

Chapter 1

Summary and Overview

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INTRODUCTION

In 1987, OTA issued a comprehensive report on Alzheimer's disease and other diseases that cause dementia, *Losing a Million Minds: Confronting the Tragedy of Alzheimer's and Other Dementias* (831). That report described the devastating impact of dementia on the person and the equally tragic consequences for the person's family. It discussed the care needs of people with dementia and the complementary roles of families, community agencies, and other paid service providers in meeting those needs. The report described Federal policy options to increase services, educate and train service providers, improve quality of care, and provide adequate funding for services through public and private sources.

A survey of family caregivers of people with dementia, conducted for OTA in 1986, raised one issue not addressed in the 1987 report. The survey found that, in addition to many other problems, family caregivers have great difficulty locating services. Many caregivers said they did not know what services were available in their community. When asked what kind of help they needed to care for their relative with dementia, the caregivers identified the need for assistance in locating people or organizations that provide care as second most important, following only the need for a paid companion to give the caregiver a rest (926).

Many of the State task forces and committees that have studied the problem of Alzheimer's disease and other diseases that cause dementia have noted the difficulties people encounter in locating needed services (see reports from Arizona (37), California (99), Connecticut (142), Florida (215), Georgia (246), Illinois (351), Iowa (360), Kansas (396), Kentucky (408), Maryland (497), Massachusetts (500), Michigan (530), Minnesota (536), Missouri (543), Nebraska (592), New Jersey (599), New York (602), Ohio (621), Oklahoma (626), Texas

(790), Virginia (870), and Wisconsin (920)). The Wisconsin Task Force on Alzheimer's Disease and Other Irreversible Dementias reported:

Alzheimer's family members often tell distressing stories about not knowing where to go for help, going from one service provider to another in a vain search for assistance, and being misinformed about the availability of services or eligibility for programs (918).

Family caregivers told the task forces and committees in other States:

I tried to ascertain just where and what I might do to get some help. My help came from a support group. Nobody else knew anything (599).

After a 3-year search, I am just learning of the different resources that are available. Why didn't I know sooner (412)?

We just scratched and dug on our own (531).

Many of the services and resources are, indeed, available. They are not well publicized so people don't know where to go for help. As an educated person who is part of the health care system, I found it difficult to obtain help for my father. Someone older, more upset, or confused and not well versed in our system might have found it impossible (412).

An adult day care provider told the Maryland Task Force: "Families don't even know what to ask for and may go through a maze of blind alleys before help is obtained" (696). The Texas Alzheimer Task Force concluded that: "One of the greatest burdens of the family caregiver is the lack of knowledge of community resources and the ability to obtain these resources" (790).

This OTA report analyzes the problem families and others face in locating and arranging appropriate services for people with dementia and discusses Federal policy options for the development of a system to resolve the problem. This chapter provides an overview of the problem and discusses the factors that determine

what kind of system is needed to link people with dementia to services, including the relevant characteristics of people with dementia, of their families and other informal caregivers (if they have any), and of the service environment. The chapter presents a framework, including the essential components and criteria, for an effective system to link people with dementia to services. It describes many of the public and private agencies, organizations, and individuals that currently help some people with dementia and their caregivers find services. Lastly, the chapter identifies and discusses Federal policy options with respect to the development of an effective system to link people with dementia to services. The policy options address questions such as whether the system should serve people with dementia exclusively or other people as well, whether the agencies or organizations that constitute the system should also be responsible for allocating services and funding for services, and whether those agencies or organizations should be designated by the Federal Government or by the States.

In the abstract, the development of an effective system to link people with dementia to services seems far removed from the terrible personal losses associated with dementia for patients and their families. The need for such a system comes alive, however, for people who try to find appropriate services for a relative, friend, or client with dementia and confront the existing lack of accurate information about services and about funding for services and the often bewildering array of public and private agencies, individuals, funding sources, eligibility criteria, rules, and regulations that constitute the service environment in many communities.

Although the need for an effective linking system is clear, establishing such a system will be difficult, in part because of “turf issues.” Many public and private agencies, organizations, individual health care and social service professionals, service providers, and others currently link some people with dementia to services and consider this function as part of their role. Designating certain agencies, organi-

zations, or professional or provider groups to constitute a system to link people with dementia to services will engender resentment and resistance from the agencies, organizations, and professional and provider groups that are not chosen. One alternative is to designate a consortium of agencies and organizations to constitute the linking system in each community, but the process of creating and maintaining an effective consortium is not without its own difficulties. Given these obstacles, some people might argue that it is best not to try to establish an effective linking system. On the other hand, without such a system, some, and probably many, people with dementia will not be connected to appropriate services, and families and other informal caregivers, who already must bear the physical and emotional demands of caregiving, will continue to experience the frustration of not being able to obtain accurate information and assistance in locating and arranging services.

Overview of the Problem

Diseases that cause dementia destroy a person's ability to understand events and people in his or her environment and to plan for and take care of himself or herself. Alzheimer's disease and many other diseases that cause dementia are progressive, so that over time the affected individual becomes less able to function independently and more dependent on others for care. Eventually, many people with dementia become so debilitated that they require total care, 24 hours a day, for the rest of their lives.

As a dementia patient's condition worsens, his or her family and friends are faced with severe emotional losses—loss of the person they knew and meaningful aspects of the relationship they had with that person. They are faced simultaneously with the person's need for supervision, physical care, and many other kinds of assistance to compensate for his or her lost abilities. Because people with dementia often live for many years after the onset of symptoms, the family's experience of emotional loss and the patient's need for care are frequently prolonged.



Photo credit: Suzie Fitzhugh

Alzheimer's disease and many other dementing diseases destroy a person's ability to plan for and take care of herself or himself. As a dementia patient's condition worsens, the person must depend increasingly on her or his family or friends for supervision, physical care, and many other kinds of assistance to compensate for her or his lost abilities.

People with dementia who have no family or friends face alone their loss of memory and other cognitive functions and their decreasing ability to care for themselves independently. Although they manage on their own for a while, eventually they also need 24-hour care and supervision.

Some diseases that cause dementia are reversible with available treatments, but most are not. A careful medical evaluation can identify reversible dementias and indicate appropriate treatment, but there is no known cure for

Alzheimer's disease or many of the other diseases that cause dementia. OTA's 1987 report stressed the importance of biomedical research to find ways to prevent or cure those diseases. That report concluded that such solutions are not likely in the near future. Until effective methods of prevention or cure are discovered, ways must be found to take care of people who suffer from the diseases.

Formal services, including medical, nursing, and social services; adult day care; in-home,

nursing home, and respite care; and legal and financial counseling, can lessen the physical and financial burden for families and others who are taking care of people with irreversible dementia.¹ Good formal services—those that are appropriate to the needs of the person and his or her caregivers—also may mitigate the potentially devastating emotional impact of dementia on the family, support the patient's remaining abilities, and perhaps lessen the patient's anxiety and suffering.

As awareness of Alzheimer's disease and other diseases that cause dementia has increased in the past few years, appropriate services have been developed in many communities. Such services are not available everywhere, however, and more services are needed in most communities. Where appropriate services are available, they are often expensive, especially when they are needed for prolonged periods. Public funding and private insurance coverage for them frequently are inadequate.

Even if appropriate services are available and affordable or reimbursable through public programs or private insurance, families and others still may not be able to find them. This problem is, in part, due to the complexity and fragmentation of services at the community level. In many communities, health care, long-term care, social, and other services for people with dementia (and for people with other chronic conditions) are provided by numerous public and private agencies and individuals. The services are not coordinated, and the providers have different rules about whom they serve and what they offer. Public funding is available for some services through Federal, State, or local programs, but each program has complex regulations about who is eligible, what services are covered, who provides them, for how long, and in which settings. Since there is seldom any information about the quality of services provided by different agencies and individuals, families and others often have no basis for selecting one over another. Many families and

others suffer, as a result. According to the Alzheimer's Association:

A recurring theme in the history of each family's problems is the difficulty experienced in finding both medical and social resources for the diagnosis, management, and, particularly, the care of the patient whose mind and body are failing (16).

Physicians, other health care and social service professionals, service providers, and others refer some patients and their families to services and sometimes arrange services for them. Many public and private agencies and organizations provide information and referrals and case management to help people find services. The assistance provided by those individuals, agencies, and organizations meets the needs of some people with dementia and their families, but other patients and families do not get any assistance in locating and arranging services. Some families contact one agency after another in a haphazard, lengthy search for needed services. That process adds to the frustration of families who are already coping with the emotional losses associated with dementia and with the patient's need for physical care and supervision. In the end, some patients do not receive any services, and some receive services that are not appropriate for their needs.

For families and other informal caregivers, the problem of locating and arranging services is only one of the difficult aspects of caring for a person with dementia. Likewise, from a public policy perspective, the problem of locating and arranging services is only one of the problems that restrict access to appropriate services for people with dementia. Four other problems that restrict access to appropriate services are:

- the lack of sufficient services,
- . the lack of adequate funding for services,
- . the lack of education and training for service providers, and
- . the poor quality of some services.

¹See table 1-2 later in this chapter for a list of the services that maybe needed for people with dementia.

The focus in this report on the problem of locating and arranging services is not intended to detract from the importance of the other four problems, all of which were discussed at length in OTA's 1987 report (831). Ideally, through the combined efforts of public and private agencies and organizations, high quality services provided by well-trained individuals and adequate funding for services would be available to all people with dementia. That outcome is unlikely, however, at least in the near future.

Moreover, even if the other four problems were solved, the lack of effective methods of locating and arranging services would continue to restrict some people's access to appropriate services. Evidence discussed later in this report indicates that high quality services may not always be used, even when funding is available. Some patients and families do not know about the services. Other patients and families may need help in defining their needs, understanding how the available services can help, and arranging services. Even if high quality services were available everywhere, the problem of access would not necessarily be solved for those people.

In addition, an effective system to link people with dementia to services might help to resolve some of the other problems that restrict access. For example, precise information about service gaps often is a crucial factor in political and administrative decisions to establish or fund new services. If agencies that link people with dementia to services kept accurate records of the services that are needed but not available in their communities, that information might be used by policymakers to establish or fund new services.

A system to link people with dementia to services might also play a role in improving quality of care. OTA's research indicates that most agencies that help people find services do not have formal procedures to evaluate the quality of services to which they refer people, but some agencies do have such procedures (see ch. 5). It is reasonable to expect that if agencies gave their clients information about the quality

of available services or referred them only to service providers who met certain standards, over time providers would try to meet the standards, and quality of care would improve generally. This report considers whether a linking system should concern itself with the quality of services to which it refers people, and if so, how.

The relationship between a linking system and funding for services is problematic. Many agencies that link people to services also help them find sources of funding for services. Public and private funding for services are not adequate, however. In 1988, 1989, and 1990, several bills were introduced in Congress to expand Federal funding for a variety of long-term care services. Provisions in most of the bills indicate that the agencies designated to administer the new benefits also would link people to services. Although the expanded funding for services proposed in the bills would benefit many people with dementia, it is not clear that the linking process proposed in the bills would meet their needs. In addition, some members of the advisory panel for this OTA study and other commentators are opposed to having the same agencies link people to services and administer or control funding for services. They fear that agencies that control funding for services may restrict, rather than facilitate, clients' access to needed services in order to limit the cost of the services to the agency. Both those concerns are discussed later in this chapter.

The issues of locating and arranging services, service availability, funding, provider education and training, and quality of care are interrelated. Some people might argue that one of the other issues is more important than locating and arranging services, and that limited public funds should be spent to create services, increase funding for services, support provider education and training, or improve quality rather than to develop an effective linking system. Clearly, however, better methods of linking people with dementia to services are necessary to ensure that they have access to appropriate care.

Congressional Interest

In recent years, with growing public awareness of and concern about Alzheimer's disease and other diseases that cause dementia, Congress responded first by funding biomedical research. Federal funding for biomedical research on Alzheimer's disease increased from less than \$4 million in fiscal year 1976 to more than \$140 million in fiscal year 1990. Federal funding for health services research also has increased, although much more slowly.

Legislation to improve access to services is just beginning. In 1987, the reauthorization of the Older Americans Act (Public Law 100-175) included new in-home services for frail, elderly people and specifically designated people with Alzheimer's disease and related disorders as eligible for the services. Each of the bills introduced in Congress in 1988, 1989, and 1990 to expand Federal funding for long-term care services defined eligibility for the services explicitly to include people with dementia. Most congressional attention has focused thus far on the issues of service availability and funding for services, however. Less attention has been paid to the question of how to link people with dementia to the services they need.

The topic of this report spans many Federal programs and crosses the jurisdictional lines of several congressional committees. The study was requested by the Senate Committee on Labor and Human Resources, Senator Charles E. Grassley, the House Committee on Energy and Commerce, and the House Select Committee on Aging. OTA received letters of support for the study from the Senate Special Committee on Aging; Senator Frank H. Murkowski, ranking minority member of the Senate Committee on Veterans' Affairs; the House Committee on Veterans' Affairs; and Congresswoman Olympia J. Snowe.

The primary concerns of the requesting committees and individual members of Congress were to improve access to appropriate services for people with dementia and to support family caregivers. The committees were particularly

concerned about access problems in the Federal programs over which they have jurisdiction—i.e., Medicare, Medicaid, Older Americans Act programs, and programs of the U.S. Department of Veterans Affairs. The requesters were also concerned about the complexity and fragmentation of services and the competing claims of different agencies and professional groups that each of them should be the designated case manager. The requesting committees asked OTA to identify methods of locating and arranging services that are successful in some localities and might serve as models for other localities. The requesters agreed that a publicly funded system to link people with dementia to services should support the efforts of private groups, not supplant them, and several requesters stressed the need to evaluate the role of voluntary organizations in the service delivery system.

Locating Services for Mrs. D: A Case Example

The true story of one family's efforts to locate and arrange services for a relative with dementia (Mrs. D) is related in box 1-A. The process of finding services is different in every case: each person is different; some people with dementia do not have a family or other informal caregiver; families vary; and the number and type of service providers and the availability of public and private funding for services differ in every locality. Nevertheless, the experience of Mrs. D and her family contains some common themes and illustrates the impact on people of the fragmentation of services at the community level and the lack of an effective system. The story covers only a 1-month period. Many families of people with dementia experience similar problems for years.

Mrs. D has several advantages that many people with dementia do not have. She is not poor; she has a supportive family; and there are a substantial number of service providers and some public and private funding for services available to her. Despite those advantages, locating and arranging services for Mrs. D proved to be a difficult, frustrating process.

Box 1-A—Locating Services for Mrs. D

On February 29, 1988, Mrs. D, a 70-year-old widow, was hospitalized as a result of convulsions. She had been living alone in an apartment below the apartment of one of her three sons. The family knew that she was becoming confused, but when it turned out that the convulsions occurred because she mistakenly took too much of a prescribed diuretic medicine, they realized that she needed more supervision and assistance than she had been getting.

One son who lives 300 miles away took leave from work, and he and his two brothers and their wives who live in the area began to work together on a plan for Mrs. D. Their father had died the year before, after 8 years in a nursing home, and they were determined to arrange care for her at home.

On March 4th, while Mrs. D was still in the hospital, the hospital discharge planner gave the family a list of eight home care agencies in the area and suggested that they contact the local Medicaid office to determine whether Medicaid would pay for Mrs. D's home care.

One son called all the home care agencies. He was asked repeatedly whether he wanted a "homemaker" or a "home health aide." When he inquired about the difference, he was told that a homemaker was cheaper than a home health aide. One agency said that homemakers do not touch the patient, whereas home health aides do. Other agencies said this distinction was not true of their homemakers and home health aides, but they did not offer a better explanation of the difference between homemakers and home health aides.

The home care agencies quoted prices ranging from \$7 to \$12 an hour. Since Mrs. D needed supervision for as many as 16 hours a day, the cost could be \$112 to \$192 a day. Several agencies said they did not think Medicaid would pay for home care for her. Moreover, most of the agencies said that because of staff shortages, they could only "try to find someone." The family finally chose the nonprofit home care agency, partly because it had the lowest prices. Arrangements were made for a home visit.

One son contacted the Medicaid agency and was told that Medicaid might pay for a homemaker for up to 10 hours a day, 7 days a week. First, however, various procedures were needed to determine whether Mrs. D's physical condition and functioning were sufficiently impaired to meet Medicaid requirements for home care and whether she was financially eligible for Medicaid. Her income was slightly above the State Medicaid limit, but as her sons understood it, if she used part of her income to pay for some home care services, Medicaid might cover the rest.

On March 8th, the hospital called to say that Mrs. D was to be discharged that day. The family had expected she would be in the hospital at least 4 more days. One son called the doctor, who first said that Medicare would not pay for any more days in the hospital and that they had to take Mrs. D home immediately. The son argued that she had to stay at least 3 more days. Finally they agreed that she would be discharged in 2 days.

In the meantime, one son called the county Office on Aging, an agency that serves as the local area agency on aging (AAA) and as such is federally mandated to ensure the availability of information and referral for elderly people. He was asked whether Mrs. D needed "weatherization assistance" or food stamps. When the answer was no to both questions, he was told that the Office on Aging could not help.

The family continued to call every agency they heard about. They were repeatedly referred to the Office on Aging, and they called back once. That time, they got a completely different response, but again a response that was irrelevant to Mrs. D's situation.

Thus far, the family had not been given a diagnosis for Mrs. D's confusion. Her primary physician had said: "You know, it happens to all old people. She may improve." One son was convinced that she had an irreversible, dementing disease, but the other two sons accepted the doctor's hopeful suggestion that she might improve. As the difficulty of arranging home care and the potential cost of the services became clearer to the family, the three sons argued with each other about whether the services were really needed and, if so, for how long.

At a certain point, someone (the family can't remember who it was) suggested that they call the local senior center. The woman who answered the phone at the senior center said that the person they needed to talk to was out sick, and they would have to call back. She added however, that her mother had Alzheimer's disease and that she knew of three adult day centers in the area that provided good care for people with dementia. She gave the family the name and telephone number of the one she thought was best.

(continued on next page)

Box 1-A—Locating Services for Mrs. D-(continued)

Mrs. D's family had not considered adult day care for her and did not know much about it, but one son called. He talked to the director of recreation and volunteer programs who gave the impression immediately that he understood the problem, knew about dementia, and might be able to help. The son arranged to visit the day center and called the hospital to have *Mrs. D's* records sent there so the center could decide whether to accept her.

On March 10th, *Mrs. D* came home even though the arrangements for her care had not been settled. Her sons continued calling service providers. They found it was difficult to supervise and care for her and at the same time make calls to arrange services. In the next 2 days, eight different people came out to evaluate *Mrs. D*. Some came from the home care agency, and some came from the Medicaid agency. The sons did not understand exactly who any of these people were or how they related to each other.

Mrs. D was very confused. She did not always recognize her son from out of town, who was staying with her. Frequently she got angry at him and at her daughter-in-law who lived in the apartment above her (whom she referred to as "that government lady upstairs") because they would not let her cook and do other things she wanted. She liked all the "visitors" who came to evaluate her. Once she was home, it was clear to everyone that she should not be left alone. Some family members began to wonder whether home care was even possible.

On March 12th, the son from out of town went home. The plan was that starting the next Monday, a home health aide paid by Medicaid would stay with *Mrs. D* seven days a week from 9:00 a.m. to 3:00 p.m. The family had hired another aide who would work from 3:00 to 9:00 p.m. and would be paid from *Mrs. D's* income. The son and daughter-in-law in the apartment upstairs would watch out for her at night. An application for adult day care was pending.

On March 14th, the first aide did not show up. It turned out she had quit the agency the previous Friday. The aide the family had hired privately came on time and worked out well. The next day an aide from the agency also came on time. The rest of that week went O.K. *Mrs. D* "fired" both aides frequently. The agency aide went to the daughter-in-law upstairs, who reassured her that *Mrs. D* needed help and told her that she should stay. The aide whom the family had hired turned out to be an easy going person with a lot of common sense; she didn't need to ask whether she should stay.

At the end of the week, the adult day center said that *Mrs. D* could come there, 5 days a week, starting in 10 days. The aide from the agency misunderstood, thought the plan was starting sooner, and did not show up for work the next Monday, leaving *Mrs. D* alone. In the meantime, one of *Mrs. D's* sons hired a college student to come in from 6:30 a.m. to 8:30 a.m., three mornings a week, because he was afraid that she was not safe alone then.

The adult day center has a grant for some of its costs, and clients are not required to pay a fee, but they are encouraged to "contribute." *Mrs. D's* family was told that her "contribution" would be \$15 a day.

