

**Chapter 6**

**Long-Term Care  
Services and Settings:  
An Introduction**

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# Long-Term Care Services and Settings: An Introduction

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The availability, appropriateness, quality, and cost of long-term care services for persons with dementia are major concerns for their families, for health care and social service providers, and for Federal, State, and local government. Many residents of nursing homes and board and care facilities and many recipients of long-term care services at home are persons with dementia. Yet families complain that long-term care services are frequently not available for such persons or, when available, are of poor quality, inappropriate for the needs of the person with dementia, and/or too expensive (122). Many health care and social service providers agree.

Government concerns about long-term care for persons with dementia arise from the complaints and urgent requests for help from families and others who care for them. On the other hand, the current and potential cost of providing appropriate long-term care services for the growing number of persons with dementia in this country is a grave concern. The congressional letters of request for this OTA assessment reflect both concerns.

This and the following six chapters take up these concerns. This chapter presents an overview of existing long-term care services and settings and the Federal Government's current role in long-term care. Chapter 7 discusses the relatively recent but growing phenomenon of long-term care services designed specifically for people with dementia, including special care units in nursing homes and board and care facilities and adult day

care and home care services tailored to their needs. Other chapters consider aspects of long-term care that are most directly affected by Federal legislation and regulations, and thus most likely to be addressed by Congress:

- patient assessment and eligibility for publicly funded services (ch. 8);
- the training of health care and social service providers who treat individuals with dementia (ch. 9);
- quality assurance procedures for nursing homes, board and care facilities, and home care services [ch. 10];
- Medicare and Medicaid coverage of long-term care (ch. 11); and
- overall financing of services for persons with dementia (ch. 12).

Although an increasing number of long-term care facilities and agencies are providing services designed specifically for individuals with dementia, OTA estimates that fewer than 2 percent of such persons are receiving special services. The vast majority who receive any formal long-term care services are cared for by facilities and agencies that provide essentially the same services for everyone. Thus, the description of services and care settings in this chapter reflects what is currently available to most people with dementia. It also provides a basis for understanding why families and health care and social service providers are complaining to Congress and why many of them are so enthusiastic about the development of special services for these patients.

## WHAT SERVICES ARE NEEDED FOR PERSONS WITH DEMENTIA?

services for people with dementia include a wide variety of medical, social, rehabilitative, and legal services (see table 6-1). While some of those listed are not usually considered long-term care

services—for example, physician, legal, and dental services—they are needed intermittently over the prolonged period of illness that characterizes many dementing conditions.

Table 6-1.—Care Services for Persons With Dementia

<i>Physician services:</i> Diagnosis and ongoing medical care, including prescribing medications and treating intercurrent illness.	<i>Telephone reassurance:</i> Regular telephone calls to individuals who are isolated and often homebound.
<i>Patient assessment:</i> Evaluation of the individual's physical, mental, and emotional status, behavior, and social supports.	<i>Personal emergency response systems:</i> Telephone-based systems to alert others that an individual who is alone is experiencing an emergency and needs assistance.
<i>Skilled nursing:</i> Medically oriented care provided by a licensed nurse, including monitoring acute and unstable medical conditions; assessing care needs; supervising medications, tube and intravenous feeding, and personal care services; and treating bed sores and other conditions.	<i>Transportation:</i> Transporting people to medical appointments, community facilities, and elsewhere.
<i>Physical therapy:</i> Rehabilitative treatment provided by a physical therapist.	<i>Recreation/ services:</i> Physical exercise, art and music therapy, parties, celebrations, and other social and recreational activities.
<i>Occupational therapy:</i> Treatment to improve functional abilities; provided by an occupational therapist.	<i>Mental health services:</i> Psychosocial assessment and individual and group counseling to address psychological and emotional problems of patients and families.
<i>Speech therapy:</i> Treatment to improve or restore speech; provided by a speech therapist.	<i>Adult day care:</i> A program of medical and social services, including socialization, activities, and supervision, provided in an outpatient setting.
<i>Personal care:</i> Assistance with basic self-care activities such as bathing, dressing, getting out of bed, eating, and using the bathroom.	<i>Respite care:</i> Short-term, in- or out-patient services intended to provide temporary relief for the primary caregiver.
<i>Home health aide services:</i> Assistance with health-related tasks, such as medications, exercises, and personal care.	<i>Dental services:</i> Care of the teeth, and diagnosis and treatment of dental problems.
<i>Homemaker services:</i> Household services, such as cooking, cleaning, laundry, and shopping, and escort service to accompany patients to medical appointments and elsewhere.	<i>Legal services:</i> Assistance with legal matters, such as advance directives, guardianship, power of attorney, and transfer of assets.
<i>Chore services:</i> Household repairs, yard work, and errands.	<i>Protective services:</i> Social and law enforcement services to prevent, eliminate, or remedy the effects of physical and emotional abuse or neglect.
<i>Supervision:</i> Monitoring an individual's whereabouts to ensure his or her safety.	<b>Case management:</b> Client assessment, identification and coordination of community resources, and followup monitoring of client adjustment and service provision.
<i>Paid companion/sitter:</i> An individual who comes to the home to provide supervision, personal care, and socialization during the absence of the primary caregiver.	<i>Information and referral:</i> Provision of written or verbal information about community agencies, services, and funding sources.
<i>Congregate meals:</i> Meals provided in a group setting for people who may benefit both from the nutritionally sound meal and from social, educational, and recreational services provided at the setting.	<i>Hospice services:</i> Medical, nursing, and social services to provide support and alleviate suffering for dying persons and their families.
<i>Home-delivered meals:</i> Meals delivered to the home for individuals who are unable to shop or cook for themselves.	

SOURCE: Office of Technology Assessment, 1987.

Some of the services are defined primarily in terms of who provides them (e.g., physician and dental services, and physical, occupational, and speech therapy). Others are defined by the government programs that pay for them (e.g., skilled nursing and home health aide services paid for by Medicaid and Medicare); by the needs of recipients (e.g., supervision and paid companion); or by their intent (e.g., respite care and hospice services). Because they are defined in different ways, they overlap conceptually. For example, adult day care, respite care, and hospice services each include many of the others, and adult day care can be a form of respite care.

people with dementing illnesses live at home or in nursing homes, in board and care facilities, or, to a lesser extent, in State mental hospitals. Most of the services listed in table 6-1 can be provided

in any of these settings. A few apply only to patients living at home, such as homedelivered meals and home health aide services, but basically the same services (meals and assistance with medications, exercises, and personal care) are also provided to residents of nursing homes, board and care facilities, and State mental hospitals.

The list of the services in table 6-1 represents an ideal that is seldom realized. Many services are not available at all in some localities or are available in insufficient quantity to meet local needs. Moreover, some services are not available in certain settings. For example, mental health services are seldom available in nursing homes, in board and care facilities, or at home.

The ideal for services and settings is sometimes described as a continuum of care, implying that

the services and settings can be ordered to correspond to the increasing disability and care needs of patients. Such ordering may be valid for physically impaired patients. However, current knowledge of the course of dementia-causing diseases and the care needs of persons with dementia at different stages of their illnesses is insufficient at present to serve as a basis for specifying an order for long-term care services and settings. For example, nursing homes are usually placed at one end of the continuum of care—indicating that they are appropriate for severely disabled persons—while adult day care and home care are services closer to the other end—indicating that they are appropriate for less severely disabled individuals. Yet some people in the early or middle stages of dementia may need institutional care, and some families and adult day care centers are managing extremely debilitated dementia patients at home. Therefore, although the goal of providing a full range of services and settings for persons with dementia remains, the criteria for ordering them in a continuum of care are unknown.

Later sections of this chapter discuss the four settings in which persons with dementia live—the home, nursing homes, board and care facilities, and State mental hospitals—and two non-residential settings—adult day care centers and community mental health centers. Each section reviews what is known about the number of such persons in the setting, the services they receive, and the problems they experience in obtaining services.

Hospitals provide acute medical care for dementia patients, and some also provide care for pro-

longed periods for such patients, often because no other care setting is available. However, incentives for shorter length of stay associated with the Medicare Prospective Payment System and other government and private cost containment measures are expected to decrease the use of acute care hospital beds for long-term care. At the same time, in response to these and other changes in health care delivery, a growing number of hospitals are developing home care and adult day care services, and a few are converting acute care beds to chronic or long-term care. In addition, hospitals continue to play a pivotal role in referring patients to other community agencies for long-term care (11). This aspect of their role in long-term care is discussed later in this chapter.

Inpatient hospice units are a potential care setting for persons with dementia. They primarily serve terminally ill cancer patients, however. Persons with dementia are seldom treated, partly because they may be more difficult to manage than other patients; and partly because of fears about malpractice litigation since persons with dementia may not be competent to consent to withholding or withdrawal of treatment (115,116). To increase the use of hospice services for persons with dementia would require adapting hospice methods to the needs of cognitively impaired people and greater knowledge of the physical, emotional, and social aspects of patient functioning in the late stages of dementia. Since inpatient hospice units seldom serve dementia patients at present, they are not discussed in this chapter.

## THE CURRENT ROLE OF THE FEDERAL GOVERNMENT IN LONGTERM CARE

The United States has no national long-term care policy, but the Federal Government is extensively involved in providing, funding, and regulating a wide range of long-term care services. At least 80 Federal programs provide or fund such services, either directly or indirectly. The five programs described in table 6-2 are the major sources of Federal funding for long-term care (88). Their role in funding services for dementia patients is

discussed briefly here and at greater length in chapters 11 and 12.

The programs listed in table 6-2 pay for a substantial proportion of all long-term care in this country. In 1983, Medicaid paid about \$12.4 billion for nursing home care, which represented 43 percent of all public and private spending for such services. Medicare paid \$500 million, or about

**Table 6=2.—Major Federal Programs That Fund Long-Term Care Services****Medicare/Title XVIII of the Social Security Act**

Medicare is the Federal insurance program intended to provide medical care for elderly people. Generally those who are 65 or older are eligible, and about 95 percent of these Americans are enrolled in Medicare. People under 65 who have been receiving social security disability payments for at least 2 years are also eligible. Medicare provides reimbursement for hospital and physician services and limited benefits for skilled nursing home care, home health care, and hospice. By law, Medicare does not cover custodial care.

**Medicaid/Title XIX of the Social Security Act**

Medicaid is the joint Federal/State program intended to provide medical and health-related services for low-income individuals. Medicaid regulations are established by each State within Federal guidelines; eligibility requirements and the long-term care services that are covered vary significantly among the States. In general, however, Medicaid pays for nursing home and home health care for individuals who meet financial and medical eligibility requirements. In some States Medicaid also covers adult day care and in-home services such as personal care and homemaker services.

**Social Services Block Grant/Title XX of the Social Security Act**

The Social Services Block Grant provides Federal funding to States for social services for elderly and disabled people, among others. There are no Federal requirements for specific services that must be provided, but many States use a portion of their Social Services Block Grant funds for board and care, adult day care, home health aide, homemaker, and chore services. States determine the eligibility requirements for these services and may require means tests.

**Title III of the Older Americans Act**

Title III of the Older Americans Act provides Federal funding to States for social services for people over 60. The specific services that are provided are determined by each State and local Area Agencies on Aging, but Title III funds are often used for home health aide, homemaker, and chore services; telephone reassurance; adult day care; respite care; case management; and congregate and home-delivered meals. Means tests are not used to determine eligibility, but Title III services are supposed to be targeted to elderly people with social or economic need.

**Supplemental Security Income (SSI)**

SSI is the Federal income support program that provides monthly payments to aged, disabled, and blind people with incomes below a minimum standard (\$336 for individuals and \$504 for couples in 1966) and assets below \$1,700 for individuals and \$2,550 for couples. States may supplement the Federal benefit for all SSI recipients in the State or for specified groups, such as those living in board and care facilities. Some States also provide SSI supplements for home health care and homemaker services.

SOURCE: U.S. Congress, Office of Technology Assessment, *Technology and Aging in America*, OTA-BA-264 (Washington, DC: U.S. Government Printing Office, June 1985); U.S. Congress, Congressional Research Service, "Financing and Delivery of Long-Term Care Services for the Elderly," Oct. 17, 1985.

2 percent of all spending for nursing home care (88). Both programs require eligible individuals to contribute their own resources to pay for part of the cost of their care. For example, individuals who are covered by Medicaid in a nursing home and who receive a social security check or any other income are required to pay almost all of it to the nursing home.

