
Chapter 7

Technologies, Functional Impairment- and Long-Term Care

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Technologies, Functional Impairment, and Long-Term Care

Introduction

Long-term care for the elderly includes a variety of health and social services provided for individuals who need assistance because of physical or mental disability. The increasing number of elderly persons in our society, particularly those over 85 who most frequently need long-term care, is expected to intensify the demand for services and place additional strain on agencies, delivery systems, and funding programs. This chapter examines Federal concerns in long-term care, the needs of the disabled elderly, and technologies appropriate for addressing those needs and improving services and service delivery. These technologies include:

- assessment technologies to identify functional impairments and facilitate matching of the individual with long-term care services;
- technologies to maintain or increase independent functioning, including assistive devices and rehabilitation services;
- technologies to assist formal and informal caregivers; and
- service delivery systems to improve access to appropriate long-term care.'

Discussion focuses on problems that impede the use of available technologies and limit the development of new technologies.

What is long-term care?

Although there is no single accepted definition of long-term care, it is generally agreed that the goal of long-term care is to maintain or improve the ability of the individual to function as independently as possible and that services will be needed over a prolonged period, even if they are only needed intermittently. Medical care is seen as an essential component of long-term care, but a variety of other services are also considered important (44).

Long-term care is generally concerned with functional impairments, such as limitations in the individual's ability to move around independently; to feed, dress, or bathe himself; or to perform housekeeping functions such as shopping, cooking, or cleaning. While acute care is most often directed toward treating or curing disease, long-term care is generally directed toward compensating for functional impairment and maintaining or improving the functional capacity of the individual.

In the past, definitions of long-term care have often encompassed only services provided in institutional settings such as nursing homes and extended-care facilities, but most recent definitions include a broader range of services that may be provided in an institution or in the home or the community (68,109). The following definition, developed for the 1981 White House Conference on Aging, emphasizes the broad range of services and the kinds of individuals served:

Long-term care represents a range of services that address the health, social, and personal care needs of individuals who, for one reason or another, have never developed or have lost the capacity for self-care. Services may be continuous or intermittent, but it is generally presumed that they will be delivered for the "long-term," that is, indefinitely, to individuals who have demonstrated need usually measured by some index of functional incapacity (130).

Although long-term care services are needed by some disabled individuals of all ages, this chapter addresses only the long-term care needs of the elderly.

The need for long-term care

Estimates of the number of elderly individuals who need long-term care services depend on the definition of long-term care that is used and the

kinds of impairments that are seen to create a need for long-term care. About 7 percent of individuals 65 to 74 and more than 40 percent of those over 85 have functional impairments that may indicate a need for long-term care. Many of these individuals are not using formal long-term care services: some receive assistance informally from family or friends; others live in communities that lack the formal services they need. Some elderly individuals cannot pay for services and are not eligible for those provided by government programs. Others are not aware of available services or simply prefer not to use formal long-term care services.

At present there are almost 1.3 million elderly individuals in nursing homes at any one time. Another 150,000 to 200,000 elderly individuals are residents of board and care facilities (88), and many elderly persons are receiving one or more long-term care services in their homes or communities.¹ Adult day care facilities, hospice programs, and congregate housing facilities also provide long-term care services in some communities.

The need for formal long-term care services is expected to increase dramatically in the future as a result of rapid growth in the number of elderly individuals in the population (see ch. 2). One researcher has estimated that the number of elderly individuals in nursing homes will rise by more than 50 percent by the year 2000 (29), requiring construction of up to 10,000 new nursing homes. Demand for other long-term care facilities and services can be expected to increase proportionately. Factors that would alter these projections are changes in the prevalence of chronic disease and functional impairment among the elderly and in the ability and willingness of family and friends to provide long-term care services informally.

Over the past 50 years, advances in public sanitation, hygiene, and medical care have lowered mortality from infectious diseases, and individuals who might have died earlier of these causes now live long enough to develop functional impair-

ments related to chronic diseases. Medical treatment has also lowered mortality from heart attacks, strokes, and some cancers, but there is currently no evidence that the onset of chronic disease and functional impairment has been postponed (98). Future medical advances that reduce mortality for the elderly may result in greater numbers of elderly individuals with chronic diseases that lead to functional impairment (81), thus increasing the need for long-term care. Yet medical research focused specifically on the chronic conditions that cause functional impairment could result in methods of treatment or prevention that would significantly decrease the number of elderly individuals needing long-term care (29,81).

Changes in regulations for government programs that fund acute care services can also affect demand for long-term care. For example, recent changes in Medicare reimbursement for hospital care are increasing the demand for long-term care services. The prospective reimbursement system based on diagnosis-related groups (DRGs) instituted October 1, 1983, has created incentives for early discharge of hospital patients. Many elderly individuals who are discharged earlier from hospitals need continuing convalescent care in nursing homes or in the community. Technologies that have been available primarily in hospitals are also needed in alternative settings in the community to care for these individuals.

Government involvement in long-term care

Current government involvement in long-term care includes funding and regulation of many long-term care services through Federal programs such as Medicare, Medicaid, Supplemental Security Income (SSI), the Title XX Block Grant, Title III of the Older Americans Act, and services provided through the Veterans Administration (VA). (These programs are described in the technical memorandum at the conclusion of this chapter.) State and local governments participate in funding and regulation of services provided through these Federal programs and also fund and regulate some long-term care services of their own. Public spending for Federal programs providing long-term care services in fiscal year 1980 is summarized in table 12.

¹ In 1980, about 890,000 elderly individuals received home health care services funded by Medicare, and about 140,000 elderly individuals received Medicaid-funded home care services (126). There are no reliable estimates of the number of elderly individuals who paid privately for home care services.

Table 12.—Public Expenditures on Long-Term Care Service by Program, Fiscal Year 1980^a

Service category	Total reported expenditures in U.S. (thousands of dollars)	Percentage distribution by program ^b					
		Medicaid	Medicare	Title III Older Americans Act	Supplemental Security Income	Title XX	Veterans Administration ^c
T o t a l	\$13,454,224.2	76.3%	6.9%	5.2%	2.7%	5.4%	3.5%
Nursing home	8,586,008.0	92.3	3.6 ^d	—	—	—	4.1
Board and care	505,991.4	—	—	—	73.1	4.0	22.9
Adult day care	20,585.9	3.3	—	—	—	96.7	—
Home health	775,383.3	18.2	80.8 ^e	—	—	—	1.0
Personal care and housekeeper chore	667,602.4	32.6	—	6.3	—	61.1 ^f	—
Community	462,147.2	—	—	45.2	—	54.8 ^g	—

^aLess than 0.05 percent.^bThese programs serve individuals of all ages, not only the elderly.^cEach of these programs is described in the technical memorandum at the conclusion of the chapter.^dExpenditures for fiscal year 1979.^eThis column does not total because some services that are not discussed in this chapter and services for retarded adults are not included, expenditures for calendar year 1979.^fNursing home ombudsman services—\$3,789.0 thousand.^gPresidential care and treatment services.^hExpenditures for calendar year 1980.ⁱIncludes services reported under the following categories: homemaker, chore, and home management.^jIncludes access, community (other than legal), and in-facility services.^kIncludes services reported under the following categories: special services for the blind, education and training, transportation, health related, special services for the disabled, other, socialization, transitional case management, protective services for adults, placement, housing, improvement, counseling, recreational, diagnosis and evaluation, and emergency.

SOURCE: Cohen, 1983 (25).

Rising public expenditures for long-term care services are a major concern of government at all levels. Public spending for long-term care has increased sharply over the past 20 years and is expected to continue growing as a result of increases in the number of elderly persons, expansion of services, and escalating health care costs. For example, more than one-third of all Medicaid expenditures are now for nursing home care. Despite Federal and State efforts to contain costs, expenditures for nursing home care continue to grow (119), threatening the capacity of the Medicaid program to provide other benefits for indigent elderly and nonelderly recipients.

In addition to rising costs, another major governmental concern in long-term care is the availability of appropriate services for the disabled elderly. Although there is currently no comprehensive Federal policy on long-term care, the programs cited earlier reflect government intent to provide for some of the long-term care needs of the elderly. Relevant public policy issues include:

- availability of long-term care services in local communities;
- access to these services, including information and referral, and funding;

- appropriate matching of the needs of the individual and the services provided;
- provision of services in the least restrictive setting; and
- quality of available services.

Government concern for controlling public expenditures in long-term care appears to conflict with government efforts to assure access to appropriate long-term care services (81). Increased use of technology can address both concerns. Biomedical research on chronic disease and rehabilitation technologies that help to maintain or improve independent functioning may decrease the need for long-term care, thus limiting costs and improving quality of life for the elderly. Assessment technology and technologies to assist caregivers and improve the service delivery system can lead to more appropriate treatment and more efficient use of available resources.

Technology and long-term care

Technology has traditionally been given very little emphasis in long-term care. The importance of functional impairments in causing the need for long-term care has been cited repeatedly in re-

search reports and government publications, but the role of technology in compensating for functional impairments has received relatively little attention. Assessment technologies to identify functional impairments have not been widely used outside research and demonstration projects and specialized geriatric assessment centers. Long-term care providers, including nursing homes and informal caregivers such as family and friends, have not generally used available technologies to facilitate caregiving and improve quality of care.

Some specific reasons for the lack of emphasis on these technologies are discussed later in this chapter. One common factor that limits the use of these technologies is the overriding emphasis on medical care and skilled nursing care in the Federal programs that fund long-term care services. By defining need in terms of medical and skilled nursing care, these programs tend to obscure other needs, including the need for technologies to identify and compensate for functional impairments and assist caregivers and the need for alternative forms of care.

The influence of Federal funding mechanisms on the long-term care system

At present Medicare and Medicaid pay almost half the total cost of nursing home care in this country, and more than half of all nursing home patients are paid for in part by these public programs.² It is estimated that Medicare and Medicaid also pay for more than half of all home care in this country (94). As a result, Medicare and Medicaid regulations that define eligibility for services affect a very large proportion of those receiving long-term care.

In addition to defining eligibility requirements, Medicare and Medicaid regulations define the kinds of services covered, the kinds of agencies certified to provide reimbursed services, and minimum standards for the number and qualifications of personnel employed by these agencies. State governments can add to Federal requirements, and some agencies provide services and staffing above Medicare and Medicaid guidelines, but because cost containment is a constant concern, many agencies limit their services and staffing to Medicare and Medicaid requirements. Even individuals who pay privately for long-term care services may be affected by Medicare and Medicaid regulations because the agencies that pro-

vide services to them are often structured and staffed to meet these requirements.³

Medicare and Medicaid were enacted in 1965 primarily to provide medical care for the elderly and the poor, with emphasis on acute care in the hospital and the physician's office. Medicare coverage for nursing home care was designed to provide skilled nursing care immediately following hospitalization. Medicaid coverage for long-term care was intended to assure adequate health care services for low-income persons but not to provide supportive or custodial care.

Since their inception, both programs have been stretched to provide some services that are not medically related, but the emphasis remains on medical care. Eligibility for Medicare-funded nursing home care depends primarily on medical diagnosis and the need for skilled nursing care, and Medicare-funded home care services are health-related services authorized by a physician. Eligibility for most nursing home and home care services funded by Medicaid depends on medical condition.

²Using 1976 data, the General Accounting Office estimated that 54 percent of elderly nursing home residents were receiving some Medicaid support (119); other data indicate that the figure may be as high as 75 percent (134).

³Although some facilities, agencies, and providers do not provide services for any Medicare or Medicaid reimbursed patients and so are not affected by Medicare and Medicaid regulations, most facilities serve both Medicare or Medicaid patients and individuals who pay privately for their care. In these agencies, the services and staff available to private-pay patients are often determined indirectly by Medicare and Medicaid regulations.

Because Medicare and Medicaid fund such a large proportion of long-term care services, the emphasis on medical diagnosis and medical treatment in these programs tends to define the kinds of long-term care needs that are recognized and the services and technologies that are available.⁴ Physician services and prescribed medical treatment are obviously very important for impaired elderly individuals, and accurate medical diagnosis is essential for planning medical and non-medical care, but evaluation of appropriate technologies for this population requires recognition of needs for both medical and nonmedical forms of care. The following examples illustrate how the emphasis on medical and skilled nursing care in Federal funding programs can lead to inappropriate treatment and distort data on the need for long-term care.

The family and physician of an elderly individual who is mentally confused decide that he can no longer live alone and that a nursing home is the only available option for 24-hour care. Because he cannot afford to pay the monthly bill, he is admitted to the nursing home under Medicaid, with a diagnosis of chronic heart disease and a treatment plan that emphasizes the need for medical care. (This diagnosis and treatment plan are necessary to establish eligibility for Med-

icaid funding.) In the nursing home, which is structured and staffed to provide physical care, the confused patient is placed on a wing with physically impaired patients and treated as if he were physically impaired. Technologies and care methods appropriate to deal with his confusion are not used. A survey of nursing home residents will later pick up the diagnosis and treatment plan from his chart, and the fact that he was admitted because of mental confusion will be lost.

An elderly woman with severe osteoarthritis needs some personal care services such as help with bathing or dressing and some related house-keeping services in order to continue living independently. Medicare regulations specify that in order to justify reimbursement for these services, skilled home health care services such as nursing, physical therapy, speech therapy, or occupational therapy must also be needed. The home care agency has a choice of not providing the needed personal care services or of sending out a skilled professional to visit the patient to justify continuing visits of the home health aide, who provides personal care. If services are provided, the patient's records will show that she needed skilled care although she and the service providers know that she needed primarily personal care and housekeeping assistance.⁵

⁴Ntany long-term care agencies have been created since Medicare and Medicaid came into effect and have designed their programs to serve Medicare and Medicaid patients and conform to relevant Federal regulations.

⁵Surveys based on a review of patient records cannot pick up these instances of inappropriate treatment because patient records must be written to show that the patient needed services that are reimbursable under Medicare and Medicaid, or payment will be denied. Only an independent assessment of patient needs could provide accurate data.

Functional impairment and the need for long-term care

Despite the emphasis on medical diagnosis and medical care in the existing long-term care system, virtually all research on the long-term care needs of the elderly shows that medical diagnosis is usually not a good predictor of the need for services. Individuals with the same diagnosis vary greatly in their need for long-term care. For example, some individuals with heart disease, chronic respiratory disease, or degenerative osteoarthritis need to be in a nursing home; others manage well

on their own. The important factor in determining the need for long-term care, including both formal and informal services, is the functional status of the individual; i.e., which functions he or she is able to perform and which functions he or she needs help with (50,68,140).

In fact, the elderly often measure their own health in terms of functional impairment. They may say that they are in good health when they



Photo credit: Phyllis Eisen

Many elderly individuals function independently despite underlying chronic conditions.

are able to function independently in spite of underlying chronic diseases (68). Likewise, they may fear the frailty and dependency associated with functional impairment more than specific diseases (.53). While chronic diseases often cause functional impairment, it is functional impairment that most often leads to a need for long-term care.

The distinction between chronic disease and functional impairment is very important in identifying long-term care needs and technologies that are appropriate for addressing these needs. Technologies that do not affect underlying disease conditions but improve the functional status of the individual can decrease the need for long-term care. For example, devices or techniques that allow an individual to bathe, dress, and feed himself will decrease his need for long-term care services. In contrast, medical treatments that alter disease conditions but do not improve functional status will not affect the need for long-term care. Thus, an individual with heart disease, hypertension, and degenerative osteoarthritis may need assistance in functioning only because of the osteoarthritis; medical treatment to control the hypertension will not affect his current need for long-term care services.

Precise medical diagnosis is essential for the treatment of disease, and diagnoses are available for many elderly patients, yet they often do not specify the disease conditions that are causing functional impairment. Diagnosis related to functional impairments is important for planning treatment because while long-term care patients

often have several diagnoses, including **some** presently incurable diseases, the condition that is causing the need for long-term care may be curable. For example, incontinence, which has been cited as the cause of nursing home placement for many patients, may often be treatable, allowing the possibility that the patient could return home even when his other chronic disease conditions are unchanged.⁶

Functional impairment in the elderly population

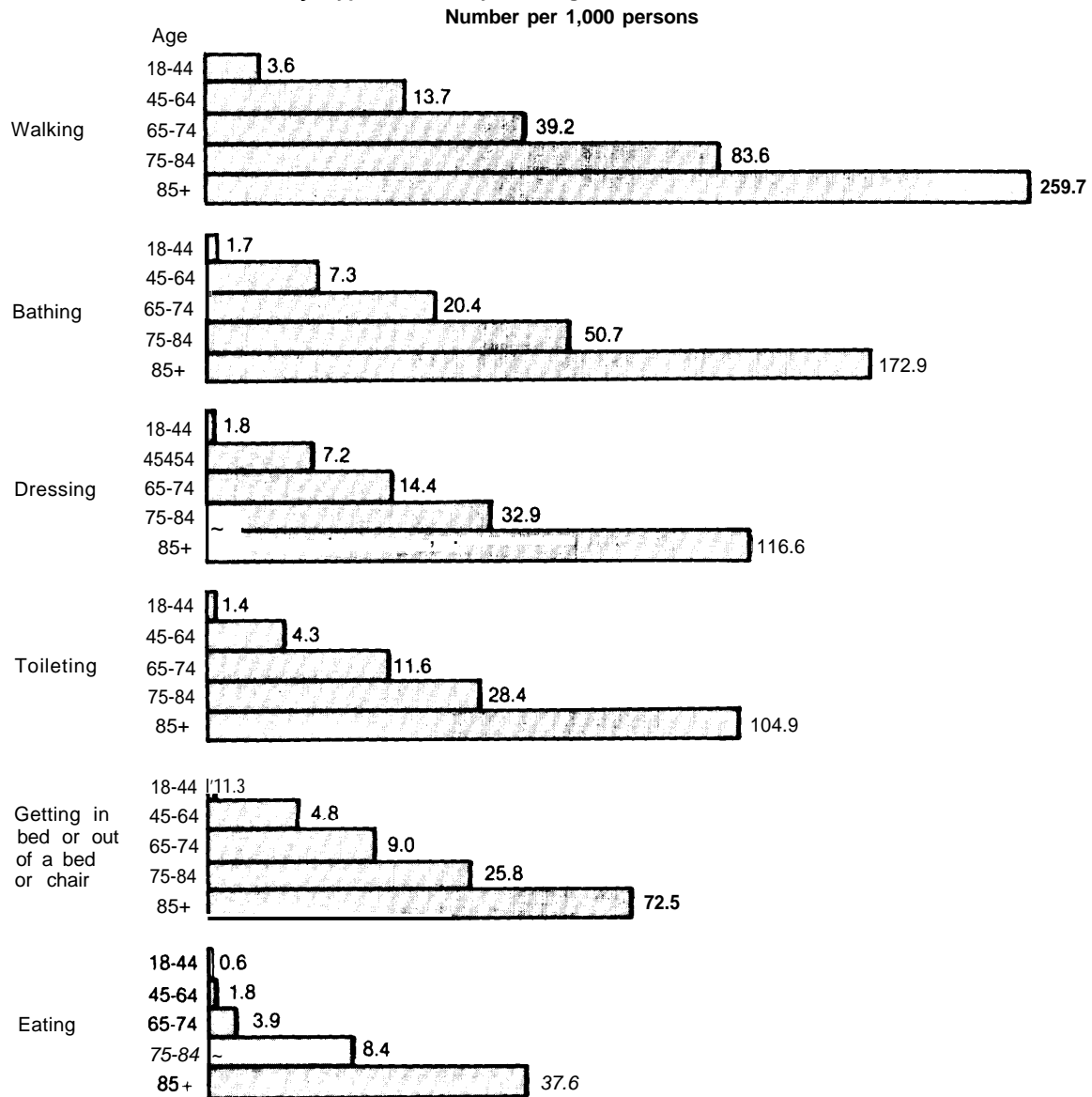
The extent of functional impairment among the noninstitutionalized elderly is illustrated in the following graphs which show the rates of dependency in six basic physical activities (fig. 19), and in home management activities (fig. 20). These illustrations highlight the relationship between increasing age and functional impairment. Rates of dependency for each activity at least double between each age category and triple between ages 75 to 84 and over 85. The very old, those over 85, are from 5 to 10 times more likely to need assistance with these activities than the young-old, those who are 65 to 74.

Among the noninstitutionalized elderly, more than 425,000 individuals are bedridden, including about 1 percent of those 65 to 74 and more than 5 percent of those over 85. About 800,000 individuals over 65 either have a device to control bowel or bladder function or have other trouble with bowel or bladder control; this figure includes about 2 percent of those 65 to 74 and about 11 percent of those over 85 (129).

Overall estimates of the number of noninstitutionalized individuals who need assistance from another person in some daily activity are shown in table 13, which again illustrates the dramatic increase in need for assistance with increasing age. Almost 44 percent of those over 85 need or are receiving assistance with some daily activities. As the number of individuals in this age group

⁶Medical diagnosis related to functional impairment could also provide valuable information for government planning and policy-making since the need for most long-term care services is dependent on the prevalence of disease conditions that cause functional impairment. Although the annual Health Information Survey conducted by the National Center for Health Statistics provides data on the prevalence of acute and chronic conditions and the prevalence of disability and impairment, there is currently no way to identify which acute and chronic conditions are causing disability and impairment because medical diagnoses related to specific impairments and disabilities are generally not available.

