Long-term care, as the term suggests, is care provided over a sustained period of time. It may be continuous or intermittent. Besides the length, the name does not reflect other characteristics of this type of care. It is generally understood, however, that long-term care is not of an acute nature. It differs from acute care not only in its duration but also in the intensity and expected outcome of service. It is not concerned with curing disease or preventing mortality (Weiner, 1994).

Long-term care is concerned with individuals’ functional incapacity for self-care, and this incapacity may never be completely overcome. The functional incapacity or impairment might have resulted from any combination of physical, cognitive, emotional, and social factors (Kane & Kane, 1981). Therefore, the need for this type of care cannot be predicted by the presence or absence of a particular medical problem (Malone-Rising, 1994). The care is aimed at reducing the degree of functional impairment and enabling the person to attain the highest level of health and well-being by improving his or her functional ability.

Functional ability is defined in several ways. The general areas of function are physical, cognitive, emotional, and social. Physical functioning is frequently viewed as a person’s ability to perform activities of daily living and instrumental activities of daily living. Basic activities of daily living include ambulating, bathing, dressing, toileting, and eating; instrumental activities of daily living are those necessary to maintain independent living, such as preparing meals, shopping, housekeeping, telephoning, and managing finances. A person’s ability to perform these functions is rated as either full, partial, minimal, or nil. It is affected by physical, mental, and social conditions and economic status. The person may be (a) independent, (b) requiring mechanical assistance, (c) requiring personal assistance, or (d) unable to do specific activities (Evashwick & Branch, 1987). Measures of the ability to perform these activities are diverse.

Recipients of long-term care are both the old and the young. They can be categorized into three groups: the elderly, nonelderly adults, and children. The elderly, being at greatest risk of functional disability, form the majority of the users of long-term care. Nonelderly adults needing this type of care are those with long-term disabilities resulting from (a) accidents such as spinal-cord injury, (b) heart attacks and strokes, (c) multiple sclerosis, (d) cerebral palsy, (e) developmental disabilities, and (f) chronic mental illness.
Disability for nonelderly adults is generally defined in terms of their ability to perform income-producing work. Most children requiring long-term care are those with developmental disabilities.

It is difficult to determine precise numbers of those who need long-term care; different sources of data use different definitions of functional disability and employ different data collection methodologies. Here, we mention the rising number of older adults in the United States, most of whom live in noninstitutional settings. Depending on the number of functional disabilities they experience, however, the number of those needing community-based long-term care varies. According to the AARP Public Policy Institute (Houser, Fox-Grage, & Gibson, 2006), 40% of older adults in 2005 had a disability. Currently, 4 out of 5 adults over age 50 (or 70 million individuals) have been diagnosed with at least one chronic condition. In 2005, about 10 million Americans received long-term care (Komisar & Thompson, 2007), which cost almost $207 billion (Burman & Johnson, 2007).

The settings for long-term care are numerous and varied: (1) institutions such as nursing homes; (2) “quasi-institutions” such as boarding homes and various other kinds of living arrangements, including foster homes, shared housing, and Elder Cottage Housing Opportunity units; (3) community-based ambulatory program sites; and (4) the care recipients’ own apartments in retirement villages and life-care communities, as well as their own homes within the regular community. It is unclear what the “institutional” long-term care settings are and how they differ from one another. The following statement from Brody (1977), made almost 35 years ago, is still true:

Distinctions are blurred, and different institutional names mean different things to different people in different places at different times. A few of the names used in referring to institutions that provide long-term care are homes for aged, homes or hospitals for chronically ill, nursing homes, geriatric centers, rehabilitation hospitals, county homes, veterans’ homes, and psychiatric hospitals. (p. 29)

On the other extreme, ambulatory sites for long-term care include physicians’ offices; outpatient clinics; comprehensive assessment clinics—both pediatric and geriatric; day-care centers for adults and children with disabilities; day hospitals; mental health clinics; alcohol and substance abuse rehabilitation centers; and senior centers providing wellness, informational, educational, recreational, and social group programs, transportation, and congregate meals. In-home care may include home health; homemaker and personal care services; high-technology home therapy (e.g., kidney dialysis, respiratory care, tube feeding); use of durable medical equipment; hospice, home visiting, and telephone contact services; respite and attendant services; and home-delivered meals. A set of financial programs such as home equity conversion, reverse annuity mortgage, and sale/lease-back programs make more cash available to elderly homeowners and thereby allow them to continue living in their communities.

As is evident from the above discussion, long-term care includes health and social services. Experts do not agree about the boundaries between this type of care and many other service sectors, such as primary health care, mental health, and adult social services (Kane, 1987). This type of care, however, differs from acute care in that it involves such “life choices” as where to live and how to live (Merrill, 1992). As stated above, other than one’s own home, living arrangements may include retirement communities, senior housing, congregate care facilities, and adult family homes.

We have included in this chapter a discussion of hospice care even though only a few of the ideas about and attributes of long-term care presented above apply to it. Like other forms of long-term care, hospice care is not concerned with curing disease or preventing mortality. It is aimed at making the last stage of a person’s life pain-free and peaceful. Whereas the need for other forms of care cannot be predicted by the presence or absence of a particular disease, the presence of a terminal illness creates the need for hospice care. Whereas other forms of care are aimed at improving the care recipient’s functional ability, the aim of hospice care is to deal with the needs of a person beyond the relevance of functionality. Like the recipients
of other forms of care, those receiving hospice care are both old and young, but the old dominate the scene. Unlike the lack of clarity about who needs the different kinds of long-term care and the settings where that care can be best provided, there is a consensus about who needs hospice care and the venues for its provision.

**History of Social Work in Long-Term Care Settings**

As pointed out earlier, long-term care is provided in many settings— institutions, quasi-institutions, outpatient centers, and clients’ own homes. The history of social work involvement in long-term care is different in different settings. Because we have focused on the care provided through nursing homes, community residential care settings, and home-based/near home-based programs, we look at the history of social work in these separately. Because of the special nature of hospice care, a separate section is devoted to social work in that area.

**Social Work in Nursing Homes**

The history of social work in nursing homes is not long. Social workers, like other health care professionals, were rarely involved in nursing homes prior to 1965. The Social Security Act amendments of 1965 led to many changes. The law required hospitals to enter into transfer agreements with extended care facilities, and the provision of social services was included as a requirement for certification of an extended care facility (Clark, 1971). Nevertheless, nursing homes continued to be on the periphery of the medical establishment. Not only did the health care provided to nursing home residents remain of questionable quality, but the psychosocial needs of those residents also continued to be given minimal attention. Legal requirements were met in many ways. Some nursing homes valued social work education and employed social workers with appropriate professional degrees; others hired a “social work designee,” someone often without any social work training and experience. These nursing homes contracted with a professionally trained social work consultant to guide the social work designee in attending to the psychosocial needs of residents. Many nonprofit sectarian nursing homes employed qualified social workers, even those with master’s degrees, whereas many private for-profit nursing homes tried to do without them (Greene, 1982). This situation continues. The federal government requires all nursing homes with more than 120 beds to employ a full-time qualified social worker who may or may not have a degree in social work [1]. The federal regulations do not clarify if facilities with 120 or fewer beds need to hire a social worker but can do so on a part-time basis. This is important because 70% of the nursing homes in the country have fewer than 100 beds. States have the option of extending or strengthening the federal regulations. State requirements for qualifications of nursing home social workers greatly vary (Bern-Klug, 2008).

Social work roles and functions in nursing homes have varied vastly. At the one extreme, nursing home social workers may deal mainly with admission-related financial arrangements and coordination of services, organization of recreational activities for residents, and attendance to a resident’s obvious social needs. At the other extreme, social workers’ professional skills may significantly affect most dimensions of the nursing home’s functioning. They may provide services to (a) residents, (b) families of residents, (c) nursing home staff, (d) nursing home policymakers, and (e) the community in relationship to the nursing home. In the nursing home industry as a whole, social workers in the latter group have been more an exception than the rule. In their study of skilled nursing facilities, Pearman and Searles (1978) identified the above five areas of unmet social service needs. As a conceptual road map for exploring the social work territory in the nursing home world, their findings have as much relevance today as they did 30 years ago. Since then, the psychosocial needs of nursing home residents have been reviewed as part of the quality-of-life issue.
Nursing home reform legislation (Omnibus Budget Reconciliation Act of 1987 [P.L. 100-203]) made the goal of enhancing the quality of life of nursing home residents a part of the national policy. Regulations under that law, implemented in October 1990, require all nursing homes to identify the medically related social and emotional needs of their residents and assist them in the adjustment to the social and emotional aspects of their illness, treatment, and stay in the facility. Every nursing home of more than 120 beds is also required to provide social work services. Variance in the degree and nature of social work as practiced in nursing homes, however, persists. Simons, Shepherd, and Munn (2008) reviewed the research-based literature on social work in long-term care settings, including nursing homes, and found evidence of social work’s contribution to meeting the needs of nursing home residents. The studies they mentioned include (1) Malench (2004), which found that nursing homes employing qualified social workers are more likely to provide family support groups; (2) Osman and Becker (2003), which discovered positive influence of social workers in the implementation of advanced directives; and (3) Newcomer, Kang, and Graham (2006), which found that residents in the intervention group (receiving social work case management) had a higher rate of discharge and shorter median length of stay than the usual care group.

Social Work in Community Residential Care Settings

Most information about the involvement of social work in community residential care settings comes from the Department of Veterans Affairs’ residential care programs; community residential arrangements for deinstitutionalized persons with mental illness, mental retardation, and developmental disability; models of care designed to keep older adults out of nursing homes in the state of Oregon; and foster care for children who cannot live with their natural families. Community residential care serves persons who are less impaired than those in nursing homes and more impaired than those who are still living in their homes. It gives residents more privacy and autonomy than is available in nursing homes and is economically more efficient than providing services in individual homes (Lehning & Austin, 2010). However, there is not much in research-based literature on the evaluation of community residential care, partly because of the lack of uniformity in the definitions of this type of care (Wilson, 2007). Social workers have played many roles and performed many functions in these programs. On the one hand, they have identified, trained, supervised, and monitored foster care providers. On the other hand, they have created, organized, and supervised foster care and other living arrangements. They are also involved in the working of group homes, sheltered residential facilities, and life-care communities in different capacities.

Social Work in Home-Based/Near Home-Based Care

Given the complexity of home-based/near home-based care, it is difficult to talk definitively about the extent of social work involvement. It has varied considerably. In some settings and programs, social workers have occupied center stage; in others, they have been on the periphery; and in still others, they have been hardly visible. In social service programs for the elderly, social workers have functioned as program planners and organizers; case workers and case managers; and supervisors and pacesetters for paraprofessional and volunteer service providers. In health clinics and mental health centers, they have functioned as psychosocial therapists and service coordinators. In agencies serving people with disabilities, they have provided such services as psychosocial assessment and intervention; case management and coordination; environmental manipulation; and protection from physical abuse, neglect, and financial exploitation. They have helped families of people with disabilities deal with the physical, emotional, and social stress of
caring. They have worked with multidisciplinary
teams serving people with disabilities and the
community at large on their behalf.

Social workers have played these varied pro-
fessional roles despite the constraints on social
work activities imposed by reimbursement rules
of various funding sources. In home health care
agencies, the social work role has been secondary.
Although Medicare conditions for home health
agencies mandate that social services be made
available to patients, they do not require that a
social worker see these patients or be involved in
the planning for their care. A nurse usually deter-
mines the need for social work intervention.
Medicaid-funded programs are even less clear
about the role of social workers. There is no uni-
form requirement that social work services be
available to patients, and even when needed,
payment for these services is not reimbursed by
the program (Cox, 1992). The review of research-
Based literature by Simons et al. (2008) found
several studies of social work in home health
care, primary care, and modality-specific pro-
grams such as community-based case manage-
ment programs. Some of these explored the
impact of the setting and payment systems on
social work practice, and others focused on the
efficacy of social work.

Social Work in Hospice Care

Hospice care for the terminally ill and their
families is a recent development. It represents an
approach to caring based on a philosophy that
emphasizes quality of life of the dying patient.
The core belief is that the terminally ill should
die pain-free and with dignity and that their fami-
lies should be supported to ensure that happens.
Dame Cicely Saunders started the hospice move-
m ent in England in 1967, when hospice care
was first provided in the inpatient setting of
St. Christopher’s Hospice in London. The move-
ment brought about a change in the way we think
about dying (Brooks, 2010). Saunders had a rich
and varied professional background. She had
been trained as a nurse, physician, and social
worker (Raymer & Reese, 2008). Hospice is a
form of palliative care, which is defined by the
World Health Organization (2011) as

an approach that improves the quality of life of
patients and their families facing the problems
associated with life-threatening illness, through
the prevention and relief of suffering by means of
early identification and assessment and treatment
of pain and other problems, physical, psychosocial,
and spiritual.

However, there are differences between hos-
pice and palliative care [2]. Hospice is a philoso-
phy of care more than a place of care or a subset
of service (Beder, 2006). As the movement spread
to other parts of the world, the local conditions
and needs influenced the actual delivery of ser-
vices. The first American hospice was started in
Branford, Connecticut, in 1974, and others that
followed developed a character of their own. They
grew as grassroots community movements against
such faults of the American health care system as
its focus on technology and cures, and its ten-
dency to view many terminally ill individuals as
“failures” and subsequently “abandon” them
because nothing more could be done (Raymer &
Reese, 2008). Hospice focused on aggressive pal-
liative care provided in a patient’s own home. In
2009, there were about 5,000 hospice programs in
the country, and an estimated 1.56 million termi-
nally ill patients (and their families) received
hospice care (National Hospice and Palliative
Care Organization [NHPCO], 2010).

Hospice embodies (1) social work values of
self-determination, dignity and empowerment of
patients, service, and social justice, and (2) social
work focus on patient and family as a unit of ser-
vice, interdisciplinary care, and comprehensive
services that deal with all dimensions of life. Social
workers have been a part of the hospice scene from
the beginning. They play several professional
roles—most as social work clinicians, some also as
bereavement counselors and coordinators of volun-
teeer services, and a few as administrators.

In all sectors of long-term care, social work-
ers currently play many professional roles and
perform important functions. Some roles and functions are likely to persist although they may have to be reemphasized and asserted. Others will have to be assumed in view of the changing situation and needs of long-term care facilities.

**Future Social Work Roles in Long-Term Care Settings**

Chapter 3 identified the major needs of the long-term care sector as (a) nursing homes improving their public image, becoming a part of an integrated continuum of services, and extending themselves into the community; (b) community residential care settings increasing their visibility, increasing their resources, and improving their service performance; (c) home-based/near home-based program agencies improving the overall quality of their care (so their services are appropriate, comprehensive, well-coordinated, and sensitive to the unique situations of their clients); and (d) hospice organizations reducing barriers to the utilization of their services by minority patients and their families, and improving their access to people living in rural areas. Table 7-A below lists the social work roles geared to meeting these needs. A discussion of these roles follows the table.

