PART

I

Introduction: The Changing Long-Term Care Scene

Long-Term Care Today: Turbulent Times

Learning Objectives

After completing this chapter, readers will be able to:

1. Define the current long-term care system, including how it developed, and key strengths and weaknesses in the system.

2. Define the term *continuum of care.*

3. Identify and define the consumers and providers of long-term care.

4. Define institutional and noninstitutional care, and the strengths and shortcomings of each approach.

5. Identify the changes taking place in long-term care today.

■ Introduction

Nearly three decades ago, management guru Peter Drucker (1980) wrote about the need for managers to manage for change during turbulent times. He was talking about business in general, which was experiencing and continues to experience changes at the very core of its operating styles. It may have taken a while for the field of long-term care to catch up with other businesses in that respect, but the 1990s and early 2000s have seen it reach full status as an industry that is also deeply engrossed in "turbulent times." While acute care—primarily meaning hospitals—achieved that somewhat dubious distinction a number of years earlier, not far behind other industries, long-term care has taken a bit longer. Yet, today the symptoms of that organizational turbulence are seen in all aspects of long-term care.

Competition among long-term care providers has become much more common than has been experienced in the past, not only from similar types of providers (nursing homes, community-based home care agencies, government-run mental health institutions), but also from new entries in the field (assisted living, new housing options), as we explore in more depth in Chapter 9. There was a time when any form of advertising was considered bad form throughout the healthcare system. Now, healthcare

providers, including all types of long-term care providers, are engaging in regular, often highly sophisticated (and correspondingly expensive) advertising, utilizing all of the tools available to them through the commercial media. It is somewhat ironic in a system with more than enough demand to go around (a topic we discuss in more detail later) that long-term care organizations are competing for consumers. The explanation for that seemingly odd fact is that they are competing for those consumers with certain types of reimbursement, particularly those who are able to pay for their own care.

Long-term care providers have increasingly experienced the need to operate in a highly efficient, cost-effective manner, as third-party payers have become much more restrictive in defining the types and amounts of costs for which they will pay. That has led to the previously unthinkable—downsizing, including layoffs. It has also motivated many providers of long-term care to engage in various forms of reengineering, attempting to maintain or expand their particular portion of the market through reorganization.

The forces the long-term care system is now feeling, in many cases for the first time, are forces that have been acting on other segments of the healthcare industry for several decades. Those forces have seen some hospitals close because they were unable to demonstrate their need or were unable to compete with others with whom they shared a service area. Other hospitals have formed healthcare networks, resulting in mergers, formal affiliations, and contract management agreements as a means of survival. Long-term care providers had not, until relatively recently, been involved in those networks, nor had they been pressured to do so.

That all changed, with a rapidity that caught many long-term care providers unprepared. No longer could those previously isolated providers in the long-term care system remain aloof from the rest of the system. No longer could they stay within their own limited spheres of activity and service as they had in the past. The players in long-term care in the beginning of this new millennium had to be aware of, and be prepared to deal with, unprecedented changes. They came to expect and anticipate competition and intrusion not only from other segments of that system, but also from hospitals and from entrepreneurial newcomers from outside of the conventional system.

The strategic position of traditional long-term care facilities, primarily nursing homes, was not unlike the position of the United States prior to World War I, finding it difficult to recognize that other players were entering the arena in which they had long played. Like the United States during that time, traditional long-term care organizations now realize that they can no longer survive in an isolationist mode. They came to realize—some willingly, some reluctantly—that they represent only small portions of an ever-expanding industry.

Your author teaches a class in "Leadership in Health Administration" to adult healthcare professionals enrolled in a course leading to college degrees in healthcare or long-term care administration. The course is a hybrid, taught through a combination of five weeks of online classes and one week on campus. Students come from all

over the United States and from numerous other countries, and they represent the full gamut of training and experience in various segments of the healthcare industry. Most are healthcare managers, ranging from first-line supervisors (charge nurses, department heads) to chief executive officers (CEOs) of hospitals, nursing homes, or other healthcare organizations. They come to the class with a great deal of experience in all phases of the healthcare system. In fact, during one class, one of the students conducted a survey and determined that the students in that one class represented a total of 370 years of healthcare experience and represented a cross section of healthcare and long-term care professionals.

Class sessions in recent years have demonstrated two significant trends not seen in earlier groups. First, the number of students engaged in some aspect of long-term care has grown significantly compared with those working in acute care. Second and more dramatic by far, is the proportion of students who are undergoing, or have undergone, some type of downsizing, reengineering, or reorganization. The end result, the result most critical to the individual managers involved, is that they have had to adjust their career goals and have had to find new ways in which to participate in this, their chosen field.

While organizational change is common throughout the healthcare industry, there seems to be some correlation between the number of individuals affected and the number involved in long-term care. There appear to be two converging trends at work here. First, there are those already engaged in some form of long-term care who are experiencing the trauma of organizational turnover, and who are seeking to find more secure positions within that system. Second, and probably of more importance to the future of the long-term care industry, are those whose entire experience has been in acute care, but who are now seeing long-term care as a better opportunity for career advancement. Together, these two groups are a very real, sometimes poignant, reminder of the turbulence taking place in the long-term care system today.

The degree to which long-term care organizations have evolved and continue to evolve, the disruption of established routines, the unsettled future of the industry, the threats to organizational stability, and the rapid pace with which the environment is changing are all symptoms of the times. They describe not so much the status of the long-term care system today, but rather the dynamic forces acting on that system and the way in which it has reacted to those forces.

Before we investigate how those forces affected the evolution of long-term care, we need to define the system as it exists today and why it exists in the first place.

■ Defining the Long-Term Care System

Let us begin with definitions of a couple of terms, and then put them aside, for they serve only to set the stage for a more detailed discussion. First, the long-term care system is often defined according to what sets it apart from other forms of health care.

In doing so, the terms *chronic care* and *long-term care* are generally used interchangeably. Both are used in the context of an extended type of care that is required over long periods of time, with temporary, short-term breaks, but which goes on in most cases, for the remainder of the individual recipient's life. In fact, the term *extended care* was commonly used for a time to describe what we now define as long-term care. Long-term care is also thought of, not always accurately, as any care after acute care (see Chapter 4 for more detail).

While both terms, chronic care and long-term care, are used at one time or other in this text, the term "long-term care" will predominate. That is not because there is anything wrong with the term "chronic care" but because it is less commonly found in general usage.

Second, when defining the long-term care system in terms of those who provide its services, "long-term care" has been used most often in reference to nursing homes exclusively. Although that is an inaccurate application of the term, it has evolved over time because, as discussed later in this chapter, nursing homes have traditionally been the predominant providers of long-term care services. As other providers and other types of long-term care services have developed, and will undoubtedly continue to develop, it is only right that the more all-encompassing use of the term be used, and will be herein.

Perhaps the long-term care system is best defined in terms of the people who require and use it. They are described in one instance as "functionally dependent on a long-term care basis due to physical and/or mental limitations" (Binstock, Cluff, & Van Mering, 1994). Another, more detailed description of long-term care consumers is "those persons requiring healthcare, personal care, social, and supportive services over a sustained period of time" (Continuing Care Council, 1992). The type of consumers who use long-term care is discussed at length later in this chapter.

■ How the Long-Term Care System Came About

Long-term care, as we know it today, has taken a long time to develop. Unlike the acute care (hospital) system, which became highly institutionalized in the mid-19th century, a formal system of long-term care took much longer to evolve. In fact, during most of the 20th century it was what one writer described as "a comparatively drab backwater in the overall scene of U.S. health care" (Binstock et al., 1994). The public knew little about long-term care and cared not much more. There was not the clearly identifiable population of seriously ill or injured, difficult for the community to ignore. Nor, with notable exceptions such as tuberculosis, did those needing long-term care pose as great a threat to the community as did patients involved in active epidemics.