The center could not provide transportation for *Mrs. D*. They have plans to purchase a bus in the future to pick up clients, but they do not expect to pick people up from as far away as *Mrs. D's* apartment. Medicaid can pay for transportation to the doctor and the hospital but not to the adult day center because, according to Medicaid regulations, it is a "social day center," Medicaid could pay for transportation to a center that it defined as a "medical day center." *Mrs. D's* family pointed out to the Medicaid case worker that Medicaid was paying the home care agency \$11 an hour for an aide from **9:00** a.m. to 3:00 p.m. (although the aide got only \$4.50) and that the adult day care would cost Medicaid nothing. The worker said that Medicaid's regulations on "social day centers" and "medical day centers" were firm and that no exception could be made in this case.

Luckily, the aide that the family was paying privately said she would come every morning, get *Mrs. D* ready, take her to day care, and bring her home again in the afternoon. The family was paying her \$7 an hour. Medicaid agreed to pay for another aide for 10 hours a day on weekends.

As of March 25th, the family was confident that the adult day center would provide good care. Since it is affiliated with a nursing home, they believed that she had "one foot in the door there" if she eventually needed nursing home care. They hoped the private aide they found would stick with the job. They were worried about *Mrs. D* at night, and for a few days they worried about what to do if she refused to go to the adult day center. Then they decided that she just didn't have that choice.

SOURCE: Office of Technology Assessment, 1990.

FACTORS THAT DETERMINE THE KIND OF SYSTEM THAT IS NEEDED TO LINK PEOPLE WITH DEMENTIA TO SERVICES

In addressing the question of how to link people with dementia to appropriate services, OTA made no assumptions about what kind of system would be needed. By system, in this context, OTA means a group of interacting agencies and/or organizations that form a network that serves the common purpose of linking people with dementia to services. The system does not necessarily have to be federally administered, nor does it have to be implemented by a single category of agencies nationwide.

OTA's staff and the advisory panel for the study considered many possible systems, ranging from a relatively simple telephone information and referral system that would refer families and others to needed services to a comprehensive service system that would not only locate and arrange but also provide and pay for many of the services a person with dementia might need. The staff and advisory panel also considered whether the system—of whatever kind—should serve people with dementia exclusively or people with dementia and people with other diseases and conditions as well.

OTA concluded that three factors determine the kind of system that is needed to link people with dementia to services:

- the characteristics and service needs of people with dementia;
- the characteristics of their families or other informal caregivers (if they have any); and
- the characteristics of the service environment, including the number and type of agencies and individuals that provide services in a community and the sources of public and private funding for services.

The following discussion presents some general information about dementia and about each of the three factors that is relevant to determining what kind of system is needed to link people

with dementia to services. Although the discussion identifies some common characteristics of patients, families, and service environments, it gives equal emphasis to their heterogeneity, since an effective system to link people with dementia to services must be responsive to their diverse needs and situations.

Characteristics and Care Needs of People With Dementia

On the basis of a 1985 review of epidemiologic studies, OTA estimates that there are now about 1.8 million Americans who have *severe* dementia: that is, they are so incapacitated that others must care for them continually (152). OTA estimates that an additional 1 million to 5 million Americans have *mild or moderate* dementia.

The prevalence of dementia increases with age. The 1985 review of epidemiologic studies found that the prevalence of *severe* dementia increases from less than 1 percent of people under age 65, to about 1 percent of those age 65 to 74, 7 percent of those age 75 to 84, and 25 percent of those over age 85 (152). Because of the aging of the U.S. population, the number of people with dementia will increase dramatically in coming decades.

Diseases That Cause Dementia

Dementia is a clinical syndrome characterized by the decline of mental functions in an alert individual. It can be caused by more than 70 diseases and conditions, including the following:

- progressive degenerative diseases, including those in which dementia is inevitable, such as Alzheimer's disease and Pick's disease, and those in which dementia may or may not occur, such as amyotrophic lateral sclerosis (ALS) and Parkinson's and Huntington's diseases;
- cardiovascular diseases that decrease blood supply to the brain: this can cause loss of brain tissue in the form of many small strokes (multi-infarct dementia) or one or more large strokes; bleeding into the brain,

usually related to hypertension, can also cause loss of brain tissue;

- severe depression;
- intoxication caused by prescription and nonprescription drugs and alcohol;
- infections that affect the brain, including Creutzfeldt-Jakob Disease and acquired immunodeficiency syndrome (AIDS);
- metabolic disorders;
- nutritional disorders;
- normal pressure hydrocephalus; and
- space-occupying lesions, such as brain tumors and subdural hematoma (847).

Alzheimer's disease is by far the most common cause of dementia. A study of noninstitutionalized individuals over age 65 in East Boston, Massachusetts, found that 91 percent of the individuals who had moderate or severe dementia had Alzheimer's disease, including 84 percent who had only Alzheimer's disease and 7 percent who had Alzheimer's disease plus another dementing illness (192).² Less than 5 percent had dementia caused by cardiovascular disease. The extent to which these findings from the East Boston study can be extrapolated to the population as a whole is unclear. Prior to the release of the findings from East Boston, other researchers had estimated that Alzheimer's disease accounted for only 50 to 60 percent of all cases of dementia, and that cardiovascular diseases accounted for 10 to 20 percent of all cases of dementia (399,794). Many researchers and clinicians have noted that Alzheimer's and other diseases that cause dementia coexist in some people (399,554,704,794).

Dementia in people with AIDS has received considerable attention from researchers, clinicians, and the media. Although prevalence estimates vary, researchers agree that most AIDS patients develop dementia at some time in the course of their illness (590,654). People with

AIDS dementia face many of the same problems in locating appropriate services as people with other dementing diseases and some additional problems as well. This report does not address the difficult problems in locating services that confront AIDS patients specifically.

This report's main focus is on problems in locating and arranging services for people with Alzheimer's disease and other dementing diseases that primarily affect elderly people. Accurate identification of the disease that is causing dementia in an individual often is difficult, however. In Alzheimer's and some other dementing diseases, a diagnosis can only be confirmed with certainty by an autopsy after the patient's death (847). Diagnostic accuracy for Alzheimer's disease (confirmed by autopsy) approaches 90 percent in some specialized centers but is lower in other settings (226,400,831). Because of the lack of certainty about diagnosis in many cases, this report uses the generic phrase "people with dementia" except in describing research or programs that target people with a specific disease—usually Alzheimer's.

Cognitive and Self-Care Deficits

By definition, dementia involves some degree of memory loss. Other cognitive abilities frequently diminished or lost in dementia include intelligence, learning ability, problem solving, judgment, comprehension, attention, and orientation to time and place and to oneself. Language abilities, including the ability to express oneself meaningfully and to understand what others communicate, usually also are affected.

Researchers and clinicians have described a general progression of cognitive losses that typifies Alzheimer's disease and other primary degenerative dementias (339,511,710,711). It is important to note, however, that individuals with primary degenerative dementias vary in the

²The study in East Boston involved administering a brief memory test to 3,623 noninstitutionalized individuals over age 65 and then providing a comprehensive evaluation for 467 of those individuals, including 170 individuals who had performed well on the brief memory test, 101 individuals who had performed at an intermediate level on the test, and 196 individuals who had performed poorly on the test (192). Based on an analysis of the results of the comprehensive evaluations, the researchers concluded that at least 10.3 percent of all people over age 65 have Alzheimer's disease, including 3 percent of those age 65 to 74, 18.7 percent of those age 75 to 84, and 47.2 percent of those over age 85. Extrapolating to the population as a whole, these figures suggest that there are now about 4 million people with Alzheimer's disease in the United States. The prevalence of severe, moderate, and mild dementia due to Alzheimer's disease cannot be ascertained from the East Boston data.

rate and order in which cognitive losses occur (62,77). Individuals with multi-infarct and other dementing diseases also vary in the type, progression, and ultimate severity of their cognitive losses. Because of these variations and because, at any one time, individuals with dementia are at different points in their disease, people to be served by a linking system will differ greatly in the type and overall severity of their cognitive deficits.

People with dementia also differ in their self-care abilities. Variations in self-care abilities reflect, in part, the type and severity of individuals' cognitive deficits, their remaining cognitive abilities, and coexisting physical or emotional conditions. Cognitive deficits due to dementia often limit a person's ability to perform activities such as shopping, cleaning, cooking, using a telephone, and handling money, which are often referred to as "instrumental activities of daily living" (IADLs). As the person's cognitive deficits increase, the person also may become unable to independently perform personal care activities, such as bathing, dressing, or using the toilet, which are often called "activities of daily living" (ADLs). The person may forget how to perform any of the activities or even that they are necessary. Many dementing diseases cause neurological changes that create movement and gait disorders, swallowing disorders, speech impairments, and similar conditions that also limit a person's self-care abilities. Variations in self-care abilities also relate to environmental factors; for example, some people with dementia can perform certain activities in a familiar environment but not an unfamiliar one. Thus, the individuals to be served by a linking system will vary in the type and overall severity of their self-care deficits.

Self-care deficits generally increase as the severity of a person's cognitive deficits increase (217,293,787), but the correlation between the two is not exact. Some people with significant cognitive deficits are independent in self-care activities, and others with mild cognitive deficits have significant self-care deficits (760,895, 913).

Psychiatric and Behavioral Problems

Depression and other psychiatric and behavioral problems are common in people with dementia. Depression can cause dementia or co-exist with another dementing disorder. Differential diagnosis is difficult in such cases, but research indicates that one-fifth to one-third of people with Alzheimer's or another dementing disease have coexisting depression (695,704, 705).

Depression in people with dementia generally responds well to treatment (usually antidepressant medications) (444,512,682,705). If a person's cognitive deficit is due only to depression, his or her normal cognitive status may be restored with treatment. If the depression coexists with another dementing disorder, treatment usually does not improve the person's cognitive status. Often, however, it improves the person's mood and functioning—important considerations from the point of view of families and other caregivers (680,697).

Other psychiatric disorders that occur in some people with dementia are:

- suspiciousness and paranoia, identified in one-fourth to one-half of people with Alzheimer's disease (295,429,525,681,728, 787);
- visual and auditory hallucinations, found in at least one-fourth of people with Alzheimer's and other dementing diseases (242,525,681,728,787);
- withdrawal and reduced emotional responsiveness, found in three-quarters of the people with Alzheimer's disease in one study (729); and
- agitation and restlessness, found in 24 to 89 percent of people with dementia, depending on the study (242,479,729,787).

Behavioral problems that occur in some people with dementia are wandering, hitting, severe emotional outbursts, and disruptiveness at night (295,479,681). Not all people with dementia have behavioral problems, but when such problems occur, they often cause anxiety,

embarrassment, fear, anger, and exhaustion for families and other caregivers. Even if the disease that causes a person's dementia cannot be cured, psychiatric disorders and behavioral problems associated with it usually can be alleviated with changes in the person's daily activities, modifications to his or her environment, training for caregivers in how to respond, medications, and in some cases, counseling and relaxation therapies for the patient.

Coexisting Medical Conditions

Many people with dementia have other medical conditions unrelated or only peripherally related to their dementing disease (71,211,479,921). A random sample of people with dementia served by a community mental health center in Washington State, found, for example, that they had an average of more than three co-existing medical conditions. A third or more of the people had cardiac or vascular conditions, arthritis, and/or visual or hearing impairments (see table 1-1). Any coexisting medical condition can exacerbate a dementia patient's cognitive and self-care deficits and complicate his or her care. Conversely, treatment of the condition can maintain or restore the person's physical health and maximize his or her functioning (74,487,680,908,915).

People With Dementia Who Live Alone

Most studies of people with dementia show that virtually all such people live either in the community with someone else or in a nursing home or other residential care facility (see, for example, Friss, 1989 (235); George, 1983 (242); Lusky et al., 1988 (479)). At the start of this assessment, OTA assumed that very few people with dementia were living alone and that those few probably were not severely cognitively impaired. OTA also assumed that a linking system would interact primarily with family members and other informal caregivers and should be designed to respond to their needs.

Table 1-1--Coexisting Medical Conditions in 100 People With Dementia Served by the Community Mental Health Center in Spokane, Washington, 1988

Illness/Condition	Percent of people affected
Cardiac	40%
Vascular	31
Hypertension	34
Stroke	26
Arthritis	37
Vision impairment	50
Cataracts	30
Glaucoma	10
Hearing impairment	34
Speech impairment	19
Stomach ulcer	14
Chronic obstructive pulmonary disease	12
Cancer	11
Diabetes	11
Hernia	10
Parkinson's disease	9
Seizures	9
Osteoporosis/kyphosis	8
Urinary tract infection	8
Thyroid	5
Prostate	5
Diverticulitis	5
All others	12
None	7
Unknown	2

SOURCE: R. Raschko, director, Elderly Services, Spokane Community Mental Health Center, Spokane, WA, letter to the Office of Technology Assessment, U.S. Congress, Washington, DO, Mar. 8, 1988.

All those assumptions were wrong. The studies that show very small proportions of people with dementia living alone are based on interviews with family members and other informal caregivers. OTA's review of population-based studies and studies that focus on patients rather than caregivers shows that at least 20 percent of people with dementia live alone and that some of them are severely impaired. The Epidemiologic Catchment Area (ECA) Survey, a large-scale, population-based study conducted in five sites in the early 1980s, found that 24 percent of people with severe cognitive impairment were living alone.³ The proportion varied considerably among sites, from 15 percent in New Haven, Connecticut to 44 percent in Durham, North Carolina (842). Twenty-one percent of people with dementia who were seen at the six California Alzheimer's Disease Diag-

³Severe cognitive impairment was defined in the survey as a score of 17 or less on the Mini-Mental State Examination (218). By that definition, the prevalence of severe cognitive impairment at the five sites averaged 1.3 percent in people over age 18 (range: 1.2 to 3.3 percent) (842).

nostic and Treatment Centers in 1985, 1986, and 1987 lived alone (225,227). Among people served by the National Channeling Demonstration Project, 24 percent of those with severe dementia and 33 percent of those with moderate dementia lived alone (149).

Except for anecdotes, very little information is available about people with dementia who live alone. Data on 100 people with dementia who were receiving services from a community mental health center in Washington State in 1989, show that those who lived alone were somewhat less functionally impaired than those who lived with a caregiver: 80 percent of those who lived alone had limitations in ADLs, compared to 96 percent of those who lived with a caregiver. However, those who lived alone were older; their income was lower; and they had been receiving services from the community mental health center for a longer period (687). No data are available to compare the mental status of people in the two groups.

The large proportion of people with dementia who live alone is surprising. Some people with dementia who live alone have someone to help them—an important consideration with respect to both their service needs and the kind of system that is needed to link them to services. Among the 100 people with dementia who were receiving services from the community mental health center in Washington State, half of those who lived alone had an involved relative or friend (687). Extrapolating from those data and OTA's estimate that at least 20 percent of people with dementia live alone, one could hypothesize that at least 10 percent of all people with dementia live alone and have no one to help them. Some support for that hypothesis comes from data on people with dementia seen at the six California Alzheimer's Disease Diagnostic and Treatment Centers in 1987, 10 percent of whom had no relative or friend to help them (227). OTA is not aware of any other sources of data on this issue.

Service Needs of People With Dementia

Because of their cognitive and self-care deficits and psychiatric and behavioral problems (if any) people with dementia generally need supervision and assistance with many different kinds of activities. Families, friends, and others usually provide this care informally, but they cannot always provide all the assistance the person needs, and some people with dementia do not have anyone to care for them informally. People with dementia also need professional and specialized services that informal caregivers generally cannot provide.

Table 1-2 lists the many different kinds of services that may be needed for people with dementia and their families or other informal caregivers. Not all the services are needed for any one patient. Patients' and caregivers' needs change over time, however, and individual patients may need many of the services sometime in the course of their illness.

All the services listed in table 1-2 also are used for nondemented people with physical impairments. The cognitive deficits of people with dementia alter the nature of the services they need, however. Providing medical care, legal services, personal care, or other services for a demented person is quite different from providing the same services for a nondemented person, in part because the demented person often is unable to understand or cooperate with the provider. For that reason, even vision and dental care may be different for demented people. Various providers also differ in their knowledge about dementia and are more or less skilled in working with people with dementia.

Implications for an Effective System To Link People With Dementia to Services

Because of their diverse service needs, an effective system to link people with dementia to services must be able to refer them to many different kinds of health care, long-term care, social, and other services—ideally, to all the services listed in table 1-2—provided those services are available in the person's commu-

Table 1-2-Services That May Be Needed for People With Dementia and Their Families

Most of these services may be needed by and can be provided for patients who are living at home, in a nursing home, or in another residential care facility, such as a board and care facility, adult foster home, or sheltered housing.	
Diagnosis	Protective services
Acute medical care	Supervision
Ongoing medical supervision	Home health aide
Treatment of coexisting medical conditions	Homemaker
Medication and elimination of drugs that cause excess disability	Personal care
Multidimensional assessment	Paid companion/sitter
Skilled nursing	Shopping
Physical therapy	Home-delivered meals
Occupational therapy	Chore services
Speech therapy	Telephone reassurance
Adult day care	Personal emergency response system
Respite Care*	Recreation/exercise
Family/caregiver education and training	Transportation
Family/caregiver counseling	Escort service
Family support groups	Special equipment (ramps, hospital bed, geri-chair, etc.)
Patient counseling	Vision care
Legal services	Audiology
Financial/benefits counseling	Dental care
Mental health services	Nutrition counseling
	Hospice
	Autopsy

*Respite care includes any service intended to provide temporary relief for the primary caregiver. When used for that purpose, homemaker, paid companion/sitter, adult day care, temporary nursing home care, and other services included on the list constitute respite care.

SOURCE: Office of Technology Assessment, 1990.

nity. A linking system also should be able to refer people with dementia to service providers who are knowledgeable about dementia and skilled in working with people with dementia, again, provided there are such providers in the community. As noted earlier, many people with dementia have co-existing medical conditions unrelated or only peripherally related to their dementia. Since it is the whole person—not just his or her dementia—that is linked to services, the system should be able to refer patients to services or sources of information about services for co-existing medical conditions as well.

Certain services are needed early in the course of a patient's illness. An accurate diagnosis should be obtained as early as possible, both to identify reversible dementias and to let patients, families, and others know what is causing the person's cognitive and self-care deficits and psychiatric and behavioral problems, if any.

Legal services also are needed early in the course of progressive dementing diseases, while patients still are able to make decisions about their property and future care and to execute legal documents (e.g., wills, trusts, durable powers of attorney, and living wills) that express their wishes on these matters. A linking system should be able to inform people with dementia, their families, and others about the importance of accurate diagnosis and early legal counseling. To do so, the system has to be in contact with them early in the course of the patient's disease.

Families and others often are not aware that the psychiatric and behavioral problems associated with dementia may be treatable, even if the underlying disease that causes the dementia cannot be cured. Likewise, they may not be aware of the impact of treatable coexisting medical conditions on the person's cognitive and self-care abilities. A linking system should take an active role in informing people that those problems and conditions may be treatable and should encourage them to seek appropriate treatment.

Dementia patients' characteristics affect not only the kinds of services to which a linking system must be able to refer them and the timing of the referrals but also many aspects of the linking process itself. Patients' cognitive deficits complicate the linking process, making it more difficult to connect demented than nondemented people to services. For example, people with dementia are far less likely than nondemented elderly and disabled people to refer themselves for services. People with dementia often are unaware of their own limitations and do not realize they need services. They are unlikely to be able to arrange or participate in arranging services for themselves, to remember service arrangements that have been made for them, or to remember and report problems with the services they receive (934).

People with dementia who live alone present a difficult challenge to anyone trying to locate and arrange services for them. Case managers interviewed for this OTA study said that such



Photo credit: Eastern Area Agency on Aging

A linking system must be available to people with dementia and their families early in the course of the patient's disease to inform them about the importance of obtaining an accurate diagnosis and early legal counseling.

people require more services and greater involvement of the case manager than people with dementia who live with a caregiver (see ch. 3). As noted above, some people with dementia who live alone have a relative or friend who helps them. People with dementia who live alone, and have no relative or friend to help them often are physically and emotionally isolated, fearful, and suspicious. They may be the most difficult patients to link to appropriate services. They also may be the most in need of services. To be effective, a linking system must have methods of reaching and working with them, as well as with patients who have an informal caregiver to help them.

Many decisions are involved in the process of linking people with dementia to services, including decisions about what services are needed, who will provide them, who will pay for them, and, perhaps most importantly, whether the patient will be cared for at home or in a nursing home or other residential care facility. Because of their cognitive deficits, people with dementia may not be able to make those decisions for themselves, thus raising difficult questions about who should make the decisions and on what basis. Some people with dementia retain sufficient cognitive abilities to make decisions about services for themselves, but their decisionmaking capacity is likely to be uncertain and

fluctuating (see ch. 4). Regardless of who ultimately makes the decisions, patients' cognitive deficits complicate decisionmaking in the linking process.