As a result, the 45 percent of total nursing home spending covered by Medicare and Medicaid actually represented a much larger proportion of all nursing home residents, perhaps as high as 65 to 75 percent nationally (37,114) and 85 to 90 percent in some States (21). This somewhat complicated point is important for understanding the extent of government involvement in nursing home care: that is, although Medicaid and Medicare pay less than half the total cost of nursing home care, anyone who receives any Medicaid or Medicare funding—whether it is \$1 or \$1,000—for nursing home care (i.e., 65 to 90 percent of all residents) is a "Medicaid or Medicare patient" for purposes of regulatory requirements discussed below.

The proportion of home care paid for by the programs listed in table 6-2 is not known, but experts estimate that Medicare and Medicaid pay for one-third to one-half of all home care (18,72). In 1983, Medicare spent about \$1.5 billion for home health care, and Medicaid about \$600 million. Social Services Block Grant funds for in-home services for recipients of all ages amounted to some \$555 million in 1983. Expenditures for in-home services under Title III of the Older Americans Act are not known, but the fiscal year 1985 appropriation for all Title III services (except congregate and home-delivered meals) amounted to \$256 million (88).

Little is known about the total cost of board and care or adult day care or the proportion of those costs that is covered by publicly funded programs. However, about 43 percent of all residents of board and care facilities receive Supplemental Security Income (SSI) (58), and Social Services Block Grant funds are used for board and care in some states. Likewise, Medicaid, Social Services Block

Grant, and Title III funds are used for adult day care in some States (15).

Because government programs pay for such a large portion of long-term care services, government regulations play a significant role in defining and structuring the entire care system. Legislation and program regulations that define which long-term care services are covered determine to a great extent what services are available at all. Thus, for example, Medicare and Medicaid legislation and regulations that restrict coverage to medical and physical care services have resulted in these services becoming predominant over social and mental health services in the long-term care system as a whole. (The impact of Medicare and Medicaid coverage policies on the availability of appropriate services for persons with dementia is discussed in ch. 11.)

Similarly, legislation and regulations that define eligibility requirements determine which individuals receive any publicly funded services. For instance, Medicare legislation and regulations define eligibility in terms of the medical and skilled nursing care needs of the patient; as a result, individuals who need only personal care and supervision are ineligible. Long-term care is costly, especially when services are needed for prolonged periods, as is often the case for someone with dementia. Since relatively few individuals or families have sufficient income or assets to pay privately for services for an extended amount of time, the eligibility requirements for publicly funded services determine to a great extent who receives services, at least for extended periods. Some individuals, however, are given wrong diagnoses or diagnoses that are not directly related to their care needs in order to meet the eligibility requirements. (The impact of Medicare and Medicaid eligibility requirements on access to long-term care for dementia patients is discussed in ch. 11. Alternate methods for determining eligibility are discussed in ch. 8.)

Legislation and program regulations also define which facilities and agencies may provide covered services. Federal regulations determine which nursing homes and home health care agencies are certified to provide Medicare-funded services. Federal, State, and local government regulations de-

termine which facilities and agencies are certified to provide services funded by Medicaid, the Social Services Block Grant, Title 111 of the Older Americans Act, and SSI.

Certification and licensing requirements regulate aspects of each facility's physical plant, *services* that must be provided, and the number and type of health care and social service professionals and others who must be available in each facility. For example, regulations specify overall staff-to-resident ratios for nursing homes that care for Medicare and Medicaid recipients; the number of required physician visits per year; and the minimum level of involvement of dietitians, social workers, physical therapists, occupational therapists, pharmacists, and other professionals. Although some nursing homes have a physical plant, services, and staffing levels that exceed Medicare and Medicaid requirements, many barely meet the minimum requirements (37). (Licensing and certification procedures and the role of government in regulating quality of care in long-term care facilities and agencies are discussed in ch. 10.)

The Federal Government's significant role in funding long-term care is well known. Less well recognized is the extent to which Federal legislation and regulations and State legislation and regulations developed within those Federal guidelines determine what services are available, who receives them, and who provides them. Moreover, since Medicaid pays for such a large proportion of all nursing home care, the program's reimbursement rates also have a significant impact on the prevailing charges for nursing home care (38). In many localities, Medicaid rates function as a floor for nursing home charges.

Even the long-term care services available to individuals who pay privately are determined in large part by Federal and State program regulations and reimbursement rates. This is because these individuals are often treated in facilities and by agencies that also serve Medicare and Medicaid patients and are, therefore, subject to those programs' requirements for physical plant, services, and staffing.

A final component of the Federal Government's role in this area is the Veterans Administration (VA), the largest, single provider of long-term care

services in the country. As of 1983, VA operated 99 nursing homes, with an average daily census of 8,849 residents, and 16 large board and care facilities (called domiciliary care facilities) with an average daily census of 6,852. VA also paid for nursing home care in non-VA facilities for a daily average of 10,212 veterans, for board and care in private homes for a daily average of 11,195 veterans, and for nursing home and board and care in 45 State veterans' homes in 33 States, with a daily average of about 11,000 veterans. Home care services were provided through 30 of the 172 VA Medical Centers for more than 7,000 veterans.

Adult day care was provided at 5 VA Medical Centers and respite care at 12 (111).

The pervasive role of the Federal Government in providing, funding, and regulating long-term care underlines the importance of national legislation and regulations in determining access, quality, and cost of care. Although Federal policies affect the availability of services for anyone in need of long-term care, they particularly affect those who require services for extended periods, including many persons with dementia.

### CONCEPTUAL ISSUES IN LONGTERM CARE OF PERSONS WITH DEMENTIA

Several basic conceptual issues arise repeatedly in discussions about long-term care for persons with dementia and underlie policy-related questions about eligibility, personnel and training, quality assurance, and financing. These issues are summarized below; their policy-related implications are introduced here and discussed at greater length in relevant chapters.

• ***What are or should be the relative roles of families and formal long-term care services in the care of persons with dementia?***

This question (also discussed in ch. 4) is answered in different ways by different people. Some people believe that formal long-term care services completely replace services once provided by the family. Thus they believe that when a family is overcome by the burden of care and gives up, long-term care facilities and agencies should take over. Other people believe that formal long-term care facilities and agencies provide specific services that families cannot provide, such as skilled nursing care, occupational or physical therapy, or, on a simpler level, assisting an elderly caregiver with bathing a patient he or she is unable to lift. Thus, they believe that when such services are provided in the home, they forestall nursing home placement, allow individuals to remain at home longer, save public dollars, and mitigate the burden of care for families, without taking over tasks family members are able to perform.



Photo credit: ADRDA and Peter Carol, Photosynthesis Productions, Inc.

Families and paid caregivers may be equally capable of providing some long-term care services for persons with dementia.

Still others believe that families and formal long-term care facilities and agencies are equally capable of providing needed services and that formal services should be used on an intermittent basis to provide relief for a family. This model of care—the respite care model—appears to be evolving concurrently with the growing recognition of the care needs of persons with dementia and may, in fact, be developing in response to their care needs. Specifically, respite care would be a uniquely appropriate model of care if those with dementia are seen to require supervision and assistance with



activities of daily living (services that many families can provide) more frequently than others receiving long-term care, and to require skilled nursing care, occupational therapy, and physical therapy (services that families ordinarily cannot provide) less frequently.

It is unclear whether one of these models is most appropriate for everyone with dementia or whether the appropriate model depends on patient characteristics, family characteristics, stage of illness, or all three. Obviously, the question of responsibility for the care of persons with dementia involves both providing provision of services and paying for them. Theoretical and practical considerations in deciding who should pay for long-term care for persons with dementia are discussed in chapter 12.

**• How does the concept of respite care relate to the underlying rationale for existing long-term care services?**

Long-term care services funded by Medicare and Medicaid are intended to address medical and health-related needs, while services funded by the Social Services Block Grant and Title III of the Older Americans Act are meant to meet specific social service needs. In contrast, respite care aims to temporarily relieve families of caregiving responsibilities. It can involve any services that fulfill that purpose and often consists primarily of patient supervision during the absence of a family caregiver.

In general, using long-term care services funded by Medicare and Medicaid for respite care is inconsistent with the current intent of the programs, and regulations often restrict such use. (Medicare and Medicaid waiver programs discussed in this chapter and ch. 11 do sometimes allow respite care.) Similarly, the intent and regulations of programs that fund specific social services must be stretched when the need is not necessarily for these services but rather for a temporary caretaker. Thus, the concept of respite care and the underlying rationale for existing long-term care services are mismatched: existing services are intended to address specific needs, while respite care does not imply specific services. Further, the emphasis in existing services is on a patient and his or her needs; respite care, although required be-

cause of an individual's condition, responds primarily to family needs.

These conceptual differences raise questions about the kinds of services that should be included in respite care programs and how they can be defined in legislation and regulations. The difference in focus on the needs of recipients versus those of families raises questions about how to determine eligibility for publicly funded respite care services and whether it should be based on individual needs, family needs, or some combination. (The difficulty of defining and measuring family needs for the purpose of eligibility determination is discussed in ch. 8.)

**• What is the appropriate role of mental health services and settings in the care of people with dementia?**

Primarily for historical reasons, most individuals with dementia receive long-term care services from facilities and agencies that focus on medical and physical care needs. Relatively few are cared for in State mental hospitals or other psychiatric facilities or receive services from outpatient mental health centers. Moreover, mental health professionals, such as psychiatrists, clinical psychologists, psychiatric social workers, and psychiatric nurses, are seldom employed in nursing homes or other facilities and agencies that provide long-term care for those with dementia (9,92). Although experts agree that dementia is an organic condition and not a mental illness per se, the emotional and behavioral problems often associated with it suggest that the expertise of mental health professionals may be particularly relevant to the care of persons with dementia (34,69,70).

In nursing homes and in board and care facilities, residents with dementia and those with chronic mental illnesses, such as schizophrenia, are sometimes considered to have similar care needs. However, the emotional and behavioral problems of nursing home residents are seldom identified or evaluated (123). As a result, it is not clear whether the problems and long-term care needs of these two groups are similar. It is also unclear whether either or both groups could be better cared for in mental health settings. It is interesting to note that in some countries a significant portion of long-term care services for elderly

people is called “psychogeriatric care.” In the United States, although many State mental hospitals have psychogeriatric units and VA maintains some psychogeriatric wards (12 in 1981) (111), the concept of psychogeriatric care is not widely recognized, nor are long-term care services usually provided in this model.

For Federal policy purposes, the question of the role of mental health services and settings in the care of persons with dementia has implications for personnel and quality assurance regulations and requirements for funding for mental health services in nursing homes and board and care facilities. For example, Medicare and Medicaid do not require nursing homes to provide mental health services for residents (9,34). If such services are believed to be important for individuals with dementia, changes in these regulations may be needed. A related issue is whether government should promote long-term care for persons with dementia in mental health facilities.

• ***Can the long-term care needs of persons with dementia who are under 65 be adequately met within the existing system?***

Individuals with dementia usually receive long-term care services in facilities and agencies that primarily serve elderly people. It is unclear whether the long-term care needs of younger people differ significantly from those of older ones and whether the needs of both groups are equally well (or poorly) met in these settings. In addition, eligibility requirements for some long-term care services exclude those who are under 60 or 65, and the process of establishing eligibility for other programs, such as Medicare, is considerably more difficult for those under 65 (see ch. 11). Whether and how long-term care services should be adapted to the needs of younger persons with dementia and whether public funding programs should be restructured to include all everyone with dementia on the same basis is an important policy issue.

• ***What is the role of the Veterans Administration in providing long-term care services for dementia patients, and how are VA services related to non-VA services?***

Although VA provides and funds long-term care services for many veterans, providing services for those with dementia is problematic for two reasons. First, VA services are provided on a priority basis to veterans with service-connected disabilities. Since dementia is seldom service-connected, veterans with dementia are accorded a lower priority than those with a service-connected disability. About 70 percent of those receiving VA services do not have service-connected disabilities (89), but an OTA survey of family caregivers found that 45 percent of persons with dementia who applied for VA long-term care services were refused, most often because of lack of a service-connected disability (122). A second problem is that VA services have traditionally focused on the veteran and not the family. Providing respite care would require a change in this traditional focus (112).

Despite these problems, VA is providing services for many veterans with dementia. In fiscal year 1983, VA hospitals and nursing homes treated 11,200 veterans with a primary diagnosis of a dementing disorder and about 9,000 others who had dementia as a secondary diagnosis. VA has developed several special care units for persons with dementia (112), and the agency is currently surveying all its facilities to determine service availability and gaps for such persons (19).

Over the next 15 years, the number of veterans in older age groups—and therefore at greater risk for dementia—will increase dramatically. In 1980, some 3 million veterans were over 65, but by 2000 that number will increase to 9 million, representing 63 percent of all males over 65 (111). In view of this very large population base, VA could build more facilities, purchase care for veterans in non-VA facilities, restrict eligibility for no-cost services, or limit the services it covers. Legislation passed by Congress in 1986 limits eligibility for veterans with non-service-connected disabilities to those who have incomes of \$15,000 or less for a single veteran, \$18,000 or less for a veteran with one dependent, with \$1,000 added for each additional dependent. Veterans with non-service-connected disabilities and income above these levels may receive VA services if the services are available and if the veteran contributes to the cost of care (106).