Figure 19.—Dependency in Basic Physical Activities Because of a Chronic Health Problem, by Type of Activity and Age: United States, 1979



SOURCE: U.S. Department of Health and Human Services, Public Health Service, National Center for Health Statistics, "Americans Needing Help To Function at Home," No. 99, Sept. 14, 1983.

grows, the need for formal and informal long-term care services will increase rapidly.

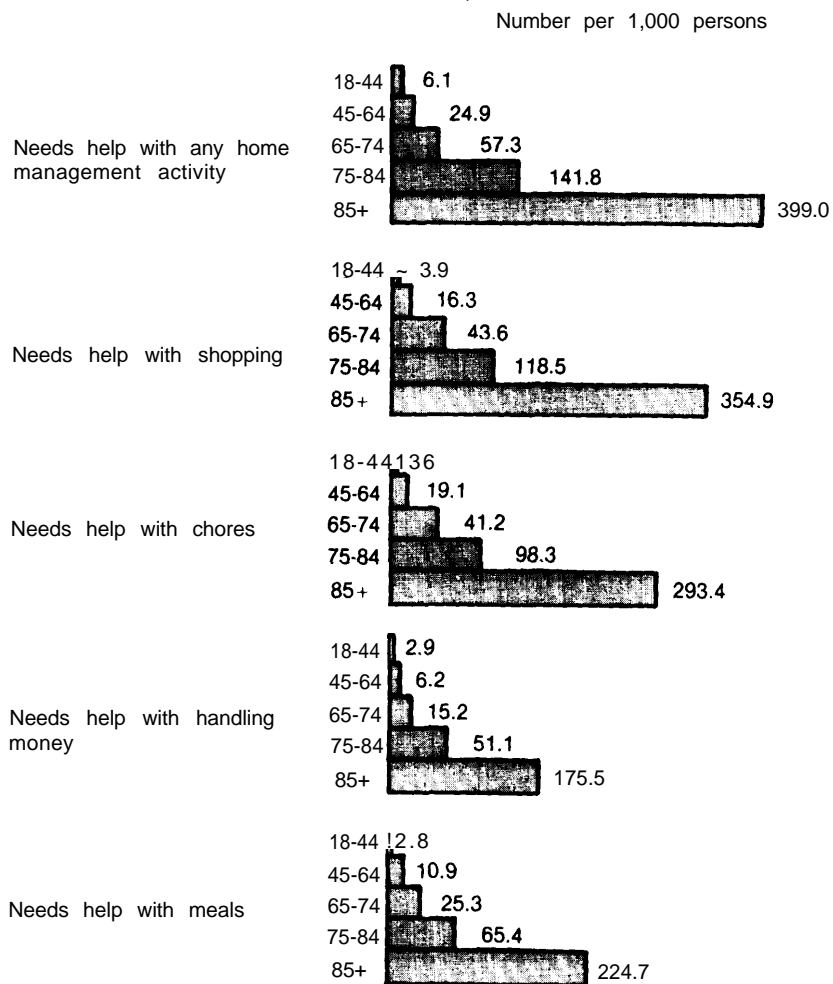
Causes of functional impairment

Many acute and chronic diseases and mental and emotional disorders can limit the ability of the older individual to function independently. (The prevalence of chronic disease in the elderly is discussed in app. A.) Chronic diseases with especially high prevalence among the elderly include heart disease, hypertension, arteriosclerosis, os-

teoarthritis, diabetes, and diseases of the urinary system. In some individuals these diseases result in inability to perform basic self-care and home management activities. Vision and hearing impairments are also very common among the elderly and frequently cause functional impairment.⁷

The functionally impaired elderly include both those who become disabled after age 65 and those who were disabled at earlier ages but are now over 65. This latter group can be expected to increase significantly as a result of biomedical advances that prolong the lives of developmentally disabled and physically handicapped individuals.

Figure 20.—Dependency in Home Management Activities Because of a Chronic Health Problem, by Type of Activity and Age: United States, 1979



SOURCE: U.S. Department of Health and Human Services, Public Health Service, National Center for Health Statistics, "Americans Needing Help To Function at Home," No. 92, Sept. 14, 1983.

Table 13.—Number of Individuals and Rate per 1,000 Who Need the Help of Another Person in One or More Selected Activities by Age: United States, 1979

Age	Needs help of another person	
	Number in thousands	Rate per 1,000
45-64	1,357	31.2
65-74	1,043	69.2
75-84	1,101	160.3
85+	674	436.5

SOURCE: U.S. Department of Health and Human Services, public Health service. National Center for Health Statistics, "Americans Needing Help To Function at Home," Advancedata, No. 92, Sept. 14, 1983.

Acute conditions that can cause functional impairment among the elderly include those resulting from untreated infections and drug interactions. The complex relationship between the need for acute medical care and long-term care among the elderly is not discussed in this chapter, but it should be noted that the need for long-term care for an elderly individual is often first recognized when the individual is hospitalized for an acute medical condition. Once this condition has been

treated, it becomes obvious that the individual is not able to function independently and may have needed long-term care services even before the acute condition developed.

Mental and emotional conditions that cause functional disability include organic conditions such as Alzheimer disease and multi-infarct dementia, and functional disorders such as depression. It is estimated that 5 to 15 percent of individuals over 65 have Alzheimer disease (123), and 2 to 7 percent have clinically diagnosed depression (36). Estimates of the extent of undiagnosed depression in the elderly are much higher.

The relationship between mental and emotional conditions and functional impairment in elderly individuals has received little research attention, but a recent study by Brody and Kleban (15) compared functional impairment in three groups of elderly individuals: those with normal mental functioning, those with a history of diagnosed functional mental illness for which inpatient or outpatient treatment had been received, and those with senile dementia. The chronic diseases and functional disabilities of these groups are presented in table 14.

The researchers point out that although almost all the subjects had one or more chronic conditions, the mentally normal group was basically independent in self-care and home management activities; the group with functional mental dis-

orders was somewhat more dependent, with a significant proportion needing help with home management activities; and the individuals with senile dementia were most dependent, with a large proportion needing help with personal care and almost all needing assistance with home management activities. Dementia was highly correlated with functional impairment.

Other studies also indicate a correlation between dementia and functional impairment. For example, special tabulations of survey data on nursing home and community dwelling older persons indicate statistically significant correlations between impaired cognitive ability and incontinence of bowel or bladder (Pearson correlations ranged from 0.63 to 0.73) (86). These data agree with findings of Ouslander, et al. (75), that the majority of incontinent patients in seven nursing homes studied were also cognitively impaired. Patients with frequent incontinence were significantly more likely to be cognitively impaired than those with occasional incontinence.

The relationship between mental confusion and functional impairment is a very important consideration in the development of technology for long-term care because technologies that are appropriate for individuals who are not confused are often inappropriate for those who are confused. Organic brain disease is known to cause a progressive decline in the individual's mental functioning and self-care abilities: patients become

Table 14.—Most Frequent Preexisting Health Conditions and Functional Dependencies (percentage by groups)

Preexisting health conditions	Normal	Functional	Senile dementia	Dependent in	Normal	Functional	Senile dementia
Arthritis	66	63	56	Toileting	0	0	35
Foot trouble.	45	35	35	Feeding.	0	0	26
Visual impairment.	33	56	56	Dressing	2	5	50
High blood pressure	33	41	53	Grooming	0	7	47
Circulation problems	31	26	62	Home mobility	0	2	29
Hearing impairment	27	43	26	Bathing	2	16	79
Diabetes	25	9	24	Cutting toenails.	16	44	91
Elimination problems	22	52	59	Telephoning 0	2	62	
Digestive problems.	14	33	38	Shopping (food)	16	35	97
Nervous breakdown	0	40	0	Food preparation.	2	9	79
				Housekeeping	10	23	88
				Laundry	8	26	
				Transportation	8	30	94
				Taking medications	2	5	82
				Handling finances	4	14	97

NOTE: Data for normal and functional groups obtained from subjects data about dependencies of senile dementia group obtained from collaterals.

SOURCE: Brody and Kleban, 1963 (16).

increasingly forgetful and confused and eventually may become unable to dress, bathe, and feed themselves because they cannot remember how; they become incontinent because they cannot find the bathroom or remember how and when to use a bathroom. About 50 percent of nursing home residents have symptoms of confusion, but it is not known how many or what proportion of these individuals are unable to care for them-

selves as a result of confusion and how many are functionally impaired as a result of other chronic physical conditions. Some individuals may be functionally impaired as a result of both mental confusion and physical conditions. Identifying the cause of functional impairment is crucial for the appropriate use of rehabilitation technologies with these patients.

Long-Term care services

The existing long-term care system includes services provided informally by family and friends and formal services provided in institutions, in the community, and in the patient's home. The following description of the kinds of individuals who are receiving services and the characteristics of the agencies and caregivers provides a background for the identification and evaluation of technologies appropriate for these patients, agencies, and caregivers.

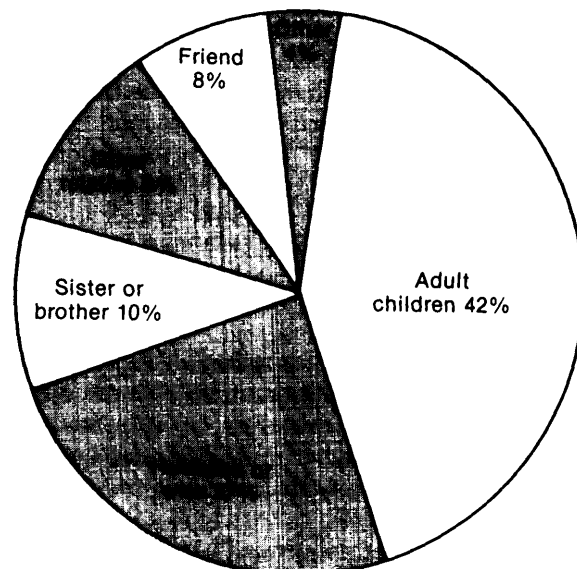
Informal long-term care

Families play a predominant role in providing long-term care services for the elderly. A 1975 study by the General Accounting Office (GAO) of the elderly population in Cleveland, OH, concluded that families were providing more than 50 percent of all long-term care services received, and that as the impairment level of the individual increased, so did the proportion of services provided by the family. For the extremely impaired group, families provided 80 percent of needed services (115).

While the spouse and adult children of the disabled elderly are the most frequent source of informal support, other relatives and friends also provide assistance: of the 87 percent of elderly subjects in the Cleveland study who identified an individual as their primary source of help, most cited adult children or their spouse, but a significant number named a brother or sister, another relative, or a friend (114) (see fig. 21).

Informal support provided by family and friends can help to avoid or delay institutionalization, and

Figure 21.-Source of Support for the Disabled Elderly, Cleveland, OH, 1975



SOURCE: U.S. Congress, U.S. Comptroller General, General Accounting Office, Apr. 19, 1977 (114).

elderly persons who live alone are at greater risk of nursing home placement. The GAO study found that of those persons who were institutionalized during the following year, none had been living with spouse or adult children, and three-fourths had been living alone (115). Similarly, a study of severely disabled elderly people receiving services from a home care agency in Philadelphia showed that none of the individuals lived alone: 46 percent lived with their children, 20 percent lived with a spouse, and 34 percent lived with other relatives and friends (18).

Several recent reports suggest that the increase in numbers of working women may limit the availability of family members to care for the impaired elderly (11)(96)(113). Although no statistics are available to test this hypothesis, a study of the attitudes of elderly women, their daughters, and granddaughters found that the daughters, and particularly the granddaughters believe that the elderly should be able to depend on their families to help them. At the same time, the respondents agreed that working daughters should not quit their jobs in order to care for elderly parents (16). These findings are significant because daughters provide the great majority of informal supports to elderly parents.

The availability of technologies to lessen the burden of caregiving could increase the ability and willingness of families to keep elderly relatives at home. These technologies include:

- assistive devices that increase the ability of the impaired individual to perform some functions independently;
- devices and procedures that help with lifting, turning, transferring, bathing, dressing, and feeding functionally dependent persons;
- devices and procedures to assist with the problems of the mentally confused individual, such as wandering, forgetfulness, being up all night, and the catastrophic emotional reactions that characterize some Alzheimer disease patients;
- home care systems to provide services the caregiver cannot provide and to teach caregiving procedures; and
- respite care systems provided in the home or community that temporarily relieve the caregivers of their responsibilities.

Technologies to facilitate physical care may be particularly important for the spouse and adult children of the impaired elderly because these individuals are often elderly themselves and may have chronic conditions that limit their energy, strength, and capacity to provide physical care. Several recent reports have also documented the value of support groups in providing information and emotional support for caregivers. These technologies are discussed later in this chapter.

Formal long-term care services and settings

Formal long-term care services are provided in nursing homes, board and care facilities, and in the elderly person's home. Adult day care, hospice care, respite care, and congregate housing services are also available in some communities. These services are often said to form a continuum of care arranged to reflect the elderly person's increasing need for assistance. At one end of the continuum are inpatient facilities providing 24-hour skilled nursing care, and at the other end are community agencies that provide supportive **services** such as meals-on-wheels, chore services, and transportation for the elderly. In between are board and care facilities that offer personal care on a 24-hour basis and home health agencies that provide skilled nursing care and personal care in the home.

The continuum of care concept reflects a combination of two underlying questions about the individual's need for care. The first is whether the individual needs 24-hour care; that is, can the individual safely be alone at all? The second question concerns exactly what kind of care the individual needs: skilled nursing care, personal care, or supportive care. Skilled nursing care includes medically prescribed treatments such as tube feedings, dressings, catheterization, and monitoring of medical conditions that can only be done by a trained nurse. Personal care includes services such as bathing, dressing, feeding, and assisting the patient to get up and get to the bathroom, while supportive services include shopping, housekeeping, chore service, and transportation.

In the past, few formal long-term care services were available in the home, and individuals were sometimes admitted to nursing homes for skilled nursing care or personal care even when they did not need 24-hour care. In some communities this is still true, but in other communities skilled nursing care, personal care, and supportive services are available both in institutional settings and in the home. The availability of home care services makes it increasingly important to carefully assess the individual's need for 24-hour care. Provision

of appropriate long-term care services depends on matching of available resources with the individual's need for 24-hour care and/or skilled nursing care, personal care, or supportive care,

Ideally, a wide range of long-term care services would be available in each community, and elderly individuals could select the services they need. In fact, some services are not available in certain jurisdictions, and some are available only to those able to pay privately. Even when services are available in the community, it is often difficult for the elderly and their families to find out about them. Physicians and other health care professionals are frequently unaware of available services (24). Decisions about long-term care are often made in an atmosphere of crisis that is compounded by lack of information about available resources and lack of coordination of long-term care services at the community level.

NURSING HOMES

At present, there are approximately 20,000 nursing homes in the United States, providing beds for about 1.5 million residents, about 85 percent of whom are elderly. About 5 percent of those over 65 are residing in nursing homes at any one time. This number includes less than 2 percent of those 65 to 74, but more than 20 percent of those over 85 (125).

Nursing homes provide 24-hour care, skilled nursing services, and personal care in an institutional setting. Care is given by nurses or by nursing assistants supervised by nurses with written orders from a physician. In addition to skilled nursing care and personal care, nursing homes provide a type of sheltered housing, including room and board, housekeeping, and meal service, and 24-hour supervision. For some patients, this combination of sheltered housing, supportive services, and 24-hour supervision is more important than any specific nursing services available in the facility.

Funding for Nursing Home Care.—More than half the cost of nursing home care is funded by government programs, primarily Medicaid. As figure 22 illustrates, the remaining 47 percent is paid by patients and their families (45 percent) and by private insurance (less than 2 percent).

Residents.—Nursing home residents are most often admitted on the basis of medical diagnosis and need for nursing care. According to the National Nursing Home Survey, primary diagnoses on admission include cardiovascular diseases (40 percent), mental disorders such as senile psychosis, chronic brain syndrome, senility, mental retardation, and alcoholism (20 percent), diabetes (6 percent), arthritis and rheumatism (4 percent), hip fracture (2 percent), cancer (2 percent), and other (26 percent). Functional impairments are seldom formally evaluated on admission, but the survey indicates that most nursing home residents need assistance with basic physical activities (see fig. 23). More than 20 percent of nursing home residents required help with all six activities (128).⁸ A comparison of nursing home residents and disabled elderly individuals in the community shows that three characteristics strongly predict nursing home placement: 1) dependency in toileting or eating, 2) dependency in bathing and dressing, and 3) mental disorders (1381).

Nursing home residents are not a homogeneous group. They include: 1) terminally ill patients who have been discharged from a hospital because no further hospital care is needed; 2) individuals admitted from a hospital for recuperation and rehabilitation following surgery or a fracture; and 3) individuals who are medically stable but functionally impaired, due to chronic physical or mental conditions. About one-third to one-half of nursing home residents are discharged within 3 months (51,65); these tend to be individuals who have been admitted from a hospital with a diagnosis of cancer, stroke, or hip fracture. A 1981 study indicates that about one-half of these short-stay patients died either in the nursing home or in the hospital shortly after discharge from the nursing home; 41 percent returned home, and 13 percent were transferred to another health care facility. In contrast, individuals who stay longer in the nursing home are more often admitted from home and include a higher propor-

⁸ Some evidence suggests that nursing home residents are now more dependent and more functionally impaired than in the past (119). This trend will accelerate as hospitals discharge sicker patients to nursing homes in response to the Medicare prospective payment system. Results of the 1985 National Nursing Home Survey can be expected to document this change.

Figure 22.—Percentage Distribution of Nursing Home Expenditures in the United States, 1979

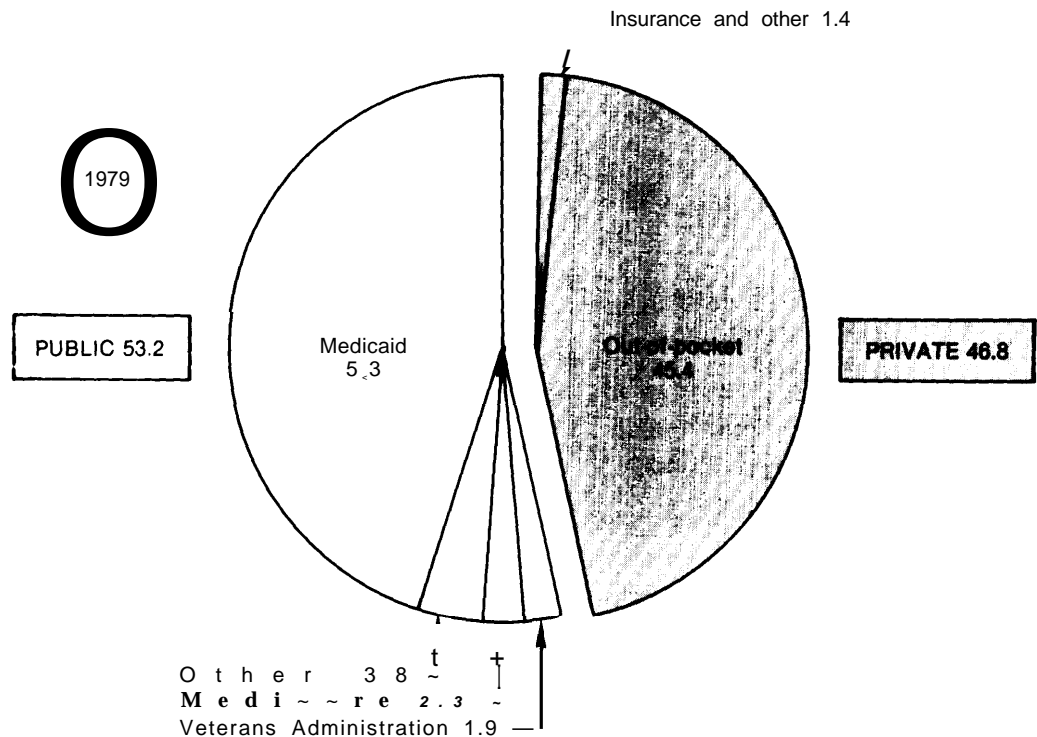
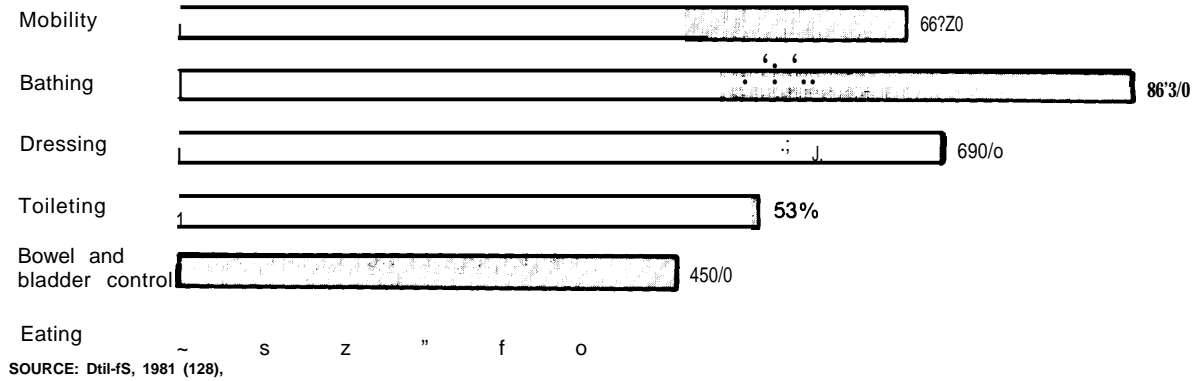


Figure 23.—Percent of Nursing Home Residents Who Need Assistance With Basic Physical Activities: United States, 1977



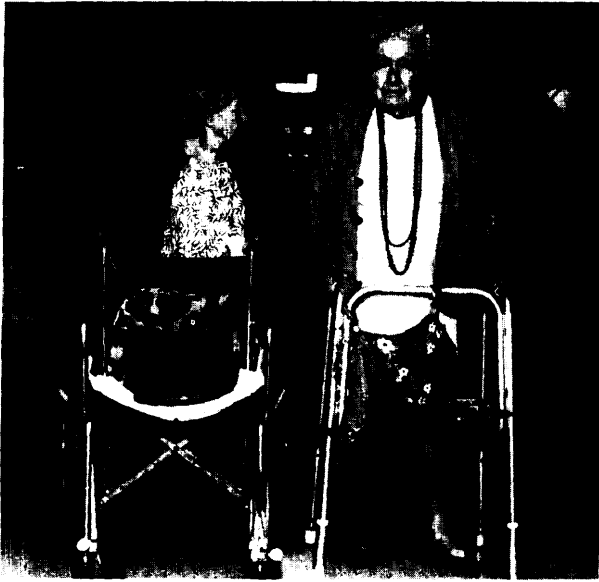


Photo credit: Gretchen Kolsrud

Many nursing home residents are medically stable, but require long-term care because of functional impairments.

tion of those with mental disorders; one-fourth of long-stayers had a primary diagnosis of mental disorder or senility compared with only 3 percent of short-stayers (51). These long-stay patients constitute the largest proportion of nursing home residents at any particular time.