<table>
<thead>
<tr>
<th>Table 7-A Future Social Work Roles in Long-Term Care Settings</th>
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<tbody>
<tr>
<td>• Social worker as a helper with adjustment to the nursing home</td>
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<tr>
<td>• Social worker as a sustainer of resident-family relationships</td>
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<tr>
<td>• Social worker as a contributor to the nursing home as a therapeutic community</td>
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<tr>
<td>• Social worker as a community liaison and community organizer</td>
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<tr>
<td>• Social worker as a recruiter of community residential care providers</td>
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<tr>
<td>• Social worker as a trainer of community residential care providers</td>
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<tr>
<td>• Social worker as a provider of support and monitor of quality of care</td>
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<tr>
<td>• Social worker as a contributor to the agency’s continuous quality improvement</td>
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<tr>
<td>• Social worker as a case manager and service coordinator</td>
</tr>
<tr>
<td>• Social worker as a contributor to improving hospice access to people living in rural areas</td>
</tr>
<tr>
<td>• Social worker as a helper in reducing barriers to hospice services for minority patients</td>
</tr>
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</table>

**Social Work Roles in Nursing Homes**

It is likely that as more and more educated, assertive, and hitherto politically active elderly enter nursing homes, emphasis on quality of life will increase. These elderly will demand improvements in services. Hubbard, Werner, Cohen-Mansfield, and Shusterman (1992) described the development of “seniors for justice,” a political and social action group of nursing home residents in the greater Washington, D.C. area, and how this not only gave a group of cognitively intact nursing home residents a sense of empowerment and enhanced self-esteem but also resulted in many other positive changes. In the future, nursing homes will realize the importance of social work skills for dealing with the psychosocial needs of their residents, as well as for intervening at the system level for positive changes. Social workers’ involvement with the community on behalf of their nursing home will be like icing on the cake. That involvement will enable them to use their professional skills for, on the one hand, more comprehensive and meaningful work with and on behalf of their clients and, on the other hand, a more effective integration of the nursing home with community health and human services. Such integration would enhance the public image of the nursing
home. Hence, social workers will play many roles vital to nursing homes in the future.

**Social Work Role in Helping Residents Adjust to the Nursing Home Environment**

Even now, most nursing home social workers view helping residents adjust to the nursing home as one of their most important roles, although the time devoted to it is inadequate for the residents’ psychosocial needs and the workers’ professional satisfaction. They know that the decision about placement and the actual entry into a nursing home are difficult experiences for most people. Feelings of loss with the potential for depression, helplessness, and hopelessness are common (Solomon, 1983).

Vourlekis, Gelfand, and Greene (1992) compared the views of nursing home social workers and administrators on (a) psychosocial needs of residents and families and (b) functions performed and expected to be performed by the social worker. Both groups agreed on three of the five top-ranked needs. These three needs were for support/help with (a) transition to the home, (b) feelings of loss throughout the stay in the home, and (c) relatedness and intimacy issues. This finding may reflect the beginning of convergence of different opinions on the appropriate roles and functions of nursing home social workers. In the future, adjustment to the nursing home environment will have many more implications, with more end points of placement than is currently the case. Nursing home residents move back and forth between nursing homes and acute care hospitals until they die either in the nursing home or at the hospital. In the future, they will have many more options.

**Social Work Role in Improving Residents’ Relationships With Their Families**

The warmth and meaningfulness of human relationships are among the ingredients of quality of life. As the enhancement of residents’ quality of life becomes an important goal of nursing homes, social workers will assume this role with the aim of increasing meaningful involvement of families in the lives of nursing home residents. Families do not necessarily abandon members who are old and disabled when they can no longer care for them at home. The decision regarding the placement of a family member in a nursing home is often as painful for the family as it is for that member. Even if nursing home placement is not abandonment by the family, feelings of abandonment are part of the reality of institutionalization. Beyond the initial crisis of placement, families need help staying involved in the lives of their institutionalized family members. Families in the future will become increasingly more diverse structurally and weaker in their emotional and social resources. Consequently, they will need more assistance, encouragement, and professional direction in sustaining mutually fulfilling relationships with their loved ones in nursing homes.

**Social Work Role in Making the Nursing Home a Therapeutic Community**

For maximum impact of the social work presence in nursing homes, social workers should go beyond work with individual residents and their families and contribute to the conversion of the nursing home into what Jones (1953) called a therapeutic community. Social workers are generally involved in dealing with “difficult” residents and families, admissions and discharges, and institutional “crises,” and are able to use their professional skills effectively in the resolution of these problems. They can easily add another dimension to that role and make significant contributions to the organizational health of nursing homes and the quality of their services so that these homes do not breed difficult residents and problem situations. This contribution requires addressing three sets of variables: (a) the organizational policies, procedures, and routines; (b) staff attitudes, opinions, relations, and perceptions of organizational climate; and (c) meaningful involvement of residents and their families.
Social Work Role in Improving the Nursing Home–Community Relationship

For nursing homes to become important elements in the coordinated and comprehensive continuity of health care in the future and also to improve their public image, they must do some creative and proactive reaching-out work in the community. No other nursing home professional is as well acquainted with the community’s health and human services network and as used to coordinating services as the social worker. Besides knowledge of the community’s formal and informal resources and of case management skills, he or she also possesses basic community organizational know-how. With little extra imagination and creativity, nursing home social workers can take on this role and make significant contributions to the field of long-term care, as well as to the viability and healthier public image of their institutions.

Social Work Roles in Community Residential Care Settings

In view of our earlier discussion of the needs of community residential care settings, the following social work roles will attain prominence in the future.

Social Work Role in Recruiting Community Residential Care Providers

The search for noninstitutional approaches to the needs of people requiring long-term care will continue and likely will become more essential as families are less able emotionally and financially to care for their aged members with disabilities. Identification, recruitment, and retention of individuals and families willing to provide this type of care will become an important social work function. With the advantage of their experience in the fields of child welfare and mental health, social workers will be able to take on this role with creativity.

Social Work Role in Training Community Residential Care Providers

Appropriate training, supervision, and support of those caring for children; adults with emotional, mental, and physical disabilities; and the elderly are necessary for the success of community residential care programs. Most care providers have the desire to serve their fellow human beings and the ability to relate to them warmly, but they often lack an understanding of (a) needs and problems, general as well as specific, of those under their care; (b) appropriate responses to those needs and problems; (c) community resources relevant to those needs and problems; and (d) approaches to accessing those resources.

Social Work Role in Supporting and Monitoring Community Residential Care

The technical knowledge and know-how of community residential care is important for effective service, but care providers also need appreciation, encouragement, and support from their sponsors, organizers, and employers. Very often, those they serve cannot show their appreciation for the services provided. This is particularly essential in view of the fact that society generally tends to value and reward the least those who perform the most difficult and unpleasant tasks. Social workers will be able to fill that important gap.

Social Work Roles in Home-Based/Near Home-Based Care

Social workers will have opportunities to demonstrate their unique skills in response to the needs of the in-home and near-home health care organizations identified earlier. No other professionals are more suited by their training, philosophy, and experience to make significant contributions to the quality-of-care efforts or to deal with such problems as the (a) lack of a holistic view of human problems, (b) inability to devise
comprehensive approaches to those problems, and (c) difficulty in providing coordinated services. The following are some ways that social workers can serve these organizations.

Social Work Role in the Organization’s Continuous Quality Improvement

The total quality management (TQM) philosophy demands total organizational commitment to continuous improvement in quality of care; an organizational culture that encourages participation by all who use the organization’s services; and ongoing feedback from patients, families, and health care practitioners. This patient-inclusive approach, when compared with traditional provider-centered approaches, is one of the greatest challenges presented by the Joint Commission on Accreditation of Health Care Organizations’ Agenda for Change (Lehr & Strosberg, 1991). The challenge becomes awesome when one considers the nature and structure of in-home care (which make monitoring of quality difficult); the lack of regional, state, or national norms for such care; and the problems encountered in in-home care agencies. These problems include unprofessional conduct on the part of service providers, which takes the form of disregard for dignity, autonomy, and independence of the client; tardiness and absenteeism; inappropriate service and inadequate records; drug and alcohol abuse; and theft and fraud. Social workers will be able to contribute positively to the efforts for quality improvement.

Social Work Role in Case Management and Service Coordination

In the future, the recipients of health and human services will be more educated and avid consumers of health care information, aware of their rights, and vocal in their demands. They will not tolerate services that are not appropriate, adequate, comprehensive, and culturally sensitive and proper. That stance will increase the importance of case management and service coordination. Their professional philosophy and training give social workers a holistic view of human problems and comprehensive approaches to those problems. They will have opportunities to demonstrate their superior abilities to perform this role.

Social Work Roles in Hospice Care

A national survey of 66 hospices by Reese and Raymer (2004) found that increased social work involvement in hospice care was significantly associated with lower costs; better team functioning; more patient and family issues being addressed; reduced levels of pain, medication, and other costs; fewer visits by other team members; and enhanced client satisfaction. This indicates that at the micro level of intervention, social workers are doing impressive work. They have the necessary knowledge and skills to do equally well at the mezzo and macro levels. The needs of hospice organizations that we have identified require social work intervention at those higher levels. The pertinent social work roles will include (1) improving hospice access to people living in rural areas and (2) reducing barriers to the utilization of hospice services by minority patients.

Social Work Knowledge and Skills

Before we discuss the knowledge and skills needed for social work practice in long-term care in relation to the identified roles, we make a few general observations and list general principles proposed by the Institute of Medicine (2001) that should guide efforts to improve the quality of long-term care.

Earlier, we referred to the person in environment as the unique social work perspective and to systems theory as providing a useful model for conceptualizing this perspective. Similarly, the concepts of “enabling” and “empowerment” are operationalized as important elements of social work practice. These are useful for practice in long-term care settings as well. The helping world is discovering the validity of the social work
perspective and practice principles. A comprehensive perspective on the client’s reality, encompassing the person and the environment as well as a life span view, is becoming popular. Other professionals are adopting the social work client-worker relationship, marked by equality, as the principle of equal partnership between clients and helpers.

Because the major recipients of long-term care services are the elderly and the disabled, social workers should understand the laws—federal, state, and local—that reflect the various policies and service programs for these populations. They should judge these policies and programs by the underlying value that people have a right to services designed to maximize their capacities to meet basic human needs (Brody, 1977). Maslow’s conceptualization of human needs can be used to determine, for example, the extent of a nursing home’s work toward the improvement of its residents’ quality of life in compliance with the Omnibus Budget Reconciliation Act of 1987 (Umoren, 1992).

Social workers should recognize that despite the fundamental rights that the elderly and the disabled have as citizens and the government policies addressing their special needs, society tends to view and treat these people as less than equal. Often, society’s negative view of the aged and the disabled is accepted and believed by the aged and the disabled themselves. They need to be treated as populations at risk.

Within the overall needs resulting from their old age or disability, there are tremendous variations among individuals. Old age or disability does not affect all individuals and their families in a standard way. Numerous variables in myriad ways result in peculiar reactions, situations, and needs of these people. Social workers should be sensitive to the universal as well as the unique elements of their realities and build those into plans for intervention, whether in the form of case-level therapeutic work or class-level advocacy.

Although disability affects an individual in many ways, it does not define his or her total being. Social workers should consciously desist from making or accepting such assumptions as the following: (a) Disability is located solely in the biology of persons with disabilities; (b) when a person with a disability faces problems, the impairment causes the problems; (c) the person with a disability is a “victim”; (d) disability is central to the self-concept, self-definition, social comparisons, and reference group of the person with the disability; and (e) having a disability is synonymous with needing help and social support (Fine & Asch, 1988).

Social workers should also be in tune with major developments and philosophical shifts in the fields of chronic physical disabilities, chronic mental illness, and developmental disabilities. Overall, movement has been away from the traditional psychotherapeutic models in favor of educational models (Hirschwald, 1984).

The professional development work in the areas of palliative and hospice care is quite impressive. Not only has the NHPCO (2005) produced the Hospice Standards of Practice, but the National Association of Social Workers (NASW, 2004) also has created the NASW Standards for Social Work Practice in Palliative and End-of-Life Care. Several journals publish material of educational value for social workers. These include American Journal of Hospice and Palliative Medicine, Hospice, and Journal of Social Work in End-of-Life and Palliative Care. Other social work journals such as Health and Social Work, Social Work in Health Care, and Journal of Gerontological Social Work are also sources of new ideas and information. Living with Dying: A Handbook for End-of-Life Health Care Practitioners (Berzoff & Silverman, 2004) is an impressive addition to the field. Social workers have the basic knowledge and skills for direct practice, interdisciplinary and multidisciplinary teamwork, organizational work, and community-level interventions. They can refine their professional abilities to take on the roles we identified earlier to meet the current and future needs of hospices.

The following are the general principles recommended by the Institute of Medicine (2001):

1. Long-term care should be consumer centered rather than solely provider centered.
2. A system of consumer-centered long-term care should be structured to serve people with diverse characteristics and preferences.

3. Reliable and current information about the options available and the quality of care provided should be easily accessible to allow people to make informed choices about long-term care.

4. Access to appropriate long-term care services is both a quality-of-care and a quality-of-life issue.

5. Measures of the quality of long-term care should incorporate its many dimensions, especially quality of life.

6. Providers should be held accountable for their performance in providing high-quality long-term care, including the outcomes of care they could affect.

7. A motivated, capable, and sufficient workforce is critical to quality long-term care.

8. Improving the quality of long-term care requires sustained government commitment to develop and implement fair, effective regulatory and financing policies.

9. Improving quality of care must be an ongoing objective. Building the capacity for high-quality long-term care depends on improved knowledge of the practices and policies that contribute to the well-being of people using that care.

(pp. 31–33)

Social Worker as Helper With Adjustment to the Nursing Home

The nursing home reform law (P.L. 100-203) requires, among other things, that nursing homes assist their residents in adjusting to the social and emotional aspects of their illness, treatment, and stay in the facility. Because improving their public image is the major need of nursing homes, meeting the needs of residents and acquiring a reputation for that will simultaneously benefit both clients and the institutions. Social work skills are superbly appropriate for both purposes. Here are a few suggestions for social work with new residents adjusting to the nursing home environment:

1. Anticipate the possibility that the cognitively intact elder or person with a disability entering the nursing home has a negative image of the place as a setting for long-term care. Whether the resident comes from a hospital or from home, the decision about placement in a nursing home is always painful. He or she may also experience a sense of being abandoned by the family. The decision to enter can trigger feelings of loss, which without intervention often result in depression with concomitants of helplessness and hopelessness. This can happen so easily because the decision to enter is an acknowledgment to self and others of diminished capacity to care for oneself (Solomon, 1983, pp. 86–87).

2. View this as a stressful event for the individual and plan on reducing the stress. Because most nursing home social workers are involved in preadmission planning, it will be comparatively easy to build some stress-reduction elements into the preadmission and postadmission protocol. These elements can include a preadmission visit to the family member with a two-fold purpose: (a) giving information about the institution, answering questions, giving the person a good feel for the institution in terms of both its pluses and minuses, and suggesting ways of preparing the individual for the move, and (b) obtaining information about the individual and his or her modes of functioning.

3. Use the information about the person to develop creative ways of making the institutional environment congruent with his or her previous modes of functioning (Solomon, 1983). Use crisis intervention skills in dealing with the person’s transition to the nursing home. Make sure that attention is given to such issues as privacy, possessions, display of family pictures, and decorations in the room. This will give the individual a sense of control. A general demonstration of warmth, interest, and concern on the part of the staff will convey the message that he or she is welcome and is among caring and concerned people. These simple and inexpensive gestures will yield positive results in assisting the person’s adjustment.
4. **Stimulate or support aggressive mobilization of psychological resources so that the person does not withdraw and fall prey to depression.** The mastery of adjustment is dependent on the person’s ability to mobilize his or her aggressive feelings and to remain active (Solomon, 1983). The “how” of this stimulation will depend on an assessment of the individual’s personality, style, and resources. Therefore, do a thorough psychosocial assessment.

5. **Encourage family and friends to visit often and spend more time with the newly placed individual, at least during the first few days and weeks.** The importance of these visits is reflected in a quote from a nursing home resident who asked a friend to visit often “so I will know I am alive” (Williams, cited in Kane, 2001). Explore family conflict, guilt, feelings of abandonment, and other effects of placement on the family; help them deal with these; and encourage open communication between them and the resident. The aim of this extra effort is to remove psychological hurdles from the path of the institutionalized member’s adjustment, to sustain the family’s positive involvement in that member’s life, and to win allies in the nursing home’s efforts to improve its public image.