Lastly, the prevalence of co-existing medical conditions among people with dementia has implications for how they, their families, and others perceive their problem and service needs and how they are likely to enter the service system. For the purposes of this discussion, one could imagine a continuum of people with dementia that extends from a person who has dementia and no co-existing medical problems at one end to a person who has one or more serious medical problems and (often unnoticed) dementia at the other end.

The latter type—a person with serious medical problems and unnoticed dementia—is exemplified in the findings of two studies. One study concerned people who were hospitalized following a heart attack or heart surgery (53). Although all the subjects were considered free of any dementing illness, the researchers found that 40 percent had significant memory impairment and disorientation, and another 30 percent had milder cognitive deficits. Another study that concerned people hospitalized following hip fractures also found that 40 percent had significant cognitive deficits (67). These patients were in an acute medical care setting and had obvious medical care needs. If they continued to be cognitively impaired at the time of hospital discharge, appropriate planning for their post-hospital care would require taking their cognitive status into account. This would mean raising questions about whether the patients could comply with treatment recommendations (e.g., medication schedules and rehabilitation procedures) and whether the patients who had previously lived alone could safely continue to do so.

Patients such as those in the two studies just mentioned would benefit from a linking system that is skilled in working with people with dementia. On the other hand, since their cognitive deficits were not identified by hospital staff,

it is unlikely these patients would have been referred to a linking system designated to serve people with dementia exclusively if such a system existed.

Hospitalized patients with unrecognized dementia represent one extreme on the continuum. OTA does not know how many such patients there are. In the middle of the continuum are people who have an identified dementing disease and co-existing medical conditions. From the perspective of this assessment, they would be categorized as people with dementia. In contrast, some families, physicians, and others would categorize them in terms of their other medical conditions and regard the dementia (if noted at all) as a complicating factor in the treatment of those conditions.

How families, physicians, and others perceive people with dementia determines to a great extent how they enter the service system. It also determines the type of agency or individual a patient or family will approach, be referred to, or accept assistance from in finding services. If a linking system is designated to serve people with dementia exclusively, it is unlikely to be used for those who have a dementing disease but are not perceived by their families, physicians, or others as "people with dementia."

Characteristics of Families and Other Informal Caregivers

Families, friends, neighbors, and others provide care informally for most people with dementia, and many families and other informal caregivers also link people with dementia to services (85,199,479,749). They may contact an information and referral or case management agency or contact service providers directly to arrange services. Other caregivers are unable to arrange services themselves. In either case, the characteristics of families and other informal caregivers affect the linking process, and understanding those characteristics is essential for determining what kind of system is needed to link people with dementia to services.



Photo credit: Cleveland Chapter of the Alzheimer's Association

Families and others who do not think of the person they are caring for as a "person with dementia" are unlikely to turn for help to a linking system that is designated to serve people with dementia exclusively.

Who Are the Informal Caregivers?

Informal caregivers of people with dementia are diverse. They vary with respect to their age, sex, and relationship to the patient; whether they live with the patient; their socioeconomic status; their educational, ethnic, and cultural background; their work and other caregiving responsibilities; and many less easily documented factors, such as the quality of their relationship with the patient and their attitudes about caregiving and the use of services.

No national data are available on the characteristics of informal caregivers of people with dementia. One study in North Carolina of 501 caregivers of people with dementia found that 54 percent were spouses, 33 percent were adult children of the patient, 10 percent were siblings or other relatives, and 1 percent were friends (242). The caregivers ranged in age from 21 to 90, with an average age of 58. Seventy percent were women.

Some families care for more than one impaired person. A study of middle-aged women who were caring for their elderly mothers found that one-fourth also were assisting another elderly relative (83). The study described a couple in their early 30s, about to have their first child, who were caring for the wife's terminally ill mother and the confused grandmother for whom the mother had been caring.

Some people with dementia have several caregivers. Often, a primary caregiver provides most of the physical care and supervision, while other relatives and friends help out occasionally. These "secondary caregivers" frequently help to locate and arrange services (199,749). For that reason, patients who have a secondary caregiver maybe more likely than other patients to receive services (483).

Although many informal caregivers are healthy and most are cognitively normal, some are physically frail, and some are almost as confused as the person they are assisting. One spouse or sibling who has been taking care of the other spouse or sibling for some time may become physically or cognitively impaired, or both. In that event, a linking system is confronted with the difficult task of arranging services for two impaired people living together, in effect, without a caregiver.

Employed Caregivers—At least one-third of caregivers of people with dementia are employed, full or part-time (242,448,655). Interviews with employed caregivers of demented and nondemented people and their employers indicate that caregiving and job responsibilities frequently conflict. Even if caregivers can arrange daytime care for the patient, they need to call service providers, take the patient to appointments, and go to government offices to apply for benefits during work hours. Worry about the patient also interferes with their productivity (198,233,443,603,797).

Employed caregivers of elderly people indicate that one of their greatest needs is for information about available services and sources of funding for services (443). A study that

compared employed caregivers of cognitively impaired v. physically impaired elderly people found that the caregivers of the cognitively impaired people were more likely than the caregivers of the physically impaired people to express a need for information about services (740a). To be effective, a linking system must be accessible to employed caregivers and be responsive to their needs.

Long-Distance Caregivers—Many American families are geographically separated. The adult children or other relatives of a person with dementia may live far away but still try to function as long-distance caregivers. Little is known about long-distance caregivers of people with dementia. Commentaries on long-distance caregivers of elderly people in general indicate that they face extreme difficulties in trying to arrange and monitor services for a relative in another community (17,1 16,188). Such problems probably are more severe when the elderly person has dementia and cannot provide accurate information about his or her condition or monitor the services he or she receives. To be accessible to long-distance caregivers, a linking system must be identifiable in some uniform way nationally so that caregivers know who to contact for assistance.

Ethnic Minority Caregivers—Ethnic minority caregivers differ from each other in many ways, but there are some characteristics and attitudes that occur more frequently in ethnic minority groups than other societal groups and have implications for the kind of linking system that would meet their needs. The most obvious example is language differences. A linking system must be able to communicate with caregivers in a language they understand well because the details and decisions involved in locating and arranging services are both complex and emotionally loaded (866). More subtle differences are perceptions of dementia (e.g., whether it is seen as an illness, a part of normal aging, or "craziness" and attitudes about the use of services, both of which are influenced by each group's cultural heritage, beliefs, traditions, and customs. The special aspects of

linking ethnic minority people with dementia and their caregivers to services are discussed later in this chapter.

Informal Caregivers of Nursing Home Residents With Dementia—Many informal caregivers continue to regard themselves as the primary caregiver after their relative or friend with dementia is admitted to a nursing home (198,244). Some visit daily and assist with personal care. Many continue to arrange medical and other services and to handle the person's financial affairs. Some try to arrange in-home services that would allow them to bring the person home. Thus, relatives and friends of nursing home residents with dementia are likely to continue to need and use a linking system.

Caregivers' Experience of Burden

Taking care of a person with cognitive and self-care deficits and psychiatric and behavioral problems can be exceedingly difficult. Having to watch the person's inevitable deterioration compounds the caregiver's distress. For these reasons, the family of a person with dementia is often the second victim of the disease.

Caregiver burden has been described in terms of:

- objective patient characteristics and behaviors that create demands on the caregiver;
- the caregiver's subjective experience of those demands; and
- the objective impact of caregiving on the physical and mental health, social participation, and financial status of the caregiver (932).

Patient characteristics and behaviors that are particularly burdensome for some caregivers include incontinence, severe functional impairments, hallucinations, suspiciousness, agitation, wandering, catastrophic emotional reactions, disruptiveness at night, behaviors dangerous to the patient or others, and the patient's need for constant supervision (125,295,681,938).

Not all caregivers experience those characteristics and behaviors as burdensome, however,

and there is a surprising lack of correlation between patient characteristics and behaviors and the caregivers' subjective experience of them (244,643,668,938). Some caregivers' subjective experience of burden is less than might be expected given the objectively difficult situations they face (291,937). Moreover, many caregivers have positive feelings about caregiving and pride in their ability to manage difficult caregiving situations (125,242, 448,643).

To note those positive feelings and the lack of correlation between patient characteristics and behaviors and caregivers' subjective feelings of burden is not to minimize the problems faced by caregivers. In fact, informal caregivers of people with dementia experience more subjective feelings of burden and more negative consequences of caregiving (e.g., increased use of alcohol and psychotropic drugs, reduced immune function, and reduced participation in social activities than caregivers of other elderly people or other comparison groups) (71,242,291,296,41 1,415, 610,612,740a). The discussion here is intended only to highlight the complexity and diversity of caregivers' subjective experience of the demands of caregiving.

Anecdotal evidence suggests that the individuals who link people with dementia to services are not always aware of that complexity and diversity. For example, a physician, nurse, social worker, or other individual may observe a patient with severe cognitive and self-care deficits and frequent behavioral problems, assume the family is experiencing intolerable burden, and determine that nursing home placement is the only service option. The family, on the other hand, may feel that they are managing relatively well and may just want some respite care. When confronted with a recommendation for nursing home placement, the family may conclude that the individual making the recommendation does not understand, and the family may withdraw completely. As a result, the opportunity to link the patient and family to appropriate services is lost (see ch. 3).



Photo credit: Bill Adams

Taking care of a person with dementia can be exceedingly difficult. Nevertheless, many caregivers have positive feelings about caregiving and pride in their ability to manage difficult caregiving situations.

The opposite situation may also occur. A physician, nurse, social worker, or other individual may observe a patient with mild cognitive, self-care, and behavioral problems and assume wrongly that the family is not experiencing burden. If the patient and family are not linked to appropriate services, however, the patient may be at risk of inadequate care.

Many factors mediate between patient characteristics and behaviors that create demands on a caregiver and the caregiver's subjective experience of burden. Some of those factors are unchangeable (e.g., the age and sex of the caregiver), but other factors sometimes can be changed. One such factor is the caregiver's appraisal of the patient's characteristics and behaviors (297,487,533,938). Caregivers who view a patient's memory and behavioral problems as a direct consequence of a disease generally are less bothered by them than caregivers who view the same problems as in the patient's control, saying, for example: "If she paid attention, she wouldn't be so forgetful," or "He just does that to annoy me" (88). Education for caregivers about dementing diseases and their likely effects may lead to reappraisal of

some problems and reduction in caregivers' experience of burden.

Coping mechanisms, such as seeking information, problem solving, and emphasizing positive feelings can also reduce subjective feelings of burden for some caregivers (88,295,610,938). Caregiver training and counseling can help some people increase their coping skills. Family support groups often give caregivers new ideas about how to solve or minimize problems and support to try those ideas (487,938).

Finally, social support provided by relatives, friends, church groups, and voluntary associations may reduce a primary caregiver's experience of burden (242,297,610,749,937). Family group meetings that involve other relatives and provide information about a patient's disease and its expected impact can sometimes reduce the primary caregiver's sense of isolation and increase the emotional support and practical assistance he or she receives (487,936).

Implications for an Effective System To Link People With Dementia to Services

To be effective, a linking system must be accessible to all kinds of informal caregivers and responsive to their diverse needs, including both the needs of caregivers who are as capable of locating and arranging services as any case manager and only need an accurate list of available services and the needs of caregivers who are completely incapable of locating and arranging services and are almost as impaired as the 'patient.' The system also must be responsive to differences among caregivers in their subjective experience of caregiving.

Lastly, a linking system must be aware of the potentially modifiable factors that affect caregivers' subjective experience of burden (i.e., their appraisal of patient characteristics and behavioral problems, their coping mechanisms, and available social supports). Interventions to modify those factors may reduce the caregivers' subjective experience of burden—a worthwhile end in itself—and change caregivers' views about the kinds of help they need to care for the

patient—an important consideration for a system that is intended to link people with dementia to appropriate services. Some agencies that link people with dementia to services provide caregiver education, training, counseling, and support services that may modify those factors. Other agencies refer caregivers for such services. In either case, a linking system must recognize the importance of the services, or caregivers will not receive them.

Characteristics of the Service Environment

The kind of system that is needed to link people with dementia to services depends not only on the characteristics of patients and their informal caregivers but also on what services and sources of funding for services exist in a community. If sufficient services and funding and accurate information about both were available, the number of people who would need help to obtain services would be relatively small, although some, and perhaps many, people still would need help in defining the patient's needs, overcoming their own reluctance to accept help, and arranging services. At the other extreme, if there were no formal services or funding for services in a community, the functions of a linking system would be limited to helping people define their needs and mobilizing relatives, friends, and other informal resources to meet those needs. The reality in most communities is that there are some (although usually not enough) services and sources of funding for services, and accurate information about them often is not available. As a result, many patients and families need help not only to define their service needs but also to understand what services and funding are available and to locate and arrange available services and funding.

Types of Agencies and Individuals That May Provide Services for People With Dementia

In any given community, the kinds of services that may be needed for people with dementia may be provided by many different types of agencies and individuals. This is not to say that all the services are available, but that *if* they are available, they may be available from any of a

great variety of agencies and individuals. Individual service providers include professionals in private practice (physicians, lawyers, nurses, social workers, psychologists, occupational therapists, physical therapists, speech therapists, audiologists, dentists, and dietitians), paraprofessionals, and nonprofessionals who provide homemaker, transportation, chore, and other services.

In some communities, the needed services are provided by public agencies. State departments of health, human resources, aging, social services, mental health, and public welfare or public assistance may provide some of the needed services through regional and local offices. Counties and other local governments provide some of the needed services through local health care, social service, and mental health agencies. Some local governments have community service councils, health coordinating councils, and community action programs that provide some of the services.

The U.S. Department of Veterans Affairs (VA) provides some of the services for eligible veterans, primarily through its 172 medical centers (see ch. 6). The U.S. Department of Defense provides some of the services for eligible military personnel and their dependents in military hospitals and clinics. Hospitals and clinics of the Public Health Service and the Indian Health Service also provide some of the services for eligible people.

Area agencies on aging (AAAs), community mental health agencies, community health agencies, adult day centers, home health agencies, homemaker, chore, respite, and transportation service agencies, and senior centers provide some of the services in some communities. Voluntary associations, such as the Alzheimer's, Parkinson's, and Huntington's disease associations, also provide some of the services, often through their State and local chapters.

Some hospitals and nursing homes provide some of the needed services on an outpatient basis, in addition to their traditional inpatient and residential care services. Private social

service, nursing, family service, and senior service agencies provide some of the services in some communities. Other potential providers include churches, community ministries, the Salvation Army, YMCA, YWCA, United Way, and other service and philanthropic groups.

Not all those agencies exist in every community. If they do, though, they may provide services needed by people with dementia. Given the diverse needs of such people, many of the agencies are possible sources of assistance.

Factors That Limit the Availability of Services

Because there are many potential service providers does not mean that enough services are available or that a patient's needs can be met. As discussed in chapter 2, many details about an agency's services determine whether the services are really available to a particular patient and whether they meet his or her needs. These details include the agency's general eligibility criteria and any additional eligibility criteria for a specific service, the exact nature of the service, when and where it is provided and for how long, what it costs, and whether there is any source of funding for it other than client fees. These kinds of details often reflect regulations and requirements associated with the agency's funding source (e.g., Medicare, Medicaid, State programs). They may also reflect State or local government licensing or certification requirements; the agency's mission, objectives, and history; and the training and preferences of its staff (391,481,641,821,83 1).

The details of each agency's services change from time to time, especially in response to changes in regulations and requirements associated with its funding sources (641,821,922). Federal, State, and local governments and private associations and foundations initiate new services and terminate others. Publicly and privately funded research and demonstration projects that provide services also begin and end. Some of the changes are small, but their cumulative impact is to create a constantly changing service environment.

The number and type of agencies and individual providers vary in rural and suburban or urban areas. Some areas are 'service rich,' and others are "service poor." Rural areas are likely to be service poor. Some rural counties have no hospital, and a few have no physician. Many lack mental health professionals and other service providers. Because of low population density, residents of rural areas often have to travel a long distance to obtain services, and in some areas, there are not enough people with similar problems to justify specialized services (55,58,771,912).

Linking people with dementia to appropriate services in areas that have very few services is difficult. On the other hand, the more services there are in a community, the greater the complexity of the service environment. At one extreme, United Seniors Consumer Cooperative, a private consumer health care cooperative in Washington, DC, identified 130 public and private agencies that offer transportation services for elderly people in the Washington area (800). Obtaining enough information about those agencies to select an appropriate provider is difficult.

Sources of Public and Private Funding for Services

Services for people with dementia may be paid for by the individual, his or her family, public programs, or private, third-party sources. Since people with dementia often need services for years, they are likely to need public or private third-party funding in addition to their own resources. There are many potential sources of such funding. At least 80 Federal programs pay for services that may be needed for people with dementia or provide funds so people can purchase the services (828). Many State and local government programs, private agencies, and voluntary and charitable organizations also pay for services or give people funds to purchase them. Publicly and privately funded research and demonstration projects pay for services in some communities. Lastly, some people have private insurance that covers some services.

Factors That Limit the Availability of Funding for Services

The existence of many potential sources of funding for services does not mean that adequate funding is available. Each source has rules that limit the availability of funding by restricting who is eligible and what services are covered. Eligibility may be restricted on the basis of a person's age, income, assets, diagnosis, physical or mental condition, residence, family composition, and other factors. Coverage may be restricted by rules about the type of service that can be paid for; the profession, training, and/or licensure of a person who can be reimbursed for providing the service; the setting in which it can be provided; and its duration and frequency (124,391,641,831). The rules in each of these areas are interrelated, so that a particular service is paid for only if it is provided to a patient with a certain diagnosis or condition, by a certain provider, in a certain setting, for a given time period. To further complicate this already confusing situation, the eligibility and coverage regulations of funding sources change from time to time.

It is often unclear whether a person with dementia fits within the eligibility requirements for some funding sources, particularly Medicare and, to a lesser degree, Medicaid, that base eligibility on a person's physical condition and physical care needs. People with dementia frequently are determined to be ineligible for funding for services through these programs (124,186,479,831). On the other hand, some people with dementia receive services paid for by the programs. This may occur because of real differences in the physical condition and care needs of different patients, differences in the way a patient's condition and care needs are described on an application or billing form, or different interpretations of a program's regulations by its administrators.

Turf Issues Among Agencies and Individuals That Provide Services for People With Dementia

Turf issues are prevalent among the agencies

and individuals that provide services for people with dementia. Simply stated, turf issues arise when one agency, type of agency, or type of professional or nonprofessional service provider regards the care of people with dementia as its turf and believes that it, rather than another agency, type of agency, or service provider, offers the 'right' services for such people. Turf issues arise at the national, State, and local level and add to the complexity and fragmentation of the service environment.

Turf issues in the care of people with dementia arise between mental health and aging services agencies; health care and social service agencies; agencies that serve only people with dementia and agencies that serve elderly or disabled people in general; neurologists and psychiatrists; social workers and nurses, hospital-based home health care agencies, free-standing home health care agencies, and independent home care workers; for-profit and nonprofit agencies; and myriad other combinations of agencies and professional, paraprofessional, and nonprofessional service providers.

Sometimes, turf issues reflect self-serving competitions between agencies and individual providers for the public and private funds that pay for services and the jobs required to provide the services. Often, however, turf issues reflect sincere differences of opinion about which agencies and individuals provide the "right" services for the clients. Many of the agencies and individuals that provide services for people with dementia now have served the same kinds of clients for years, although not necessarily identifying them as people with dementia. As attention to Alzheimer's disease and other diseases that cause dementia has increased recently, those agencies and individuals claim—often legitimately—special expertise and skill in the care of people with dementia and regard the care of such people as their turf.

Sometimes, there is no explicit competition or difference of opinion about which agency or individual provider offers the "right" services for people with dementia. Instead, each agency,

type of agency, or type of individual provider regards the care of people with dementia as its turf and is simply unaware of others who serve the same kinds of clients.

Services for people with dementia generally are provided in one of several broad systems of agencies and providers—i.e., the medical or physical care system, the mental health system, the social service system, the public health system, the public assistance system, and the aging services system. These systems are delineated by the Federal programs that fund them, the education and training of people who work in them, and historical divisions among State and local government agencies that administer the services they provide. Although not rigidly differentiated, the systems generally are not integrated with each other. Service providers in one system may not be aware of services in other systems. Moreover, agencies and individual providers in the same system tend to have a common perspective on dementia and the ‘right’ services for people with dementia. Thus, they may have greater understanding of and confidence in services provided by other agencies and individuals in the same system than those in other systems. For all these reasons, referrals are more likely to occur within a system than from one system to another. For example, agencies in the aging services system may not refer clients to services provided by the mental health system, and vice versa.

The Complexity of the Service Environment for People With Dementia

The large number of agencies and individuals that may provide services for people with dementia, the large number of potential sources of funding for services, and the complicated and changing rules that limit the availability of both services and funding create an extremely complex service environment in many communities. Some communities have fewer agencies and individual service providers than others, but the rules that limit the availability of services and funding for services remain.

