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Nursing Homes

As she approached her mother's room at Prairie View Manor, Sharon thought about the day she had had to come to grips with the reality that Eleanor, then 84 years old, needed nursing home care. She had promised her mother that she would never put her in a nursing home. This promise would nearly break Sharon mentally and physically, jeopardize her marriage, and drive a wedge between her and her children. At first, the extra work cleaning Grandma's house, caring for the yard, and taking her shopping and to the doctor was welcomed. The whole family pitched in to make it work. Eleanor went to the adult day program every day where the family knew she was safe while they were at work and at school. When Eleanor became more frail, her falls more frequent, and the incontinency too difficult to manage, Sharon brought her mother to live with her. Even with a leave of absence from her job, Sharon became exhausted trying to manage her mother's care. Her husband became more and more angry about all the time Sharon was spending caring for her mother, and her children resented their having to give up some of their activities to help care for Grandma. Why, thought Sharon, had it taken her so long to seek nursing home care? Eleanor was content. She loved her little room with a view across the countryside. Most happily for Sharon, her mother was still able to participate in limited activities and enjoy the company of a few new friends.

The words *nursing home* conjure up negative images, and most older adults and their families dread the thought of residing there. Sharon, like many other family members, goes to great lengths to avoid nursing home placement—even when such placement would be physically and psychologically beneficial for everyone. Despite the negative image nursing homes have, they are a critical part of the long-term care continuum in our communities and provide a wide range of vital services to those who live there.

Because nursing homes are a part of the long-term care continuum, many refer to nursing homes as long-term care facilities. Indeed, these facilities have evolved into more than *nursing* homes—they are places in which a wide range of restorative, rehabilitative, and medical services are delivered. The term *nursing home*, however, is still frequently used in the literature. Therefore, we will use the terms *long-term care facilities* and *nursing homes* interchangeably in our discussion. In this chapter, we review policies that have been instrumental in creating the existence of long-term care facilities and present a profile of users and programs. The chapter ends with a presentation of the many challenges that lie ahead for long-term care facilities.

Policy Background

The growth of the nursing home industry parallels the passage of federal policy that evolved in the first half of the 20th century (Waldman, 1985). Prior to the enactment of Social Security, Medicare, and Medicaid, many older adults had few options if they needed medical and personal care. In some communities, older adults were boarded out to families that agreed to provide care in their homes, many of which were in homes of retired nurses—thus the basis for the term *nursing home* (Crandall, 1991). In the early part of the century, almshouses or “poor farms” cared for many frail older adults, persons with mental illnesses, and those who were chronically ill. An estimated 60% to 90% of the persons living in almshouses were over age 65 (Fischer, 1978). Almshouses were deplorable places, and the few states that had old age assistance payments and, later, Social Security, would not send payments to almshouse residents (Small, 1988). Older adults who were financially well off had the option of living in old age homes run by ethnic or religious groups; German and Scandinavian immigrants built Lutheran Homes; and Jews and Methodists built their own facilities (Waldman, 1985). The 1950 amendments to the Social Security Act of 1935, allowing residents of institutions to receive benefits and health providers to directly receive payments for services, helped expand the creation of nursing homes. But the real impetus to the creation of the nursing home industry came with the enactment of Medicare and Medicaid. Both Medicare and Medicaid provide payments to nursing homes—Medicare for acute care and Medicaid for long-term care for those with low incomes (Crandall, 1991; Small, 1988). Since the enactment of Medicare and Medicaid, the rate of nursing home use doubled from 2.5% to 5% of persons 65 and older (Small, 1988). In 1995, there were 18,911 nursing facilities in the country (Administration on Aging, 1995b).

Payment of Nursing Home Care

The cost of nursing home care is approximately \$30,000 per year (Spillman & Kemper, 1995). Thus, because of the high cost of nursing home care, many older adults and their families are concerned about having the resources to pay for care or are concerned about becoming impoverished while paying for care. Presently, there are four sources of payment of nursing home costs: Medicaid, Medicare, out-of-pocket, and long-term care insurance.

Most nursing homes are certified by the Health Care Finance Administration (HCFA) and are eligible to receive reimbursement for their services to persons qualified for Medicaid and Medicare. Annually, Medicaid pays approximately 47% of nursing home care for eligible individuals. Medicaid offers nursing home coverage to low-income individuals who meet income, asset, and medical guidelines. Medicare plays a limited role in covering nursing home costs because it pays only for *skilled nursing* services (24-hour care provided by a registered nurse, under a physician's supervision) and does not cover custodial care. Medicare pays 4.4% of nursing home costs (Spillman & Kemper, 1995).

Out-of-pocket payments made by older adults and their families amount to approximately 46% of nursing home care expenses (Spillman & Kemper, 1995). Because of the limited sources that help pay for long-term nursing home care costs, a small but growing number of adults have purchased long-term care insurance policies.

According to the Health Insurance Association of America, long-term care insurance policy sales have risen an average of 27% a year (or as many as half a million policies annually) since 1987, and approximately 3.4 million policies have been sold by 118 companies (Coronel & Fulton, 1995). Private insurance pays approximately 1% of nursing home costs (Wolf, Weisbrod, & Stearns, 1988). Older adults have been slow to purchase such policies because of the availability, cost, limited benefits, and a belief that Medicare will cover long-term care costs. The extent to which long-term care insurance will play a role in paying for long-term care costs in the future is unknown (see Zedlewski et al., 1990).

Users and Programs

Resident Characteristics

The decision to place an older adult in a nursing home is a difficult one for family and friends. Contrary to popular perception, families do not “dump” their older members in nursing homes at the first available opportunity. Like

For Your Files **Long-Term Care Insurance**

The National Insurance Association of America has posted on their Web page a consumers' guide to long-term care insurance. Here is a summary of some key points. Visit their site to read the entire guide:

<http://www.hiaa.org/library/iguides/ltc.html>

Most long-term care insurance policies are indemnity policies that pay a fixed amount for each day of care received. Fixed amounts range from \$40 to \$200 per day, depending on the terms of the policy. Good policies will adjust the benefit amount each year (about 5%) to keep up with inflation.

The cost of long-term care insurance depends on the age of the beneficiary and the level of benefits and deductibles. For example, a policy offering \$80 per day for 4 years, with a 20-day deductible, costs a 50-year-old approximately \$50 per year, a 65-year-old about \$855 per year, and a 79-year-old \$3,641. The younger the age at purchase, the lower the cost; most companies, however, do not sell long-term care insurance to individuals under age 50.

Most policies cover skilled, intermediate, and custodial care as well as skilled and nonskilled home care, physical therapy, and care provided by homemaker home health aides. Some policies also cover adult day care and respite care. There are, however, exclusions for preexisting conditions and some types of disorders. Policies generally limit benefits to a maximum dollar amount or days of care.