Different subgroups of nursing home residents need different types of care and different technologies for appropriate treatment. For example, terminally ill patients might be best cared for with methods based on the hospice model, which emphasizes pain-control technologies and emotional support systems; individuals admitted for rehabilitation need assistive devices, physical and occupational therapies, and effective linkage with community agencies for continued care following discharge. Among the long-stay patients, appropriate technologies depend partly on the mental status of the patient; for mentally competent patients, technologies to maintain or improve physical functioning are appropriate. For those who are mentally impaired, environmental design technologies, cognitive therapies, and technologies to maintain physical health are more appropriate. For the new group of patients who are discharged early from hospitals as a result of the Medicare

prospective reimbursement system, appropriate technologies may be monitoring equipment and nursing care systems now used primarily in hospitals.

Some nursing homes provide technologies and systems of care appropriate to the different needs of unique subgroups of patients, but many nursing homes provide a relatively uniform system of care for all patients. This is due partly to lack of comprehensive assessment procedures to identify individual needs and partly to insufficient staff to provide individualized systems of care. Professional nurses who are trained to assess patient needs and plan individualized treatment are often in short supply in nursing homes and also perform many other functions in the facility, such as skilled medical treatments, supervision of largely untrained nursing aides, and time-consuming recordkeeping required by Federal and State regulations.

Recent research that identifies subgroups of nursing home residents (47,51,62)63,64,65)66) provides a strong knowledge base for defining distinct care needs of these subgroups, but this research is based on retrospective analysis, and it is not known how effectively nursing home patients can be identified as belonging to one subgroup or another at the time of admission. In addition, there is no consensus about whether patients with similar needs are best cared for in separate facilities, separate sections of the same facility, or mixed in with other kinds of patients as they usually are now. Further research is needed to clarify these issues.

Research on care systems designed for confused patients is particularly needed. Although about 50 percent of all nursing home residents have symptoms of mental impairment and some nursing home residents have longstanding emotional and behavioral problems, such as psychiatric conditions, alcoholism, and drug abuse, most nursing homes are not structured or staffed to meet the needs of these patients (95). Within the existing care system, mentally and emotionally impaired patients require more staff time than physically impaired patients (39)128). Some care providers believe these patients can be more easily and effectively cared for in a setting designed specifically to meet their needs.

Research on appropriate patterns of care for nursing home residents is currently funded through two Teaching Nursing Home Programs, one sponsored by the National Institute on Aging (NIA) and the other sponsored by the Robert Wood Johnson Foundation. NIA has awarded grants to five programs, each emphasizing treatment of specific disease conditions or functional impairments (124). The Robert Wood Johnson program is sponsoring affiliations between 11 nursing schools and local nursing homes (23). In addition to these programs, a few long-term care facilities have received public and private funding for the development of model nursing home services (58). Objectives of all these programs include investigation of disease processes in the elderly, evaluation of functional assessment measures, and development of treatment approaches.⁹ Training opportunities for physicians, nurses, social workers, and other caregivers are provided. As these programs develop, models of care for specific subgroups of patients will be developed and refined.

BOARD AND CARE FACILITIES

Board and care facilities include a wide range of residences that provide room and board and some degree of protective supervision on a 24-hour basis. Unlike nursing homes, these facilities are not considered medical care institutions. Nursing care is generally not provided, but residents may receive assistance with some personal care activities such as bathing or dressing. Supportive services, such as cooking, cleaning, and laundry are also provided. Although board and care residents may have private rooms, they generally do not have private apartments because of the need for 24-hour supervision.

There are now about 30,000 board and care facilities in the United States, serving about 350,000 individuals, including elderly, mentally retarded, and mentally ill residents. Although no exact figures are available, it is estimated that about one-third to one-half of board and care residents are elderly. (Some of the elderly are mentally retarded and mentally ill, and some of those who are classified as mentally ill or mentally retarded are over

65.) Board and care facilities range in size from small adult foster homes and group homes to large residential care facilities and some retirement homes. Each State recognizes and licenses certain types of board and care facilities; although each State has some unlicensed board and care facilities, a recent study shows that 85 percent of all facilities are licensed (88).

Funding for Board and Care.—About one-third of residents pay privately for care. Among the other two-thirds, many receive Federal Supplemental Security Income (SSI) payments and use this income to pay for their care. In addition, States are allowed to supplement the Federal minimum SSI benefits, and by 1983, 34 States and the District of Columbia provided supplements for persons living in board and care facilities (52,131).

Residents.—Although very little information is available about the characteristics of elderly residents of board and care facilities, a recent study of residents of these facilities in seven States indicates that some residents needed assistance with basic self-care activities, such as bathing (26 percent), dressing (11 percent), walking (9 percent), and using the toilet (4 percent). Larger percentages of residents needed assistance with home management activities such as laundry (64 percent), cleaning, (55 percent), managing money (46 percent), shopping (43 percent), and taking medicine (43 percent). Chronic physical conditions of residents included degenerative joint diseases (36 percent), circulatory and heart disorders (25 percent), hearing impairments (22 percent), and respiratory diseases (14 percent). Perhaps more significant is the large percentage of residents with mental impairments. The researchers found that about 40 percent of the residents were mentally ill, disoriented, or exhibited memory impairment. *O About 28 percent of the residents had previously resided in an institution for the mentally ill, while 21 percent had lived in a nursing home (31).

These data reflect a seriously disabled population with extensive physical and mental impairments. While no research is available to verify the

⁹Treatment goals include rehabilitation and discharge of some patients and lifelong supportive care for others.

¹⁰One-third of residents were assessed as mentally ill. Another one-third of residents were disoriented or exhibited mental impairment. These two groups overlapped, and one of the researchers has estimated that 40 percent of all residents were in one or both subgroups (104).

primary reasons that residents need board and care services, it is likely that the high prevalence of mental illness, disorientation, and memory impairment explains much of the need for care. These confused and mentally ill residents are more likely to require supervision and assistance with laundry, cleaning, managing money, and taking medicine rather than personal care such as bathing, dressing, and walking. (It is interesting to note that the study did not find any residents who were incontinent or needed assistance with eating, the two primary risk factors for nursing home placement.)

The cost of board and care facilities varies widely but is generally one-third to one-half the cost of nursing home care. Despite this relatively low cost, several problems limit demand for board and care homes; these include the generally poor reputation of these kinds of facilities¹¹ and lack of available information about the facilities, the services offered, and the cost of care. In addition, the pervasive emphasis on medical v. nonmedical forms of care in our society and the availability of Medicaid funding for nursing home care but not board and care limit demand for these facilities. The major factor restricting the supply of board and care homes is the low levels of reimbursement for providers (88).

Since the cost of care in most board and care facilities is substantially less than nursing home care, it is important to consider whether some nursing home residents could be cared for in board and care facilities. Both settings provide 24-hour supervision, and while some nursing home residents need skilled nursing care that is not available in board and care facilities, many actually receive little or no skilled nursing care. For these individuals, many of whom are the long-stay patients discussed earlier, board and care homes might provide a long-term care option that is cheaper and less personally restrictive than living for many years in a nursing home.

Technologies appropriate for the board and care population include:

- assessment technologies to identify individuals who can be best served in these kinds of facilities;
- assistive devices to improve the physical functioning of residents; and
- technologies for caregivers, including devices and care methods appropriate for mentally impaired residents.

In addition, improved information systems are needed to increase awareness of this long-term care option among the elderly, their families, and health care providers.

HOME CARE

Long-term care services provided in the home include medical, social, and supportive services designed to maintain the individual in the community and compensate for impaired functioning. Most medical and social services that are available in nursing homes can also be provided to individuals at home, but three problems restrict the use of these services: 1) lack of home care services in some communities, 2) lack of coordination of home care services in many communities, and 3) limited public funding for supportive services in the home. In this section, home care services are defined, and appropriate use of home care services is discussed. Because much attention has been focused on whether the availability of home care services can decrease the use of nursing homes, this question is also discussed.

Funding for Home Care Services.—Public funding for home care services is provided through Medicare, Medicaid, the VA, the Title XX Block Grant, and Title III of the Older Americans Act. Medicare and Medicaid fund primarily health care services, and complex regulations govern the kinds of services that are reimbursed. The Title XX Block Grant and Title III of the Older Americans Act fund primarily supportive services (see the technical memorandum at the conclusion of this chapter). Private insurance pays for some skilled nursing, physical therapy, and speech therapy provided in the home. Individuals and families also pay privately for home care services, but since these services are purchased independently from both agencies and individuals, little information is available about the kinds and cost of services used.

¹¹The American Bar Association has recently finalized a model State statute for board and care facilities that includes standards for physical environment, staff qualifications, resident rights, and administrative sanctions for noncompliance.

Clients.—Home care services are listed in table 15. The kinds of elderly individuals who use home care can be inferred from the wide variety of services that are available. Some patients have been recently discharged from the hospital and require nursing care and supervision of medical treatments. In fact, increasingly complex and sophisticated medical treatments, such as intravenous fluid replacement, antibiotic therapy, chemotherapy, enteral and parenteral nutrition, hemodialysis, and continuous ambulatory peritoneal dialysis, can now be provided in the home. Other patients need rehabilitation services such as physical or speech therapy that may have been started in the hospital but can continue in the home. Supportive services such as home delivered meals, homemaker, and chore services may be needed by the same individuals who need skilled nursing care or rehabilitative services and also by another large group of individuals with functional impairments that restrict their ability to shop, cook, or care for their homes.

Table 15.—Elements of Long-Term Care in the Home

Skilled nursing care: Medically oriented care provided by a licensed nurse to include monitoring of acute and unstable chronic medical conditions, evaluation of the patient's care needs, injections, care of wounds and bed sores, tube feedings, and clearing of air passages. Skilled nursing care is usually authorized by a physician.
Physical therapy: Rehabilitative therapy provided by a qualified physical therapist.
Speech therapy: Therapy provided by a qualified speech therapist to improve or restore speech.
Occupational therapy: Therapy provided by a qualified occupation therapist to improve functional abilities.
Medical social services: Assessment, referral, and counseling services related to the medical care needs of the patient.
Home health aide services: Assistance with simple, health-related tasks, such as medications and exercises, and personal care services provided under the supervision of a licensed nurse.
Personal care: Assistance with basic self-care activities such as bathing, dressing, getting out of bed, eating, and using the bathroom.
Homemaker services: Household services such as cooking, cleaning, laundry, shopping, and escort service.
Chore services: Household repairs, yard work, and errands.
Home-delivered meals: Meals delivered to the home for individuals who are unable to shop and/or cook for themselves.
Telephone reassurance: Regular telephone contact to individuals who are isolated and often homebound.

SOURCE: Office of Technology Assessment.

Home Care Services as a Substitute for Nursing Home Care.—It has been believed for many years that home care services could help to maintain impaired elderly individuals in their homes and avoid nursing home placement. Although this belief offers the hope of cost savings and has been used as an argument for increasing home care services, a recent GAO study of demonstration programs offering expanded home care services found that these services did not reduce utilization of nursing homes. GAO concluded:

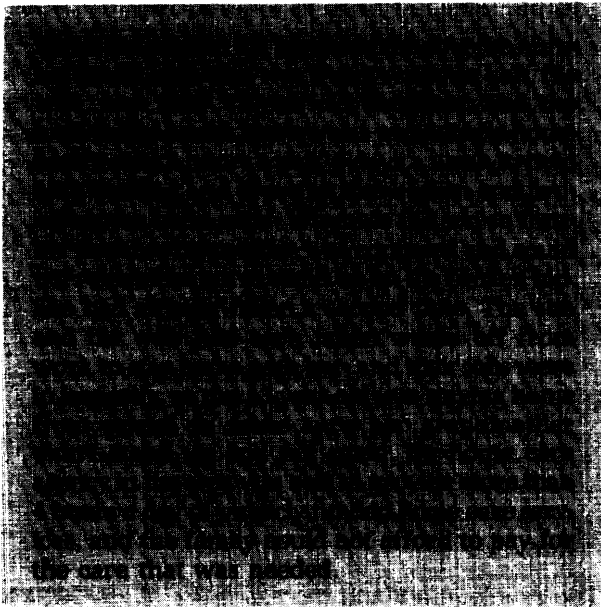
For some subpopulations of the elderly, providing home care services may decrease the use of nursing homes. However, more work, including the refinement of assessment tools, is needed to better define and identify individuals for whom nursing home use can be reasonably decreased (118).

The development and increased use of assessment technologies is discussed later in this chapter.

one reason that home care services do not reduce utilization of nursing homes is that many individuals who are at risk for nursing home placement need 24-hour care because they cannot be safely left alone or because they need assistance many times a day at widely separated time intervals. Formal home care services are seldom available on a 24-hour basis because of cost, and in many communities, publicly supported home care services are limited to only a few hours a day. As a result, if the individual lives alone or if no family member is available on a 24-hour basis, institutional care may be necessary.

As indicated in the example, formal home care services are not an appropriate long-term care option for elderly individuals who are too confused to remain safely alone and have no one to stay with them when the home care provider leaves. Increased use of comprehensive assessment technologies could help to identify individuals for whom board and care facility or a nursing home is a more appropriate long-term care option than home care.

Frantic calls were received at several nursing homes from a middle-aged seeking nursing home bed for his 73-year old mother. She had little income, had broken her hip and was



Technologies in home care include:

- assessment technologies to identify patient needs and appropriate care methods;
- patient-care devices that have been used in hospitals but can be adapted for use in the home, and methods for teaching the elderly and their families to use these devices;
- assistive devices to decrease functional impairment, and techniques for training individuals to use these devices;
- environmental design technologies to accommodate the functional impairments of elderly individuals; and
- improved service delivery systems to increase awareness and appropriate access to home care services.

In addition, the information technologies discussed in chapter 6 could be used to meet some of the home care needs of the impaired elderly. For example, interactive television could be used to provide training in the use of devices and to answer questions about medical treatments provided in the home.

ADULT DAY CARE

Adult day care centers provide health and social services for impaired elderly individuals. Services vary among programs but frequently include supervision, personal care, group activities, meals,

recreation, and exercise in addition to medical and medically related services such as physical therapy and speech therapy. Availability of these services in a centralized setting is convenient for both clients and health care providers (106). Two types of adult day care have been identified: 1) rehabilitation-oriented programs designed primarily to provide medical care and physical therapy, and 2) multipurpose programs designed to provide social stimulation for impaired and isolated elderly individuals and respite for the families who have been caring for them (132). The number of adult day care facilities in the United States has increased from fewer than 20 in 1970 to between 700 and 800 at present (1).

Funding for Adult Day Care.—Clients and their families often pay for some or all of the cost of adult day care themselves. Adult day care is an optional Medicaid service; as of 1984, eight States were providing Medicaid reimbursement for adult day care (127). In addition, 35 States provided adult day care with title XX funds, and several States provide adult day care services through demonstration projects funded under the Medicaid waiver program (24). Medicare does not cover adult day care programs, although some medical and physical therapy services provided for adult day care clients are covered by Medicare.

Clients.—Several studies have examined the characteristics of adult day care clients. A 1976 study of four programs showed that 56 percent



Photo credit: Suburban Hospital, Adult Day Care Program, Bethesda, MD

Adult day care programs can provide socialization and group activities in addition to medically related services such as physical therapy.

of the participants were severely dependent in activities of daily living, requiring assistance in eating, transferring (moving from bed to chair and chair to bed), or toileting, or were incontinent; another 16 percent were moderately impaired, requiring assistance with bathing or dressing, but not eating, transferring, or toileting (106). Another study comparing clients at an adult day care center with residents of a nursing home and individuals living independently in an apartment facility for the elderly found that the day care clients were most disabled in physical health, mental health, and activities of daily living, while the residents of the nursing home were most limited in socioeconomic areas, such as informal social supports and financial resources (85). A third study found that day care clients were generally less impaired than nursing home residents, but of the 25 most impaired day care clients, only 2 were living alone (111). These findings suggest that adult day care can be an appropriate resource for severely impaired individuals as long as they have sufficient informal supports and financial resources to maintain themselves at home when they are not at the day care center.

Technologies appropriate for adult day care include assessment technologies to identify elderly individuals who could be cared for in these settings and information systems to increase awareness of this long-term care option among the elderly, their families, and other service providers.

Some adult day care programs are designed specifically for mentally impaired individuals, with emphasis on consistency in program and staff to limit daily changes that are confusing to clients and environmental design that allows maximum independence without compromising safety (95). Evaluation of the efficacy and cost of these programs is needed. Treatment methods for mentally impaired individuals that have been developed in adult day care settings may provide a model of care for these patients that can be used in other long-term care settings.

HOSPICE

Hospice programs provide supportive services for individuals with terminal illness. Hospice is a method of care, not a place, and hospice care

can be provided in a hospital, nursing home, or in the patient's home. Services include nursing care, medical social services, homemaker, home health aide services, and counseling for the patient and the family. In addition, short-term inpatient care is often available for crises. The technology of pain control is central to the hospice concept, and emphasis is on quality of life rather than aggressive medical treatment and prolongation of life.

The first hospice was established in this country in 1973, and by 1983 there were an estimated 1,100 to 1,200 hospice programs in the United States (49). Medicare benefits have been available for hospice care since November 1, 1983. Up to 6 months of hospice care can be covered.

Because hospice care is believed to be less expensive than hospitalization, Medicare coverage of hospice care may result in cost savings (121), but some experts question whether these savings will materialize. A recent study compared terminal cancer patients treated in a hospital-based hospice program with those who received conventional care. Hospice patients reported more satisfaction with their care than conventional care patients, but the cost of hospice care was the same or greater than the cost of conventional care. No significant differences were found between the groups in survival time, pain symptoms, or days in the hospital. While the conventional care patients spent more days in nursing homes than hospice patients, the majority of both groups died in the hospital; only 3 percent of the hospice patients and 7 percent of the conventional care patients died at home. Although hospice programs are designed to decrease the number of invasive diagnostic and curative treatments, the data show little difference between the two groups on these variables (49). These results raise questions about the real differences between hospice care and conventional care. Further research is needed, including comparison of methods, costs, and outcomes in hospices based in different settings, such as hospitals, nursing homes, and home care agencies.

Hospice care is a resource for terminally ill patients currently being cared for in nursing homes or in the community. Identification of terminal patients can present a difficult diagnostic proce-

ture for certain subpopulations, and the development of more precise guidelines and diagnostic criteria is needed. Improved service delivery technologies are also needed to make information about the hospice alternative available to appropriate patients and their families.

RESPIRE CARE

Respite care is temporary care provided for the impaired elderly to relieve the primary caregivers. Respite care can be provided in nursing homes, board and care facilities, or in the individual's home, and can range from several hours up to a week or longer. Public funding for formal respite care programs is available in some communities through the Title XX Block Grant and Title 111 of the older Americans Act. There is no Medicaid funding for respite care under the general program, but respite care is part of 15 of the 26 approved Medicaid 2176 waiver programs for the elderly (138). (See the technical memorandum at the end of this chapter for a description of the Medicaid 2176 waiver program.) In addition, home health care, personal care, and homemaker services funded through Medicare, Medicaid, Title XX, and Title III may be used by some families as respite care, since caregivers are able to leave the home when the aide or homemaker is present,

CONGREGATE HOUSING

Congregate housing for the elderly, which is discussed in chapter 9, is included here because the design features and supportive services available in some congregate housing facilities compensate for the functional impairments of elderly residents and thus postpone or avoid the need for other long-term care services. Physical design features such as emergency call buttons, grab-bars in the bathroom, and safety features on ovens have been built into many publicly and privately funded congregate housing facilities for the elderly. Some of these facilities also provide optional supportive services such as meals and housekeeping that can eliminate the need for shopping and some home management activities. Alarm systems in each apartment provide psychological security for physically impaired individuals. Opportunities for socialization and recreational activities in the facility can help to maintain emotional well-being.

