PART I

Introduction: The Changing Long-Term Care Scene
In 1980, management guru Peter Drucker 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 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 beginning to be 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, subacute care). There was a time when any form of advertising was considered bad form throughout the health care system. Now, health care providers, including all types of long-term care providers, are engaging in regular, often highly sophisticated (and correspondingly expensive) advertising, using 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 will 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 are experiencing 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 health care industry for the past two decades. Those forces have seen many 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 health care 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 has all changed, with a rapidity that has caught many long-term care providers unprepared. No longer can those previously isolated providers in the long-term care system remain aloof from the rest of the system. No longer can they stay within their own limited spheres of activity and service as they have in the past. The players in long-term care in the late 1990s and in the beginning of the next millennium must be aware of, and be prepared to deal with, unprecedented changes. They must 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, is 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 U.S. during that time, traditional long-term care organizations are now realizing that they can no longer survive in an isolationist mode. They have come to realize—some willingly, and some reluctantly—that they represent only small portions of an ever-expanding industry.

The author teaches a class in “Leadership in Health Administration” to adult health care professionals enrolled in courses leading to college degrees in health care or long-term care administration. Though the students complete the majority of their courses through a distance education pro-
gram, they also attend summer residencies on campus during which the Leadership course is taught. Those students come from all of the United States and from numerous other countries and represent the full gamut of training and experience in various segments of the health care industry. Most are health care managers, ranging from first line supervisors (charge nurses, department heads) to Chief Executive Officers (CEOs) of hospitals, nursing homes, or other health care organizations. They come to the class with a great deal of experience in all phases of the health care system. In fact, during a recent class, one of the students conducted a survey and determined that the students in that one class represented a total of 370 years of health care experience. They are discussed here because they represent a cross section of health care 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 to 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 health care 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 beginning to experience 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 are evolving, 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 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.

While both terms, chronic care and long-term care, will be 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 will be 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.” Another, more detailed description of long-term care consumers is “those persons requiring health care, personal care, social, and supportive services over a sustained period of time.” The type of con-
sumers who use long-term care will be 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 this century it was what one writer described as “a comparatively drab backwater in the overall scene of U.S. health care.” 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 that will be 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 century, 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.\(^5\)

**The Growing Role of Government in Long-Term Care Financing**

Up to that point there had been very little government involvement in long-term care, that involvement 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 the 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 the 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,\(^6\) 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 the 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 paper work. For both state and federal governments, 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 numbers 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 a lack of funding. 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 health care 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 acts 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; 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 pay-
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 health care regulations, they are intended to assure 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 health care 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 impact 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 health care 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 health care 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 has also caused certain problems for long-term care providers and policy makers. These successes in extending longevity have 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, written twenty years ago, 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 health care programs to meet the needs of a more vigorous aged population.8

However, it should not be assumed that nothing was done in response to that and similar warnings. Many groups and individuals have 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 have become commonplace. They and a multitude of similar procedures unheard of in earlier generations have come to be thought of as almost routine. 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, the patients’ 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 Health Care Costs and the Impact on Long-Term Care

Government programs, such as Medicare and Medicaid, have not been alone in trying to reduce the costs for health care. Private insurance compa-
nies, employers who are the largest purchasers of insurance, and individu-
als paying their own bills all have become very concerned about rapidly
escalating costs. As a result, several new forms of health care financing
and delivery have developed, most notably managed care, discussed in
detail in Chapter 11 (Long-Term Care Reimbursement). That new empha-
sis on cost-effectiveness has impacted the long-term care system quite sig-
nificantly, 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 pre-
set 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 has come to be known as “quicker
and sicker” discharges.

These pressures on providers to discharge patients at predetermined
times is not new. From its earliest inception, Medicare denied reimburse-
ment for care beyond certain points. The law included a section requiring
providers to conduct a process known as Utilization Review, intended to
assure that the Medicare system did not pay for care beyond that which
was determined to be necessary. What is new in recent years is the in-
creased involvement of other payers and the compressing of allowable
lengths of stay.