Although VA has traditionally limited care for veterans with non-service-connected disabilities, such as dementia, the families of these individuals often expect VA to provide care and sometimes complain to their Representative or Senator when it is denied. Several bills have been introduced in Congress to require VA services for veterans with dementia. For example, HR 1102 would have required VA to allocate 10 percent of its long-term care beds to dementia patients. This bill was not enacted.

As the number of elderly veterans increases, Federal policies that provide long-term care in VA facilities for veterans with dementia would relieve non-VA facilities of the burden of caring for them but would simultaneously increase VA expenditures. Policies that allow the agency to purchase care from non-VA facilities would also increase VA expenditures but eliminate the need to build more VA facilities. Policies that deny VA services and coverage of services in non-VA facilities would shift the burden and cost of caring for veterans with dementia to non-VA facilities and to Medicare and Medicaid. Thus, VA eligibility and funding policies affect the need for non-VA facilities and services and Medicare and Medicaid expenditures for long-term care. Although the problem of integrating VA and non-VA long-term care services has received considerable attention in general (96)105)110)111,120), the relationship of the two in providing services for persons with dementia has received little attention.

**• *What long-term care services can and should be provided for persons with dementia in rural areas?***

Many rural areas lack long-term care facilities, and lengthy travel times may make services such as adult day care impractical. Long distances and insufficiently trained personnel can also interfere with delivery of home care services. In some cases, lack of home care and adult day care may result in early placement of individuals with dementia in long-term facilities far from their homes. In other cases, lack of services intensifies the burden for families who care for them at home. Analysis of long-term care policy options should include consideration of their effect on persons with dementia in rural as well as suburban and urban areas.

**• *How do the long-term care needs of minority group members with dementia differ from those of nonminority group members?***

Little is known about the care of minority group members with dementia. Although epidemiologic research indicates no difference in the prevalence of most dementing conditions among minority groups (see ch. 1), differences in attitudes, beliefs, and other characteristics among such groups may affect the way persons with dementia are regarded by their families and the larger community—for example, whether they are seen as physically ill, mentally ill, or simply old. Ethnic and cultural factors affect patterns of informal caregiving and the use of medical, mental health, and social services. They also determine the most effective methods of informing patients and their families of available services (54). Differences in minority group characteristics affect the validity of assessment procedures used to determine eligibility for services (see ch. 8), and they have important implications for staffing requirements and quality assurance regulations for long-term care facilities and agencies.

Because minority group status is frequently associated with low income, minority group members are more likely than others to depend on publicly funded programs that are means-tested. For example, 22 percent of black elderly and 25 percent of Hispanic elderly received SSI in 1981, compared with only 5 percent of the elderly population in general (57). Thus SSI policies can be expected to have a greater impact on access to long-term care services for minority group members than for the general population. Similarly, a higher proportion of blacks and Hispanics use VA as their sole source of health care (111). Therefore, VA policies may affect long-term care for minority groups disproportionately.

Different minority groups vary greatly on a wide range of characteristics, and no generalizations can be made about how all or even the majority of these groups react to and care for persons with dementia. Examples from minority groups are used throughout this and the following chapters to point out variations in patient care needs, informal caregiving patterns, and formal service utilization that are relevant to the development of public policy. At the same time, OTA recognizes

the considerable differences in attitudes, beliefs, and characteristics within and between minority groups, and no stereotypes are intended.

• ***What is the appropriate balance of institutional and noninstitutional long-term care services for persons with dementia?***

Some publicly funded programs, notably Medicaid and the VA, have encouraged institutional long-term care over home care in general (81,88, 111). Long-term care experts agree, however, that services for all kinds of patients should be provided in the home whenever possible and that program regulations should be changed to promote home care and services such as adult day care for those living at home. This approach is generally accepted for those with dementia, and as a result, families, health care and social service providers, and others are asking for increased services for individuals with dementia who are living at home.

The bias in favor of home care is strong, and nursing homes and other such institutions are often perceived negatively. At the same time, the OTA survey of family caregivers found that 80 percent agree that “a patient with a severe case of Alzheimer’s disease should be living in a nursing home” (122). Similarly, the Massachusetts Governor’s Committee on Alzheimer’s Disease found that “because all patients with Alzheimer’s Disease who survive long enough eventually require total care, the majority end up in institutions” (27). Thus institutional care is seen as unavoidable for many individuals in late stages of dementing illnesses.

For several reasons, institutional care may also be appropriate for some patients in earlier stages of the illnesses:

- Because of decreased cognitive ability and judgment, most individuals with dementia require 24-hour supervision. Those who do not have a family member or other person willing and able to provide that supervision may need institutional care, regardless of their other care needs, because the cost of 24-hour supervision at home is usually prohibitive.
- For family caregivers, behavioral disorders of some persons with dementia maybe emo -



Photo credit: ADRDA and Peter Carrol, PhotoSynthesis Productions, Inc.

Families and health care and social service providers agree that home care is the first choice of persons with dementia.

tionally intolerable. In addition, some family caregivers who are smaller than the patient or who have sensory impairments may be physically at risk from some behavioral disorders. Such disorders may be more likely in the early or middle rather than the late stages of the illnesses.

- Although the home is often said to be the least restrictive setting for long-term care, individuals who wander and whose behavior is socially unacceptable may actually require fewer restrictions in institutional settings that allow such behaviors.
- Some environmental adaptations believed to facilitate improved functioning are feasible in institutional settings and adult day care centers but less so in the home. Social stimulation is also easier to provide in a group setting.
- In situations where the relationship between the patient and caregiver is poor, institutional placement may be necessary to avoid possible neglect or abuse at home.

For these reasons, institutional care may be the most appropriate long-term care option for some individuals with dementia even if they are not in the late stages of the illness, when total nursing care is needed, and even if formal home care services are available. The prevailing negative attitudes about nursing homes and other institutional set-

tings increase the guilt of family members who decide that institutional placement is the best course. Such attitudes also discourage the use of nursing homes for respite care and may discourage some family members from remaining involved with their relative after placement.

**• Do persons with dementia require special long-term care services?**

Perhaps the most important conceptual issue in long-term care for persons with dementia is whether they constitute a definable group with distinct care needs. The related policy issue is whether the Federal Government should create incentives for developing special long-term care services for them. Although most people agree that the long-term care system needs improvement, in general, some argue that the needs of this group are different and that special services and settings are needed. Others believe that everyone who requires long-term care has special care needs, and that making the existing system more responsive to the needs of each individual is a better approach than singling out one group for special care.

These two points of view raise important theoretical questions that have received little attention despite the growing interest in special serv-

ices for persons with dementia. One overriding question is whether the category “dementia patients” is conceptually clear. Who is included? Only those with Alzheimer’s disease or other primary degenerative dementias? What about individuals with multi-infarct dementia or Huntington’s disease, or elderly persons with physical conditions that have dementia as a side effect of the disease or its treatment? If a category can be delineated, what are the long-term care needs of that group? Are their needs sufficiently similar—and sufficiently different from those of other patients—to warrant a separate care system?

The corresponding practical questions are whether persons with dementia can be accurately distinguished from other long-term care patients, which services they need, who can best provide them, and how much they should cost. Thus far, these questions have been answered in different ways by the many different individuals, groups, and agencies that have developed special services for persons with dementia. At the point when Federal, State, or local government begins to provide or fund special services for persons with dementia, these questions require answers that can be translated into eligibility requirements, staffing and quality assurance regulations, and reimbursement guidelines.

## LONGTERM CARE SETTINGS AND SERVICES

The following sections describe six settings that provide long-term care services for persons with dementia and other persons. Each section discusses the nature of those who are served, the quality of care, and access to the services for persons with dementia and their families.

Three distinct systems provide long-term care services:

1. the medical or physical care system, which includes nursing homes and home health care agencies and is funded primarily by Medicare and Medicaid;
2. the aging services system, which includes Area Agencies on Aging and homemaker and home nutrition providers and is funded by Title III, the Social Services Block Grant, and State and local funds; and

3. the mental health system, which includes State mental hospitals and community mental health centers and is funded by Medicaid, a Federal block grant, and State and local funds.

Persons with dementia are seldom differentiated from others who receive services in each of these systems. Thus individuals with dementia who receive services in the medical or physical care system are grouped conceptually with physically impaired elderly people, and increasingly both groups are described in terms of limitations in their self-care abilities or activities of daily living (ADLs). Those with dementia who receive services through the aging services system are grouped with physically impaired elderly people, and both groups are described under the rubric “frail elderly,”

Finally, persons with dementia who receive services through the mental health system are grouped with those who have chronic mental illnesses, and both sets of patients are described as “mentally ill.”

Individuals with dementia are seldom identified as a discrete group in long-term care research, and as a result, there are few studies comparing them with others who receive long-term care in terms of their characteristics, care needs, or experiences with facilities and agencies. Failure to identify them as a discrete group occurs partly because interest in these patients as a group has developed only recently, partly because of conceptual and practical difficulties in defining the group, and partly because aspects of the existing long-term care system, including eligibility, certification, and reimbursement regulations, tend to discourage their identification as a group.

Information in the following sections is largely from research in which the study populations include an unknown number of individuals with dementia. Although the population of elderly State mental hospital patients with a diagnosis of organic brain syndrome clearly includes many persons with dementia, it is more difficult for example to identify such persons in the three categories that have been used in research on board and care facilities: aged, mentally ill, and mentally retarded residents. Thus the accuracy of available information about the number of people with dementia in each setting varies. Moreover, for most settings, no comparisons are available of the characteristics and care needs of persons with and without dementia, or of the services most frequently provided for each group.

The following sections draw on the OTA survey of family caregivers (122) described in more detail in chapter 4. In addition, in the past few years, several State-sponsored committees and task forces have studied services for persons with dementia, and their reports specifically address the needs of these persons. Some of their findings are cited here; in general, they are based on anecdotal reports and should be interpreted as such.

The six long-term care settings described below are:

1. State mental hospitals,

2. nursing homes,
3. board and care facilities,
4. home care,
5. adult day care centers, and
6. community mental health centers.

### ***State Mental Hospitals***

State mental hospitals are usually large psychiatric facilities that provide acute and long-term care for mentally ill people. They are seldom included in reviews of long-term care settings, but until 30 to 40 years ago, they were the formal long-term care setting used most frequently for persons with dementia. Since then, factors largely unrelated to the care needs of such persons have resulted in decreased use of State mental hospitals for institutional care of persons with dementia and increased use of nursing homes and, to a lesser extent, board and care facilities.

During the 1700s and early 1800s, people who could not live independently because of acute or chronic physical or mental impairments and who had no source of informal care lived in locally supported almshouse. It is not known how many individuals with dementia lived in almshouse because the category “dementia patients” was unknown at that time; many of the diseases that cause dementia were not understood, and confusion was seen as a natural concomitant of old age. Some portion of those in almshouse undoubtedly had a dementing disorder, however.

Beginning in the mid-1800s, mentally ill people who would previously have been placed in almshouse were instead cared for in State-supported mental hospitals, called asylums. At first, these facilities admitted only patients with acute mental illnesses. Over the next century, however, and particularly after 1900, State mental hospitals provided care for an increasing number of chronically mentally ill and senile people (29,60). By 1946, some 44 percent of all first admissions to State and county mental hospitals had a diagnosis of organic brain syndrome (not including drug- or alcohol-induced organic brain syndrome) (102), and 30 percent of the residents of State mental hospitals were over 65 (48). Even though the term dementia was not used to describe the ailments of these individuals, it is clear that many and perhaps most of them had dementing illnesses.

In the late 1940s and 1950s, several developments combined to create a new direction in treatment of those with mental illness—the community mental health movement. This movement grew in part from the recognition that large State mental hospitals had become primarily custodial facilities where little treatment was provided, and in part from the development of psychotropic drugs and brief therapy methods that made outpatient care feasible for many patients. The movement, with its primary tenet that mental health services should be provided in the community whenever possible, led to the process of deinstitutionalization. As a result, between 1955 and 1980, the overall population of State mental hospitals decreased by 75 percent (44)(60). Likewise, between 1946 and 1972, the proportion of first admissions to State mental hospitals with a diagnosis of organic brain syndrome dropped from 44 to 10 percent (102).