Instead, until quite recently, most long-term care was provided by informal caregivers, such as families and friends (a topic discussed in more detail later), religious organizations, and community groups formed specifically to help those less fortunate than themselves. During the 19th century, and well into the 20th, families took care

of their own members when possible. Several generations lived together, with the young caring for the old and the old caring for the young. It was a widely accepted way of life. While it can generously be assumed that such care was usually motivated by a sincere desire to help, or an inherent sense of obligation, there were other motivations as well. There was a stigma attached to admitting need for assistance from others. "Responsible" members of society avoided accepting charity whenever possible, often to the point of causing considerable hardship for themselves and their families. In addition, people were often ashamed to admit that a family member was physically or mentally handicapped, apparently based on a feeling that they were somehow at fault for the family member's affliction.

Whatever the reasons, most long-term care was provided at home. What few institutional resources were in place consisted of "homes" for those with no family able (or willing) to provide for them. Mostly, those resources took the form of almshouses or poor farms, perpetuating the negative societal image of those needing help simply to survive. Those homes usually cared for people with a variety of needs, with little distinction made between serving those requiring mere shelter and food and those needing supervision and functional assistance closer to what is now known as long-term care. The elderly, homeless, unemployed or unemployable, and people unable to care for themselves (including those with moderate levels of mental illness or retardation) were housed together and received much the same care. Whether sponsored by church groups, fraternal or ethnic organizations, or community-based charities, it was essentially a voluntary form of welfare. People qualified more often because of poverty than because of illness. This was the primary method of providing services for the needy up to the 1920s (Goldsmith, 1994). There are numerous reasons for the way the long-term care system developed, including the following:

The Growing Role of Government in Long-Term Care Financing

Through the first two decades of the 20th century, there had been very little government involvement in long-term care, happening only when private resources could not be found. Even when public agencies stepped in to help out, it was usually at a level close to the community. Long-term care institutions, usually in the form of asylums, were sponsored by local, county, and occasionally state agencies. Those institutions were created as much to protect society from the necessity of having to see those "unfortunates" as it was to protect those receiving the care. Thus, long-term care institutions were often built on large tracts of land far away from community centers. Many public facilities still exist on those large, remote sites, although a community may have grown up around them.

That situation was soon to change irrevocably. The Great Depression of the 1930s caused the numbers of people unable to care for themselves to multiply many times, seemingly overnight, far outreaching the resources available through family and voluntary sponsorship. With passage of the Social Security Act of 1935 and other, related

welfare programs, the federal government became deeply involved in care of society's needy, particularly the aged, blind, and families with dependent children. This has been identified as the indirect beginning of the nursing home industry (Goldsmith, 1994) from which the many other forms of long-term care have grown.

Over the next several decades, the federal government expanded its role in financing care of the needy and of those requiring certain specific levels of health care. It did so by passing numerous amendments to the original Social Security Act. This was especially true during the 1960s, with passage of the landmark Medicare and Medicaid amendments (Title XVIII and Title XIX). With the advent of Medicare and Medicaid came funding for hospital and medical care for the elderly and for those who could not afford such care. That funding produced a variety of results for different people and organizations. For most individuals, it meant relief from the increasing cost of getting care or being able to get needed care for the first time. For hospitals and doctors, it meant a new source of revenue, a reduced need to provide free care, a greatly increased demand for their services, and far more regulations and paperwork. For both state and federal government, it meant a new commitment to providing services for their constituents and an ongoing problem in finding the funds to do so.

Unfortunately, those planning the Medicare and Medicaid programs greatly underestimated the impact of those programs. They based their projections of need largely on the number of people being served at the time, with a modest increase expected. In fact, there was a large, unanticipated reservoir of need that was not being met, specifically because of the lack of funding for it. Many people had gone without all but the most critical medical care when they had to pay for it themselves or when they had no way of paying for it. When reimbursement became available through these government programs, they soon flooded healthcare providers, seeking help.

While Medicare and Medicaid—with their new availability of payment for care and the resulting larger-than-expected demand for services—had the greatest impact on hospitals and physicians, they also provided both direct and indirect stimulus for the slowly developing nursing home industry. Medicare included coverage for certain limited types of long-term care, in the form of skilled nursing facilities (SNFs) providing high-end nursing home care. Medicaid provided an even broader range of nursing home coverage.

Although often confused by the public, even to this day, the two programs contain significant differences. Medicare was designed to serve the elderly, the blind, and certain categories of the permanently disabled, without regard to ability to pay, while Medicaid serves the "medically indigent"—those unable to pay for their own health care.

There are other differences in the two programs beyond the varying eligibility requirements. Medicare coverage is intentionally limited, both in what health care it covers and in the duration of the coverage. Medicaid provides more extensive coverage, in effect for as long as the person needs it, and as long as that person can meet the financial means test required to qualify, but still does not cover all long-term care services.

Those differences have had a significant effect on long-term care as it has developed. Medicare, with its limitations on coverage, often stops paying for long-term care when much more care is needed. At that point, individuals and families are forced to "spend down" (i.e., use up their own financial resources) in order to become eligible for Medicaid. In addition, while Medicare is a federally funded program, Medicaid is funded by a combination of federal and state taxes. As demand for long-term care services has grown over the decades, many states have found themselves struggling to pay for their shares of the funding for those services. The Medicaid Act provides certain levels of coverage below which states cannot go, but gives the individual states considerable leeway in determining what and how much they can cover. Some states provide much more than others, resulting in (1) inequities in coverage, (2) movement by recipients from one state to another where benefits are more liberal, and (3) attendant difficulty for some states in funding the programs.

Because Medicare and Medicaid command such a large portion of the long-term care reimbursement picture—nearly three-quarters, according to the American Association of Homes and Services for the Aging (AAHSA, 2008)—and because they have traditionally covered institutional care more fully than other types of care, the nursing home component of long-term care has grown, while the others (e.g., home care, day care) have not, at least until recently.

The Impact of Regulations on Development of the Long-Term Care System

The effect of Medicare and Medicaid on the long-term care system has not been limited to that caused by the nature and amount of reimbursement provided. With any government program that provides funding comes regulation. The government, at whatever level, simply wants to protect its investment and issues regulations to do so. In the case of Medicare and Medicaid, the regulations have been extensive—both in the scope of their coverage and in the length of the written regulations themselves. As with most other healthcare regulations, they are intended to ensure accomplishment of two objectives: that care paid for by the government is of sufficiently high quality and that it is purchased at the lowest possible price. The impact of the regulations relating to these two laws, and other related regulations, on the providers of long-term care has been great. That impact has ultimately been felt by the consumers of care. Just as available services are determined in large part by the amount of reimbursement for them, so are they influenced by the regulations governing them. When the cost of meeting regulations has been seen by providers of care as too high in relation to the revenue available for providing that care, those services have ceased to exist. On the other hand, when regulations have made it easier for providers to balance cost, revenue, and quality, services have generally been more available.

Federal and state healthcare regulations have often been used to accomplish a third objective: limiting or expanding the availability of services in specific segments of the

industry or in defined geographic locations. This is done to improve access in underserved areas or to reduce costs attributed to oversupply in other areas. Some such regulations are specifically designed to do just that, to affect the availability of services. Perhaps the two most notable regulations in that category are the Hill-Burton Act (the Medical Facilities Survey and Construction Act of 1946) and the Certificate of Need provisions in the National Health Planning and Resources Development Act of 1974.

The Hill-Burton Act built hospitals in underserved areas from the late 1940s until well into the 1960s. The act provided funding for those hospitals but used regulations related to that funding to influence where new hospitals were built. At first, there was little, if any direct impact on long-term care, but increasing the availability of hospitals in rural areas eventually had a positive impact on other services, including long-term care. Also, a 1954 amendment to the act made some nonprofit long-term care facilities eligible for construction funding, but only in severely restricted instances.

Several decades later, in a direct reversal of the intent of Hill-Burton, certificate of need (CON) programs were enacted, designed to reduce the amount of expansion of healthcare facilities. The federal law mandated that each state develop a CON program requiring approval before any new construction or expansion could take place. Those regulations had a much more direct impact on long-term care than did previous laws, because nursing homes were covered by their provisions. Although largely dismantled during the 1980s, CON laws are still in effect in some states, with widely varying degrees of enforcement.

