

Toward an Ideal System

Learning Objectives

After completing this chapter, readers will be able to:

1. Identify the characteristics of an ideal long-term care system, with particular attention to accessibility, quality, and cost.
2. Describe what it means for the long-term care system to be consumer-driven, including an understanding of consumers' rights and the responsibilities that go along with those rights.
3. Identify the roles of formal and informal caregivers and ways for those resources to be coordinated.
4. Define the components of a full and uniform assessment of a consumer's service needs.
5. Discuss the need for incentives for providers and consumers to improve the quality and effectiveness of care and to use the long-term care system wisely.

■ Introduction

Having seen in Chapter 1 what the current long-term care system looks like, let us now look at how an ideal system might appear. A truly ideal long-term care system does not, and probably never will, exist. The needs of the consumers are too great and change too regularly for that to occur. In addition, other forces acting on the long-term care system are so dynamic it is unlikely that any system can react to them in an optimum way. Forces such as managed care, limits on funding availability, piecemeal regulations, and competition from within and without the system will keep the system off balance for years to come. In addition, we can safely say that the future will bring new pressures on the system that we cannot even imagine today.

However, there are certain characteristics that would be present in an ideal system—elements that would be essential for the system to be successful. In this chapter, we examine those characteristics.

The basis for our discussion is a document entitled *Criteria for Designing or Evaluating a Long-Term Care System* (Saint Joseph's College of Maine, 1993; termed simply *Criteria* hereafter). The *Criteria*, shown in their entirety in Appendix A, were developed by the Continuing Care Council and the Long-Term Care Management Institute of Saint Joseph's College for use in designing a new long-term care system or for evaluating any current or proposed long-term care system. The *Criteria* were created during the early days of the healthcare reform debates in the 1990s. During those debates, which actually focused on healthcare financing more than on healthcare delivery, long-term care was barely discussed. When it was, it was pretty much an afterthought. When questioned at the time about their failure to consider long-term care in the administration's reform plans, one official stated that it would simply be too expensive to include it.

Given that mindset at the national level, many groups around the country got involved in attempting to positively influence the future of health care in general and long-term care in particular. The *Criteria* came about as the result of one such effort, a symposium, held in Rockport, Maine, in September 1991. The symposium, "Vision 2000: Defining New Models for Long-Term Care," was co-sponsored by the Maine Health Care Association, the Home Care Alliance of Maine, the Maine Chapter of the National Council of Senior Citizens, and the Area Agencies on Aging. Over a period of three days, your author, serving as "symposiarch," engaged more than 200 participants in an effort to define an ideal long-term care system. Those participants came from more than 20 organizations representing long-term care consumers, providers, regulators, and payers.

The tone of the symposium was set by Bruce Jennings, then assistant director of the prestigious Hastings Center, who defined a "moral vision for long-term care," and Dr. Warren Davidson, a geriatrician from Monckton, New Brunswick (Canada), who described his experiences with long-term care consumers. The symposium participants then proceeded to work together to identify the essential elements of an ideal long-term care system. It was a valuable exercise of constructive interaction among representatives of the various segments of the system, in which they gained an understanding of each other's seemingly irreconcilable points of view and developed a remarkable degree of consensus on the issues.

From the notes taken during that symposium, the *Criteria* evolved, primarily through the efforts of the Long-Term Care Management Institute. They were reviewed, critiqued, and refined by the Continuing Care Council, a long-term care advisory organization made up of representatives from all segments of the long-term care system, an organization that also developed as a result of the 1991 symposium.

Let us use the *Criteria* as a foundation for construction of a long-term care system as it should be. While each criterion is important in its own right, it is only when taken as a whole that they represent an optimum system. It is recognized that there is some duplication and overlapping of criteria, but that serves to emphasize the importance of certain aspects of long-term care. The criteria are stated as general precepts against which a long-term care system should be measured. Each of them is accompanied by

several statements identifying the benchmarks a system must accomplish to meet that particular criterion. In our discussion, we examine why those benchmarks are important and how they might be achieved.

■ **Criterion I. The long-term care system should be based on recognition of the needs, rights, and responsibilities of individuals.**

The system should be for and about those who use long-term care. Its consumers are individuals, and they deserve to be treated as such, with dignity and respect. Long-term care involves the most intimate aspects of their lives, and the system's ultimate goal should be no less than to enable them to function at their highest achievable level. It should do everything possible to assist them to live as valuable members of society. They do have value. The system's job is to recognize and maximize that value.

A. The long-term care system should be consumer-driven.

Availability and utilization of long-term care services should be based on the needs of the consumers of those services, rather than on the needs of providers, reimbursement agencies, or politicians. The current long-term care system is largely reimbursement-driven, with the availability or lack of availability of services being dependent on the availability of funding for those services. The system should do more to make those services available when and where they are needed by consumers without concern for financing or eligibility.

To achieve that end, the system will have to overcome many logistical difficulties. It will have to find ways to provide the right mix of services for all consumers, recognizing them as individuals, even though their needs vary greatly. There are many factors causing those differences. First, there is their uneven distribution throughout rural, urban, and suburban areas, with all of the variations of need caused by that distribution. The need for services will also vary according to other demographic factors, including age, education level, and availability of family or other informal caregivers.

Even if providers try to provide a broad enough range of services to meet the needs of all, and even if adequate funding exists, those providers can be expected to encounter other problems, including regulatory prohibitions and finding the right types and number of properly trained staff.

Not only should consumers be the primary focus of services, they should also play a major role in determining which services to access, and when. While the terms "client-centered," "consumer-oriented," and "consumer-focused" are used frequently, the preferred term here is "consumer-driven." It was chosen carefully, and only after considerable debate, because it more accurately defines the consumers' role in an ideal long-term care system. They should be positioned to take charge of their own care as

much as possible, and the system and all of the players in it have an obligation to do all possible to assist them.

That is not to say that consumers must always get all of the services they might want. One of the problems with the current system is the attitude by many that they are entitled to services because “somebody else is paying for them.” That attitude must change for the system to have any chance of success, but it will not be easily done. Here we get into the difficult area of balancing consumer wishes with actual needs. Should the long-term care system guarantee that consumers may use any services they wish, whenever they wish, or should there be some requirement to justify actual need? How are their real needs measured, and by whom?

These are not questions easily answered, but there is hope that a satisfactory balance between wants and needs can be achieved by careful definition of eligibility criteria. Those criteria should be developed with input from both consumers and providers. One solution may be that overall parameters will be set, within which the consumers are allowed to choose the services they receive. Or the system might be built on the basis of a “cafeteria plan” with built-in incentives for consumers to use it appropriately. Such incentives could include co-pay provisions or other financial motivators. Consumers have shown that they can and will use the system wisely if given incentives to do so.

B. The long-term care system should meet all consumer needs.

An ideal system should address the full range of consumer needs, rather than meeting only some of them. It must be a comprehensive, “full-service” system, providing all needed long-term care services, including both in-home care and a full range of institution-based services. Unavailability in that system of any single service can have major consequences both for the consumer and for the rest of the system. For the consumer, it can mean a less desirable outcome or a lengthened care process. For the system, it could mean having to compensate for the unavailable service by providing care in an inefficient, costly, perhaps ineffective manner.

In addition to meeting those consumer needs inherent in long-term health care, if the system is to be comprehensive, it must also arrange for or have connections to other social needs such as housing and transportation. Otherwise, the continuum will be neither complete nor effective. Long-term care consumers should not have to be concerned with which system they are in or with having to know how to move from one system to another.

C. The long-term care system should focus on the individual, recognizing that individuals have unique needs.

Consumers of long-term care services vary greatly, and their needs vary accordingly. To begin with, their particular functional disabilities have the most direct impact on determining what services are necessary. Their ability or inability to perform any of

the activities of daily living (feeding, bathing, transferring, toileting, and dressing) defines their level of independence, which in turn creates the need for services. For example, someone who needs assistance in bathing and dressing can probably get by with one or two visits each day by a home care provider, while another person who needs assistance with feeding and toileting would probably be better served in a long-term care facility where assistance is available at all times.