The complexity of services at the community level has been cited so frequently in discussions about health care, long-term care and social services for elderly and disabled people that it has become a cliché. Nevertheless, in the course of this study, OTA’s staff was repeatedly amazed by that complexity. As one learns more about services and funding for services in a certain community, the service environment appears more, not less, complex. It is clear that there are some services and sources of funding for services in virtually every community but generally unclear whether those services and sources of funding are really available to people with dementia and what proportion of such people they serve.

Two factors make the service environment especially complex for people with dementia—even more complex than it is for elderly and disabled people in general. First, the service needs of people with dementia cross the boundaries of the broad systems of agencies and individual providers cited earlier to a greater degree than the service needs of most nondemented people. Second, in many communities, there are new services for people with dementia that are not well known and may serve very few patients but often provide good care to those they serve. One commentator describes the array of small, new services for people with dementia as a “cottage industry” (698).

Implications for an Effective System To Link People With Dementia to Services

The complexity of the service environment in many communities makes it clear why families and others have difficulty obtaining accurate information about services and funding for services. It also makes clear the need in all communities for an accurate, up-to-date list of available services and sources of funding for services. OTA does not have comprehensive data on how many communities have such a list, but evidence from various sources suggests that many communities do not (see ch. 2). Because of the large number of potential service providers and funding sources and the changing rules

that affect their availability, maintaining an accurate list of services and sources of funding for services for people with dementia is difficult. Yet, such a list is essential for linking them to appropriate services.

At the start of this assessment, OTA's staff thought that the biggest problem families and others face in trying to obtain accurate information about services and funding for services is lack of information. In the course of the assessment, it became clear that wrong and partial information are at least as big a problem. For example, people who contact an agency or individual for information may be told that there are no services when, in fact, there are services, or vice versa. Likewise, they may be told that there is a service, e.g., an adult day-care center, 30 miles away when there is another center much closer. Given the complexity of the service environment and the lack of an accurate list of services and sources of funding for services in many communities, it is easy to understand why families and others receive wrong information or only partial information about services and sources of funding.

Having an accurate list of services would not change the complexity of the service environment at the community level or make up for the lack of sufficient services. It would improve access, however, and, by letting people know what services exist, it would allow for more appropriate use. Likewise, having accurate information about funding sources would not change the complexity and fragmentation of public and private programs that pay for services or make more funding available. It would increase the likelihood that people would receive benefits for which they are eligible.

It is important to note that families and others need to know not only what services and funding for services are available, but also what services and funding are not available. They need both types of information in order to plan realistically

and to make informed decisions about the care of their relative or friend with dementia.

REASONS WHY PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS MAY NOT USE SERVICES

No national data are available on the percentage of people with dementia who use paid services. The findings of 11 small-scale studies reviewed in chapter 3 indicate that only about one-quarter to one-half of all people with dementia who live in the community use any paid services other than physicians' services (71,88,117,223,227,242,291,41 1,479,448,774, 926). Among those people with dementia who do use paid services, many use very few services, use them infrequently, and/or use them very late in the course of their illness. The findings of two of the studies suggest that, on average, people with dementia use fewer paid services than people with physical impairments (71,255).

There are many reasons why people with dementia and their caregivers may not use services. Lack of knowledge about services is one reason—and, in the view of family caregivers and service providers in Cuyahoga County, Ohio, who were interviewed for this OTA study, it is the most important reason. Three-quarters of the caregivers and service providers who were interviewed said that people's lack of knowledge about services is usually a reason people do not use services (186).⁴

Knowledge about services has two components:

- general awareness of services, referred to in this report as *service consciousness*, and
- knowledge about a specific service, including who provides it in a community, referred to in this report as *service knowledge* (43 1).

Interviews with family caregivers of people with dementia in Cuyahoga County, Ohio, found

⁴The results of the study conducted for OTA in Cuyahoga County are discussed in chs. 2 and 3. A full report on the study can be obtained from the National Technical Information Service in Springfield, VA (see app. A).

that, depending on the specific service in question, up to 92 percent of the caregivers lacked service consciousness—that is, they had never heard of the service. Again, depending on the service, up to 96 percent of the caregivers lacked service knowledge—that is, they could not identify a specific provider in the community (186) (see ch. 2).

Other barriers to the use of available services are the cost of the services and the inability of patients and caregivers to arrange the services. Three-quarters of the caregivers interviewed in Cuyahoga County, Ohio, said that inability to pay for services was a reason why they did not use services. Half the caregivers said that not knowing how to arrange services was a reason they did not use them (186).

Often, it is fear of future costs rather than the current cost of services that stops caregivers from using services. Some caregivers who participated in Duke University's Respite Care Demonstration Project (see ch. 3) said they did not know how long services would be needed for their relative with dementia or whether they eventually would have to pay for nursing home care. Given those uncertainties, they were reluctant to spend even \$10 a week for respite services (291).

Many other perceptions and feelings of people with dementia and their caregivers also are barriers to their use of services. As noted earlier, people with dementia frequently do not recognize their impairments and do not know they need services. In addition, many of them have been or are afraid they will be exploited by service providers, especially nonprofessional in-home workers (286,934). Paranoia and suspiciousness, present in one-fourth to one-half of all people with dementia, exacerbate those fears. Some people with dementia isolate themselves from everyone, including service providers, because they are afraid that if anyone finds out how poorly they are managing, they will be put in a nursing home.

Families and other informal caregivers may be reluctant to use services for many reasons.

Some informal caregivers do not perceive a need for services, either because they do not feel burdened by the demands of caregiving, or because they do not regard the person with dementia as being sick or having a disease. Many caregivers also feel that they should provide all the patient's care themselves and that it is wrong to turn to outsiders for help (514,670,933). Others fear that people will criticize them for shirking their obligation to the patient if they use paid services. Such criticisms or even the anticipation of them discourage caregivers from using services (514,936).

Caring for a person with dementia may require few skills that informal caregivers do not have, although often it requires all their time and energy. As a result, some caregivers feel guilty about using services they could—at least in theory—provide themselves. Others feel—often realistically—that no one can take as good care of the person as they can.

Some family caregivers do not use services because they are embarrassed about" patient behaviors, such as hallucinations, delusions, and agitation, that suggest the patient is mentally ill, and they want to conceal the behaviors from other people, including service providers (72,291,533,936). Others are afraid that the patient will be upset by new services or that the service providers will not be capable of caring for the patient. Caregivers who have a bad experience with one provider often are reluctant to try again (88,117,186,291 ,533,670,936). Some caregivers are so overwhelmed by feelings of sadness, guilt, frustration, and anxiety that they cannot think clearly about how services might benefit them or the patient (88,137,201,533, 610,916,936). Lastly, some caregivers feel uncomfortable about making decisions for the patient, including decisions about the use of services (533,669).

For any of those reasons, some people with dementia and some caregivers never use paid services other than physicians' services. Others eventually use services, but not until long after the time when an objective observer would have



Photo credit: Peter Carroll

Some caregivers do not use services because they feel—often realistically—that no one will take as good care of the person with dementia as they can.

said they needed help. By that time, their need for help is so great and so immediate that the process of locating and arranging services takes place in an atmosphere of crisis. Moreover, even though by then the patients and caregivers need help immediately, the feelings and perceptions that made them reluctant to use services before often have not been resolved. As a result, they are ambivalent and emotionally conflicted, which further complicates the linking process.

Some people with dementia and informal caregivers who do not use services do not need them. Others who say that they do not need services—or that they do not need services “yet”—probably do need the services for the well-being and safety of the patient and the well-being of the caregiver (88,514). It is unclear whether or to what extent public or private agencies, individual health care and social service professionals, service providers, or even family members should encourage patients and caregivers to use services that they say they do not want or need. On the one hand, encouraging people who say they do not want services to use them seems absurd when there are not enough services to meet the needs of people who are asking for them. On the other

hand, some commentators have noted that it is often the most isolated patients and objectively burdened caregivers who say they do not want or need services (88,291,688). One might argue that those patients and caregivers are more in need of services than other patients and caregivers and that society should reach out to help them.

FRAMEWORK FOR AN EFFECTIVE SYSTEM TO LINK PEOPLE WITH DEMENTIA TO SERVICES

The characteristics of people with dementia, of the family and other informal caregivers of such people (if they have any), and of the service environment that were discussed in the preceding sections imply certain requirements for an effective linking system. This section discusses the essential components and criteria for such a system. Figure 1-1 illustrates those components and criteria.

Four Essential Components of an Effective Linking System

Drawing on the information presented in the preceding sections and in chapters 2 and 3 of this report and on their own knowledge about and experience in working with people with dementia, the advisory panel for this OTA study concluded that an effective system to link people with dementia to services must include four components:

- public education,
- information and referral,
- outreach, and
- case management.

Before reaching that conclusion, the OTA advisory panel considered and ruled out other possible components, such as diagnosis; caregiver education, training, and counseling; and legal and financial services. The panel determined that although these services are important for people with dementia, they are not essential components of an effective linking system and that patients and their families could be referred

Figure 1-1—Essential Components and Criteria for an Effective System To Link People With Dementia to Services

Components of an Effective Linking System

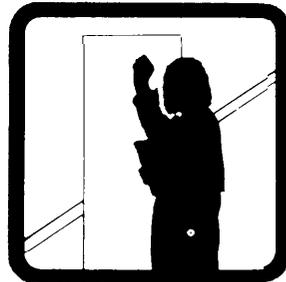
The system must provide:



Information and referral



Case management



Outreach



Public education

Criteria for an Effective Linking System

The system must be:

- easily identifiable nationwide
- available throughout the patient's illness
- able to work with people with dementia who have no informal caregiver
- * able to serve long-distance caregivers
- informed about available services and funding for services for people with dementia
- "dementia-friendly" and "dementia-capable."

SOURCE: Office of Technology Assessment, 1990.

by the linking system to other agencies, organizations, and individuals that provide the services.

The OTA advisory panel also ruled out a linking system that left out any of the four components cited above—for example, a system that provided only information and referral. Lastly, the panel considered whether the four components must be provided by a single agency or whether a consortium of agencies could provide them effectively. The panel concluded that a consortium of agencies could constitute an effective linking system if a genuine connection existed among the agencies so that clients would not “fall through the cracks,” as they often do now.

Public education, in the context of this report, means providing programs and materials to help people understand dementia and the kinds of services that may be helpful for individuals with dementia. Such programs and materials include pamphlets, articles, newsletters, and other publications; posters, press releases, and public service advertising in various media; radio and television programs; audiotapes and videotapes; teaching packets and curricula; and lectures, community meetings, and conferences.

Information and referral, in the context of this report, means providing information about and referrals to specific services and sources of funding for services in a community. The process can occur by telephone or in person.

As noted earlier, caregiver's lack of knowledge about services is one of the major reasons that people with dementia do not use services. Both public education and information and referral are needed to increase people's knowledge of services. Public education programs and materials are likely to increase service consciousness, i.e., general awareness of services, among the people they reach and therefore increase the likelihood that those people will search for

information about specific services when the need arises. Public education programs and materials usually do not provide information about specific services. Information and referral programs do provide information about specific services in a community and therefore are likely to increase service knowledge. Information and referral programs can only assist people who contact them, however, and people who lack a general awareness of services may not contact an information and referral source.

Outreach, in the context of this report, means using an active method of identifying individuals with dementia and caregivers who need assistance but are unlikely to respond to public education programs or to contact an information and referral source on their own.⁵ Outreach methods to identify isolated individuals with dementia and isolated caregivers include: screening individuals at places like senior centers and senior nutrition sites; having health care and social service professionals and other service providers who interact with elderly people and their families identify people with dementia who may need help; and sending paid or volunteer workers out to apartment buildings, public housing facilities, and other sites to look for people who may need help.

The outreach method that most closely matches the needs of isolated people with dementia and isolated caregivers is a “gatekeeper program” that makes use of the observations of individuals, such as mail carriers, utility meter readers, apartment managers, police, pharmacists, grocers, and delivery people, who come into contact with many individuals in the course of their regular activities. Through a gatekeeper program, these individuals—the “gatekeepers”—are trained to identify isolated elderly people who may need assistance and to notify a central agency. That agency is responsible for contacting the person and assessing his or her need for

⁵Some agencies and commentators use the term outreach in a sense that is different from the sense in which it is used by OTA in this report. They use it to refer to programs or services that an agency provides outside the agency. Some of these programs and services—e.g., lectures given by agency staff members to senior citizens groups or other community groups—are effective in reaching some people with dementia and their caregivers but are unlikely to reach isolated, confused patients or isolated caregivers. In the context of this report, such programs are considered public education.



Photo credit: Bill Adams

“Gatekeeper” programs in some jurisdictions rely on mail carriers and utility meter readers to identify isolated people with dementia who may need help.

assistance.⁶ The first gatekeeper program in the United States was implemented in Spokane, Washington in 1978 (688). Gatekeeper programs are now in effect in many other jurisdictions (97,148,320,456,688).

Case management, in the context of this report, means a process that includes five core functions:

1. assessing a client’s needs,
2. developing a plan of care,
3. arranging and coordinating services,
4. monitoring and evaluating the services delivered, and
5. reassessing the client’s situation as the need arises.

Case management is widely cited as a potential solution for many problems in health care and long-term care for various client populations and various types of agencies. Different agencies and commentators use the words ‘case management’ to mean very different things, however, and the confusion and disagreement about what case management is makes it difficult to communicate clearly about case management and its role in a linking system.

Most commentators agree that case management includes the five functions just listed (22,43,59,1 10,271,382,572,574,581,657,757,769,891,902), but agreement about these five functions does not resolve the confusion and disagreement about what case management is. For one thing, some commentators believe that case management includes additional functions—notably, case finding, screening, client education, and counseling. More importantly, the implementation of the five case management functions varies depending on many factors, including the type of agency or organization providing the case management; whether the agency provides services in addition to case management; what the goals, educational background, and experience of the case manager are; and how big the case manager’s caseload is. These same factors also influence the relative amount of emphasis the case manager and the agency place on each of the case management functions.

Many agencies that allocate long-term care services and funding for services use case managers to determine people’s eligibility for the benefits, to authorize the services and funding, and to monitor and account for their provision and use. When case managers are responsible for these essentially administrative tasks, the five core case management functions are modified to include the tasks. For example, service arrangement is modified to include

⁶Some individuals have told OTA they believe that the outreach procedures used in gatekeeper programs may invade the privacy of people who are identified as potentially in need of assistance. In contrast, individuals who administer gatekeeper programs have told OTA that they have procedures for gaining the trust of a person they contact in response to notification by a gatekeeper and for obtaining at least informal consent from the person to assess his or her needs (95,689). Given the cognitive deficits of people with dementia, their capacity to give consent is problematic, and safeguards must be built into any outreach program to protect their rights.

administrative procedures for authorizing services and funding. Monitoring and reevaluation are modified to include administrative procedures to recertify the client's eligibility and to account for resources used.

Some descriptions of case management, particularly in agencies that allocate services and funding for services, make case management sound like a series of administrative procedures to authorize and account for services and funds in accordance with the agencies' policies and regulations. Other descriptions of case management, in those agencies and in general, emphasize its clinical features and portray the case manager more as a professional helper, problem-solver, and client advocate than as an administrator of benefits. Some commentators believe that there is a fundamental conflict between the role of the case manager as a helper, problem-solver, and advocate for the individual client and the role of the case manager as an administrator of benefits. Others believe the two roles are compatible. In practice, many case managers perceive themselves as performing both roles simultaneously and without conflict (47).

If it were possible to distinguish between case management as a clinical process and case management as an administrative process and to call one "case management" and the other something else, it would be easier for everyone to communicate clearly about case management. That distinction does not hold up in reality, however, because the two processes are completely integrated in the practice of many case managers (see ch. 3).

Because of the confusion and disagreement about what case management is, OTA tried at first to avoid using the words "case management" in this report, and to focus on the five core functions instead. That effort failed because the core functions are relevant to both clinical and administrative case management—the same words are used to describe what case managers do in both instances. OTA then tried to delineate the specific procedures that might be involved in case management, but that effort

also was unsuccessful in distinguishing among different kinds of case management.

The case management cited in this report as one of the four essential components of a system to link people with dementia to services is the clinical process in which the case manager is a helper, problem-solver, and client advocate. One of the policy issues discussed in this chapter is whether a system to link people with dementia to services also should allocate services, in which instance, the case manager presumably would also have to be an administrator of benefits. Alternatively, each client could have two case managers, one of whom is an advocate and helper, and the other is an administrator and allocator of benefits. These options are discussed later in the chapter.

It is important to emphasize that not all people with dementia and their caregivers need outreach and case management. Outreach is needed only for very isolated patients and caregivers. Case management is likely to be needed at least at some points in the course of their illness by all people with dementia who live alone and have no relative or friend to help them. Case management is also likely to be needed by some individuals with dementia who have an informal caregiver, for example, those whose caregivers are unable to define their service needs, reluctant to use needed services, or unable to arrange services for any reason. Because of the complexity and fragmentation of the service environment in many communities, individuals with dementia who need several different services may need a case manager to arrange and coordinate the services of multiple providers. On the other hand, some families and other informal caregivers function as case managers themselves (85,92,1 10,467,477,753,778), and more caregivers might be able to do so if accurate information about services and about funding for services were readily available.

Criteria for an Effective Linking System

Many criteria for an effective system to link people with dementia to services have been suggested in the previous sections. The most

important of those criteria are reviewed here:

- The agencies that constitute the linking system must be uniformly identifiable throughout the country—perhaps by the use of a common name, logo, or telephone number—so that people know whom to call for assistance in locating and arranging services.
- Because certain services (e.g., accurate diagnosis and legal services) are needed early in the patient’s illness and because the service needs of people with dementia change over time, the linking system must be available to individuals with dementia and their caregivers throughout the course of the patient’s illness.
- The system must be able to work with families and other informal caregivers and with people with dementia who live alone and have no one to help them.
- The system must be able to serve long-distance caregivers.
- The agencies that constitute the linking system must develop and maintain an accurate list of services and sources of funding for services that encompasses all the kinds of services that maybe needed for people with dementia, including services provided by each of the broad systems of agencies and providers (e.g., medical or physical care, mental health, social service, public health, public assistance, and aging) and any new or specialized services for people with dementia.
- The linking system must be “dementia-friendly” and “dementi-capable.”

One of the policy issues discussed in this chapter is whether the linking system should serve people with dementia exclusively or should serve people with dementia and people with other diseases and conditions as well. In thinking about this issue, it is helpful to distinguish among three concepts—“dementia-friendly,” “dementia-capable,” and “dementia-specific.” *Dementia-friendly* means the linking system is responsive to people with dementia and their caregivers. *Dementia-capable* means

the system is skilled in working with people with dementia and their caregivers, knowledgeable about the kinds of services that may help them, and aware of which agencies and individuals provide such services in a community. *Dementia-specific* means the system serves only people with dementia. An effective system to link people with dementia to services must be dementia-friendly and dementia-capable, whether or not it is dementia-specific.

The components and criteria discussed in this and the preceding sections define to a great extent what it means for a linking system to be dementia-friendly and dementia-capable. Clearly, the staff of the linking system must be knowledgeable about the usual characteristics and service needs of people with dementia and their families and other informal caregivers. At the same time, the staff of the linking system must be attuned to the diversity of people with dementia and their caregivers. The staff of the linking system must be aware, for example, of the cognitive and self-care deficits typically associated with dementia and their implications for patients’ service needs. To identify appropriate services for individual patients, however, the staff of the linking system also must be aware of the heterogeneity of cognitive and self-care deficits in people with dementia and the lack of correlation between cognitive and self-care deficits in some patients. Likewise, the staff of the system must be aware of the diversity among caregivers in their perceptions of the demands of caregiving and their subjective experience of burden.

As discussed in chapter 2, many agencies that provide information and referrals for people with dementia do not keep records on the people they serve by either diagnosis or condition (186,756). That agencies do not keep such records does not prove that the individual social workers, nurses, or other people who provide information and referrals for the agency are unaware of patients’ diagnoses. It suggests that could be the case, however. If people with dementia are not identified as such by a linking system, they will not be referred for specialized



Photo credit: Peter Carroll

Sometimes, “being connected” to someone who knows the patient and is available to answer questions and respond to caregivers concerns is the only assistance a family wants or needs.

services even if the services are available; publications that could be helpful to the caregivers will not be provided; and common characteristics of patients that influence their service needs and the process of linking them to services may not be recognized. In order to be dementia-capable, the agencies that constitute the linking system must identify their clients with dementia as such.