The Results of Past Successes

Much of the development of the long-term care system has resulted from the many improvements in medical care over the past century. The healthcare system's ability to prevent many previously fatal illnesses and to treat others has kept people alive longer, producing an ever-increasing population needing extensive long-term care of one sort or another. Not only are more people living to use long-term care services, but they are living long enough to need long-term care over a period of many more years.

This progress has been extremely beneficial to the elderly, but it has also caused certain problems for long-term care providers and policy makers. These successes in extending longevity created an additional demand for services and an increased level of expectation of further clinical advances. While those problems should have been anticipated, little attention was given to them or to their solutions. One early long-term care administration text did predict that these breakthroughs would "magnify the difficulties and ambiguities in defining the role of the elderly and in setting priorities for long-term care programs" and called for drastic changes in long-term care and healthcare programs to meet the needs of a more vigorous aged population (Levy & Loomba, 1977).

However, it should not be assumed that nothing was done in response to that and similar warnings. Many groups and individuals worked hard to change attitudes and

practices concerning the elderly, some with considerable success. However, those programmatic efforts have been hard pressed to move with the rapidity of clinical advances or with the speed at which the elderly population was growing and changing.

Such dramatic medical procedures as organ transplants, replacement of knees and hips with artificial joints, and nonsurgical correction of cataracts became commonplace. They, and a multitude of similar procedures, unheard of in earlier generations, have come to be thought of as almost routine and we are now experiencing much more sophisticated tools and procedures. Any one of them has the potential to extend an individual's life or functional independence for decades, and it is not uncommon for some people to benefit from several of them over a period of years. Yet, while these medical advances extend life—and allow individuals to overcome or postpone specific functional disabilities—their health may be worsening in other areas, compounding the need for long-term care. For example, an artificial joint replacement will allow a person to be more independent physically, but other concurrent complications such as loss of sight or hearing may create other long-term care needs.

Efforts to Reduce Healthcare Costs and Their Impact on Long-Term Care

Government programs, such as Medicare and Medicaid, have not been alone in trying to reduce their costs for health care. Private insurance companies, employers who are the largest purchasers of insurance, and individuals paying their own bills have all become increasingly concerned about rapidly escalating costs. As a result, several new forms of healthcare financing and delivery developed, most notably managed care (discussed in detail in Chapter 10). That emphasis on cost-effectiveness affected the long-term care system quite significantly, especially through the practice of reducing institutionalization to the barest minimum.

Because of rising costs, particularly in acute care settings, third-party payers have increasingly pressured providers to reduce lengths of stay, even when that meant discharging patients to other levels of care. Some payers, particularly managed care organizations (MCOs), have placed preset limits on how long patients may stay in a hospital for treatment of a given illness. The result is that many such patients have been transferred to long-term care organizations requiring much more care than would have been the case in the past, a practice that came to be known as "quicker and sicker" discharges.

These pressures on providers to discharge patients at predetermined times was not new. From its earliest inception, Medicare denied reimbursement for care beyond certain points. The law included a section requiring providers to conduct a process known as utilization review, intended to ensure that the Medicare system did not pay for care beyond that which was determined to be necessary. What was new was the increased involvement of other payers and the compressing of allowable lengths of stay.

This trend affected the long-term care system in several ways. First is the increased level of care required in the various segments of long-term care. People who would have remained in hospitals in the past are now cared for in nursing homes. Many of those

who used to receive care in nursing homes are now getting their care in assisted living or residential care facilities or at home. That, in turn, has produced other changes in the system. It has increased the acuity of patients at each level, has changed staffing requirements accordingly, and has forced facilities and agencies to add new services to meet the increased needs of their clients. It also led to development of several new types of care delivery, such as assisted living and subacute care.

The trend toward quicker and sicker discharges has also been a factor in the development of integrated care systems or networks. As providers have attempted to respond to pressures to move patients to the lowest acceptable level of care, some have found that they needed to obtain services to which they can refer those patients. Others are on the receiving end of referrals and have discovered the advantages of allying themselves with referral sources as a means of maintaining a high occupancy level.

Long-term care providers have become much more market conscious and competitive as a result of these pressures. While some have sought to protect their niche in the market by affiliating with integrated networks, others have actually begun providing the services themselves. Hospitals have increasingly converted portions of their facilities to long-term care programs as a means of filling empty beds and securing a place to which they can discharge their patients. Both hospitals and nursing homes have begun to add home healthcare services as a continuation of that trend.

■ The Components of the Long-Term Care System

Long-term care evolved slowly at first, but stimulated by the many competing pressures discussed herein, it has developed into an extremely complex system that consumers and providers alike have difficulty understanding. There are many players involved, including consumers, providers, payers, and regulators. The payers and regulators have had, and will continue to have, major influence on how the long-term care system develops and functions. They have been mentioned briefly in this chapter and are discussed in detail in Chapters 10 and 11.

At this point, and as a means of setting the stage for later discussions, let us identify the consumers and providers of long-term care.

The Consumers of Long-Term Care

One indication of the complexity of the long-term care system is the fact that those individuals using the system do not even carry a commonly agreed-upon label, a descriptive name. When they are in acute or subacute care settings, they are called *patients*. In most other long-term care institutions, they become *residents*. Yet, community-based care providers usually refer to them as *clients*. One author even referred to them as *constituents*, pointing out the reciprocal relationship inherent in the interface between those seeking care and those providing it (Kissick, 1994). It is an intriguing

idea, but what those users of long-term care have in common is that they are *consumers*, which is what they will be called herein.

Unlike in the acute healthcare system, long-term care consumers are not usually defined by a single disease or condition. Instead, they require services because of functional disabilities—limitations on their ability to function independently (Evashwick, 2005). While those functional disabilities may be caused by one or more specific diseases, it is the disability itself that is addressed by long-term care, rather than the disease. In fact, long-term care consumers typically suffer from more than one underlying ailment, resulting in the functional deficits. An individual might have functional limitations caused by a combination of such diseases as diabetes, arthritis, and heart disease, any one of which could be disabling by itself. In addition, it is not uncommon for the chronically ill, particularly the elderly, to also suffer some loss of cognitive ability. A new analysis suggests that about 3.4 million Americans age 71 and older—one in seven people in that age group—have dementia, and 2.4 million of them have Alzheimer's disease (U.S. NIH, 2007). Any inability to understand the nature of their disability and to follow their care plan makes it that much more difficult to care for them or to assist them in caring for themselves.

Elderly Users of Long-Term Care

Consumers of long-term care represent a broad spectrum of people who rely on the system for assistance. They are largely, though not exclusively, elderly. While a growing number of nonelderly need long-term care for a variety of reasons, it is still the aged members of our society who use the lion's share of long-term care services. The most elderly among them (those over 75 and even over 85 years of age) use the long-term care system at a disproportionate rate.

Their numbers are growing rapidly, and are projected to continue to grow. According to the U.S. Census Bureau (2008), the number of people in the United States over age 65 was approximately 37 million in 2006, and it is projected to reach 71 million by the year 2030 and 87 million by 2050. The number of people over age 85 is expected to grow from 5 million in 2006 to more than 9 million in 2030 and 21 million in 2050.

Yet, even those consumers who fall into the broad category of "elderly" or "aged" can no longer be lumped together as a homogenous, easily defined entity. As their numbers have grown, and as the medical and care delivery innovations described earlier make it possible for an increasing variety of individuals to join that select group, they have become more diverse. That diversity has produced a broad range of interests, differing personal values, and considerable disagreement about what constitutes an optimum quality of life. No longer can long-term care consumers be cared for in a "one-size-fits-all" delivery system. Their needs are as diverse as they are. Providers, payers, regulators, and long-term care policy makers have all had to learn to differentiate among these dissimilar consumers to find new ways to accommodate them and

their needs. While many innovative solutions have been found, the effort has been of only limited success to date.