For elderly people, deinstitutionalization resulted primarily in reduced use of State mental hospitals and increased use of nursing homes and related care facilities. Table 6-3 documents the magnitude of this change,

Increased use of nursing homes was spurred by the enactment of Medicaid in 1965, which for the first time provided public funding for nursing home care on a national basis. With the introduction of Supplemental Security Income (SSI) in 1972, a federally guaranteed minimum income for elderly and disabled people was available for the first time. Moreover, some States provided additional funds for SSI residents in board and care facilities. The availability of SSI and State SSI supplements encouraged the discharge of persons with dementia (and of other State hospital residents) to board and care facilities (48).

**Table 6-3.—Residents of Mental Hospitals and Homes for the Aged Who Were 65 or Older: 1950, 1960, 1970, and 1980**

Type of institution	Rate per 100,000 persons 65 or older			
	1950	1960	1970	1980
Mental hospitals,	1,150	1,074	563	200
Homes for the aged/dependent	1,769	2,342	3,966	4,835

SOURCE Based on P. Lerman, "Deinstitutionalization and Welfare Policies in the Welfare State in America: Trends and Prospects," *American Academy of Political and Social Sciences—1985 Annals* 479: 132-155, 1985.

Historically, changes in the primary locus of institutional care for persons with dementia—from almshouse to State mental hospitals, and from there to nursing homes and board and care facilities—have occurred primarily in response to financial incentives. Placing these persons in State mental hospitals instead of almshouse transferred the cost of their care from local to State government (29). Similarly, placing them in nursing homes and board and care facilities instead of State mental hospitals transferred part of the costs to the Federal Government through Medicaid and SSI (48,60). There is no evidence that these changes occurred in response to the care needs of individuals with dementia, or that their care needs and the effect on them of changes in the locus of care were even considered.

The number of persons with dementia in State mental hospitals is not known. The 1980 census counted 51,000 elderly people in all mental hospitals (48), and some observers suggest that many of them have dementia even though their diagnoses may indicate mental illness (6). The National Association of State Mental Health Commissioners recently appointed a Task Force on Alzheimer's Disease that will develop estimates of the number of persons with dementia in such facilities (49).

Current admission practices in many State mental hospitals discourage admission of persons with dementia who can be managed in other settings (64,68), but clearly some, and perhaps many, are admitted. The Rhode Island Legislative Commission on Dementias Related to Aging described why persons with dementia might be transferred from nursing homes to State mental hospitals:

If . . . the patient becomes aggressive, combative or in some manner endangers himself, other patients, or members of the nursing home staff, and such behavior cannot be controlled adequately through the use of physician-ordered pharmacological or physical restraints, the nursing home facility will then arrange for his transfer to one of the state . . . hospitals. Transfer may also be initiated if the patient wanders continually and cannot be restrained or monitored effectively (68).

In some cases, State mental hospitals are able to adjust medications to bring the behavior of these

persons under control so that they can return to the nursing home.

Persons with dementia who are living in the community are sometimes brought to State mental hospitals because of behavior that is considered dangerous to themselves or others, and some are brought in by the police on an emergency basis when they are picked up wandering in the streets (27). How often such situations occur is not known, however.

Although State mental hospitals have been criticized for providing only custodial care, some persons with dementia receive excellent treatment in these facilities, as the Massachusetts Governor's Committee on Alzheimer's Disease heard:

To my surprise and relief our experience with (the) State Hospital turned out to be a positive one during most of my father's 18-month stay there. He was taken off all medication immediately. The doctors, nurses, and attendants we met there were kind and competent. Within six weeks my father's behavior had adjusted to the point where it was thought that he could function in a nursing home. On the recommendation of the hospital social worker my father was placed in a particular nursing home. She brought him there on a Friday. We decided to give him a few days to adjust to his new surroundings. On Sunday afternoon my mother, brother, and I walked into my father's room to find him tied to a chair, naked, drugged, and in a pool of urine. I called up the social worker at (the hospital) and told her what we had found. She said she would investigate. The next day she found my father in the same condition and returned him to (the) State Hospital where he stayed until he died 18 months later (27).

Although little consideration has been given to providing long-term care for persons with dementia in State mental hospitals, at least one State task force has proposed developing a demonstration special care unit in one facility (68). Such a unit could provide a model of care based on a mental health rather than medical or physical care principles. One problem with this approach is that care in State mental hospitals can cost considerably more than in nursing homes. Since Medicaid funding is available for elderly patients in mental hospitals, the cost of care for Medicaid-eligible elderly people is shared by the Federal and State govern-

ment. Medicaid does not cover those under 65 in mental institutions, and there is variation among States in how these patients are paid for. Generally, however, the cost is borne by State and local government.

### ***Nursing Homes***

Nursing homes are health care facilities that provide 24-hour supervision, skilled nursing services, and personal care. They are now the most frequently used institutional setting for persons with dementia. Care is provided primarily by nurses and by nurse's aides under their supervision. Although both Medicare and Medicaid regulations emphasize the nursing component of nursing home care, many persons with dementia do not need skilled nursing services, and for them the most important components of nursing home care may be 24-hour supervision and personal care.

At present, there are 14,000 to 15,000 nursing homes in the United States, with about 1.5 million beds (37,77). (Both the National Master Facility Inventory (NMFI) and the National Nursing Home Survey include a large number of facilities (about 11,000 in the 1982 NMFI) that do not employ any nurses or provide nursing services. These are discussed in the section on board and care facilities in this chapter.) About 75 percent of nursing homes are for-profit facilities, 20 percent are non-profit, and 5 percent are government-owned (101).

In 1982, some 7,000 nursing homes were certified to provide Medicare and/or Medicaid skilled nursing care and are called skilled nursing facilities (SNFs). About 5,500 others were certified to provide Medicaid intermediate level care (101) and are called intermediate care facilities (ICFs). Many nursing homes have some beds certified at the SNF level and some at the ICF level. Another 1,500 nursing homes, although they provided nursing care, were not certified by either Medicare or Medicaid (77).

The main difference between skilled nursing facilities and intermediate care facilities is that Federal regulations require SNFs to provide 24-hour services by licensed practical nurses (LPNs) and to employ at least one registered nurse on the day



shift, 7 days a week. ICFs must have at least one LPN on duty during the day shift 7 days a week. State Medicaid regulations that define SNFs and ICFs vary greatly, and the proportion of nursing homes in each category also varies. For example, all or almost all nursing homes in Arizona and Connecticut are certified as SNFs, while almost all those in Iowa and the District of Columbia are certified as ICFs. Few differences have been found in the kinds of individuals cared for in SNFs and ICFs in different States, and the Institute of Medicine's Committee on Nursing Home Regulation recently recommended that the distinction between them should be dropped (37). The impact of such a change on access to nursing homes by persons with dementia requires further analysis.

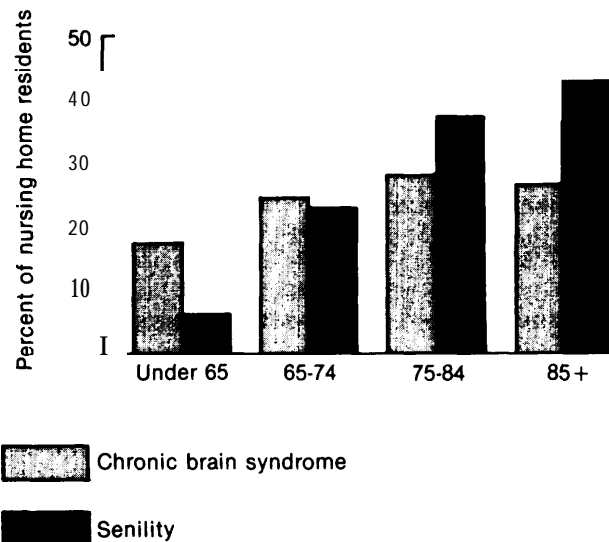
Nursing home bed supply varies widely, from a low of 22 beds per 1,000 elderly residents in Florida to a high of 94 in Wisconsin (94). Total bed supply increased steadily from 1963 to 1977, but the rate of increase has slowed since then, partly in response to State efforts to limit bed supply in order to contain Medicaid expenditures. Since 1977 the supply has grown at a rate slower than the growth in the population age 75 or older, thus limiting access to nursing home care in general (94,114).

### Residents With Dementia in Nursing Homes

Until recently, scant information was available about the number of persons with dementia in nursing homes. The 1977 National Nursing Home Survey found that 7 percent of residents had a primary diagnosis of chronic brain syndrome, and 2 percent had a primary diagnosis of senility without psychosis (97). NO information was obtained about other diagnoses associated with dementia. However, nurses were asked about each resident's chronic conditions. According to the nurses, about 25 percent of all residents had chronic brain syndrome and 32 percent were senile, with prevalence increasing with age (see figure 6-1) (97).

The difference between the small proportion of nursing home residents with a primary diagnosis of chronic brain syndrome or senility and the much higher proportions identified by the nurses is partly explained by diagnostic practices

Figure 6-1.—Nursing Home Residents With Chronic Brain Syndrome or Senility as Assessed by Nurse Respondents, by Age, United States, 1977



SOURCE: U.S. Department of Health and Human Services, Public Health Service, National Center for Health Statistics, *Characteristics of Nursing Home Residents, Health Status, and Care Received: National Nursing Home Survey, United States, May-December 1977*, series 13, No. 51, DHHS Pub. No. (PHS) 81-1712, Hyattsville, MD, 1981.

that resulted in underdiagnosis of dementia, as discussed in chapters 1 and 3. In addition, Medicare and Medicaid policies that define eligibility in terms of medical and nursing care needs discourage the use of diagnoses that suggest the need for personal care and supervision instead. (See also the discussion of the "50 percent rule" in ch. 11.)

Since 1977, diagnostic practices have changed considerably, and higher proportions of nursing home residents now have a primary or secondary diagnosis of dementing disorders, at least in some States. A 1985 survey of Texas nursing homes found that 45 percent of the residents had a diagnosis of Alzheimer's disease and an additional 21 percent had diagnoses of other dementing disorders (86). A 1984 survey of New York nursing homes found that 41 percent of residents had a diagnosis of a dementing disorder (22).

Although some observers believe that dementia, and particularly Alzheimer's disease, is now being overdiagnosed for nursing home residents, research based on assessments of cognitive status rather than diagnoses suggests that at least

40 percent have a dementing disorder, and in some facilities the proportion is even higher. A 1983 study in Rhode Island using a cognitive rating scale to assess mental status found that 40 percent of those under 80 and 50 percent of those older had dementia (68). Another study found that 56 percent of the residents of a Maryland nursing home had a primary degenerative dementia, another 18 percent had multi-infarct dementia, and 4 percent had dementia associated with Parkinson's disease—a total of 78 percent with dementing disorders (70).

In addition to residents with cognitive impairment caused by the dementing disorders that are the subject of this OTA assessment, nursing homes serve people with cognitive impairments caused by acute and chronic diseases, by drugs taken to treat those diseases, by pain or terminal illness, and by mental retardation. They also serve people who appear to be cognitively impaired because of hearing and speech impairments or emotional withdrawal associated with depression. Nurses, nurse's aides, and other staff often do not distinguish between cognitive impairments caused by dementing disorders and those due to these other factors. (Some of the difficulties involved in making such distinctions are discussed in ch. 8.)

Little research has been done on the characteristics and care needs of persons with dementia in nursing homes. One study (70) found that many of these persons have coexisting psychiatric disorders (e.g., delusions, hallucinations, or depression) and behavioral disorders (e.g., restlessness, agitation, wandering). The length of stay of nursing home residents varies greatly, and several studies indicate that residents with mental disorders, including chronic brain syndrome and senility, tend to be among those who stay longest and, therefore, may be more likely than other residents to become eligible for Medicaid (42,53).

Many nursing home administrators and employees believe that persons with dementia are more difficult to care for and require more staff time than other residents. A study of Maryland nursing home residents found that those with behavioral disorders required 35 percent more staff time than those without behavioral disorders; however, the residents were not identified by diag-

nosis or cognitive status (2). To investigate this question, OTA contracted with Rensselaer Polytechnic Institute for a retrospective analysis of data collected in the development of a new reimbursement system for New York State nursing homes, called RUG-II. Initial findings showed that nursing home residents with a diagnosis of dementia varied greatly in terms of limitations on activities of daily living, behavioral disorders, and care needs (22),

The New York State data included no measure of cognitive status, so the severity of dementia could not be determined. Nevertheless, an attempt was made to develop a rough index of severity by combining data on five survey items that may be related to cognitive status—resident's learning ability, motivation, refusal to care for self, expressive communication, and receptive communication/comprehension. (The wording of these items and the resident descriptors used to develop the index of severity are presented in app. A.) Analysis of the New York State data using resident diagnosis and the index of severity showed that persons with dementia were in general more impaired than other residents in activities of daily living and behavior, and that their level of impairment became greater with increasing severity of the dementia. For example, a greater number of those with dementia required continuous supervision with eating or had to be fed by hand; 61 percent of those in the high severity group required assistance compared with about 6 percent in the low severity group. Similar results were obtained for dressing, bathing, toileting, bowel and bladder control, and personal hygiene.

