as physician's assistants or nurse practitioners. Primary care is brought to the patients who reside in nursing homes, whereas those residing in less institutionalized settings such as retirement living communities or personal care homes commonly visit the primary care physician's office.
- Mental health care delivered by community-based mental-health outpatient clinics and psychiatric inpatient hospitals.
- Specialty care delivered by community-based physicians in specialty practices, such as cardiology, ophthalmology, dermatology, or oncology. Certain services are also delivered by freestanding chemotherapy, radiation, and dialysis centers. Other services are provided by dentists, optometrists, opticians, podiatrists, chiropractors, and audiologists in community-based clinics or mobile units that can be brought to a long-term care facility.
- Acute care delivered by hospitals and outpatient surgery centers. Acute episodes in

a LTC setting require transfer of the patient to a hospital by ambulance.

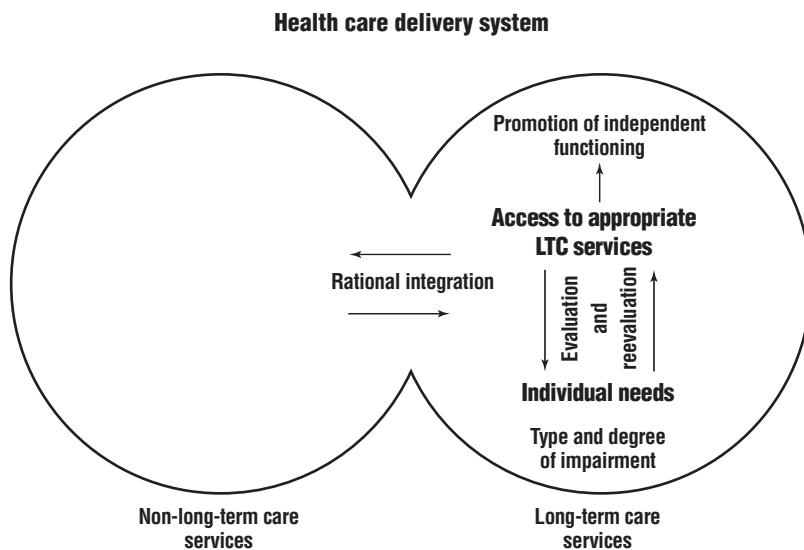
- Diagnostic and health screening services offered by hospitals, community-based clinics, or mobile medical services. Some common types of services brought to LTC facilities include preventive dentistry, X-ray, and optometric care.

## Rational Integration of Long-Term Care and Complementary Services

The LTC delivery system cannot function independently of other health care services. Hence, the LTC system must be rationally linked to the rest of the health care delivery system (Figure 1–4). In a well-integrated system, patients should be able to move with relative ease between needed services. At least some streamlining and coordination of services can be achieved through information technology, such as electronic health records.

Types of services comprising the broader health care continuum are summarized in Table 1–1. Long-term care patients, regardless of where they may be residing, frequently require a variety of services along the health care continuum, dictated by the changes in the patient's condition and episodes that occur over time. As an example, a person living at home may undergo partial mastectomy for breast cancer, return home under the care of a home health agency, require hip surgery after a fall in the home, and subsequently be admitted to a skilled nursing facility for rehabilitation. This individual will need recuperation, physical therapy, chemotherapy, and follow-up visits to the oncologist. Once she is able to walk with assistance and her overall condition is stabilized, she may wish to be

**Figure 1—4** Key Characteristics of a Well-Designed LTC System



moved to an assisted living facility. To adequately meet the changing needs of such a patient, the system requires rational integration, but the flow of care is not always as smooth as it should be. Integrated care also requires an evaluation of the patient’s needs in accordance with the type and degree of im-

pairment and a reevaluation as conditions change. Depending on the change in condition and functioning, the patient may move between the various levels and types of LTC services and may also need transferring between LTC and non-LTC services.

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**Table 1–1** The Continuum of Health Care Services

<b>Types of Health Services</b>	<b>Delivery Settings</b>
Preventive care	Public health programs Community programs Personal lifestyles
Primary care	Physician's office or clinic Self-care Alternative medicine
Specialized care	Specialist provider clinics
Chronic care	Primary care settings Specialist provider clinics Home health Long-term care facilities Self-care Alternative medicine
Long-term care	Long-term care facilities Home health
Subacute care	Special subacute units (hospitals, long-term care facilities) Home health Outpatient surgical centers
Acute care	Hospitals
Rehabilitative care	Rehabilitation departments (hospitals, long-term care facilities) Home health Outpatient rehabilitation centers
End-of-life care	Hospice services provided in a variety of settings

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### **For Further Thought**

1. How does long-term care differ from other types of medical services?
2. How can a nursing home facilitate the delivery of total care?
3. Why is it important that caregivers in long-term care settings not perform every task of daily living for the patient? How much should caregivers do for patients who have functional impairments?
4. For nursing home residents, dignity and privacy issues are often more important than clinical quality. Identify some staff practices that will promote each individual's privacy and dignity.

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## For Further Learning

Administration on Aging: A federal agency established under the Older Americans Act.

[www.aoa.gov/](http://www.aoa.gov/)

Family Caregiver Alliance: A nonprofit organization set up to provide information and resources to address the needs of families and friends providing long-term care at home.

<http://www.caregiver.org>

The George Washington Institute for Spirituality and Health: Affiliated with the George Washington University, the Institute is a leading organization on educational and clinical issues related to spirituality and health.

<http://www.gwish.org/>

The Meals On Wheels Association of America: This organization represents those who provide congregate and home-delivered meal services to people in need.

<http://www.mowaa.org/index.asp>

National Council on Aging: A private, nonprofit organization providing information, training, technical assistance, advocacy, and leadership in all aspects of care for the elderly. It provides information on training programs and in-home services for older people. Publications are available on topics such as lifelong learning, senior center services, adult day care, long-term care, financial issues, senior housing, rural issues, intergenerational programs, and volunteers serving the aged.

[www.ncoa.org](http://www.ncoa.org)

National Mental Health Association: The country's oldest and largest nonprofit organization that addresses all aspects of mental health and mental illness.

[www.nmha.org](http://www.nmha.org)

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