No longer can we predict what elderly individuals would prefer when it comes to making decisions about such critical topics as medically prolonging life, self-determined death, and using biomedical technologies to postpone aging. They (the elderly) have forced society in general, and the providers of long-term care in particular, to recognize them as individuals with individual desires and needs, not as an easily defined cluster of people with common, easily solved problems.

They have learned to exert their rights. They have the right to have a say in their care. They no longer are willing to simply do what the professionals determine to be best for them. Instead, they are learning to be more assertive in selecting the care they receive. Increasingly, they are demanding the right to choose quality of life over treatment. That has forced providers to include elderly consumers more in developing care plans. Elderly consumers have the right to live and receive care in their own homes when possible or in a homelike atmosphere if institutionalization is required. As a result, nursing facilities and other institutional providers have paid more attention to facility design and furnishings.

The Elderly as a Political Force

One result of the growth of the elderly, both in numbers and in their need for long-term care services—not a minor result by any definition—has been their growing economic and political power. Three decades ago, the elderly were described as "not well organized for exerting political influence" (Levy & Loomba, 1977). Yet, since the 1990s, the elderly have become a potent, well-organized, much-listened-to constituency. They are better informed than previous generations and have become increasingly assertive in voicing their concerns. Formal organizations of the aged, such as AARP, the Council of Senior Citizens, and the Gray Panthers, have learned how to exert their influence effectively in Congress and in state legislatures. The extent of that influence and the ability of those advocacy organizations to mobilize constituent support produced a major surprise for many of the nation's elected officials when they succeeded in defeating a well-intended catastrophic insurance law. That law would have required a larger than previously experienced contribution by the elderly. In defeating the measure, they sent a clear message that they not only did not want it, but would not abide having such decisions made about them without their input.

More recently, older Americans, led and supported by those well-organized advocacy organizations, have demonstrated their strength in debates over virtually all major policy issues affecting them, including national healthcare reform, Medicare restructuring, and how state and federal Medicaid funds are allocated among different types of long-term care providers. They have become a force to be reckoned with, demanding a major role in determining their futures and accepting the responsibility that goes with that role.

Nonelderly Long-Term Care Users

While the elderly are by far the most visible group of users of long-term care services, there are younger consumer populations to be considered. In fact, the elderly (defined here as age 65 or older) make up only about 63 percent of the total long-term care population. The remaining 37 percent are 64 and younger (Rogers & Komisar, 2003). Those younger long-term care consumers include the physically handicapped and the mentally handicapped. In either case, people in these two categories are somewhat more likely to be suffering from a single, albeit disabling, disease or condition than are the elderly. Among those included in this group are handicapped children, victims of traumatic injury, ever-younger patients with Alzheimer's disease, those suffering from AIDS, and those afflicted with some degree of mental disease or mental retardation. Like the elderly, they rely on long-term care services to assist them in carrying on their everyday lives as closely to normal as is possible, given their functional constraints.

The Physically Handicapped

Those who need long-term care due to one of the many different types of physical disability are a very special group of consumers. Their care needs are complex and intensive. Their functional limitations are frequently extreme yet are often combined with a near total absence of mental or emotional disability. They have high expectations for themselves, are generally quite knowledgeable about their afflictions, and are often demanding—thus providing major challenges for the long-term care system.

Some of the physically handicapped are in need of long-term care from the time of their birth, if they are handicapped as the result of congenital defects or birth accidents. Although largely unrecognized by the public as users of long-term care services, these handicapped children may, as the result of the good care they receive, live to be adults. They include patients with such debilitating diseases as spina bifida, muscular dystrophy, and cerebral palsy. As administrator of a facility devoted to caring for patients such as these for more than a decade, your author witnessed innumerable cases in which families of these patients would have been effectively destroyed had it not been for the long-term care services available to them.

They (those suffering from congenital illness) are joined by an unfortunately growing number of young adults needing long-term care because of physical (e.g., traumatic head injury) and/or chemical (e.g., drug overdose) accidents. Taken together, these younger-than-usual long-term care consumers represent only a small percentage of the overall long-term care consumer population. However, as individuals, they are some of the most fragile members of society, and they and their families are among those most reliant on the long-term care system for sustenance and support. They are among the heaviest individual users of the full range of long-term care services, and use those services for many years—much longer than typical elderly long-term care consumers— thus creating a disproportionate burden on the long-term care system.

Like the elderly, these younger chronically ill persons, particularly those with spinal cord injuries and those suffering from AIDS, have become politically active. Advocacy organizations, representing mostly young adult paraplegics and quadriplegics, were largely responsible for passage of the Americans with Disabilities Act (ADA), which forced businesses and organizations to make significant changes in physical accessibility to their buildings and in their employment and customer service policies. AIDS advocates have been nearly as effective.

The Mentally Ill/Mentally Retarded

Another, even less visible, segment of the long-term care consumer population includes those suffering some type or degree of mental illness or mental retardation. They, often being afflicted from birth or at a relatively early age, also use highly intensive long-term care services for many years. As a group, they have long received less attention than their elderly or physically handicapped counterparts. Several factors have contributed to that, including the relative difficulty involved in diagnosing and categorizing their illnesses, and most of all, the societal stigma traditionally attached to the mentally ill or retarded, or to anyone who acts differently from what is considered "normal."

The Baby Boomers: Future Long-Term Care Consumers

While this chapter is devoted to presenting the long-term care system as it now exists, including a discussion of current users of that system, it would not be complete without at least brief mention of a separate population of soon-to-be-consumers who have the potential to impact the system more than any single group to come before them. They are known as baby boomers, the name given to the large numbers of people born in the period following World War II, between 1946 and 1964. When the first of them begin to retire, around 2011, approximately 40 million Americans will be 65 and over. By 2025, when the youngest of the baby boomers reach retirement age, the number of Americans aged 65 and over will have grown to 63 million (U.S. Census Bureau, 2008). That growth in the number of elderly will translate to corresponding growth in the number of chronically ill or disabled requiring long-term care services. One source notes that among people turning 65 in 2007, 69 percent will need some form of long-term care, with the number growing to 12 million elderly needing long-term care by 2020 (AAHSA, 2008). Their impact on the long-term care system will go far beyond mere numbers, however. They will be better educated and will demand much more from the system.

Providers of Long-Term Care

Long-term care is primarily health care and is usually thought of in that sense. However, because it is more geared to the consumer's level of independent functioning than to medical condition alone, other societal forces play a significant role in the success of that care. Social and economic factors such as availability and affordability of housing, homemaking assistance, and transportation, while not always thought of as part of

long-term care, often determine how well the long-term care system works for an individual consumer. Long-term health care is usually so closely intertwined with those nonhealth services that the two systems (health and social) should not be treated as separate. Yet, in reality, they usually are. To attempt to fully discuss all of the other social service systems that affect long-term care would be somewhat prohibitive—and probably confusing. Thus, this book's primary focus is on the long-term healthcare system and includes the providers most directly related to that system. While there is not a distinct section dealing with other societal forces, they and their impact are referenced throughout. The exception to that is housing, which has become so important to long-term care, with its many new options, that it is discussed in detail in Chapter 6.

The current system of long-term care providers has developed in a seemingly hit-or-miss fashion. That is largely because it has grown in response to three factors that are not necessarily orderly themselves: (1) need, (2) demand, and (3) availability of reimbursement. Each is influenced to some degree by the others. To begin with, *need* and *demand* are not synonymous, particularly where consumers are not primarily responsible for payment, as is the case in long-term care. As demonstrated, there is considerable unmet need in the long-term care system, often because there is no reimbursement available. On the other hand, consumers sometimes want services that they really may not need—especially if they know that third-party reimbursement for those services is available.