Long-term care needs relate to the functional disability a person has, not to the underlying illness or condition causing the disability. However, the nature of that illness or condition also has a bearing on the extent of services needed. This is particularly true if cognitive ability is affected in any way. If he or she is unable to make care-related decisions on his or her own, it adds an entirely new dimension to determining what is best for him or her. People suffering from brain damage, Alzheimer's disease, or simply old age require different types and intensities of service than those with cardiac problems or those with degenerative bone disease. The long-term care system should be flexible enough to recognize those needs and to adapt the services provided accordingly.

However, the system needs to go beyond matching services to the functional limitations impacting those using it. Personal characteristics such as age, gender, and ethnic background also play an important role in defining consumers as individuals. Those limitations may also be related to, or caused by, other factors (psychological, social, and financial) that must be considered.

The long-term care system should recognize all of these differences and have the capacity to match services to them. It will not be easy, but it is essential.

D. The long-term care system should respect different cultures and cultural values.

The United States is a mix of many cultures and ethnic groups, each of which has its own set of values and practices resulting from those values—practices that are central to their lifestyles. The long-term care system should be capable of recognizing those differences and at least attempting to accommodate them. For example, people from Asian cultures appear to place more importance on caring for elderly family members at home than do members of some Western societies. A flexible long-term care system would take that into account in deciding which services to make available.

One of the more visible differences among cultures is the type of food preferred. Being able to eat the foods we like plays an important part in how we define the quality of our lives. Yet, until recently, most nursing facilities paid little attention to satisfying the seemingly exotic culinary wishes of their residents, ignoring their importance. More and more of them are now finding ways to meet those wishes. An ideal system would go much farther in doing so.

The long-term care system should recognize and adapt to these and other, equally important, cultural differences, taking into account matters such as religious observances and personal choice of dress. These are important elements of what defines people as

individuals and as members of particular cultures. What they do may not be as different as how they choose to do it. How they go about their daily activities is usually a result of a lifetime of cultural and environmental influences. The long-term care system owes them the respect shown by accommodating them as much as possible.

In addition to cultural traits, each consumer has personal habits and lifestyle peculiarities that also have developed over many years. An ideal system would go to great lengths to address each individual's personal and cultural preferences in an attempt to raise the quality of life for that person. While attempting to do that raises the issue of conflict between individual desires and the wishes of the larger community, it is an issue that must be faced (see Chapter 12).

E. The long-term care system should promote quality, dignity, and self-improvement for consumers.

A primary goal of long-term care is assisting people with disabilities (including those functional disabilities brought on by advancing age) to live a more satisfying and productive life; thus, the system should be built on a foundation of respect for those individuals. There should be an underlying philosophy that all of us, not only those of sound body, are valuable members of society.

The system should demonstrate that it values older adults and those with chronic disabling conditions. It can do that in many ways. To begin with, respect for consumers can be shown in the way providers interact with individual consumers. They should deal with the person, not with the disability. The system can also do so in a more global manner. It can promote a positive approach to living with chronic illness and dependency. There should be no stigma attached to being old or disabled, yet today there is. All of the participants in the long-term care system can help to remove that stigma by showing that consumers are valued for who they are, not for the disability they have or for what they cannot do. This is an area wherein the long-term care system can, and should, lead.

The long-term care system, and society in general, should allow long-term care recipients to continue to contribute to life and to the community. Each of them has something to offer, be it nothing more than their years of experience. The system should place emphasis on allowing people to make whatever contribution they can. We all have a need to be needed, perhaps our greatest need. Our self-worth is diminished if we feel that we are not contributing something useful to those around us. One of the ways in which the system can, and does, allow its consumers to contribute is by promoting their highest achievable level of functioning and by showing society in general, and people as individuals, that they do have value. However, even that is not always enough. Once that has been accomplished, the system needs to be creative in matching each person's skills and functional abilities to productive tasks and finding ways for them to contribute, sometimes in ways that they would not have imagined.

We are not saying here that the current system is doing nothing in this area. To the contrary, it has done much. Long-term care providers already do much to make it possible for elderly and handicapped people to be useful members of society and should be applauded for what they do. However, such efforts are usually localized, not systemic. The system must do much more to ensure that all consumers benefit.

F. The long-term care system should balance consumer rights and responsibilities.

A truly consumer-driven long-term care system would expand the rights of those relying on the system. They would be much more influential in terms of their roles in it, as they should be. However, those rights should carry with them corresponding responsibilities. Both long-term care consumers and their families should be allowed and encouraged to participate in designing and implementing plans of care, including making care-related decisions. After all, who has more at stake in the outcome than they? That does not mean that they should ignore the advice of long-term care professionals, but that they should be actively involved in the process. As members of the care team, they should accept their share of accountability for the success of the team's efforts. In doing so, they would find incentives to do their utmost to cooperate with—and support—the care plan, thus greatly improving the likelihood of success of that plan.

In addition to their involvement in the actual plan of care, consumers must also take greater responsibility for their own lifestyle choices, choices that affect the success or failure of the care plan. If the long-term care system, or the overall healthcare system, is to meet their needs in an optimum fashion, they should be expected to do whatever they can to support that plan and to improve their level of independence. They should refrain from practices that are harmful or actions that jeopardize their ability to function. That may mean giving up long-held practices such as smoking or eating foods that are not good for them.

At this point, we begin to get into some difficult areas of philosophy and ethics. In asking people to make such lifestyle changes, we are in effect limiting something we strongly advocate: their right to choose. However, that right is not all-inclusive. Long-term care consumers, particularly those living in nursing facilities or other group settings, must accept their responsibility as members of the larger care community. That often means subordinating their personal needs and desires to the interests of the larger group. To a degree, the success of any type of long-term care can be measured by how well those interests are balanced and by the relative satisfaction (happiness) of all involved.

Lastly, consumers in the long-term care system should share some responsibility for financing their care when it is appropriate for them to do so. Whether it involves co-payment, purchase of long-term care insurance, or some other form of financial participation, they should make some contribution if they are able to. That would relieve some of the pressure on the system to pay for the services they receive. Accepting

some degree of financial responsibility, no matter how small, also gives consumers an incentive to use the system wisely and appropriately. There should, of course, be exemptions for those who cannot afford to pay anything. There must be a safety net to ensure that no one is denied services on the basis of finances, but the extent to which those who can contribute do so impacts the success of the overall system.

G. The long-term care system should offer consumers a choice of service providers and service delivery modalities.

As we have noted repeatedly, the consumer's right to choose should be respected and encouraged whenever possible. Without multiple options, however, there is little opportunity for choice. The long-term care system should provide consumers with numerous types of choices. First, they should have choices among kinds and levels of care. They should have a choice between home care or care in a nursing facility, providing those types of care that are appropriate for them. However, in making those choices, they should understand that there may be trade-offs involved. For example, a nursing facility usually means some loss of independence but, in return, provides more security and a higher level of care and assistance. Home-based care, on the other hand, swaps a lower level of service for a higher level of independence. The consumer should be provided with enough information to understand those differences and to make an intelligent decision.

To the degree possible, consumers should also have multiple providers to choose from within each type of care. Ideally, those providers would each deliver the same quality of care, but would offer differences in amenities, style, and/or ambiance, factors important to an individual's lifestyle. Consumers should have the option of choosing between facility A and facility B.

■ Criterion II. The long-term care system should be easily accessible.

Accessibility to services depends on several components, including availability of those services, financial coverage, physical logistics (location, style, etc.), and the degree of complexity of the consumer's needs. The long-term care system should address all of those factors individually and collectively in the interest of providing maximum accessibility with a minimum of hassle for those using it.