Anyone interested in purchasing long-term care insurance should compare policies before they buy. Also check out *Consumer Reports*, which conducted in-depth reviews of long-term care insurance policies in 1988, 1991, and 1995. AARP also has resource materials available.

Sharon at the beginning of the chapter, they go to great lengths exploring other alternatives and often insist on providing caregiving activities at the expense of their personal well-being (Brody, 1985; Smallegan, 1985). Families provide an estimated 80% to 90% of long-term care to older adults while they are living in the community and continue providing assistance even after nursing home placement (Bowers, 1988; Stone et al., 1987). Nursing home placement is a community resource that is most often the last alternative used by families.

According to the U.S. Bureau of the Census (1996a), nearly 1.6 million older adults live in nursing homes, and the size of the nursing home population

increased by 29% from 1980 to 1990. The increase in the percentage of oldest-old adults in nursing homes, however, is less than the increase in the size of the oldest-old population, suggesting that the rate of institutionalization of oldest-old persons might not increase as rapidly as the oldest-old population itself (65+). On the basis of past nursing home use rates, Kemper and Murtaugh (1991) estimated that the lifetime risk of institutionalization is 43% for those reaching age 65 in 1990 and that an estimated 52% of women and 33% of men would use a nursing home during their lifetimes.

Length of stay in a nursing home varies among different subpopulations as well. For example, length of stay for persons 65 years of age and older is longer for women than for men—26 months and 19 months, respectively (Freedman, 1993). Of older adults entering nursing homes for the first time, 42% die there (Dick, Garber, & McCurdy, 1994). Researchers have discovered several personal characteristics associated with the likelihood of living in a nursing home.

Age

Not surprisingly, the majority of nursing home residents are over age 75 (see Exhibit 19.1). Almost half (45%) of all nursing home residents were 85 years of age, whereas only 8% of community-dwelling older persons are 85 or older. The median age at first admission was 81 for men and 84 for women (Dick et al., 1994).

Sex

Mirroring the demographic characteristics of the older adult population, more nursing home residents are women. Seven of 10 residents are women; 34% of persons living in nursing homes are women over 85. Of women who died at 90 or older, 70% had lived in a nursing home (U.S. Bureau of the Census, 1996a).

Race

Older adults of color are underrepresented in nursing homes. As shown in Exhibit 19.2, smaller percentages of older persons of color 65 and older and 85 and older live in nursing homes compared with white elders. The differential use in nursing home care has been attributed to cost, discrimination, personal choice, and social and cultural differences (Moss & Halamandaris, 1977, cited in Yeo, 1993). According to testimony given by family members and professionals, Moss and Halamandaris concluded that all four reasons may be operating to different degrees in keeping older adults of color from

Exhibit 19.1 **Selected Characteristics of Nursing Home Residents and Community-Dwelling Residents**

<i>Subject</i>	<i>Living in Nursing Homes</i>	<i>Living in the Community</i>
Total Number (in thousands)	1,318	26,343
Age		
65 to 74	16.1%	61.7%
75 to 84	38.6%	30.7%
85+	45.3%	7.6%
Sex		
Women	74.6%	59.2%
Men	25.4%	40.8%
Race		
White	93.1%	90.4%
Black	6.2%	8.3%
Other	0.7%	1.3%
Marital Status		
Widowed	67.8%	34.1%
Married	12.8%	54.7%
Never married	13.5%	4.4%
Divorced/separated	5.9%	6.3%

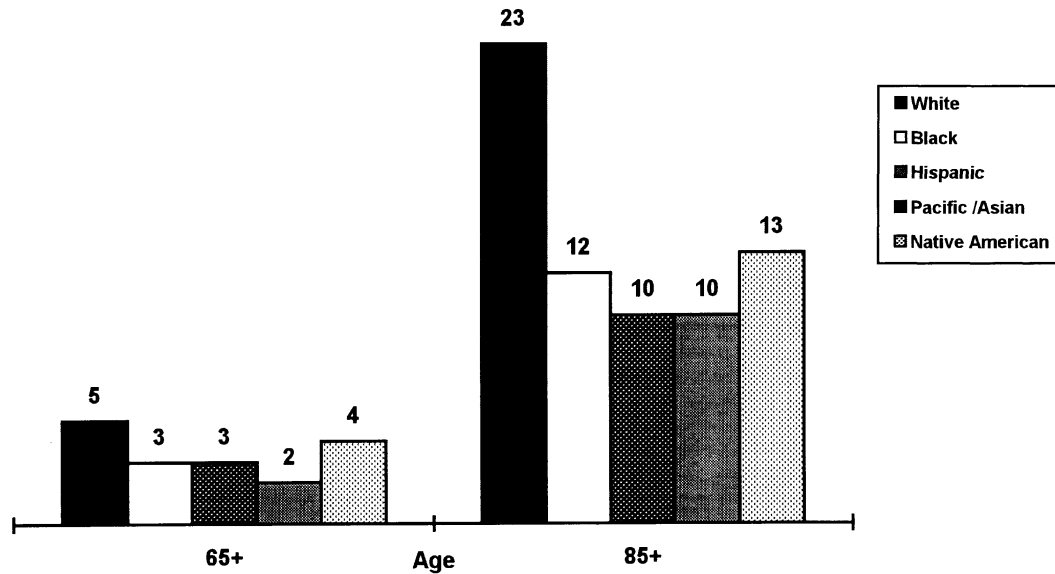
SOURCE: U.S. Bureau of the Census, 1996a, Table 5-7.

receiving nursing home care. For example, among Pacific Asian elders, language differences and cultural differences were the most predominant explanations; among older blacks, cost and discrimination were the most important factors. Native American elders cited cost and personal choice as the most important. Older Hispanic adults identified more barriers to use than other groups—language and cultural differences, discrimination, and cost.

Marital Status and the Availability of a Caregiver

Widowed older adults represent the majority of those who live in nursing homes, followed by those who never married. Not surprisingly, the lack of an available caregiver, such as a spouse, adult child, or other relative, increases the likelihood of nursing home placement (Wingard, Jones, & Kaplan, 1987).

Exhibit 19.2 **Percentage of Long-Term Care Facility Residents by Race and Age**



SOURCE: American Association of Retired Persons Minority Affairs Initiative (1987).