Most congregate housing facilities in this country have been built within the past 20 years. Over time, administrators at these facilities have had to deal with the increasing physical and mental impairments of their aging residents. In some facilities, residents have been required or encouraged to move out when their functioning decreased below the level established for admission. In other facilities, these residents are not required to move, and in some facilities, increased services have been provided to help compensate for impairments and maintain independent functioning.

Both physical and mental impairments of residents can limit their ability to function adequately in congregate housing. Physical problems such as severe illness, the need for frequent monitoring of medication, and being bedridden interfere with the individual's ability to live independently, and residents with these problems usually transfer to other long-term care settings. Mental and emotional problems, incontinence, and accident proclivities are also seen as very disruptive by managers and other residents, but individuals with these problems often do not see the need to move (13), which can create difficult administrative problems for managers.

In summary, congregate housing is an appropriate long-term care option for some physically impaired individuals. The level and type of impairment that can be safely accommodated depends on the availability of supportive services and physical design features for the handicapped in each facility. Congregate housing is usually not an appropriate option for mentally impaired individuals because of the lack of 24-hour supervision. Federal policy initiatives to increase the availability of congregate housing and encourage provision of services for physically impaired residents are discussed in chapter 9.

Issues in long-term care settings and services

Several general issues related to long-term care services and settings are discussed in this section, including the comparative cost of care in various settings and the perception of settings as distinct caregiving systems.

COMPARATIVE COSTS OF CARE

Accurate comparison of the cost of various long-term care services is difficult because costs vary from one city to another and from rural to urban areas. Within communities, costs vary depending on the agency providing the service and the source of payment. For example, Medicare usually pays considerably more for specific services than Medicaid. Cost comparisons are further complicated by the inclusion of room and board in the cost of some long-term care services, such as nursing home care, but not in the cost of other services, such as home care and adult day care. Despite these difficulties, some generalizations can be made about relative costs of care.

In general, nursing home care costs more than other forms of care because the per diem rate is relatively high and most patients receive care for extended periods. Private patients usually pay the highest rate, followed by VA and Medicare patients, and then Medicaid patients. For calendar year 1979, the average per diem rate was \$63.73 for VA patients, \$38 for Medicare patients, and \$23.59 for Medicaid patients (24). The cost of care in board and care facilities varies widely, but is generally one-third to one-half the cost of nursing home care. In early 1980, the average cost in board and care facilities was about \$10 a day (88). In comparison, the average daily cost of hospital care was \$226 in 1979 (120), and the average Medicare reimbursement for hospital care was \$182 per day (126).

The cost of home care depends on the type of services provided and the source of payment. Medicare payments for home care are relatively high. Reimbursement guidelines for the year ending June 30, 1980, were: skilled nursing care, \$41.80 (urban) and \$38.05 (rural); home health aide visits, \$33.00 (urban) and \$27.70 (rural) (116). Medicaid payments for home care services are generally much lower. For example, in Colorado in 1980, one home care provider received \$45 for a skilled nursing visit under Medicare but only \$28 from Medicaid) and \$10.24 for a home health aide visit under Medicare but \$4 from Medicaid (117). In Washington, DC, in 1980, Medicaid paid \$23.75 to \$27.63 for skilled nursing visits, \$8.61 to \$10.50 per hour for personal care, and \$2.90

per hour for homemaker services (117).¹² No information is available about the cost of home care services paid for by individuals.

These figures indicate that the Medicare rate for a single skilled nursing visit is similar to the Medicare rate for a day of nursing home care. Since the cost of home care does *not* include room and board and other living expenses, the overall cost of care for an individual who needs daily skilled nursing care at home can be higher than the cost of nursing home care. Most home care patients do not, however, require or receive daily skilled nursing visits; the nurse may go out once or twice a week or less, with intervening visits of a less expensive home health aide. Home care is thus usually less expensive than nursing home care. The Medicare reimbursement for a home health aide visit was about 75 to 85 percent of the Medicare reimbursement for a day of nursing home care, and also does not include the cost of room and board. The Medicaid payment for 1 hour of personal care in the home in Washington, DC, was about one-third to one-half the average per diem Medicaid payment for nursing home care nationwide.

The cost of adult day care varies according to the type of program. Those with a rehabilitation emphasis cost about twice as much as programs with a social emphasis, and some adult day care costs the same or more than nursing home care. A 1976 study of four adult day care programs with a rehabilitation emphasis showed that the average per diem cost was \$52 a day, but with a wide range of \$18.54 to \$88.17 (106). Adult day care clients seldom attend every day, however. The same study found that average attendance was 70 days per person per year with a range of 48 to 114 days between the four sites (106). As a result, the overall monthly cost of adult day care is significantly less than nursing home care and may be similar to the cost of a board and care facility.

The cost of hospice care and respite care depends on the kinds of services used and the frequency of utilization. At present, Medicare reim-

¹²It is likely that the lower Medicaid reimbursement rates discourage providers from serving Medicaid recipients

bursement for hospice care is limited to \$53.17 a day for a maximum of 6 months.

Congregate housing is considerably less expensive than other long-term care services. In federally subsidized housing, residents who are eligible for section 8 subsidies pay 30 percent of their income for rent. Monthly rent for other elderly individuals can range from \$400 per month up to \$1,200 to \$1,500 or more, depending on the facility and the amenities provided.

A recent study focused on costs and outcomes for individuals receiving services in four settings—nursing homes, geriatric day hospitals (adult day care centers), board and care facilities, and senior centers. Applicants were screened and statistical methods were used to develop subgroups of similar individuals receiving services from each type of agency.¹³ After 9 months, no consistent significant differences were found between subgroups on a wide variety of outcome measures, including utilization of skills for independent living, community integration, unmet service needs, and living conditions. There were, however, significant differences in the cost of care. Considering total expenses for individuals in each subgroup, the adult day care was most expensive (about \$48 per day),¹⁴ followed by nursing home (about \$40 per day), senior center (about \$34 per day), and board and care (about \$31 per day). These figures include the costs of acute care services, formal and informal long-term care services, and living expenses in the community. When only the cost of formal long-term care services is calculated, the order is changed: nursing homes are slightly more expensive than adult day care and more than twice as expensive as board and care facilities, while senior center services were least expensive (102).

Although these data were derived through a complex analysis of patients and services provided in a limited number of settings in Pennsylvania

and Delaware, they raise important questions about the differences between services and costs of care in various long-term care settings.

SETTINGS AND SERVICES AS DISTINCT CAREGIVING SYSTEMS

Long-term care services are most frequently described using a model in which each of a variety of agencies provides unique services appropriate for specific subgroups of patients. Current funding mechanisms and most long-term care decision-making systems assume that this description represents reality. In this system, only those technologies appropriate to each subgroup of patients would be used in certain agencies.

An alternative model of long-term care includes many agencies, each providing a wide range of services to a broad mix of patients with a variety of needs. The discussion of long-term care settings and services in this chapter indicates that this model more accurately represents current reality. Increased use of technology in this model is more difficult and more expensive because many different kinds of technologies will be needed in each setting. For example, technologies that are appropriate for residents of a single nursing home could include hospice care techniques and pain-control technologies; a wide range of assistive devices and rehabilitation services, including physical, occupational, and speech therapy; technologies for caregivers; patient monitoring devices; and environmental design technologies. The cost of making these technologies available in the nursing home would be very high.

The question of whether it is more effective to provide a unique set of services in each setting or a wide range of services to a variety of patients depends not only on the relative costs of increasing the use of technology. It also depends on the feasibility of dividing patients into subgroups and the impact on patient morale and quality of care of moving patients when their needs change. Three questions relevant to these issues can be raised:

- Can available assessment measures effectively identify care needs for a large proportion of long-term care patients, including both the services the patient needs and those he does not need?

¹³Many applicants to each agency were not included in this study because their needs and/or characteristics were different from those of individuals in the identified subgroups. The authors emphasize that their results are *only* applicable to the kinds of individuals they studied.

¹⁴The adult day care services discussed here were rehabilitation-oriented services provided in a hospital as opposed to socially oriented services that are much less costly.

- How frequently do the needs of individual patients change, resulting in the necessity for different services and technologies?
- What is the impact on patients of moving them when their needs change?

Anecdotal evidence suggests some negative effects of moving patients, including increased disorientation in a new setting and lowered morale as a result of separation from friends and a familiar setting. Balancing these negative effects against

the positive aspects of receiving care in a setting uniquely structured to meet one's needs is an issue that requires further research. The relative ease and lower cost of increasing the use of technology in a long-term care system with each agency providing a unique set of services is only one factor in the decision about which model of long-term care services is most beneficial for patients.

Technologies in long-term care

Assessment technologies

Assessment technologies include both formal assessment measures used to evaluate the individual and knowledge about how and when to use these measures and how to evaluate the results. Effective assessment procedures are important both for good patient care and for sound public policy. Planning appropriate long-term care for a disabled elderly individual requires an understanding of the condition of the individual and the complex interaction of physical, mental, social, and environmental factors that result in functional impairment and create the need for long-term care services. Similarly, sound public policy decisions about the administration and financing of long-term care services require reliable and valid information about functional impairments and the need for services in the elderly population (140).

CURRENT USE

A large number of assessment measures have been developed over the past 25 years in the United States, and are being used in long-term care research, demonstration projects, and specialized geriatric assessment centers. Most of these measures emphasize the functional status of the individual, and some also assess social and environmental factors that affect the need for long-term care services. Experts in gerontology and long-term care agree that comprehensive functional assessment is essential for the evaluation of elderly individuals for long-term care pur-

poses and that formal assessment measures are important tools for gathering the necessary information, yet most physicians and other long-term care service providers are not using these tools.

The failure of physicians and long-term care providers to use comprehensive assessment measures may be based in part on lack of knowledge about these technologies. Perhaps more important is the fact that Medicare and Medicaid eligibility for most long-term care services is not based on a comprehensive functional assessment of the patient, and no standard assessment is required for individuals who pay privately for long-term care services. Thus physicians and long-term care providers are not required to use comprehensive assessment measures and are often reluctant to spend the additional time needed to complete the assessment.

Failure to use comprehensive assessment measures can result in failure to identify treatable conditions. For example, a recent study of incontinence in nursing home patients (75) found that 50 percent of the residents were incontinent, but only 14 percent of these incontinent patients had this problem listed by their physicians, and very few were receiving any treatment for it. While identification of incontinence would result from a thorough medical evaluation, many nursing home residents do not receive thorough evaluations. Use of a comprehensive assessment measure by the physician or another health care professional could increase the probability of identifying these conditions.

Many research projects and demonstration programs have used comprehensive assessment measures to identify appropriate long-term care services for elderly individuals. For example, one study evaluated the use of comprehensive assessment for frail elderly individuals living at home and awaiting placement in a nursing home; as a result of the assessments, about 60 percent were recommended for and assisted in receiving long-term care outside a nursing home, including 23 percent who received supportive services at home, and 30 percent who were placed in supervised boarding homes (140). Other studies have demonstrated the use of comprehensive assessment measures for identification of inappropriate use of services and unmet needs in the community and for patient planning and treatment evaluation in nursing homes (38,48,140).

There is as yet no consensus on the validity of studies showing positive results of the use of comprehensive assessment measures. Some experts believe that the state of the art in assessment technology may not be sufficiently developed to provide positive results (17). One recent study indicates that the use of comprehensive assessment measures is effective in improving patient outcome only in certain groups of patients (91a). ongoing research at specialized geriatric assessment centers around the country can be expected to clarify these questions.

ASSESSMENT MEASURES

Although an enormous number of variables are related to functional impairments and long-term care needs, it is generally agreed that the most important can be grouped in a few general categories or domains, including: 1) need for medical treatment, 2) physical functioning, 3) mental functioning, and 4) social functioning and environmental fit. In each category, evaluation of the residual strengths of the individual is as important for long-term care decisionmaking as the identification of deficits and problems. In the following sections, variables in each of the categories and problems with measurement are discussed.

Measurement of Need for Medical Treatment.—Most assessment instruments designed for impaired elderly individuals include an evaluation of specific medical care needs, such as the need

for tracheotomy, respiratory therapy, or intravenous medications. The need for frequent physician services, skilled nursing care, physical therapy, occupational therapy, and speech therapy is also usually evaluated. This information is important because the availability of needed medical care services in the community and in long-term care institutions may affect appropriate placement of the individual. No problems in the assessment of information in this category have been noted (140).

Measurement of physical Functioning.—Assessment instruments designed to evaluate physical functioning include measures of general physical health, such as bed days, restricted activity days, and predicted life expectancy; measures of self-care activities, such as bathing, dressing, and feeding; and measures of home management and independent functioning, such as shopping, cooking, using a telephone, taking medications, and managing money. Although many of the same activities are included in several measurement instruments, differences in wording and scales may mean that results using different instruments may not be comparable and some instruments may be more useful in certain settings than others (43).

Several conceptual problems in the measurement of physical functioning have been noted. First, the functional ability of elderly individuals is known to vary from day to day as a result of fatigue, acute illness, and other factors, making it difficult to arrive at a single measure of physical functioning. Second, both motivation and opportunity affect physical functioning (43), and there may be a need to distinguish between those who are unable to perform a certain function under any circumstances, those who are not motivated to perform the function, and those who do not have an opportunity to perform the function, such as nursing home residents who do not need to cook and often are not allowed to shower without assistance. Third, functional ability can sometimes be improved with the use of assistive devices, and assessment measures differ in the way that functioning with the use of an assistive device is handled (43).

Assessment measures have been used extensively in the National Long-Term Care Channeling Demonstration Program described later in this

chapter. Preliminary findings on the use of these measures indicate several areas of physical functioning that are not adequately evaluated with available measures. These include: 1) deficits in vision, hearing, and speech that can have a major impact on the ability to function independently, 2) the relative ease or difficulty with which an individual performs a certain function, and 3) the individual's potential to perform a certain function in a different setting or with rehabilitation training (77). Each of these issues is important for the evaluation of an individual's need for long-term care services.

Measures of Mental Functioning.—Assessment instruments have been developed to measure three main aspects of mental functioning: cognitive functioning, affective functioning, and general mental health. Measures of cognitive functioning focus on orientation to person, place, and time; personal and current information; attention; comprehension; and memory. Measures of affective functioning focus primarily on depression, and measures of general mental health generally screen for psychiatric illnesses (43).

Valid assessment of mental functioning is even more difficult than assessment of physical functioning, partly because of problems in defining conditions such as "confusion," "dementia," "disorientation," and "depression" (84)(140). In addition, mental functioning in the elderly is often affected by acute and chronic illnesses and by medications prescribed for these illnesses (43); as these physical factors change from day to day, mental functioning may also change. It is also difficult to separate cognitive impairment from depression since some depressions have symptoms like dementia in the elderly (43). For these reasons, the reliability and validity of measures of mental functioning have been difficult to establish. It has been suggested that the available measures of mental functioning should be used only as gross screening tools for identifying individuals who need more intensive evaluation (140).

A major problem in using measures of mental functioning in long-term care is that the relationship between impaired mental function and a need for long-term care services has not been established. It is known that some individuals with considerable memory problems are able to func-

tion safely in their familiar home environment, while others who perform well on tests of memory may be subject to occasional or continuous confusion or agitation that limits their ability to function independently (140).

Some recent research indicates that severity of functional impairment may be related to the loss of specific cognitive functions. One study suggests that individuals with primary losses in memory and orientation had less severe functional impairment, while those with primary losses in attention and recognition were more severely impaired (133). Commonly used mental status measures that emphasize memory and orientation may therefore *not* distinguish accurately between those who are able to care for themselves and those who need assistance with self-care as a result of mental impairment (142). Increased understanding of the relationship between loss of specific cognitive functions and the need for long-term care services is important for identifying individuals who need care, designing appropriate care systems, and estimating the future size of the long-term care population.

Measurement of Social Functioning and Environmental Fit.—Evaluation of social and environmental functions affecting the impaired individual is important for decisionmaking in long-term care (43,140). Informal support provided by family and friends often allows mentally and physically impaired individuals to remain at home rather than be placed in a nursing home. Similarly, the characteristics of the individual's environment, including the physical layout and any rules, regulations, or external constraints will often affect his well-being and his ability to function independently (43).

Despite the recognized importance of social supports and environmental characteristics for the impaired elderly, it has been difficult to develop valid assessment tools to measure these factors. Although the general concepts of social functioning, social supports, and environmental fit are clearly related to long-term care needs, it is difficult to specify the aspects of these concepts that are most relevant to long-term care decisionmaking. In addition, interpretation of results is complicated by lack of norms and by important differences in the way that individuals react to social



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and environmental realities (12,43). For example, some individuals may be satisfied with much less social interaction and fewer social activities than others. Similarly, rules and environmental constraints that are experienced as very restrictive by some individuals may have a neutral or positive effect on others. Objective measurement of the complex interaction between the individual's preferences and expectations and the reality of his physical and social environment is difficult.

Kane and Kane (43) have discussed measurement tools in three categories: social interactions and resources, personal coping and subjective well-being, and environmental fit. Some measures in each of these categories have been developed for use in long-term care decisionmaking, while others were designed for use with the well elderly or for individuals of all ages. Measures of social interactions and resources generally include items about the existence and location of family and friends, frequency and quality of intergenerational contacts, and other social activities. Measures of personal coping and subjective well-being include scales on life satisfaction, morale, happiness, adaptability, and coping skills. The third category, environmental fit, includes measures to describe the individual's environment, rules, reg-

ulations, and programmatic aspects of his living situation, and the fit between his characteristics and aspects of his environment.

Multidimensional Measures. -Multidimensional assessment measures are designed to provide information about many different aspects of client functioning, including physical, mental, social, and environmental. Examples include: the Sickness Impact Profile (SIP), developed to assess the outcome of health care; the Older Americans Resources and Services instrument (OARS), developed at Duke University and used in a GAO study in Cleveland, OH; the Comprehensive Assessment and Referral Evaluation (CARE), developed for the United States-United Kingdom Cross-National Project; and the Patient Appraisal and Care Evaluation (PACE), developed by four universities for use in the management of patients and for administrative and research purposes (43).

Issues of reliability and validity have been particularly troublesome with multidisciplinary measures, particularly questions about inter-rater reliability and how to evaluate the validity of these measures. Several general issues affecting the use of multidisciplinary measures and all geriatric assessment technologies are discussed here.

ISSUES IN ASSESSMENT TECHNOLOGY

which Instrument to Use.—The large number of available assessment tools presents a difficult choice for geriatric practitioners. Many of these measures have been developed for research or demonstration projects. Measures developed for research and demonstration programs are often too long to be practical for widespread use by geriatric practitioners.¹³ In addition, researchers have often devised new instruments or adapted existing instruments to precisely serve the purpose of their projects; this increases the number of available instruments and does not help to test the validity or reliability of existing measures (20).

Assessment can serve a variety of purposes, including description, screening, diagnostic and treatment planning, monitoring changes, and pre-

¹³It has been estimated that under the existing payment structure family physicians, general practitioners, and internists cannot be expected to spend longer than 5 additional minutes in assessment of their elderly patients (45).

dieting outcome; certain assessment measures are believed to be more appropriate for one purpose than another (43). A concise pamphlet for practitioners on available assessment tools and appropriate uses is needed.

Incentives for Use.—As described earlier, there is little incentive for widespread use of assessment measures. Comprehensive functional assessment is generally not required for public funding of long-term care services, and neither Medicare nor Medicaid provide reimbursement for the physician's time spent in functional assessment. Required use of a comprehensive functional assessment measure as part of eligibility determination for publicly funded long-term care services would create an incentive for use of these measures. A 1977 report by the Institute of Medicine has recommended this approach:

The Federal Government should reimburse for long-term care provided to the functionally dependent elderly . . . Eligibility for Federal reimbursement of long-term care should be based on a comprehensive assessment process (41).

Functional assessment is "recommended to serve a 'gatekeeper' function for long-term care services as well as to assure appropriateness of care for the individual patient" (41).

Selection or development of a comprehensive functional assessment instrument for determining eligibility for publicly funded long-term care services would require choices about the most important factors to measure and the most appropriate structure and wording for the test instrument. The required use of such an instrument would, however, eliminate uncertainty about which one to use, and repeated use of the same instrument would allow for extensive evaluation of reliability and validity and subsequent refinement of the instrument.

Physicians and other long-term care providers now spend considerable time on forms to establish eligibility of patients and clients for publicly funded long-term care services. A comprehensive functional assessment measure might be substituted for other currently required forms. Since public funds pay such a large proportion of long-term care services, agencies required to use an

assessment measure for publicly funded services might gradually extend the use of this measure to privately funded services as well.

The Value of Scoring.—Some assessment measures result in numerical scores on individual sections or an overall score on all sections of the test. These scores are used to indicate degree of impairment in physical or mental functioning, or the extent and kind of services needed, and can also be used to measure improvement or deterioration in an individual patient. In some States, scores on comprehensive assessment measures are used to determine eligibility for certain long-term care services; for example, in New York State elderly individuals who score over 180 on a comprehensive functional assessment measure are eligible for Medicaid-funded nursing home placement (140).