The data also showed that residents with a diagnosis of dementia were more likely than others to be wanderers, but that wandering was most frequent among those in the low and middle severity groups and decreased in the high severity group. Other behavioral disorders, including verbal abuse, physical aggression, and regressive or inappropriate behavior also occurred more frequently among residents with dementia (22) (see app. A).

These findings suggest that although many nursing home residents who do not have dementia require substantial assistance with activities of daily

living, on average those with dementia require more aid. Because they are also more likely to have behavioral disorders, residents with dementia generally require more staff time. Thus, as nursing home administrators and employees maintain, persons with dementia are frequently “heavy care patients.” The more severe the dementia, the more assistance is needed, although behavioral disorders appear to lessen at the highest level of severity. It should be noted, however, that these data were collected almost entirely in facilities that do not provide special services for persons with dementia. As discussed in chapter 7, some nursing homes with special services for these persons report decreased limitations in activities of daily living and behavioral disorders among their residents.

### **Quality of Care for Residents With Dementia**

Nursing homes have been criticized for a long list of deficiencies that affect all residents, regardless of cognitive status. The criticisms range from widespread complaints about inadequate attention to residents’ emotional and social needs and need for privacy to less frequent but serious complaints about dangerous medication errors and resident abuse and neglect (37,105). This assessment does not discuss these general problems in nursing homes except to note that some deficiencies are related to low levels of reimbursement for Medicaid patients and to Medicare and Medicaid regulations that focus on physical and nursing care needs to the exclusion of emotional and social ones.

In addition to problems that affect all nursing home residents, some care practices even in “good” nursing homes are inappropriate for persons with dementia:

- Cognitive status is not routinely assessed. As a result, the primary reason the person with dementia needs nursing home care is not identified or evaluated. Although some residents with dementia need nursing home care because of other physical problems, failure to identify cognitive deficits affects the quality of their care overall.
- Most nursing home personnel are not trained to care for people with dementia and are not

aware of management techniques that could lessen functional disability and behavioral disorders.

- Medications that could reduce agitation and other behavioral problems associated with dementia are frequently not used, sometimes because the physician is not aware of the behavioral problems but more commonly because he or she does not know which drugs to use or in what dosage. In some cases, individuals with dementia are given the wrong drug or excessive doses of drugs that increase their confusion and may cause extreme drowsiness and falls.
- Most nursing homes are designed to accommodate residents who are relatively immobile, and there is seldom enough space for those with dementia who may be physically active until the late stages of their illness. Restraints are frequently used to keep them from wandering or restless pacing, and some develop physical disabilities associated with forced immobility. Since exercise is seldom part of the daily routine, residents with dementia who are capable of physical activity often become increasingly agitated.
- The regular practice of rotating staff from one unit to another is a problem for persons with dementia who may be able to remember staff they see every day but cannot remember over longer periods of time and may become agitated when repeatedly confronted with caregivers they do not recognize.
- Increased noise and activity associated with shift changes, fire drills, or even activities that are pleasant for other residents, such as a parade through the nursing home of schoolchildren in Halloween costumes, can be agitating for people with dementia. The disembodied voice heard over an intercom can also be confusing.

Staff-to-resident ratios in most nursing homes may be inadequate for residents with moderate to severe dementia. It is possible, however, that in nursing home units designed specifically for persons with dementia, good care can be provided without higher staff-to-resident ratios (see ch. 7).

Residents from minority groups may have particular difficulty adjusting to nursing home care because of differences in attitudes, expectations,

and typical behavior patterns. Those with dementing disorders may have even more difficulty because they often cannot understand or adapt to these differences. And those who are non-English speaking are most severely affected for they cannot communicate with staff or other residents at all.

In many areas of the country, nurse's aides are primarily from minority groups, and some are recent immigrants. When the residents of the home are predominantly of the majority culture, misunderstandings and tension can develop between the staff and the residents. Residents with dementia may be particularly unable to understand and adjust to staff from minority groups or from other countries. By the same token, however, such staff members are able to communicate with and relate to residents from the same minority group or country who might otherwise be isolated in the facility. The care of non-English speaking residents with language deficits associated with dementia is greatly facilitated if someone on staff speaks the residents' original language.

Residents with dementia not only experience problems in nursing homes but also create them. Due to deficits of memory and judgment, they may touch, move, or take other residents' possessions. In addition, their agitation, restlessness, noisiness, and occasional physical or verbal aggressiveness can upset other residents. Some nursing homes place cognitively impaired and cognitively normal residents in the same room, sometimes because they fail to consider cognitive differences but more often because they believe that the cognitively normal resident can help orient the cognitively impaired one. Although the efficacy of this approach has not been tested, other providers believe it is generally unfair to nondemented residents to be placed in a 24-hour living situation with someone with dementia and that residents with similar cognitive abilities should be roommates (1,13,121). Research on the effects of pairing residents with and without cognitive impairment is needed.

Despite the many problems of nursing home residents with dementia, the OTA survey of family caregivers found that 55 percent of those who had experience with a family member living in a nursing home reported that the care was excel-

lent or good, and that only 16 percent reported that it was poor or very poor. Comparing these findings with the answers to other questions on the survey indicates that families who had experience with nursing homes had more positive attitudes about them than families who had no such experience (122). It is possible, however, that these attitudes mask a feeling of guilt about having placed a family member in a nursing home.

Few examples of positive experiences of dementia patients in nursing homes are found in the literature, but anecdotal evidence suggests that some people benefit from placement:

Mrs. P, suffering from Alzheimer's disease, had been living with her daughter, a tense woman who had difficulty tolerating Mrs. P's repetitious questions and seemingly aimless "fussing around the house." Over a period of months, the daughter became increasingly irritated and often spoke sharply to Mrs. P, who grew more and more agitated in response. Finally, when Mrs. P began to have occasional episodes of incontinence, her daughter could tolerate the situation no longer and placed her in a nursing home.

Mrs. P had a pleasant personality, and despite her increasing confusion, she was well liked by the staff. She did not receive any special services, but she enjoyed weekly activities, such as bingo and sing-alongs, and was obviously content to sit near the nurses' station much of the day, talking to staff and other patients and watching the goings on around the unit. Since staff expectations for her were not high, she felt more comfortable with herself than she had in her daughter's home. The daughter also felt calmer and was able to express genuine affection for her mother during her frequent visits,

Over a period of 5 years Mrs. P's disease progressed to the point where she was bedridden, and it was no longer possible to communicate with her. However, it was clear that her life in the nursing home had been better than it would have been at her daughter's home.

Evaluating the experience with nursing home care of a dementia patient and of his or her family is difficult partly because the patient is often unable to formulate or express feelings and thoughts. Some families maybe relieved that they no longer have to provide 24-hour care, although many feel intense guilt about the placement. Research indi-

cates that quality of life for caregivers who place a relative with dementia in a nursing home improves in some ways and not in others (16). These mixed findings and the difficulty of distinguishing between the debilitating effects of progressive dementias and the effects of poor care may preclude valid generalizations about the individual and family experiences.

### Access to Nursing Home Care

It is clear from the large number of residents with dementia in nursing homes that such individuals are regularly admitted. At the same time, several problems continue to restrict access for some people with dementia:

- Nursing homes are reluctant to admit someone they believe will be difficult to care for or require disproportionate amounts of staff time.
- In States where Medicaid reimbursement levels are exceptionally low, nursing homes are reluctant to admit individuals who are likely to stay long enough to deplete their private funds and become eligible for Medicaid.
- Nursing homes are especially reluctant to admit Medicaid recipients who they believe will be difficult to care for and for whom the Medicaid reimbursement rate is low. (Case mix reimbursement systems that may reverse this disincentive are discussed in chs. 8 and 12.)
- In some States, Medicaid policies restrict eligibility for publicly funded nursing home care for persons with dementia. (These problems are discussed in detail in ch. 11.)

The limited supply of nursing home beds in many States restricts access for all types of people and is a particularly severe problem in rural areas. When bed supply is limited, access to nursing home care for individuals with dementia may be restricted disproportionately for the reasons above.

In general, the proportion of minority group residents in nursing homes is lower than would be expected from their proportion in the population as a whole. That may reflect barriers to access (e.g., lack of information, discrimination, cost, and geographic location of the facilities), personal choice, greater availability of informal home care,

or a combination of all three (10,54,61,80). No information is available about the proportion of minority individuals with dementia in nursing homes.

Short-term nursing home placement to provide respite for family caregivers is an important service but one that is frequently not available (28,68). Nursing homes may be reluctant to provide short-term respite care because the costs of staff time and administrative procedures associated with admission and discharge are not adequately reimbursed at the prevailing daily rates. In addition, beds used for respite care may be vacant more frequently than other beds (46). Anecdotal evidence suggests that persons with dementia are often disoriented, agitated, and difficult to care for when first moved to any new setting. They may also be more likely to wander off during the first days after admission to a nursing home than they would be if they were accustomed to the facility. Such behaviors upset more permanent residents, particularly if they detract from staff attention to the “old timers” (32). For these reasons, nursing homes may be more reluctant to admit someone with dementia for short-term respite care than other types of patients. Research is needed to evaluate the frequency of these problems and to develop potential solutions.

### Board and Care Facilities

Board and care facilities are nonmedical residences that provide room and board and 24-hour supervision. Some also provide personal care and a variety of other services. They differ from nursing homes in that they generally do not provide nursing care. They differ from boarding homes and congregate housing facilities because they generally provide 24-hour supervision. However, there are no clear-cut boundaries, and some facilities might be classified differently by different observers. Some large facilities provide board and care in some sections and nursing home care in others (59).

Board and care facilities vary in size from adult foster care homes for one or two individuals, to personal care homes and group homes that may serve 3 to 10 or more, retirement homes and homes for the aged that serve up to 100 or more,

and large domiciliary care facilities that serve several hundred residents. The number and type of board and care facilities vary greatly in different States. In addition, one study identified more than 20 different names used for these facilities around the country (67).

Board and care facilities also vary in the type of care they provide. In adult foster care homes, for example, one or several residents may be cared for by one person who shops and cooks for them and assists with bathing and dressing. Care is informal, and the atmosphere may be homelike. In contrast, residents of large domiciliary care facilities are cared for by a staff with a formal daily schedule and structured activities. Between these extremes, tremendous variety exists in patterns of care.

Board and care is sometimes referred to as "residential care" or "community care," while nursing home care is called "institutional care." The first two terms have positive connotations in contrast to the last one, but the positive image they convey may not apply to all board and care facilities. Although many small board and care facilities and some larger ones are homelike or residential, larger facilities are often just as institutional as any nursing home. Furthermore, some nursing homes are closely involved with their communities, while some board and care facilities are isolated. Thus the distinction between "residential" or "community care" in board and care facilities and "institutional care" in nursing homes can camouflage real differences in atmosphere and patterns of care in specific facilities. These terms are not used to differentiate board and care facilities from nursing homes in this report.

Little is known about the services provided in board and care facilities. One study of small facilities (up to 13 residents) in Pennsylvania showed the following services were provided: laundry (97 percent); personal shopping (83 percent); cleaning a resident's room (80 percent); transportation to social activities (77 percent); handling money (65 percent); supervising or administering medications (65 percent); assistance in bathing (37 percent); and assistance in dressing (26 percent) (75). Similar services are required by State programs that regulate some types of board and care facilities (67).

No Federal Government agency has responsibility for collecting data on board and care facilities, and the definitions of these facilities used by different researchers vary significantly. Accurate national figures are therefore not available. Several sources estimate that there are at least 30,000 board and care facilities in this country, providing beds for 350,000 or more people (67,98). Other sources estimate that if facilities that serve only one or two residents are included, there may be 100,000 or more (73). Still others believe that both these estimates are low and that, in fact, we have no idea how many such facilities there are (84).

State and Federal programs pay for a significant portion of board and care. Although neither Medicare nor Medicaid covers these services, many board and care residents receive Federal SSI benefits. In 1983, 34 States and the District of Columbia provided supplemental payments for SSI recipients who lived in board and care facilities (100). VA provides board and care in 16 large domiciliary care facilities and pays for board and care in State Veterans Homes and small group homes. In addition, some States (20 in fiscal year 1984) use a portion of their Social Services Block Grant funds for adult foster care. Total spending for this purpose is not known because States are no longer required to report how they spend Block Grant Funds. In 1980, however, before Title XX funding was converted to the Social Services Block grant, Title XX funds constituted about 4 percent of all public funding for board and care, while SSI accounted for 73 percent and VA accounted for 23 percent (15).