6. **Encourage the resident to join group activities.** It is likely that the nursing home already has some organized group work going on. If not, be instrumental in starting groups that can benefit residents. The therapeutic effects of group experiences are being increasingly realized, and group approaches will become even more popular in the future. Groups are believed to be particularly suitable for work with the elderly because of the advantages of economy, socialization, and emotional validation. Nursing homes can be appropriate settings for innovations in group modalities of social work intervention. Dhooper, Green, Huff, and Austin-Murphy (1993) tested the efficacy of an eclectic group approach to reducing depression in elderly nursing home residents and found the approach effective. Other models have been tried with different groups of nursing home residents. For example, Hyer and associates (1990) applied a cognitive behavioral model to two groups of older people with stress-related problems: recent (adjustment reaction or grief) and remote (posttraumatic stress disorder). Capuzzi, Gross, and Friel (1990) discussed five types of groups: (a) reality orientation, (b) reorientation therapy, (c) reminiscing, (d) psychotherapy, and (e) topic-specific and support groups. Group approaches are being tried even with those who are cognitively impaired, the goal being reminiscence, reorientation, and rehabilitation (Salamon, 1986). The gerontological literature is growing richer in ideas and suggestions for effective group work (e.g., see Abramson & Mendis, 1990; Chung, 2005; Fernie & Fernie, 1990; Greenberg, Motenko, Roesch, & Embleton, 2000; Ng & Chan, 2008; Stones, Rattenbury, Taichman, Kozma, & Stones, 1990).

Here, we reiterate the age-old social work practice principles. Social work activity guided by these principles will effectively help a resident deal with the transition and adjustment to the nursing home environment:

- **Be honest and open** with the client; people respond to authenticity and genuineness.
- **Start where the client is**; begin with the client’s definition of the problem.
- **Maximize the client’s choices and options**; there is always room for reducing the “institutional effects” of nursing homes—increasing the degree of privacy, independence, and convenience, and decreasing the rigidity of schedules and controls and the extent of isolation from the outside world.

### Social Worker as Sustainer of Resident-Family Relationships

Although the family in the future will change in its structure and resources, its meaningfulness for its members will not diminish. Variations based on ethnic, racial, and regional differences will occur in that meaning, however. For most elderly, the family will continue to be a crucial reference point. We have discussed admission
into a nursing home as a stressful event for the person concerned. It is also a serious and painful crisis for the family (Dobrof & Litwak, 1977). Even when care for the person at home is stressful and draining emotionally, physically, financially, and socially (Dhooper, 1991), many familial caregivers continue to experience considerable emotional stress and subjective burden after the loved one’s institutional placement (Colerick & George, 1986; Pratt, Schmall, Wright, & Hare, 1990; Zarit & Zarit, 1982). Families need help dealing with the emotional and other consequences of placement of a loved one and sustaining mutually fulfilling relationships with him or her. Social workers may benefit from the following suggestions:

1. **Keep abreast of the emerging literature on family involvement in long-term care settings.** A book edited by Gaugler (2005) presented and discussed several programs for and approaches to family involvement, including the Family Visit Education Program, Family Involvement in Care, Partners in Caregiving, The Eden Alternative, Family Councils, participation of certified nursing assistants in family involvement, support group intervention for family members, story sharing between families and staff, and web-based interventions.

2. **Keep in mind that, in general, the visibility and concern of the family have a positive effect not only on the mental health of the institutionalized person but also on the quality of care he or she receives.**

3. **Be instrumental in establishing and supporting institutional practices/facilities that encourage family visits.** These may include open visiting hours, coffee shops and lounges for family members to spend time with the resident, encouragement for bringing special food treats, and many open channels of communication between nursing home staff and families (Solomon, 1983).

4. **View the person’s admission as a crisis for his or her family.** Explore the crisis and provide necessary assistance. “The developmental task which accompanies the crisis of admission is that of maintaining close family ties while feeling angry, hurt, afraid of rejection and abandonment, and most of all feeling deeply sorrowful” (Solomon, 1983, p. 90). Depending on a host of factors, the nature and extent of the crisis for each family varies. For families with a history of severe relationship problems, maintaining closeness may be complex and challenging. Such families are becoming more the rule than an exception, partly because people are living longer and have more time for experiences that are sources of conflict and alienation.

In some cases, they [schisms] are about property disputes, with the elderly believing they have been financially mistreated in some business arrangement with their children or grandchildren. In other cases, the conflicts may result from disapproval either by the parents or their children of the other’s marriages, divorces, child-rearing practices, career pursuits, smoking, alcohol and other substance abuse, religious choices—the lists are endless. (Harbert & Ginsberg, 1990, p. 136)

In general, family members may feel an element of guilt, whereas the reactions of the person being placed may reflect anger, rejection, and separation.

5. **While assessing the family’s situation, reactions, coping style, and resources for adjustment, look for their potential and capacity for sustaining ongoing family relationships** (Greene, 1982). At the same time, acknowledge and validate the enormity of the task before them. Provide and/or procure for family members the needed help from within the nursing home or from outside in the community. The help the social worker can provide may include brief casework, education and consultation, mediation between family members and the resident, and an offer of membership in an ongoing family-support group, if available.

Families of patients with dementing illnesses such as Alzheimer’s disease have special problems of transition when the patient must be
placed in a nursing home. Most families have cared for their member at home for 5 to 7 years after the diagnosis (Cheek, 1987) and have experienced and adjusted to numerous burdens caused by the member’s progressively worsening condition. Morgan and Zimmerman (1990) identified factors that made the transition from in-home care to institutional care less stressful for spousal caregivers. They clustered these factors into five categories: (a) emotional support, (b) control of situation, (c) acceptability of nursing home, (d) acceptance of situation, and (e) permission/command by an authority figure. Transform ideas from such findings into the strategies for intervention with these families.

6. **Encourage the family to reminisce together.** Since Butler (1963) first described the therapeutic value of reminiscing, life review therapy has been found to be a viable approach to helping the elderly maintain self-esteem, reaffirm a sense of identity, and work through personal losses. Family reminiscing can also be a powerful method of bringing families together. As Solomon (1983) put it,

> The elderly relative is given the opportunity to be valued in her entirety with strengths as well as weaknesses and dependencies. Younger people are given the chance to learn from the struggles of the past and to preserve those struggles. And for the family, reminiscence becomes the family legacy; it can ensure family continuity; it is the preservation of the past, which ensures the future. (p. 94)

Reminiscence is particularly helpful if family members seem not to know what to talk about during their visits.

7. **Take on the responsibility of coordinating activities for all the staff and helping them incorporate family involvement into the resident’s care.** This involvement will add another meaningful dimension to the family’s visits. This can be done through regular participation in patient care conferences and sharing the family’s needs and concerns, interpreting the behavior of the family and resident, and suggesting ways of involving the family in the resident’s life (Dobrof & Litwak, 1977; Greene, 1982).

8. **Attend to the special needs of families whose members are becoming disoriented and confused.** Such families may find it increasingly more difficult to maintain their interest in visiting. They can be taught basic reality orientation techniques. Families thus trained can make their visits with the resident meaningful and also supplement the nursing home staff’s efforts to keep the patient alert and oriented. Explore and assist in this form of family involvement.

Family members whose relatives are severely disoriented need help. If they come to visit, they experience emotional frustration, pain, and upset, and if they do not come to visit, they feel guilty. On the one hand, they need to know that their visits are important and to hear that keeping their visits short or less frequent is OK. On the other hand, family members visiting a demanding, talkative relative can use help setting limits without feeling guilty (Greene, 1982).

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**Social Worker as Contributor to the Nursing Home as a Therapeutic Community**

Helping the nursing home provide a therapeutic environment essential for the optimal quality of life and independent functioning of the residents is one of the social work responsibilities under NASW standards. This can be done through a multipronged approach that includes (a) advocating on behalf of all residents, with the aim of easing stringent organizational routines, policies, and procedures; (b) advocating for and helping residents create and maintain a mechanism for their active involvement in the working of the institution, with the aim of ensuring that their voices influence the organizational policies and practices; and (c) educating staff and administrators, with the following goals:

1. Sensitizing them to the importance of the residents’ cultures for their well-being, with the aim of incorporating aspects of their culture into care

2. Making them aware of the rights of residents and their social and emotional needs, with the aim of individualizing planned programs for residents
3. Training them, with the aim of improving their (a) attitudes toward residents, (b) knowledge of the needs of residents, (c) understanding of roles of all involved in caregiving, (d) cooperation and communication, and (e) integration of care of residents (Pearman & Searles, 1978).

The following suggestions are likely to be helpful for social workers in operationalizing the above approach:

1. **Consider themselves the best suited for this role of contributor to the nursing home as a therapeutic community because of the social work belief system and training.** Social workers believe in individuals’ right to self-determination and self-direction. They have learned how to clearly communicate that belief and to generate a desire to exercise that right. They have been trained to offer people choices, encourage decision making, and stimulate active participation in problem solving. Hence, they should take the responsibility of providing leadership in the facility’s efforts to become a therapeutic community.

2. **Share with administrators the emerging literature on the benefits of changing the nursing home’s milieu for the residents, staff, and institutional image in the community.** We mentioned culture change in nursing homes in Chapter 1, and Misiorski (2003) described the process of changing nursing home culture. Help administrators realize that residents who are involved in decisions about their care and caregiving policies and procedures reveal healthier and happier attitudes (Blair, 1994–1995). When residents are a part of the decisions concerning themselves, their autonomy and self-worth are upheld (Lindgren & Linton, 1991), and that has a positive effect on their motivation. That, in turn, makes the work of the staff worthwhile. It is satisfying to work with those who are actively involved in their care, are motivated to benefit from the service, appreciate the work being done, and are intent on drawing the best out of the service providers. The residents’ participation in the running of the institution further benefits the staff because it leads to a more smoothly run facility (Grover, 1982). Similarly, the interest and energy of families can be a tremendous resource if channeled into the care of their institutionalized members and the needs of the nursing home.

3. **Use advocacy skills to motivate or reinforce the support of administrators and staff in favor of changes.** Share with them the relevant principles and approaches, seek ideas and input, and neutralize resistance. The following are a few examples of helpful strategies:

   - The hospice ideology has a special appeal for those who work with the dying, and nursing home staff also experience death often. The hospice approach is based on principles that include a total needs emphasis, increased resident autonomy, a community ideology, and a multidisciplinary team orientation that cuts across levels of staff hierarchy. These principles can be relevant for humanizing nursing home environments (Munley, Powers, & Williamson, 1982).
   - The health promotion movement has generated principles and techniques that can be applied to the task of motivating and involving the nursing home residents in their care and the life of their “home.” Health promotion emphasizes the residents’ responsibilities and incorporates their abilities into the management of their disabilities. The social work concepts of “enabling” and “empowerment” have significant relevance for health promotion work.
   - Resident councils or committees are a popular approach to encouraging the involvement of residents and the creation of a community spirit in a nursing home. Helpful information about how to form these councils and encourage reluctant residents is becoming available (e.g., see Blair, 1994–1995; Grover, 1982; Miller, 1986).
   - Group work is used not only for therapeutic purposes with nursing home residents but also for converting nursing homes into therapeutic communities. Whereas therapeutics may be the main purpose of many groups such as activity, art therapy, exercise, humor, movement therapy, music therapy, poetry therapy, reality orientation, reminiscence, and psychodrama groups, these also enrich the lives of residents and thereby change the atmosphere of the place. Various types of discussion, governing, and activities groups can also be organized to create an integrated therapeutic milieu. Johnson, Agresti, Jacob, and Nies (1990) described the
history of group work in the nursing home unit of a Veterans Affairs medical center that culminated in an ongoing weekly video program. That program, over time, created *therapeutic persona*—characters that are “outrageous, funny, and ridiculous, yet which represent some unacknowledged common experience of the residents. These characters then serve as the basis for an ongoing series of video skits” (p. 209). These authors hold that “the collective awareness of these characters provides an endless source of jokes and kidding during the week and serves to support an environment of intimacy among staff and residents” (p. 216), and that contributes to the building of a therapeutic community.

- Adelman, Frey, and Budz (1994) described the process of creating and maintaining the community spirit in a residential facility for persons with AIDS. During the entry phase, the newcomer is assisted through several formal strategies, including a buddy system, an orientation packet, support group meetings, and postentry interviews. The full participation of residents is facilitated through such strategies as weekly house meetings, a three-member elected residents’ council, private meetings between residents and the director of the facility, support group meetings, and postentry interviews. During the last phase, the resident is offered practical, psychological, and spiritual assistance in preparing for death, and others (residents and staff) go through elaborate community coping rituals.

4. To encourage families as active members in the lives of residents, a multifold approach is effective. We earlier discussed approaches to involving families in the planning and implementation of individual care programs, as well as those to help them sustain meaningful relationships with their institutionalized member. Family members can also function as volunteers, performing important chores within the nursing home or in the community on behalf of the nursing home. It is not uncommon for family members to offer assistance, for example, in such group activities as outings and trips for residents. Volunteers add an important element to the community spirit of the facility. Maximize communication between families and the nursing home. This should be done both formally and informally. One nursing home created a family information center in its main lobby (Conroy, 1994), where official communications, notices of upcoming events, health and welfare service announcements, and appeals for volunteers were displayed. Orientation and ongoing support groups serve several purposes. These enable family members to know the place, get acquainted with the staff, contribute to the care of their loved one, and understand how they can add to the quality of the place and its services. Devise arrangements whereby the contributions of families as volunteers are publicly recognized and appreciated.

Wildon (1994) discussed going beyond “home” and creating a hometown to generate a sense of community in the facility. Her nursing homes participate in July 4th festivities. Their efforts yield impressive results. “More than 20,000 fellow community service members take part in an old-fashioned Independence Day complete with car shows, kid games, local radio and television personalities and dignitaries, and fireworks—all on our campus” (p. 9). They also have an elaborate holiday gift-giving program and other Christmastime activities. Their presents-for-patients program matches residents without families with people in the community, who visit them at Christmastime and bring gifts (“Conference,” 1994). These activities give nursing home residents and their families a touch of the holidays to which the whole community has contributed.

There are also other ways of involving the community and expanding the world of nursing home residents. Identify the community ties that existed before their admission and reestablish those ties.

Many residents had group associations such as church or synagogue, veterans’ organizations, Golden Age Clubs, fraternal orders, and charitable or service organizations. Identifying those links to the community can lead to invitations for them to visit or to arrange for the resident to attend their meetings. (Brody, 1977, p. 268)
Social Worker as Community Liaison and Community Organizer

The strategies of community work we discussed in Chapter 4 are equally applicable for helping nursing homes extend themselves into the community. Here, we focus on the social worker’s role in helping the nursing home improve its image in the community. Starting with the assumption that a good image of an entity depends on its doing good, looking good, and letting the world know it is good, the social worker as a nursing home’s liaison with the community can adopt a multipronged approach. The following are a few suggestions on the “what” and “how” of that approach:

1. Help the nursing home in the provision of the best possible care that is resident centered, family involved, and community conscious. We have already discussed some ways of incorporating into their care the wishes and preferences of residents and involvement of their families. Attending to the total needs of residents, understanding and accommodating the needs of families, and involving families meaningfully in the care of their loved one impresses the families, who carry their positive impression into the community.

2. Mix and match the various strategies to make families believe that the nursing home cares about them and their need to maintain family integrity despite the placement of a member. Mintz (1994) recommended assessing needs, establishing a “buddy system,” starting a support group, establishing a caregiver resource center, inviting families to social events, suggesting a family council, encouraging family involvement with other residents/activities, designating family-staff liaisons, involving families in care planning, and making visiting easier. Build into the admission protocol a requirement for (a) asking every family about its greatest need and expectation for help, (b) processing that information, and (c) planning an appropriate intervention. The answers to most families’ needs lie in already existing services or arrangements.

3. Survey families of nursing home residents semiannually about their satisfaction with the nursing home services and their suggestions for improvement. Sample survey forms are available from the American Health Care Association Quest for Quality program (Wood, 1994). Also, institute a program for regular follow-up of discharged residents to see how they are doing and whether they are getting the needed community-based services. This follow-up can be done through telephone calls by volunteers. Share the findings of these family surveys and follow-up contacts with care providers at all levels, seek their reactions and suggestions for improvement, and urge management to take the same seriously.