A. The long-term care system should be universally accessible.

Ideally, services should be available to all who need them, not limited to certain groups. Availability should be based primarily on functional, not financial or political, criteria. People should be deemed eligible for services on the basis of their need for assistance

in overcoming or living with functional disabilities. For example, a person's ability to accomplish activities of daily living (ADLs) should play a significant part in the eligibility decision.

Many portions of the current system already utilize ADLs as a criterion for eligibility, but they usually also include other criteria, such as financial status, enrollment in group insurance plans, or the nature of the consumer's underlying illness or condition. In the ideal system, those other factors would not be included in determining access to services. In reality, the current system is far from that ideal, but it can move closer to it, perhaps in incremental steps, placing increasing emphasis on functional needs as opposed to other qualifying factors.

Functional criteria should be uniform, both in content and in application. All consumers, and potential consumers, of long-term care services should be treated equally and should be measured against the same standards. The process of applying those criteria must be equitable. It is not easy to maintain that equality and fairness when dealing with so many different consumers.

B. The long-term care system should be user-friendly.

The system should be uncomplicated for the consumer to access and use. However, that is easier said than done. The system should be based on a sound, demonstrated philosophy of customer service. While there has recently been considerable well-intended attention given to customer service in the current system, it is still very difficult for anyone to understand or use. That lack of understanding leads to inefficient and often inappropriate use of the system. Even those who are involved in one aspect or another of long-term care, the "experts" in the field, experience that difficulty when confronted with using the system for themselves or for family members. It often comes as somewhat of a shock for them to realize what it is like to be on the other side, to experience the fragmentation, duplication, confusion, and impersonality of the system. If they find it so puzzling and overwhelming, imagine how intimidating it is for a consumer who has had little or no contact with long-term care, particularly an elderly person. In an ideal long-term care system, or one even approaching the ideal, that would not be the case. Entry into the system, and advancement from one segment of the system to another, would be easy and user-friendly.

Paperwork required by the long-term care system should be minimal and should be understandable to the vast majority of consumers. It should avoid jargon, acronyms, and technical terms. Nevertheless, the system should recognize that many consumers will still need assistance, no matter how simplified it becomes. Assistance in completing necessary paperwork should be readily available.

Financing and approval processes should be simplified as much as possible. The long-term care system should be coordinated to the point where consumers do not have to submit to repeated documentation of their eligibility. Once accepted into the

system, they should not need reapproval until some significant aspect of their situation changes. The numerous, repetitive approval processes inherent in the current system are annoying and time-consuming. They are also very unsettling for people who worry about whether they will still maintain critical eligibility. It is important to them to know that their status in the system is secure.

In a system that is truly user-friendly, there should be no excessive delays in service. Again, this is not just a matter of customer convenience, although that is a very important consideration. Delays in meeting the needs of long-term care consumers may actually reduce their functional independence and may eventually increase the amount of care required.

C. The long-term care system should provide care in the least restrictive environment.

The system should facilitate the provision of care in the setting and service modality that will provide the best combination of appropriate care, quality of life, and cost-effectiveness for each individual. The caregiving environment should provide each consumer with an optimum level of freedom and independence. In doing that, it will be important for all of the participants in the long-term care system—including providers, payers, regulators, and consumer advocates—to understand that the least restrictive environment will be different for each person. While a person's home is most commonly the "least restrictive environment," it is not always the case. The amount of assistance needed by an individual may actually be more easily accomplished in a more formal, institutional setting that then results in more real independence. The location wherein long-term care is provided is an important determinant in making the system accessible.

D. The long-term care system should encourage single-site care availability.

The system should be designed to provide, to the degree possible, all necessary services to consumers without requiring them to deal with multiple sites and/or providers. Availability of several needed services in one setting makes it much more convenient for the consumer, an element central to accessibility. Current "aging in place" programs and the growing number of organizations providing multiple types and levels of care in single locations are recognition of the value consumers place on having those services easily available. Single-site availability is often more than a matter of simple convenience. Such programs also allow spouses to remain together, or at least nearby, even when their individual care needs vary. They make it possible for people to receive care in familiar surroundings, with familiar caregiving staff, should their conditions change. Because those changes are frequently of relatively short duration, not having to move from setting to setting avoids a great deal of disruption in their lives.

In the ideal long-term care system, payment mechanisms and associated regulations would be designed to encourage and facilitate more provision of single-site availability of services, not discourage it as is often the case today. Currently, facilities attempting to offer multiple levels and modalities of care must comply with different, sometimes conflicting, regulations. They also find that some of the services they offer are reimbursable by third-party sources and others are not. To be easily accessible, the system must move to reduce or eliminate that fragmentation.

■ **Criterion III. The long-term care system should coordinate professional, consumer, family, and other informal caregiver resources.**

There are many resources potentially available to long-term care consumers, including professional (provider) resources and informal resources provided by family members, other volunteer caregivers, and sometimes the consumers themselves. Currently, these resources are not well coordinated, if coordinated at all. Chronic conditions are different from acute conditions and require a different kind of care. There needs to be more of an integrated network of professional expertise combined with a far greater reliance on informal (nonprofessional) caregivers.

A. The long-term care system should integrate professional, community, family, and other informal caregiver efforts.

The various sources of available support must be integrated if consumers are to take fullest advantage of the system. Without such integration, they will encounter frequent, disruptive gaps in availability of services. Equally troublesome is costly duplication of effort. A well-designed long-term care system would avoid those two extremes. It would meld those professional and nonprofessional resources into a partnership wherein each segment assists the other, ultimately benefiting the consumers they serve.

B. The long-term care system should evolve from the current medical model to a holistic model of service delivery.

The overall healthcare system in this country is based primarily on acute and episodic care. It should encourage more involvement of nonmedical personnel in care giving and in problem solving. The field of long-term care is much broader than just its clinical components. The system needs to strengthen its focus on *care* as opposed to *cure*. There are many nonclinical professionals who currently provide valuable services, but they still operate largely under a medical model. The system should focus its efforts more on the whole individual and less on specific clinical or functional characteristics. Many nontraditional care delivery methods, such as wellness programs, have found

a place in the long-term care system. The system needs to do much more to encourage them and to stimulate new, innovative programs.

C. The long-term care system should involve families in case management and care delivery.

The system should make better use of informal caregivers as an integral part of formal care plans. Family members already play a valuable role in many cases, particularly in home-based care but also in institutional settings. As one early long-term care text put it, “The family invented long-term care of the elderly well before that phrase was articulated, making the shift from episodic short-term care sooner and more flexibly, more willingly, and more effectively than have professionals and the bureaucracy” (Eisdorfer, 1989). Their efforts should be better coordinated with the efforts of professional caregivers to allow them to perform at their best. In fact, they would usually benefit from being given an opportunity to work under the supervision of those professionals.

The system should also facilitate informal caregiving by providing more assistance, even financial resources, to family caregivers. Studies have shown that 70 percent of non-institutionalized elderly receiving long-term care rely solely on informal caregivers (AHRQ, 2002). Yet, there usually comes a time when those informal caregivers can no longer provide all of the care needed. In many cases, only a relatively small amount of assistance would be required for them to continue providing the care at home.

The past several decades have seen considerable change in the structure of the typical American family. The need for both husband and wife to work, growing distances separating family members as they move for employment-related reasons, and an increasing incidence of single heads of household have all contributed to making it more difficult for families to care for their own.

As the large population of baby boomers and subsequent generations continue to age, these societal trends will continue and expand. They will make it less easy to find informal caregivers. The ultimate impact on the system will be a need for more readily accessible formal services.