### **Residents With Dementia in Board and Care Facilities**

Much less is known about residents of board and care facilities than about residents of nursing homes, and no research has been reported on those with dementia. Studies have generally identified three groups of residents: the aged, mentally ill, and mentally retarded residents. One survey found that among 230,000 board and care residents for whom information was available, about 45 percent were elderly, 37 percent were mentally ill, 15 percent were mentally retarded, and the remainder were substance abusers or persons

placed by the courts (67). The groups overlap, however, and some of the mentally ill and mentally retarded residents are elderly, and vice versa.

Among the mentally ill and elderly residents are an unknown number of persons with dementia. One study of applicants for Pennsylvania facilities found that 36 percent of the mentally ill group and 38 percent of the elderly group needed supervision due to disorientation or memory impairment (74). Another study of board and care residents in seven states found that about one-third were disoriented or exhibited some memory impairment (17). However, no diagnoses are available to determine the cause of these conditions.

Many residents of board and care facilities have psychiatric diagnoses or a history of psychiatric hospitalization. For example, 27 percent of those in board and care facilities in five States were found to have a history of psychiatric hospitalization (58). Among residents of VA board and care facilities, 55 percent of those in the large domiciliary care facilities and more than 70 percent of those in smaller homes had a primary diagnosis of psychiatric disorder (15). It is not known how many of the residents with psychiatric diagnoses or a history of psychiatric hospitalization actually have a dementing disorder.

### **Quality of Care for Residents With Dementia**

Board and care facilities may be particularly appropriate care settings for many individuals with dementia because they provide protective supervision but are often less restrictive than nursing homes. Moreover, board and care usually costs one-third to one-half as much as nursing home care. However, many of these facilities provide inadequate care (17)(85)(90)) and residents with dementia are particularly unlikely to be able to report or resist poor care. Among board and care facilities identified in one national survey, about 85 percent were licensed by the States, but licensing requirements often focus on physical plant and fire and safety code regulations rather than quality of care. Furthermore, few States regularly inspect these facilities [67]. (Quality assurance standards and inspection procedures for board and care facilities are discussed in ch. 10.)

Although no research has been done on board and care specifically for those with dementia, there are reports of good care in some facilities that serve individuals with dementia along with others. For example, one study (108) described an adult foster care program in Hawaii that serves elderly clients, 38 percent of whom were significantly disoriented and 40 percent were incontinent of bowel and bladder. The study reported positive relationships between the foster families and the residents and improvements in self-care abilities and continence over time.

In contrast, anecdotal evidence suggests that there are instances of very poor care:

Mrs. N, an 89-year-old black woman with no family, was brought to the hospital emergency room in a state of severe malnutrition and dehydration. She was confused on admission and remained confused even after her nutritional status had improved with treatment. Investigation by the local Adult Protective Services Unit revealed that Mrs. N and two other elderly women with dementia had been living for an unknown period in a filthy apartment, cared for by a man who took their SSI checks every month, visited them daily during the week and brought them food, but apparently left them entirely alone on weekends. None of the women had relatives who visited them, and while little specific information could be obtained about their care, their physical condition suggested that they had received little care and little to eat.

It is not known how often such situations occur.

When board and care is provided by one person, changes in that individual's physical or mental health can jeopardize the safety and continuity of care for residents, just as changes in a family caregiver's physical or mental health can jeopardize the care of a person with dementia at home. For many board and care facilities, there is no established procedure for notifying a relative of the resident or another responsible person when such problems arise.

### **Access to Board and Care Facilities**

Access to board and care facilities for all kinds of people is limited by lack of information about them. Although some facilities, especially large retirement homes and VA domiciliary care facil-

ities, are well known in their communities, others are largely unknown, even to health care and social service providers. The OTA survey of family caregivers found that 55 percent did not know whether board and care was available in their area—a larger proportion than those who did not know about the availability of other long-term care services (122). Some States have case management programs that place people in board and care facilities, and some continue to monitor resident adjustment after placement (59). However, these programs are often limited to certain types of facilities and certain types of people, particularly mentally retarded individuals and those who receive public funding.

The cost of board and care may also limit access for all kinds of people, including those with dementia. Although board and care is considerably less expensive than nursing home care, it often costs more than the individual's social security or SSI benefit and any State SSI supplement (83).

In some localities, there are no board and care facilities. For example, one survey of six States identified several rural counties without any such facilities (76). Lack of SSI supplements for board and care in some States and extremely low SSI supplements in other States discourage the development of these facilities, thus limiting access to this form of care for all types of people (67,85).

For someone with dementia, access may be restricted because providers sometimes refuse to accept residents with behavioral problems or incontinence. The six-State survey cited above found that 35 percent of board and care operators refused to admit people with behavioral problems, night wanderers, and people with bowel or bladder problems (31).

Little is known about minority group access to or use of board and care facilities. Some research suggests that minorities may be excluded from specific kinds of facilities. For example, few black people live in homes for the aged (12). In contrast, many board and care providers, especially in small facilities, are black, at least in some localities. In the Pennsylvania domiciliary care program, 30 percent of the providers but only 13 percent of the residents were black (76). No information is

available about access to or use of board and care facilities by Hispanic elderly or other minorities.

### ***Home Care***

Home care services include medical, social, and supportive services provided in someone's home. They range from complex, technologically sophisticated interventions, such as the administration of intravenous antibiotics and nutritional support, to relatively simple interventions, such as home-delivered meals. Between these extremes are services such as skilled nursing care, physical therapy, speech therapy, occupational therapy, home health aide, personal care, homemaker, paid home companion, and chore services. (These services were defined earlier in table 6-1.)

Family caregivers who responded to the 1985 OTA survey said that each home care service they were asked about was important for their family member with dementia:

- **96** percent said that a paid companion who can come to the home a few hours each week to give caregivers a rest is essential, very important, or important;
- **94** percent said that home health aide services—that is, a person paid to provide personal care such as bathing, dressing, or feeding—are essential, very important, or important;
- **93** percent said that a paid companion who can come to the home and provide overnight care is essential, very important, or important; and
- **87** percent said that visiting nurse services—a registered nurse to provide nursing care—are essential, very important, or important (122).

Unfortunately for persons with dementia and their families, some of these services do not correspond to the services usually funded or provided by public programs. Although some families can pay privately for home care services, the long duration of dementing illnesses and thus the long period during which services are needed mean that families must often turn to publicly funded services or do without.



Federal funding for home care is provided by Medicare, Medicaid, the Social Services Block Grant, Title III of the Older Americans Act, and VA. Medicare is the largest payer for home care, and Medicare expenditures for home care have grown rapidly during the past 10 years. However, in 1983 they still constituted only 2.7 percent of Medicare spending (88). Medicare is a medical insurance program, and its coverage of home care is limited to the following medically related services:

- part-time or intermittent skilled nursing care;
- physical therapy, speech therapy, and occupational therapy;
- medical social services provided under the direction of a physician;
- medical supplies and equipment (other than medicines); and
- part-time or intermittent home health aide services.

Medicare services must be prescribed by a physician and provided by an agency certified to participate in the program, of which there were 5,237 in 1985 (35).

Federal regulations do not restrict the number of home health care visits that can be covered and the period of time over which they may be received, but because of the requirement that Medicare-covered home health care services must be “intermittent,” daily visits for more than 2 to 3 weeks require additional documentation by a physician. Home care providers complain that some Medicare intermediaries who handle reimbursement routinely deny payment for daily visits that extend for more than 2 to 3 weeks and that the intermediaries are erratic in their reimbursement decisions. Testifying before the Subcommittee on Health of the Senate Finance Committee, the director of a home health care agency stated:

A visiting nurse association in the Southwest was denied all visits to an 80-year-old Alzheimer’s disease victim for March and April after being reimbursed for daily visits in previous months. Then the intermediary turned around after denying these two months, and paid for two additional months of daily visits . . . there is no consistency at all in those types of decisions.

The patient had [decubitus] ulcers. I have the pictures here . . . I would like to enter these pic-

tures in with our testimony in the record. [Ten pictures of severe decubitus ulcers are submitted.] You cannot look at these photos and not see that this man had the need for the daily visits; and the . . . intermediary looked at the pictures and denied the visits anyway (103).

For many persons with dementia, home health aide services are the most useful Medicare-covered home care service. Covered services include assistance with medications and exercise; personal care, such as bathing, dressing, and feeding; and homemaker services when these can be shown to prevent or postpone placement in a nursing home or other institutional setting. To be eligible, however, the patient must also need skilled nursing care, physical therapy, or speech therapy—a condition that many with dementia do not meet. Using a home health aide as a paid companion—one of the services considered essential by many family caregivers—is not legitimately covered by Medicare.

Studies by the General Accounting Office and the Health Care Financing Administration indicate that Medicare reimbursement for one-fourth to one-third of all home health care claims was or should have been denied—sometimes because the individual was not eligible for such services, according to program regulations, but more often because the person received too many visits (91,109). It is not known how many individuals with dementia actually receive any Medicare-covered home health care services or how many receive services for which reimbursement is later denied.

Statistical analysis of the characteristics of a national sample of people receiving Medicare-covered home health care services indicates that six clinically distinct groups can be identified (56). Four of the groups generally do not include cognitively impaired people:

1. people with acute medical problems such as cancer;
2. people with hip or other fractures;
3. people with acute and chronic medical problems and limitations in self-care abilities; and
4. people with severe circulatory and respiratory problems.

The other two groups, which do include cognitively impaired people, are:

5. people who have many chronic medical conditions, including senility and stroke, but few acute or severe conditions and few limitations in self-care abilities; and
6. people with severe neurological impairments, including senility and stroke, and significant difficulty in self-care abilities.

Among all six groups, group 5 received the lowest amount of Medicare reimbursement for home health care services, while group 6 received the highest amount—an average of six times as much. The primary differences between the two groups are the absence or presence of acute medical care problems and limitations in self-care abilities. These findings suggest that persons with dementia and with acute medical problems and severe limitations in self-care abilities may receive substantial Medicare reimbursement for home health care services, and that those with fewer acute medical problems and fewer limitations in self-care abilities probably receive much less. The latter group may be among home care recipients for whom reimbursement is frequently denied.

Medicaid also covers home health care services, although in 1983 they accounted for less than 2 percent of all spending in the program (88). Within Federal guidelines, States determine what services their Medicaid programs cover, and tremendous variation exists. Although some States have legislative, regulatory, and administrative policies that make a range of services available to Medicaid-eligible people, others do not (14). Federal regulations require State Medicaid programs to cover skilled nursing care and home health aide services. Personal care is optional; as of 1983, only 25 States and the District of Columbia covered it (95). Even so, three-quarters of Medicaid home care expenditures were for personal care (18). All Medicaid-covered home care services must be ordered by a physician, and home health aide and personal care services must be supervised by a licensed nurse.

In many States, home health care services covered by Medicaid match the needs of someone with dementia more closely than those covered by Medicare; however, only people who meet Medi-

icaid financial eligibility criteria can receive Medicaid-covered services. The criteria include limits on income and assets that vary among States but are low everywhere and extremely low in some States. As a result, even where Medicaid covers the home care services for a person with dementia, the allowable income and asset levels are so low that it is difficult to support the person in the community. When a spouse is involved, he or she must also live at these low income and asset levels (see ch. 11 for further discussion of this problem),

In 1981, Congress authorized the Medicaid 2176 waiver program to allow States increased flexibility in the home care services they provide. Under this program, States may provide home health aide, homemaker, personal care, and respite services as long as these services are said to prevent nursing home placement. States may target the expanded services to specific areas and to certain groups of people instead of making them available statewide and to all Medicaid-eligible individuals.

As of April 1985, 95 waiver applications had been approved: 50 include services for the aged and disabled and 4 including services for the mentally ill. Among waiver programs for the aged and disabled, 11 included home health aide services, 26 included homemaker services, 18 provided personal care, and 24 provided respite care (87). The number of persons with dementia who receive services through these programs is not known. Since recipients must meet Medicaid financial eligibility requirements, however, services are generally available only to those with low income and assets. In some States, individuals with income up to three times the SSI level in the community are eligible for 2176 waiver benefits, but they must have medical expenses higher than the difference between their income and the SSI benefit level (see ch. 11 for a description of the 2176 waiver program).

Funding for home care services through the Social Services Block Grant and Title III of the Older Americans Act is administered at the State and local levels, and little information is available about services provided and the financial or other factors used to determine eligibility. Although many

States use these funds to provide personal care, homemaker, and chore services not covered by Medicare or Medicaid, they are generally insufficient to meet demonstrated need (27,28,88). Again, the number of persons with dementia who receive home care services through these funding sources is not known.