As discussed in a later section of this chapter, OTA has included Alzheimer's Association chapters as one of the 11 categories of agencies that Congress could, at least in theory, designate as the basis for a national system to link people with dementia to services. For that reason, Alzheimer's Association chapters are discussed at some length in chapter 8. Regardless of any other role the Alzheimer's Association and its chapters might play in a national linking system, however, they have a clear role to play in defining what it means for a linking system to be

dementia-friendly and dementia-capable. Health care and social service professionals, service providers, and others have useful ideas on this subject, but the Alzheimer's Association has been and continues to be the definitive source on the attitudes and concerns of Alzheimer's caregivers. Voluntary associations that represent people with other diseases that cause dementia and their caregivers also have a role to play in defining what a dementia-friendly and dementia-capable linking system would be. These groups should advise and monitor the system on an ongoing basis.

The Role of a Linking System as a Source of Potential Support

Many researchers and clinicians have commented on the importance to caregivers of “being connected” to someone who knows the patient and the caregiver and is available to answer questions about the patient's condition and respond to the caregivers concerns (257,412,483,610,934). Sometimes, that person is a physician, but it may be anyone who is knowledgeable about dementia and sensitive to caregivers' concerns.

Sometimes, “being connected” —referred to as *potential support* by one research group (610)---is the only assistance a family wants or needs. Yet many agencies and individuals who work with people with dementia do not have a mechanism for providing that assistance on an ongoing basis, in large part because there is no public or private funding for it. As a result, they are only able to meet caregivers' need to be connected in the context of providing specific services for the patient.

One member of the advisory panel for this study noted that being connected often is the basis for appropriate use of services later on:

It has been my experience that caregivers reach out often and fleetingly for information regarding potentially helpful services and programs over a period of months or years before they actually decide on help. It is quite important to have personal contact with a patient and a family—from one to three times—in order to

do an assessment that leads to appropriate guidance, care and referrals.

Often, once the visit has been done, families previously resistive to care or intervention may agree to assistance, and they also find their own funds to pay for services hitherto thought to be too expensive, unattainable, or irrelevant. The engagement of the caregiver seems to be a critical step in the process of giving care and support and one about which I have seen little or nothing documented (283).

Providing a source of potential support for patients, families, and other caregivers may be one of the most important functions of a linking system. If so, the function should be defined more clearly, differentiated from other functions of the system, such as information and referral and case management, and planned for specifically in the system.

AGENCIES, ORGANIZATIONS, AND INDIVIDUALS THAT LINK SOME PEOPLE WITH DEMENTIA TO SERVICES

Many public and private agencies and organizations, individual health care and social service professionals, service providers, and others currently provide one or more of the four functions OTA considers essential components of an effective linking system (i.e., public education, information and referral, outreach, and case management) for at least some people with dementia. Some of these agencies, organizations, and individual professionals and service providers work almost exclusively with people with dementia, and some work with people with other diseases and conditions as well. For some, linking people to services is their primary function. For others, their primary functions are providing health care, long-term care, social, or other services, and they link people to services in conjunction with providing those services.

The study conducted for OTA in Cuyahoga County, Ohio, found that many agencies pro-

vide information and referrals for people with dementia in the county.⁷ OTA's contractors identified 324 agencies in the county that they thought might provide services of any kind for people with dementia and sent a questionnaire to each agency (186). Of the 97 agencies that responded, 71 said they provide information and referrals for people with dementia. No attempt was made by OTA's contractors to find out whether any of the agencies that did not respond to the questionnaire also provide information and referrals for people with dementia, and some may. Moreover, the questionnaire was not sent to voluntary associations or individual health care and social service professionals who are also potential information and referral sources. Thus, the total number of information and referral sources in the county is probably much higher.

Having a large number of agencies, organizations, and individuals that provide information and referrals for people with dementia is good in the sense that there are many places to which families and others can turn for help. On the other hand, providing information and referrals is not the primary function of many of the agencies, organizations, and individuals. Interviews with representatives of agencies that said they provide information and referrals for people with dementia in Cuyahoga County, Ohio, indicate that the agencies generally did not have comprehensive lists of services or lists of sources of funding for services (186). Since it is time-consuming to maintain an accurate list of services and funding sources, individual health care and social service professionals and service providers also are unlikely to have such lists. The large number of agencies, organizations, and individuals that provide information and referrals for people with dementia, often without an accurate resource list, increases the likelihood that people will receive wrong or only partial information about services and funding for services.

⁷The findings of the study conducted for OTA in Cuyahoga County, Ohio, are discussed in chs. 2 and 3. A full report on the study is available from the National Technical Information Service in Springfield, VA (see app. A).

Turf issues, discussed earlier with respect to providing services for people with dementia, arise at least as strongly with respect to linking them to services. That is partly because agencies, organizations, and individual professionals and service providers perceive that whoever links people to services controls which services are used and who gets paid for providing them (46,661).

In the course of this assessment, OTA found that virtually every type of agency, organization, and individual professional and provider that works with people with dementia is aware of and concerned about the problem of locating and arranging services for them. Virtually every such agency, organization, and individual perceives itself as effectively linking some people with dementia to services, and many of them propose to solve the problem of locating and arranging services for people with dementia by expanding their role in the linking process. Often those proposals are made without consideration or even awareness of the many other types of agencies, organizations, and individuals that also link people with dementia to services.

The following subsections of this chapter describe various agencies, organizations, and individuals that provide one or more of the four functions OTA considers essential for linking people with dementia to services. The discussion is not all-inclusive. Its intent is to give a sense of the many different types of agencies, organizations, and individuals involved and the diversity of their approaches. The first subsection describes some of the private agencies, organizations, and individuals that link people to services. The second subsection describes three Federal agency programs that provide one or more linking functions for people with dementia. The following two subsections summarize OTA's findings with respect to State programs and service systems and community

service systems that link people to services and the State and local agencies that implement those programs and service systems.

One of the policy issues discussed in this report is whether Congress should designate a single category of agencies nationwide to constitute a system to link people with dementia to services or, alternatively, mandate that each State designate the agencies that would make up the linking system in that State. In analyzing this issue, OTA identified 11 categories of agencies that Congress could, at least in theory, designate as the basis of a national linking system for people with dementia if Congress chose to establish a system composed of a single category of agencies. The last subsection explains how OTA identified the 11 categories of agencies and presents OTA's conclusions with respect to the current capability of any of the 11 categories of agencies to function as a national system to link people with dementia to services.⁸ The information presented in the subsection on State programs and service systems that link some people with dementia to services pertains to the other alternative—i.e., that Congress could mandate that each State designate the agencies that would make up the linking system in that State.

Private Agencies, Organizations, and Individuals That Link Some People With Dementia to Services

A variety of private agencies, organizations, and individuals link some people with dementia to services or sponsor programs that do so. Examples of those agencies, organizations, and individuals are discussed in this subsection. None of these entities serves people with dementia exclusively, but all of them serve some people with dementia.

Most of the agencies in the 11 categories of agencies that Congress could, at least in theory, designate as the basis of a national linking

⁸As discussed later in this section, the 11 categories of agencies that it would be at least theoretically possible for Congress to designate as the basis of a national linking system for people with dementia are AAAs, community mental health centers, community health centers, Alzheimer's Association chapters, Family Survival Project, States' regional Alzheimer's diagnostic and assessment centers, hospital-based geriatric assessment programs, home health agencies, social health maintenance organizations (S/HMOs), On Lok Senior Health Services, and adult day centers.

system for people with dementia are private agencies and organizations. They are discussed at length in chapter 8 and are not discussed in this subsection.

Private Companies' Elder Care Programs

In recent years, concern has increased in the business community about the problems of employees who are caring for elderly relatives (233). As a result, some private companies now provide elder care programs for their employees. These programs typically furnish information about community services for elderly people and sometimes offer company employees caregiver support groups, flexible work schedules, unpaid leave to allow them to attend to caregiving responsibilities, and counseling about problems in taking care of an older person (151,443,659).

IBM has gone significantly beyond many other companies in helping its employees and retirees find services for themselves or for elderly relatives. In 1988, IBM initiated its Elder Care Referral Service, which provides information about available services, personalized counseling to help people clarify their service needs, referrals to community service providers, and short-term followup to determine whether the employee's or retiree's needs were met (16,659,660). Work/Family Elder Directions, the private agency in Massachusetts that administers IBM's Elder Care Referral Service, sub-contracts with agencies in 175 communities in which there are a significant number of IBM employees or retirees to provide the information and referral, counseling, and short-term followup that are part of the Elder Care Referral Service. IBM employees or retirees who live in other areas of the country can call Work/Family Elder Directions for assistance.

To select the agencies that would implement IBM's Elder Care Referral Service, Work/Family Elder Directions conducted a community-

by-community analysis (659). That analysis led to the conclusion that there was no single category of agencies that could provide the service in all 175 communities. The agencies that eventually were selected to provide the service include AAAs, family service agencies, visiting nurse and other home health agencies, information and referral agencies (e.g., United Way information and referral), case management agencies, multipurpose senior service agencies, protective service agencies, and a few hospitals. Some of the agencies receive a basic fee intended to cover a certain number of cases at a per case rate; because they have staff and phone lines dedicated to the IBM project, those agencies receive the fee whether or not they serve the projected number of IBM clients. Other agencies get a fixed fee for each IBM client they serve. In 1988, the program served 8,100 IBM employees or retirees.

Since 1988, several other private companies have contracted with Work/Family Elder Directions for similar programs (659). These companies include Arthur Anderson and Co., Aetna Life and Casualty, several divisions of Colgate-Palmolive, Johnson and Johnson, and several divisions of CIBA-GEIGY. Other private companies have contracted with AAAs and other public and private agencies for such programs (450,577).⁹

United Seniors Health Cooperative

United Seniors Health Cooperative is a private, nonprofit organization in Washington, DC, that furnishes its members with information and assistance in obtaining services and negotiates with service providers for discounts and special services for its members. Elderly people and their families can join the cooperative for an annual fee. The cooperative was established in 1987 and, by July 1989, had 12,000 members (208). To OTA's knowledge, it is the only organization of its kind in the country.

⁹Certain Federal Government agencies also contract for elder care programs for their employees. Since 1988, the Office of Personnel Management has contracted with a private agency in Landsdale, Pennsylvania, the Partnership Group, to provide telephone consultations, educational materials, onsite workshops, and personalized information and referrals for their employees who are caring for an elderly relative. From early 1989 to May 1990, the Social Security Administration contracted with the partnership Group for similar assistance for its employees in 7 Southeastern States.

The cooperative provides information about services and about sources of funding for services. It has developed a computerized 'Benefits Outreach and Screening Service' that identifies a person's potential eligibility for more than 50 Federal, State, and local funding programs. To use the service, an individual completes a questionnaire about his or her finances, medical condition, and other information. The information is fed into a computer, which reviews the available funding programs, identifies benefits the person is potentially eligible for, and prints out a list of those benefits and instructions on how and where to apply for them. The software package for the "Benefits Outreach and Screening Service" is available, and agencies in several areas of the country have purchased it (799). As of late 1989, the software was being adapted for use in New York State, where it will not only identify the benefits a person may be eligible for but also print out completed applications for six public programs that pay for services (208).

Connecticut Community Care, Inc.

Connecticut Community Care, Inc. (CCCI) is a private, nonprofit organization that provides case management for public agencies, corporations, foundations, and individuals in Connecticut. CCCI evolved from Triage, one of the first long-term care demonstration projects in this country (see ch. 7). When the demonstration ended, CCCI was established to continue and expand the Triage model of case management (677). OTA is aware of some other private, nonprofit case management agencies like CCCI in other parts of the country.

In 1988, CCCI expected to serve 7,000 clients, including elderly individuals referred by Connecticut's Department of Aging, AAAs, and the State Medicaid agency. Those public agencies pay CCCI on a per case basis for assessments, care planning, service arrangement and coordination, and service monitoring. CCCI allocates and arranges a wide range of health care, long-term care, social, and other services paid for by the public agencies (409,677).

In 1988, CCCI began providing case management for individuals on a fee-for-service basis (75). The organization offers comprehensive case management that includes the five core case management functions, but individuals also can purchase single case management functions, such as assessment or service coordination (see ch. 3).

Private Geriatric Case Managers

Private geriatric case managers are individual professionals (generally social workers or nurses) and others who provide client assessment, care planning, service arrangement and coordination, monitoring, and a variety of services for elderly people on a fee-for-service basis. The case management and services generally are highly personalized to respond to the individual needs of each client. Although no data are available, anecdotal evidence indicates that many clients of private geriatric case managers have dementia (136,450).

Private geriatric case managers often work independently or with one or two other case managers under the umbrella of an incorporated firm. A 1986 survey of 117 private geriatric case management firms, conducted by Interstudy, found that 65 percent of the firms employed only 1 or 2 case managers (357). Their caseloads also tended to be small—one-third worked with 10 or fewer clients per year. Most had been in business 3 years or less. Seventy percent of the firms were independent, and the remaining 30 percent were affiliated with hospitals, social service agencies, or nursing homes. Their fees ranged from \$13 to \$100 an hour, with 53 percent charging \$50 an hour.

Private geriatric case managers sometimes are hired and paid by a relative of an elderly person, but some elderly people hire and pay a case manager themselves. More than half of the private geriatric case management firms that responded to the Interstudy survey said they provide case management for elderly people who live alone (357).

Private geriatric case managers and private geriatric case management firms often assist long distance caregivers. As of 1988, for example, Aging Network Services of Bethesda, Maryland, had developed a network of 250 social workers in communities across the country that could be hired by families or others to assist an elderly person in another locality (450).

Some private geriatric case management firms contract with public agencies to provide case management for the agencies' clients. In general, however, private geriatric case managers serve people who are ineligible for case management through public agencies because their income and assets exceed the agencies' eligibility criteria.

Elderlink

The National Association of State Units on Aging, a private association, is working with its members and other agencies to develop "Elderlink" a national telephone information and referral program for elderly people (577). The program was initiated in Illinois in 1989 (148) (see figure 1-2). The primary objective of Elderlink is to assist long-distance caregivers in locating services for a relative or friend who lives in another community (577). The planning committee for Elderlink included representatives of State units on aging and AAAs—two types of agencies that are designated by States to implement certain provisions of the Older Americans Act. State units on aging are public agencies, but AAAs include public and private agencies. If and when Elderlink is established nationwide, it is likely to reflect a partnership of public and private agencies.

Life Care and Other Residential Care Communities and Programs

Life care communities (sometimes referred to as continuing care retirement communities) are organizations that provide housing and a variety of services for their residents in a campus-like setting or a single building (784). Typically, life care communities provide health care, long-term care, social, and other services, such as

meals, transportation, and housekeeping, for their residents who need such services. Many life care communities also provide nursing home care. The provision of these services in a single setting eliminates for residents of the life care communities many of the problems in locating and arranging services that are the topic of this OTA report. Elderly individuals are usually admitted to life care communities while they are still able to function independently. As they age, some residents of life care communities undoubtedly develop dementia, but OTA is not aware of any information about the number of individuals with dementia living in life care communities.

Recently, OTA has received a number of calls from private agencies and organizations that are developing or considering developing residential care communities specifically for people with dementia. Although each agency and organization has somewhat different plans, most intend to provide apartments for people with dementia and their spouses, supportive services for the individuals and their families, adult day care, and nursing home care on the same campus. Some agencies and organizations also intend to provide a variety of services for people with dementia who do not live on the campus, e.g., diagnosis, multidimensional assessment, in-home and institutional respite care, caregiver education and counseling, and support groups. A major objective of these residential care communities is to provide a single place to which families and other caregivers can turn for help throughout the course of the patient's illness. The residential care communities are intended specifically to resolve the problem of locating and arranging services for people with dementia.

An alternative to a residential care community is the "life care at home" model of care developed by the Bigel Institute for Health Policy at Brandeis University and currently being tested in several sites with funding from the Robert Wood Johnson Foundation and the Pew Foundation (135,783). People who enroll in a "life care at home" program pay an entry

Figure 1-2—A Brochure Publicizing Elderlink, a National Telephone Information and Referral Program for Elderly People Initiated in Illinois in 1989

Linking families to services across the miles...

1-800-252-8966
(VOICE and TDD)

WHAT IS ELDERLINK?

ELDERLINK is a toll-free, telephone access system that helps long distance caregivers obtain information, referral and linkage to support services for their older loved ones.

In today's mobile society, families sometimes live miles apart. If you find yourself in the role as primary caregiver for a loved one in another city, county or state and don't know where to turn for help, ELDERLINK can provide the answer.

ELDERLINK was developed by the Illinois Department on Aging in cooperation with other state offices on aging that are a part of the National Association of State Units on Aging.

HOW DOES ELDERLINK WORK?

By calling 1-800-252-8966, the Illinois Department on Aging can identify the people and agencies, statewide and nationwide, that can assist you in obtaining the needed care for your loved one.

If you live in Illinois but your aging relative lives in another state, ELDERLINK will tell you how to "plug in" to that state's network of services for older people. In other words, they'll save you some frustration by helping you identify the appropriate agency to assist your relative.

If your aging relative *does* live in Illinois, ELDERLINK will actually contact a local agency that will visit your family member, determine individual needs and eligibility for various benefits, and work with you to arrange services.

ELDERLINK

Help For the Long Distance Caregiver

The Illinois Department on Aging

ILLINOIS CARES ABOUT ITS SENIORS

1-800-252-8966
(VOICE and TDD)

SOURCE: Illinois Department on Aging, Springfield, IL, 1989.

fee, monthly fees, and copayments for certain services. The program, in turn, is obligated to provide a wide range of services intended to allow them to continue living at home for as long as possible. The services include nursing home care, home health aide and homemaker services, respite care, adult day care, and some routine medical care. Decisions about which services individuals receive are based on an assessment and care plan developed by a case manager. The case manager arranges any services provided by the program and helps the enrollees arrange services that are not provided by the program (e.g., transportation and home maintenance). Initially, “life care at home” sites will enroll only healthy older people, thus excluding people with dementia. For people who enroll in such a program and later become demented, however, the “life care at home” model is likely to eliminate most problems in locating and arranging services.

Federal Agency Programs That Link Some People With Dementia to Services

The Federal Government provides partial funding for many agencies and organizations that link some people with dementia to services, but the three programs described in this subsection are fully or primarily funded by Federal agencies—two by the National Institute on Aging and one by the Health Care Financing Administration. All three programs are quite new.

The Alzheimer’s Disease Education and Referral Center

In 1986, Congress mandated, through Public Law 99-660, that the National Institute on Aging establish a clearinghouse to disseminate ‘ ‘information concerning services available for individuals with Alzheimer’s disease and related dementias and their families. ’ ’ In 1987, the National Institute on Aging contracted for market research to determine the attitudes and knowledge about Alzheimer’s disease among the general public. The results of the research show that although virtually all the individuals who participated in the research had heard of

Alzheimer’s disease, few had in-depth knowledge of the disease or where to go for help (850). The research participants identified several sources of information about Alzheimer’s disease, notably the media, physicians, the library, hospital/community outreach programs, and local telephone health information lines (765). Most of the research participants said they preferred a local source of information because local sources are more accessible and more likely to provide personal attention, but many of them recognized the potential benefits of a national source, e.g., credibility, access to the latest research findings, and access to information about resources outside the local community.

In 1987, the National Institute on Aging contracted for a survey of Alzheimer’s Association chapters to determine the number of calls received by the chapters (an average of 10 to 30 calls per month);, the source of the calls (family members, social workers, respite care providers, and friends of Alzheimer’s Association members); the types of information requested by callers (information about the symptoms and the progression of the disease, the latest research findings, and sources of financial assistance); the chapters’ perception of the types of information needed (better financial and legal information, medication information, information on the latest research findings, information on sexuality and intimacy, and educational materials for physicians); and the chapters’ perception of the best formats for that information (videotape, printed materials, large print materials, and Spanish language materials) (765). In early 1988, the National Institute on Aging convened a planning conference of experts on Alzheimer’s disease education, treatment, and caregiving to determine needs and identify gaps in information dissemination (691,850).

Despite this research and planning effort, the process of establishing the mandated clearinghouse engendered many of the same turf issues and concerns discussed earlier in this chapter. The major concerns with respect to the clearinghouse pertained to the possible duplication of

efforts with other organizations that already provide information about Alzheimer's disease and dementia and differences of opinion about which agency or organization is best able to provide that information.

In 1989, the National Institute on Aging awarded a contract for the operation of the mandated clearinghouse, referred to as the Alzheimer's Disease Education and Referral (ADEAR) Center. The ADEAR center will develop and maintain an online database, available to the public, that includes books, articles, and other publications and materials about Alzheimer's disease and programs for dementia patients, their caregivers, and the professionals who work with them. The center will respond to requests for information from anyone (850). It will translate the latest scientific and technical information about Alzheimer's disease into language comprehensible to the lay person, identify gaps in the current literature for the lay person, develop new publications to fill those gaps, and revise outdated publications.