Until relatively recently, there was not a lot of empirical research into the degree to which family caregivers prevent institutionalization, but the Agency for Health Care Research and Quality (AHRQ), an agency of the U.S. Department of Health and Human Services, is conducting studies in that area. AHRQ’s charge includes improving quality, enhancing access to appropriate services, and ensuring that the services provide value for the money spent (AHRQ, 2007). That type of research is sorely needed to support the anecdotal evidence so observable among caregivers. The pressure on informal caregivers, be they family, friends, or others, is of considerable consequence. They are subject to physical, emotional, and financial strain. One study showed that some 44 percent of caregivers report that their caregiving activities cause physical strain, and 15 percent report that they have experienced a physical or mental health problem due to their caregiving activities (National Academy on an Aging

Society, 2000). They must balance their caregiving duties with their jobs and/or their responsibilities to other family members. Programs providing assistance to them would be beneficial almost beyond imagination.

There are many excellent programs already in existence, but they are not uniformly available. One such type of assistance is adult day care. Fully explained in Chapter 7, adult day care provides daytime relief for caregivers and a supervised, stimulating setting for the person receiving the care. It regularly allows family members to remain employed without necessitating placement of the long-term care consumer in an institutional setting. Other similar programs, such as hospice and respite care, also provide assistance to the informal caregivers in the form of actual services. Hospice care helps those with terminal illnesses by assisting with caregiving chores and lending moral and spiritual support. Respite care is designed to relieve the primary caregivers from their duties for short periods of time, while maintaining the level of care given.

There is very little, if any, availability of direct financial assistance for informal caregivers. Yet, it would often be much less expensive to provide a small amount of reimbursement to them than to utilize the more formal types of services. There are several barriers to doing that. One is the question of quality assurance. There are many existing processes for checking the competency of professionals, but it is much more difficult to do so with informal caregivers. Government agencies and insurance companies are reluctant to provide financing for care unless they have assurances of its quality. They are concerned not only about the welfare of the recipients of that care, but also about possible liability should someone be injured.

There is also the usually unspoken, but very real, issue of competition with the formal system. Organizations representing healthcare professionals tend to resist attempts to allow what they see as potential replacement by untrained civilians.

■ **Criterion IV. The long-term care system should be an integral part of the health and social system to promote integration, efficiency, and cost-effectiveness.**

Long-term care cannot exist in a vacuum, nor can it meet all of the needs of its consumers. It is only one segment of the overall societal system, one of several subsystems. Like the other subsystems—acute health care and various social services—long-term care meets some of the needs of those who depend on it but must rely on its complementary counterparts to meet the rest. In an ideal system, those disparate elements would be integrated, interactive parts that make up the whole.

There has been much movement toward integration within the healthcare system in recent years (see Chapter 8 for a more detailed discussion), but much more is needed. Ties, both formal and informal, between acute care and long-term care organizations should be increased and enhanced. Doing so will expand the capabilities and expertise of each of them.

A. The long-term care system should include a full continuum of services.

Consumers in that larger system should experience no break in services from one subsystem to another. They should not have to worry about differences in accessibility, financing, or quality. The system should be virtually “seamless,” a term that has become popular in describing a system without gaps.

While the system needs to be comprehensive in the breadth of services it provides, it also needs depth in terms of its ability to provide similar services to vastly differing groups of consumers. The services provided in the system should be designed such that they will meet the needs of all with chronic illness, not just the elderly. Because the elderly are such a large part of the population using long-term care services, we tend to think only in terms of them. However, there are many others who need long-term care and whose needs may be somewhat different. Younger long-term care consumers (such as handicapped children, young adults handicapped by traumatic injury or AIDS, and those suffering from mental disease or mental retardation) each have their own specific needs.

Meeting those needs adequately often means special care units, additional training of long-term care personnel, and, most importantly, an understanding of long-term care consumers of all types and their varying requirements. Units or facilities designed to specialize in caring for a particular segment of the long-term care consumer population have become more popular, but they still face several barriers inherent in the current system.

Providing a full continuum of services also requires changes in the way professional personnel are trained and distributed. Physicians, for example, have traditionally been drawn to the more visibly attractive types of care, primarily acute care. The number of fully trained geriatricians is still small relative to other specialists, but that is changing slowly as medical schools have begun to put more emphasis on primary care (including chronic care), spurred in part by federal funding incentives. The system has to do much more to provide an adequate number of physicians and other clinical specialists if it is to meet the growing numbers of persons needing long-term care in the near future.

Nurses have also tended toward acute care in the past, in most cases a reflection of the nature of their training as well as the excitement involved in faster-paced care settings, not to mention the higher salaries. There has been some positive change in that area also. New types of long-term care, such as assisted living and subacute care, with their more visible success, seem to be attracting more nurses away from the acute sector. Also, the organizational turbulence described in Chapter 1 has hit the acute care sector particularly hard and somewhat earlier than long-term care, resulting in layoffs and downsizing, which has left many nurses looking for other career opportunities, most for the first time. They have found long-term care to be different and more attractive than they had previously thought it to be.

Physicians and nurses are not the only professionals that the long-term care system has had trouble recruiting. It has experienced similar difficulties with other employee

groups. Long-term care relies much more heavily than acute care on certified nurse assistants, and others with less formal training. Because of their lack of specialization, they have more employment opportunities outside of the long-term care system, often at a higher rate of pay. The work they do is not glamorous; it is often unpleasant and physically demanding. While most long-term care employees find extrinsic rewards in caring for the functionally disabled (fortunately), their tangible rewards are not all that great.

Improvements to date in the training and recruitment of staff are only the beginning of what will be required in the long-term care system of the future. Creative approaches to using existing and potential future categories of personnel more efficiently and effectively are needed.

How well the long-term care system is able to find innovative ways to utilize personnel and care settings depends in large part on the extent to which it is able to identify and differentiate among the several types of consumers. It must be built on an acceptance of their differences and an understanding that creative care methods are needed.

B. The long-term care system should include a full and uniform assessment (initial and ongoing) of the consumer's needs.

All involved with the long-term care system need to have a better awareness of the extent to which people needing care differ and of the alternative system components that are required to service them. The first step in meeting all of their needs is identifying and quantifying those needs. We have made progress, but the long-term care system cannot function optimally unless we continue to improve on that understanding.

Improved understanding requires an assessment that is comprehensive and detailed. It requires an assessment that addresses all of the individual's needs, including medical, social, and financial. There should be one review process that takes these factors into account, rather than several different, uncoordinated processes. It must focus on the whole person, rather than the parts that make up that whole. To accomplish such a comprehensive appraisal, the several parts of the system have to work together more closely and have to share information about those they serve. They have to break down barriers to coordination, barriers that may be caused by any number of factors, including professional parochialism, financial competition, and technological naiveté. Any system that intends (or wishes) to be integrated must make both clinical and financial information about all clients available at all service sites almost instantaneously.

We noted earlier in this discussion that services should be available on the basis of the functional needs of each person, not on the needs of, or for the benefit of, those who pay for care. That is not to say, however, that there can be no financial involvement in assessing the need for care. Those who can contribute financially to meeting their needs should do so. The costs of providing long-term care are great; the system should take advantage of any and all opportunities to reduce the impact of those costs, including participation by those consumers who are able to do so. What the system

must avoid is using the financial portion of the initial assessment to determine if care is to be provided, rather than how it will be reimbursed.

If the long-term care system is to provide good care—to say nothing of promoting integration, efficiency, and cost-effectiveness—it must be built on an understanding of chronicity. The assessment that determines which services a person gets must reflect that understanding. Historically, there has been so much focus on the acute care system, and those it serves, that there has been little attention paid to the specific needs of the chronically ill and the differences between the two groups. Yet, chronic illness is the principal cause of changes in health status and quality of life (Kodner, 1993). There has been a great deal of conspicuous progress made in curing illnesses, but somewhat less in caring for those with chronic maladies. That shortcoming has not been intentional, nor was it based on any conscious discrimination against long-term care or those who need it. It has been simply a case of the most demonstrably devastating (i.e., life-threatening, painful, or disfiguring) diseases and conditions receiving the most attention, getting the lion's share of available resources, and benefiting from the most sensational clinical advances.