The types and numbers of long-term care service providers available today are directly the result of those three factors (need, demand, and financing). When one, two, or all three of them are present to a sufficient degree, providers of specific services appear. As a result, the mix of provider organizations and the respective roles of each in the system are constantly changing. Even the names associated with specific provider types tend to change with alarming regularity. More often than not, those name changes come about as the result of some new regulation, and its definition of the provider. For example, what were formerly called "nursing homes" are now referred to as "nursing facilities" because of the Omnibus Budget Reconciliation Act (OBRA) of 1987. "Boarding homes" are now "residential care facilities." Some terms such as "extended care" were created by earlier regulations, but they have long since been replaced in common usage by others, again created by later legislative action.

All of this makes for a very confusing situation. Providers must keep up with pertinent regulations affecting the classification of their services. Regulators, on the other hand, must strive to keep up with changes initiated by the providers. Ultimately, it is consumers who are caught in the middle. Even when, as is usually the case, changes take place in the best interests of the consumers, it becomes very difficult for anyone to understand the makeup of this ever-changing system. As the old saying goes, "You can't tell the players without a program."

In an attempt to assist in that understanding, Part II consists of individual chapters describing in detail the predominant types of long-term care providers. The following is a brief listing of them.

Nursing Facilities

Formerly called nursing homes, nursing facilities are healthcare facilities licensed by the states offering room, board, nursing care, and some therapies. They include facilities certified by Medicare as skilled nursing facilities (SNF) and others that used to be called intermediate care facilities (ICF), the primary difference being the amount of nursing care and the number of therapies provided. Skilled nursing facilities provide 24-hour nursing care plus such other services as intravenous therapy, oxygen therapy, wound care, physical therapy, occupational therapy, speech pathology, and nutritional teaching. Nonskilled facilities provide less intensive nursing care and may offer some of the other services, but do not do so on a regular basis. See Chapter 3 for more information.

Subacute Care

One of the newer terms in long-term care, subacute care has grown as a cost-effective alternative for those individuals needing more than nursing facility care and less than hospital care. Subacute care facilities or units provide highly skilled nursing care, therapies, and more medical supervision than nursing facilities. It is highly focused care designed to bridge between acute and long-term care, with a relatively short length of stay (although longer than is typical of acute care hospitals). In subacute care, multidisciplinary teams work toward a goal of moving the patient to home or a lower level of care.

Both government payment sources (primarily Medicare) and managed care organizations favor subacute care as a means of providing intensive, high-quality care at a lower cost. Hospitals and nursing facilities see it as a means of filling empty beds and gaining a growing portion of the healthcare market. Subacute care is described in detail in Chapter 4.

Assisted Living/Residential Care

Assisted living/residential care provides relatively independent seniors with assistance and limited healthcare services in a homelike atmosphere. Assisted living services include 24-hour protective oversight, food, shelter, and a range of services that promote the quality of life of the individual (NCAL, 2007). See Chapter 5 for more information.

Elderly Housing Options

Elder housing includes simple housing (owned and rental), age-restricted retirement communities, senior apartments, co-housing, independent living, congregate housing, and continuing care retirement communities (CCRCs). This is a growing area of long-term care, both in size and importance. See Chapter 6 for more information.

Community-Based Services

Increasingly, both to satisfy the desire of long-term care consumers and to save costs, care is being delivered in the community, not in institutions. The most prominent types

of such community-based care services are home health care, adult day care, and hospice care. See Chapter 7 for more information.

Home healthcare services are provided in the consumer's home. Those services might include any combination of the following: care management, nursing care, therapies, dietary consultation, wound care, or homemaker services. They are not provided on a round-the-clock basis, but for a few hours daily as needed. Home health care is seen as a major means of avoiding institutionalization.

Hospice care provides emotional and physical support for persons with terminal illness. It is usually provided in the home, often by volunteers.

Adult day care provides daily (not overnight) services for chronically ill individuals who are not able to function on their own but are able to live at home with the assistance of informal caregivers. It provides meals, social and educational activities, assistance with personal care, and supervision for the care recipient. At the same time, it provides a few hours of relief for the caregivers, often allowing them to maintain employment.

■ The Argument over Institutional versus Noninstitutional Care

Long-term care providers are often categorized as either "institutional" or "noninstitutional." Nursing care, assisted living care, subacute care, and housing services are usually considered to be institutional care because most of their care is provided in facilities developed for that purpose. Home care, adult day care, and hospice care are usually provided in the consumer's home, thus are thought of as noninstitutional (community-based) care.

The distinction, however, is not as clear as it seems. Hospice care regularly has both an institutional and noninstitutional component. So does assisted living in some situations. Adult day care is often provided in nursing facilities, but it is essentially community-based. Also, provider organizations are increasingly offering not only multiple levels of institutional care, but also noninstitutional services such as home care. For that reason, in the following discussion, the distinction will be between institutional and noninstitutional services, not among providers.

One of the primary ways in which payers have tried to reduce healthcare costs in recent years has been an increased emphasis on community-based, noninstitutional services (such as home care) and an ongoing effort to reduce the number of nursing home beds. Shifting of funding from institutional to noninstitutional services, combined with changing eligibility rules designed to accomplish the same end, has been quite successful in the past several decades. These efforts have been strengthened by a decision by the U.S. Supreme Court, known as the Olmstead Decision, that rules denying the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability, that the Americans with Disabilities Act may

require states to provide community-based services rather than institutional place-ments for individuals with disabilities, and that states have an obligation to move in-dividuals with disabilities from institutional settings into more integrated settings in the community (Mathis, 2004). While home care services have grown significantly during that time, the number of nursing homes has declined.

The reasoning behind such efforts has been twofold:

1. Long-term care consumers, particularly the elderly who make up such a large portion of that population, prefer to receive care in their own homes.
2. Home care is less expensive than institutional (nursing home) care.

Both of those arguments are valid in their broadest sense. Yet, both have shortcom-ings when put into practice.

First, the idea that most people would prefer to be cared for at home is a "no-brainer." Of course they would! While some individuals recognize and want the secu-rity and socialization that comes with institutional care, most are more comfortable in their own homes, surrounded by familiar objects. It is only natural that people feel more secure and less threatened in the homes that they have built for themselves and, of major importance, homes in which they are in command. When they are uprooted, frequently after having spent as much as a half-century in the same environment, and are forced to live in a communal setting over which they have little control, they are understandably unsettled, uncomfortable, and distressed.

Yet, advocates of community-based care continue to conduct study after study showing that people prefer to be cared for at home. They would do well to refocus their efforts toward identifying those long-term care consumers who would be better served by care in their homes.

As for the idea that home-based care is less expensive—it is, when used in moder-ation. When taken as a whole, institutional care (from the most expensive subacute or skilled nursing care to the less expensive assisted living care) is more costly than home care. Yet, when compared on an hour-by-hour basis, it is less expensive to care for institutional residents with a staffing of one staff person for multiple residents than it is for one-on-one home care. Numerous studies have shown that home-based care, contrary to popular belief, is not necessarily less expensive. Much of the reason for that is that nursing facilities and home care agencies tend to serve different populations, with those requiring more intensive, continuous care going into institutions and those who are less frail being cared for at home.

To a degree, the argument over home-based versus institutional care is somewhat spe-cious and irrelevant. It generates more emotional response than factual, for a couple of reasons. To begin with, it is not an either/or situation. There is enough demand for long-term care services to go around. The rapidly growing population of elderly (and others) needing long-term care will ensure that the supply of services—in whatever form—is not likely to overtake the demand for such services in the foreseeable future.

Also, some individuals are better cared for at home, while others would be better served in nursing homes or other long-term care institutions. Consumers who can generally care for themselves with the support of certain types of assistance—such as help with activities of daily living (ADLs), including feeding, bathing, dressing, toileting, and transferring—are capable of home-based care, which is less expensive and which poses less of an intrusion on their independence. Such care, usually available on an à la carte basis, permits them to maintain their all-important sense of self-reliance, providing only that level and extent of care that is needed. It has the added advantage of being flexible enough to easily expand or contract as the consumer's needs change.