This trend has impacted 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 residential care facilities or at
home. That, in turn, has produced other changes in the system. It has in-
creased the acuity of patients at each level, has changed staffing require-
ments accordingly, and has forced facilities and agencies to add new ser-
vices to meet the increased needs of their clients. It has also led to the
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 ac-
ceptable 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 health care 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 elements 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 will be discussed in detail in Chapter 10 (External Control of Long-Term Care) and Chapter 11 (Long-Term Care Reimbursement).

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.

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 has referred to them as constituents, pointing out the reciprocal relationship inherent in the interface between those seeking care and those providing it. It’s 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 health care 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. 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. Any inability to understand the nature of the disability and to follow the 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 non-elderly 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. The number of people in the U.S. over age 65 now stands at approximately 31 million and is projected to reach 55 million by the year 2020, with those over 85 expected to grow from 3 million to more than 13 million.

Yet, even those consumers who fall into the broad category of “elderly” or “aged” can no longer be lumped together as an 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 innova-
tive 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 begun 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. Two decades ago, the elderly were described as “not well organized for exerting political influence.” Yet, in 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 the American Association of Retired Persons, 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 health care 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.

Non-Elderly Users of Long-Term Care

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 55 percent of the total long-term care population. Of the remaining group, 42 percent are working-age adults and 3 percent are children. 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 acquired immune deficiency syndrome (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, 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. There are innumerable cases in which families of these patients would be effectively destroyed without the long-term care services available to them.

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 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, which required businesses and organizations to make significant changes in physical accessibility to buildings and in 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 are 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 Users of Long-Term Care

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 the year 2010, approximately one out of seven Americans will be 65 and over. By the year 2030, when the youngest of the baby boomers reach retirement age, the number of Americans aged 65 and above will have grown to 70 million, more than twice what it was in 1990. 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. 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 non-health 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 impact long-term care would be somewhat prohibitive, and probably confusing. Thus, this book’s primary focus is on the long-term health care system, and will include the providers most directly related to that system. While there is not a distinct section dealing with other societal forces, they and their impact will be referenced throughout.
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: need, demand, and 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 we will see, 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 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: Long-Term Care Service Providers 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 health care facilities licensed by the states offering room, board, nursing care, and some therapies. They include facilities certified by Medicare as Skilled Nursing Facilities (SNFs) and others that used to be called Intermediate Care Facilities (ICFs)—the primary difference being the amount of nursing care and the number of therapies provided. SNFs 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. Non-skilled facilities provide less intensive nursing care and may offer some of the other services, but do not do so on a regular basis.

Assisted Living/Residential Care

Assisted living is the name given to those programs not licensed as nursing homes (nursing facilities), providing personal care to people needing assistance in activities of daily living (ADLs). Residential care includes boarding homes, Continuing Care Retirement Communities (CCRCs), and adult foster homes. There is much confusion over these terms, and state regulations governing the facilities vary greatly (see Chapter 4, Assisted Living/Residential Care).

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. They provide 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 home or to 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 subacute care as a means of filling empty beds and gaining a growing portion
LONG-TERM CARE

of the health care market. A detailed description is provided in Chapter 5 (Subacute Care).

Adult Day Care

Adult day care provides daily (not overnight) services for chronically ill individuals who are not able to function on their own, but who are able to live at home with the assistance of informal caregivers. Adult day care 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. A detailed description is found in Chapter 6 (Adult Day Care).

Home Health Care

Home health care services are provided in the consumer’s home. Services might include any combination of the following: care management, nursing care, therapies, dietary consultation, wound care, or homemaker services. Services 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

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

THE ARGUMENT OVER INSTITUTIONAL VS. NONINSTITUTIONAL CARE

Long-term care providers are often categorized as either “institutional” or “noninstitutional.” Nursing care, assisted living/residential care, subacute care, and adult day care are usually considered to be “institutional” care because most of the care is provided in facilities developed for that purpose. Home care and hospice care are usually provided in the consumer’s home and are thought of as “noninstitutional” (sometimes also described as “community-based” care).