Clinical innovations such as organ transplants, reversal of birth defects, and life-extending surgical procedures are fully deserving of the attention they have received, but so are new long-term care delivery methods. They may not be as interesting to the public, but are every bit as important to the consumers involved.

C. The long-term care system should provide emphasis on, and reimbursement for, illness prevention efforts as an integral part of the overall system.

While preventive services are not usually seen as part of the long-term care system, their impact on the system must be considered, because that impact can be significant and long-lasting. For example, strokes and heart attacks are among the largest reasons people become functionally disabled and require long-term care. Yet, experience has shown that the number of strokes and heart attacks can be reduced greatly with early prevention efforts, including smoking prevention or cessation, proper diet, and exercise. Similarly, other debilitating diseases such as osteoporosis can be avoided, or at least delayed with early treatment. AIDS, which could potentially become one of the leading causes of long-term care disability, can be prevented.

While these and many other disabling diseases can be avoided with adequate prevention efforts, others are not yet avoidable. We have not found ways to prevent diseases such as multiple sclerosis, muscular dystrophy, and Parkinson's disease, but research continues toward that end. Prevention or cure of any of those diseases would significantly reduce the need for long-term care. Look at the impact of the Salk and Sabine polio vaccines or the virtual elimination of tuberculosis by modern antibiotics. With the sophistication of current medical research, similar discoveries are very possible.

However, remember that it is not the disease that leads to long-term care. It is the disability resulting from that disease. Even without the ability to prevent the disease, early and effective treatment can delay that disability in many cases. That treatment is a form of prevention.

Illness prevention efforts and the degree to which they are successful will play a role in shaping the future of the long-term care system. Their impact on the system may not be felt to any significant extent in the near future, but current emphasis on prevention will pay off in the long run and must be an integral part of the overall system. What one author has termed “preventive gerontology” should become an integral and accepted part of the long-term care system (Kodner, 1993). There has been one small step in that direction. The 1997 federal balanced budget act expanded Medicare coverage of cancer screening, bone-density tests, and services for diabetes patients. The changes provided Medicare beneficiaries with preventive testing that has been effective with other populations.

D. The long-term care system should be planned and coordinated to reduce fragmentation and inefficiencies.

As we have noted here repeatedly, long-term care must be integrated with the other subsystems into an overall system if it is to be effective and efficient. However, there is another dimension to such integration. It should also integrate systemwide coordination with local and regional autonomy.

In Chapter 1 we referenced Dr. Connie Evashwick’s description of a continuum of care (Evashwick, 2005). Her definition applies to both an overall system and a variety of local or regional systems. A major challenge facing policy makers now and in the future is finding ways to integrate many independent continuums into a coordinated whole without impinging unnecessarily on their individual independence and autonomy.

The difficulty of finding that balance is reflective of the healthcare reform debates of the early 1990s. One reason for the failure of those debates to produce a national healthcare system (in reality, they were looking at a national healthcare financing system), was the participants’ inability to agree on the respective roles of the federal and state governments. Melding local or regional continuums of care into an overall long-term care system will be every bit as difficult. Yet, it must be done if that overall system is to be at all successful.

E. The long-term care system should be based on outcome-oriented accountability.

If the system is to achieve any significant level of integration and coordination, it must include ways to hold each of its elements accountable. Providers of long-term care services should have a high degree of accountability both to those using their services

and to those paying for the services. To attain that accountability, the system should focus on outcomes, not on process as is largely the case with the current system.

To begin with, the system should be designed to gauge results, particularly as they affect quality of life, instead of looking at how those results are obtained. There are three basic ways of measuring quality: structure, process, and outcome (Donabedian, 1988). To date, long-term care quality has been measured largely according to process and structure. Process-based measurement focuses on how the services are provided and whether they follow accepted procedures. A somewhat simplified example of a process measure is the OBRA (Omnibus Budget Reconciliation Act) requirement governing the frequency of meals and bedtime snacks in nursing facilities. While its intent is presumably to ensure that residents of those facilities receive adequate nutrition, the regulation, like so many others, holds the provider accountable for what it does and how it does it, not for achieving the desired result.

Structure-based measurement also looks at how things are done but addresses the organizational configuration of providers as a means of evaluating their ability to perform. Again using OBRA as an example, providers must maintain prescribed staffing levels. It is assumed that those staffing requirements, when met, will ensure a base level of care quality.

Outcome measures evaluate quality based on the success of the end result. In a system in which outcome measures are the rule, providers would be held accountable for producing the desired effect for the consumer, not for how they went about doing it.

As we might imagine, process and structure measures require a great deal of documentation and paperwork, both of which are frustrating for providers. In any system, even one that bases accountability on outcomes, there must be documentation, but there should be an attempt at elimination of unnecessary paperwork. Time spent by providers doing paperwork is time not spent providing care.

However, providers are not the only ones burdened by paperwork in the current system. Consumers, their families, and their advocates must also wade through mounds of paper, first to determine eligibility, then to secure and maintain reimbursement. For them, the forms they must complete are not only onerous, but very confusing. An ideal system would find ways to simplify the process for them.

A long-term care system that was truly outcome-oriented would contain incentives to improve the quality of care delivered rather than inspecting for lack of quality. The emphasis should be on rewarding providers for giving care that is above average. Currently, providers are reviewed by state surveyors to determine if they meet a minimum level of quality and are cited if they fall below that minimum in any area. That aspect of the system must be maintained to the extent that providers must not be allowed to give substandard care, but the emphasis should be on exceeding the minimum whenever possible.

Most long-term care providers will tell you that they could do a better job than they are doing at present but that there are disincentives in the system that make it very difficult for them to do so. Many of those disincentives are built into the current

method of reimbursement. It pays on the basis of process and structure. There is little, if any, financial reward for exceeding the minimum levels of quality on which reimbursement is based, or for producing better outcomes.

The long-term care system should be flexible enough to promote innovation and positive change. Not only is innovation not encouraged in the current system, it is actually discouraged. There is so much emphasis on strict adherence to process and structure, it is very difficult to innovate. The system should seek new and better ways of meeting the needs of long-term care consumers, and reward providers who advance those new methods. Successful business organizations recognize the need to set aside funds for research and development into better operating methods. The long-term care system can afford to do no less.

In addition to being outcome-based, the standards against which quality is measured should be consistent, both in their development and application. Presently, standards of care vary considerably, depending on several factors. They differ according to the source of payment for services. Public and private reimbursement sources often have different requirements, as do individual payers even within those categories.

Managed care programs have introduced an entirely new element into the equation by placing more emphasis on cost-effectiveness than do traditional insurance plans. While cost-effectiveness and operational efficiency do not always affect quality of care directly, the degree to which they are required cannot help but have some impact on it. That impact is not always negative, by any means, nor is there any intent here to imply that managed care programs are any less concerned about providing high-quality care. What it does mean is that the standards against which providers are measured may be made up of a different balance of those elements.

Within Medicaid—the primary funding source for many long-term care providers, particularly nursing facilities—standards vary from state to state. The Omnibus Budget Reconciliation Act of 1987 (OBRA) went a long way toward reducing that variation by setting much more rigid national standards to which state Medicaid programs and the providers they oversee must adhere. However, there is still considerable leeway for individual states to impose standards that are different. That inconsistency is particularly problematic for the increasing number of long-term care organizations doing business in multiple state jurisdictions.