4. Identify the unmet community needs for which the nursing home has the resources and initiate activities to meet those needs. The identification of needs can be accomplished informally through ongoing contacts with human services professionals and organizations, contacts regarding the coordination of services for specific clients or problems and issues of interest to the local professional community, or through formal needs assessment. In Chapter 4, we discussed approaches to needs assessment. Several areas of need can be explored. The combined efforts of the American Association of Homes for the Aging and the Catholic Health Association of the United States produced a document, Social Accountability Program: Continuing the Community Benefit Tradition of Not-for-Profit Homes and Services, that suggests a number of activities for responding to community needs (Trocchio, 1993):

- Services that can improve quality of life, such as offering intergenerational recreation programs, providing respite care, becoming part of a communitywide recycling program, and encouraging residents to volunteer in community charitable projects
- Services that can improve health status, such as screening blood pressure and other health conditions and teaching sessions on health promotion and disease prevention at health fairs, providing immunization services, helping with meals-on-wheels programs, and making space available for various self-help and support groups
- **Services that can improve accessibility to needed services**, such as providing information and referral services for such vulnerable groups as AIDS patients and the elderly, opening an adult day care, offering comprehensive assessment services to the elderly, initiating a physician referral program for physicians who participate in Medicaid, and working with other community groups to provide primary care for the homeless.

- **Services to help contain the cost of health care services**, such as offering free or discounted services to those unable to pay for them, donating unneeded equipment or food to homeless shelters and other programs, and becoming part of telephone reassurance programs for shut-ins or latchkey children.

- **Services that reach out to minorities, the poor, persons with disabilities, and other underserved persons**, such as opening child-care programs for families unable to pay full cost, teaming up with community schools to develop self-esteem programs for children with learning disabilities, providing internships for persons with disabilities from sheltered workshops, making facility vans available to disability groups, establishing an “adopt-a-grandchild” program with children of single-parent families, and operating a legal clinic for the community elderly.

- **Services that demonstrate leadership and the role of the facility**, such as offering rotations for medical, nursing, and other health professionals; participating in research on innovative ways of caring for patients; participating in efforts to reduce such problems as overmedication among the elderly; sponsoring radio and television talk shows on important issues; and sponsoring such events as a volunteer opportunities fair.

5. **Share with the nursing home administration the information about community needs, their extent, and the potential for the home to extend itself into the community.** The initiation of a new program requires consideration of many variables, including its financial viability and marketing. Provide meaningful input on many of these variables. Impressive literature is available on the establishment of long-term care services. For example, Henry (1993) described some important dos and don’ts of opening an adult day-care center.

Wood (1994) is of the opinion that, to enhance their image, nursing homes should choose one or two charity groups (e.g., Alzheimer’s Association, Arthritis Foundation, feeding the homeless) and assist them by raising money or donating staff time. Many such groups can use the services of social work professionals and the resources of local human service agencies. Be instrumental in the nursing home’s involvement in such groups.

6. **Let the public know about the agency’s efforts and accomplishments.** This can be done by (a) developing and distributing an annual community benefit report; (b) incorporating community benefit efforts in all the facility’s communication tools—newsletters, calendar of events, advertisement, bulletin boards, speeches to community groups, and other reports to the board and the public (Trocchio, 1994); and (c) taking advantage, for publicity, of opportunities that make the facility newsworthy and cultivating an ongoing relationship with the local media. Its innovative programs, community involvement, human-interest stories, and special celebrations make a nursing home newsworthy. Make the staff mindful of events that may be of interest to the general public and the media (“Conference,” 1994). Create an information file that lists the media (all newspapers, magazines, radio stations, television stations), appropriate contact persons, and requirements (e.g., formats for news releases, preferred types of stories, length restrictions, lead times, and deadlines for submitting items). Invite reporters to cover events or send news items and stories followed by notes of appreciation, provide them with accurate information in usable format, and help them meet their deadlines (Chapman, 1989).

7. **Undertake outreach educational programs targeted at families of potential nursing home residents.** Since the passage of the Patient Self-Determination Act of 1991, nursing home residents (and their families) are playing a larger role in decisions about their care. By encouraging the use of advance directives, the 1991 act extends the autonomy of patients into the period when they can no longer communicate. In most places, social workers are responsible for giving patients
information about the law, telling them about advance directives, inquiring about their choices, and having them sign the necessary papers. However, this is done at the time of admission.

Unfortunately, the sheer volume of paperwork involved in an admission meant that patients and family members often may not devote enough attention to such crucial question as who could serve as proxy decision makers if the resident cannot communicate. (Stoil, 1994, p. 8)

Although social workers implement this law, the community education part of its provisions is neglected. The lack of public education and inadequate attention given to this issue at the time of admission results in the family being forced into making a difficult decision in a crisis situation and experiencing conflict with the nursing home. Social workers can minimize these problems and enhance the image of the nursing home by undertaking outreach educational programs targeted at families of potential nursing home residents.

Social Worker as Recruiter of Community Residential Care Providers

Community residential care facilities are the best solution for those who have no families or whose families can no longer care for them at home and who do not belong in a hospital or a nursing home. The availability of these facilities can also be reassuring to elderly parents unable to continue caring for their middle-aged child with mental retardation. “The knowledge that family life and a sense of stability will go on without a need for institutionalization can also alleviate fears held by the disabled person” (Sherman & Newman, 1988, p. 171).

The prospect of going to a family-like environment is also reassuring to the elderly who are ready for discharge from a hospital but cannot go home and do not want to go to a nursing home. For many old and disabled persons, foster care can at least postpone, if not prevent, nursing home placement. In view of the advantages of this type of care, there is the need to create more foster care settings for the frail elderly and persons with mental illness, mental retardation, and developmental disability. Although foster care has a long history, the general public does not know of adult foster care. Social workers in hospitals, social service departments, and agencies serving the elderly and persons with mental illness and mental retardation must consider the development and promotion of this type of care as an essential part of their professional responsibilities. Here are a few helpful suggestions:

1. Explore ways of educating the public about the need for families and individuals willing to provide this type of care and to receive the satisfaction of providing care. Approaches to public education can range from mass media communication to word of mouth. Discussing New York State, Sherman and Newman (1988) stated that recruitment is primarily by television and radio public service announcements (PSAs), newspaper advertisements, transit cards on subways and buses, and word of mouth. Lawrence and Volland (1988) recruited foster home caregivers through advertisements placed in the classified sections of city and suburban newspapers.

Although newspaper advertisements are not very expensive, PSAs on radio and television are free of cost, and the audience reached is large. Under the Communications Act of 1934, radio and television stations licensed by the Federal Communications Commission were required to give free time to PSAs, and the time devoted to this public service was taken into consideration when their licenses came up for renewal. During the Reagan administration, that requirement was changed so that radio and television stations are no longer required to air PSAs. Most stations, however, still provide this service. If their agency does not have a public relations department, social workers can take on the job of preparing and having a PSA aired. This involves a twofold action: (a) preparing a statement, rehearsing it, and tape-recording it, and (b) calling the radio station newsroom, identifying oneself, and giving the statement.
If the station airs the announcement, send a letter of thanks. If it does not, write and ask why (Klein & Danzig, 1985).

Besides the use of mass media, selling the idea of adult foster care and recruiting of foster families can be done through talks and presentations at churches, offices for the aging, and parent-teacher association meetings (Talmadge & Murphy, 1983). Use creativity and imagination in deciding the “what” and “how” of these presentations so that they are audience appropriate. Stress the benefits of such care for both the provider and the receiver.

Foster family care doesn’t require extensive outlays of money for bricks and mortar; rather, it takes advantage of the spare bedrooms of empty-nesters, widows and widowers, and others who can so usefully contribute to the lives of the less fortunate, and in the process enhance their own. (Heckler, 1984)

2. In response to the PSA, newspaper advertisement, or talk given at a meeting or from an acquaintance, some potential care providers will contact the worker’s agency for more information. Express an appreciation for their interest and arrange for an in-person interview with them at their home. Use the visit to their home for a threefold purpose: (a) giving information about foster care and expectations from the caregiver, (b) assessing the person’s values and nurturing skills, and (c) determining the appropriateness and adequacy of the home for accommodating persons with special needs. Give them information about the range of people needing care, the needs of these people in general, the efforts made to match persons needing care and the caregiving family, and the type of support that will be available from the worker’s organization and what can be expected from other local health and human service agencies.

The general consensus is that no particular set of demographic variables combines to make an ideal foster care provider. Therefore, look for indicators of such intangible qualities as concern for others, desire to help, urge to give, empathy, and ability to nurture. These may be reflected in the interactions of the potential care provider with children and family members and the responses to questions about the motivation for the new role. With his focus on family foster care for persons with chronic mental illness, Carling (1984) listed the following among those who are usually screened out as care providers: (a) people who depend on foster care for their principal source of income, (b) people with criminal convictions, (c) current service providers (because of potential conflicts of interest), (d) people with other family members not supportive of family foster care, (e) people with grossly inappropriate or unhelpful beliefs, and (f) people who want to be “therapists.” Similarly, look for the adequacy of the physical environment and setup of the place, with an eye to its potential for becoming a home for a stranger.

Social Worker as Trainer of Community Residential Care Providers

Despite their importance, the desire and willingness to take on the role of a caregiver for a vulnerable stranger are not enough for the effective performance of that role to the satisfaction of all concerned. Training becomes an important variable that can make caregiving a satisfying and successful endeavor. As the professional responsible for training of care providers, the social worker should consider the following suggestions:

1. Make the training a multipurpose activity. Training can be used as an extension of the recruitment effort for screening potential caregivers. It should be used for creating and maintaining a positive relationship with the care provider. It should be so structured that various foster care providers are encouraged to get to know one another and to form an informal peer support system. The formal coming together and informal ongoing contacts among care providers thus generated can lead to their organizing themselves as advocates for their needs and for greater recognition of their contribution to the field of health care.
2. **Let the principle of flexibility guide their choice of the “when” and “where” of training sessions.** Make it convenient for care providers to attend as many sessions as possible, and also give them incentives to do so. The incentives may be in the form of assistance with transportation, recognition for their service, and coverage of care during their absence from home (Carling, 1984).

3. **Make the content of the training appropriate for the caregiving role.** Important variables that should be considered include the needs of the residents for whom these care providers are or will be caring, their educational background, their health-related knowledge, and their caregiving experience. It is wise to do a simple needs assessment and make that the basis for topic selection. The topics generally considered essential for such training can be clustered into the following groups:

- **Safety and crisis care:** home hazards and accident prevention, first aid, and emergency assistance
- **Drug management and medical treatment:** administration of medication, effects and side effects of medications, common diseases (e.g., in the elderly), signs of illness, infection control, and medical follow-up
- **Food and nutrition:** basic nutrition and special diets
- **Activities of daily living:** basic personal care, use of adaptive equipment and aids, client independence, and realistic expectations
- **Issues related to chronic illness and aging:** experience of losses (sensory and social), depression, mental confusion, aging process, behavioral aspects of mental illness, and death and dying
- **Caregiving and help seeking:** stresses of caregiving, effects of caring on the family, dealing with stress, problem solving, and using community resources (Carling, 1984; Oktay & Volland, 1981; Sherman & Newman, 1988; Sylvester & Sheppard, 1988)

In the foster care program for the frail elderly developed by Johns Hopkins Hospital, the training lasted a week, and at the end of the training course, “potential caregivers were tested on items such as patient’s personal care, diet, common illnesses, CPR, psychosocial and emotional needs. Those who passed the test were ready to be matched with an appropriate patient” (Lawrence & Volland, 1988, p. 28).

4. **Involve professionals with knowledge and expertise in the areas to be covered in the training.** For hospital-based social workers, it is not likely to be difficult because all professionals are directly or indirectly interested in early and appropriate discharge of patients and will be willing to contribute to the development of new residential care facilities. Social workers not associated with hospitals will need to use their contacts with human services professionals in the community to stretch the resources of their agency for training.

### Social Worker as Provider of Support and Monitor of Quality of Care

 Provision of ongoing support is a necessity for the success of long-term care. When a family begins taking on this responsibility, the need for support is extensive. Vandivort, Kurren, and Braun (1984) considered the first 3 months crucial. During this period, the caregiver is adjusting to a new role, and the resident is adjusting to a new environment. This support can take the form of (a) the worker’s frequent visits (at least once a month), (b) easy availability between visits, (c) help in identifying and articulating the resident’s needs, (d) assistance with designing a plan for care, (e) linking the caregiver with other sources of services for the resident, (f) quick and appropriate response to crisis situations, (g) aid in organizing and keeping the minimal record of care expected or required by the state certifying or licensing agency if applicable, (h) arrangements for respite and backup care, and (i) periodic retraining or refresher programs. Here are a few suggestions:

1. **Mix and match the various forms of support to address the specific needs of care providers.** Let the principle of individualization of people,
their needs, and circumstances guide the selection and combination of the various modes of support. The Caregiver Well-Being Scale (Berg-Weger, Rubio, & Tebb, 2000) is a comprehensive instrument that can be used for assessment, intervention, and evaluation of social work support of family caregivers. “The scale addresses caregiver’s emotional status, physical needs, spiritual or reflective times, special contacts and supports, and whether she or he is able to maintain a personal living environment on a daily basis” (p. 261). Consider using it as needed.

2. Handle the crisis situations carefully so that the crisis becomes a source of new insight, strength, and positive change. View the client, other residents, and the care provider as all in “crisis” during an emergency and conduct a “postincidence” evaluation to identify what could have predicted the crisis and what could be alternative responses (Carling, 1984).

3. Remember that quality of support is often more meaningful and helpful than its quantity. Try to convey the message that staff are there to strengthen the care provider’s commitment and ability to care and that the caregiver, the resident, and the worker are a team bent on deriving the best results from the joint effort.

4. The quality of care will depend on the combined effect of training, support, and other factors, such as matching of residents and caregivers and continuous monitoring of the care arrangement. Matching is a difficult task, particularly in the beginning, when there is no good intuitive feeling for the care provider and his or her home. Until the social worker gets to the stage in the relationship with the care provider when she or he knows what type of resident would fit into that provider’s home, it will be helpful to (a) solicit from the care provider information about what type of resident would be ideally desirable; (b) share with the care provider as much information about the prospective resident as possible, while protecting the need for privacy and confidentiality; (c) give the prospective resident a clear picture of the foster home; (d) arrange for the care provider to meet the client/patient in the hospital; (e) arrange, whenever possible, for a visit of the prospective resident to the caregiver’s home to give both a chance to decide whether the arrangement is suitable (Sherman & Newman, 1988); and (f) consider as many of the following prospective resident’s characteristics and preferences as possible:

- Personality characteristics
- Social interests
- Personal habits
- Gender
- Race
- Religion
- Cultural factors
- Smoking
- Pets
- Children
- Location
- Medical needs
- Mental health needs
- Rehabilitation needs
- Support service needs
- Alcohol/drug problems
- Wheelchair accessibility (Carling, 1984)

Assurance of quality of care in a safe and healthy environment will result from several efforts. Use follow-up visits to the foster home to provide support and give necessary direction and supervision to the caregiver. In one study, Sherman and Newman (1988) found that about two thirds of care providers considered personal follow-ups beneficial to both residents and providers. The visits should be scheduled as well as unscheduled.

Review the resident’s progress and care plan periodically, and modify it in view of his or her changing condition and needs, if needed.

Get to know the residents well enough for them to talk candidly. They can add to the validity
of impressions about the quality of care and the success of placement.

Most residents are likely to have health care needs requiring the services and involvement of several agencies and professionals. Act as the case manager and use the opportunities provided by that role to monitor the effectiveness and efficiency of the foster home as part of the total package of care.