The center will also set up a national toll-free telephone information line. As of April 1990, the toll-free line was not operational, but National Institute on Aging officials expected that it would be operational by the end of 1990. According to National Institute on Aging officials, callers to the toll-free line "will be provided information on the center and its services and be referred to other national and State organizations for more specific information on services in their locale" (850). The center will work with a variety of other organizations to disseminate information about Alzheimer's disease (e.g., the Alzheimer's Association, the American Association of Retired Persons, State units on aging, and AAAs).

Alzheimer's Disease Research Centers

The National Institute on Aging funds 15 Alzheimer's Disease Research Centers (ADRCs) at university medical centers nationwide. The ADRCs conduct biomedical and clinical research about Alzheimer's disease. As part of their clinical services, the ADRCs provide

diagnostic evaluations and followup care for people with Alzheimer's disease. One aspect of the followup care is referrals to community services. Recently, the National Institute on Aging has encouraged the 15 ADRCs to develop satellite clinical care facilities in order to expand the number of people and geographic areas they serve.

In addition to clinical services and referrals for individuals with Alzheimer's disease, the ADRCs provide public education about dementia and the care of people with dementia. Some of the ADRCs have developed informational materials about Alzheimer's disease, and some ADRCs have cosponsored with the Administration on Aging caregiving conferences for family caregivers and other interested individuals. The staff of the ADRCs also respond to requests from the general public for information about and referrals to community services, although this is not one of the ADRCs' primary functions. OTA does not know how frequently ADRC staff members respond to calls from the general public for information about and referrals to services.

The Medicare Alzheimer's Disease Demonstration

In 1986, Congress mandated, through Public Law 99-509, that the Health Care Financing Administration conduct at least five 3-year demonstration projects to determine the effectiveness, cost, and impact of providing comprehensive services for Medicare enrollees who have Alzheimer's disease or a related disorder (504). The comprehensive services to be provided through the demonstration projects include adult day care, in-home services, and education and counseling for family caregivers. In 1988, eight demonstration sites were selected. Four of the sites are nonprofit organizations, three of which are sponsored by consortia of local agencies. The other sites include a hospital-based diagnostic and assessment program, a mental health center, a combined nursing home/community care organization, and a private, for-profit physician group practice

organization. Each site is expected to enroll 500 patients, half of whom will be assigned to a control group.

Two models of care are being tested: one model in which the demonstration sites receive up to \$300 a month for services for each patient, and each case manager works with 100 patients, and another model in which the demonstration sites receive up to \$500 a month for services for each patient, and each case manager works with 30 patients. The case managers are responsible for arranging and coordinating services for the patients. Patients and their families must pay for 20 percent of the cost of services covered by the demonstration projects.

As of June 1990, most of the demonstration sites were still enrolling patients, and no conclusions had been reached with respect to the effectiveness, cost, or impact of the expanded services and case management. Anecdotal evidence suggests that some of the demonstration sites were having difficulty enrolling patients, particularly patients in the early stages of a dementing disease. Some observers have suggested that this difficulty may reflect a failure by some of the sites to implement effective outreach procedures to identify individuals and their caregivers who might enroll in the project. Other observers have suggested that the difficulty of enrolling patients in the early stages of a dementing illness may reflect the reluctance of families and others to acknowledge or call attention to the patient's illness.

State Programs and Service Systems That Link Some People With Dementia to Services

All States have procedures by which they link at least some people with dementia to services. In thinking about States' procedures for linking people to services, it is useful to distinguish between linking programs and service systems. As defined by OTA:

- . linking *programs* are programs that perform one or more of the functions OTA concludes are essential for an effective

system to connect people with dementia to services (i.e., public education, information and referral, outreach, and case management); and

- *service systems* are organizational entities that pool funds from several sources and integrate the functions of various agencies in a given geographic area in order to create a consolidated system; one function of service systems is to connect people to services.

An important difference between linking programs and service systems is that linking programs can be added to the service environment in a State or community without changing the structure, function, or relationship of existing agencies or the way services are funded. In contrast, the creation of a service system necessarily changes the structure, functions, and relationship of existing agencies and funding procedures.

Many States have programs that link at least some people with dementia to services, and some States have a service system that links some people with dementia to services. Most State linking programs and service systems are for elderly people or elderly and disabled people, in general. Recently, however, some States have developed dementia-specific linking programs. OTA is aware, for example, of at least 14 States that, in 1989, had a statewide telephone information and referral program specifically for people with dementia (see ch. 7). Missouri is one of a few States that have both a statewide telephone information and referral program for elderly people and a statewide telephone information and referral program for people with Alzheimer's disease and their caregivers (219).¹⁰ In addition to maintaining telephone information and referral programs, some States, such as New York and New Jersey, have published resource directories for family caregivers and others that list available services for people with dementia (601,606).

¹⁰Missouri's information and referral programs for elderly people and people with Alzheimer's disease are described in box 7-A in ch. 7.

Some States have developed or paid for the development of public education programs and materials about dementia and services for people with dementia. In Alaska, for example, the Older Alaskans Commission has given grants since 1984 to the Alzheimer's Disease Family Support Group (a private organization in Anchorage) to provide such programs (282,576). Additionally, public education has been one of the primary functions of the State task forces and committees that have studied the problem of Alzheimer's and other dementing diseases.

As noted earlier, gatekeeper outreach programs have been established in many jurisdictions. Often these programs are a joint initiative of the State department, division, or commission on aging, local AAAs, and utility companies (320). Illinois has a statewide system of gatekeeper programs administered by the Illinois Department on Aging and local AAAs in conjunction with several utility companies and rural cooperatives. With the addition in 1989 of Commonwealth Edison in northern Illinois, the gatekeeper programs now cover the whole State (148).

Lastly, all States have at least one program that provides case management for elderly people, although some of these programs serve very few people (354). Some States provide case management through an independent case management program; some States provide case management as a component of a program that also pays for services, such as a Medicaid 2176 Home and Community-based Waiver program (see ch. 7); and some States provide case management through several different programs. State programs that provide case management generally are not dementia-specific, but they do serve at least some people with dementia.

State programs that link some people with dementia to services are administered at the State level by different agencies in different States and by several agencies in some States. State aging agencies (departments, divisions, commissions, etc.) probably administer more of the existing linking programs than any other

type of State agency, but many other types of State agencies (e.g., State departments of health, social services, or human services and State Medicaid agencies) are also involved.

At the local level, State programs that link some people with dementia to services are implemented by numerous kinds of agencies, including local offices of various State and county departments, city government agencies, AAAs, and many types of private agencies. Often, several different local agencies are involved. In some States, programs that link some people with dementia to services are implemented by agencies that have no counterpart in other States.

The number of States that provide and/or fund linking programs that serve at least some people with dementia is impressive and is growing, but it is also true that some States do not have such programs, and some States have linking programs that only serve a small percentage of all people with dementia and their caregivers. In addition, the four functions identified by this OTA assessment as essential components of an effective linking system for people with dementia (i.e., public education, information and referral, outreach, and case management) generally are not provided through the same State program, so people with dementia can easily "fall through the cracks" between programs.

State programs that link people to services are extremely diverse. That diversity makes it difficult to design a national linking system that would build on rather than duplicate or disrupt the existing programs. If Congress mandated a single category of agencies to constitute a national linking system, that decision would undoubtedly engender resistance from State agencies that administer linking programs that would be duplicated or disrupted by the congressional mandate.

In the past 10 to 15 years, in addition to, or instead of, establishing public education, information and referral, outreach, and case management programs, some States have developed a consolidated service system. These service sys-

terns are often referred to as “long-term care systems.” They generally connect their clients to a range of health care, long-term care, and social services, including services provided or paid for by the system.

States’ purposes in developing consolidated service systems have been:

- to reduce the complexity and fragmentation of services;
- to connect people to the services they need;
- to limit unnecessary use of nursing home care;
- to gain control over public, and especially State, expenditures for health care and long-term care services;
- to create an organizational and administrative structure that allows for efficient and appropriate use of limited services and funds by targeting available services to the people who need them most and avoiding duplication of local agencies’ efforts; and, ultimately,
- to shift some of the public funds now spent on nursing home care to in-home and community services (353,362,372,374, 587).

The development of a State service system may involve several kinds of changes in agencies and procedures at the State and community level, including:

- the designation of a single agency at the State level to administer and oversee all the Federal and State programs that pay for services;
- the designation of a single agency at the community level to administer services paid for by all Federal, State, and local government programs;
- the pooling of funds from different programs to pay for services; and
- the establishment of a uniform client assessment procedure, including the use of a common assessment instrument, for services paid for by various programs.

States’ consolidated service systems include case management as a central component. The

role of the case manager in such systems is often quite different from the traditional case management role in which the case manager coordinates or “brokers’ services from various community agencies for an individual client; in a consolidated service system, a case manager more often administers and allocates services that are already coordinated by the structure and functions of the system.

Consolidated service systems reduce the complexity and fragmentation of the service environment for the people they serve and generally make it easier for those people to connect to appropriate services, but many of the existing State service systems do not serve all types of people with dementia. Some systems do not serve people under age 60 or 65, and many State service systems focus primarily or exclusively on low-income people and/or people with severe functional impairments.

Targeting public funds for services to low-income people and people with severe functional impairments seems entirely appropriate, but such targeting is not necessarily appropriate for linking functions. As discussed earlier, people with dementia and their families need help in linking to services at all stages of the patient’s illness, including the early stages when the patient is not severely impaired. Patients and families with all levels of income and assets and patients under age 60 or 65 also need help in linking to appropriate services.

Like State linking programs, State consolidated service systems are extremely diverse. Oregon, Wisconsin, and Illinois are three States that have gone further than most in creating consolidated service systems (see ch. 7). These three States’ systems have common elements—including a method of coordinating the administration of various programs at the State level and methods for coordinating local agencies’ functions—but there is great diversity even in these common elements. Oregon coordinates the administration of programs at the State level through a single State agency; Wisconsin uses a human service umbrella agency; and Illinois

uses an interagency coordinating committee. Likewise, in each State, different types of agencies have been designated to administer services at the local level—AAAs in Oregon, county social service departments and “County 51 boards” in Wisconsin, and home health, senior service, and a variety of other kinds of public and private agencies in Illinois (587).

Perhaps, the most important observation to be made about existing State service systems is that considerable time and effort were required to develop them, and difficult organizational and turf issues had to be resolved in the process. Most of the systems were developed incrementally. Among the obstacles they faced were:

- inflexible requirements and regulations of the Federal programs that pay for services;
- administrative and organizational characteristics of State agencies that were established in the past to implement Federal program requirements and, once established, are hard to change (436); and
- resistance from interest groups that fear that the consolidation of programs and funding sources at the State level will reduce overall funding for the client population they represent.

Linking programs are easier to establish than consolidated service systems, because, as noted earlier, linking programs can be established at the State or community level without substantially changing the structure, functions, or relationships among existing agencies and without engendering the intense organizational and turf issues that must be overcome in the process of creating a consolidated service system. On the other hand, linking programs do nothing to reduce the fundamental complexity and fragmentation of the service environment, so the problems that patients and families encounter in connecting to appropriate services because of the complexity and fragmentation of the service environment remain.

If Congress designated a single category of agencies to constitute a national linking system, States that have developed consolidated service

systems would have to change their systems or, alternatively, accept the existence of several systems—an outcome they have already spent considerable time and effort to avoid. Conversely, if Congress allowed each State to select the agencies that would constitute the linking system in that State, States that have developed consolidated service systems could incorporate the components of the linking system into their existing service systems.

Community Service Systems That Link Some People With Dementia to Services

Some local communities have developed service systems that link at least some people with dementia to services. Four examples of such systems are described briefly here and at greater length in chapter 7. Two of the systems (the ones in Tulsa, Oklahoma, and Linn County, Iowa) serve elderly people in general, and two (those in northern New Hampshire and northwestern Ohio) are dementia-specific. Each of the systems was developed and is operated by a consortium of public and private agencies. A different approach to coordinating services at the community level currently being developed in Cleveland, Ohio, is also described.

In 1983, five local agencies that provided funds for in-home services in Tulsa, Oklahoma, agreed to coordinate their services by adopting uniform definitions of services and service units, pooling their funds, and jointly contracting for the services (556). Building on the success of that effort, Tulsa established the Nation's first public long-term care authority in 1987. The purpose of the authority is to create a single administrative structure to pool funds for services and coordinate service delivery. It is hoped that the authority eventually will coordinate the delivery of all services—acute and long-term services; in-home, institutional, and community-based services; and publicly and privately funded services (557). Participating in the establishment of the Long-Term Care Management Authority of Tulsa were the local AAA, the State Medicaid agency, the VA Medical Center, the city and county of Tulsa,

and the local United Way agency. The first project of the authority is a pilot case management project, funded by the Administration on Aging, to provide ongoing case management for elderly Medicaid and VA clients.

A different approach to linking elderly people to services has been in effect since 1981 in Linn County, Iowa, where a consortium of local agencies that provide services for elderly people established the Linn County Case Management Project. The member agencies include the local AAA; the local mental health, family service, United Way, substance abuse, and community action agencies; two hospitals; three home health agencies; an adult day center; a senior center; and two county government agencies. The member agencies use a uniform assessment instrument to evaluate elderly clients who come to them for services. Twice a month, a case management team composed of representatives of the member agencies meets to review new cases, develop care plans, and assign responsibility for managing the care of each elderly person to one of the member agencies. In the opinion of its member agencies, the Case Management Project has reduced fragmentation and duplication of services in the county and minimized turf issues among the agencies (80,463).

A community service system that specifically links people with dementia to services was established in 1987 in northern New Hampshire by a consortium of public and private agencies that joined to create the "North Country Alzheimer's Partnership Project." Two private, nonprofit agencies—Tri-County Community Action Agency, Inc. and Crotched Mountain Community Care, Inc.—jointly provide client assessments and ongoing case management for the project. They also provide information and referrals and family caregiver education, counseling, and support services. In-home services are provided by six local home health agencies. The project provides a single entry point and coordinated service delivery for people with dementia (551,614).

The ACCESS Project in northwestern Ohio is another community service system that specifically links people with dementia to services. The ACCESS project is operated by a consortium of 10 public and private agencies that have been receiving funds from the State of Ohio since 1987 to provide case management and in-home and adult day services for people with dementia (156,196). Family Service of Northwest Ohio, a private, nonprofit agency, is the lead agency for the project. Everyone who receives services through the ACCESS project receives case management (196). ACCESS also has a strong caregiver education program. One component of the program is educational workshops conducted in various locations by the East Center for Community Health. The other component is in-home caregiver education, conducted primarily by a nurse from the Medical College of Ohio who uses a video cassette recorder and tapes about Alzheimer's disease to provide individualized caregiver education about dementia and services for people with dementia (156).

In Cleveland, Ohio, several agencies that serve elderly people, people with Alzheimer's disease, and other client populations have taken a different approach to coordinating services: the agencies have co-located on a common campus, called the Fairhill Institute for the Elderly. As of June 1990, more than 10 agencies had established offices on the campus, including the Alzheimer's Center of University Hospitals of Cleveland, the Joseph M. Foley Elder Health Center of University Hospitals of Cleveland, the Geriatric CARE Center of the Case Western Reserve School of Medicine, the Cleveland Chapter of the Alzheimer's Association, the central Cleveland office of the Benjamin Rose Institute, the Retired Senior Volunteers Program of Cleveland, and the administrative offices of Golden Age Centers of Greater Cleveland. The concept of the Fairhill Institute is that the co-location of agencies will allow elderly people, including people with dementia and their caregivers, easy access to a variety of services and will simultaneously provide opportunities for joint educational programs for the agencies'

staff, encourage joint planning, and minimize competition and turf issues among the agencies.

***Agencies That Might Be Designated To
Constitute a National Linking System for
People With Dementia***

At the start of this assessment, OTA identified 11 categories of agencies that Congress could, at least in theory, designate to constitute a uniform national system to link people with dementia to services, if Congress chose to establish a system composed of a single category of agencies nationwide. The 11 categories of agencies were selected because agencies in each category currently link at least some people with dementia to services; because agencies in each category are discrete entities that could be identified and funded directly from the Federal level; and because agencies in each category are currently part of a nationwide “system” of agencies or could conceivably be expanded to serve the entire country. The categories of agencies OTA identified on the basis of these criteria are:

- area agencies on aging (AAAs),
- community mental health centers,
- community health centers,
- Alzheimer’s Association chapters,
- Family Survival Project,
- States’ regional Alzheimer’s diagnostic and assessment centers,
- hospital-based geriatric assessment programs,
- home health agencies,
- social health maintenance organizations (S/HMOs),
- On Lok Senior Health Services, and
- adult day centers.

Some of these categories of agencies (e.g., Alzheimer’s Association chapters and States’ regional Alzheimer’s diagnostic and assessment centers) serve only people with dementia, and others serve other people as well. Some of the categories of agencies (e.g., AAAs, Alzheimer’s Association chapters, and Family Survival Project) link people to services as one of their primary functions. Others link people to serv-



Photo credit: Stan Welt Family Survival Project

Family Survival Project, a San Francisco-based agency, helps caregivers of brain-impaired adults locate and arrange services. Most people who contact Family Survival Project are caring for an individual with dementia.

ices secondarily to their other functions. In addition to linking people to services, all the categories of agencies provide some kinds of services, but the specific services vary from one category of agencies to another.

OTA analyzed each of the 11 categories of agencies in terms of its current capability to function as the basis of a national system to link people with dementia to services. The analysis is presented in chapter 8 and is not repeated here. In chapter 8, each of the 11 categories of agencies is described briefly. The extent to which each category of agencies serves people with dementia and the extent to which each category of agencies provides public education, information and referral, outreach, and case management are discussed. Lastly, the advantages and drawbacks to designating each of the categories of agencies as the basis of a national system to link people with dementia to services are summarized.

The idea of a national linking system composed of one category of agencies nationwide is appealing because such a system would be easy

to publicize, easy for families and others to remember, and readily accessible to caregivers at a distance. On the other hand, OTA's analysis of the 11 categories of agencies indicates that no single category is currently capable of functioning as an effective national system to link people with dementia to services.

In each of the 11 categories of agencies, OTA identified one or more examples of agencies that effectively link people with dementia to services. These agency examples are highlighted in chapter 8. That there is at least one such agency example for each category of agencies indicates that other agencies in the same category could be modified so that they would also effectively link people with dementia to services.

As discussed in chapter 8, each of the 11 categories of agencies has positive features that would contribute to its ability to function as an effective national system to link people with dementia to services, but each category of agencies also has drawbacks. Some of the categories of agencies generally underserve elderly people and people with dementia. Other categories of agencies that do serve people with dementia focus primarily on family caregivers and lack procedures for working with people with dementia who live alone and have no informal caregiver to help them. For several of the categories of agencies to add the linking functions they do not currently provide or expand the types of clients they serve to include people with dementia at all levels of severity and in all stages of their illness would change the agencies so greatly that their primary functions would be compromised and the agencies' unique contributions to the care of people with dementia and other client populations might be lost.

OTA's analysis suggests that a consideration even more important than any drawbacks to designating any of the specific categories of agencies, however, is that designating any single category of agencies to constitute a national linking system would duplicate and disrupt existing linking programs and service systems in many States and localities.

OTHER CONSIDERATIONS IN CREATING AN EFFECTIVE LINKING SYSTEM FOR PEOPLE WITH DEMENTIA

In addition to the components and criteria for an effective linking system discussed earlier, there are several other issues that must be considered in creating a linking system for people with dementia:

- what special procedures may be needed to link ethnic minority people with dementia to services;
- what procedures will be used to determine whether individuals are able to make decisions about services themselves, and, if not, who should make the decisions;
- whether the system will concern itself with the quality and appropriateness of services to which it links people, and if so, how;
- who will be responsible for linking veterans with dementia to VA and non-VA services; and
- how the system will relate to agencies that might be designated to administer any new, federally funded, long-term care benefits.

Each of these issues is discussed briefly in this section. The first four issues are discussed at greater length in chapters 2, 4, 5, and 6, respectively. The related policy questions are whether, in mandating a linking system that would serve people with dementia, Congress should require that the system have explicit procedures for linking ethnic minority people with dementia to services, making decisions about services, evaluating and/or assuring the quality and appropriateness of services to which it links people, and linking veterans with dementia to VA and non-VA services, and if so, what those procedures should be.

Special Problems in Linking Ethnic Minority People With Dementia to Services

Ethnic minority people constitute about one-fifth of the U.S. population. About 12 percent of all Americans are black; 6 percent are Hispanic,

including people of Mexican, Puerto Rican, Cuban, and other Spanish/Hispanic origin; 1.5 percent are Asian American, including people of Chinese, Hawaiian, Korean, Philippine, Vietnamese, Cambodian, Asian Indian, and Japanese origin; and 0.6 percent are Native Americans, including Eskimo, Aleut, and American Indian people (492).