Reimbursement is not the only source of inconsistency in the development and application of standards of care. Those standards also vary based on regulations, which may or may not be linked to reimbursement. Standards often differ from one type of provider to another. While the method and location of care delivery are different depending on whether the provider is a nursing facility, an assisted living provider, or a home healthcare agency, the quality of care given should be the same. Thus, the standards against which that quality is measured should be the same. Again, that is not easy to accomplish using process or structure standards. Outcome-based standards would lend themselves much more readily to consistent application.

■ **Criterion V. The long-term care system should be adequately and fairly financed.**

Even a long-term care system that is consumer-driven, not reimbursement-driven, is heavily influenced by the amount of financing available and by the method by which that financing is applied. The emphasis should be on ensuring that it is adequate and applied fairly. In such a system, providers will not always have all of the reimbursement they desire, nor will payers always be able to reduce that reimbursement as much as they may wish. Adequate financing means enough to provide the desired level of quality, while fairness requires a balance between cost-effectiveness and meeting the wishes of consumers. Quality of care must always be the common denominator.

A. The long-term care system should utilize public and consumer resources to ensure universal access to services.

All available resources, public and private, should be considered in providing services for current and future consumers. A feature of the current long-term care system that promises to become even more prominent in any future system is that demand for services will always place a great strain on available financing. For that reason, the system must do a better job utilizing all potential funding resources, including both public and private.

Public funding of long-term care—usually Medicare and Medicaid—will be especially hard hit unless alternative methods are found. That means that new, innovative means of factoring in private financing must be found. It means greater emphasis on public/private partnerships, a concept beginning to receive attention. There have already been a number of attempts to develop such partnerships. During the early part of the last decade, the Robert Wood Johnson Foundation funded a number of demonstration projects. They were designed to provide incentives to increase private participation in long-term care financing, with an ultimate objective of reducing the demand on public funding, freeing it for use as a financial safety net for those who need it.

Much of the focus of those and other public/private partnership efforts is on getting consumers to purchase private long-term care insurance. To date, while such insurance is generally available, with many coverage and payment options, there has not been a rush by consumers to purchase it. There are several reasons for that. First, if long-term care insurance is to be cost-effective, with premiums set at an affordable level, it should be purchased while the consumers are relatively young. As with most insurances, the premium rates escalate greatly if people wait until they are likely to need it before making their initial purchase. For example, at age 75, the premium is estimated at two and a half times greater than if purchased at age 65 and six times higher than if bought at age 55 (Alexander, 2007).

Today's young adult and middle-aged populations are beset by many other financial demands that they see as more pressing than securing protection against something

that might happen in the distant future or might not happen at all. Various studies have shown that they are not preparing adequately for old age or retirement. Faced with more immediate concerns such as getting by on a daily basis, putting the kids through college, and taking care of their own parents, they tend to not show much concern with something as far off as long-term care.

Second, many of them have little awareness of long-term care, what it entails, or what it costs, although as more baby boomers reach middle age, they are beginning to gain that awareness. They have been called the “sandwich generation” because so many of them are caring for both their children and their parents. As they find it necessary to gain entry for their parents into the long-term care system, they encounter their own problems dealing with that system. Many of those problems revolve around financial coverage or the lack of it. An increasingly common response from them is “I want to find a way to prevent the necessity of my children having to go through this when I get old and need long-term care.” One solution for them is to purchase private long-term care insurance.

Lastly, there is the belief by many consumers that public funding sources (“the government”) will take care of them. Their taxes support those sources, so why should they pay again? The long-term care system of the future will need to do much more than the current system to educate consumers about the system, its requirements and shortcomings, and their role in it (see criterion VI).

B. The long-term care system should provide incentives for consumers to use services in an appropriate and cost-effective manner.

The overall cost of the system can be controlled by avoiding excessive and unnecessary use. There will always be the potential for wasteful, inappropriate use of long-term care by consumers, but much can be done to reduce it. The current system’s disincentives for providers were discussed earlier. There are also inherent disincentives for consumers. It is not uncommon for payers to require an acute care stay or a visit to a physician’s office as a prerequisite for some types of long-term care. They do so to ensure that the care is justified. Unfortunately, when those rules are rigidly cast, they result in unnecessary use of the most expensive types of care. As an example, people using home-based care on an extended basis often must see a physician periodically to maintain their eligibility. That office call is often pro forma, serving no other purpose than to meet the rules.

While consumers of long-term care need to be better informed about how to use the system, they are much more aware of its problems than we give them credit for. Just about any discussion with a long-term care consumer produces anecdotes about receiving unneeded care or unused medical supplies because “Medicare paid for them.” In general, they do not wish to abuse the system or use it excessively. It is up to the system to assist them in using services wisely and appropriately.

C. The long-term care system should provide incentives for consumers to self-finance their care.

Long-term care consumers and their families should be encouraged to pay for their own care when possible. The fundamental purpose of public funding should be to provide for those who cannot provide for themselves. There has been discussion of late about requiring some form of means test to qualify for Medicare—either limiting it solely to the medically indigent elderly or requiring some degree of financial participation by them based on their ability to pay. That concept has been advanced as a way of preserving the Medicare system, which is in danger of dissolution as demands on it exceed its funding capability. It is a concept vigorously resisted by the elderly and their advocacy groups, groups that have shown their political muscle in the past. They argue that they have paid into the Medicare trust fund for years and now deserve to benefit from it, regardless of their own financial status. Proponents of the idea counter with the argument that other taxpayers should not be subsidizing the very wealthy.

Medicaid, unlike Medicare, was designed from the first as a welfarelike payment mechanism to help those without other sources of payment for care. Those who need long-term care, be they elderly or not, may qualify for Medicaid, but are required to “spend down” their assets before it takes effect. That perception has created a great deal of concern. It has also caused considerable controversy as consumers and their lawyers seek ways to protect property or savings that they intended to pass on to their children and grandchildren, creating an unplanned entitlement program at the expense of Medicaid. Government, on the other hand, is working hard to prevent them from “getting a free ride.” In 1996, federal legislation made divesting of assets for the purpose of qualifying for Medicaid illegal.

If consumers are to be expected to pay for some or all of their care in lieu of having Medicare or Medicaid do it, they are going to expect something in return. The system will need to provide incentives as well if such drastic changes are ever to be accepted. One type of incentive that is a cornerstone of the public/private partnerships described earlier would allow people to shelter and pass on more of their assets in return for providing portions of their own long-term care coverage through purchase of insurance. Although there are many ways to do that, the goal is to reduce the amount of public funding required by encouraging consumers to provide private coverage. Any plan that does that successfully will have a significant, positive impact on both Medicare and Medicaid.

Another type of incentive that seems to receive favorable review is the tax break. Whether it rewards them for paying for their long-term care directly or for purchasing insurance, a tax deduction or credit provides a tangible incentive for those who support the public system with their taxes. Again, there has been some progress along those lines, but only a beginning. The Health Insurance Portability and Affordability Act of 1996 (HIPAA) allowed taxpayers, for the first time, to treat long-term care insurance premiums as deductions similar to other health insurance premiums. An increasing

number of states are offering various tax incentives, including deductions, credits, or both, for the purchase of private long-term care insurance.

Even the financial support for family caregivers mentioned when we discussed criterion III would be a form of incentive. They would, in effect, be making in-kind contributions through their time and effort. The cost of the care they provide, even with some added subsidy, is still much less than the cost of similar care provided in a formal setting.

If the long-term care system is to survive financially, it must find other, creative ways to reduce the burden on the public financing portion of that system. The innovative efforts that have been tried to date are heartening, but they must be expanded greatly.

D. The long-term care system should avoid causing impoverishment of consumers and families.

While consumers and their families should be encouraged to contribute to the cost of their care, that contribution should be limited to prevent undue hardship. There is little to be gained in the long run by depleting all of the assets of long-term care consumers and their families. It only speeds up the process by which they come to rely more heavily on public funding sources. Yet, failure of the system to provide adequate financing, and overly zealous attempts to hold families accountable, often combine to cause exactly that type of hardship. A system that is fairly financed would do all possible to avoid causing harm in the name of doing good.