Although scoring has been used extensively for research and administrative purposes, there is great concern about the validity of this process. Little information is available about the relative importance of various aspects of functioning. It has been pointed out that these scoring systems often assume that "the items being scored consist of a systematic, ordinal set of characteristics of a single phenomenon (e.g., total physical functional disability, total mental disability, total physical plus mental disability, etc.) (140). In fact:

The items being scored are rarely if ever of an ordinal nature, (and) there is no basis for assuming an ordinal relationship (between items) in which a given score would represent a given degree of total mental function and a specific higher score would represent a predictably proportionately better level of total mental functioning (140).

The use of overall scores for the evaluation of an individual patient tends to obscure information about specific problem areas, but scores on selected test items can be used the way the results of lab tests are used, to indicate the presence or absence of a problem that requires further analysis (140).

Who Should Do the Assessment.—Comprehensive functional assessment involves two steps: collection of the necessary information and analysis of the information. Each of these procedures

can and is being done in various settings by individuals with or without special training in geriatric assessment, by physicians, social workers, or nurses, and by teams of health care professionals, each collecting and analyzing information in his area of expertise. Information can also be collected and analyzed by computer. The decision about who should do the assessment depends on numerous factors that interact:

- the purpose of the assessment,
- availability of funding for collection and analysis of the information,
- availability of trained staff to do the assessments,
- degree of confidence in the reliability and validity of the assessment instrument, and
- beliefs about the role and importance of clinical judgment in the collection and analysis of the information.

Some experts have suggested that since many physicians have been reluctant to spend the time needed for comprehensive assessment, these assessments should be available through geriatric assessment centers in local jurisdictions. At present, comprehensive functional assessment measures are sometimes used for research and administrative purposes without the additional evaluation of a trained professional, yet it is generally believed that adequate patient care and long-term care planning require clinical judgment. In fact, some experts believe that assessment measures should only be used as general screening tools to identify individuals who need further evaluation by trained professionals. Others believe that formal assessment tools are not needed for patient care when a trained professional is available to evaluate the patient; even in this case, however, assessment measures can help remind the clinician of important factors to evaluate. In addition, the common language of the assessment measure provides a method for teaching geriatric care and communicating between disciplines (91).

The role of the patient and his preferences has received relatively little attention in discussions of comprehensive assessment measures. Since patient motivation and expectations are known to affect response to chronic disease and impair-

ments, this issue needs more attention. In this context, adequate procedures for maintaining confidentiality of patient records are especially important since information about all aspects of the patient's functioning is available on the assessment form.

Assistive devices and rehabilitation techniques

Technologies to maintain or increase the independence of the elderly include assistive devices and rehabilitation techniques that compensate for functional impairment. For some individuals the appropriate use of these technologies will postpone or eliminate the need for institutionalization or extensive home care services; for others the use of assistive devices and rehabilitation techniques can reduce the burden of care on family and friends. In nursing homes and board and care facilities, these technologies can improve the quality of life for residents by maintaining some level of independent functioning and decreasing the need for staff assistance.

The goal of rehabilitation is to maintain or restore independent functioning, rather than to cure disease. For the elderly, this approach is particularly important because many of the diseases that affect the elderly are not curable at present. Rehabilitation technologies can help an individual to function independently despite underlying disease conditions. Even relatively small improvements in functioning can make a difference in self-care ability. For example, a stroke victim who can learn to transfer from bed to wheelchair and wheelchair to commode can be independent in many self-care activities (140). Similarly, an individual with severe tremor due to Parkinson's disease can continue to feed himself using devices such as splints and special eating utensils, thus avoiding the need to be fed and associated feelings of dependence and loss of control.

REHABILITATION TECHNOLOGIES

Many assistive devices have been developed to compensate for functional impairment. They range from such simple devices as a long-handled soap to help an individual with limited arm mo-

tion to bathe himself to such highly sophisticated devices as voice-controlled robots for bedridden patients that are being developed by the Veterans Administration/Stanford University Robotic Aid Project (32). Some examples of assistive devices to compensate for common impairments of the elderly are shown in table 16.

Sources of information about assistive devices include computerized data systems and catalogs produced by public agencies and private manufacturing and retail companies. ABLEDATA, a computerized data base sponsored by the National Institute for Handicapped Research, currently lists more than 6,000 products for disabled

Table 16.-Examples of Assistive Devices for the Functionally Impaired Elderly^a

Impairment	Simple devices	Complex devices
Vision	Lighted magnifying glass Large-print books	Electronic reading machine that converts printed material to speech
Hearing	Hand-held speaking tube or horn	Infrared hearing system that transforms an audio signal via infrared light beam to a receiver worn by the listener, thus suppressing background noise that is a problem for hearing aid users (57)
Speech	Manual communication board; the individual points to a symbol or what he wants to say	Electronic communication board with memory and print-out capability. The individual uses a switch to activate a cursor on the board to indicate words or messages (19). Portable speech synthesizer (8)
Memory	Pad to keep notes for reminders	Clock radio system that verbalizes reminders and automatically controls some appliances
Mobility	Braces and splints Canes, walkers, and wheelchairs Ramps	Computerized electrical impulse device to stimulate muscles and allow paralyzed persons to walk (40) Voice-controlled, electric wheelchair that can open doors and manipulate switches (8) Electric chairlift for stairs
Upper extremity weakness	Reachers and grippers Levers to facilitate turning door knobs and faucet handles	Prosthetic control system using electronic sensors and mechanical transducers to operate a prosthetic arm (8)
Bathing	Shower or bathtub chair Long-handled soaper	Hydraulic bath lift Horizontal shower (19)
Dressing	Velcro fasteners Clothing that opens in front	No complex devices known
Eating	Utensils with built-up handles	Automatic feeding machine (56)
Toileting	Bedside commode	Commode with automatic toilet flusher, warm water bidet and hot air drying in a push-button unit (19)
Shopping	Shopping cart for a wheelchair user Prepackaged, freeze-dried meals	Shopping by computer
Cooking	Suction gripper to hold a jar to be opened	Robot that can prepare meals (56)
Environmental control	Switches and controls on extension cords that can be reached by the patient	Computerized remote environmental control system to allow a bed or chair-bound patient to adjust lights, radios, TVs, thermostats, and other electrically controlled appliances (19)

^a these devices were selected to illustrate the kinds of assistive devices that are available. Thousands of other devices are also available.

SOURCE: Office of Technology Assessment.

persons of all ages. other computerized data systems include "Accent on Information," a proprietary system developed by Raymond Cheevers, and "Automated Retrieval of Information on Assistive Devices" (ARIAD), developed and maintained by Louisiana Tech University (108). Several catalogs list assistive devices for the elderly. For example, A *Catalogue of Products and Services To Enhance the Independence of the Elderly*, compiled at Drexel University, lists more than 250 products, including appliances, special clothing, and communications devices (5). The American Association of Retired Persons and the Western Gerontological Society are completing a catalog of about 400 devices that assist older persons to live independently at home. The catalog will be published in early 1985 (54).

In addition to assistive devices, many rehabilitation techniques are used by physiatrists (physicians who specialize in rehabilitation), physical therapists, occupational therapists, nurses, and other health care professionals to assist disabled persons to maintain or improve their functioning. Rehabilitation techniques are included in this section with assistive devices because they are alternative technologies for maintaining independence and because the effective use of assistive devices often depends on the simultaneous availability of rehabilitation services and procedures (55). Like assistive devices, rehabilitation techniques can be simple procedures such as teaching a stroke victim and his family how to lay out his clothes to allow him maximum independence in dressing, or complex procedures such as the use of electronic sensing devices to provide biofeedback to a disabled person who is not able to sense the position of his feet or arms.

Appropriate rehabilitation technology for any individual depends on an evaluation of functional impairments and residual function; that is, which functions the individual is not able to perform and which abilities and functions he retains. Assessment of the individual should determine the need for a simple device or a more complex one. often both a device and rehabilitation services are needed. For example, a person with degenerative joint disease may need both a cane or walker and physical therapy in order to maintain mobility. Successful use of rehabilitation technologies de-

pends as much or more on matching the individual and the appropriate technology as it does on the existence of sophisticated devices and rehabilitation techniques (26).¹⁶

CURRENT FEDERAL INVOLVEMENT IN RESEARCH AND DELIVERY OF REHABILITATION TECHNOLOGIES

Many Federal Government agencies have programs of research, evaluation, or funding of rehabilitation technologies. Most of these are directed toward the needs of disabled individuals of all ages and focus on certain types of devices, a particular step in the process of designing and evaluating devices, or provision of devices and rehabilitation services to individuals.

The National Institute of Handicapped Research (NIHR)¹⁷ is the lead agency responsible for initiating, funding, and coordinating Federal research to benefit disabled persons of all ages. NIHR's long-range plan, submitted to Congress in January 1981, included recognition of the special needs of the disabled elderly and a commitment to relevant research. NIHR currently funds 21 Rehabilitation Research and Training Centers, including two focused specifically on the needs of the elderly: one at the University of Pennsylvania and the other at Rancho Los Amigos Rehabilitation Hospital, in affiliation with the Ethel Percy Andrus Gerontology Center and the School of Medicine of the University of Southern California (122,135).

Federal funding for some assistive devices and rehabilitation services for the elderly is available through Medicare and Medicaid, and to a limited extent through State rehabilitation agencies supported in part by grants from the Rehabilitation Services Administration. The VA is a major provider of assistive devices and rehabilitation services for disabled veterans of all ages and is the Nation's largest purchaser of assistive devices (69).

¹⁶There is continuing debate about how to allocate research and delivery resources between simple, relatively inexpensive devices and technologically sophisticated devices. This debate at a policy level tends to focus more on devices than on the needs of the individual (34).

¹⁷NIHR was created by the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978 (public Law 95-602) which moved the existing research programs of the Rehabilitation Services Administration in the Department of Health, Education, and Welfare (now, the Department of Health and Human Services) to the Office of Special Education in the Department of Education.

The VA funds research in rehabilitation technology for disabled persons of all ages through its Rehabilitation Engineering Research and Development Program (122).

FACTORS AFFECTING THE USE OF REHABILITATION TECHNOLOGIES BY THE ELDERLY

Despite the availability of thousands of assistive devices and rehabilitation techniques, several problems limit the use of these technologies by the elderly:

- The elderly often have several functional impairments associated with multiple chronic diseases. Devices and techniques appropriate for one impairment may not be usable because of other impairments the individual has.
- Cognitive impairment can interfere with an elderly individual's ability to use an assistive device or respond to a rehabilitation technique.
- Negative stereotypes about the elderly and their potential for rehabilitation limit the interest and enthusiasm of rehabilitation specialists, and sometimes the elderly and their families, for obtaining and using rehabilitation technologies.
- Limited availability of skilled rehabilitation personnel in long-term care settings restricts access to assistive devices and rehabilitation services.

Other problems limit the use of rehabilitation technologies by disabled persons of all ages. These include difficulties with production, marketing, funding, and repair of assistive devices. Lack of effective methods for getting devices from inventors to individuals who need them is a major obstacle to the use of these technologies (122).

The Impact of Multiple Impairments.—Many elderly individuals suffer from multiple chronic diseases with resulting functional impairments, and this affects the kinds of assistive devices and rehabilitation techniques they can use effectively (19). Rehabilitation technologies are often designed to compensate for impairment by substituting another function, yet this substitution of one ability for another is difficult when multiple impairments are present in the same individual.

For example, an elderly individual who cannot walk because of an amputation, hip fracture, or osteoarthritis may not have the stamina to use crutches or a walker because of cardiovascular or respiratory disease. Similarly, an elderly blind person with paralysis of an arm due to stroke or decreased tactile sense due to diabetes will not be able to use braille to read.

Assessment of all the individual's functional impairments and residual strengths is a prerequisite for matching the individual and appropriate devices and services. Locating devices for an individual with a specific combination of impairments often requires a wide knowledge of available devices or a time-consuming search through catalogs. Although data are not available, it is likely that many assistive devices purchased for elderly individuals with multiple impairments are not used because the individual lacks the residual abilities needed to use the device.

Physiological changes that occur with normal aging can also restrict the use of rehabilitation technologies. These changes include decreases in visual acuity and hearing ability, decreases in touch sensitivity and fine motor control, decreased grip strength, and decreased capacity of the body to respond to environmental extremes (4). While these changes may not limit the functioning of the healthy elderly individual, they lessen capacity to compensate for impairments resulting from acute and chronic disease. For example, decreased grip strength may not interfere with the functioning of the healthy elderly person but can hamper the ability of a mobility-impaired individual to use a cane or grab-bars effectively. Awareness of the physiological effects of normal aging is essential for the design of rehabilitation technologies for the elderly.

The Impact of Confusion on the Use of Rehabilitation Technologies.—Although only a small percentage of all elderly persons have symptoms of confusion or organic brain disease, large percentages of the long-term care population are affected, including up to 50 percent of nursing home residents and 20 percent of community dwelling elderly over 80. The impact of confusion on their ability to use rehabilitation technologies has received little research attention, al-

though anecdotal evidence indicates that it is an important factor.

A recent study of patients in rehabilitation facilities in Canada (99) showed that confused patients did not respond well to standard rehabilitation techniques. After a year 59 percent of not-confused patients had returned home, but only 16 percent of the severely confused patients had done so. The authors conclude:

The standard rehabilitation approach depends on the patient learning ways to deal with the disability and practicing techniques taught by the therapist. Intellectual dysfunction impairs learning ability. Accordingly, it is not surprising that our data demonstrate this approach is not more effective than a standard supportive approach in which spontaneous improvement can occur.

The authors recommend the development of rehabilitation methods specifically for confused patients.

Confusion restricts the ability of the disabled elderly person to learn to use assistive devices such as walkers, hearing aids, or simple devices to help in dressing, bathing, or eating. Sometimes it is even difficult for the confused person to remember what the device is for. Failure to assess cognitive functioning may result in the purchase of assistive devices that are inappropriate for the patient.

Research findings about the effectiveness of rehabilitation technologies are also affected by the existence of mental confusion in the long-term care population. Formal research that does not distinguish between patients who are confused and those who are not may reach ambiguous conclusions, reflecting a mixture of positive results with one group of subjects and negative results with another group. Similarly, informal evaluations by long-term care providers who use rehabilitation technologies may produce neutral or negative results because many patients are too confused to learn to use the devices or respond to the rehabilitation techniques. As a result, providers often become discouraged about the efficacy of these technologies in general. Formal research that is clearly structured to differentiate between confused and not-confused subjects can help to identify technologies appropriate for these two groups of patients.

Negative Attitudes About the Rehabilitation Potential of the Elderly.—The belief that the elderly deteriorate inevitably, both physically and mentally, is widespread in our society, and affects the elderly, their families, health care professionals, and long-term care providers. The sense of hopelessness resulting from this belief is a significant barrier to the use of rehabilitation technologies.

As a result of these negative stereotypes, many elderly persons resist thinking of themselves as old and deny impairments that they think make them seem old. They may refuse to use assistive devices such as canes, walkers, and hearing aids that call attention to impairments even though use of these devices might help to maintain independent functioning. Other elderly persons, especially those who are recovering from a debilitating acute illness, accept the negative stereotypes about the inevitable deterioration and adopt a sense of hopelessness about recovery (19). In this state of mind, they are unlikely to respond well to rehabilitation services.

Family and friends of disabled elderly persons can be an important source of motivation and concrete assistance in obtaining assistive devices and helping the individual to install or learn to use them. Family members can help locate rehabilitation services, provide transportation, and encourage the disabled individual to cooperate with the rehabilitation plan, but family and friends who accept the stereotyped view that deterioration is inevitable are unlikely to offer encouragement and assistance in obtaining these services.

Health care professionals and rehabilitation specialists often share society's negative view of the elderly. Most physicians and nurses prefer younger patients and those whose ailments are curable (87), and some rehabilitation counselors also exhibit bias against the elderly (110). These negative attitudes result in lack of enthusiasm for the rehabilitation of the elderly and relative lack of rehabilitation research and services for this age group (61). Nevertheless, a recent study of rehabilitation in the very old patient (76) showed significant improvement in 79 percent of the 97 patients studied, all of whom were over 85. Interestingly, a computer search of U.S. literature failed to find any previous study of rehabilitation results with very old patients (76).



Photo credit: Gretchen Kolsrud

Many elderly patients can improve significantly with appropriate rehabilitation services.

The authors of a 1983 report emphasize the importance of well-designed research and clinical trials on rehabilitation of the elderly. They state:

We want to avoid the self-fulfilling prophecy that shows elderly persons at poor risk for rehabilitation because statistics show less good results when, in fact, fewer therapies were offered in the first place (46).

They point out that evaluation of the rehabilitation potential of elderly patients is difficult when so few of them are ever offered rehabilitation at all.

Limited Availability of Skilled Rehabilitation Personnel in Long-Term Care Settings.—Most rehabilitation services and technologies for the elderly are provided in hospitals by physiatrists, physical therapists, occupational therapists, speech therapists, and nurses. As home care services have expanded, some of these rehabilitation specialists have begun working outside the hospital setting. As yet, however, too few are available to meet the needs of nursing home residents and community dwelling elderly. For example, occupational therapists are trained to evaluate functional impairment, locate or design appropriate assistive devices, and teach individuals to use them. Of the 35,000 members of the American Occupational Therapy Association, fewer than 3,000 work with elderly patients, and most of these work in hospitals.

Medicare funding for rehabilitation services outside the hospital is restricted by complex regulations about who provides the service and in which setting. Moreover, the patient must show improvement; services needed to maintain functioning are not reimbursable. Medicaid funding for rehabilitation services is available in some States, but coverage is limited, and the level of reimbursement is usually considerably below customary charges for these services.

Rehabilitation services for nonelderly adults are often provided and paid for by State rehabilitation agencies. These agencies receive 80 percent Federal funding as mandated by the Rehabilitation Act of 1973 and provide extensive services, including physical and mental rehabilitation, income maintenance during rehabilitation, transportation, counseling, mobility training for the blind, and telecommunication, sensory, and other assistive devices (122).

Although the Rehabilitation Act of 1973 includes no age criteria, it specifies that services be directed toward making the disabled person employable. This focus on employability has resulted in the virtual exclusion of the elderly from these services (71); figures from the Rehabilitation Services Administration for 1978 show that of the 290,213 persons who received rehabilitation services through federally funded State rehabilitation agencies, only 2.2 percent were over 65 (14).

The Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendment of 1978 (public Law 95-602) extended eligibility for federally funded rehabilitation services to severely disabled individuals who do not have employment potential. Mandated services include architectural modifications of homes and other living environments, attendant care, physical therapy, and assistive devices to help disabled individuals to function as independently as possible within their families or communities and to prevent or postpone institutionalization (139).

This focus on independent living services would seem to address the needs of the disabled elderly, except for two continuing problems. First, although some funds have been appropriated to set up rehabilitation programs for independent living, no funds have yet been appropriated to pay for the mandated services. Secondly, the elderly are in direct competition with younger disabled persons for services under these programs. Given the traditional focus of rehabilitation agencies on younger persons, the obvious need for rehabilitation services in the younger age group, and funding limitations, it is unlikely that the disabled elderly will receive substantial benefits from these programs without a significant redirection of financial and staff resources.

problems in Production, Marketing Funding and Repair. -Ongoing difficulties in the production, marketing, funding and repair of assistive devices also restrict the use of these technologies by the disabled elderly. These problems include:

- **Inadequate Production and Marketing of Needed Products:** Many potentially useful devices are invented but never produced or marketed because companies are reluctant to invest in the manufacture of devices without an identifiable market for the product (7,55). In many cases the number of disabled people who can actually benefit from a certain device is relatively low, potential users are often difficult to identify (33), and small companies that are frequently the source of innovative products may lack the financial or staff resources to launch the kind of marketing campaign needed to reach potential users.
- **Lack of Information About Available Technologies:** Lack of information about assistive

devices and rehabilitation techniques is an ongoing problem. Although computerized data systems and catalogs of devices have been developed to solve the problem, the information gap persists. Researchers complain that it results in frequent instances of "reinventing the wheel" (10, 107). Disabled individuals, their families, and service providers continue to have difficulty finding out about appropriate technologies. Meanwhile, companies with innovative products and services struggle to find ways to make their products known to service providers and the disabled (34).

- **Lack of Financial Resources to Pay for Assistive Devices and Rehabilitation Services:** Three financial factors restrict purchases of rehabilitation technologies. First, disabled individuals as a group have lower than average income and are often unable to pay for these devices and services (55,122). Second, many devices are unexpectedly expensive because of the high costs of designing and marketing products to this relatively small group (33). Third, the many public and private agencies and programs that pay for rehabilitation technologies have uncoordinated and inconsistent definitions of who is eligible and what devices and services will be paid for.¹⁸ Decisions about whether a device is covered under a certain program may vary from one part of the country to another, and can be made retroactively, so that neither the disabled individual nor the provider knows in advance whether the device or service will be paid for. In addition, the amount of payment for a specific device or service may be less than the full cost, and some devices are not covered at all (69). OTA has found that as a result of the lack of coordination among funding sources, "users and providers are either unable to take advantage of available technologies or must spend enormous amounts

¹⁸Availability of funding for specific devices influences their production and use. Under some public programs, such as Medicare and Medicaid, such funding is authorized only when the devices are deemed "medically necessary." Hearing aids, glasses, dentures, and communications devices are not covered by Medicare because they are not considered medically necessary, although they do compensate for functional disabilities of disabled persons (122). In some cases, disabled persons find themselves with an inappropriate device because it is the only one that is funded (55,73).

of time providing the coordination needed to best assist each individual" (122).