Conversely, institutional care provides the security, supervision, medical/nursing oversight, and functional assistance needed by those long-term care consumers who are generally unable to function safely and adequately with minimal support. It is constant, as opposed to periodic, care.

The difficulty of determining accurately how many residents currently in nursing facilities could be appropriately cared for in community-based care is illustrated by one report that placed that number somewhere between 15 and 70 percent (Spector, Reschovsky, & Cohen, 1996). That wide range in identifying how many could be moved from nursing homes to home care or community-based personal care homes is the result of using three separate definitions. One was very permissive, excluding only residents with substantial care needs or presenting a danger to themselves. A second definition, excluding a few more types of care needs, produced a figure of 47 percent who could be moved. The least exclusive (most restrictive) definition eliminated residents with certain conditions such as an inability to perform activities of daily living (ADLs). It found that only 15 percent could be appropriately cared for at home.

The point worth noting here is not which of these definitions is most accurate, if any, but that there is little agreement on how to determine the appropriateness of different types of care. It is a question not easily answered, because those trying to make the determination of what is appropriate are alternately influenced by issues of cost, quality, and choice.

■ Long-Term Care as Part of a Continuum

One approach to defining the interrelationship among long-term care providers is to consider them collectively as a continuum of care. Dr. Connie Evashwick was one of the earliest (and still one of the leading) advocates for considering our health and social system as a comprehensive, integrated continuum of care. In her book, *The Continuum of Long-Term Care*, she defines a continuum of care as "an integrated, client-oriented system of care 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" (Evashwick, 2005).

Also, the term "continuum of care" may be used to refer to the overall system as we are doing here, or it may refer to a specific subsystem serving a defined geographic area or a particular service population, such as the integrated care networks described in Chapter 8. The elements of a continuum remain the same. It is client oriented, comprehensive, and integrated.

The Continuum Is Client Oriented

Long-term care and other health and social services should revolve around the consumers (clients), rather than forcing the consumers to revolve around the services. In Chapter 2, we discuss an ideal long-term care system using the somewhat stronger term "consumer-driven." That term was chosen after lengthy debate as a way to denote that the consumers should have some control in how and when they use the long-term care system. Whichever term is chosen, the point is that the client (consumer) is the focus of the system and all of its components.

The Continuum Is Comprehensive

A long-term care system, be it localized or the overall U.S. long-term care system, must provide all of the services needed by its consumers if it is to be a true continuum. A list of services should include at least health promotion/illness prevention, ambulatory care, inpatient acute care, residential long-term care, community-based long-term care, and housing. It should be noted that services are being added all of the time. The consumers involved may require any or all of those services at one time or another. The key is being able to give consumers access to the services when they need them (Evashwick, 2005). A continuum also covers more than the services usually associated with long-term care. It includes services such as acute care and housing services if it is to be considered comprehensive. If any of the services are missing, or if they are not appropriate for a particular consumer's needs, gaps in coverage are created.

The Continuum Is Integrated

Evashwick (2005) emphasizes that a continuum of care is an integrated system of care—more than just a collection of fragmented services, but one that includes mechanisms for organizing those services and operating them as an integrated system (Evashwick, 2005).

Dr. Bruce Vladeck, former head of the U.S. Health Care Financing Administration (HCFA)—now known as the Centers for Medicare & Medicaid Services (CMS), the agency that oversees Medicare and Medicaid—presented an entirely different, and enlightening, way of looking at the continuum (Vladeck, 1987). His descriptions of the continuum have stood the test of time. In that text, he described the continuum of

care in common, easy-to-understand terms. Perhaps his most valuable contribution is in identifying what the continuum is not.

First, it is not a ladder, which has been the accepted model for much of health care but simply does not fit the users of long-term care services (Vladeck, 1987). The "ladder" concept suggests that everyone progresses (or regresses) from acute care through the various levels to the other extreme of the continuum. An often unrecognized fact about long-term care is that it is not static. Most individuals using long-term care move from one level of need to another on a random, unpredictable basis. It was long assumed that long-term care was a one-way street, moving from relative independence to complete dependence. As more discrete types of care have become available, it has been shown that most long-term care recipients move relatively often from one level of care need to another. They may regress from one level of functional independence to a lower level for a time, only to regain their ability to care for themselves (usually as the result of good therapy services). Periodic episodes of acute illness are not infrequent, particularly with the frail elderly. Experience has shown that long-term care is a dynamic process. Any individual may well move from one level of care to another, from one type of care delivery modality to another, and back again, perhaps several times over a period of years.

For the same reasons, the continuum of care is not a set of concentric circles (Vladeck, 1987). A set of concentric circles is another frequently used means of visualizing the continuum of care, with acute services at the hub and less intensive services in the outer circles. All this model really does is change the direction of perceived movement from up/down (in the ladder model) to inside/out. It has many of the same flaws as the ladder concept, in that long-term care consumers do not move smoothly from one ring to another. They often utilize portions of services from several levels of care.

One of the most popular organizational tools of the 1990s was the matrix. A three-dimensional matrix model is another way of describing the continuum of care, but as Vladeck explains, it still falls short (Vladeck, 1987). It fails to take into consideration the many human dimensions involved.

He goes on to develop a couple of his own metaphors, a user-friendly computer and a root system, to describe the continuum. Actually, they are not much better. In trying to understand the concept of a continuum of care, we should try to avoid getting too tangled up in visual images. Rather, we should work at understanding that it is a comprehensive, integrated system designed to meet the very complex needs of a highly vulnerable population. Its shape is not important, but the results are.

■ Strengths and Weaknesses in the Long-Term Care System

The long-term care system, being very much in the middle of a turbulent time, has both strengths and weaknesses. Let us look at the more prominent of them.

Strengths

The long-term care system, while less than perfect, has provided essential care to a very large, very diverse population for a long time. While it is human nature to dwell on the weaknesses of the system (a prerequisite to overcoming those weaknesses), the system also has its strengths, which should not be overlooked.

Response to Changing Needs

Even as it has been evolving, the long-term care system has responded to the changing needs of its consumers. In fact, that responsiveness has been a cornerstone of its evolution. As new needs have arisen, new modes of delivery have developed to meet them. For example, as new or newly identified diseases such as Alzheimer's disease have come along and have produced an entirely new set of consumer needs, new treatment methods have been found to better care for those particular populations.

Its Uniquely American Nature

The long-term care system in the United States has evolved in ways that fit the attitudes of our particular society. The system has resisted efforts to impose on it those elements that appear to work in other societies. That may not appear to all readers as a strength, but it represents certain values that are somewhat unique to this culture, including strong reliance on personal responsibility, resistance to heavy government involvement, and fierce defense of individuals' right to choice. Whether we agree with each of those, they represent ideas that are deeply ingrained in American society. The seemingly haphazard way in which the long-term care system has developed is a form of recognition that there are vast geographic, ethnic, economic, and social differences in this large country and that it will be difficult to find any monolithic system that meets all of those needs equally.

The Dedication of Caregivers

There are many criticisms of the current long-term care system, as we shall see. However, the vast majority of people working in long-term care are highly dedicated to the welfare of those for whom they care. It is that dedication that has allowed the long-term care system to survive its turbulent history and to serve its consumers as well as it has. There are far too many situations where the quality of long-term care and the quality of life of those dependent on such care are sacrificed because of incompetent or greedy providers. However, emphasis on those situations overlooks the many providers and their staff members whose primary allegiance is to their consumers. (Note that later in this chapter, the poor image of long-term care providers is identified as part of what is wrong with the current system.)

Increasing Focus on Customer Service

In recent years, the long-term care system has become increasingly concerned with what has been known in other industries as customer service. As long-term care consumers have become more aware of their options, and have been more willing to demand

amenities that will improve the quality of their lives, they have in effect become better consumers. It is to the credit of the providers in the long-term care system that they have sought ways of providing those amenities. They have often turned to successful companies such as Walt Disney Enterprises and some of the large hotel chains to learn how to make the long-term care they provide more satisfactory and more responsive to the needs and wants of their customers.