Many long-term care consumers and their families today find themselves caught in a dilemma. They do not have adequate resources to pay for long-term care out of their own pockets but are not poor enough to be eligible for government programs such as Medicaid. The only way they can qualify for assistance is to become medically indigent.

E. The long-term care system should provide incentives for providers to develop cost-effective measures.

Just as providers of long-term care services could improve the quality of care if given incentives to do that, so could they also improve the cost-effectiveness of the system. Held to one-size-fits-all process and structure standards that determine how they provide care leaves little opportunity for innovation. Nor are there many financial rewards for operating in an efficient, cost-effective manner. The long-term care system should allow more flexibility to innovate, realizing that quality must never be jeopardized by cutting costs. Incentives to function more efficiently could include allowing the providers to actually share in the cost savings but might be nothing more than increased freedom to be creative without being penalized for doing so. Many successful organizations have long known that those people closest to the work—on the front lines, so to speak—are the ones most likely to conceive and implement better ways of working. That fact has been rediscovered with much fanfare in recent years by Dr. W. Edwards Deming and

his total quality management (TQM) process. TQM utilizes front-line workers to improve both product quality and cost-effectiveness. While many providers in the long-term care system have embraced TQM and successors such as continuous quality improvement (CQI), the system as a whole could do much better in providing incentives for providers to be cost-effective.

F. The long-term care system should develop payment mechanisms that allow efficient providers to adequately compensate staff and that allow for appropriate operating surplus and/or return on investment.

One way of getting providers to operate more efficiently is to reimburse them in a manner that encourages them to employ well-qualified, properly trained staff. That does not necessarily require that they be reimbursed more, although one of the major complaints by providers is that they cannot hire adequate staff because of their reimbursement levels. If some providers are efficient enough to provide high-quality care by hiring superior staff, the system should include some flexibility in its payment scheme that would allow them to apply some of their cost savings to paying those staff at adequate rates. In the long run, the system would benefit.

Another incentive for providers would be an allowance for an appropriate operating surplus or return on investment. The operative word here is *appropriate*, meaning neither too much nor too little. The stories we hear of long-term care providers making exorbitant profits are all too common and all too true. However, they do not represent the majority of providers. Yet, the current system, in an effort to avoid those extremes, makes it difficult for others to even make the type of return on investment deemed acceptable in other industries. It has been said that most regulations are designed to deal with the worst 2 percent of those they cover. The other 98 percent are penalized because of them.

The long-term care system is made up of an unusual mix of for-profit and not-for-profit providers. Both sectors should continue to have significant roles in the future, and the rules and regulations that govern the system should be adaptable enough to accommodate both. There was a time when some segments of health care, most notably hospitals, were primarily not-for-profit and were expected to operate at a loss as a community service. That is no longer true, even for hospitals. Providers of care, regardless of the nature of their ownership, must now operate efficiently and above the break-even line if they are to survive. The long-term care system should recognize that it is in its long-term best interests to allow providers to get an appropriate return on investment and to encourage them to reinvest in their organizations.

G. The long-term care system should operate within the limits of a well-conceived budget.

It might appear to be stating the obvious to say that the system needs to have a well-conceived budget. However, the current system does not, nor has it ever. It is fragmented,

with numerous discrete parts, and it is sadly lacking in coordination. It should function within the same budgetary constraints as the organizations of which it is composed. Those constraints often result in limiting available funds. Of perhaps as much importance, a well-conceived budget spells out how those funds may be used. It also includes clear benchmarks by which progress can be measured. More than anything else, a sound budget lets all of those governed by it know exactly what they have available in the way of resources and the parameters within which they must stay.

Developing such a budget for the long-term care system is an ideal that may be extremely tough to accomplish. A budget is not something that is easily developed or implemented in pieces or in incremental steps, but rather tends to become viable only when all pieces come together. Thus, we are not likely to see any major progress on this goal in the near future.

Integrating the separate payers, public and private, into a unit that would be cohesive enough to function within a single budget is a daunting task. Getting the many discrete, dissimilar providers under such an umbrella promises to be even more so.

H. The long-term care system should provide significant flexibility to enable consumers to meet long-term care needs as each consumer defines those needs.

The financing of the system should reflect the needs of individuals (as identified in criterion I). There is no way the system can be truly consumer-driven if the financing mechanism(s) cannot accommodate different types of care and needs. Long-term care consumers want simplified access to a wide range of services and a predictable payment mechanism (Evashwick, 2005).

Meeting this goal will require an intriguing blend of flexibility and coordination. In the long-term care system, services should determine financing rather than financing determining services. As we have pointed out before, the services received by any individual consumer should be based on that individual's needs. Ideally, financing would not be part of that calculation of service need, but would only come into play afterward.

I. The long-term care should be based on uniform financial eligibility criteria.

When financial criteria are applied, they should be uniform. Remember, financial criteria should be used only to determine the type and amount of payment received by a consumer, not to decide whether services are provided. Those criteria should not eliminate anyone from eligibility for coverage, nor should they make a difference in whether they receive services. They must only be applied in the interests of determining how much the individual will pay. The standards used in that determination should be comprehensive enough to apply to all consumers fairly. They should be fair and equitable in their design and in the way they are practiced.

■ **Criterion VI. The long-term care system should include an education component to create informed consumers, providers, reimbursers, and regulators.**

The gaps between the current long-term care system and an ideal system are great. Bridging those gaps will not be easy. Perhaps the best weapon for doing so is education. Only when all involved understand the nature of long-term care—how it works and how it could work—will there be significant progress.

A. The long-term care system should include community education.

The public must be informed about long-term care, including available service options, limitations, and access methods. One of the most striking characteristics of the current system is the general lack of understanding about what the long-term care system offers, how it is accessed, who is eligible, and what is covered. While those who manage the system—the providers, payers, regulators, and policy makers—have done a pretty poor job of educating the public, they are not the sole cause of the problem.

There are numerous other factors at work here. To begin with, as we explained earlier, the system is so complicated it tends to defy easy understanding. Second, the public has not been particularly interested in becoming better educated concerning long-term care, nor have they really had to be. It, like other forms of health care, has historically been provided for them, with little emphasis on whether they understood it or wanted it. They had little say in the matter, or at least thought so. One of the reasons they have not been interested in learning more about long-term care is that they have been given the impression that it would be provided for them. So, why worry? Neither Medicare nor Medicaid was meant to meet all of the healthcare needs of the elderly or the medically indigent, but the political hoopla with which they were introduced led many to believe that they would.

Times have changed and with them, the need for public education. No matter how good the system is, people cannot use it effectively unless we turn them into informed consumers. Our ability to do that will be critical to the success of any future system of care. None of these *Criteria* can be realized without an effective education component. To date, that component has been mostly ineffective.

There is an interesting, and paradoxical, aspect of this problem. If we were to search out and catalog the consumer information that now exists concerning long-term care, the amount of such information available would probably be surprising. So would the quality and accuracy of that information. So, why is it not getting to consumers? Why is it not effective in making them better informed? The problem is not always lack of information, but often involves ineffective delivery of that information. While much information is currently available, it is not meeting the need. Barriers

to achieving the ideal include consumer apathy; fragmented, conflicting, and/or overlapping sources of information; and inadequate, inconsistent methods of delivering the information.

In part, for the reasons just mentioned, consumers are not really looking for it, nor do they yet see the need for it. When they do seek information about long-term care, it is usually when they need to access the system immediately, which is too late in most cases. At that point, they are too emotionally involved and under too much pressure to fully comprehend all of the necessary information. To be effective, consumer education must take place long before the onset of need for services. It should preferably take place over a period of years so that consumers and their families are prepared to make the necessary choices.