Functional Status

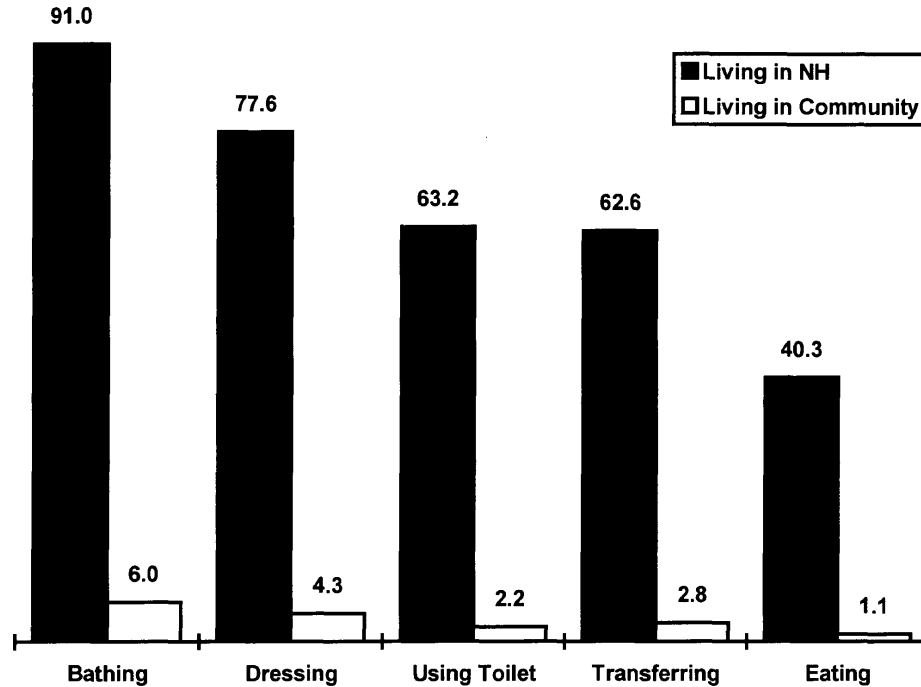
A majority of residents of nursing homes have multiple impairments in ADLs for which they need assistance. Exhibit 19.3 shows the percentage of nursing home residents and community residents who need assistance in bathing, dressing, using the toilet, transferring, and eating. A large number of nursing home residents need assistance in all five ADLs, compared with community-dwelling older adults. More than 60% of nursing home residents need assistance in four of the five ADLs, whereas less than 7% of community-dwelling older adults need assistance in any of the five ADLs.

The percentage of residents needing assistance with ADLs increases with age. Higher percentages of residents 85 years of age and older need assistance with bathing, dressing, using the toilet, transferring, and eating and are incontinent, compared with younger residents. Thus, the majority of nursing home residents are quite old and in need of personal care assistance in a number of ADLs (see Exhibit 19.4).

Long-Term Care Facilities

Nursing home care is provided predominantly by for-profit enterprises. More than 40% are affiliated with a nursing home chain (Phillips & Hawes, 1996).

Exhibit 19.3 **Percentage of Nursing Home Residents and Community Residents Needing Assistance in Daily Activities**



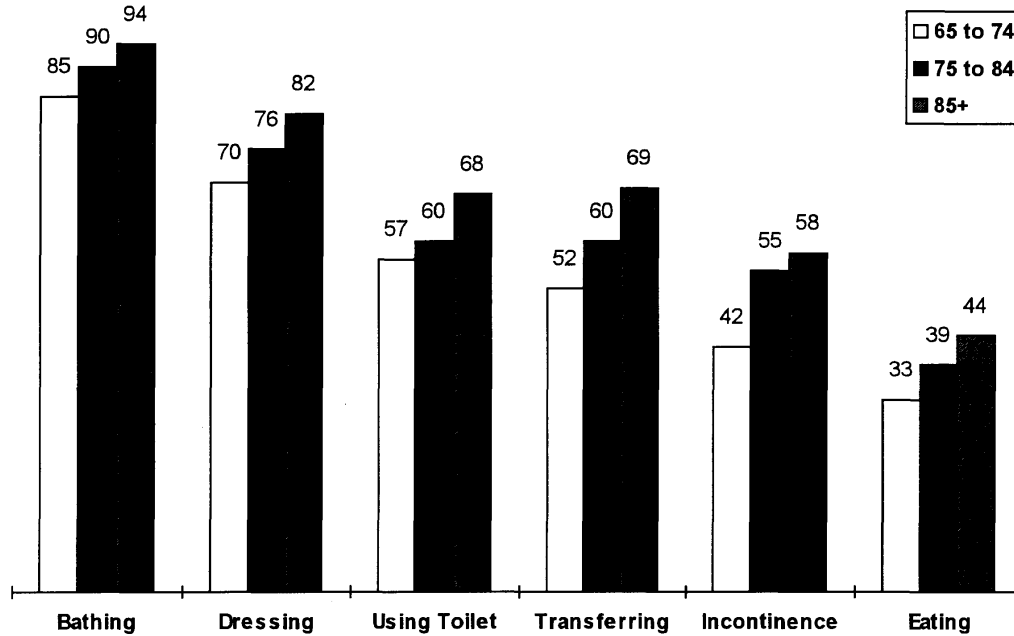
SOURCE: Compiled from U.S. Bureau of the Census, 1996a, Table 5-7.

Nonprofit nursing homes have an average of 101 beds, and for-profit homes average 87 beds; occupancy rates are, on average, around 95% (Sirrocco, 1988). The American Association of Homes and Services for the Aging (1988) reported that 2,108 of the more than 4,000 member agencies are associated with ethnic or denominational organizations. Such homes are sponsored by religious organizations including Baptist, Catholic, Mennonite, Jewish, and the United Church of Christ. Others are under national sponsorships, such as the British American Home; a few are racially specific such as the Eliza Bryant Center in Cleveland, which serves only older blacks (Kaplan & Shore, 1993).

Levels of Care

Prior to federal legislation passed in 1987, nursing homes had two levels of care on which reimbursement was based. Nursing homes were categorized as skilled nursing facilities or as intermediate care facilities. Skilled nursing facilities were designed to care for residents who needed skilled nursing care

Exhibit 19.4 **Percentage of Nursing Home Residents Who Need Assistance, by Age and Activity**



SOURCE: Hing (1987).

that was more medically oriented. Residents in intermediate care facilities required custodial, rather than skilled nursing, care. These classifications were based on Medicare and Medicaid payment criteria for nursing home care. Because the two levels of classification did not accurately reflect the variations in the functional abilities of nursing home residents, the federal government replaced the dichotomous classification with one designation—the nursing facility (Boondas, 1991). The HCFA, which administers Medicare and Medicaid, is in the process of designing a different classification system in six demonstration states. The nursing home case mix and quality demonstration project is testing a case mix classification system known as Resource Utilization Groups: Version III (RUG-III). Under the RUG classification system, nursing homes can use seven major classification groups for cost reimbursement—rehabilitation, extensive services, special care, clinically complex, impaired cognition, behavior problems, and reduced physical functions (Zbylot, Job, McCormick, Boulter, & Moore, 1995). The seven major groups are further divided into 44 case mix groups based on intensity of ADL needs. Such classification reflects the many types of residents in need of nursing home care. In part because of the increase in the number of

residents with diverse health care needs, nursing homes are expanding the range of services they offer.