VA provides relatively little home care compared with the amount of hospital, nursing home, and board and care services it provides. Only 30 of 172 VA Medical Centers provide home care services, and veterans who live far from these centers do not have access to VA home care. Estimates for fiscal year 1985 indicated that about 15,000 veterans would receive home care, but the need for these services is much greater. For example, VA figures indicate that 460,000 veterans will need home care services by 1990 (1 I 1). No breakdown of these figures for veterans with dementia is available.

### **Persons With Dementia Receiving Home Care Services**

As indicated, the number of persons with dementia who receive federally funded home care services is not known, and OTA is unaware of any national or State data on the number who receive any publicly or privately funded home care services. The eligibility criteria for relevant Federal programs discourage identification of this group by focusing on different types of needs: medical, skilled nursing, and health-related needs (Medicare, Medicaid, VA); social service needs (Social Services Block Grant); or age-related needs (Title III of the Older Americans Act). Although several national, State, and community surveys include measures of cognitive status and information about service utilization (52), these data have not yet been analyzed to determine the number or proportion of persons with dementia who receive home care services or, conversely, the proportion of all home care recipients who have a dementing disorder.

Despite this lack of information, it is clear that individuals with dementia constitute a significant proportion of home care recipients, at least in some programs. For example, one study of 50 people who received home care services following hospitalization in Little Rock, Arkansas, found that

48 percent had mild or moderate cognitive impairments, and 10 percent were severely impaired (24).

A person's mental status may affect the efficacy and chance for success of formal home care services. National data indicate that mental status is one of the most important predictors of nursing home placement. For example, analysis of data from the 1977 Health Interview Survey and the 1977 National Nursing Home Survey showed that 66 percent of elderly persons with diagnoses of mental illness (including cognitive impairments and functional mental illnesses) are in nursing homes. By contrast, only 22 percent of those with cancer, digestive, metabolic, or blood diseases and a smaller proportion of those with other diagnoses are in nursing homes (119). Similarly, hospital data suggest that cognitively impaired persons are much more likely than other patients to be discharged to nursing homes (20,71). These findings imply that persons with dementia are more difficult to maintain at home than others who need long-term care. They also raise questions about whether formal home care services can be effective in keeping someone with dementia at home and whether it is more difficult to arrange home care services for such a person. OTA is not aware of research that addresses these questions.

One characteristic that limits the usefulness of home care services for some persons with dementia is their need for 24-hour supervision. Although not unique to this group, this need is probably universal among persons with dementia. While some families can provide 24-hour supervision, persons with dementia who have no family cannot be safely maintained at home without 24-hour formal care—a service that is seldom available.

One home health aide who works for a Medicare-certified home health care agency has 11 elderly clients, most of whom live alone. She visits six of them daily and the others on alternate days, to help with bathing and dressing, and—for those who live alone—shopping, cooking, and other housekeeping chores.

Agency policy is that the home health aides do not visit clients who live in rural areas on days when the county schools are closed because of snow. The aides have been told that their services are intended to be “part-time and intermittent,” as required by Medicare regulations and



Photo credit: **ADRDA** and Peter Carrel, Photosynthesis Productions, Inc.

Some families are able to provide 24-hour care for a relative with dementia.

that their clients are not supposed to need 24-hour care.

On this “snow day,” however, the aide decides to visit one of her clients anyway. The client is confused, and the aide is always worried about how she will manage between the aide’s daily visits. In good conscience, the aide cannot imagine failing to check in on the woman. It is not the aide’s decision whether or when the woman should be placed in a nursing home, and in fact her instructions do not mention the woman’s increasing confusion—only her need for assistance with bathing, dressing, shopping, and cooking.

Data from the 1979 Home Care Supplement to the National Health Interview Survey indicate that individuals who need supervision plus assistance in activities of daily living and medical care use formal home care services more often than those who need only assistance in activities of daily living and medical care (79). Further, some 56 percent of those 65 or older who needed home care also needed supervision all or most of the time (78). However, it is now known how many of these people had a dementing disorder. Analysis of these data in terms of the cognitive status of home care recipients might clarify the relationship between dementia, the need for 24-hour supervision, and the use of formal home care services.

For many years it has been believed that home care services can help people who need long-term care remain in their homes and avoid nursing home placement, thus reducing expenditures for nursing home care. Many studies have tested this hypothesis, and although some are methodologically flawed, analysis of the findings indicates that home care services do not, in general, substitute for nursing home care. Nor are home care services generally less expensive than nursing home care, although they often improve the quality of life for those who remain at home (36,93,117).

Analysis of the reasons for these unexpected results is beyond the scope of this assessment. However, it appears that none of the studies considered the effect of the individual’s cognitive status on whether home care services prevent institutionalization. One recent study indicated that caregiver characteristics and caregiver well-being are more important predictors of placing someone with dementia in a nursing home than any characteristic of the person (16). However, the person’s cognitive status could affect caregiver well-being or, alternatively, the emotional or behavioral characteristics associated with dementia could be intervening variables that affect caregiver well-being and thus decisions about placement. Further research is needed on the factors that predict institutionalization of persons with dementia and therefore the potential impact of home care services on such decisions.

### **Quality of Home Care Services for Persons With Dementia**

Several problems limit the quality of home care services for persons with dementia:

- The services most needed—paid companion, homemaker, personal care, and 24-hour supervision—are frequently not available. Home care services that can be used for respite care are particularly difficult to find (28,40,68).
- Many of the people who provide home care services are not trained to work with individuals with dementia (68), and they may create more problems for the patient and the primary caregiver than they solve.

- There are few standards or procedures for monitoring quality of home care services for anyone, particularly someone with dementia,

In addition, different expectations about the role of the family and the role of the paid home care worker can cause problems. Although there may be little disagreement about the role and responsibilities of a nurse, physical therapist, occupational therapist, or speech therapist who provides home health care, the responsibilities of a home health aide who provides personal care and homemaker services may be difficult to distinguish from those of the family. This lack of clear roles and responsibilities can lead to tension. Home care workers sent out to provide home health care may become upset by a family's requests or demands for services that do not match the worker's job description. Likewise, family caregivers may become upset when services they want are not provided (41). Families and home care workers can also disagree about how much help the patient needs (32).

Close supervision of home care workers by the agency is virtually impossible, and families complain that some of these employees do not do their jobs. For example, one woman told the Massachusetts Governor's Committee on Alzheimer's Disease about a home health aide who seldom showed upon time, and when she finally arrived did little more than watch the woman care for her mother (27). Anecdotal reports indicate that some home care workers do not show up at all or merely sit and watch television. Theft, neglect, and exploitation of cognitively impaired people by home care workers have also been reported. Although it is not known how often such problems occur, they are clearly a cause of concern, especially for families who live a considerable distance from the person receiving the care (47).

### **Access to Home Care Services**

In many areas, access to formal home care services by persons with dementia can be limited by lack of any home care services, lack of appropriate services, lack of funding, and fragmentation of the service delivery system. Home care services of all kinds are particularly difficult to obtain in rural areas. National data indicate that elderly

people who need home care services do without them more frequently in farm areas than in urban, suburban, or rural, nonfarm areas. At the level of ADL impairment at which informal caregiving is usually augmented by formal home care services, almost twice as many people do without formal services in farm areas than in all other geographic locations (79). These findings are not specific for persons with dementia, but the Kansas Alzheimer's and Related Diseases Task Force has documented the difficulty of finding home care services for such persons in rural areas of the state (40).

Problems in obtaining appropriate home care services have been discussed throughout this section. One overriding problem is the emphasis on medical and skilled nursing services in Medicare, Medicaid, and VA home health care programs, as opposed to the personal care, supervision, and social services most often needed by persons with dementia. A second problem that has received almost no attention concerns home care services for different ethnic, cultural, and socioeconomic groups. When services are provided in the home, differences among groups and individuals in lifestyle, expectations, attitudes, and patterns of interpersonal behavior are particularly salient and can affect acceptance of the services, the level of trust and cooperation that can be achieved between the paid home care worker and the patient and family, and the overall efficacy of the service. Adaptations of home care services for different ethnic, cultural, and socioeconomic groups are needed.

The cost of services can also limit access, and many home care services are expensive. One woman told the Kansas Alzheimer's and Related Diseases Task Force:

I was told that I might be able to get someone in for an hour a day—that might be long enough to bathe and dress my husband. When I asked how much I was told it would cost \$40 an hour from the minute they left their office until they returned (40).

Some agencies provide home care services on a sliding fee basis, but the client's share of the cost may still be high (64). As a result, some families hire maids to provide home care services. One

study showed that 41 percent of caregivers of persons with Alzheimer's disease hired private maids or sitters because it was cheaper than paying for home care services from a home health care agency. Most of the other caregivers did not use any home care services (25).

A final and serious problem that affects access to home care services is the complexity and fragmentation of the service delivery system. Although in some localities there are no agencies to provide home care services, in other areas there are many such agencies, each providing a variety of services with differing eligibility requirements and reimbursement procedures (114).

The complexity of Federal regulations on what home care services are covered, who can receive them, and who can provide them is compounded by interpretations of Federal Medicare regulations by Medicare intermediaries; State legislation, regulations, and administrative policies that determine Medicaid coverage and eligibility requirements; and State and local regulatory and administrative decisions about the use of Social Service Block Grant and Title III funds. In addition, some services are available through State and local programs unrelated to Federal funding sources, or through private nonprofit groups, each of which has its own eligibility, coverage, and reimbursement guidelines.

Several States have created programs to pool and administer funds that are available for home care. Examples are the Massachusetts Home Care Corporations and the Maryland Gateway 11 program. Both provide home health aide, personal care, and homemaker services using more liberal and flexible eligibility criteria than are applied elsewhere. The primary problem they face is inadequate funding to meet the home care needs they identify (27,28). Thus even these programs are frequently unable to provide appropriate home care services for persons with dementia.

### ***Adult Day Care Centers***

Adult day care centers provide a range of health, mental health, and social services for physically, emotionally, and cognitively impaired and socially isolated people. The centers all provide some com-

mon services, but they differ in their emphasis and the clients they serve. Several types have been identified in the literature (33,118). Some emphasize medical and rehabilitative services, such as physical, occupational, and speech therapy, and serve people who are recovering from physical illnesses such as stroke. Other centers emphasize personal care, supervision, socialization, and activities, and serve mentally retarded and developmentally disabled adults or frail elderly persons and those with dementia. A third type emphasizes mental health services, supervision, socialization, and recreation, and serves primarily mentally ill people, some of whom have been discharged from public and private mental hospitals. The three types overlap, and some analysts have questioned how closely this typology reflects real differences between existing centers (8).

Before 1972, there were fewer than 10 non-psychiatric adult day care centers in the United States. By 1977, that number had grown to 300, and by 1982-83, there were between 700 and 1,000 centers serving 15,000 to 20,000 people (33,55,65). A 1985-86 survey sponsored by the National Institute of Adult Daycare (NIAD) received responses from 847 centers, and the report suggests that 1,200 is a conservative estimate of the number of existing centers (8).

Unlike nursing homes and home health care agencies, adult day care centers have developed largely without Federal regulation. As a result, they vary greatly in physical setting, clientele, staffing, mode of operation, and services provided. To some extent, this diversity reflects local needs and resources (7).

Adult day care centers may be located in buildings used solely by the center or in hospitals, nursing homes, senior centers, churches, schools, community centers, clinics, housing for the elderly, private homes, or life care communities. A few are open 7 days a week, but most are open 5 days a week (7). Many clients do not attend every day, however; one study of four centers found that the average days of attendance ranged from 48 to 114 days per person per year (82). Although the services provided in different centers vary, as mentioned earlier, many centers have similar goals—to avoid premature or inappropriate institu-

tional placement, to maximize client functioning, to provide respite for family caregivers, and to provide supportive services in the community (8).

According to the NIAD survey, the average cost of adult day care is \$27 to \$31 a day (8). However, some programs cost significantly more (65). Medicare does not cover adult day care per se, but may cover medical or skilled nursing care and physical and speech therapy provided for adult day care clients. Adult day care is an optional service under Medicaid, and some states cover it either as a separate service or as part of clinic or outpatient services (15). Coverage is usually limited to centers that provide medical and rehabilitative services as opposed to those that emphasize personal care, supervision, and activities (45). Financial eligibility criteria further limit Medicaid-covered adult day care to persons with low income and assets.

Nevertheless, the NIAD survey found that Medicaid and participant fees were the two main sources of funding for adult day care centers (8). Adult day care is an allowable service under the Medicaid 2176 waiver program, and as of April 1985 it was a part of 42 of the 95 approved 2176 waiver proposals—26 for the aged and disabled, 14 for the mentally retarded and developmentally disabled, and 2 for the mentally ill (87).