The number of people with dementia in ethnic minority groups is not known. The age-specific prevalence of Alzheimer's disease is generally believed to be the same for ethnic minority groups as for the population as a whole, but some differences in the prevalence of other diseases that cause dementia (e.g., multi-infarct disease) have been noted. For a variety of reasons, the percentage of people over age 65 is lower in ethnic minority groups than in the population as a whole, but that proportion is growing rapidly. Between 1970 and 1980, it increased 40 percent for blacks, 91 percent for Hispanics, 31 percent for Asian Americans, and 71 percent for Native Americans. This rapid growth in the age group in which dementia generally occurs portends rapid increases in the overall numbers of ethnic minority people with dementia (864).

There are long-standing concerns about limitations on access to services and underutilization of all kinds of services by ethnic minority people (26,153,159,284,432,454,553,845,861). At the start of this OTA assessment, however, no research was available on problems that interfere with the process of linking ethnic minority people with dementia to services. OTA contracted for an exploratory study to identify such problems (866). The study was conducted in Los Angeles and San Diego Counties, California, and involved interviews with black, Hispanic, Japanese, and American Indian caregivers and staff members of agencies that work with each of the groups.¹¹ When the interviews were complete, the contractors and OTA staff met with the interviewers and service providers for

the black, Hispanic, and Japanese caregivers to discuss the results and policy implications.¹² It was not possible for OTA staff to meet with the American Indian group within the time frame of the study.

As discussed in chapter 2, the results of the exploratory study and discussions with the interviewers and service providers suggest that ethnic minority people with dementia and their caregivers have several special needs with respect to information about services and funding for services. First, some members of certain ethnic minority groups do not speak English at all or well enough to communicate about the details of service availability and funding for services. That information must be available to them in their native language.

Language is not the only problem, however. The cultural heritage, traditions, customs, and beliefs of ethnic groups create differences in how and when members of a group perceive the problem of dementia, who is expected to be the caregiver, what that individual or individuals' responsibilities are, whether formal services are acceptable, and how and when they are sought (160,315). Information about dementia and services for people with dementia must reflect awareness of those cultural differences. Cultural values and concerns also are relevant in selecting service providers for ethnic minority people with dementia. The linking system must be knowledgeable about agencies' and individual providers' capacity to work with people of different cultural backgrounds.

Demographic variables, such as income and educational background, vary both among ethnic minority groups and within a given group. Information about services for people with dementia must be tailored to economic and educational differences as well as to cultural differences.

Lastly, for cultural, demographic, and historical reasons, many ethnic minority people live in

¹¹OTA's contractors intended to include Chinese and Korean people in the study but were unsuccessful in arranging the necessary interviews.

¹²The meeting participants are listed in app. A.



Photo credit: On Lok Senior Health Services

In some communities, there are agencies that serve primarily one ethnic minority group. On Lok Senior Health Services in San Francisco serves primarily individuals of Chinese descent.

communities largely composed of members of the same group. In these communities, there is generally an infrastructure of individuals and associations recognized by the community as sources of information and assistance with a wide range of problems (380). There also may be agencies that primarily serve one ethnic group. If information about services for people with dementia is to reach patients and their caregivers, it must be available through those individuals, associations, and agencies.

The caregivers interviewed for the exploratory study conducted for OTA in Los Angeles and San Diego Counties represent only one

segment of the population of caregivers of ethnic minority people with dementia—caregivers who are already connected to services of some kind (866). The service providers, interviewers, and OTA’s contractors pointed out that many ethnic minority people with dementia and their caregivers are not connected to services. They said dementia frequently is not identified in ethnic minority people, sometimes because families regard patients’ cognitive deficits and behavioral problems, if any, as part of normal aging, but more often because families are ashamed of some symptoms of dementia and hide the patient.

The impression of OTA’s contractors and the interviewers was that the problem of dementia is only one of many health and mental health problems facing service providers in ethnic minority communities. Available resources are stretched thin, and agencies are overwhelmed by many urgent needs. Moreover, some providers are not knowledgeable about dementia or appropriate services for people with dementia (866).

The most surprising finding of the study conducted for OTA was the difficulty OTA’s contractors experienced in locating ethnic minority caregivers of people with dementia who were willing to be interviewed (866). Many caregivers who were contacted were not willing to be interviewed or even to acknowledge that their relative or friend had dementia. OTA’s contractors concluded that the difficulty they encountered in finding caregivers to interview was similar in some ways to the difficulty a linking system would have in connecting with ethnic minority people with dementia and their caregivers. Likewise, the method that was at least partially successful for the researchers—working through the ethnic minority community infrastructure and ethnic minority agencies—is probably the best way for a linking system to connect with those people. Some patients and their caregivers are not in contact with the community infrastructure or ethnic minority agencies, however. Other outreach methods would be needed to connect with them.

Ethnic minority groups are distinguished by differences in language (if any), culture, demographic factors, and by people's awareness that they are part of the group. Although language differences usually are not a factor for nonminority people, all Americans have a cultural background and demographic characteristics that are likely to affect their perceptions of dementia, their expectations about caregiving responsibilities, and their attitudes about the use of formal services. Clearly, a system to link people with dementia to services should be responsive to the diverse perceptions, expectations, and attitudes of both minority and nonminority people with dementia and their caregivers.

Questions About Making Decisions About Services for People With Dementia

Cognitive deficits associated with dementia affect the capacity of people with dementia to make decisions about services for themselves and raise difficult questions about how their capacity to make decisions should be determined and how decisions should be made for people who are not capable of making decisions for themselves. Those questions often are obscured by the practical difficulties involved in locating and arranging services in a complex service environment and by the severe time constraints within which decisions about services must be made in many instances. Nevertheless, the questions are inherent and unavoidable in the process of linking people with dementia to services. Every agency and individual that arranges services for people with dementia answers them in some way---either explicitly, with formal or informal procedures for determining decisionmaking capacity and making decisions for clients who are not capable of deciding for themselves, or implicitly, by the way such decisions are made. The way the questions are answered involves fundamental legal rights of the patient and complex legal and ethical issues. The rights and issues are at stake whether or not the individuals who make or participate in the decisions are aware of them.

Most agencies that arrange services for people with dementia do not have explicit procedures either for determining clients' decisionmaking capacity or for making decisions (or designating someone to make decisions) for clients who are not capable of making decisions for themselves (see ch. 4). Individual case managers and others who work directly with clients necessarily act on judgments about their clients' decisionmaking capacity and about who should make decisions for clients that are not capable of deciding for themselves, but the case managers and others may not be conscious of making such judgments or knowledgeable about the implications of the judgments.

If an agency or individual that arranges services for people with dementia is unaware of the legal rights and legal and ethical issues involved in decisionmaking, those rights and issues will not receive adequate attention. Having explicit procedures for determining decisionmaking capacity and making decisions for clients who are not capable of making decisions for themselves does not guarantee that people with dementia who are capable of making decisions always will be given the opportunity to make them or that the right surrogate decisionmaker always will be chosen. Having such procedures does focus attention on the legal rights and legal and ethical issues at stake in decisionmaking and makes it more likely that those rights and issues will be considered in the way decisions about services are made.

If Congress mandated a national system to link people with dementia to services, Congress could require the agencies that constitute the system to have explicit procedures for determining decisionmaking capacity and making decisions (or designating someone to make decisions) for people who are not capable of making decisions for themselves. In establishing such procedures, agencies would have to address many difficult questions, including:

- . What criteria should be used to determine decisionmaking capacity?



Photo credit: Alzheimer's Association and Rush-Presbyterian/St. Luke's Medical Center

The process of connecting an individual with dementia to services often involves difficult judgments about whether the individual is capable of making decisions about services for herself or himself and, if not, who should make the decisions.

- Who should be involved in determining a person's decisionmaking capacity?
- What procedures should be used to enhance the decisionmaking capacity of individuals with dementia, while at the same time protecting decisionally incapable individuals from potentially harmful decisions?
- How should surrogate decisionmakers be selected?
- What procedures should be followed when a decisionally incapable person's relatives disagree about which one of them should be the surrogate decisionmaker?
- How should nonfamily caregivers be involved in decisions about services for the individual they are caring for?
- What criteria should guide surrogate decisions?

- Under what circumstances should the agencies refer an individual for formal guardianship?

One of the most difficult questions faced by any agency or individual that links people with dementia to services is the relative importance that should be given to the needs, preferences, and best interests of the family v. the patient's needs, preferences, and best interests. In 1983 and 1984, a Wisconsin program, Consumer Directed Services (CDS) Initiative, gave 70 individuals with chronic disabilities, including some people with dementia, vouchers to purchase services. Each participant—called a 'consumer' by the project—had a service coordinator, whose job it was to help the person define

his or her service needs and select services. According to the project final report:

One of the first questions all CDS staff had to grapple with was ‘who is the consumer?’ This question arose when the person in need of long term support had significantly diminished mental capabilities and when family members and other natural supporters were deeply involved in providing direct support to the person.

It was in these instances that CDS staff had the greatest difficulty in sorting out the interests of the consumers from the interests of the family. Frequently, there were competing interests within the family. It may seem obvious that the consumer in such a situation is the disabled person, and that CDS staff should have focused on facilitating that person’s interests. In doing extended assessments of people’s situations, however, CDS staff found that involvement of the family and other support network members was so vital an element that their interests could not be separated from those of the disabled person (919).

Chapter 4 discusses the question, “who is the consumer?” (or “who is the client?”) and discusses the implications of various answers to the question with respect to decisions about services for people with dementia.

Further analysis and debate is needed about many of the difficult questions about decision-making that are inherent in the process of linking people with dementia to service. In addition, case managers and others who participate in the linking process probably would benefit from training about the legal rights, legal and ethical issues, and clinical considerations involved in the way judgments are made about an individual’s decisionmaking capacity and about who should make decisions for people who are determined to be decisionally incapable.

Determining the Quality and Appropriateness of Available Services

The quality and appropriateness of all kinds of services that may be used for people with dementia vary greatly from one agency and individual service provider to another. Because

of their cognitive deficits, people with dementia are particularly vulnerable to inappropriate or poor-quality care. They may be unable to identify or articulate their care needs, to evaluate the services they receive, to remember and report instances of poor care, or to be believed. Families and other informal caregivers realize that people with dementia are vulnerable, and they are often extremely concerned about the quality and appropriateness of services they may use for their relative or friend with dementia.

Books, pamphlets, and articles about services for people with dementia suggest that families and other informal caregivers are responsible for selecting good services and that information about the quality and appropriateness of available services—on which they could base their selection—is available from a variety of sources, including relatives, friends, and acquaintances who have used the services; physicians, nurses, social workers, and other health care and social service professionals; professional and provider associations, the Alzheimer’s Association, caregiver support groups, information and referral agencies, hospital discharge planners, case managers, long-term care ombudsmen, AAAs and other aging network agencies, various State and local government agencies, and government regulatory programs. OTA’s analysis indicates that accurate information about the quality and appropriateness of services is sometimes available from most of these sources but is not consistently available from any of them (see ch. 5). Moreover, obtaining accurate information about the quality and appropriateness of service from those sources may take time and abilities that people with dementia and some informal caregivers do not have.

A linking system could take several different approaches in addressing the difficulties people have in obtaining accurate information about the quality and appropriateness of services. It could refer patients and families to specific sources of information about quality and appropriateness; it could provide patients and families with information about the quality and appropriateness of services it refers people to or arranges for

them; it could refer patients and families to or arrange for them only services that meet certain standards of quality and appropriateness; or, if the linking system provides services, it could assure the quality and appropriateness of those services directly. All these alternatives presuppose that there are' accepted criteria for evaluating the quality and appropriateness of services for people with dementia and that information about quality and appropriateness is available somewhere. As discussed in chapter 5, however, many conceptual and practical difficulties in defining and evaluating quality and determining what makes services appropriate for people with dementia hinder the development of such criteria and information.

In the public debate about services for people with dementia, concerns about the quality and appropriateness of services are often considered secondary to concerns about the insufficient availability of services. Some health care and social service professionals, case managers, government planners, policy analysts, and others whom OTA asked about evaluating the quality of services for people with dementia responded that there is often no choice about services. In many localities, they said, families are lucky if there are any services available-let alone services that are appropriate for a person with dementia and of high quality.

Certainly, the concern about insufficient availability of services is legitimate. On the other hand, even when services are available, families' concerns about the quality and appropriateness of services are sometimes the determining factor in their decisions about whether or not to use the services. In the view of some families in some situations, services that are available but of poor quality or inappropriate for the patient may just as well not exist.

The best approach to helping families and others locate good services depends in part on which agencies are designated to constitute the linking system. Conversely, it would be unwise to designate for this purpose agencies that, for any reason, cannot either provide patients,

families, and others with information about quality and appropriateness or assure directly the quality of services it links them to. These considerations are discussed in chapter 5. Also discussed there is the unresolved question of the role of a linking system with respect to the quality and appropriateness of services to which it links people with dementia who have no relative or friend to help them and would not be capable of using information to evaluate services for themselves, even if the information were available.

Linking Veterans With Dementia to VA and Non-VA Services

By the year 2000, there will be 9 million veterans over age 65, including two-thirds of all American men over age 65 (854). As the number of elderly veterans increases, so will the number of veterans with dementia. The VA estimates that there will be 600,000 veterans with dementia by the year 2000 (76).

The VA operates the largest health care system in the United States and currently provides many of the kinds of services that may be needed for veterans with dementia. Those services include acute medical care, diagnostic and assessment services, nursing home care, domiciliary care, hospital-based home care, adult day health care, institutional respite care, and some specialized services for individuals with dementia. In the course of this assessment, one OTA staff member visited several VA medical centers that are providing specialized services for veterans with dementia, some of which are described in chapter 6.

Not all health care and health-related services that are needed for veterans with dementia are available through the VA, however. Some services, such as in-home respite care are not provided by the VA at all. Other services are provided only at certain VA medical centers. As of 1989, for example, 100 of the 172 VA medical centers provided institutional respite care, and only 15 of the 172 VA medical centers provided adult day health care (837). Moreover, most VA health care and health-related services

are provided at VA medical centers. Since the 172 VA medical centers are not uniformly distributed across the country, and since some have very large catchment areas, veterans and their caregivers may have to travel long distances to obtain VA services, and some may not be able to obtain the services (481,662,724,823). Lastly, many VA services are furnished on a "space available" basis, so that even if the services a veteran needs are provided by a VA medical center the veteran can reach, he still may not receive the services because the programs that provide them are full.

The eligibility criteria for VA services also limit access to the services for veterans with dementia. The VA has complex eligibility criteria that give highest priority for VA services to veterans with service-connected disabilities and veterans with low income (see ch. 6). Since most diseases that cause dementia occur late in an individual's life, long after he or she is discharged from military service, dementia is seldom considered a service-connected disability. Some veterans with dementia have another service-connected disability or have low income, but veterans with dementia who do not have a service-connected disability or low income generally have low priority for VA services. As a result, their chances of receiving VA services are highly dependent on whether there is "space available" in the programs that provide the services they need.

Some people believe the VA should provide all the health care and health-related services that are needed for all veterans, including veterans with dementia. Others believe that for financial and other reasons, the VA should not or cannot provide all needed services for all veterans. This OTA report does not address the questions of what services the VA should provide or for whom. It focuses instead on the processes by which veterans with dementia are (or are not) linked to the VA services for which they are eligible and to non-VA providers for services they need but cannot obtain through the VA. The report assumes that, although the amount and types of services provided by the

VA and the eligibility criteria for VA services will undoubtedly change from time to time, it is unlikely that the VA will ever provide all the services that may be required by all veterans. As a result, veterans with dementia will need to be linked to both VA and non-VA services.

Problems of several kinds interfere with the process by which veterans are linked to VA services. As mentioned earlier, the eligibility criteria for VA services are complex. Veterans and their families often do not understand the criteria and may assume the veteran is not eligible for services when he is, or vice versa. They also may not be aware of potentially beneficial services provided by the VA. Many non-VA agencies and individual professionals and service providers who work with people with dementia also do not understand the VA's eligibility criteria and may not be knowledgeable about VA services, so they cannot give veterans and their families accurate information about the services, and they may fail to refer individuals to the VA who would be eligible for services. As a result, some veterans and their families never apply to the VA for services, even though the veteran is potentially eligible. Interestingly, some caregivers of veterans with dementia who were receiving good care from the VA told OTA staff that they had learned about the services completely "by accident" (see box 6-C inch. 6).

Until recently, the VA itself has not been fully aware of the kinds of services it is providing for veterans with dementia. In 1988, the VA conducted a survey of all 172 VA medical centers to find out what programs and services were available for veterans with dementia (76). The results of the survey have been compiled into a directory for internal VA use in referring veterans and their caregivers to services and responding to public inquiries about the location of services for veterans with dementia across the country. The directory cannot solve the problem of determining whether an individual veteran with dementia will actually receive VA services, however, because that determination depends to

a great extent on space availability at the time the veteran needs the services.

Other problems interfere with the process by which veterans with dementia are linked to non-VA services. According to several sources, the most difficult problem encountered by the VA in linking veterans to non-VA services is the complexity and fragmentation of non-VA services at the community level—the same problem encountered by anyone who tries to locate and arrange services in many communities (481,854, 860). Each VA medical center's Social Work Service has a community services coordinator whose job is to identify non-VA services in the community and to coordinate VA and non-VA services. The VA has also developed a software system to help the Social Work Service at each VA medical center maintain an up-to-date list of non-VA services. The community services coordinator position is staffed only half-time at many VA medical centers, however, and, as noted throughout this OTA report, the complexity and fragmentation of non-VA services in many communities make it difficult for anyone to maintain an accurate, comprehensive resource list. As a result, some VA personnel who refer veterans with dementia to non-VA services may not be aware of potentially helpful services in the community.

The Social Work Service at each VA medical center has primary responsibility for linking veterans to non-VA services through its hospital discharge planning and case management functions (see ch. 6). Although VA hospital discharge planning and case management are undoubtedly effective in connecting many veterans to non-VA services, there are two groups of veterans who may not receive the assistance they need:

- VA hospital discharge planning and case management are provided primarily, although not exclusively, for veterans who are already receiving or are eligible to receive VA services, but many veterans with dementia are unlikely to receive or to be eligible for VA services and therefore

may not receive help from the VA in finding non-VA services, and

- VA case management generally is more readily available for veterans who live near a VA medical center; some VA medical centers have very large catchment areas, and many veterans in their catchment areas live far from the center; as a result, these veterans may not receive help from the VA in finding non-VA services (236).

Without effective methods for linking veterans with dementia to both VA and non-VA services, some, and probably many, veterans with dementia will not receive the services they need. As the number of veterans with dementia increases in the next decade, the demand for services for these veterans and the need for effective methods of linking for them to services will also increase. The policy issue discussed at the end of this chapter is the appropriate division of responsibility between the VA and a non-VA linking system for connecting veterans with dementia to services.

Because of the complexity of the eligibility criteria for VA services, especially as they interact with the factor of space availability, only the VA can finally link veterans to VA services. The non-VA linking system would have to be knowledgeable about VA services and eligibility requirements, however, in order to know when to refer veterans with dementia to the VA.

With regard to linking veterans with dementia to non-VA services, there are two options. If a national linking system were established, it could assume the primary responsibility for linking veterans with dementia to non-VA services. Alternatively, the VA could assume the primary responsibility for linking veterans with dementia to non-VA services. These options are discussed at the end of this chapter.

Lastly, it is clear that the VA is an important provider of services for some, and perhaps many, veterans with dementia. For that reason, the VA must be involved in the planning and operation of a national system to link people

with dementia to services regardless of the specific responsibility it has for linking veterans with dementia to non-VA services.

The Relationship of the Linking System to Congressional Proposals for New Long-Term Care Benefits

As mentioned at the beginning of this chapter, several bills have been introduced in Congress in 1988, 1989, and 1990 to expand Federal funding for a variety of long-term care services. Provisions in most of the bills indicate that the agencies designated to administer the new benefits also would link people to services. This report does not evaluate any of the legislative proposals specifically. Some general statements can be made, however, about differences between the linking system discussed in this report and the linking functions that would be authorized by many of the proposed bills. First, to OTA's knowledge, none of the proposed bills include the provision of public education, information and referral, or outreach—three of the four components that OTA concludes are essential for an effective system to link people with dementia to services. Second, the case management that is part of the proposed bills would only be available to people who meet the eligibility requirements for the services to be authorized by the bills—usually impairments in two or more activities of daily living (ADLs). Presumably, anyone who received the services authorized by the proposed bills also would receive case management, since case managers would administer the services. In contrast, the case management that is a component of the linking system discussed in this report would be available to anyone who needed it, regardless of the severity of their impairments or their eligibility for any particular service. No one would be required, however, to receive case management as a condition for receiving any other assistance from the linking system.