Subacute Care

Many long-term care facilities now offer a wide range of rehabilitative services to persons of all ages. Most notable of these services include subacute care units. *Subacute care* is provided to patients whose needs fall between acute hospital care and traditional nursing home care. Some subacute care units cater to a specific target population. For example, subacute units might specialize in serving rehabilitation patients who need help recovering from hip replacement or spinal cord injuries. Other subacute units are considered to be “medical subacute” units and serve patients who need intensive medical care, such as ventilator care, wound care, or IV therapy. Typically, subacute units require staff to be more highly trained, require more physician involvement, and use interdisciplinary teams to plan and monitor care. The growth of subacute care has been encouraged by Medicare’s prospective payment system that pays hospitals a flat rate for care, resulting in a shorter length of stay (see Chapter 11). A shorter length of stay, in turn, encourages patient care in these “step-down” or subacute units. Studies of the effectiveness and efficiency of subacute care units are being conducted; it is generally thought that postacute care is a cost-effective alternative to inpatient acute hospital care (Office of the Assistant Secretary for Planning and Evaluation, 1995).

Specialized Alzheimer’s Unit

In the last decade, increasing numbers of nursing homes have created specialized services to care for persons with Alzheimer’s disease and other dementias. Included in these efforts are cluster settings, in which persons with dementia are grouped together on a floor or unit, and special care units (SCUs) that are housed in separate wings or buildings. SCUs have increased in part because of the special care needs of persons with various types of dementias. For example, persons with dementia are more likely to need assistance with ADLs, need help remaining continent, have psychiatric symptoms (delusions and hallucinations), and have behavioral problems (e.g., wandering and physically hurting self or others) than those without dementia (DHHS, 1991; U.S. Congress, Office of Technology Assessment, 1992). In response to a congressional request, OTA conducted a comprehensive review of the available research that exists about SCUs. The authors of the report concluded that because there is not a single agreed-on definition of SCU, it is difficult to determine the number of SCUs in existence across the

country. Their best estimate, based on national data, is that 8% to 10% of nursing homes have SCUs for persons with Alzheimer's disease or dementia and that more facilities report having plans to create such units. Not surprisingly, larger nursing homes are more likely than smaller ones to have SCUs, and nursing homes in the West were more likely to report having SCUs than were homes located in other geographical areas. The majority of nursing homes indicated that residents of SCUs are charged more for their care than are residents in non-SCUs. Descriptive studies show that units vary greatly in their patient care philosophy, number of residents, physical design, staffing patterns and ratios, activity programs, and patient care practices. Patient care philosophies included goals such as to provide a safe, secure, and supportive environment for residents; reduce feelings of anxiety; maintain optimal levels of physical and cognitive functioning; and provide holistic care. The number of residents living in SCUs ranged from less than 10 to more than 40. Studies show that on average, SCU residents are younger, white, and male and are more likely to have a specific diagnosis, such as Alzheimer's disease, compared with other residents with or without dementia. SCU residents also were less likely than other nursing home residents with dementia to have impairments in ADLs but were more likely to exhibit behavioral problems.

According to the OTA (1992) report, most SCUs had some special environmental adaptations for residents, including alarm or locking systems, secured areas for wandering, and color coding of rooms and personal markers to help residents find their way around the unit. Many of the SCUs provided some type of specialized training for staff; these units had a higher staff-to-resident ratio than did non-SCUs. In addition, studies indicated that SCUs had activities designed to increase stimulation and reduce resident stress. Activities offered to residents in SCUs included singing, exercises, games, painting, field trips, reality orientation, and reminiscence therapy.

Some argue that segregating persons with dementias from other nursing home residents improves resident well-being, enhances family interaction and satisfaction, increases staff satisfaction, and improves the nursing home experience for residents who do not have dementia (Maas, 1988; Ronch, 1987). Others argue that there are no discernible differences in resident outcomes for those living in SCUs (Rabins, 1986; Ronch, 1987). Slone, Lindeman, Phillips, Moritz, and Koch (1995) evaluated studies of effectiveness of SCUs and concluded that existing studies are inconclusive because some investigators reported improvements in residents' ADL performance, mood, behavior, and cognition, whereas others found no differences in these outcomes. These seemingly contradictory findings are due to the difficulty in controlling for sampling variations and the differences in SCU care delivery, treatment, and outcome measurement.

For Your Files Special Care Unit in Lynden, Washington

The Christian Rest Home, a 150-bed nursing home in Lynden, Washington, has had a special care unit since 1988. The 15-bed special care unit was established because of staff concerns about the safety and well-being of residents with dementia who wander or have other behavioral symptoms that cannot be handled on the facility's regular units.

The special care unit consists of resident bedrooms, an activity/dining area, and an enclosed outdoor courtyard. Physical changes were made to the building to create the unit: (a) A set of doors was installed in an existing partition off the resident bedrooms and the activity/dining area; (b) a door was made in an exterior wall to give the residents access to the enclosed courtyard; and (c) keypad-operated locks were installed on the exit doors; the doors open when a number code is punched in on the keypad, and the doors open automatically when the alarm goes off. These physical changes cost less than \$5,000.

Some residents of the special care unit have been transferred to the unit from other parts of the nursing home; other residents have been admitted directly from home. Although all the special care unit residents have dementia in the opinion of the facility staff, a few have not had a diagnosis of dementia in their medical records.

The objectives of the unit are to ensure the residents' safety, to reduce agitation and behavioral symptoms, to maintain independent functioning, and to improve the residents' quality of life. The staff members perceive resident agitation and behavioral symptoms as significant expressions of feelings and unmet needs. They attempt to understand and respond to those feelings and needs in the belief that by doing so, they will reduce agitation and behavioral symptoms and improve the residents' quality of life. Although many of the residents exhibited severe behavioral symptoms before coming to the unit, the unit staff reports that these symptoms are relatively easily managed on the special care unit.

Formal and informal activity programs are conducted on the unit. Each afternoon, there is a formal activity program, such as a weekly Bible study and music group, a weekly reminiscence group, a weekly "validation" group, and "high tea"—a Monday afternoon event with real china and lace tablecloths. Other activities, such as food preparation and singing, take place informally on the unit. One resident who likes to fold laundry is encouraged to do so. Family members are welcome on the unit at any time. Staff members know the residents' families and involve them in decisions about the residents' care. Staff members report that family members often thank them for the help they give the residents and the emotional support they give the family members.

During the day, the staff on the special care unit consists of one registered nurse, who functions as the unit coordinator, and two nurse aides. A licensed practical nurse and two other nurse aides take over for the evening shift. Because staff consistency is considered important for the unit, the unit staff members generally are not rotated to other units.

Special care unit residents are discharged from the unit when the staff considers that the residents can no longer benefit from the unit. Several spouses of former special care unit residents have created an informal support group that meets almost daily in the facility, presumably to replace the emotional support they previously received from the unit staff.

SOURCE: U.S. Congress, Office of Technology Assessment (1992).