- **Lack of Available Repair Services for Assistive Devices:** Difficulties in obtaining repair services for devices such as hearing aids and wheelchairs limit their usefulness. Repairs frequently take weeks or even months and are often costly. Replacement parts are hard to find, and for someone who is dependent on the device for an important functional disability, the time spent waiting for repair of the device can be very difficult (27).

INITIATIVES TO INCREASE THE AVAILABILITY OF REHABILITATION TECHNOLOGIES

Evaluative Research.—More research on the efficacy, safety, and cost of commonly used devices such as wheelchairs and hearing aids is needed, as are comparisons of outcomes when devices are used alone or in combination with rehabilitation training. Evaluation of rehabilitation technologies is one focus of the National Institute of Handicapped Research, The Veterans Administration, with its large population of disabled elderly veterans and its ongoing programs in both research and the provision of devices and services, also provides an ideal setting for evaluative research.

Assessment.—Accepted, valid, functional assessment measures are a prerequisite for evaluation of rehabilitation technologies and appropriate matching of individuals and technologies. Especially significant factors to measure are multiple functional impairments, mental impairments, and psychosocial factors that affect the capacity of the individual to use available technologies.

Public Education About Device.—Initiatives to increase awareness of available rehabilitation technologies include advertising of specific products and public service advertising about the importance of rehabilitation technologies in maintaining independence and well-being. Advertising of specific products is clearly the responsibility of private industry, and some advertising of this kind, i.e., incontinence supplies, is currently underway in major national markets. Development of advertising for assistive devices has been difficult because the elderly tend to reject age-related product identifications (2). The design of advertising messages that emphasize both age and

disability is even more difficult, and media advertising directors have been reluctant to accept advertising for assistive devices because of anticipated negative reactions to content. Although advertising for some types of assistive devices appears in magazines directed to the elderly and those with a health care focus, these publications do not reach all the individuals who might benefit from rehabilitation technologies or the families who often assist in obtaining them.

Public service advertising is an option that has not yet been tried. Advertising could emphasize the importance of assistive devices in maintaining independence and counter the widespread belief that using these devices implies that an individual is old, useless, and unattractive. Although the potential impact of this approach remains speculative, it is relevant to consider the positive effect on attitudes and demand for hearing aids when president Reagan first appeared in public with a hearing aid. Ads could refer to available sources of information about specific devices and encourage careful evaluation of both the needs of the individual and the appropriateness of the device chosen.

Awareness of Health Care and Service Providers.—Initiatives are needed to increase awareness of rehabilitation technologies among health care professionals and other service providers, such as physicians, nurses, social workers, physical therapists, occupational therapists, speech therapists, and staff members at senior centers, senior nutrition programs, and senior housing facilities. Although some of these individuals may have received training in some rehabilitation technologies, few have any knowledge of the wide range of technologies available. Retailers of assistive devices are generally untrained or trained through inservice programs provided by the manufacturers of the devices. They may develop expert knowledge about the devices they carry but rarely receive training in assessment techniques.

The development of training programs for health care professionals and service providers has been a major focus of the two Rehabilitation Research and Training Centers in Aging funded by NIHR. Curricula and audiovisual aids for training in rehabilitation of the elderly are being de-

signed to increase knowledge about the elderly and to counter negative attitudes about rehabilitation potential, but the impact of these training programs has been limited by staff and funding restrictions at the centers, which were established only 3 years ago.

Rehabilitation counselors in State rehabilitation agencies generally have training in both assessment and rehabilitation technologies but lack funding and appropriate goals for working with the elderly. Increased funding for independent living services mandated by the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendment of 1978 is needed. Realistic goals for rehabilitation of the elderly are also needed. In addition to goals such as increased independence and self-care, it is important to recognize the roles the elderly can fill as volunteers in the community and caregivers in their own families (9).

Assistive Device Centers.—"Aids Centers," located throughout Sweden, enable disabled persons to look at assistive devices, try them out, and consult with rehabilitation specialists about which devices would be most helpful (35). In the United States, the Department of Justice maintains a Sensory Aids Center to evaluate and customize technological aids for its visually impaired and deaf staff members (112). In Sun City, a retirement community in Arizona, residents have organized a lending service for health care and rehabilitation appliances. Financial support is also available through the community for prostheses, glasses, and hearing aids (93). Development of assistive device centers in other locations would increase access to rehabilitation technologies by the elderly.

Funding. -Increased funding for rehabilitation technologies through Medicare and Medicaid is unlikely at present because of budget limitations, and without increased funding, coverage cannot be extended to new categories of assistive devices. Nevertheless, development of nationally consistent standards for Medicare and Medicaid coverage would facilitate provision of devices.

The need for increased public funding for assistive devices and rehabilitation services is not clear at present. The use of these technologies is limited primarily by lack of information, negative attitudes, and lack of a professional group

with responsibility for assessment and matching of individuals and rehabilitation technologies for the elderly. Lack of funding discourages purchase of some expensive and technologically sophisticated devices, but many devices are relatively inexpensive, and recent reports tend to refute the idea that most of the elderly are poor (4). It is not clear how many elderly persons would be unable to pay for these devices if they knew about them and believed that the devices would help to maintain independence.

Technologies for caregivers

Technologies for caregivers include devices and procedures to facilitate and improve caregiving. Long-term care has traditionally been labor-intensive, with little emphasis on technology. Few labor-saving devices are used, and caregivers, including both informal caregivers and paid personnel, often receive little or no training in efficient methods of care. As a result, staff turnover is very high in long-term care facilities, and families and other informal caregivers become overburdened and exhausted.

Many technologies have the potential to facilitate long-term care. In this section, technologies to assist caregivers with three types of care are reviewed: 1) care for individuals with medical or skilled nursing care needs, 2) care for physically impaired individuals, and 3) care for mentally impaired individuals.

CARE FOR INDIVIDUALS WITH MEDICAL OR SKILLED NURSING CARE NEEDS

In the past few years, medical treatment that was previously provided only in hospitals has become increasingly available outside the hospital. This change has been spurred by the hospital utilization review process that discourages unnecessary hospitalization and by the availability of reimbursement for home health care through Medicare, Medicaid, and private insurance. The new Medicare prospective reimbursement system (DRGs) is increasing the need for medical services outside the hospital. Medical care devices and skilled nursing care are needed in the home and in nursing homes for patients who are discharged earlier from hospitals and continue to need medical treatment.

At present most nursing homes primarily provide personal care and supportive services under the supervision of a registered nurse. *g Patients who are acutely ill or need complex medical treatment are sent to the hospital because most nursing homes do not have the resources to provide the required treatments. As hospitals respond to the prospective reimbursement system, nursing homes are being pressured to accept patients who

¹⁹As of 1979 only 15 percent of nursing home staffs were registered nurses (RNs), compared with 46 percent of hospital staffs, resulting in a nurse-to-patient ratio of 1 to 49 in the nursing home compared with 1 to 4-5 in the hospital (68). RNS in nursing homes are responsible for supervision of nursing aides and many other administrative tasks in addition to medication-monitoring and medical treatments.



Photo credit: Gretchen Kolsrud

Rehabilitation services can lessen the burden on caregivers by maintaining function even in the very frail elderly patient,

need more acute care and more complex care than has been provided in the past.

Technologies to provide more complex medical care in nursing homes include diagnostic and monitoring equipment and devices for sophisticated medical treatment. In addition, ancillary personnel with training in the use of these technologies will be needed. It has been suggested that geriatric nurse practitioners and nurse clinicians are well qualified to provide skilled and acute care services in nursing homes (67).²⁰

The availability of medical technologies and qualified nursing personnel is primarily dependent on payment levels and reimbursement policies of Medicare, Medicaid, and private insurance companies. At present, payment for nursing home care is generally not high enough to cover the cost of sophisticated medical technologies and highly trained personnel. Cost-based reimbursement policies with increased allowance for medical devices and skilled personnel would create an incentive for nursing homes to upgrade the level of care they can provide, but would also increase the cost of nursing home care. Federal and State initiatives to limit reimbursement for nursing home care restrict the provision of acute and skilled care services that may be required by the patient group that is discharged earlier from hospitals under DRGs.

To a great extent, nursing homes can choose the patients they admit (see ch. 8). Without increased reimbursement for medical technologies and skilled nursing personnel, nursing homes are unlikely to admit patients with acute and skilled care needs because they do not have the resources to care for them. This creates severe hardship for patients who need ongoing medical care in an institutional setting and for hospitals forced to choose between discharging patients without adequate continuing care or keeping patients they are not being paid for.

Although the availability of medical care technologies and skilled nursing care in the home has

²⁰The geriatric nurse practitioner is a nurse with a master's degree in gerontologic nursing and training in managing patient care, providing routine physical care and physical tests, and acting as liaison with the patient's physician. In addition, the geriatric nurse practitioner can provide staff training in the use of medical care technologies (42).

increased greatly in the past few years,²¹ demand for home health care will continue to rise as a result of the Medicare prospective reimbursement system. Primary concerns here are the continuing availability of highly trained nurses to provide skilled care and the existence of efficient mechanisms for testing and approving medical technologies for use in the home. Medical device regulation, which is the subject of several recent government reports²² is not discussed here. The availability of skilled health care professionals to provide assistance and training for the patient and the family in the use of sophisticated medical devices is an important factor in the successful use of these technologies.

CARE FOR PHYSICALLY IMPAIRED INDIVIDUALS

Physically impaired elderly persons may require assistance with personal care activities such as bathing, dressing, eating, toileting, and mobility. Technologies to assist with these functions include devices that increase the ability of the elderly person to function independently (discussed in the previous section of this chapter), devices to assist the caregiver directly, such as machines to lift and move patients, and techniques to facilitate physical care.

Although many devices and techniques for caregivers are available, they are not widely used, and caregivers are often unaware of these technologies. Two factors interact to perpetuate this situation: First, caregiving is not generally recognized as a skill in our society. The focus is on curing rather than skilled caregiving (60). Second, and related to the first factor, is the relatively low status of most caregivers. It has been pointed out that:

²¹In contrast to the nursing home situation, payment is available for many medical care devices and skilled nursing visits in the home. In fact, Medicare reimbursement for one skilled nursing visit approaches the cost of a day of nursing home care in some parts of the country, although the nursing homes also provides 24-hour personal care, room and board, laundry service, and other supportive services.

²²GAO, "Federal Regulation of Medical Devices-Problems Still to Be Overcome," September 1983; House Subcommittee on Oversight and Investigations, "Medical Device Regulation: The FDA's Neglected Study," April 1983; and Office of Technology Assessment, "Federal Policies and the Medical Devices Industry," OTA-H-230 (Washington, DC: U.S. Government Printing Office, October 1984).



Photo credit: Gretchen Kolsrud

This automatic chair lift is used to raise the patient comfortably into the whirlpool bath.

Caring roles are for the most part performed by women with limited education, training, and professional identification and prestige. These are low paying jobs with virtually nonexistent status (60).

Even when these low-status caregivers develop effective caregiving techniques, there is little recognition of their skills or diffusion of the techniques to other caregivers.

Nurses, occupational therapists, and physical therapists are skilled in developing caregiving techniques for specific patients, but relatively few occupational therapists and physical therapists are employed in long-term care settings. Nurses provide training for nursing assistants in nursing homes and for home health aides and homemakers in home care agencies. Nevertheless, the lack of recognition for caregiving as a skill and the low status of caregivers limit the extent and effectiveness of this training.

Family members and other informal caregivers are particularly unlikely to know about and use available devices and techniques. In many cases, the informal caregiver is the elderly spouse, who

has particular difficulty lifting and moving the patient in order to bathe or dress the patient or get him or her into a wheelchair. In fact, some nursing home placements occur when the caregiver has fallen or injured himself/herself trying to lift or move the patient. Packaging of information about devices and techniques for informal caregivers in a form that is easy to understand and use is an important priority in long-term care. Many devices for physical caregiving are designed for use in an institutional setting, and there is a need for devices developed specifically for home and the informal caregiver.

CARE FOR THE MENTALLY IMPAIRED INDIVIDUAL

A large proportion of nursing home and board and care residents are mentally impaired, and many families are caring for severely confused elderly individuals at home, yet there has been relatively little attention paid to caregiving technologies appropriate for these individuals. The focus of Federal funding programs on physical illness and medical treatment has tended to obscure the care needs of mentally impaired individuals, but recent interest in Alzheimer disease has resulted in a growing literature on caregiving techniques for all mentally impaired patients. Some of this information is new, but much of it reflects existing knowledge of long-term care providers who have developed expertise in caring for these patients.

Effective care for mentally impaired individuals involves techniques for handling a variety of difficult problems. Table 17 lists the problems cited by families caring for mentally impaired individuals with Alzheimer disease, multi-infarct dementia, and other organic brain diseases (82). Technologies to address three of these problems, forgetfulness, agitation and catastrophic emotional reactions, and wandering, are discussed here.

Forgetfulness.—Increasing forgetfulness is characteristic of mentally impaired individuals and ranges from forgetting where one left certain objects to forgetting one's spouse and children and forgetting how to dress, eat, and use the bathroom. Memory training techniques have been tested with some evidence of short-term gain but little lasting improvement (143). Further research on a variety of approaches to maintaining memory function is needed.

For individuals with severe forgetfulness, caregivers can often help to maintain orientation with reminders about the date, the time, and other daily information. Several simple devices can also be useful. Labels on objects can remind the individual of the name of the object and illustrate its use with a simple drawing. Signs on doors, especially bathroom doors, can also be helpful. In one facility when a patient is so confused that he cannot answer any questions about himself, a color-

Table 17.—Behavior Problems of Patients Cited by Families

Behavior	Number of families responding	Number of families reporting occurrence (%)	Number of families reporting behavior to be a problem (%)
Memory disturbance.	55	55 (100/0)	51 (93/0)
Catastrophic reactions.	52	45 (87)	40 (89)
Demanding/critical behavior	52	37 (71)	27 (73)
Night waking	54	37 (69)	22 (59)
Hiding things.	51	35 (69)	25 (71)
Communication difficulties.	50	34 (68)	25 (74)
Suspiciousness	52	33 (63)	26 (79)
Making accusations	53	32 (60)	26 (82)
Meals	55	33 (60)	18 (55)
Daytime wandering	51	30 (59)	21 (70)
Bathing	51	27 (53)	20 (74)
Hallucinations	49	24 (49)	16 (42)
Delusions	49	23 (47)	19 (83)
Physical violence	51	24 (47)	22 (94)
Incontinence	53	21 (40)	18 (86)

SOURCE: P. V. Rabins, et al., *Journal of the American Medical Association*, 246(3):333-335, July 16, 1962. Copyright 1982, American Medical Association.

ful poster is placed outside his room, giving his name and some information about his family and his past and providing staff and visitors something real to talk to the patient about (136).

Little information is available about effective techniques for maintaining the individual's memory of how to care for himself (bathing, eating, toileting, etc.). This is partly because in many long-term care settings, no distinction is made between patients who need help with these functions because of mental impairment and those who need help because of physical impairment, and staff members tend to provide the same kind of assistance for both groups. Informal caregivers often provide physical assistance instead of using techniques that support the individual's ability to perform self-care functions himself. Research on effective techniques for maintaining memory of self-care functions is needed.

Agitation and Catastrophic Emotional Reaction—Agitation and catastrophic emotional reactions are major problems for caregivers. These behaviors are related to memory loss because the individual becomes agitated and angry when he cannot remember or understand people and events in his environment. Although there are no devices to cope with this problem, medication can be used. Unfortunately some medications that are frequently used for this purpose also reduce alertness and other cognitive functions.

Certain caregiving techniques and systems can decrease the frequency and severity of agitation and catastrophic reactions. Informal and paid caregivers can learn to divert the individual's attention from upsetting issues or events and to avoid presenting the individual with tasks he is not able to perform (82). In addition, caregivers can be aware of the impact of daily events on the mentally impaired individual. For example, in the institutional setting, mentally impaired individuals may become agitated when shift changes or visitors to the facility cause high levels of activity and noise. An understanding of the effect of these events on the confused person can result in environmental and scheduling changes that decrease the frequency of catastrophic emotional reactions.

Wandering.—Wandering is a difficult problem for families and long-term care facilities because

mentally impaired patients, particularly those with Alzheimer disease, are often physically healthy and able to wander away quickly, becoming lost and endangering their safety. As a result, they require constant supervision.

Some mentally impaired wanderers believe they are going to a specific place or accomplishing a specific job, while others seem to wander aimlessly, drawn from one stimulus to another (105). This behavior often increases when the individual becomes agitated, and one study has suggested that wanderers may be individuals who had a life-long pattern of responding to stress with activity, such as walking or pacing (70).

Methods for preventing wandering have included the use of drugs, which often have side effects that worsen the individual's physical and mental condition, "protective devices" that involve tying the patient to a chair, and locked doors that prevent the individual from leaving a certain area. In a long-term care institution, the availability of a locked nursing unit allows the wanderer to move around freely within the unit; the locked unit is, however, very restrictive for other residents who are not confused (28). For the informal caregiver, living in a totally locked space with a mentally impaired individual can be extremely stressful.

Technologies for wanderers include devices, programs, and environmental design to allow some freedom of movement while maintaining the caregiver's sense of certainty about where the individual is. Some long-term care facilities have installed electronic monitoring systems that activate an alarm at the nurses station when a patient wearing the signaling device goes through a monitored doorway. These devices cost up to \$1,000 per monitored door. Other facilities have installed special door knobs and locks that can easily be opened by mentally normal patients, staff, and visitors, but not by mentally impaired patients. Programs for wanderers include frequent structured and unstructured opportunities for physical exercise, such as exercise groups and walks with staff or visitors. Environmental design technologies include living areas and outdoor spaces structured with pathways that allow the individual to wander within an overall enclosed space.

SUPPORT GROUPS FOR CAREGIVERS

Support groups for informal caregivers have been formed in many communities. Most of these groups are designed primarily to provide emotional support by encouraging caregivers to discuss the complicated feelings and difficult decisions involved in caring for impaired elderly individuals. In addition, support groups allow for sharing information about mental and physical impairments, available resources, and techniques of caregiving (37). Although there has been very little emphasis on technologies for informal caregivers, these groups could provide an opportunity for exchanging information about available devices. By providing emotional support and information for informal caregivers, support groups can help to decrease stress and may increase the willingness and capability of families to maintain impaired individuals at home.

PROGRAMS FOR PHYSICALLY AND MENTALLY IMPAIRED INDIVIDUALS

Effective systems of caregiving include not only devices and procedures for physical care but also a program of social and recreational activities. While these activities provide diversion and entertainment, they can also increase the patient's involvement with others and with his environment. Activities designed to foster a sense of usefulness, involvement, and responsibility can help to overcome feelings of helplessness that are common among long-term care patients. Examples of these activities include:

- resident councils and other self-government activities;
- formal and informal opportunities for individuals to assist other patients, such as the Retired Senior Volunteer Program (RSVP) that has been set up in some nursing homes to recognize and support volunteer efforts of patients for other patients;
- group projects to benefit the nursing home or a community agency, such as the "Rock and Roll Jamborees" held in some nursing homes to benefit the Heart Association;
- opportunities to care for plants or gardens; and
- pet visitation programs.



Photo credit: Gretchen Kolsrud

In Montgomery County, MD, 4-H clubs have trained parakeets to be given as pets to nursing home residents.

By supporting the patient's sense of active involvement and competence, these activities can increase self-esteem and counter feelings of helplessness and dependency that undermine motivation for independent functioning and self-care.

Long-term care delivery systems

Methods of providing long-term care services for the elderly include organizations and funding mechanisms for developing and coordinating resources and matching the needs of the individual with appropriate services and facilities, such as nursing homes, board and care facilities, home care, adult day care, hospice, and congregate housing. Some or all of these services are available in most communities, but the complexity and fragmentation of long-term care services at the community level make it difficult to connect elderly individuals with the services they need.

Decisions about long-term care are often extremely traumatic for the elderly and their families. These decisions are frequently put off until a crisis point is reached because of the intense

emotional issues that are involved. The elderly fear loss of independence and the possibility that they will have to move from a familiar home environment. Families may experience a combination of sadness about the elderly individual and guilt that they are unable or unwilling to provide the care that is needed. Within this complex emotional environment the fragmentation of the service delivery system at the community level compounds the trauma to the elderly individual and the family.

This section discusses the existing service delivery system, and alternative methods for linking the individual with appropriate long-term care services.

THE PATCHWORK OF SERVICES

In most communities long-term care services are provided by a variety of public and private agencies with differing eligibility requirements, services, and funding mechanisms, resulting in what one author has called a "patchwork array of services" (24). The services are generally not coordinated. overlapping services and gaps in available services are common, and there is often no single source of information about what services are available. As a result, it is difficult for patients, their families, physicians, and other health care and social service providers to locate appropriate services. When impaired elderly individuals need several long-term care services from different agencies, coordination can be very difficult (3,132).