Critics will say that they have done so only because of the increasingly competitive nature of the field. That may sometimes be the case, but the motivation for this focus on customer service is of less importance than the end result, which has been a major benefit for both those using the services and the system itself.

Development of Innovative Types of Care

For a variety of reasons—including the desire to provide better service, the need to secure a larger portion of a competitive market, and simple creativity—the long-term care system has shown considerable capability to create new and innovative ways of meeting the needs of their consumers.

Aging in Place   One such innovation is known as "aging in place." It is based on acknowledgment of the need to tailor services to the particular requirements of individuals. Aging in place recognizes that consumers' long-term care needs vary from time to time and is designed to bring services to them rather than moving them to where the services are available. The idea is that long-term care recipients should live in a stable, home-like setting that is familiar and comfortable, in which services can be provided. The difficulty in implementing the concept lies in the logistics required to have all necessary services available at a reasonable cost. There have been, and continue to be, numerous highly successful projects aimed at solving that problem.

Multi-Level Facilities   Multi-level facilities are a variation of living in place—long-term care facilities that provide several different levels of care in the same location. While not allowing residents to stay in the same specific setting as living in place would, it does allow them to stay in the same facility. Such facilities provide some or all of the services of the long-term care system. Most common are the more traditional institutional services, nursing facilities (skilled and nonskilled), assisted living/residential care, and various types of supported independent living arrangements.

When individuals need a different level or type of care, either temporarily or permanently, they move from one floor to another or one unit to another, staying within the overall organizational campus. In doing so, they remain in a familiar environment, with familiar staff, subject to familiar rules and regulations. A particularly valuable aspect of such an arrangement is that it minimizes separation of elderly couples. Even if one of them needs to move to another unit, the spouse is not all that far away and can visit regularly.

Adult Day Care   These programs were designed to provide relief for family members who provide long-term care for relatives in their homes. In such programs, the consumer

spends a few hours a day in a supervised setting outside the home, often within a nursing facility. The concept recognizes the need of such caregivers for some free time to hold jobs or to attend to their own matters. In many cases, adult day care availability is the difference between keeping the care recipient at home with his or her family or having to institutionalize him or her. In addition, day care provides valuable social interaction, including structured activity programs. Adult day care programs are described in detail in Chapter 7.

Long-term care providers have also found an especially innovative and highly successful variation of adult day care—inclusion of pediatric day care in long-term care programs designed primarily for the elderly. Pediatric day care has been around for a long time, providing safe, supervised baby-sitting activities for preschool children while their parents work. In time, various long-term care organizations, particularly nursing facilities, began offering on-site child day care for their employees as a recruitment and retention benefit. They discovered the value of allowing the children and the elderly residents to interact, benefiting both groups. Many long-term care organizations now schedule joint activities for the children and the residents, creating a simulated grandparent–grandchild relationship.

Integration Efforts

Perhaps the most significant and promising innovation in the long-term care system has been the move toward more integration of services. Development of integrated health systems (IHSs) has progressed rapidly in recent years. They represent an important development in the evolution of the long-term care system toward a true continuum of care. Some integrated systems are still in relatively early stages of their development, learning what works and what does not. Others have worked through that phase. While some such experiments failed, those that have succeeded are sound, tested organizational forms able to better serve the needs of their customers. Chapter 8 examines the integration phenomenon in detail.

Weaknesses

It would be an understatement to say that the current long-term care system has its flaws. Its weaknesses and the need to overcome them in such a dynamic environment pose major challenges for all involved with the system: providers, payers, regulators, and policy makers. The rapid growth in the number of people needing long-term care now and projected to need it in the near future compounds the need to find some solutions fast. Let us look briefly at some of the weaknesses in the long-term care system as a prelude to seeking ways to address them.

A Reimbursement-Driven System

All of this has created one of the greatest problems with the long-term care system as it exists today: It is reimbursement-driven! Providers have come forward to meet

needs for which there is reimbursement, but have been understandably reluctant to create services for which they will not be paid, or for which reimbursement is extremely limited.

The long-term care system, like the rest of the American healthcare system, is reimbursement-driven rather than consumer-driven. The type and amount of service available to individual consumers is more often than not dependent on the type and amount of financial coverage they have. Whether they are covered by private insurance or government programs such as Medicare or Medicaid, their services are restricted to those included under that program. Eligibility requirements, co-pay responsibility, duration of coverage, and selection of providers all affect the availability and accessibility of services, and all vary depending on the reimbursement source.

Instead of focusing primarily on the needs of individual consumers, the system focuses on payment availability, resulting in gaps in services for many consumers. For example, people whose insurance provides coverage for home care services may be able to stay at home, while others with the same functional disabilities might have to be admitted to a nursing facility because their coverage is limited to institutional care. The length of time spent in a specific type or level of facility is also dependent on the source of third-party reimbursement. These problems have been exacerbated somewhat by the advent of managed care which, while being more efficient, has tended to impose more restrictions on the types and amounts of care received, based on cost.

Inequitably Distributed Services

Long-term care services are not equally available to all who need them. This is partly, but not entirely, due to the nature of long-term care reimbursement. Other factors contributing to that inequality include limitations caused by geographic and political boundaries and uneven availability of certain types of professional staff. Availability of care can depend on whether those needing it have reimbursement coverage or on the source of that coverage. Where they live can also make them eligible or ineligible, as can other demographic factors such as age or socioeconomic status. Even when they are eligible, services are often not available to them.

Any or all of those factors can contribute to long-term care being available to some and not to others. One of the biggest challenges for the long-term care system is making services available and accessible to all who need them. Without such equity, the system is not seamless nor can it be considered a true continuum.

A Fragmented and Uncoordinated System

The long-term care system is fragmented, consisting of numerous parts that should be interrelated and integrated, but are not. That fragmentation comes from several sources, including the many different payers and types of reimbursement, the independent nature of providers, and not least of all by the fragmented regulations governing the system.

To begin with, the lack of coordination in the system affects providers of care. It has become popular in recent years to talk of creating a "level playing field," meaning that all players in the game have equal opportunities, face similar obstacles, and play by the same rules. In long-term care, there is no level playing field—nor any semblance of one. Different segments of the industry (e.g., providers, payers, regulators) each have their own set of forces determining how they proceed. Those forces usually involve financing or regulations. As noted earlier, uneven availability of reimbursement is a major reason for the fragmentation of the system. Uncoordinated regulations also contribute to that problem. Nursing facilities are subject to different rules and regulations than are home care agencies or even more closely related services such as assisted living. Some types of care, such as subacute care, are caught in the middle, with regulations from both acute care and nursing care applying to them. Multi-level long-term care organizations often have to meet several differing, often competing regulations.

Even within one provider type, there are also differences from one geographic area to another. For example, by federal law all states must license nursing home (nursing facility) administrators. Yet, there are no overall standards governing how they do so, and there is great variation from one state to another. One organization, the National Association of Long-Term Care Administrator Boards (NAB), continues to work toward some degree of uniformity in that area, but still has much work to do.

While this fragmentation makes it difficult for providers of long-term care services to do their jobs, the real impact is on the consumers. The providers deliver different services in different situations, to different consumer groups, and in response to different regulations. Consumers end up working with numerous providers at the same time, with little if any coordination. Each provider works within its own arbitrarily defined boundaries, presenting consumers with a confusing mishmash of rules to understand and follow.

The effect of all of this goes beyond mere confusion and inconvenience. It can also result in inferior care. A nursing home may send a resident to a hospital for treatment of an acute episode of illness, without filling the hospital staff in on all of that person's other care requirements. The hospital, in turn, may make discharge plans for a patient without knowing all of his or her social needs. Some of that is caused by poor planning and communication among providers of different levels of service, but much of it is caused by the fragmentation of the overall system.