Staffing Patterns

Nursing homes have a variety of professionals and paraprofessionals who provide care to their residents. The number of staff in each area depends on the number of beds; those certified by Medicare and Medicaid have to meet certain staffing requirements. Nursing homes generally have departments that are responsible for resident or social services, administrative services, rehabilitation, nursing, supportive services, and dietary services. Social services staff work with residents and their families to assist them in adjusting to the social and emotional aspects of living in the facility. In addition, social service staff offer medically related social and psychological treatment goals for residents. Nursing homes with 120 beds or more must employ a director of social services; smaller homes may employ a social service director on a consultant basis (Allen, 1987).

Mental health services may be provided by staff or contracted out with mental health professionals in the community. Facilities are also required to offer residents an activities program that enhances their physical, social, and psychological well-being. Staff in the activities department usually have training in recreational or therapeutic programming and are responsible for developing and implementing social and recreational activities for all residents. Activities staff also are responsible for recruiting, training, and using volunteers to assist with activities. Administrative services staff are responsible for processing admissions and financial accounting. Rehabilitation services such as physical, occupational, and speech therapies can be provided by qualified staff or contracted with outside companies. The goal of various therapies is to help the resident achieve the desired level of functioning in ADLs (Allen, 1987).

Support services staff tend to the cleanliness of the facility, laundry, and maintenance of the physical systems in the nursing home. Staff in the dietary department are responsible for the nutritional needs of the residents. Nursing

departments are in charge of the delivery of nursing and personal care services to its residents. Nursing homes employ registered nurses and licensed practical nurses to deliver and oversee medical care, whereas certified nurse aides (CNAs) provide much of the personal care of the residents.

Staff retention has been a problem in many nursing homes across the country in part because of the stressful nature of the work and the low wages (Foner, 1994). Especially problematic are the turnover rates of CNAs. CNAs are responsible for approximately 80% of direct resident care, yet turnover rates in some facilities have been as high as 75% in a given year (Harrington, 1991). Factors associated with job satisfaction and turnover rates of CNAs include wage levels, job characteristics, interpersonal relationship with nursing staff, lack of involvement in care planning and assessment of residents, and lack of advancement opportunities (Banaszak-Holl & Hines, 1994; Foner, 1994; Wacker, 1996).

Activity Programs

As mentioned above, nursing homes are required to provide activity programs that enhance residents' physical and mental well-being. Indeed, researchers have shown that participation in activities is important to residents' quality of life (Lawton, 1989; Riddick & Keller, 1991). Nursing homes frequently offer discussion groups, religious groups and services, music programs, raised garden beds, pet visitation, exercise programs, and of course, bingo. One activity that fosters a helping relationship between nursing home residents and young adults are intergenerational learning programs. The purpose of these programs is to bring young people and older adults together in a way that allows both older and younger adults to assist one another. For example, an intergenerational learning program between one Illinois nursing home and a local elementary school provided both residents and students with positive interactions (Angelis, 1990). Students helped residents with letter writing and other activities, while residents often read to students and engaged in playing games. Students and residents exchanged cards and presents on birthday and participated in intergenerational group activities. In addition, several residents attended classes at the elementary school, and a school activity newsletter was sent to the residents every month. Intergenerational programs involving students and residents offer students an educational experience and improve resident well-being.

Resident Rights and the Ombudsman Program

As we discussed earlier in the chapter, older adults living in nursing homes suffer from multiple physical or cognitive impairments. By its very nature,

Best Practice **Community Certified Nurse Aide Training Program**

Many long-term care facilities and home health agencies struggle to recruit and retain CNAs. Training is done by most agencies on a continuing, as-needed basis. Professionals in Greeley, Colorado, decided to work together to improve the recruitment and retention rates of CNAs.

Representatives from four local nursing homes, three home health agencies, the local hospital, a residential care facility for persons with disabilities, AIMS Community College, and the gerontology program at the University of Northern Colorado came together to work on solving the CNA turnover problem in their community. With a grant from the Retirement Research Foundation, the group established the Community Certified Nurse Aide Training Program. Now all individuals who wish to become CNAs receive training through the program. The community training center offers continuity of training and a community focal point for CNA training needs.

The students receive more hours of training than required by law and, once hired, spend a week with a trained preceptor before working on their own. After they have been on the job for a month, they return to the training center for two follow-up sessions that cover topics such as teamwork, stress management, time management, and death and dying. The training program is also responsible for training the preceptors who work with the newly hired CNAs at their facilities. With the assistance of AIMS Community College, a CNA recruitment video was created, and recruitment efforts are conducted throughout the county.

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institutional living tends to compromise individual choices. Thus, long-term care ombudsman programs were created to act as advocates for older adults living in nursing homes and board and care homes. In response to concerns raised about the quality of care provided in nursing homes, the federal government funded seven nursing home ombudsman demonstration projects in the early 1970s to establish a mechanism for receiving and resolving complaints regarding the delivery of nursing home care, to document problems in nursing homes, and to test the effectiveness of using volunteer ombudsmen (U.S. Senate Special Committee on Aging, 1993). By 1975, the AoA funded small resident rights programs in all 50 states, and in 1978, the ombudsman program was incorporated into the Older Americans Act. In 1981,

For Your Files **National Citizens' Coalition for Nursing Home Reform**

The National Citizens' Coalition for Nursing Home Reform, founded in 1975, is a nonprofit consumer advocacy group whose mission is to ensure quality of care for people in the long-term care system. There are more than 300 state and local member groups and approximately 1,000 members in 40 states. The coalition reviews and distributes information on legislative and regulatory issues; develops training and resource materials for those who act as advocates for nursing home residents; and connects local, state, and national organizations with long-term care experts and resources. The coalition also publishes a variety of resource materials and books, including the *Quality Care Advocate*, a bimonthly newsletter on issues relating to nursing home care and the use of restraints, and a recent book titled *Nursing Homes: Getting Good Care There*.

For more information, contact National Citizens' Coalition for Nursing Home Reform, 1424 16th Street NW, Suite 202, Washington, DC 20036-2211, 202-332-2275 (<http://www.aginet.com/nccnhr>).

ombudsmen were also directed to serve persons living in board and care homes. In 1995, there were 565 local ombudsman programs in the United States handling some 162,338 complaints (AoA, 1995b). Congress established separate authorization of \$20 million for the ombudsman program in 1988; in 1992, Congress appropriated \$8.3 million for ombudsman and elder abuse programs. In the reauthorization of the OAA in 1996, ombudsman services have been reorganized under Title III-B and have \$4.449 million earmarked for such services (AoA, 1997a).

Under the OAA, each state must establish and operate a long-term care ombudsman program. Under the direction of a full-time state ombudsman, programs are directed to (a) identify, investigate, and resolve complaints regarding welfare of nursing home residents; (b) provide for the training of staff and volunteers working in ombudsman programs; (c) represent the interests of the residents before governmental agencies; (d) provide information to public agencies regarding the problems of nursing home residents; and (e) monitor the development of laws and regulations affecting the care of residents (U.S. Senate Special Committee on Aging, 1993).