The fragmentation of agencies and services at the community level is partly a result of the way these services have developed over time. New agencies have been created in response to specific needs, and there is often no comprehensive plan for how the new services will mesh with existing services in the community.

Another and perhaps more important cause for the fragmentation is the complexity and lack of coordination of regulations controlling government programs that fund these services. As stated earlier, government funding programs have a substantial impact on the kinds of services that are available at the community level. Although some private agencies do not accept any govern-

ment funding, most agencies and long-term care facilities provide at least some government-funded services, and as a result, their services and eligibility requirements usually reflect government regulations. Government regulations about services that are "reimbursable" often define which services are available in the community because agencies tend to develop and provide those services that will be paid for. Similarly, regulations about the qualifications of agencies that are certified for reimbursement through government programs often define the kind of agencies that will be developed.

Unfortunately, the government programs that have such a major impact on long-term care services are themselves uncoordinated. A 1977 GAO report described four Federal programs that provided funding for home care services at that time: Medicare, Medicaid, Title XX of the Social Security Act, and Title III of the older Americans Act. The report concluded that "the various Federal home health programs defy coordination" (115). Since that time, new regulations have tended to increase the complexity of these programs,²³

Other Federal, State, and local programs that affect the availability of long-term care services include Social Security, Supplemental Security Income (SSI), benefits available through the Veterans Administration, and programs developed and funded by State and local health departments and social service departments. Each of these government programs has differing eligibility requirements, benefits, and funding mechanisms, increasing the complexity of the long-term care system at the community level and limiting access to appropriate services by the elderly.

METHODS FOR IMPROVING COORDINATION AND ACCESS TO LONGTERM CARE SERVICES

The fragmentation of the long-term care system has been noted for more than 20 years (21,100), and several methods have been developed to improve coordination and access to services. These include: 1) efforts to coordinate agencies and services at the community level, 2) case

²³State and local regulations also affect eligibility, benefits, and funding for three of these programs; Medicaid, Title III of the Older Americans Act, and the Title XX Block Grant.

management approaches designed to locate and coordinate services for the individual, and 3) efforts to provide a full range of long-term care services within a single agency or program. These methods are reviewed briefly here, and government initiatives to increase the role of individuals in planning their own long-term care are discussed.

Each of these methods can be seen as an attempt to rationalize the system at the community level. While each is effective in some ways, they cannot change the underlying problem, which is the lack of coordination in the major Federal programs that regulate and finance long-term care.

Coordination of Agencies and Services at the Community Level.—Methods to improve coordination at this level can include:

- formal mechanisms for exchanging information between agencies, such as the regular meetings of long-term care providers now held in some communities;
- development of a directory of all long-term care services available in the community;
- development of a centralized information and referral service;
- mutual referrals and cooperation in handling individual clients (case conferencing); and
- joint planning and policymaking to avoid duplication and gaps in available services.

In the past, efforts to coordinate services have been organized by public agencies, such as the health department or the department of social services, or by a private agency or voluntary association founded for this purpose. This remains the pattern in some communities; in others, the Area Agency on Aging (AAA) has become the lead agency for coordination of services. one of the mandated functions of the AAAs, which were established by the older Americans Act, is coordination of community services for the elderly (3); in some communities AAAs have provided funding and organizational support for each of the approaches listed above.

Efforts to coordinate services have been only moderately successful in most communities; inflexible Federal and State regulations, that often cause much of the complexity in the system, have

been a limiting factor. Moreover, community agencies may resist coordination because of a commitment to existing agency structure and policies, C)ne author has pointed out that successful coordination of agencies and services is a time-consuming and expensive process requiring a leader who is “a super-being with optimum political skills, administrative competence, missionary fervor, and familiarity with the entire range of professional interventions and management techniques” (21).

Case Management Program—A second method for coping with the fragmentation of the long-term care system and improving access to appropriate services is case management, a system for “developing and coordinating client care plans and monitoring the treatment process” (125). In the context of the complex array of long-term care services, it is the function of the case manager to assess the needs of the client, develop a plan of care, and arrange services to implement the plan. Many State and local communities have established case management programs, and a 1980 study by Andrus Gerontology Center identified more than 300 such programs. Most of these programs, however, did not coordinate a comprehensive range of services; some coordinated only social services, while others coordinated mainly health care services (125).

Case management was a major component of several long-term care demonstration projects funded by the Federal Government in the 1970s²⁴ These projects were designed to test whether home and community based long-term care services could substitute for nursing home care, and the case manager was responsible for assessing the client’s needs and referring the client to appropriate services. All of the projects also provided new home care services or new funding for services that were already available. Evaluation of the effectiveness of the case management approach in these projects is difficult because changes in client outcome could have resulted

²⁴ of these demonstration projects are ACCESS, in Monroe County, NY; the Alternative Health Services Project in Georgia; the Community Based Care Systems for the Functionally Disabled in Washington State; the Wisconsin Community Care Organization; and Triage, in Connecticut.

from the case management, the new long-term care services, or both. None of the projects included a research design to test the efficacy of case management in reducing fragmentation of long-term care services for the clients (125).

In 1980, the Department of Health and Human Services and the Administration on Aging jointly funded the National Long-Term Care Channeling Demonstration Program specifically to evaluate the effectiveness of case management in reducing fragmentation of services. Ten States are participating in the program to test two models of case management. Five States are using the "basic" channeling model that includes assessment of client needs, care planning, and arrangement of appropriate long-term care services. The "complex" channeling model being tested in five other States includes the basic case management functions plus several additional features: the case manager has authority over the amount and duration of noninstitutional health and social services the client receives, and the cost of services for all clients is capped at a level equal to 60 percent of the cost of nursing home care in the demonstration area. The Channeling Demonstration Program will run from 1982 to 1985, and result are expected to provide definitive answers about the effectiveness of case management in facilitating client access to appropriate long-term care services (79).

The Facilitator and the Gatekeeper.—The functions of the case manager in long-term care demonstration projects (including the channeling program) illustrate two different approaches to service delivery. In some demonstration programs and the "basic" channeling model, the case manager functions primarily as a facilitator, assisting clients to obtain appropriate services. In other demonstration programs and the "complex" channeling model, the case manager also functions as a gatekeeper, controlling and limiting access to services, especially high-cost services such as institutional care. Although there has been little discussion in the literature of the relationship between these two roles, they seem to involve inherent internal inconsistencies for the case manager who must decide whether to arrange for all the services the client needs or to focus on limiting costs. For the individual client who needs certain

long-term care services, the facilitator approach could be expected to result in provision of those services. It is not clear whether the same services would be provided when the gatekeeper approach is used. Comparison of the results of the two models of channeling may help to resolve this question.

The distinction between these two approaches reflects the two primary concerns of government in long-term care: concern with cost control and concern with providing access to appropriate services for the elderly. In the absence of a comprehensive national long-term care policy, the relative emphasis on these concerns can be expected to vary from one government program to another and from one community to another in a manner that is in many instances both confusing and inequitable.

Targeting.—Targeting of long-term care services to the most impaired individuals combines the facilitator functions of assessment and identification of needs and the gatekeeper functions of controlling and limiting access to services. Many analysts of the long-term care system have emphasized the importance of targeting services in order to control costs while providing essential services (80,118). While the concept of targeting represents a merging of the facilitator and gatekeeper functions, its implications require further definition. Decisions about the kind and amount of services that will be provided with government funding are a matter of public policy, and the concept of targeting does not in itself answer the difficult questions about resource allocation or resolve the ambivalence of government about its central concern in long-term care.

Use of Computerized Information Systems.—The complexity of agencies, services, funding mechanisms, and client needs at the community level suggests a possible application for computer-based information systems in long-term care. Computers are now being used in health and social service agencies for applications such as recordkeeping and program analysis, and some service providers have begun to use computerized information systems to aid in matching individual needs and available long-term care services (72). OTA has not assessed the efficacy of this ap-

preach, but it appears to provide an improved information base for long-term care decisionmaking. Concerns about the impact of this approach on client autonomy and confidentiality of client information should be resolved prior to implementation of these systems.

Provision of a Comprehensive Range of Long-Term Care Services Through a Single Agency or Program.—A third method for increasing the coordination of long-term care services and facilitating client access to services is provision of a comprehensive range of long-term care services by a single agency or program. The Veterans Administration is the largest and best known example of this approach. Other examples are social/health maintenance organizations and agencies offering life care contracts. Recently hospitals have become more involved in the provision of long-term care services. Each of these agency types is discussed briefly with emphasis on its effectiveness in overcoming the fragmentation of long-term care services.

The Veterans Administration (OTA).—The VA provides an extensive system of long-term care services including nursing home care, board and care, and home care. Adult day care, hospice, and respite care are also available in some areas (80). Institutional services are provided in VA Medical Centers and domiciliary care facilities, while home care services provided by the VA are most often available in areas near the VA Medical Centers (79).²⁵ Eligibility for VA services depends on a complex system of entitlements focused first on the presence of service-connected disability and secondly on measures of need and ability to pay (97). Although there has been little emphasis on targeting mechanisms, increased targeting of services is an option being considered in response to the increasing number of veterans eligible for VA services. The VA employs a large number of social

workers who are responsible for patient assessment and coordination of services within the VA system and for contracted services in the community (80).

Although analysis of VA long-term care services is beyond the scope of this report, two points are relevant to the functioning of the VA as a delivery system. First, the cost of VA long-term care services such as nursing home and home care programs is higher than similar services provided by other government or private agencies (97). It is unclear whether these higher costs are related to the level of care needed by VA patients, the quality of care provided by the VA, or possible inefficiencies in the VA system of delivering services. Second, many elderly individuals who are eligible for long-term care through the VA choose instead to use non-VA services, relying on Medicare, private insurance, and personal funds to pay for these services (97). The reasons for this choice are not known, but some possibilities are: 1) lack of VA facilities near the individual's home and reluctance of the individual to leave his community; 2) the belief of some individuals that VA services are inferior to similar services provided by the private sector; and 3) a perception of the VA as a large, impersonal bureaucracy in which the preferences of the individual might be disregarded. Further analysis of these issues is needed to clarify the advantages and disadvantages of service delivery in the VA model.

Social/Health Maintenance Organizations (S/HMOs).—S/HMOs are agencies that provide a comprehensive range of long-term care services using management and reimbursement principles developed by HMOs (health maintenance organizations) to deal with the fragmentation of services in the community and avoid unnecessary hospitalization and nursing home care. Cost control is a major focus of the S/HMO. Clients pay a predetermined monthly rate and are thereby eligible for services they need including acute medical care, nursing home care, adult day care, home health care, housekeeping, and chore services.

On Lok is a San Francisco agency that has been using HMO principles to provide a comprehensive range of long-term care services in the Chintown-North Beach area since 1979 (101). On Lok's own research indicates that their clients used less

²⁵The VA also contracts with private nursing homes and community home care agencies to provide services when VA facilities are full or when there are no VA facilities in a given geographical area. These contracted services are not relevant to this discussion of services actually provided by a single agency, but it is interesting to note that when the VA contracts with community agencies for services it cannot provide, it experiences many of the same problems in coordination of services that have been described in the beginning of this section. At present, there is ongoing discussion and debate within the VA about how the VA can best coordinate its services with non-VA services in the community.

hospital care and less nursing home care than a comparison group and that measures of physical health and functional status indicated more improvement in the On Lok group than the comparison group (74). The On Lok cost per client per day in 1981 was \$37.68, which includes all medical and social services but not the cost of housing, food, or other living expenses. Although accurate comparison is difficult, the Medicaid rate for skilled nursing home care in California at that time was \$36.88 per day, which does not include costs of hospitalization, physician's services, or physical therapy. If the cost of these services is included, On Lok estimates that the true cost of care for patients in skilled nursing facilities would be comparable to On Lok's cost plus the housing and living expenses of On Lok clients (101).

While there is some question about the validity of the results of the On Lok research because of the comparison group used, there is considerable interest in the S/HMO approach. At present, several S/HMO sites are being developed by Brandeis University as part of a 3-year demonstration project funded by the Health Care Financing Administration. Evaluation of the results of this project is expected to provide information about the efficacy of the S/HMO approach for delivering services and improving client access to appropriate care (118).

Some researchers believe that the S/HMOs will reduce the cost of long-term care by substituting home health and nonmedical home care services for hospital and nursing home care (30). The Federal Office of Management and Budget (OMB) disagrees and expects that S/HMOs will raise the cost of long-term care and create a precedent for providing nonmedical services that are not currently covered by Medicare and Medicaid (89).

Life Care Communities—Life care communities are long-term care systems that provide a continuum of services for elderly residents, including homes or apartments for independent living, home care services, and infirmary or—in many instances—nursing home care. Hospital care is usually not provided, but individuals are guaranteed that they can return to the life care community following hospitalization.

There are about 275 life care communities in this country, providing housing and care for about 90,000 elderly people (6). Most life care communities are privately owned, and many are run by religious organizations. Elderly individuals are usually admitted while they are still able to function independently. Payment of the initial membership fee and a monthly fee guarantees the individual long-term care for the rest of his life. Because the membership fee and monthly fees are often very high, this type of long-term care has been used primarily by relatively wealthy individuals, but religiously based and nonprofit life care communities do admit some low and moderate income individuals. Sometimes Medicare or Medicaid reimbursement is available for home care or nursing home services provided in these communities.

Life care communities allow the elderly individual to select a system of long-term care before he needs any services, thus increasing his sense of control over his future. In addition, the availability of a range of services within the same community eliminates the need to move to a completely new environment when services are needed, thereby avoiding the trauma that is often associated with moves.

Despite these positive indications, reported financial and management problems of some life care communities have dampened enthusiasm for this long-term care option (59). Poor financial planning, often related to lack of accurate statistics about life expectancy for residents, has led to several bankruptcies (92), and a recent report has pointed out the need for improved actuarial planning (141). About one-third of States have laws governing life care communities, and other States are considering legislation (78). Legislation to protect the financial investment of residents and at the same time encourage the development of life care communities could make this option available to more elderly individuals.

Many of the Nation's largest nursing home chains have begun to diversify into housing and home care services for the elderly. In testimony before the Senate Subcommittee on Aging, July 14, 1983, Arnold Richman, chairman of Merid-

ian Health Care, described his company's recent involvement in the provision of home care services including skilled nursing care, homemaker and chore services, and respite care. The company has developed housing for the elderly and is considering development of a retirement community with rental apartments for the elderly and a nursing center that would provide board and care services and skilled nursing care. Mr. Richman stated:

While it is difficult for a proprietary provider of services to be a direct provider of life care services, we believe there is a significant untapped need for the rental concept which does not have associated with it the large entry or endowment fees typically associated with life care (90).

Evaluation of the potential role of profit-making organizations in the development of life care communities to serve low and moderate income elderly is needed. Such an evaluation should focus on the cost of care and the effectiveness of this approach in reducing the fragmentation of long-term care services.

Hospital-Based Service Delivery Systems.—With the advent of government-initiated cost control programs, particularly the Medicare cost-based reimbursement system (DRGs), hospitals have become more involved in developing and coordinating long-term care services. The cost control systems limit reimbursement to the hospital when the patient no longer needs acute care, but most hospitals are reluctant to discharge patients without appropriate plans for continuing care. In order to provide discharge options for their patients, some hospitals are developing or acquiring nursing homes, home care agencies, adult day care centers, and community outreach services, while others are establishing formal transfer agreements between the hospital and these long-term care agencies.

Advantages of hospital-based service delivery systems are: 1) the prominence of hospitals in the community which makes them a well-known center for service delivery, and 2) the availability of physicians in the hospital to provide and supervise long-term care. Lack of physician involvement in nursing homes and home care agencies has been a major concern for many years, and

affiliation of long-term care agencies with hospitals offers the possibility of alleviating this problem (22). Provision of long-term care services within the hospital system could also allow easier transitions for patients between acute and long-term care settings.

In many communities, empty hospital beds are driving up the cost of hospital care. Affiliation with long-term care agencies provides a guaranteed source of patients for some of these hospitals. Other hospitals are using empty beds to provide long-term care in the hospital. This approach could lessen the need to build new nursing homes and decrease costs associated with empty hospital beds. In some rural areas, Medicare reimbursement is now allowed for these "swing beds" that can be used for acute or long-term care services depending on current need (22).²⁷

One disadvantage of hospital-based service delivery systems is that the hospital is a medical care facility, and hospital coordination of service delivery can result in overemphasis on medical care and lack of social or nonmedical services. The fact that reimbursement is more often available for medical care than for social services is an additional incentive for hospitals to provide primarily medical services. This tendency to medicalize the long-term care system is a problem because of the relatively high cost of medical care compared to social or nonmedical services and because in some instances nonmedical services are more appropriate for the patient. Further analysis of the impact of hospital-based service delivery systems on the kinds of services provided and the cost of care will be needed as this method of coordinating long-term care services is more widely used.

Government Initiatives To Increase the Role of Individuals in Developing Their Own Long-Term Care Plans.—This option has thus far received very little attention for several reasons. First, long-term care is frequently seen as medical care, and planning is seen to require medical expertise. Sec-

²⁷Medicare and Medicaid regulations and some State and local regulations prohibit hospital provision of long-term care services and acquisition of long-term care facilities to avoid restraint on competition between local agencies.

end, individuals who need long-term care services are often treated as if they were so mentally and physically disabled that they cannot make long-term care plans for themselves. Third, there is a sense of crisis that surrounds long-term care decisionmaking and interferes with the deliberate consideration of individual preferences and alternatives for care. Finally, the complexity and fragmentation of long-term care services make it difficult for individuals to understand what alternatives are available.

In fact, information reviewed in this chapter indicates that functional impairments rather than medical conditions are most apt to cause a need for long-term care services and that increasing proportions of individuals in each older age group need assistance with personal care and house-keeping services. To the extent that functional impairments and the resulting need for long-term care services can be anticipated by the elderly, it is possible that some individuals could plan for these services.

Government initiatives to encourage and assist individuals to plan for their own long-term care

could focus on public information programs to increase awareness of:

- functional impairments and their impact on the need for long-term care services,
- the potential for rehabilitation of the elderly and the role of assistive devices in maintaining and increasing independent functioning,
- the kinds of long-term care services that are available, and
- the importance of housing and living arrangements in postponing the need for more formal long-term care services.

Clearly the development of a more rational and coordinated system of long-term care services would also help individuals to plan long-term care for themselves.

One of the greatest fears of the elderly is becoming frail and dependent on others, Government initiatives to encourage elderly individuals to plan for themselves may help to alleviate this fear and assure them continuing control of their lives.

Findings

The need for long-term care is expected to increase dramatically in the future as a result of several factors:

- growth in the number of elderly individuals, particularly the very old who frequently need long-term care services,
- decreasing age-specific mortality that results in larger numbers of elderly individuals living longer with chronic diseases and functional impairments, and
- changes in medical practice and reimbursement-mechanisms that result in limiting inpatient care and the length of hospital stays and promoting delivery of health care services in the home and the community.

Increasing need for long-term care will place strain on families, existing agencies, and service delivery systems. Public and private expenditures for formal long-term care services which have

grown rapidly in the past 20 years, will continue to rise.

Technology has not been widely used in long-term care. Identification of technologies that are appropriate for this population requires a needs assessment, but this assessment is complicated because government programs that regulate and fund more than half of long-term care services in this country tend to define the kind of needs that are recognized, emphasizing medical and skilled nursing care and obscuring the need for other forms of care. Survey data collected from agencies serving Medicare and Medicaid patients reflect this influence.

In contrast to this emphasis on medical and skilled nursing care, research indicates that long-term care services are most often needed as a result of functional impairment; that is, limitations in the individual's ability to function independ-

ently. Medical treatment can cure some of the conditions that cause functional impairment, but other conditions are not curable at present. Bio-medical research has been focused primarily on conditions that cause death, but conditions that cause functional impairment are not necessarily the same as those that cause death. Research on conditions that cause functional impairment could result in effective treatments and decreased need for long-term care.

In the absence of effective medical treatments, alternative approaches to maintaining independent functioning are needed, such as assessment technologies to identify functional impairment and assistive devices and rehabilitation techniques to compensate for functional impairment. Use of these technologies has been limited because of the focus on medical and skilled nursing care, and because physicians and other long-term care providers lack training in their use. Reimbursement for the use of assessment technologies is limited, and there is disagreement about the reliability and validity of existing assessment measures. Factors restricting the use of assistive devices include lack of information about available devices, the difficulty of selecting appropriate devices for individuals with multiple impairments, and negative attitudes of elderly individuals, their families, and many health care professionals about the rehabilitation potential of the elderly.

Some elderly individuals have mental conditions that cause functional impairment and a need for long-term care. While it is known that about half of residents of nursing homes and board and care facilities have mental conditions that cause confusion, it is not known how many of these individuals are functionally impaired as a result of confusion, how many are functionally impaired as a result of other chronic conditions, and how many have both physical and mental conditions causing impairment. The development of devices and care techniques for confused patients has received little attention although families and formal long-term care providers often have great difficulty caring for these individuals.