The distinction, however, is not as clear as it seems. Hospice care regularly has both an institutional and noninstitutional component, as does assisted living in some situations. 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 follow-
ing discussion, the distinction will be between institutional and noninstitu-
tional services, not providers.

One of the primary ways in which payers have tried to reduce health
 care costs in recent years has been an increased emphasis on community-
based, noninstitutional services such as home care, in an ongoing effort to
reduce the number of nursing home patients. Shifting of funding from in-
stitutional to noninstitutional services, combined with changing eligibility
rules designed to accomplish the same end, has been quite successful in the
past couple of decades. 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. First, 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. Second, home
care is less expensive than institutional (nursing home) care. Both of these
arguments are valid in their broadest sense, yet, both have shortcomings
when put into practice.

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 security and socialization that come 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 may 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 con-
sumers 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 moderation. 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. One extensive study conducted recently at the University of Michigan found that home care rarely substitutes for institutional care and usually raises costs.\textsuperscript{19} 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 specious 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 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 usually less expensive and poses less of an intrusion on their independence. Such care, usually available on an a la carte basis, permits them to maintain their all-important sense of self-reliance, providing only the level and extent of care that is needed. Home-based care has the added advantage of being flexible enough to expand or contract easily 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 a recent report by the federal Agency for Health Care Policy and Research (AHCPR), a major source of funding for health care research. AHCPR researchers placed that number somewhere between 15 and 70 percent.\textsuperscript{20} 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 those 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 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, as 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 is still one of the leading advocates for considering our health and social system as a comprehensive, integrated continuum of care. In her book Managing the Continuum of 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.”21(p.23)

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 9 (Competition/Cooperation/Integration). 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. Chapter 2 (Toward an Ideal System) uses the somewhat stronger term “consumer-driven.” That term was chosen after lengthy debate over 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 used, the point is that the consumer (client) is the focus of the system and all of its components.

The Continuum Is Comprehensive

A long-term care system, whether local or national in scope, must provide all of the services needed by its consumers if it is to be a true continuum. A list of services included in the continuum is shown in Figure 1-1. It should be noted here that services are being continually added. The consumers involved may require any or all of those services at one time or another. As one author has put it, “Ideally, they [services in the continuum] begin with an effort to prevent deterioration or dependency and end only

Figure 1-1 Services and Integration Mechanisms of the Continuum of Care. Source: Reprinted from C. Evashwick, Definition of the Continuum of Care, in Managing the Continuum of Care, C. Evashwick and L. Weiss, eds., © 1987, Aspen Publishers, Inc.
after death and suffering have been made as bearable as possible.”

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, described by one author as “no-care zones,” are created.

The Continuum Is Integrated

Dr. Evashwick emphasizes that a continuum of care is an integrated system of care—more than a collection of fragmented services. She describes some of the mechanisms that must be built into the continuum for organizing and operating those services in an integrated manner (see Table 1-1).

Dr. Bruce Vladeck, former head of the U.S. Health Care Financing Administration (HCFA), the agency that oversees Medicare and Medicaid, wrote a chapter in Dr. Evashwick’s book in which he presented an entirely different—and enlightening—way of looking at the continuum. In that chapter, 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. That has been the accepted model for much of health care, but simply does not fit the users of long-term care services. 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. 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 use portions of services from several levels of care.