One primary responsibility of ombudsmen is to protect the rights of residents. Resident rights are based on federal and state laws that are designed to protect the basic liberties of nursing home residents (see Exhibit 19.5). For

Exhibit 19.5 **Summary of Nursing Home Residents' Rights**

- A. The right to be fully informed about
 - All services available and all charges
 - The facility's rules and regulations
 - How to contact the state ombudsman and other advocacy organizations
 - the state survey reports on the facility
- B. The right to participate in their own care and to
 - Receive adequate or appropriate health care
 - Be informed of their medical condition, participate in treatment planning, and be invited to participate in care planning
 - Refuse medication and treatment
 - Participate in discharge planning and review their medical records
 - Have daily communication in their language
 - Have assistance if there is sensory impairment
- C. The right to make independent choices, including the right to
 - Know that choices are available
 - Make independent personal decisions
 - Choose a physician
 - Participate in activities of the community inside and outside the facility and to participate in a resident council
 - Vote
- D. The right to privacy and confidentiality, including the right to
 - Private and unrestricted communication with any person of their choice, including privacy for telephone calls, unopened mail, and privacy for meetings with family and friends and other residents
 - Privacy in treatment and care for personal needs
 - Have reasonable access to any entity or individual that provides health, social, legal, or other services
 - Confidentiality regarding medical, personal, and financial affairs
- E. The right to security for possessions, including the right to
 - Manage financial affairs
 - File a complaint with the state agencies for abuse, neglect, or misappropriation of their property
- F. The right to dignity, respect and freedom, including the right to
 - Be treated with consideration, respect, and dignity
 - Be free from mental and physical abuse
 - Be free from physical and chemical restraints
 - Have self-determination
- G. The right to remain in the facility, including the right to
 - Be transferred or discharged only for medical reasons, if needs cannot be met in the facility, if the health and safety of other residents are endangered, or for nonpayment of stay
 - Receive notice of transfer: a 30-day notice for transfer out of the facility, including (a) reason for transfer, (b) effective date, (c) location to which the resident is discharged, (d) a statement of right to appeal, and (e) the name, address, and telephone number of the state long-term care ombudsman
 - Have sufficient preparation to ensure a safe transfer or discharge
- H. The right to raise concerns or complaints, including the right to
 - Present grievances to the staff of the nursing home, or to any other person, without fear of reprisal
 - Prompt efforts by the facility to resolve grievances
- I. The facility must maintain identical policies and practices regarding
 - Transfer, discharge, and provision of services for all residents regardless of payment source

SOURCE: Adapted from Burger, Fraser, Hunt, & Frank (1996).

Best Practice Heart to Heart

Heart to Heart, unveiled in February 1996 in Austin, Texas, has the ambitious goal of placing a volunteer ombudsman in every nursing home in Texas. Heart to Heart is a collaborative effort between the American Association of Retired Persons and the Texas Department on Aging. AARP will use its large, well-organized volunteer organization to recruit volunteer ombudsmen throughout the state. The Department on Aging will then train and certify the volunteers. The goal is to increase the number of volunteer ombudsmen from 700 to 1,200. This will enable volunteers to be placed in the 500 homes that the ombudsman program does not cover. The volunteer ombudsmen's duties will include helping residents, families, and friends identify, investigate, and resolve complaints. The ombudsmen will seek out and visit with the more isolated residents to make sure the residents' needs are being met. Without on-site ombudsmen and with more than 1,100 nursing homes in the state, many residents and their families have no outside person to listen to their concerns. Worse, many nursing home residents have no family or friends at all.

By joining forces, AARP, a private organization, and the Texas Department on Aging, a governmental organization, together have challenged the whole state to make quality of care in nursing homes a top priority. For more information, contact the Texas Department on Aging, P.O. Box 12786, Austin, TX 78711, 800-252-2412, or the AARP state office at 512-480-9797.

example, resident rights legislation includes the rights to receive information; participate in planning all types of care; make choices and independent personal decisions; enjoy privacy in care and confidentiality regarding medical, personal, and financial matters; be treated with dignity and respect; have personal possessions that are kept safe and secure; and have advance notice of transfer or change of rooms or roommates (Burger, Fraser, Hunt, & Frank, 1996).

Ombudsmen also deal with a wide range of other issues, including resolving problems that residents might have with their public benefits or guardianship procedures. Netting, Paton, and Huber (1992) examined ombudsman program reports sent to the AoA in 1990 to determine the nature of complaints received by long-term care ombudsman programs. They found that the largest number of complaints were related to resident care and included such things as not being dressed, physical abuse, neglect, and poorly trained staff. The next most frequent category of complaints was administrative complaints about understaffing, roommate conflict, and laundry pro-

cedures, followed by resident rights. In 1995, the complaints most frequently received by ombudsmen from residents in board and care homes were about menu quality, building disrepair, administration of medication, and staff respect and attitude (AoA, 1995b).

In their study of ombudsman programs, Monk, Kaye, and Litwin (1984) identified two models of ombudsman activities. The *patient rights model* is perceived as a watchdog approach designed to create systemic change in long-term care services. The *quality of life model* is based on resolving resident difficulties with staff on a more informal level. Of course, many programs may use both elements in delivering services. Regardless of the model selected by local programs, they all rely on well-trained staff to deliver program services. Some programs use paid staff, volunteers, or a combination of both to deliver its services. In a study of ombudsman programs in 46 states, 26 states reported that they used mostly volunteer staff, and 20 used primarily paid staff (U.S. Senate Special Committee on Aging, 1993). Although using volunteer ombudsmen has some drawbacks (see Monk et al., 1984), some programs have successfully relied on volunteers to provide services. For example, the East Tennessee Advocates for Elders Program has successfully used volunteer ombudsmen since 1978 and, in 1989, had 94 volunteers who were trained or being trained as ombudsmen (Netting & Hinds, 1989). The program covers a 16-county area and serves 104 nursing homes and board and care homes.

Resident Councils

In an attempt to give residents input in the quality of care that they receive, resident councils have emerged as a vehicle to voice residents' concerns. Meyer (1991) collected data about the activities of resident councils through participant observations and interviews with residents as well as statewide resident council members and staff. Resident councils usually meet once a month with the activities director facilitating the meetings; meetings are usually attended by 15 to 30 residents. On the basis of her observations, Meyer concluded that resident councils have at least four functions. First, they make modest changes in the care they receive and condition of the home. For example, specific items discussed at council meetings included acquiring shower chairs for frail residents, more frequent adjustment of window blinds by staff, and parking of carts and wheelchairs on only one side of the hallway. Their success in accomplishing these and other goals were mixed. Resident councils were more successful in obtaining products than they were in changing procedures or services. Second, resident councils provide services to residents and the needy living in their communities. Residents make and sell handcrafted items; the funds are used to assist residents who experienced a

financial crisis or are given to charitable organizations. Third, they broaden the scope of social activities available to residents. These activities included feeding birds; planning ethnic and cultural menus and activities; and arranging social outings to nearby restaurants, zoos, and theaters. Finally, resident councils cooperate with resident councils at other nursing homes to lobby for improvements in quality of care.