5. Because adult foster care has no uniform licensing standards (Oktay, 1987), push for the certification of family foster care in the state if it does not license or certify this type of care. Most presenters at a workshop on family foster care favored “a ‘certification’ approach in which states or local agencies had flexibility in decertifying providers, viewing the certification as a privilege, rather than a right” (Carling, 1984, p. 15).

6. Encourage the caregiver to join a professional group, such as the National Association of Residential Care Facilities. Membership in an organized group can be a source of heightened morale, pride and professionalism, support and strength, and training. Professionalism provides a self-propelling force for commitment to providing high-quality care.

Social Worker as Contributor to the Agency’s Continuous Quality Improvement

Before we discuss the knowledge and skills necessary for social workers to assume this contributor role, let us briefly look at the concept of “continuous quality improvement” (CQI) and its methodology. This concept was developed in the 1930s by W. Edwards Deming and Joseph M. Juran and was originally implemented in manufacturing. In the late 1980s, its relevance to the health care industry began to be realized (Balinsky, 1994), and as O’Leary (1991a) explained,

American industry is a, if not the, major purchaser of health care. And like any good American group, they are quickly deciding that what is good for them is good for you as well. In this case, I would suggest that they are right. (p. 72)

Quality assurance (QA), the approach to quality in health care until then, was punitive in its mind-set, outlier oriented, inefficient, and frustrating. In contrast with QA as a “blame-fixing” activity, CQI is seen as an organization-wide way of life (O’Leary, 1991b). QA separated production (the service-providing unit) from inspection (the QA department), and responsibility for quality (the QA committee) from authority (the service). This separation (a) undermined teamwork, (b) delayed feedback, (c) increased cost of data collection, and (d) communicated a less than total organizational commitment to quality (Eskildson & Yates, 1991).

Quality in health care is a multifaceted and multidimensional phenomenon. Dimensions include accessibility, appropriateness, effectiveness, continuity, efficacy, and efficiency of care. Quality is also the safety of the care environment, acceptability of care as judged by the patient and family, and the qualitative interactions between patient/family and care providers (Balinsky, 1994; O’Leary, 1991a). It is believed that CQI will positively affect all facets and dimensions of quality. Eskildson and Yates (1991) considered TQM (total quality management) a new paradigm:

Important components of the new paradigm include commitment to an unrelenting focus on customer satisfaction, continuous improvement, employee involvement, “management by fact” (including the use of statistical process control), effective internal and external teamwork, emphasis on prevention (rather than inspection), cycle-time reduction, and widespread staff training in multiple areas affecting quality. (p. 38)

The basic principles of TQM according to Deming (1986) are as follows:

1. Create constancy of purpose for improvement of product and service.
2. Adopt the new philosophy of doing things right the first time.
3. Cease dependency on inspection to achieve quality.
4. End the practice of awarding business on price tag alone.
5. Improve constantly and forever the system of production and service.
6. Institute training on the job.
7. Begin leadership for system improvement.
8. Drive out fear; create trust.
9. Break down barriers between staff areas.
10. Eliminate slogans, exhortations, and targets for the workforce.
11. Eliminate numerical quotas for production; institute methods for improvement.
12. Remove barriers to pride of workmanship.
13. Institute a vigorous program of education and self-improvement for everyone.
14. Put everyone to work to accomplish this transformation.

The technology of CQI involves use of the following:

1. **Teams**—these are of three types: (a) cross-functional improvement teams, (b) quality circles, and (c) process improvement teams (Keys, 1995)
2. **Methods** such as Plan-Do-Check-Act or Plan-Do-Study-Adjust cycle and benchmarking involve identifying the best practices, studying their applications, and applying them (McCabe, 1992)
3. **Supportive infrastructure**, which is created through vertical alignment, horizontal process management, and independent assessment (McCabe, 1992)
4. **Statistical tools** such as a flow chart, cause-and-effect diagram, control chart, and Pareto diagram (Burr, 1990; Sarazan, 1990; Shainin, 1990)

Social workers in home-based and near home-based long-term care agencies should seize the opportunity offered by these agencies’ need to move toward CQI and provide leadership to their efforts. They have an edge over professionals from many other disciplines.

Applying their existing skills or building on them will ensure their readiness for the job. Their basic team-building and teamwork approaches can easily be adapted for CQI. The Plan-Do-Check-Act cycle is similar to the problem-solving process they have thoroughly grasped and practiced. Their understanding and skills for organizational work can help their agency become supportive of the CQI philosophy through structural and procedural changes. Methods of vertical alignment and horizontal process management can be incorporated into their organizational skills. Brushing up on their knowledge of statistical data display techniques would enable them to use the appropriate statistical tools for CQI. The following are some helpful suggestions:

1. **Consider the patient in the same way as a customer is considered in industry.** The application of the TQM approach to health care requires this, with regard to quality.

   Quality is a customer determination, not an engineer’s determination, not a marketing determination or a general management determination. It is based on the customer’s actual experience with the product or service, measured against his or her requirements—stated or unstated, conscious or merely sensed, technically operational or entirely subjective—and always representing a moving target in a competitive market. (Feigenbaum, 1983, p. 7)

2. **View and involve clients as active partners in the quality improvement work.** This task is difficult in health care because, traditionally, quality has been defined by the provider. A distinction is made between the technical and interpersonal aspects of health care to limit the patient’s involvement in quality assessment. It is assumed that the patient is unable to understand the technical aspects of care (Lehr & Strosberg, 1991). This situation will gradually change as, on the one hand, clients become better-educated consumers of health care services, more informed of health care techniques and procedures, more demanding of choices and options, and more conscious of their rights, and as, on the other hand, health care providers start acknowledging and appreciating the role that patients, their families, and other
informal helpers play in the recovery and/or management of patients. Social workers should realize the advantage they have over other professionals. They have been trained to treat their clients as equals, and educating and empowering them are the major social work approaches to enabling clients to exercise self-determination, solve their problems, and manage their lives.

3. Help agencies institute a threefold approach to involving clients in the CQI endeavor: (a) service protocols that require client input into all aspects of care; (b) continuing education for professional and paraprofessional service providers on techniques of encouragement, involvement, and empowerment of clients; and (c) ongoing supervision and support for service providers in the field. Besides these organization-level contributions, social workers should monitor their clients as part of the quality improvement work of the agency.

4. Recognize that, for CQI, all parts of the organization—service management as well as maintenance management—are equally important. The spirit of quality not only should be visible in the clinical and technical services but also should pervade the total organization. Studies by Bowen (1985) found that (a) a strong correlation exists between customer and employee views of service quality and the internal climate for service; (b) when employees view an organization’s human resource policies favorably, customers view the quality of service they receive favorably; (c) a positive work climate directly affects customer service for the better; and (d) human resources is an excellent vehicle for satisfying both employee and customer needs.

The concept of “customer” is much broader in TQM philosophy. It applies internally as well as externally. External customers for a home care agency include patients, families, payers, volunteers, and the community. All employees of the agency are its internal customers. All persons and units function as both “producers” and “customers” at every level and in every process of an organization (Re & Krousel-Wood, 1990). Involvement of both external and internal customers is necessary for CQI. Feedback mechanisms should be developed for different groups of external customers. Constant effort should be made not only to involve the internal customers but also to develop their full potential. This can be facilitated by such enabling principles as (a) setting clear expectations; (b) maintaining skills and providing resources; (c) providing feedback as a learning tool; (d) granting authority to act; and (e) providing encouragement, support, and recognition (McCabe, 1992).

The creation of a culture of quality and a supportive infrastructure is extremely important for CQI. Social workers can contribute to this task as advisers, technical experts, and team players. The following are a few helpful strategies:

- The agency must develop a definition of quality that is meaningful for and is understood by everyone. Management must emphasize that quality improvement is an ongoing effort and look for opportunities to demonstrate its full support for quality (Sahney & Warden, 1991). Although TQM is a participatory and decentralized approach to quality, the involvement of management must be intense and in detail in top-down priority setting and modeling (Eskildson & Yates, 1991; Kaluzny & McLaughin, 1992).

- Identification of problems should be considered an opportunity for improvement and not a means for laying blame. “Long-range thinking and planning should replace the focus on short-term results” (Sahney & Warden, 1991, p. 9).

- Vertical alignment will aid in the creation of a supportive infrastructure for quality. Vertical alignment means that everyone in the agency from top to bottom understands what the agency is trying to accomplish and how he or she fits into the big picture. This shared understanding becomes possible through the linking of goals, plans, and responsibilities from the top through all departments to each individual (McCabe, 1992). All goals, plans, policies, and procedures should aim at supporting the agency’s mission. Constant efforts should be made for improving communication throughout all levels of the organization and increasing opportunities for meaningful involvement of all employees.
It is better to focus on important processes involved in the agency’s work than on the people in those processes. Horizontal process management is aimed at improving the processes. As processes cut across departmental boundaries, this is best accomplished by a team of process implementers. “The team must be given the responsibility and authority to define and control its processes, to assess performance of the processes, and to modify the processes based on assessment findings” (McCabe, 1992, p. 137). This strategy has been presented as a nine-step methodology:

1. Find a process to improve.
2. Organize a team that knows the process.
3. Clarify current knowledge of the process.
4. Understand source of process variation.
5. Select the process improvement.
6. Plan a change or test.
7. Carry out the change.
8. Check and observe the effects of the change.
9. Accept, adopt, or modify the plan (James, 1989).

Keep abreast of the literature on the implementation of CQI in the health care field. Many hospitals and other health care organizations are making impressive efforts in this regard (e.g., Dimant, 1991; Graves & MacDowell, 1994–1995; Re & Krousel-Wood, 1990; Sahney & Warden, 1991). It would be wise to learn from their experience.

Social Worker as Case Manager and Service Coordinator

Case management is likely to continue to expand in a variety of delivery systems. Social workers should seek jobs in home-based care agencies, as well as in near home-based service agencies. In the former, they will be able to take on case management responsibilities; in the latter, they should apply their case management skills to such jobs as agency director, program planner, and direct service provider. They should keep themselves abreast of the emerging literature on the “what,” “why,” and “how” of long-term care case management. Gerson and Chassler (1995) described a 15-month project to develop case management practice guidelines. A national advisory committee was created that formulated several basic principles of case management [3]. Hyduk (2002) described the essentials of 11 community-based long-term care case management models for older adults and compared those models on a number of criteria. The models included in her analysis are (1) the National Long-Term Care Channeling Demonstration, (2) PACE (Program of All-Inclusive Care for the Elderly), (3) Social HMO, (4) Project CARE (Community Action to Reach the Elderly), (5) HMO case management, (6) CBLTC (Community-Based Long-Term Care), (7) modified CBLTC, (8) GEM (geriatric evaluation and management), (9) GEM–VA (geriatric evaluation and management–Veterans Affairs), (10) postacute case management, and (11) Physician Practice Case Management. Her analysis revealed great variation in the definition of frail older adults; that the majority of the models did not include important psychosocial variables; that many did not discuss the extent to which older adults and their caregivers are involved in decisions regarding the care process; and that most did not discuss minority status—ethnicity and other attributes of the minority elders. She urged gerontological social workers to recognize the strengths that they bring to the case management role and to embrace that role.

Some case management strategies were presented in Chapter 5. Here, we discuss more ideas regarding case management that are likely to be helpful.

Despite its popularity, case management lacks precise definition. There is no consensus on its exact nature and purpose. It can be viewed narrowly or widely. “It can be a gatekeeping mechanism to control costs and access; it can be an advocacy function to increase access to services...
and navigate a confusing array of services; or it can serve a diagnostic and prescriptive function” (Williams, 1993, p. 7).

Starting with the assumption that the underlying structure of a program’s financing has a fundamental impact on its services, Applebaum and Austin (1990) identified three models of case management: (a) the broker model, (b) the service management model, and (c) the managed care model. Case managers under the broker model do not have service dollars to spend on behalf of their clients. They develop care plans and make referrals for services from the existing service system. Under the service management model, case managers have access to funds, develop care plans, and authorize services within the predetermined cost caps. The managed care model is based on prospective financing that creates “provider risk.” Financial responsibility and liability for expenditures are shifted to provider agencies. This puts pressure on the care planning process, creating incentives for the provider to control cost. Social workers should make their understanding of these models of case management serve their agency’s mission and program objectives. We discuss social work’s role in managed care in Chapter 8. Here, we focus on the broker model of case management.

The most generally accepted components of case management are (a) eligibility determination—financial, medical, and other; (b) level of care determination; (c) assessment of needs, including medical, physical, functional, and psychosocial; (d) place of care determination; (e) care plan development; (f) service prescription or arrangement; (g) coordination of services from multiple providers; (h) budget planning for service units, time periods, or episodes; (i) reassessment of needs; (j) monitoring of delivery and quality of service; and (k) support to family (Williams, 1993). Not all programs incorporate all these functions. In home care programs, for example, the typically covered functions are assessment of needs, planning of appropriate services, ordering or provision of services, monitoring and evaluation of services, and reassessment of the need situation.

Home care programs are offered by many agencies—home health agencies, multiple-service health care providers, free-standing case management agencies, and Area Agencies on Aging. Home health agencies provide nursing and other skilled services, such as physical, occupational, and speech therapy, and home-health aide services. On the one hand, they have historically used a community health nursing model, in which the nurse goes into the home and family setting and performs the assessment, care planning, advocacy, and other roles. On the other hand, Area Agencies on Aging have traditionally focused on social services, meals on wheels, senior activities, and advocacy to the exclusion of health services (Williams, 1993). Social workers should recognize the inherent deficiencies of these models. They should make concerted efforts to move toward a model that combines and coordinates a wide array of health and social services. The integrated health/social service model (Brody, 1977) can be a good guide. That model includes the following services:

- **Maintenance services** include income maintenance and personal maintenance. Income maintenance is secured through such programs as Supplemental Security Income, Social Security, veterans’ benefits, workers’ compensation, and food stamps. Homemaker services, home-delivered and congregate meals, and chore services constitute the personal maintenance services.
- **Personal care** is provided through the services of home-health aides representing many public and private health care agencies.
- **Supportive medical services** include nursing; physical, occupational, and speech therapy services, generally provided by hospitals; health clinics; public health departments; and visiting nurse organizations.
- **Personal planning** includes counseling, advocacy, community resources mobilization, and protection services provided by social workers through family service agencies, state social services organizations, community mental health centers, and home health care and vocational rehabilitation agencies.
- **Linkages** include such services as information and referral, transportation, outreach, telephone alert, and friendly visiting services.
Even single agencies can offer packages of the needed health and social services. In some areas, the Area Agencies on Aging are capable of running comprehensive long-term care programs, and some home-health agencies have broadened their scope by including services unrelated to health.

Social workers should consider the following principles of case management proposed by Williams (1993):

- **Only certain individuals should be case managed.** This service should be offered only to those who need it. Possible criteria for selection are (a) high risk because of physical and cognitive impairments and lack of family supports; (b) eligibility for nursing home level of care but electing community-based care; (c) complex care needs; (d) short-term posthospital care needs; (e) high-cost care needs; and (f) high risk for repeat hospitalization.

- **Assessment of service needs and case management are related.** Separating assessment from case management functions is likely to create confusion, delays, and duplication.

- **Case management has multidimensional requirements.** An interdisciplinary approach to staffing is needed. At a minimum, medical and social services must be available; other consultant services could be contracted for.

- **Case management is a team effort.** Links with many types of community agencies, including hospitals, housing providers, meal providers, and others, must be forged.

- **Equity assurance is important in case management.** Services must be distributed equitably among similar clients. “A major goal of case management should be to serve the neediest and spread available resources to do so in a judicious way” (p. 27).

- **Cost control is part of case management.** Incentives for controlling costs must be built into the system.

- **Quality assurance is essential.** QA mechanisms should be made an integral part of both case management and services. These may include the use of standardized, specific, and generally understood criteria, supervision, and quality reviews.