Another reason long-term care information does not get to consumers adequately is that it is fragmented, comes from many uncoordinated sources, is not comprehensive, and is not uniformly available. Elderly advocacy organizations such as AARP (formerly known as the American Association of Retired Persons) and the National Council of Senior Citizens provide a great deal of information. Yet, by their very nature, those organizations cover very broad areas of interest to the elderly, such as retirement planning, leisure activities, and investments. Their focus on long-term care tends to be more related to protecting the rights of their constituents, but with limited information about how to actually access and use the long-term care system effectively.

On a more local level, area agencies on aging (triple As) usually provide a great deal of information about local long-term care services and how to find them. They also cover a much broader scope than just long-term care. However, because it is so critical to those they serve, long-term care issues are prominent with them. The drawback with the triple As is that they serve a defined constituency of the elderly and do not cover the full spectrum of long-term care consumers.

Providers often supply information for consumers. Some, motivated by both a sincere desire to serve and a wish to increase their market share, have been quite innovative. Toll-free information telephone lines, media advertisements, and public lectures are becoming common. Some have even opened their own “store-front” information centers, providing access and referral materials. They, of course, focus on their own services, not those of competitors. Retirement planning seminars, available to organizations or other groups, include information about long-term care.

Consumers seeking an overall education about long-term care must examine all of these sources and attempt to assimilate the information on their own. That assumes that they know where to look in the first place—not a simple task in and of itself.

The system must find better methods of coordinating available information, supplementing it when necessary, and bringing it to the attention of the public. Technological advances will assist somewhat (see Chapter 15 for more details). As more people gain access to the Internet, they will find a great deal of information about long-term care readily available. Information is already available on computer disks and CD-ROMs

and through interactive computer education programs for those who are computer proficient. However, a significant portion of the population, particularly the elderly, are not computer literate and probably will not be. For them, other, more traditional information delivery modes work best. The answer to what works best for the general public is “all of the above.” A variety of consumer education methods are required. As with the long-term care system itself, coordination is critical to the success of these efforts.

B. The long-term care system should include education for providers.

The system should provide for more geriatric education for physicians and others dealing with the elderly. Far too often, healthcare professionals fail to understand the differences between the elderly and younger patients. As we age, we encounter changes in our physiology that play a large part in determining our care needs. Changes such as increasingly fragile bones must be taken into account when treatment plans are developed. While those changes occur more slowly for some than for others, they can be expected by most. In addition to those physical changes, there may also be some decrease in memory or other cognitive ability.

Healthcare providers cannot serve the elderly adequately without a good understanding of the aging process. They must be trained to recognize the stages of that process and to treat their patients appropriately. Today, many are not. One of the most common results of that lack of training is the tendency to treat all older people as physical and mental invalids. They are individuals, with individual abilities, desires, and needs.

As the locus of care shifts more and more from hospitals to long-term care facilities or agencies, the need to educate healthcare professionals about the needs of the chronically ill will grow. While most long-term care providers understand those needs and respond well to them, other providers, including those in acute care, need to be educated more than they are at the present time.

C. The long-term care system should educate young, healthy persons to better prepare them to cope with chronic illness.

The time to deal with chronic illness and its accompanying disability is long before the onset of that illness. The long-term care system should place more emphasis on preventive education of future consumers. A better understanding of chronicity will lead to better acceptance of chronic illness in individuals and family members, and more effective, efficient use of available resources. Both they and the overall system will benefit.

When long-term care consumers do not know how to use the system, inappropriate use of services by those consumers is unavoidable. That inappropriate use of services means less-than-optimum results for the consumers. It is also inefficient. Young and middle-aged people are accustomed to using acute care services and are comfortable accessing them. They usually have little experience dealing with long-term care, do not understand what is available, and simply avoid it. They can learn to use the full continuum, but not without a consistent, concentrated consumer education effort.

■ Summary

Through the *Criteria for Designing or Evaluating a Long-Term Care System*, we have attempted to define the long-term care system as it should look. It is an intriguing and challenging exercise. However, it must be more than just a mere exercise. The gaps between the current system and the ideal are wide. Bridging those gaps requires a concentrated, coordinated effort by all segments of the long-term care field.

It may be too optimistic to think that the ideal can be achieved. However, we can come closer to it than we are today—and must do so if the system is to survive and prosper. The growth in the elderly population projected over the next several decades as the baby boomers age will test the system's ability to respond as it has not been tested before. The combination of increasing need and diminishing, or at least static, resources will require that new, more efficient delivery methods be found. Yet, the quest for efficiency and cost-effectiveness must not, in any way, compromise quality of care. Long-term care consumers will be better informed and will demand more and better services as a result. The system, its providers, and those who pay the bills must be ready to respond to those demands.

In describing what an ideal long-term care system would look like, it has been necessary to point out the shortcomings of the current system. In doing that, the impression may have been created that the situation is hopeless, that there is little good happening now. That was not the intent. There is much in the current long-term care system that is exemplary. There are many innovative providers who are finding ways to better serve the chronically ill. And they are not alone. Regulators, payers, and policy makers are working to find new solutions to the problems of the system. The remaining chapters in this book describe the system and its elements in detail. Those chapters document the current status of the system. They identify and discuss the changes that are taking place and offer a look at what can be expected in the future.

■ 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.

AARP (American Association of Retired Persons)	informal caregivers
AIDS	long-term care insurance
Alzheimer's disease	Omnibus Budget Reconciliation Act of 1987 (OBRA)
area agencies on aging	private funding sources
baby boomers	public funding sources
chronicity	respite care
consumer responsibilities	sandwich generation
consumer rights	seamless system of care
consumer-driven	single-site care availability
co-payment	uniform assessment
functional disability	uniform financial eligibility criteria
geriatrician	universally accessible

■ 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 is meant by a “consumer-driven” long-term care system?
2. What are some of the rights and responsibilities of long-term care consumers?
3. What are the components of accessibility to long-term care services?
4. What is meant by a uniform assessment?
5. What is the role of illness prevention in long-term care?
6. What are some incentives that might be provided to encourage providers to operate more effectively and efficiently?
7. What are some incentives that might encourage consumers to use the long-term care system more effectively and efficiently?
8. What is the role of education in creating a long-term care system that more closely approximates the ideal?

■ Bibliography

- AHRQ. (2002). *Characteristics of Long-Term Care (LTC) Users Living in the Community, Aged 18–64, by Type of Care, 1994*. Retrieved March 19, 2003, from Agency for Healthcare Research and Quality: <http://www.ahrq.gov/research/ltcusers/tab3txuse.htm>
- AHRQ. (2007). *Focus on Research: Long-Term Care*. Retrieved September 22, 2008, from Agency for Healthcare Research and Quality: <http://www.ahrq.gov/research/ltcix.htm>
- Alexander, R. (2007). *Avoiding Fraud When Buying Long-Term Care Insurance: A Guide for Consumers and Their Families*. Retrieved March 17, 2008, from the Consumer Law Page: <http://consumerlawpage.com/article/insure.shtml#buy>
- Donabedian, A. (1988). Quality and Cost: Choices and Responsibilities. *Inquiry*, pp. 90–99.
- Eisdorfer, C. (1989). *Caring for the Elderly*. Baltimore, MD: Johns Hopkins University Press.
- Evashwick, C. (2005). *The Continuum of Care*, 3rd ed. Clifton Park, NY: Thomson Delmar Learning.
- Kodner, D. (1993). Long-Term Care 2010: Speculations and Implications. *Journal of Long-Term Care Administration*, p. 85.
- National Academy on an Aging Society. (2000). *Caregiving: Helping the Elderly with Activity Limitations*. Washington, DC: National Academy on an Aging Society.
- Saint Joseph's College of Maine. (1993). *Criteria for Designing or Evaluating a Long-Term Care System*. Standish, ME: Saint Joseph's College of Maine.