Although resident councils were unsuccessful in changing procedures, participation in resident councils gave residents a sense of having some control over their lives and a chance to participate in beneficial activities. Meyer (1991) also identified barriers to participation in resident councils. Many residents have difficulty hearing, are entering nursing homes with more functional limitations, and have shorter average length of stays. Some residents did not participate because they felt that councils were ineffective in creating change, and others feared retaliation for voicing complaints. Overall, resident councils play an important role in improving the lives of nursing home residents. More research is needed, however, to determine ways to improve participation and outcomes.

Improving Quality of Life in Nursing Homes

The issue of quality of care has been a concern since nursing homes were formally established decades ago. Indeed, substandard resident care and resident abuse have led to nursing homes being one of the most regulated enterprises in the country. Quality of care includes a wide variety of indicators from the small details of accommodating personal preference to the delivery of personal and medical care.

Stop and consider for a moment how you begin a typical day. You get yourself up, shower and dress, and grab a bite to eat before you go on your way. You decide when to get up, what to wear, and what to eat. You also probably have routines built into your morning as well—perhaps enjoying a cup of coffee and reading the paper before having breakfast. The mere fact of residing in an institution compromises these types of personal freedoms to some extent. Higher-quality homes attempt to accommodate personal differences, employ well-trained staff, and deliver high-quality medical care.

A landmark work, *Improving Quality of Care in Nursing Homes* (Institute of Medicine, 1986), was instrumental in identifying key indicators of quality of care in nursing homes. Specific indicators that measured resident outcome and care process were identified. Negative indicators included excessive use of psychotropic drugs, high incidence of avoidable decubitus ulcers and urinary tract infections, dehydration, and considerable weight loss. Personal care indicators included whether residents' hair was neat and clean, whether they were dressed in their own clothing, whether they received daily oral

care, and whether they received prompt response to resident call lights. Nutritional and dietary indicators included assisting residents who need help eating, serving food while it is still warm, and giving residents some choice in menu selections. Finally, overall quality of care indicators included living in a clean environment in which residents are allowed to have personal possessions and furnishings in their rooms, opportunities for personal choice, participation in social activities, and treatment by staff with dignity.

The extent to which nursing homes fail to provide good quality of care has been well documented. For example, in a survey of nursing home staff, Pillemer and Moore (1989) found that 36% of nursing home staff had seen at least one resident physically abused in the last year, and 10% admitted to physically abusing residents. Eighty-one percent reported seeing residents psychologically abused—most often in the form of being yelled at. In addition, treatment of residents has been found to be related to personal characteristics. Residents with higher incomes, more personal possessions, and visitors at least once a month and who were white received better overall quality of care (Pillemer, 1988).

Although much of what is reported in the popular press and to some extent in professional publications focuses on poor-quality care provided in some homes, researchers have identified positive outcomes for residents and family members after nursing home placement. For example, Smith and Bengston (1979) found in their 2-year study of nursing home residents and their families that 70% reported that the consequences of nursing home placement was positive. Families reported a renewed or continued closeness among family members as well as a reduction in caregiving stress, which in turn resulted in more time to focus on the emotional aspects of the relationship. Families also saw improvements in residents' physical and mental health and were pleased to see residents developing new relationships with other residents. For example, one resident stated a positive outcome, "I learned to walk when I got here." Another commented, "I've gained weight. You better believe it. I was going downhill rather rapidly before [moving into the nursing home]" (AARP, 1990, p. 13).

Challenges for Nursing Homes in the Future

For most of the general public, the nursing home stands as a symbol of all that is dreaded about old age—its residents are physically and mentally impaired, they have become dependent on others to accomplish the most basic tasks of daily living, and they appear lonely and discarded by society. Popular news programs report of the abuses that occur within its confines. These images are embedded in our collective consciousness. Nursing homes do

care for those who are among the most frail and debilitated in our society; some facilities are better than others. But rather than view nursing homes with contempt, we must embrace them as necessary places within the continuum of care and work to enhance the quality of care provided to their residents. Improving quality of care is like putting together pieces of a puzzle. No one piece will solve the problems that exist in nursing homes because many pieces need to be addressed.

Reforming Reimbursement and Payment of Long-Term Care Facility Services

Having Medicaid as the largest third-party payer of nursing home care causes a number of problems. First, many have observed that Medicaid reimbursement rates are terribly inadequate, especially for those with high care needs (Swan & Benjamin, 1990). For example, in 1992, Arkansas's Medicaid program paid \$49 per day, Mississippi's paid \$58, and New York State's paid \$125. The average per day rate across all Medicaid programs was \$77.45 (Phillips & Hawes, 1996). This in turn has led, according to some scholars, to structural discrimination toward Medicaid residents in the form of long waiting lists and preferential treatment toward private-pay residents (Abend-Wein, 1991; Estes, Swan, & Associates, 1993; Grimaldi, 1982). Second, for middle-class families, the only alternative to paying for nursing home costs has been to impoverish themselves to qualify for nursing home care. How many older families, or their children, for that matter, who need to secure extended long-term care services can afford \$100 per day—more than \$30,000 per year—for nursing home care? Many health scholars have called for developing a more rational system for financing nursing home care—one that combines both public and private financing (Aiken, 1989; Estes et al., 1993). An increase in public support, either directly or through taxation, is needed, along with an increase in private sector insurance to help spread the risk of long-term care across different sectors of society and make nursing home care more affordable.

Attracting Qualified Staff and Improving Working Conditions

To increase the number of qualified staff applying for positions and working in nursing homes, we must endeavor to reduce the stigma associated with working in a nursing home among all professional and certified staff. Anecdotal evidence suggests that nursing homes are often the last employment choice of newly graduated nurses. Nursing programs can work to encourage the placement of their students into long-term care. Just as initiatives have

been developed to increase the number of nurses placed in rural areas, so too should initiatives be implemented to increase the number of nurses placed in long-term care facilities. Of course, chances of attracting qualified staff are improved if working conditions and benefits are competitive. Salary and benefits must be competitive with both the medical and nonmedical employment sectors, opportunities for professional advancement must exist, and the organizational climate must convey a sense of respect and appreciation for its employees.

Increasing Family and Community Involvement

Researchers have discovered a link between increased volunteer and family visits and improved quality of care. Staff and those in the aging network must work together to improve the amount of community involvement in nursing homes. Something as simple as having the AAA advisory board meet every month in the nursing home's conference room could increase the amount of contact between "outsiders" and the nursing home community. One facility in Boston has started a "Love Is Ageless" program that encourages all nursing homes to display a banner proclaiming that love is ageless and inviting visitors from the community. They project that if only 3 new people visited each nursing home across the country, 15,000 new visitors would result.