The broker models of case management, which emphasize referrals and linkage, generally within one service sector, are most common in long-term care settings. Even these models are often provider driven rather than client driven. Rose and Moore (1995) brought out the differences between the client-driven and provider-driven approaches. Whereas one (client-driven approach) views clients as subjects, the other (provider-driven approach) views them as objects; one looks for strengths to develop, and the other identifies problems and pathology to manage; one seeks active participation, and the other encourages compliance; the goals of the one are positive direction and self-confidence, and those of the other are improved patterns of service consumption and patient role behavior; the needs assessment is derived in one from the client’s direction, plan, and goals, and in the other from the service provider’s definitions and outputs; resources to be linked are seen in one as the total community with all its formal and informal networks and in the other as existing formal service providers; monitoring in one involves mutual evaluation of process in relation to direction plan and in the other compliance with treatment plan; and evaluation in one emphasizes increasing autonomy, growing self-confidence, and involvement with informal networks, and in the other increased units of service consumed, use of fewer inpatient days, and improved compliance. Because of their philosophical orientation and as a result of their professional training, social workers are most suited to practice client-driven approaches to case management. They should make sure they are seen as the model, as well as a source of formal and informal training, for client-centered and client-driven approaches in the agency.

In Chapter 5, we discussed strategies and techniques of brokering. Here, we reemphasize that social workers should (a) keep an updated directory of all the formal and informal resources in their community, (b) know the agency eligibility criteria for benefits and services from all the formal sources of assistance, (c) keep themselves abreast of legislation and regulations that are likely to affect policies and procedures of major agencies and programs, (d) develop an awareness of such characteristics of major
agencies as the degree of flexibility in accommodating client problems (some agencies are extremely formal and rulebound, whereas others are willing to bend the rules), (e) get to know the contact persons in as many resource agencies as possible, and (f) become involved in the community.

Join a service club, participate in community meetings, sit in on city council meetings, or attend major community events (pancake day, fireman’s chicken dinner, Fourth of July celebration, etc.). These activities will increase your knowledge of community resources and enlarge the circle of people you can call upon in times of need. (Kirst-Ashman & Hull, 1993, p. 497)

Although the case manager’s role involves brokering, case management is more than brokering. The client’s needs may require more services than are brokered for. The case manager must ensure that those needs are met effectively and efficiently. A commitment to the following principles articulated by Gerhart (1990) would be helpful:

- **Individualization of services** requires that services be developed or designed specifically to meet the identified needs.
- **Comprehensiveness of services** means that the services address needs in all areas of the client’s life.
- **Parsimonious services** means that services are well-coordinated, unduplicated, and cost-effective.
- **Fostering autonomy** requires that services and the way they are provided encourage maximum client self-determination.
- **Continuity of care** demands that case management services monitor the client’s needs as he or she moves through different settings of care—institutional and community.

Social workers as case managers should give credit to family and other informal caregivers for their work with the elderly and the disabled and “the imaginative way ordinary people invent solutions to problems that disability creates in everyday lives” (Kane, 2001, p. 294). They should also show special sensitivity to the needs and situations of those families. Family caregivers live 24 hours a day, 7 days a week with their caregiving responsibilities, struggling to balance their own needs and those of the ones they care for. Caring for a chronically ill person takes its toll in the form of such problems as family disruptions, psychological stress, physical fatigue, social isolation, financial and at times legal difficulties (Dhooper, 1991), and intrafamilial conflict. With her focus on the effects of Alzheimer’s disease, Gwyther (1995) described four types of family caregiving conflicts: (a) normative conflicts around the limits of family solidarity, (b) conflicts arising from family members’ disapproval of other members’ actions or attitudes toward the patient, (c) conflicts from disagreement over the nature and seriousness of the patient’s impairment and the most appropriate care, and (d) conflicts from perceptions that less involved family members either do not appreciate the extent of demands on the primary caregiver or disapprove of the quality of care being given. They should assess the total familial situation and appropriately address the conflicts, problems, and stresses that a family may experience.

**Social Worker as Contributor to Improving Hospice Access to People Living in Rural Areas**

As pointed out in Chapter 3, terminally ill living in rural areas are less likely to be served by hospice than are their urban counterparts. A review of relevant literature revealed a number of reasons why that is so. We group these reasons into three categories: (1) environment-related, (2) people-related, and (3) hospice-related reasons. A brief listing of these precedes our discussion of social work’s role in helping hospice improve its access to people living in rural areas. Most of the material is drawn from Burg et al., 2010; Casey, Moscovice, Virnig, and Durham, 2005; Community-State Partnerships to Improve End-of-Life Care, 2001, 2002, and 2003; Dunham, Bolden, and Kvale, 2003; Gage et al., 2000; and Haxton and Boelk, 2010.
Environment-related barriers:

1. Rural communities have higher rates of poverty and more uninsured individuals (National Advisory Committee on Rural Health and Human Services, 2008), which result in families having fewer resources for end-of-life care of their members.

2. Distance from specialized medical care denies rural dwellers easy access to diagnosis and treatment of life-threatening and terminal illnesses.

3. There is a general lack of community resources, including health and human services, in rural areas and a lack of easy access to the available resources.

4. Long distances between the hospice base location and the rural patient’s home (combined with severe winter weather and/or seasonal flooding in many parts of the country) make travel difficult, time-consuming, expensive, and risky, particularly in remote areas.

5. Nonavailability or high cost of medications and medical supplies at local pharmacies puts extra strain on the financial resources of hospice.

6. Local area hospitals, nursing homes, and home health care agencies tend to view hospice as competing with them for patients as well as for locally available health care professionals.

People-related barriers:

1. Most rural folk are independent, self-sufficient, and private.

2. They are used to not having services.

3. They tend to distrust outsiders and formal programs or do not want to abuse the “system.”

4. Most of them do not know of hospice and hospice services.

5. They believe that local physicians caring for them should meet all their needs.

6. Local physicians are less inclined to refer their terminally ill patients to hospice, either because they do not know about hospice or do not want to lose control over their patients’ care.

Hospice-related barriers:

1. Most rural hospices have low patient volume that makes it hard for them to fund full-time staff positions. They also have difficulty hiring staff willing to travel long distances in remote areas.

2. They have difficulty retaining staff because most home-based care is labor-intensive and puts staff at risk for burnout and compassion fatigue. Staff members who belong to local communities have the extra burden of providing end-of-life care to their neighbors and friends.

3. Providing hospice care in rural areas is financially straining. Medicare pays hospices a capitated per diem for delivering almost all the services needed in a day to treat a patient’s terminal illness. Furthermore, Medicare per diem rates are lower for rural hospices.

4. Financial problems also arise because rural hospices have fewer patients to spread fixed costs, and they cannot benefit from economies of scale in purchasing medications and medical supplies.

5. Late referrals to rural hospices result in shorter lengths of stay in the program, and that also causes extra financial strain because first and last days of service are most costly.

6. Long distances and other logistics problems make it difficult for rural hospices to coordinate care.

The above categorization of barriers into environment-related, people-related, and hospice-related reasons makes understanding these barriers easier, but in reality, all these intermingle and overlap to make it hard for hospice organizations to provide high-quality services in effective and efficient ways. The following observations and three sets of suggestions for social work contributions deal with all these barriers.

Two of the barriers—many rural dwellers lacking health insurance and nonavailability of health care services in rural areas because of long distances from medical diagnostic and treatment centers—are likely to become less formidable in
the future. As the various provisions of the Patient Protection and Affordable Care Act take effect, most poor in rural areas will become eligible for Medicaid and the spread of new health centers will bring health care closer. It is expected that wellness, illness prevention, early detection, and coordination of care among various settings of medical services will be the hallmark of those health care centers. Hospice social workers should include in their roles educating rural folk about their rights to health care under the new law.

Similarly, as responsible human service professionals working in an area, social workers can contribute to reducing another barrier—that is, lack of community resources or lack of access to available community-based resources. A study by Haxton and Boelk (2010) involving 339 hospice social workers from 34 states found that more than 70% viewed accessing community-based services (adult day care, mental health counseling, etc.) as very much or quite a bit of a challenge for providing social work services to rural hospice patients and families. Similarly, 60% of them considered accessing in-home services (home-delivered meals, supportive home care, etc.) very much or quite a bit of a challenge. Dealing with such challenges becomes a professional responsibility. In this study, responses to the question, “What approaches do you take to overcome challenges you face?” generated several themes.

Building relationships with other programs and professionals was perceived as even more important in rural areas, where resources are slim and fewer programs, services, and providers exist. Respondents believed that serving hospice patients and families in rural areas has to be more of a collective process involving others outside of the hospice program. (p. 542)

Establishing and maintaining regular contacts with professionals running the various health and human services programs in the area and creating a joint commitment to generating resources and improving the delivery system can go a long way to identifying needs, discussing problems, brainstorming solutions, and creating and coordinating resources.

All other barriers can be clustered according to three themes: (1) recruiting, retaining, and keeping hospice staff energized; (2) making and keeping hospices financially viable; and (3) educating rural families and physicians about hospice. Social workers will find the following suggestions helpful in dealing with each of these.

**Recruiting, Retaining, and Keeping Hospice Staff Energized**

Acknowledge the reality that the volume of work in rural hospices is not large enough to require a fleet of full-time staff. Therefore, look for potential part-time staff—individuals who have retired, are semiretired, or whose family responsibilities dictate that they work part-time. The need for and purpose of hospice is intuitively attractive to many professionals and volunteers. These can be used to appeal to the service ideal of potential employees.

If the hospice is a part of another organization such as a hospital, home-health agency, or public health department, explore the possibility of (1) employing staff from the parent agency, (2) sharing staff across programs, and (3) training staff to perform multiple roles. The first strategy will ensure that the hospice employees receive salaries and benefits comparable to similar positions in the larger organization. The second strategy is a viable solution for the fluctuations in hospice census. The third can be an adequate response to the problems of inadequate on-call coverage, travel-related expenses, etc. The Haxton and Boelk (2010) study found that the majority of social workers (57.4%) also functioned as bereavement counselors, intake coordinators, outreach coordinators, volunteer coordinators, and administrators. They can easily be role models for others in this regard.

Two dimensions of travel-related problems (i.e., long-distance travels putting physical strain on the hospice staff and economic strain on the hospice organization) can be significantly eased by (1) opening satellite offices in remote areas, (2) planning and coordinating travel to remote
areas that combines staff visits so that staff members travel together and the number of cars traveling is reduced, (3) scheduling all visits in one location on the same day, (4) deploying staff members living in communities closest to the patient and family, and (5) using telephone and other technologies (e.g., Internet) creatively to enhance the impact of in-person staff visits with patients and their families.

Retaining and keeping hospice staff energized can be done through (1) setting up a mentoring system for new employees (e.g., matching new nurses with more experienced ones); (2) maximizing communication among staff members through various means, formal and informal as well as in-person and electronic; (3) providing staff members the necessary instrumental support; (4) ensuring that all staff members get much-needed emotional support; and (5) acknowledging and reducing the risk of burnout and compassion fatigue in employees. Familiarize yourself with the growing literature on burnout, compassion fatigue, and compassion satisfaction, and draw practical ideas that can be implemented within your organization.

Making and Keeping Hospices Financially Viable

A threefold approach is needed that aims at (1) improving Medicare reimbursement for hospice services, (2) opening new streams of payment for hospice care, and (3) improving the efficiency of the existing financial resources of hospices.

1. Improving Medicare reimbursement for hospice services:
   - Know the following facts:
     a. Hospice is widely considered the first and a very successful managed care program in the country, and studies have shown that it is a more cost-effective care option than hospitals and skilled nursing homes. Buck (2006) compared hospital, skilled nursing facility, and hospice Medicare per-day charges for 1998 to 2005. Not only were the hospice charges impressively low—$131 compared with $521 for a skilled nursing facility and $4,787 for a hospital—but the growth in the cost of its care was negligible. It rose by only $18 over a 7-year period. Such cost-effectiveness of hospice has not been appropriately rewarded.

     b. The Medicare payment system for hospice care has remained largely unchanged over the years even though the gap between the actual cost of care and Medicare reimbursement for that care has been growing. Community-State Partnerships to Improve End-of-Life Care (2002) illustrated this gap with the example of the cost of drugs. Whereas per-patient-per-day cost was $15.00, the daily medication allowance was only $2.48.

     c. The average length of Medicare hospice patients’ stays in the program has been decreasing. The median length of stay in 2009 was 21.1 days, and 34.4% of patients died in 7 days or less that year (NHPCO, 2010).

     d. It costs rural hospices more to serve their clients than it costs their urban counterparts to serve theirs. Despite that, Medicare reimbursement to rural hospices is lower.

   - Generate and gather documented evidence.
     a. Make sure your organization maintains documentation of the actual cost of effective and efficient care (i.e., expenses incurred in serving rural patients and their families).

     b. Undertake and/or seek to participate in systematic research that shows the gap between the cost of care and reimbursement for that care, and proves the inadequacy of Medicare reimbursement.

   - Join existing coalitions (and/or form a coalition) and actively participate in their work for educating and lobbying members of the U.S. Congress for changes in the Medicare payment for hospice care system.

     a. There are several relevant organizations, such as American Hospice Foundation
(www.americanhospice.org/), Hospice Association of America (www.hospiceamerica.org/), Hospice Foundation of America (www.hospicefoundation.org/), National Association for Home Care and Hospice (www.nahc.org/), National Hospice and Palliative Care Organization (www.nhpco.org/), Hospice and Palliative Nurses Association (www.hpna.org), Medicare Rights Center (www.medicarerights.org/), and National Family Caregivers Association (www.nfcacares.org/). Find out what the priorities and agendas of these organizations are and how your organization can join forces with them. For creating a coalition, ideas and suggestions given elsewhere in this book will be helpful. Community-State Partnerships to Improve End-of-Life Care (2003) described the successes of coalitions in 21 states that brought about public policy reform, as well as implementing projects to educate and empower patients, families, and communities to advocate better end-of-life care; building clinical capacity among various professionals; and establishing mechanisms for quality improvement in hospitals and nursing homes. There are also examples of how to proceed. Haxton and Boelk (2010) suggested forming coalitions around end-of-life care similarly to the way Area Agencies on Aging were encouraged and funded through legislation to address pervasive social problems of the aging population.

b. In educating and lobbying members of Congress and their staff, the following positives about hospice and hospice care can be highlighted:

- The need of appropriate and adequate end-of-life care is universally recognized, and there is no political downside to this issue.
- The success of hospice as a managed care program is generally accepted and applauded.
- Hospice is a fully integrated system that provides highly skilled palliative care along with emotional, spiritual, and supportive care. It can be a model for a “best-practice” approach to other sectors of health care.
- Hospice represents a mere 1% of the Medicare budget (NHPCO, 2010).

c. The Medicare reimbursement system improvement can be done through several specific approaches or combinations thereof. These include

- raising per diem rates for hospice care;
- allowing for adjustments for case mix, urban/rural location, costly outliers, etc.;
- paying higher rates for care at the beginning and end of hospice stays; and
- paying different rates for the care of patients with cancer and noncancer diagnoses.

2. Opening new streams of payment for hospice care: This can be done through identifying and removing hurdles in the way of other sources of reimbursement for hospice care, such as state Medicaid programs and private health insurance, as well as increasing the sources and amounts of donations for hospices.

Most state Medicaid programs include hospice benefit for low-income residents under age 65. Some states do not provide Medicaid hospice benefit. Similarly, not all private insurance policies provide for hospice care. If so, state policymakers and government officials and/or insurance companies doing business in the state can be targeted for lobbying and education. They may yield to pressure and expand their coverage to include hospice care. The work of a coalition in Maine led to the passage of a law that (1) increased Medicaid hospice per diem from $106 to $130 per day for the last 6 months of life (Medicare plus 23%); (2) mandated comprehensive hospice coverage for the last 12 months of life in private insurance policies; (3) provided appropriation of $50,000 in each biennial budget to be divided among Maine’s voluntary hospices; and (4) mandated the creation of the Maine Center for End-of-Life Care (Community-State Partnerships to Improve End-of-Life Care, 2003).