Because of the emphasis on medical and nursing care in the Federal programs that regulate and fund long-term care services, alternative care systems such as board and care facilities and per-

sonal care and supportive services in the home are often not available. Physically and mentally impaired patients who need 24-hour supervision and personal care services but not skilled nursing care are often admitted to nursing homes although they might be cared for in less restrictive and less costly board and care facilities. Similarly, individuals who need personal care and supportive services at home may not receive the care they need or may receive health care services they do not need because of Medicare and Medicaid funding regulations. Negative attitudes about the concept of custodial care and fears about the cost of providing nonmedical long-term care services for the functionally impaired elderly also limit the availability of these services.

Most long-term care services are labor-intensive, and formal and informal providers receive little training in the use of devices and techniques to facilitate caregiving. Increased development and use of these technologies could lessen the burden of caregiving, allowing some families to keep elderly relatives at home longer and decreasing staff turnover in long-term care facilities.

Few medical care technologies have been used in long-term care facilities or in the home. Recently, as a result of the implementation of the Medicare prospective reimbursement system and increased emphasis on the provision of health care services at home, medical care technologies that have been available only in hospitals are being used more often in the home. This trend is expected to grow, and demand for sophisticated medical and nursing care technologies in nursing homes is also expected to grow. The increased use of these technologies outside the hospital is dependent on the availability of funding and skilled health care personnel trained to use these technologies and to teach the patient and the family to use them.

Long-term care services are provided by nursing homes, board and care facilities, and home care agencies. In some communities, adult day care facilities, hospice programs, and congregate housing facilities also provide services. Little information is available about differences between agencies in the services they provide and the kinds of individuals they serve, and it often appears that most agencies provide a wide range

of services to a variety of patients with very different needs. Increasing the use of technology in these agencies would be difficult and expensive because so many different technologies would be required to meet the varied needs of patients served by each agency.

An alternative is to classify patients according to need and to provide a unique set of technologies and care systems in each agency. The feasibility of this alternative depends on whether patients can be realistically grouped according to need and whether available assessment technologies can accurately classify patients in this way. When patient needs change frequently, the negative effect of moving can outweigh the positive effect of appropriate technologies in the new setting. These issues require further evaluation.

Lack of coordination among the Federal programs that regulate and fund long-term care services contributes to the fragmentation of services at the community level, making it difficult for the elderly, their families, and health care professionals to arrange appropriate services and increasing the sense of crisis that surrounds long-term care decisionmaking. Efforts to improve service delivery have included techniques for coordinating agency services at the community level, case management systems, and organizational approaches that provide a range of services through a single local agency. Development of a more coordinated system of services could enhance the ability of some elderly individuals to plan effectively for their own long-term care.

Research priorities

Research priorities related to the development, utilization, and evaluation of technologies to meet the needs of the long-term care population include:

- identification of the primary causes of functional impairment and biomedical research to find cures or treatments that alleviate the functional impairment;
- development of assistive devices and rehabilitation techniques for elderly individuals, particularly those with multiple impairments;
- evaluation of the relationship between mental confusion and functional impairment and the impact of mental confusion on the need for long-term care;
- identification of assistive devices and rehabilitation techniques that are effective with confused individuals;
- assessment of devices and techniques to facilitate caregiving;
- evaluation of the reliability and validity of available assessment measures in classifying patients according to service and technology needs; and
- comparison of the cost and quality of care effects of providing a variety of technologies in each long-term care agency v. moving patients to settings that provide a unique set of services and technologies to meet specific needs.

Issues and options

Use of assessment measures

Issue 1: Should Congress encourage the use of comprehensive assessment technologies?

Options:

- 1.1: Congress could maintain current levels of support for the use of comprehensive assessment measures in demonstration projects.*
- 1.2: Congress could increase funding for evaluation and consensus development on effective assessment measures.*
- 1.3: Congress could increase funding for training health care professionals and other long-term care providers in the use of comprehensive assessment technologies.*
- 1.4: Congress could mandate reimbursement through Medicare and Medicaid for physicians and other long-term care providers for comprehensive assessment.*
- 1.5: Congress could mandate reimbursement for comprehensive assessment provided in Geriatric Assessment Centers.*
- 1.6: Congress could make eligibility for publicly funded long-term care services dependent on the results of a comprehensive functional assessment measure.*

Comprehensive evaluation of the physical, mental, and social functioning of the impaired elderly individual is important for identifying medical care needs, functional impairments, and appropriate technologies and long-term services. Federal initiatives to provide training and reimbursement for health care professionals and other long-term care providers in the use of available assessment measures can be expected to increase utilization. Mandated use of comprehensive assessment measures to determine eligibility for federally funded long-term care services would have a much greater effect, ultimately leading to increased awareness of the multiple factors involved in the need for long-term care and the variety of technologies and services that are appropriate for this population.

Functional impairment

Issue 2: Should Congress mandate funding for long-term care services based on functional impairment?

Options:

- 2.1: Congress could maintain current emphasis on eligibility for services based on need for medical and skilled nursing care.*
- 2.2: Congress could expand existing programs to include eligibility for long-term care services on the basis of functional impairment.*
- 2.3: Congress could create a new program to fund long-term care services for functionally impaired individuals who do not need continuous medical or skilled nursing care.*

Research has demonstrated the importance of functional impairments in causing the need for long-term care services, but, as a result of the emphasis in Federal funding programs on medical and skilled nursing care, some elderly individuals with functional impairments are not eligible for the services they need. Providing reimbursement for services based on functional impairment would increase the number of eligible individuals and probably increase overall costs. The availability of funding for nonmedical services could, however, encourage the development of alternative care systems such as board and care facilities and personal care and supportive services in the home that are significantly less costly than medical and skilled nursing care. These alternative care systems could emphasize the use of technologies for caregivers and environmental design technologies that limit the impact of functional impairments. Since it is not known how many nursing home residents and home care clients need skilled nursing care and how many need only personal care, supportive services, and supervision, no reliable estimate can be made of the number of individuals who could be cared for with lower cost, alternative services.

Rehabilitation technologies

Issue 3: Should Congress implement policies to increase the use of assistive devices?

Options:

- 3.1: Congress could maintain current levels of support for the use of assistive devices.
- 3.2: Congress could increase funding for assistive devices through existing programs, extending coverage to devices that support independent functioning, but are not currently considered medically necessary, such as glasses, hearing aids, dentures, communication devices, lifeline devices, and devices to alter the home to compensate for functional impairments.
- 3.3: Congress could create a new program to supply assistive devices, modeled after programs currently in effect in Sweden.
- 3.4: Congress could fund a demonstration project to evaluate the efficacy of "Aids Centers" in providing and repairing assistive devices.
- 3.5: Congress Could provide support for improve the matching of individuals and devices, such as:
 - a. The use of assessment technologies to identify needs and appropriate devices.
 - b. Training to increase understanding of the use of assistive devices among long-term care providers, including physicians, nurses, social workers, and staff at senior centers and nutrition sites. This could encompass training about the kinds of devices that are available, the effectiveness of devices in compensating for functional impairment, and appropriate referrals for patients who need devices.
 - c. Training to increase awareness of the special needs of the elderly among professionals already involved in providing assistive devices, such as physical therapists and occupational therapists.
 - d. Increased emphasis on services for the elderly through State rehabilitation agencies. (These agencies receive 80 percent Federal funding through the Rehabilitation Act of 1973.)
- 3.6: Congress could fund a public education program targeted to the elderly and their families on the nature of functional impairments and use of assistive devices in compensating for impairment. Such a program could focus on countering negative attitudes about the use of assistive devices.

Issue 4: Should Congress support initiatives to increase the use of rehabilitation services for the functionally impaired elderly?

Options:

- 4.1: Congress could maintain current levels of support for rehabilitation services for the elderly. (It is expected that rehabilitation services will be provided more extensively because these services are exempt from Medicare DRGs.)
- 4.2: Congress could increase support for rehabilitation services through Medicare by eliminating restrictions on reimbursement for services that maintain functioning and limitations on the frequency of reimbursable services.
- 4.3: Congress could increase support for rehabilitation services through Medicaid by fiscal policies that encourage States to reimburse providers at higher rates.
- 4.4: Congress could mandate the provision of rehabilitation services in nursing homes as a condition for Medicare certification and encourage States to impose the same requirement for certification under Medicaid.
- 4.6: Congress could increase funding for training of rehabilitation professionals and other long-term care providers, including:
 - a. training to counter negative attitudes about the rehabilitation potential of the elderly,
 - b. training in the use of assessment measures to identify the need for rehabilitation services, and
 - c. training in techniques for rehabilitation of the functionally impaired elderly.
- 4.7: Congress could fund a public education program targeted to the elderly and their families on the nature of functional impairment and the potential of rehabilitation services for improving functional capacity and compensating for impairments.

The use of rehabilitation technologies to compensate for functional impairment is limited by negative attitudes of the elderly, their families, and health care providers about the rehabilitation potential of those over 65, lack of training for providers, and limitations on reimbursement for services to maintain functioning and devices to compensate for functional impairment. Federal initiatives to increase training for providers and reimbursement for a wide range of rehabilitation

technologies will increase use, resulting in improved functioning for many elderly individuals and decreased need for long-term care services. Demonstration of the effectiveness of these technologies can be expected to decrease negative attitudes that now restrict use.

service **delivery systems**

Issue 5: Should Congress support initiatives to improve services delivery?

Options:

- 5.1: Congress could maintain current support for coordination of services at the community level including funding for Area Agencies on Aging and Medicaid waivers that allow case management as a reimbursable service.**
- 5.2: Congress could create a federally funded case management system modeled after the Channeling Demonstration Program.**
- 5.3: Congress could provide more flexible funding and other financial incentives to encourage the development and use of a comprehensive range of long-term care services provided by single agencies**

such as hospital and nursing home based service systems, WHMOS, and life care communities.

5.4: Congress could consolidate Federal funding for long-term care services into a single program, combining funding from Medicare, Medicaid, the Title XX Block Grant, Title III of the Older Americans Act, and the VA.

The lack of coordination of Federal programs that fund long-term care is an important cause of fragmentation of services at the community level, but combining these programs into a single Federal long-term care program (option 5.4) would require major changes in legislation, regulations, and agency structures at the Federal, State, and local level. In the absence of these substantial changes, Federal support for systems to coordinate services at the community level can help to decrease fragmentation and improve access to appropriate services. Such systems include local provider groups, information and referral systems, case management, hospital or nursing home based service systems, S/HMOs, and life care communities.

Technical memorandum: Federal programs funding long-term care services

Medicare

Medicare, authorized by Title XVIII of the Social Security Act, pays for acute care services (hospitalization and physician's services, etc.) and some long-term care services for elderly and disabled beneficiaries. Almost all elderly persons are covered by Medicare.

NursingHome: Medicare pays for up to 100 days of skilled nursing care within each benefit period with substantial copayments after the first 20 days. (A benefit period begins the day an individual is admitted to a hospital or nursing home and ends when he or she has been out of the hospital or nursing home for 60 consecutive days [25]). Custodial care is not covered. In 1980, Medicare paid \$337 million for skilled nursing care for elderly individuals. This represented less than 1 percent of total Medicare expenditures and about 2 percent of all spending for nursing home care (126).

Board and Care Facilities: Not covered.

Home Care: Medicare funds skilled nursing care, physical therapy, speech therapy, occupational therapy, medical social services, and home health aide visits with the authorization of a physician.²⁷ Under Medicare regulations home health aides can provide personal care but can only perform homemaker services such as cleaning and changing beds when these services can be shown to prevent or postpone institutionalization. No chore services are provided. In 1978, a majority of the home care visits funded by Medicare were skilled nursing visits (55.7 percent), while 30.7

²⁷All home care services funded by Medicare must be authorized by a physician, and the physician is supposed to determine the extent and nature of all services provided. Nevertheless, a recent GAO study found that home care agencies were generally planning the services and most physicians were not aware of the services they had authorized. In fact, 50 percent of the physicians interviewed were not seeing the patients for whom they had authorized home care services, and very few physicians were aware of the cost of these services (1 16).

percent were home health aide visits, and 10 percent were physical therapy visits (116). Medicare regulations specify that home care services can be covered only when the recipient is homebound; it has been very difficult, however, to define homebound, and services have been funded for some elderly individuals who are able to leave home (116).

Medicare outlays for home care services increased from \$287 million in fiscal year 1976 to \$964 million in fiscal year 1981 (116), and the number of Medicare home care visits has doubled in the past 10 years; nevertheless, funding for home care services accounts for only about 2 percent of Medicare expenditures (118). There is no patient deductible for home care services under Medicare, so these services are free to the patient (116).

Adult Day Care: Medicare pays for skilled nursing, physical therapy, and occupational therapy provided in the adult day care setting, but does not cover adult day care as such.

Hospice: As of October 1, 1983, Medicare funds hospice care for terminally ill beneficiaries with a life expectancy of 6 months or less. Reimbursement has been limited to \$46.25 per day per patient, but legislation to raise this amount was approved on November 9, 1984 (P.L. 98-617).

Respite Care: Medicare home health care services may be used by some families for respite care (116).

Congregate Housing: Not covered.

Medicaid

Medicaid is a Federal-State program authorized by Title XIX of the Social Security Act. It pays for acute and long-term care services for low-income individuals, including the elderly. Because regulations governing Medicaid programs are determined by each State, within the Federal guidelines, there are significant variations between States in eligibility requirements and available services. States can limit services to individuals with incomes below a set level or they can provide services for the "medically needy," i.e., individuals whose income is below the set level only after their medical expenses have been deducted.

Nursing Home: The Federal Medicaid program defines two types of covered nursing home care: skilled care, provided in a skilled nursing facility (SNF), includes services that are needed on a daily basis, must be provided in an institution, and require the skills of professional or technical personnel; intermediate care, provided in an intermediate care facility (ICF), is health-related care for individuals who require services that are above the level of room and board and must be provided in an institution. In the SNF, a pro-

fessional nurse must be on duty 24 hours a day. In an ICF, a professional nurse must be on duty only during the day shift (25).

Although Federal regulations are quite specific, States vary greatly in their use of these two levels of care. Some States, like California and Connecticut, consider almost all the care they provide skilled care, while others, like Iowa and Oklahoma, provide almost all intermediate care. Since it is unlikely that the types of care needed by nursing home residents varies greatly between States, variation in the use of the SNF and ICF categories probably results from differences in State policies that implement the Federal Medicaid regulations (25).

In fiscal year 1980, Medicaid paid \$7.9 billion for nursing home care. This represents more than one-third of all Medicaid expenditures and about 45 percent of all spending for nursing home care (119). The Federal Government pays from 50 to 78 percent of State Medicaid costs for services and up to 50 percent of administrative costs. In recent years, Federal payments to the States have been capped at lower levels than previously (e.g., 96 percent of fiscal year 1982 dollars were available in 1983).

Board and Care Facilities: Not covered.

Home Care: Under Federal Medicaid guidelines, States are required to provide skilled nursing care and home health aide services, while other services such as personal care services, physical therapy, speech therapy, and occupational therapy are optional (25). Currently 18 States are covering personal care services including bathing, dressing, feeding, and some housekeeping services if related to a medical need (25). Services must be ordered by a physician, and home health aide services and personal care services must be supervised by a licensed nurse (138).

Medicaid expenditures for home care have been relatively low (1.4 percent of total Medicaid spending in fiscal year 1980) (25), and States vary widely in the extent to which Medicaid is used to fund home care services. In fiscal year 1980 New York accounted for 40 percent of all recipients nationwide, almost half of all Medicaid home care expenditures, and 90 percent of Medicaid expenditures for personal care (25). Medicaid payments for home care services are generally much lower than Medicare payments, and it is likely that the lower Medicaid reimbursement rates discourage providers from serving Medicaid recipients.

Medicaid 2176 Waiver Program: A 1981 amendment to the Social Security Act waived some of the requirements for Medicaid-funded home care services, allowing States to set up demonstration projects to offer home and community-based services not previously paid for by Medicaid. Services provided through the 2176 waiver program could be offered on less than

a statewide basis, so that projects could be set up in certain geographical areas and targeted to specific groups of recipients. Waiver projects must be approved by the Secretary of Health and Human Services, and total spending must be no higher than without the waiver project. Medicaid waiver applications approved by mid-1983 include 26 programs for the elderly, and many of these programs include home care services: 16 programs include homemaker services, 11 include personal care, 7 include home health care, and 5 include chore services (138).

Adult Day Care: Adult day care is an optional Medicaid service, and as of fiscal year 1984, eight States provided Medicaid reimbursement for adult day care. Several States provide adult day care through the 2176 waiver program (25,127).

Hospice: Hospice care is not currently funded by Medicaid, but New York State has requested an administrative decision by the Health Care Financing Administration to make reimbursement available under existing legislation.

Respite Care: Home care services covered by Medicaid are used by some families for respite care.

Congregate Housing: Not covered.

Title XX

Title XX of the Social Security Act was converted to "Title XX Block Grants to States for Social Services" in 1981 (118). Title XX grants are used by States primarily for social services for elderly and nonelderly individuals, and there is considerable variation between States in services provided.

Nursing Home: Not provided.

Board and Care Facilities: Some States provide limited funding for geriatric foster care with title XX funds (25).

Home Care: Home care services provided in some States with title XX funds include homemaker, chore services, and homedelivered meals, but GAO has estimated that in the States they studied, less than 13 percent of title XX funds were spent for these home care services (25). It is difficult to specify what percentage of title XX home care services were used by elderly persons, but one author has estimated that in fiscal year 1980 between \$723 million and \$1.593 billion in title XX funds were spent on long-term care services for the elderly. States vary widely in the use of these funds. For example, it is estimated that California spent about 40 percent of all title XX funds for long-term care (25).

Adult Day Care: Although more than 95 percent of publicly funded adult day care was paid for with title XX funds in fiscal year 1980, and almost all States pro-

vided some adult day care with title XX funds, total title XX expenditures for adult day care were relatively limited. It is estimated that less than 3 percent of all title XX expenditures for long-term care for the elderly were spent on adult day care (25).

Hospice: Not covered.

Respite Care: No information available.

Congregate Housing: Housing subsidies are not provided, but services for residents on congregate housing facilities are provided with Title XX funds in some jurisdictions. Examples include homemaker and transportation services.

Title III

Title III of the Older Americans Act provides funds for a variety of services for the elderly, including homedelivered and congregate meals, transportation, homemaker, and home health aide services. The Administration on Aging allocates title 111 funds to States primarily on the basis of the proportion of the State's population aged 60 and over compared with the proportion of that age group in the national population (25).

Nursing Home: Not covered.

Board and Care Facilities: Not covered.

Home Care: Home care services funded through title 111 include home-delivered meals, shopping and escort services, telephone reassurance, homemaker, home health aide, and residential repair (25). The GAO estimates that \$43 million of title III funds were spent on home care services for the elderly in fiscal year 1980 (118).

Hospice: Not covered.

Respite Care: Home care services provided with title 111 funds are used by some families for respite care. In addition, some localities provide specific respite care services with title III funds. No accurate figures are available on spending for respite care nationally.

Congregate Housing: Housing subsidies are not provided, but services for residents of congregate housing facilities are provided with title 111 funds in some jurisdictions. Examples include congregate meals and recreation services.

Supplemental Security Income (SSI)

SSI is the Federal program enacted in 1972 to provide minimum monthly payments to aged, disabled, and blind individuals who have incomes below the minimum standard. Since SSI is a cash benefit, it can be used by recipients to pay for long-term care services, but low benefit levels limit the kinds of services that can be purchased.

Nursing Home: Not covered. When SS1 recipients are admitted to a nursing home, their SS1 grant is reduced to a maximum of \$25; if they have other income, the SS1 benefit is reduced to zero.

Board and Care Facilities: Many residents of board and care facilities receive SS1 payments and use this income to pay for their care. In addition, States are allowed to supplement the Federal minimum SS1 benefits, and by 1983, 34 States and the District of Columbia provided supplements specifically for persons living in board and care facilities (52,131).

Home Care: Not covered.

Adult Day Care: Not covered.

Hospice: Not covered.

Respite Care: Not covered.

Congregate Housing: Not covered.

Veterans Administration (VA)

The VA provides a wide range of long-term care services for eligible veterans. The complex eligibility criteria for services are not discussed here.

Nursing Home: In fiscal year 1982, about 15,000 veterans were cared for in VA nursing homes with an average daily census of about 8,400 (132a). About 62 percent of these individuals were 65 or over (80). In addition, about 31,500 veterans were paid for in non-

VA community nursing homes with an average daily census of about 9,500 (132a). About 56 percent of these individuals were over 65 (80).

Board and Care Facilities: The VA operates 16 large board and care facilities with an average daily census of about 7,000. In addition, the VA places veterans in smaller board and care homes. In fiscal year 1982, approximately 13,500 veterans were living in about 3,00 supervised board and care homes: approximately 30 percent were over 65 (132a). (State veterans homes also provide domiciliary care and some nursing home care.)

Home Care: The VA provides home care services to homebound veterans through 30 VA medical centers. In fiscal year 1983 it was estimated that medical, nursing, social, and rehabilitation services would be provided for about 5,600 veterans. Veterans who do not live near one of the 30 medical centers do not have access to VA-funded home care services.

Adult Day Care: Recent legislation authorizes VA provision of adult day care through VA facilities or through contracts with non-VA providers.

Hospice: The VA operates one hospice program in Los Angeles (80).

Respite: VA home care services are used by some families for respite care.

Congregate Housing: Not covered.

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