Meeting the Care Needs of a Diverse Group of Residents

The changing nature of the health care delivery system means that the type of care provided in nursing homes will have to change as well. As more community-based alternatives emerge for persons who need custodial care, nursing homes will no doubt emerge as primary places for more therapeutic and rehabilitative care. Furthermore, the increased number of persons with AIDS who will need long-term nursing may have a hand in shaping the future of nursing homes (Aiken, 1989).

Supporting the Future of Long-Term Care Facilities

The 1995 White House Conference on Aging passed a resolution aimed at developing alternative options for funding long-term care. The delegates supported policies that establish (a) affordable public and private long-term care insurance plans, (b) uniform standards and consumer protection for long-term care insurance, and (c) the inclusion of payment for home care and community-based services in long-term care insurance policies. As the

next century approaches, long-term care facilities will be faced with a myriad of social and organizational challenges.



CASE STUDY

DEFENDING INDIVIDUAL RIGHTS: A NURSING HOME'S DILEMMA

Edna, an 83-year-old with mild dementia, has lived in a nursing home for the past 3 years. Her only remaining family is an estranged daughter. Although she can walk with assistance, she prefers to use a wheelchair. Edna has formed a strong attachment to George, a 90-year-old with moderate to severe dementia depending on the day and his stress level. George's chart also documents a diagnosis of transient ischemic attacks. George is quite handsome and is "the catch of the nursing home." Edna feels important when George is pushing her around in her wheelchair. Being with George has become a status symbol for Edna. George's roommate, Bud, has complained that he does not have any privacy. Edna and George neglect to pull the privacy curtain when they are lying in George's bed. Bud's family also has complained about how embarrassing it is, especially for younger family members, to find Edna and George in bed together when they visit. Edna's daughter called the nursing home and told the head nurse that the facility should stop this relationship because Edna and George were too old to have sex. She demanded that something be done immediately and indicated that if some measures were not taken, she would move her mother to another facility.

The staff of the facility have offered Edna and George the opportunity to room together. Some staff members are uncomfortable with this relationship because George is more confused than Edna, and they feel that she dominates the relationship. They suspect that she can be physically abusive to George if he refuses to spend time with her. They have observed such jealous behavior during group activities and in the dining room when other women try to sit next to George. Other staff members believe that to try to separate the couple would be a violation of their rights to choose their own companions. George's two sons are not adamantly opposed to George's being with Edna. They find it amusing and have joked about it in front of the staff.

Edna and George decide to be roommates. After 3 days together, George has many bruises on his arms and face. Staff members notice that he is attempting to avoid Edna. They ask George if he wants to move back into his old room, and he replies that he does. Staff members move George back to his room. Within a day, George is seeking Edna out and refuses to leave her. Staff decide to call the local long-term care ombudsman for technical assistance.

CASE STUDY QUESTIONS

1. As the long-term care ombudsman, what additional information would you like to know?
2. What resident rights are in question in this case scenario?
3. Whose interests must be considered? Do any of these interests take precedence over any of the others?
4. Do you believe it is a violation of George and Edna's rights to keep them separated? Why or why not?
5. Can you think of a creative compromise that would mostly satisfy all parties in this case? Are there any other community resources or agencies that could be called on to assist staff? Family members? George or Edna? Bud?



LEARNING ACTIVITIES

1. Visit a resident council meeting at a local nursing home. What issues were discussed at the meeting? How many residents and staff attended? Interview the chair of the resident council. Have the chair reflect on the council's accomplishments during the last year.
2. Join the *Gerinet Listserv* discussion group. For instructions on how to log on, go to the *Community Resources for Older Adults* Web site (<http://www.hhs.unco.edu/geron.htm>). Monitor the discussion during a 2-week period. What issues are discussed by the group?
3. Obtain a map of your city and mark on the map the locations of the nursing homes in your community. On the same map, draw a line around what you believe are low-income or minority neighborhoods. Where are the nursing homes located in relation to these neighborhoods? If you live in a rural area, determine how far away these facilities are from smaller rural towns. What are the implications of the geographic location of these nursing homes?



FOR MORE INFORMATION

National Resources

1. American Association of Homes and Services for the Aging, 901 E Street NW, Suite 500, Washington, DC 20004-2037, 202-783-2242.

The American Association of Homes and Services for the Aging is the national association for nonprofit organizations involved in providing health, community, and related services to older adults. It distributes free information on a variety of issues including long-term care.

2. American Health Care Association, 1201 L Street NW, Washington, DC 20005, 202-842-4444.

The American Health Care Association provides leadership in dealing with long-term care issues, offers continuing education programs for nursing home professionals, and publishes *Provider*, a monthly magazine for its members.

3. National Citizens' Coalition for Nursing Home Reform, 1424 16th Street NW, Suite 202, Washington, DC 20036-2211, 202-332-2275.

The coalition works to achieve quality of care in nursing homes by conducting advocacy training, promotes best practices in care delivery, and provides publications on institutional-based long-term care. It also operates the National Long-Term Care Ombudsman Resource Center.

Web Resources

1. Health Insurance Association of America
<http://www.hiaa.org>

The Health Insurance Association of America has a number of consumer guides online, including one on long-term care insurance. The information about long-term care insurance is comprehensive and covers such topics as "Are you likely to need long-term care?" "What kind of insurance is available?" "What do policies cost?" and "What do long-term care insurance policies cover?" It is a good primer on long-term care insurance.

2. American Health Care Association Brochure on Long-Term Care Insurance
<http://www.napsnet.com/money/35400.html>

In contrast to the above Web information on long-term care insurance, this is an announcement of how to obtain a brochure for consumers about private long-term care insurance.

3. Nursing Facility Resource
<http://www.terranet.net/users/r/rbellora/>

A nursing home administrator in Kansas has put together his own home page to share information and news about nursing home facility operations. Even for those not interested in becoming nursing home administrators, the site has information about regulations and business practices that affect the quality and level of care given to residents.

4. Office of the Ombudsman
<http://www.ombud.gov.bc.ca/index.html>

This Web page does a good job of explaining what an ombudsman is and does and how to use one. The site also has links to other related resources.

5. MedAccess

<http://www.medaccess.com>

This site's stated goal is to be the premier provider of health and wellness information. On the basis of the amount of information it contains, it comes close to achieving this goal. Tucked away under its link called *Just for Seniors* is a guide to choosing a nursing home. Visitors may also take their health quiz.

6. Guide to Nursing Homes in Florida

<http://www-wane-leon.scri.fsu.edu/AHCA/NURSDAT/index-frame.html>

Even for nonresidents of Florida, this site is worth the visit. The Agency for Health Care Administration has created a home page with links to information about tips on finding a nursing home. Visitors can search the guide by region or by key word.