Medicaid pays for care for about 8% of hospice patients, but many inconsistencies are built into this benefit. Many elderly dying patients in
nursing homes do not benefit from hospice care because of those inconsistencies. Situations differ when a patient is eligible for both Medicare and Medicaid programs and when he or she is eligible for Medicare only. When such a patient who is eligible for both Medicare and Medicaid is referred to hospice, Medicaid considers the hospice the primary caregiver and the nursing home the supplier of room and board. Medicare pays for the hospice care, and Medicaid pays the hospice 95% of the nursing home’s room-and-board rate. In such a situation, hospice must pay the remaining 5% of the nursing home’s room-and-board charge. When a patient is eligible for Medicare only and is in a skilled nursing facility, the skilled nursing facility benefit pays for the first 21 days and for the next 22 to 100 days the patient is responsible for copayment until the patient spends down his or her assets and becomes eligible for Medicaid. For a dying patient in a skilled nursing home who is eligible for Medicare only, hospice care would cost a whole lot, as he or she would be responsible for the total cost of room and board. Moreover, because Medicaid payment for nursing home care is much lower than payment under Medicare, nursing homes benefit if a new cycle of skilled nursing facility benefit begins. This often works against a referral to hospice for the patient on Medicare who had become eligible for Medicaid (because of spend-down). Instead of being referred to hospice, the patient ends up in a hospital (Community-State Partnerships to Improve End-of-Life Care, 2002).

The nature and quality of hospice care speak for it. The recipients of hospice care—patients, families, and others—are positively impressed and become the sources of or catalysts for donations to hospice organizations. Social workers should encourage their hospice to recognize, appreciate, and encourage that tendency in potential donors or helpers. They will find the suggestions for fundraising given in Chapter 6 equally beneficial in undertaking this work for their hospice organization.

3. **Improving the efficiency of the existing financial resources of hospices:** Social workers should explore or become instrumental in exploring all means of reducing the financial impact of operating in rural areas. The following are a couple of the possibilities:

- Use the pharmacy of the parent organization, such as a hospital or public health department, to buy medications or join a network of pharmacies (rather than the hospice maintaining its own); group purchasing reduces the cost of drugs and medical supplies.
- Institute the travel-related changes we discussed earlier. This will reduce the cost of travel to the homes of patients in remote rural areas.

**Educating Rural Families and Physicians About Hospice**

This can be done by the rural hospices directly as well as through others such as Medicare and local health and human services organizations. There is a general lack of knowledge and understanding of hospice, and this is probably truer of people living in rural areas than of those in urban areas. Almost half (45%) of the respondents in the Haxton and Boelk (2010) study believed that rural communities know little to nothing about hospice as a resource available to them. More than 80% of people eligible for Medicare do not know that Medicare offers a hospice benefit (Community-State Partnerships to Improve End-of-Life Care, 2002). It is safe to assume that the percentage of rural elderly in this group is even higher. Almost a quarter (22.7%) of the social workers in the Haxton and Boelk study reported that they were very much or quite a bit involved in outreach and education efforts. The foci of their involvement included patients, families, other professionals, and the broader community. They talked to friends and others (hoping that the word of mouth would travel farther) and participated in formal speaking engagements at local churches, human service organizations, and business establishments. Public education is too important for the success of rural hospices and the viability of the social work role therein to remain the concern of less than 25% of social workers. All rural hospice social workers should
consider this a part of their job responsibilities. Of all the hospice professionals, they are the most suited for this work because of their education and skills. They can easily learn and/or polish the appropriate techniques. We provided in Chapter 6 many suggestions for social workers’ educator role, which are relevant for public education about hospice as well. The following are a few hospice-specific suggestions drawn from the study by Hiatt, Stelle, Mulsow, and Scott (2007).

- Emphasize and build on the strengths of hospice, such as the philosophy, availability, and quality of its care.
- Correct the public information or impression about the weaknesses of hospice, such as the stigma of hospice care being the “end of the road” and its association with death. This can be countered by concepts such as “care at the end of life” and “dignified death.”
- Target specific audiences such as the general public, civil groups, etc.
- Use multiple means of communication.
- Reach out to minority groups and communities with culturally sensitive approaches.
- While making presentations to groups, involve bereaved family members of hospice patients who can describe the quality and benefits of hospice care.
- Work out an arrangement with the local nursing homes whereby information about hospice care is provided to residents (and their families) when they are admitted to the nursing home.

Education of local physicians about hospice requires a different approach because there are many reasons why physicians do not refer their terminally ill patients for hospice care or refer them late in the illness. Some do not know of hospice care and/or its availability in their area. Others do not refer their patients because of the difficulty in accepting death, difficulty in predicting the length of time a terminally ill patient is likely to live, reluctance to stop aggressive curative treatment, and concern at “abandoning” the care of the patient at such an important time. For some, the prognosis of 6 months or less leads to fear of indictment for Medicare fraud if the patient survives beyond the 6-month limit (Crawley, 2007).

Hospice admission by regulation must require the physician to certify that a patient is likely to die within 6 months. This is medically very difficult or even impossible with most patients and most diagnoses. In addition, a hospice referral requires a discussion between physician and patient regarding the imminence of death, for the patient will be required to relinquish his or her right to curative benefits under hospice. (Simmons, 2004, p. 819)

A study by Cherlin and her colleagues (2005) examined 218 family caregiver reports of physician communication about incurable illness, life expectancy, and hospice; the timings of these discussions; and subsequent family understanding of these issues. Many family caregivers reported that the physician never told them the patient’s illness could not be cured (20.8%), never provided life expectancy (40% of those reportedly told that illness was incurable), and never discussed using hospice (32.2%). The first discussion of the illness being incurable and of hospice as a possibility occurred within 1 month of the patient’s death in many cases (23.5% and 41.1%, respectively).

Education of local physicians can be handled in two ways:

1. The medical director of hospice should reach out and meet the local physicians periodically or as often as necessary to educate them about hospice care and the “how” and “why” of the referral process. Evans, Stone, and Elwyn (2004) did a literature review of 26 studies that examined the organization of rural palliative care and the views of professionals involved in that care. Education and strategic issues were dominant research questions. The role of primary care emerged as an important theme, and primary care professionals reported problems in symptom control and management of emotional issues. They also reported difficulty in obtaining education and training. If the hospice is a part of a chain or a member of a group of hospices, the medical director should explore the possibility of using their combined resources to offer local physicians continuing education in palliative care.

Kaufman and Forman (2005) described an educational program organized by the local hospice
for nurses and physicians in a rural county of New Mexico. Of about 150 nurses and 20 physicians, 27 nurses and 5 physicians attended the program. Nurses attended a half-day conference, and physicians attended a grand-round presentation by the medical director of the hospice. The number of patients enrolled in hospice nearly doubled in the year following the educational intervention. The hospice medical director can also work with the coalition (discussed earlier) in approaching Medicare to fund educational seminars and continuing education courses for physicians on palliative and hospice care.

2. The social worker and other hospice team members should join and mobilize the area health care providers to work toward enhancing access to health care services and improving collaboration among care providers.

Educating, empowering, and assisting health professionals to refer people to hospice, and involving them in planning and care, may serve to benefit all parties involved. Additionally, a hospice and palliative care resource directory specific to each local community may be helpful to professionals as well as families in rural settings. (Haxton & Boelk, 2010, p. 546)

Social workers, whose professional socialization emphasizes consensus building, mediation, and negotiation, can help motivate people, create conditions for exchange of ideas and collaboration, and work for policy changes at various levels.

Social Worker as Helper in Reducing Barriers to Hospice Services for Minority Patients

In order to perform this role, social workers should use a threefold approach: (1) knowing more about why various minority groups do not use hospice services, (2) reaching out to those groups and responding to their concerns, and (3) helping make hospice and its services the minority community’s own. The following are some helpful suggestions.

1. Knowing about minority groups’ resistance to hospice services. Keep abreast of the research-based literature that throws new light on the “why” of minority groups’ Resistance to use the available services and how to reduce that resistance. If and when possible, use your research skills and undertake simple surveys on topics of interest to the hospice organization regarding a particular minority community or group. Subjects of such surveys can be members of that community or group, their easily identifiable leaders or spokespersons, and human service providers in that community. Encourage and enthuse the organization for such research work. In the age of the Internet, this can be done with limited funds. The potential benefit of such efforts can be tremendous. If there is a college or university in the area the hospice serves, find out about teaching or research faculty who are or can be interested in researching the kinds of questions for which you are seeking answers.

Reese, Ahern, Nair, O’Faire, and Warren (1999) explored hospice access and use by African Americans and found several cultural and institutional barriers. Culturally, there seems to be a difference between the philosophy of life of most African Americans and the philosophy that underlies the hospice approach. Africans Americans often prefer not to plan for death and are opposed to accepting terminality; therefore, they prefer life-sustaining treatment to palliative care. In the absence of such treatment, they will use home remedies. If nothing is working, they will pray for a miracle because they believe that God determines whether a sick person lives or dies. Accepting terminality while everyone around the patient is praying for a miracle would be seen as a lack of faith. Moreover, their cultural values insist that one’s own people—family and church members—and not strangers should provide care in terminal illness. The institutional barriers that the study discovered included (1) the unfamiliarity of most African Americans with hospice, (2) a general lack of trust in the health care system and its newer approaches (lest they “end up being a guinea pig in one of their experiments”), and (3) an absence of African
Americans among health care providers. Washington, Bickel-Swenson, and Stephens (2008) did a review of the literature pertaining to the under-use of hospice services by African Americans and found similar factors as discovered by Reese and her associates (1999). Cultural, institutional, and other barriers also stand between hospice services and other minority groups. Randall and Csikai (2003) studied 110 rural Hispanics and found that most (88%) were not familiar with hospice but were willing to accept hospice care in their homes. Among the barriers were language, poverty, low level of education, and lack of health insurance.

2. Reaching out to minority groups and responding to their concerns. Acknowledge the reality of the barriers between hospice services and minority groups and plan to break or reduce them. That can involve several activities:

- **Reaching out to groups on the other side of the barriers.** The reaching out should be marked by (a) a genuine interest in the people of the group; (b) respect for their worldview and perspective on life and death; (c) empathy and a desire to serve; and (d) conscious, constant, and sincere efforts. Reaching out can be achieved directly as well as through their leaders and institutions. For example, for African Americans, these would be ministers and churches.

- **Always keeping in mind that trust building with the group or community is extremely important.** Trust building is hard because of the mistrust in many of these groups of the mainstream culture and society at large. For example, many African Americans often view white helpers as an extension of white supremacy and racism. On the other hand, to varying degrees, negative attitudes and beliefs about people in these groups abound in the larger society. Nevertheless, self-awareness in terms of social workers acknowledging their own biases, prejudices, and concepts of what is normal and healthy; ability to accept the validity of others’ perspectives on their lives and situations; willingness to consider others as culturally equal to them; and communication of genuineness, sincerity, and warmth will go a long way to build trust.

- **Recognizing that within a group or community, there is diversity across all spheres of life, including religion and theology, family functioning, socioeconomic situation, acculturation, and political involvement.** The following paragraphs will give an idea of this diversity:

We all know that Native Americans belong to more than 500 different tribes and there are differences among them based on tribal affiliation. There are also differences between those who live on reservations and those off reservations, as well as between those who live in rural areas and those in urban areas. Hence, there are differences based on the level of acculturation. Some have totally assimilated into the mainstream, while others have retained their native language, beliefs, ceremonial practices, values, and customs. Furthermore, there is no universally accepted definition of who a Native American is and what it means to be one. Of course, there are also differences based on socioeconomic status.

Asian Americans represent about 30 countries of Asia and almost as many islands in the Pacific. There are vast differences among them based on national-ethnic variations. Even those from the same country may speak different languages, profess different religions, dress differently, eat different foods, observe different customs, and have different worldviews. There are differences based on immigration status, level of acculturation, and socioeconomic status and situations.

The same is true of Hispanic or Latino Americans. There are differences among them based on the countries they came from or trace their ancestry to. Their major groups are Mexican Americans, Puerto Ricans, Cuban Americans, Central and South Americans, and Caribbeans. Although most Latinos are Catholic, more and more are turning to churches of other Christian denominations. Many Puerto Ricans are also adherents of spiritism, and many Cubans are adherents of Santeria. Sociodemographic factors also divide Latino Americans.
Even among African Americans, there are differences based on when they came to the United States. There are those who are the descendants of slaves, those who came from Caribbean islands, and those who came as immigrants from various African countries. There are differences on the basis of religion, levels of acculturation, socioeconomic status, and sociopolitical experiences (Dhooper & Moore, 2001).

However, there are some commonalities among all these groups, such as the importance of family, extended family ties, religious faith, experience of racism as Americans, and a general sense of powerlessness. Most of them also hold on to different theories of illness and suffering and approaches to healing and help.

- **Looking for commonalities between program ideals, ideas, approaches, and activities, and the views and needs of potential clients.** In any situation, there are always universal as well as unique elements. Looking for the universal and building on those creates the commonality and opens a window for understanding and intervention. Reese et al. (1999) gave an example of how the beliefs of African Americans about illness, death, treatment, and care can be seen as compatible with the hospice philosophy and approach. Their stoicism in the face of death and reliance on God’s will as resignation can be interpreted as an ability to accept one’s death without fear.

Some African Americans may feel that since God is in charge, life-sustaining treatment may not determine whether one lives or dies. These views are consistent with the hospice philosophy of acceptance of death without great fear and of preference for palliative rather than curative care. (p. 557)

Furthermore, the large familial network can be the source of family support needed for hospice care in the patient’s home.

- **Encouraging the organization to conduct public education campaigns through television ads, newsletters, booths at community festivals, and presentations at local places of worship.** Educational efforts should provide facts about life-sustaining treatments for terminally ill persons, quality and lower cost of hospice care, etc. They should also show hospice as compatible with the community’s overall views about death and the dying. In the case of the African American community, for example, that compatibility can be reflected in such ideas as “caring for one’s own,” “death as homecoming,” and “fulfillment of God’s will.”

3. **Giving minority communities some ownership of hospice and its services.** The reaching out to minority groups and communities that we suggested above will help break the cultural barriers between them and the hospice organization. The goal should be not only to make hospice services acceptable to minority groups and communities but also to make hospice and its services the minority community’s own. That will require breaking down institutional barriers through policy changes at the organizational level. Hospice should consider approaching and recruiting prominent members of the minority communities as members of the hospice board (of trustees, directors, advisors, etc.); hiring minority staff members as hospice care providers, both professional and volunteer; providing translation services; and offering culturally diverse spiritual services. With their focus on the African American community, Reese and associates (1999) made the following recommendations:

- Use churches as referral sources.
- Train African American pastors to serve as community representatives.
- Involve African American pastors on boards of directors of hospices.
- Actively recruit African Americans for full-time positions as hospice chaplains and other staff.
- Develop programs to follow patients from active treatment to palliative care.
- Provide hospice care to African Americans in nursing homes.

**Relevant Ethical Considerations**

Since most of the current and likely future recipients of social work services in long-term settings are the elderly and since, with 80% of all
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deaths occurring in individuals over age 65, death has become the province of the elderly (Kearl, as quoted in Luptak, 2004), we devote this section to issues associated with the end-of-life care and dying of the elderly. A brief description of the historical changes in the “how” and “where” of death and evolution of end-of-life care is provided as the context for our discussion.

In ancient days, people viewed death as a process that could not be helped and sought to find the meaning of death and ways to make the movement from life to death as comfortable as possible in the presence of family and friends. The struggle against death began in the 16th and 17th centuries, but even then, people died at home being cared for by their families and in the midst of their loved ones. Two centuries later, as the causes of disease were discovered, hospitals became the institutions for the study and treatment of the sick, and the process of dying became “medicalized” (Luptak, 2004). Today, most deaths in the United States take place in institutions—hospitals and nursing homes.