A Mix of Health and Social Services

The long-term care system includes or relies on a mix of health-related elements and others that are more social or economic, such as housing and transportation. Remember that the need for long-term care is generally triggered by a functional limitation resulting from a disease or condition, not by the disease or condition itself. Assistance in overcoming that functional limitation often includes services traditionally thought of as social

services. Providing appropriate housing, meals, transportation as needed, and financial or legal assistance may have a significant impact on the success of the more health-related long-term care services. Indeed, the availability or unavailability of those other services often becomes a determinant in whether long-term care is needed at all. In fact, housing—and newer forms of housing—have become so important in long-term care we dedicated a chapter (Chapter 6) of this text to them.

While health and social services can never be totally separated, they frequently involve different providers, reimbursement sources, and/or regulations. Arbitrary boundaries between long-term care and social services abound. That separation makes it very difficult to achieve any type of coordination.

Multiple Entry Points into the System

The fragmentation, inequity, and lack of coordination that are seemingly inherent in the long-term care system produce a result that makes it very difficult for consumers to access services: the many different points at which they enter the system and the different steps required to reach services from those multiple entry points. An individual consumer's need for long-term care may be identified while in the acute (hospital) system, may come from interaction with the social services system, or may come directly from home—without any prior contact with those other systems. Depending on which of these routes is followed, there may be significant differences in eligibility requirements, reimbursement, and duration of care. What is worse, should the consumer leave the long-term care system and reenter at a later time, he or she may have to start all over.

Overshadowed by the Acute System

The long-term care system has long taken a back seat to the acute care system. Hospitals, with their ever-increasing ability to save lives and cure illness, have been far more dramatically imprinted in the minds of the public than the less glamorous, ongoing long-term care, with several unfortunate results for long-term care. First, healthcare professionals, particularly doctors and nurses, have not been as likely to see long-term care as a desirable career option. Thus, there is a shortage of medical professionals trained in long-term-care-related areas such as geriatrics. Despite efforts to convince the medical profession of their worth, the numbers of practicing geriatricians are following seriously behind needed levels (Kim, 2008). It has been difficult to get those who do move from an acute care setting to long-term care to realign their thinking from a medical model to a more holistic model—to go from a "cure" mentality to a "care" mentality.

Second, both reimbursement policies and regulations affecting the long-term care system tend to be adapted from the acute care system rather than being created specifically for long-term care. An example of that is the Medicare requirement of an acute hospital stay as a prerequisite for certain types of long-term care. The original purpose

of that requirement was to avoid inappropriate and unnecessary use of long-term care services, particularly in nursing homes. It was based on the concept that only a physician could determine the need for long-term care, and then only after hospitalization. The irony is that it sometimes served to create inappropriate and unnecessary hospital stays as a means of justifying entry into the long-term care system. There is great need to move away from that philosophy toward one more suitable for long-term care.

Acute care tends to focus on and treat a person's medical condition, while long-term care looks at the total picture, the entire individual.

Poor Public Image

The long-term care system has long suffered from an unfavorable image among the public. Because nursing homes have been the predominant type of provider in years past, they have been the focus of much of that bad publicity.

Anecdotal evidence of poor care is not hard to come by. For example, one study of public attitudes about nursing homes found that nursing homes rank below drug companies in the share of adults who say they are doing a "good job" serving healthcare consumers. That same study showed that the public is somewhat wary of nursing home care: Twice as many adults say being in a nursing home makes people "worse off" than they were before (41 percent) as say that nursing homes make people "better off" (19 percent; Kaiser Foundation, 2005). While there has undoubtedly been organizational and personal abuse in the long-term care system, it is not nearly as rampant or as serious as such articles suggest.

Also, nursing homes are fighting a societal perception. They have been seen by an entire generation as places where someone goes to die or places where family members can "get rid of" a burdensome relative. These negative images often translate into tougher regulations and/or opposition to funding of long-term care. The system will be hard put to implement significant change without addressing its image problem.

Inadequate Support for Informal Caregivers

The long-term care system relies heavily on an informal group of caregivers who supplement its formal services. About 7.3 million people are informal caregivers, defined as spouses, adult children, other relatives, and friends who provide unpaid help to disabled older people living in the community. Of these, about three-fifths (or 4.2 million) are spouses and adult children; the remaining two-fifths (3.1 million) are other relatives, friends, and neighbors (CareGuide@Home, 2004). They are usually not recognized as an integral part of the formal long-term care system, nor do they receive adequate support, although there have been encouraging steps in that direction. Hospice care programs (see Chapter 7) assist families in caring for relatives with terminal conditions by providing both physical and emotional support. Respite programs provide periods of relief from caregiving chores, benefiting both patient and caregiver.

Yet, little has been done systemwide to recognize the degree to which these informal caregivers augment the formal long-term care system or to provide financial or other support and incentives for them. By failing to do that, the long-term care system is also failing to take full advantage of a potentially significant resource.

A Confusing and "User-Unfriendly" System

All of these weaknesses in the current long-term care system, when taken together, result in a system that is extremely difficult for consumers and potential consumers to access and use effectively. The fragmentation and the lack of coordination of services, financing, and regulations only serve to make the system confusing and unfriendly to anyone who must rely on it. Many an experienced "expert" in some aspect of long-term care has discovered, when confronted with dealing with the system on a personal basis, that it is very difficult to understand and use. If the experts find it difficult, imagine what the "nonexperts" encounter when attempting to access long-term care.

■ Summary

Today's long-term care system is, indeed, in a state of turbulence. It is a system that is growing at a rate far in excess of its apparent ability to accommodate to the changing needs. A host of external and internal forces is at work pushing the system to change. Yet, it is a system that has grown and developed in a random, reactive, and sometimes haphazard manner. Its history has been one of meeting needs as they become apparent, rather than anticipating those needs in a proactive approach. It is fragmented, difficult to access, and overly dependent on the vagaries of a reimbursement system that is changeable at best, fickle at worst.

On the other hand, it is a system that does respond (eventually) to demonstrated needs, one that somehow manages to provide services to those who need them the most. It is a system that depends on the dedication and ingenuity of those directly providing services to meet the changing needs of the system's consumers even when faced with confusing, sometimes incomprehensible, rules and regulations.

It is a system struggling to respond to a rapidly changing environment with creative and innovative methods of delivering services to a population that is discovering its ability to influence its own future. The worst characteristic of the current long-term care system is its lack of coordination and uniformity. Paradoxically, its best characteristic is its flexibility and ability to accommodate the different needs and wants of its many consumers.

Having defined and described the current system herein, Chapter 2 identifies an ideal long-term care system and the elements required to make it work.

■ Vocabulary Terms

The following terms are included in this chapter. They are important to the topics and issues discussed herein and should become familiar to readers. Some of the terms are also found in other chapters but may be used in different contexts. They may not be fully defined herein. Thus, readers may wish to seek other, supplementary definitions of them.

activities of daily living (ADLs)
adult day care
aging in place
AARP (American Association
    of Retired Persons)
Americans with Disabilities Act
    (ADA)
assisted living/residential care
baby boomers
certificate of need (CON)
Centers for Medicare &
    Medicaid Services (CMS)
chronic care
clients
community-based care
continuum of care
functional disabilities
home health care

hospice care
informal caregivers
institutional care
integration
integrated health systems (IHSs)
long-term care
managed care
Medicaid
Medicare
multi-level facilities
multiple entry points
noninstitutional care
nursing facilities
quicker and sicker discharges
residents
Social Security Act of 1935
subacute care
utilization review

■ Discussion Questions

The following questions are presented to assist you in understanding the material covered in this chapter. They tend to be general but lend themselves to detailed answers, which can be found in the chapter.

1. What factors have led to the development of the long-term care system as it currently exists?
2. What are some of the strengths and weaknesses of the current long-term care system?
3. Who uses long-term care services, and why do they use them?
4. Who are "baby boomers," and what is their impact on the long-term care system?
5. What is, and has been, the role of informal caregivers in the long-term care system?
6. What is a "continuum of care," and where do long-term care services fit in that continuum?
7. What types of services make up "institutional" and "noninstitutional" care?
8. What effect have government regulations had on the financing of long-term care?

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