Table 1-1  Services of the Continuum of Care

<table>
<thead>
<tr>
<th>Extended</th>
<th>Acute</th>
<th>Outreach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing facilities</td>
<td>Medical/surgical inpatient unit</td>
<td>Screening</td>
</tr>
<tr>
<td>Step-down units</td>
<td>Psychiatric inpatient unit</td>
<td>Information and referral</td>
</tr>
<tr>
<td>Swing beds</td>
<td>Rehabilitation inpatient unit</td>
<td>Telephone contact</td>
</tr>
<tr>
<td>Nursing home follow-up</td>
<td>Interdisciplinary assessment unit</td>
<td>Emergency response</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ambulatory</th>
<th>Wellness/Health Promotion</th>
<th>Housing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physicians’ offices</td>
<td>Educational programs</td>
<td>Continuing care retirement communities</td>
</tr>
<tr>
<td>Outpatient clinics</td>
<td>Exercise programs</td>
<td>Independent senior housing</td>
</tr>
<tr>
<td>Interdisciplinary assessment clinics</td>
<td>Recreational and social groups</td>
<td>Congregate care facilities</td>
</tr>
<tr>
<td>Day hospitals</td>
<td>Senior volunteers</td>
<td>Adult family homes</td>
</tr>
<tr>
<td>Adult day care centers</td>
<td>Congregate meals</td>
<td>Assisted living facilities</td>
</tr>
<tr>
<td>Mental health clinics</td>
<td>Support groups</td>
<td>Intermediate care facilities for the mentally retarded</td>
</tr>
<tr>
<td>Satellite clinics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychosocial counseling</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol and substance abuse care</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Reprinted from C. Evashwick, Definition of the Continuum of Care, in Managing the Continuum of Care, C. Evashwick and L. Weiss, eds., © 1987, Aspen Publishers, Inc.
One of the most popular organizational tools of the nineties is the matrix. A three-dimensional matrix model is another way of describing the continuum of care, but as Vladeck explains, it still falls short. 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, one 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 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 one agrees 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, 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 its consumers.

*Aging In Place* is one such innovation. It is a still largely untested idea, but one 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 it 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, homelike 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 experiments and demonstration projects aimed at solving that problem.

*Multilevel Facilities* are a variation of aging 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 homelike setting as aging 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 non-skilled), 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 far away and can visit regularly.

*Adult Day Care* 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 for some free time for such caregivers to hold jobs or to attend to
their own matters. In many cases, adult day care availability is the differ-
ence between keeping the care recipient at home with his or her family or
having to institutionalize him or her. In addition, day care provides valu-
able social interaction, including structured activity programs. Chapter 6
(Adult Day Care) describes these programs in detail.

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. Pedia-
tric day care has been around for a long time, providing safe, supervised
babysitting services 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 is the move toward more integration of services. Development
of Integrated Care Networks (ICNs) or Integrated Care Systems (ICSs) has
progressed rapidly in the past few years. They represent an important de-
velopment in the evolution of the long-term care system toward a true con-
tinuum of care. Most integrated systems are still in relatively early stages
of development, learning what works and what does not. While many such
experiments will fail, those that succeed will be sound, tested organiza-
tional forms able to better serve the needs of their customers. Chapter 9
(Competition/Cooperation/Integration) examines the integration phenom-
enon 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

One of the greatest problems with the long-term care system as it exists today is that 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 health care system, is reimbursement-driven rather than being 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, the services they receive 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, tends 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 above, 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. Multilevel 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 Boards of Licensure of Long-Term Care Administrators (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.

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 consumers 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, producing several unfortunate results for long-term care. First, health care 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. 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. As 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, and exposés abound in the popular press. For example, a 1995 article in *Consumer Reports* leads off with the statement, “A long stay in a nursing home can consign a resident’s family to financial hardship, even poverty. But choose the wrong nursing home, and you may also consign your loved one to physical and emotional hardship, including premature dependency and incontinence, even premature death.”\(^28(p.518)\) 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 one 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. Those caregivers are the family members, friends, and others who provide some or all of the long-term care needed by many consumers. According to the Family Caregivers Alliance, half are spouses and another third are adult children.\(^29\) 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 assist families in caring for relatives with terminal conditions by providing both physical and emotional support (see Chapter 8, Hospice Care). 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 the above 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 are 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 its ability to accommodate the different needs and wants of its many consumers.

Having defined and described the current system herein, Chapter 2 (Toward an Ideal System) will identify an ideal long-term care system and the elements required to make it work.
REFERENCES