The elderly did not dominate the death scene in the olden days. Most people did not live long enough to be old; they died young, and childhood deaths were also common. Throughout the 20th century, increased longevity, changes in family structure, rapid urbanization, and advances in medical technology influenced American attitudes toward the elderly and policies about end-of-life care (Kaplan, 1995). Myths about aging (e.g., old people are resistant to change, unproductive, and senile) developed. In the public mind, the litany of “D” characterized the elderly: decline, disease, disability, dementia, depression, dependency, disengagement, and death. Now, the popular attitudes are slowly turning positive. Society has gradually responded to the needs of the elderly—through Social Security, Medicare, and other programs—and their end-of-life needs are being recognized.

In the first half of the 20th century, the number of older people quadrupled because of lower birth rate, lower mortality, and lessened immigration. Sophisticated interventions became available to cure illnesses and prolong life, and medical decisions became more complicated and responsibility for decision making began to shift from individuals and families to professionals. Death denial became the prevailing orientation as dramatic shifts occurred in who died, how they died, and when they died. (Luptak, 2004, p. 8)

Thus, “the presence of physicians and hospitals at the end of people’s lives has also led to the intrusion of medical professionals and health care systems into the natural process of dying” (Mackelprang & Mackelprang, 2005, p. 315).

Another set of forces was also at work. The consumerism movement of the 1960s and 1970s affected the issues of aging also. Decision making started shifting from a model that fostered medical paternalism to one that emphasized patients’ right to self-determination, and the end-of-life care movement started. End-of-life care has become institutionalized, but the treatment choices have also expanded, which has complicated decision making. Mackelprang and Mackelprang (2005) conceptualized end-of-life care on a four-level continuum: (1) care that is palliative—alleviates pain and provides comfort but does not prolong life; (2) care that involves noninvasive efforts to preserve or prolong life and may involve oral antibiotics; (3) care that involves intravenous medications and artificial hydration and nutrition; and (4) care that involves invasive treatments such as artificial ventilation and cardiopulmonary resuscitation. Terminally ill persons have to decide the level of care they want. When they are incapable of deciding and did not make their wishes known beforehand, surrogates decide for them.

There are also interventions that hasten death, which equally require a decision by terminally ill persons or their surrogates. Mackelprang and Mackelprang (2005) put those interventions into four categories: (1) declining curative or restorative treatment, such as surgery, chemotherapy, and radiation for a cancer patient, so that death can take its natural course; (2) allowing the withholding or withdrawal of life-extending measures such as intravenous medications, feeding tubes, and ventilators; (3) allowing treatment such as the
use of high levels of morphine that results in depressed respiration and cardiac functioning; and (4) seeking assisted suicide and euthanasia. Oregon is the only state in the United States that gives people the right to die and allows physician-assisted suicides. Decisions about these options have become public, resulting in the involvement of the courts. Besides the court judgments, society has responded with such measures as the Patient Self-Determination Act of 1991, advanced directives, and do-not-resuscitate orders.

The Patient Self-Determination Act (P.L. 101-508) is the first federal law that reinforces the right of adults to refuse life-sustaining treatment. It requires all health care organizations that receive Medicare and Medicaid payments (hospitals, nursing homes, and in-home care providers) to provide adult patients information about state laws regarding advanced directives. At the time of admission, patients are asked if they have an advanced directive or desire one. If one is created, it is placed in the patient’s chart. The law also directed the Department of Health and Human Services to conduct a national campaign to inform the public about advanced directives.

Advanced directives allow competent adults to make a written statement about how they wish to be treated at the end of life, including medical care preferences. These directives include the durable power of attorney for health care and living will (also known as directive to physician) documents (NASW, 2006). The durable power of attorney for health care, or health care proxy or agent, is an individual appointed by a patient to make health care decisions if the patient becomes incompetent. A living will is written by a competent adult to control health care decisions in the event of that person’s incompetency. Every state has created legislation and a set of regulations for advanced directives. They provide that (1) patients can maintain control over what happens to them when they become physically or mentally incapable to participate in decision making; (2) guidance is given to decision makers regarding life-sustaining treatments; and (3) immunity is available to health care providers from civil or criminal liability when they honor advanced directives in the face of objections by family or surrogates (O’Donnell, 2004).

Do-not-resuscitate orders (DNRs) can be a part of an advanced directive along with a durable power of attorney, living will, and health care proxy. A DNR is an order written by a physician indicating that no cardiopulmonary resuscitation is to be performed if the patient’s heartbeat and breathing stop. This order is in response to a decision by the patient, his or her health care agent, or a family member.

Ethical Challenges. The decisions about terminally ill persons’ levels of care and interventions that hasten death, and even the societal prescriptions about the “who” and “how” of those decisions, are fraught with ethical challenges.

The issues related to end-of-life care revolve around the concept of a “good” death. However, there is no universally accepted definition of a good death. The quality of life—determined as it is by a host of socioeconomic factors, including health care—and cultural beliefs decide how individuals view death and dying. Crawley (2007) captured this reality in his question,

How does one define a “good death” for the person whose life has been constrained by disadvantage, or whose imminent death may result, in whole or in part, from societal factors responsible for socioeconomic inequalities or racial or ethnic-based inequalities? (p. 223)

In general, it is difficult for most people to discuss death and dying, partly because of death anxiety, which can include fears about the process of dying, death itself, and what happens thereafter. “Nowhere is death anxiety seen more clearly than in patients suffering from terminal or potentially terminal conditions. Facing one’s own mortality is a frightening experience that one cannot totally prepare for” (Zilberfein & Hurwitz, 2004, p. 298).

As stated earlier, the process of death has been medicalized. Advances in medical technology
have transformed previously fatal illnesses into chronic illnesses that can be treated (Callahan, 2000). Thus, death is viewed as something that should be controlled, and it continues to be seen as a medical failure (Silverman, 2004). Cure-oriented treatment to extend life is preferred over end-of-life care, and there is a reluctance to withdraw treatment (on moral or legal grounds) even when it is not working. At the same time, decisions about the use of medical technologies raise ethical questions about the equitable allocation of expensive and limited resources. The concept of medical futility—defined as treatment that will not alter the natural course of disease but may add physical, social, and emotional burdens to the patient (Schneiderman, Jecker, & Jonsen, 1990)—is gaining ground. However, there is no agreement on what the criteria for futile treatment should be and who should determine futility.

The proportion of those who have executed advanced directives continues to be low—only 1 in 4 patients has done it (Gerbino & Henderson, 2004). In the absence of these directives, as the decision-making capacity of patients diminishes, the likelihood of their wishes being ignored becomes high. This is true not only of patients being treated in hospitals but also of those receiving palliative care. Other factors become reasons for raising questions about patients’ decisional capacity and often deprive them of autonomous decision making. It is also likely that families and/or care providers will decide for those who have limited command over the English language (and must rely on others to translate and interpret their wishes), persons with psychiatric disorders, those with cognitive impairments such as dementia, ones with histories of substance abuse, and those who are incarcerated or in foster care. Csikai (2004) talked about the dilemma caused by attempts to balance the rights of self-determination of patients and their families in end-of-life care. Reese (2000) studied hospice care patients and found that caregiver denial often resulted in inpatient hospice stays for patients who had desired to die at home.

The United States is increasingly becoming a multicultural society, but in the eyes of most health care professionals, the “ideal” patient is one who shares the Western ethical precepts of truth telling and respect for patient autonomy (Davis, 2000). Patients whose cultures emphasize different values become difficult to deal with. The Patient Self-Determination Act, which is underpinned by the principle of autonomy, reflects the belief that all patients have the same belief system and that cultural differences are not important. In reality, in many cultural groups, families or elders make all vital decisions affecting a family member, may prefer that the member not be told the truth about his or her diagnosis/prognosis, and may believe that discussing death will somehow bring death on the patient. However, acculturation is another reality, and there are variations in the observation of cultural values by individuals and families. Working with such patients and their families is ethically challenging.

Social workers will find the following suggestions helpful in dealing with ethically challenging situations:

1. Strive constantly to strengthen your knowledge base of policy and practice issues pertaining to aging, death and dying, and end-of-life care. Improve and refine your assessment and intervention skills for work with clients of varied socioeconomic and cultural backgrounds. This improvement may also involve confronting your own mortality and/or unresolved grief from a personal loss (Crawley, 2007).

2. Let the NASW (2004) Policy Statement on Client Self-Determination and End-of-Life Decisions guide your professional roles and behaviors. This statement defines end-of-life decisions as choices made by a terminally ill person regarding his or her continuing care or treatment. It emphasizes the right of individuals to choose among all available care options and social workers’ responsibility to ensure that all options are presented to patients and families and that they are assisted in understanding the meaning and possible outcomes of treatments as they affect quality of life. It provides specific action steps for both worker-client–level activity and cause-related advocacy.
3. Know that despite the difficulty of defining a “good” death, consensus is emerging about the attributes of such a death. These include the following factors: (1) It happens at a very old age; (2) it is not a prolonged process (as in a coma); (3) it does not involve uncontrolled pain and suffering; (4) the dying person’s physical and emotional capacities are intact; (5) there is no loss of control or personal dignity; (6) it happens in the midst of one’s loved ones (not in isolation); (7) all family conflicts are resolved; (8) it does not cause undue burden (financial or emotional) to the family; and (9) there is meaning in the person’s death—the death matters to others (American Medical Association, 1999; Callahan, 2000; Zilberfein & Hurwitz, 2004). Deal with factors (e.g., professional attitudes and institutional policies) that make it difficult for many terminally ill persons to experience good deaths.

4. In many acute care settings, it is not uncommon to be confronted with a situation where a patient has not made his or her wishes regarding end-of-life care known and can no longer do so. In such cases, use your advocacy skills to ensure “that persons who do not explicitly state their wishes still get treatment that is close to what most people would want” (Lynn et al., 2000, p. S221).

5. In many acute care settings, palliative care is not an option in the treatment of terminally ill patients. Advocate for incorporating the palliative care perspective. That will enable caregiving professionals to remain focused on and provide for the total care needs of the patient (O’Donnell, 2004).

6. Know that sometimes the reluctance to withhold and withdraw treatment is based on moral or legal myths. “Many believe that withdrawal of life support is equated with murder and suicide. Others believe that once a treatment is initiated, it cannot be discontinued” (O’Donnell, 2004, p. 177). Understand the legal and moral contexts of withholding and withdrawing treatment, and participate in the education of all involved in such situations. “In some cases, dying patients who have lacked access to health care may view discussion of withdrawal or withholding of care as yet another example of social injustice” (Crawley, 2007, p. 227). Make sure that ethical principles of justice and equity inform decision making in all such cases.

7. Actively participate in the education of patients and their families about the legal and moral rights of patients to decide what treatment they want or do not want. Give them clear information about all the available options, and support them in their choice. Cagle and Kovacs (2009) urged that education be recognized as an essential component of professional practice. They provided a theory-based approach to education.

8. Remember that in palliative care, social workers are not as focused on individual treatment as are other members of the care team and, therefore, can focus on the overall goals of care as desired by the patient and family. Furthermore, they have a bridge role in explaining the context of care to patients and their families and explaining concerns of patients and families to staff members (O’Donnell, 2004).

9. Recognize that the principles of palliative care are reflective of the core social work values. “Viewing the individual in a holistic way, considering the family as the ‘unit of care,’ examining the client’s experience across the continuum of care, and building on the strengths of the family system are inherent to social work practice” (Blacker, 2004, p. 419).

10. Be actively involved in the ethics committee of your institution in resolving ethically challenging situations. In many such committees, social workers are playing leadership roles. Whenever an ethics committee is not available, as in the case of many hospices, participate in the meetings of the interdisciplinary group discussing ethical issues and enrich its deliberations with social work’s ethical perspective, along with case-specific information. You should suggest and participate in the development of policies.
that address common ethical issues and in the education of the hospice staff. You can make this contribution by using your communication skills, by promoting your profession’s central values of self-determination and respect for individual worth and dignity, and by helping others recognize the interplay of people and their environments (Csikai, 2004).

11. In Chapter 6, we presented a model of culturally proficient and ethical practice. Skills discussed there are relevant in the end-of-life care situations of culturally diverse patients and their families as well. Koenig (1997) suggested the following questions to enhance the cultural sensitivity of social work assessment:

- Is information about diagnosis/prognosis openly discussed in this culture? If not, how is information managed?
- Is death an appropriate topic for discussion?
- Is maintaining hope considered essential?
- How is the decision making done? Is it shared with patient/family or delegated by patient to someone else?
- How is quality of life versus quantity of life weighed?
- Does the patient/family trust that the health care providers will act in their best interest? (p. 373)

12. Reflect on how answers to the above questions will affect your intervention approach and strategies. Keep abreast of the various theories and approaches of bioethics and see how those can enrich your repertoire of knowledge and skills. Generally, added sensitivity, some creativity, extra efforts to build and retain trust, discussion with colleagues, or assistance from an ethics committee would suffice in dealing with difficult situations (e.g., telling the truth without doing undue harm) and dealing with questions of diversity and justice.

13. Csikai (2004) surveyed 110 hospice social workers in six states regarding ethical issues in hospice care. These social workers had no access to an ethics committee. The issues of assisted suicide and euthanasia were the least discussed among ethically challenging situations listed by the participants in this survey. However, 32% of them indicated that they had received a request from a patient to discuss assisted suicide and 17% had received a similar request from a family member. How should social workers respond to such requests? The NASW (2004) Policy Statement on Client Self-Determination and End-of-Life Decisions provides the following guidance.

- Facilitate client and family understanding of all aspects and options in end-of-life care.
- Assess mental health functioning to include assisting in decisional capacity determinations, depression, anxiety, suicidal ideation, and facilitate or provide intervention or referrals for care.
- Be knowledgeable about state-specific policies on end-of-life care.
- Be present (if the social worker is comfortable with being present) with a client or family in assisted-suicide situations in states where this practice is legal and requested by the client. (NASW, 2006, pp. 133–34)

Critical Thinking Questions

1. We have discussed the evolution of the societal response to death and dying. Changes in society, family, and medical science and technology have led to the medicalization of death. Medical and health care personnel and establishments are deciding when, where, and how death takes place. Assuming that the anticipated changes in the various dimensions of life (projected in Chapter 1) come true, what is likely to be the next stage in this evolutionary process and what will be the major features of that stage?

2. Study the concepts of “good death” and “medical futility” and how these are operationalized in the health care setting with which you are associated. Do the “dos” resulting from that operationalization allow for significant options for patients and their families in view of the “dos” drawn from the NASW Policy Statement on Client Self-Determination and End-of-Life Decisions? How can you increase the options and/or improve the substance of those options?
NOTES

1. As per the federal regulations, a qualified social worker is an individual with (i) a bachelor’s degree in social work or a bachelors’ degree in a human services field, including but not limited to sociology, special education, rehabilitation counseling, and psychology, and (ii) 1 year of supervised social work experience in a health care setting working directly with individuals (Bern-Klug, 2008, p. 383).

2. The goal of palliative care is similar to that of hospice care—that is, the treatment of the whole person. That involves meeting all the patient’s medical, physical, psychological, social, and spiritual needs. However, palliative care is not necessarily for those who are terminally ill. Many who receive palliative care will improve and do well, whereas the recipients of hospice care are dealing with the reality of imminent death.

3. The National Advisory Committee identified the following principles:
   - Case management is a consumer-centered service that respects consumers’ rights, values, and preferences.
   - Case management coordinates all and any type of assistance to meet identified consumer needs.
   - Case management requires clinical skills and competencies.
   - Case management promotes the quality of services provided.
   - Case management strives to use resources efficiently (Gerson & Chassler, 1995).