Some States (29 in fiscal year 1984) use Social Service Block Grant funds to support clients in adult day care (104), and some use funds allocated under Title 111 of the Older Americans Act. Other state and local funds and contributions from United Way organizations, churches, synagogues, service clubs, and other charity groups also support these centers (45).

As of 1985, the VA provided adult day care at five medical centers. Veterans with service-connected disabilities are eligible for adult day care for an indefinite period, but those with non-service-connected disabilities are limited to 6 months of this care (43).

### **Persons With Dementia in Adult Day Care Centers**

A 1984 survey of adult day care centers found that about 45 percent served persons with dementia (55). The recent NIAD survey did not ask specifi-

cially about dementia, but it did ask about characteristics of clients that may be related to dementia, such as supervision needs and incontinence. The survey found that about 45 percent of clients require supervision, and about 20 percent require constant supervision. In addition, about 8 percent are incontinent to the degree that they require changing during the attendance day (8). Many individuals in each of these categories may have dementing disorders.

Although the majority of adult day care centers continue to serve a mixed population, an increasing number are specializing in services for specific client groups (65). Specialization may evolve as providers encounter problems in serving clients with differing needs and capabilities or may occur in response to community needs (23). Adult day care centers designed specifically for persons with dementia are discussed in chapter 7.

The Alzheimer's Disease and Related Disorders Association (ADRDA), families, and many health care and social service providers are enthusiastic about the role of adult day care in the treatment of persons with dementia because they believe it can do three things: improve quality of life for these persons; provide respite for family caregivers; and perhaps postpone the need for nursing home care in some cases. The efficacy of adult day care in attaining these objectives for persons with dementia is discussed in chapter 7,

Research not specifically focused on persons with dementia indicates that adult day care programs can and do serve quite severely debilitated persons. For example, one study compared clients in an adult day care center and residents of a nursing home and found that the adult day care clients were more impaired in physical and mental health and self-care abilities than the nursing home residents, but the latter had more limited social and financial resources (166).

Although these findings indicate that severely debilitated clients can be maintained in adult day care centers, it is unclear whether adult day care is a substitute for nursing home care. Analysis of seven studies that addressed this question indicates that these centers were generally serving a different group of people than those who enter nursing homes, that the cost of adult day care was

not less than the cost of nursing home care, but that like home care clients, people in adult day care had higher morale than those in nursing homes (33).

### **Access to Adult Day Care**

Lack of a stable funding source for adult day care is a pervasive problem that limits access for individual clients and discourages the development of new centers (27,33). As discussed, many public programs and private groups provide some funding for adult day care. Still, among all long-term care services, adult day care is one of the two most commonly associated with client fees for service (the other is homemaker services) (15). At \$27 to \$31 a day, adult day care is clearly too expensive for most clients and families to afford on a regular basis.

Lack of centers also restricts access. Rural areas are particularly unlikely to have such centers because of low population density and lengthy travel time for clients. Innovative models of service delivery based on the satellite site concept have been developed (30), but OTA is not aware of any research that evaluates their effectiveness for persons with dementia.

NIAD survey data indicate that about half the centers that responded serve some black clients, and in these centers an average of 15 percent of all clients are black. About one-fourth of all centers said they serve some Hispanics, and in those centers 2 to 3 percent of the clients are Hispanic. Ten percent of centers said they serve some Native Americans, and 12 percent said they serve some Asians and Pacific Islanders (8). No information is available about why some centers serve no minority group clients.

A final factor that restricts access to adult day care is the admission and discharge policies of some centers. The NIAD survey found that many centers determine eligibility on a case-by-case basis. However, a minority reported that they deny admission to people who are incontinent, disruptive, combative, psychotic, too confused, or in need of constant supervision (8). Clearly, many persons with dementia would not be admitted to these centers.

### **Community Mental Health Centers**

Community mental health centers (CMHCs) are agencies that provide a range of mental health services to persons of all ages, primarily on an outpatient basis, although some also provide short-term inpatient care. CMHCs are not usually included in discussions of long-term care services. They are included here because they are local sites of mental health expertise—an element clearly lacking in the care provided by most long-term care facilities and agencies serving persons with dementia. Elderly people, the group that includes the vast majority of persons with dementia, have generally been underserved by CMHCs. However, some CMHC services regularly provided to other age groups and patient types, such as assessment, counseling, and support groups for patients and families, are needed by persons with dementia and not available in many communities.

Outpatient mental health centers have existed in this country for a long time, but the Federal program that created CMHCs was initiated in 1963 with passage of the Community Mental Health Services Act and subsequent authorization of Federal funding for the centers. Special services for elderly people were not required in the original act, and few such services were provided. However, amendments to the act passed in 1975 and 1978 mandated increased services for that group. In 1980, legislation was passed to provide additional funding for CMHCs with special programs for the elderly, but that legislation was never implemented because direct Federal funding for CMHCs and other programs was replaced by the Alcohol and Drug Abuse and Mental Health Services Block Grant, to be administered by the states. Federal funding for the block grant in its first year was 25 percent lower than combined Federal funding for CMHCs and substance abuse programs in the previous year (3,62,92).

No information is available about the number or proportion of persons with dementia served by CMHCs. The proportion of elderly persons among all clients served by these agencies increased from 3.4 percent in 1971 to 6 percent in 1982—still far below the proportion of elderly people in the population as a whole. The proportion of elderly people served by CMHCs did not change



from 1981 to 1984, but many CMHCs report a decrease in special programs for elderly people since 1981 (3,5).

Not all CMHCs that provide special services for elderly people also have special services for persons with dementia, but one study indicates that the two are often associated (51). The study found that CMHCs with special services for elderly people are five times more likely than other CHMCs to provide services for individuals with Alzheimer's disease and their families. Those that also had staff trained to provide services for persons with dementia were more than 8 times as likely to provide such services. And they were also more likely to provide services in satellite sites, such as nursing homes, senior centers, community residential facilities, or in the patient's home. Thus reported cutbacks in special CMHC programs for elderly people since 1981 could indicate that services for persons with dementia have also been cut back and that they are less frequently available in settings where such persons are usually seen and treated. Interestingly, CMHCs responding to the study cited above (51) reported that their most important need was for information about memory and cognitive problems in elderly people (50).

The change to block grant funding and the decrease in Federal funding for CMHCs resulted in reduced staff and increased caseloads in many centers, a decrease in the number of psychiatrists employed in CMHCs, and an increase in client fees (39,62). These changes may have affected the availability and quality of services for persons with dementia.

outpatient mental health services for persons with dementia could be provided by mental health professionals who are in private practice, including psychiatrists, clinical psychologists, psychiatric social workers, and psychiatric nurses, but research indicates that such services are seldom used by these patients. For example, the Epidemiologic Catchment Area survey in Baltimore found that no one with cognitive impairment who was over 65 had seen any mental health specialist in the preceding 6 months (26). A 1978 study found that fewer than 3 percent of the patients of mental health professionals in private practice were over 65 (107), and although this proportion has probably increased in recent years, relatively few such professionals treat elderly persons with dementia.

The original intent of the Federal legislation that created CHMCs was that those centers would provide mental health services and also would work with other community agencies and private practitioners to create a coordinated system of mental health care at the local level. This latter aspect has been particularly affected by decreases in funding, with the result that in many localities mental health services for all kinds of people are now more fragmented (39).

Despite funding cutbacks, some CMHCs do provide comprehensive mental health services for persons with dementia and their families and outreach to facilities and agencies in the community where such persons are cared for (4,63). Analysis of how these services are organized and funded could provide a model of service delivery that might be duplicated in other CMHCs.

## SERVICE DELIVERY SYSTEMS

Service delivery systems are methods for matching the needs of an individual with appropriate services. Some are relatively simple, such as providing the person or family with a list of community agencies that they can use to select the services they need. Others involve comprehensive assessment of an individual's needs, counseling with the person and family to evaluate different

care options, and followup to monitor the individual's adjustment and ensure that services are provided regularly. Still others are based on agreement among community agencies to designate a single agency as the entry point for long-term care services or to use a common assessment instrument to evaluate client needs. Another type of service delivery system is the social/Health Main-

tenance Organization (see ch. 12) and similar systems that provide a range of long-term care services through a single agency or program.

Each of these methods and many others are being used for persons with dementia and others who need long-term care. Although some have been analyzed extensively in terms of their effect on access, appropriateness, and cost of long-term care services for all kinds of people, OTA is not aware of any research that compares alternate methods of service delivery for persons with dementia.

The need for a service delivery system arises in part from the fragmentation of long-term care services at the community level and the complexity of Federal, State, and local programs that provide and fund such services. The three systems that provide services for persons with dementia—the medical or physical care system, the aging services system, and the mental health system—are generally disconnected. Gaps and overlapping services within each and between systems are common, and providers in one system are often unaware of services in the other two.

In addition to these problems, some individuals and families need assistance in evaluating their needs before they can select appropriate services. Others need counseling and emotional support to work through feelings of sadness, anger, and guilt associated with the patient's condition and care needs before they can evaluate long-term care options rationally or follow through on decisions about institutional placement or continued care at home.

Although the same problems affect everyone who needs long-term care, several characteristics may intensify the problems for persons with dementia and their families:

- persons with dementia frequently do not understand their condition and care needs and may refuse services they need;
- persons with dementia frequently lack the ability to evaluate care options, and family members or others must make important decisions for them (nursing home placement, sale of a home, etc.);
- there is no generally accepted assessment instrument to measure their care needs;

- there is no generally accepted method of evaluating their capacity to make decisions; and
- they often come to the attention of health care and social service providers and community agencies only when their need for services is desperate, and the assessment/referral/decisionmaking process frequently takes place in an atmosphere of crisis.

The need for improving in the service delivery system for persons with dementia is evident from the responses to the OTA survey of family caregivers. Many respondents did not know whether home care, board and care, respite, adult day care, or nursing home services were available. Likewise, almost half reported that they had difficulty finding a doctor who could adequately care for the person with dementia. When asked about the most important services, families identified the need for assistance in locating people or organizations that provide care and for help in applying for Medicaid, Social Security Disability benefits, SSI, and so on as the second and third most essential (following only the need for a paid companion to give caregivers a rest) (122).

The reports of several State Alzheimer's disease task forces stress the need for good information and referral systems (27,28)40). The experience of the Massachusetts Governor's Committee on Alzheimer's Disease is instructive:

At the beginning of our examination of available community services, one member was assigned the task of calling facilities on a random list and asking if they had specialized services for Alzheimer's patients. Without exception, the caller was told that such specialized services existed. When questioned more specifically) most facilities failed to demonstrate any special capability to assist the Alzheimer's client. In fact, in some cases, facilities which initially stated that they had "specialized units or services" were ill-prepared to assist an Alzheimer's patient or family member (27).

Many different agencies and community service providers are involved in matching the needs of persons with dementia to available services. Hospitals play a major role in service delivery, sometimes because no other agency has been available to serve this function. Anecdotal evidence

indicates that persons with dementia are frequently admitted to a hospital when family caregivers are no longer able to manage them, or when their ability to function independently has deteriorated to such a low level that neighbors or others insist that something must be done. In such situations, the person may or may not have an acute medical condition, but the primary (although sometimes unspoken) reason for hospitalization is the need for a long-term care plan.

Hospital discharge planning units, often staffed by social workers, are primarily responsible for developing a plan of care for patients who need long-term institutional care or formal services at home. This process—which may involve assessment of the patient's physical, emotional, and cognitive status and social supports; consultation with the patient, the family, the doctor, nurses, and others; and location of appropriate services and funding—can be time-consuming. In the past, patients sometimes remained in the hospital for prolonged periods while a discharge plan was developed. Now, however, the Medicare Prospective Payment System and other public and private programs that create incentives for shorter stays are reducing the time available for discharge planning in hospitals. Analysis of the impact of these changes on discharge planning for persons with dementia is needed.

Physicians, other health care providers, staff in agencies that serve elderly and disabled people,

and many others are also involved in referring persons with dementia to long-term care services. Staff in adult day care centers that serve persons with dementia and ADRDA staff and support groups frequently provide information about available services and assistance with decisionmaking for families of these patients.

Evaluation of alternate methods of service delivery for persons with dementia is beyond the scope of this OTA assessment. Some of the questions that need to be answered are:

- Which methods of service delivery are most effective?
- Are they best served by a delivery system that focuses on persons with dementia or by a system that serves all persons who need long-term care?
- What are the appropriate roles of families, voluntary caregiver support groups, and public and private agencies in the service delivery system?

Some answers may be found on analysis of data collected for the National Channeling Demonstration project—a large-scale study of two models of service delivery funded by the U.S. Department of Health and Human Services—and other studies of service delivery systems (52). Other answers must await the outcome of new studies and demonstration projects.

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