The linking system described in this report probably would be available to more people than the number who would receive long-term care services and case management through the

proposed bills, but the linking system would not provide any new funding for services. In contrast, the proposed bills would make available funding for many new long-term care services for people who met the eligibility requirements in the bills. The proposed bills would not necessarily provide: 1) information and referral for people in the early stages of dementia when referrals for accurate medical diagnosis, and legal and financial counseling are particularly important; 2) referrals for services that are not included in the bills; or 3) outreach to isolated people with dementia and caregivers who may need services but are unlikely to contact a long-term care agency on their own.

Combining the linking system discussed in this report and the expanded long-term care services delineated in the proposed bills would create a comprehensive long-term care system that would both cost more and help more people than either approach by itself. Combining the two approaches would have implications for several of the policy options discussed at the end of this chapter. First, the combined system necessarily would serve anyone who needed long-term care, not just people with dementia, but it still could be dementia-friendly and dementia-capable. Secondly, the agencies that administered the combined system necessarily would allocate services and funding for services. Lastly, some of the categories of agencies identified by OTA as potentially capable of constituting a national linking system would not be capable of administering the combined system.

Other Considerations

Six questions that are relevant to establishing an effective linking system for people with dementia but have not been discussed in this chapter are briefly reviewed here. The first is *the cost of a linking system*. That cost would vary greatly, depending on which agencies constitute the system and many other factors. The available information about the cost of some State linking programs is presented in chapter 7. Chapter 8 includes the available information

about funding for the 11 categories of agencies discussed there. The figures are not necessarily comparable, however, because the linking functions and other services provided by each of the categories of agencies differ so greatly. Further analysis of the cost of a linking system will be needed once decisions have been made about which agencies will constitute the system, whether the system will serve people with dementia exclusively or other people as well, and other issues.

The second question is *the role of computer technologies in an effective linking system*. Clearly, computer technologies make it easier to maintain an accurate list of services and sources of funding for service in the complex, changing service environments that exist in many communities. The difficulty of maintaining such a list is due not to lack of computer technologies, but rather to lack of agency resources committed to updating the list, turf issues that interfere with various agencies' and individuals' willingness to cooperate in developing and maintaining the list, and problems in defining and categorizing services in a way that is relevant to the needs of patients and families. These issues are discussed in chapter 2. The computerized databases being used by some agencies and organizations that link people with dementia to services are discussed in chapters 7 and 8.

The third question is *who the case manager should be*. Virtually all health care, social service, and other human service professionals and service providers manage their clients in some sense. Nurses and social workers are the case managers in many agencies that provide the kinds of health care, long-term care, and social services that may be needed for people with dementia. State agencies that allocate long-term care services often employ as case managers individuals with a college, but not a professional degree in a human service field (47).

Differences of opinion about who should be the case manager usually focus on social workers v. nurses and involve competing claims about the knowledge and skills that case manag-

ers need and which professional group has that expertise (23,31 ,46,204,265,382,558,647). Those differences of opinion sometimes result in intense turf conflicts. In many agencies, however, social workers and nurses work together constructively and comfortably, learning from each other and relying on each other's special knowledge and skills. Many commentators, including some of those who have noted the turf issues between social workers and nurses, have concluded that both are needed for effective case management (23,31 ,409,506). That seems to be a wise conclusion. All social workers and nurses are not necessarily knowledgeable about dementia or skilled in working with people with dementia. That knowledge and those skills probably are more important in creating an effective linking system than any consistent differences between nurses and social workers as case managers.

The fourth question concerns *case management standards*. The American Nurses' Association, the National Association of Social Workers, the National Council on the Aging, at least one State, some State Units on Aging, and other organizations and individuals have formulated case (or "care" management standards (22,32,572,581). OTA has not compared those standards systematically, but a brief review indicates that they are based on similar philosophies, views about the role and functions of the case manager, and concerns about clients' rights. The requirements for a national linking system might incorporate some of the core features of those standards.

Fifth is the question of *the appropriate role of physicians in linking people with dementia to services*. As discussed in chapter 2, families and other informal caregivers of people with dementia often complain that physicians are not knowledgeable about services for people with dementia and do not refer people with dementia to appropriate services (125,257,412,479,497, 500,531,599,934). On the other hand, anecdotal evidence suggests that families and other informal caregivers may be more likely to use services if they have been referred to the

services by a physician (291,931). The importance of involving physicians in the linking people with dementia to services and the difficulties involved in doing so, including constraints on physicians' time, are discussed in chapter 2.

Some commentators have suggested that people with dementia and their caregivers might be more likely to follow through on recommendations about services if the services were actually prescribed by a physician (931,944). The Alzheimer's Diagnostic and Treatment Center at the University of California/Davis Medical Center has recently developed a prescription pad for this purpose to be used by physicians in the center's service area (see figure 1-3). No information is available yet about the effectiveness of this approach.

A final question concerns *family control and the role of families in relation to a linking system*. As noted in chapter 3, families of older people frequently perform various linking functions themselves, acting as an intermediary between the older person and paid service providers (85,92,1 10,467,477,753,778). In 1988, a study was conducted for OTA in Pennsylvania to explore the question of what is special about case management for people with dementia (934).¹³ Family caregivers of people with dementia who were interviewed for that study expressed a strong desire to have control over decisions about services provided for their relative with dementia. Moreover, OTA's contractors noted that the caregivers often seemed to perceive themselves, rather than the AAA case manager who arranged services for them, as the case manager. OTA does not know whether families of people with dementia are more likely than families of nondemented elderly or disabled people to want to retain control over decisions about services for their impaired relative. In any case, allowing families to retain that control to the greatest degree possible would seem to be a worthwhile objective for a



Photo credit: M.P. Cordero-Aranda

Some, and perhaps many, families of individuals with dementia perceive themselves as the case manager for their relative with dementia and want to retain control of decisions about services for the person.

linking system. Chapter 3 discussed the role of families as "co-case managers" or "co-clients of a linking system and other issues that pertain to the relationship between families and a linking system.

CONCLUSION

Families and others who are caring for a person with dementia often experience great difficulty locating and arranging appropriate services for the person. To some degree, this problem reflects the lack of sufficient services in many communities, the lack of adequate funding for services, the poor quality of some available services, and the lack of training for service providers. These four issues were the focus of OTA's 1987 report, *Losing a Million Minds: Confronting the Tragedy of Alzheimer's and Other Dementias*, and remain to be resolved in many, if not all, areas of the country.

The difficulty families and others have in locating and arranging appropriate services also

¹³The results of the study conducted for OTA in Pennsylvania are discussed in ch. 3. A complete report on the study is available from the National Technical Information Service in Springfield, VA (see app. A).

Figure 1-3-A Prescription Form for Use by Physicians in Referring Alzheimer's Patients to Community Services, 1990

RX FOR CAREGIVERS IN 916 AREA

Name _____ Date _____

Information & Referral

- Del Oro RRC 971-0893
- Alzheimer's Aid Society 448-7001
- Sutter Senior Help Line 733-3888
- Other Community Info 442-4995

Caregiver Counseling

- Del Oro RRC 971-0893
- Mental Health Assoc. 456-2071
- Alzheimer's Aid/Support Groups 448-7001
- Other - Community private practitioners - psychologists, psychiatrists, family counselors, pastors, etc. (no specific referral)

Training & Education

- Del Oro RRC 971-0893
- Info from an array of providers available at this phone number.

Respite

- Del Oro RRC 971-0893
- Sutter Davis Guest Weekend 756-6440
- Other - day care, in-home: fee for service unless skilled health care needed and Medi-Cal or Medicare pays (no specific referral)

Case Management

- MSSP (Medi-Cal) 734-5432
- Senior Connection (pvt) 972-1114
- Other - private practitioners and home health agencies (no specific referral)

Home Health Care

- In-Home Support Services 732-3077
- Other - Home health agencies & home nursing - fee for services (no specific referral)

Adult Day Health Care

- Robertson ADHC 452-2529
- Yolo ADHC/CASA 666-8828
- Health for All ADHC/RC 885-2655 (Auburn)

Residential Care

- Licensing 973-3846
- Ombudsman 366-5554

Skilled Nursing Facilities

- Licensing 445-3281
- Ombudsman 366-5554
- Special care facilities (though others may also be appropriate):
 - Sutter Oaks Alz. Ctr 922-7177
 - Hillhaven Fair Oaks 944-4312
 - Homestead - Fair Oaks 965-4663
 - Greenhaven Country Place 393-2550

Financial Eligibility

- Medi-Cal 395-4551
- Social Security (Medicare, SSI) 551-1000
- Other - Fee for service - financial planning (no specific referral)

Legal Planning

- Del Oro RRC 971-0893
- Conservatorship 732-3827
- Other - probate, elder law practitioners (no specific referral)

Emergency/Endangerment

- Geropsych Network 732-9490
- Adult Protective Svcs 732-3077

Other

- Medic-Alert 1-800-ID-ALERT
- Nat'l Alzheimer's Assoc. 1-800-621-0379
- UCD/ADDTC 734-5496
- UCD Brain Bank 734-2885

* * * * *

Take Care of Yourself! !

_____ MD

Phone _____

UCD/ADDTC 4/27/90

reflects several other factors, including the complexity and fragmentation of services at the community level, the difficulty of obtaining accurate information about available services and funding for services, the difficulty of coordinating the services of multiple providers, and the characteristics, feelings, and perceptions of some people with dementia and some caregivers that make them reluctant to use services, unable to define their service needs, or unable to arrange services for themselves. Even if sufficient services were available everywhere, these factors would still limit access to appropriate care for some, and perhaps many, people with dementia.

Based on an analysis of the characteristics and care needs of people with dementia, their informal caregivers (if they have any), and the service environment, OTA developed a framework for an effective system to link people with dementia to services. The essential components of the system (i.e., public education, information and referral, outreach, and case management), additional criteria, and other considerations in the development of the system have been discussed in this chapter and are analyzed in greater detail in other parts of the report.

Although the need for an effective system to link people with dementia to services is clear, establishing such a system will be difficult, largely because of turf issues. Many public and private agencies, organizations, individual professionals, and service providers currently link some people with dementia to services. With a few exceptions, each of these agencies, organizations, and individuals considers itself the right one to perform that function. Moreover, many of them propose to solve the problem of locating and arranging services for people with dementia by expanding their role in the area. Some of them are unaware of the efforts of the others to link people with dementia to services. Those that are aware of the others' efforts tend to regard those efforts, or at least any expansion of those efforts, as "duplication."

OTA was surprised by the large number of agencies, organizations, and individuals that link at least some people with dementia to services. That large number is good in the sense that there are many places to which families and others can turn for help. On the other hand, in many communities, the large number of agencies, organizations, and individuals that link people with dementia to services probably results in further complication and fragmentation of the service environment. Since many agencies, organizations, and individuals that link people with dementia to services do not have an accurate list of services and sources of funding for services, some patients and families receive wrong information or only partial information about available services and funding. Establishing an effective system to link people with dementia to services will require a consolidation of the linking functions now provided by many agencies, organizations, and individuals.

Some people who reviewed this report for OTA pointed out that it would be easier to establish a national system to link people with dementia to services if the system did not have to include case management, because many of the agencies and organizations that currently link some people with dementia to services provide public education and information and referrals but generally do not provide case management. Although it is undoubtedly true that a national linking system could be established more easily if it did not have to include case management, OTA's analysis indicates that some people with dementia would not be served effectively by such a system. People with dementia who are likely to need case management are those who live alone and have no relative or friend to help them, those who have an informal caregiver who is reluctant to use needed services or unable to arrange services, and those who need services from several different providers. OTA's analysis of available data indicates that at least 10 percent of people with dementia live alone and have no relative or friend to help them. These individuals and other individuals with dementia whose caregivers are

reluctant to use needed services or unable to arrange services will not be served effectively by a linking system that provides only public education and information and referral.

Many agencies that provide services of various kinds for people with dementia provide case management in conjunction with the services—i.e., service-centered case management. An individual who is receiving case management from such an agency generally would not need long-term case management from the linking system. For such an individual, the linking system might provide only short-term case management to connect the individual to the agency originally and then be available to provide further assistance, if necessary, later on. For other individuals with dementia who need services provided by agencies that do not provide case management or services provided by multiple agencies and individuals, the linking system may have to provide ongoing case management.

A linking system is needed partly because of the complexity and fragmentation of services. If agencies' rules about whom they serve and what they provide were simpler and more flexible and the services of different agencies were better coordinated, more families and others would be able to locate and arrange appropriate services themselves.

The complexity and fragmentation of services at the community level originates to a great extent in the federally funded programs that provide or pay for services—specifically in the detailed and extensive regulations that define not only what services are covered and for whom, but also who may provide them, for how long, and in what setting. Congress repeatedly has mandated coordination among the Federal, State, and local agencies that administer these federally funded programs. Although these mandates sometimes lead to meaningful coordination, the Federal Government's own regulations often interfere with coordination at all levels of government.

In addition to establishing a system to link people with dementia to services, Congress could begin to identify and reduce the barriers to coordination and integration of services caused by Federal law and Federal regulations. This might ultimately result in consolidation of various Federal programs that fund health care, mental health, social, and other services and services for elderly and disabled people. In the short term, Congress could allow States and local governments greater flexibility to pool funds and consolidate services from different Federal programs. New federally funded services could be designed with explicit recognition of the complexity and fragmentation of existing services, and new regulations could be written in away that will reduce, not increase this problem.

POLICY ISSUES AND OPTIONS

This OTA report discusses the need for an effective system to link people with dementia to services and presents a framework, including essential components and criteria, for such a system. Seven important policy issues with respect to the system remain to be resolved. Those policy issues and the options for congressional action are discussed in this section.

ISSUE 1: Should the linking system serve people with dementia exclusively or should it serve people with dementia and people with other diseases and conditions as well?

Option A: Congress could mandate the establishment of a linking system that would serve people with dementia exclusively.

Option B: Congress could mandate the establishment of a linking system that would serve people with dementia and people with other diseases and conditions as well.

This report identifies many special problems and concerns in linking people with dementia to appropriate services. To be effective, a linking system must be both dementia-friendly (i.e., responsive to people with dementia) and dementia-capable (i.e., staffed by people who are skilled in working with people with dementia and their caregivers, knowledgeable about the kinds of

services that may help them, and aware of which agencies and individuals provide such services in the community). Some people believe that only a system that is dementia-specific could meet those requirements. They advocate the establishment of a linking system that serves people with dementia exclusively (option A).

Other people believe that individuals with dementia and their caregivers would be best served by a linking system that is not dementia-specific and that such a system could be both dementia-friendly and dementia-capable. One reason they advocate a linking system that is not dementia-specific (option B) is that some, and perhaps many, people with dementia are not identified as “people with dementia” by their families, physicians, or others. Probably this is most likely to occur if the individual has a serious physical condition in addition to his or her dementia. Families and others who do not identify the person they are caring for as a “person with dementia” are unlikely to contact a dementia-specific linking system for help in finding services. A second reason that some people advocate a linking system that is not dementia-specific is to avoid further fragmentation of the service environment by the introduction of another disease- or condition-specific element. Almost all the members of the advisory panel for this OTA assessment favored option B.

ISSUE 2: Should the Federal Government designate a single category of agencies to constitute the linking system nationwide or should each State be mandated to designate the agencies that will make up the system in that State?

Option A: *Congress could designate a single category of agencies to constitute the linking system nationwide or instruct the U.S. Department of Health and Human Services to do so.*

Option B: *Congress could mandate that each State designate the agencies that would make up the linking system in that State. Under Option B:*

1. *States could be mandated to designate a single category of agencies to make up the*

linking system in that State.

2. *States could be authorized to designate either a single category of agencies, different types of agencies, or consortia of agencies in different localities, at their discretion.*

As discussed earlier, OTA identified 11 categories of agencies that might be designated to perform the linking functions nationwide. They are AAA's, community mental health centers, community health centers, Alzheimer's Association chapters, Family Survival Project, States' regional Alzheimer' diagnostic and assessment centers, hospital-based geriatric assessment programs, home health agencies, social health maintenance organizations, On Lok Senior Health Services, and adult day centers. Under Option A, Congress would designate one of those categories of agencies to constitute the linking system.

Designating a single category of agencies to constitute the linking system nationwide would make the system easy to publicize, easy for families and others to remember, and readily accessible to long-distance caregivers. OTA's analysis indicates, however, that none of the 11 categories of agencies is currently capable of constituting an effective national linking system. Each of the 11 categories of agencies has positive features that would contribute to its ability to function in that capacity, but each category of agencies also has drawbacks. Chapter 8 discusses the modifications that would be needed in each of the categories of agencies to make it an effective national system to link people with dementia to services.

By designating a single category of agencies to constitute the linking system nationwide, Congress would risk duplicating or disrupting existing State linking programs and State and community service systems. Moreover, there are significant variations from State to State and in different localities in the capacity of agencies of the same type (e.g., AAAs) to perform the four linking functions effectively. For these reasons, many people, including almost all the

members of the advisory panel for this OTA study, believe that Congress should mandate that each State designate the agencies that will make up the linking system in that State (option B). One possible drawback to this option is that for political or other reasons, some States might designate agencies that would not create an effective linking system.

It should be noted that even if option B were chosen, the agencies designated by the States would have to be identifiable in some uniform way nationally, either by a uniform logo, telephone number, or some other method, so that people would know where to go for help in locating and arranging services.

ISSUE 3: Should the agencies that constitute the linking system also provide services?

Option A: *Congress could require that the system be composed of agencies that do not provide any services.*

Option B: *Congress could require that the system be composed of agencies that do not provide certain services.*

Option C: *Congress could allow the system to be composed of agencies that provide services.*

Some people believe that the same agency should not both link people to services and provide services because the agency may have a financial incentive to refer clients its own services, even if more appropriate services are available elsewhere. Other people believe that the linking functions are often performed most effectively by an agency that is also providing services and that patients and families prefer to have a service provider refer them to or help them locate and arrange other services.

The debate about whether an agency that links people to services should also provide services seldom specifies which services. Virtually all the agencies OTA studied offer at least some of the services listed in table 1-2. Option A would eliminate all those agencies—many of which effectively link some people with dementia to

services—from consideration as agencies that could constitute the linking system.

Option B would specify which services agencies that constitute the linking system should not provide. Congress might decide, for example, that agencies that provide nursing home or adult day care should not be part of the linking system, whereas agencies that provide diagnosis or caregiver education and training, could be part of the linking system. On the other hand, Congress could decide that agencies that provide nursing home or adult day care could constitute the linking system, but that diagnosis and caregiver education and training should not be provided by agencies that constitute the linking system. Option C would allow agencies that provide any services to constitute the linking system.

In thinking about these options, it is helpful to distinguish between linking functions that are service-centered v. linking functions that are comprehensive. Service-centered case management connects people to services in conjunction with providing services for them. Comprehensive case management takes place independent of the provision of any particular services (657). Some agencies that provide services furnish only service-centered case management: that is, they generally provide case management only for people who are receiving or expected to receive their services. One of the main reasons why such agencies provide service-centered case management is that public and private programs that pay for services usually do not pay for case management for people who are not receiving or expected to receive services.

Agencies that provide services can provide comprehensive case management (and presumably other linking functions), as shown by the home health care and mental health agencies that provided comprehensive case management for the National Channeling Demonstration Project (30). The experience of the National Channeling Demonstration Project indicates that case managers in agencies that provide services can be effectively insulated from finan-

cial pressures to refer clients to services of their own agencies rather than more appropriate service of other agencies (30).

ISSUE 4: Should the agencies that constitute the linking system allocate services and funding for services?

Option A: *Congress could mandate that the agencies that constitute the linking system be prohibited from allocating services or finding for services.*

Option B: *Congress could mandate that the agencies that constitute the linking system be permitted to allocate services and finding for services.*

Option C: *Congress could mandate that the agencies that constitute the linking system be required to allocate services and funding for services.*

Some agencies that link people with dementia to services also allocate services and funding for services. As noted earlier, some people are opposed to having the same agency or individual case manager perform both functions because they believe the agency and the case manager will not advocate for clients and may restrict clients' access to needed services in order to limit the cost to the agency of services provided for them. They would advocate option A. Other people believe that having the same agency perform both functions creates an efficient service delivery system and that clients are much more likely to receive services when an agency or case manager has services and funding to allocate than when the agency or case manager simply arranges any available services. They would advocate option C. If the linking system were to be combined with expanded long-term care benefits, the combined system would be administered by the same agencies at the community level, and option C would have to be chosen. Option B would allow whomever designates the agencies that constitute the system to designate either type of agency.

ISSUE 5: Should the agencies that constitute the linking system be required to have

explicit procedures for determining their clients' decisionmaking capacity and making decisions about services for clients who are incapable of making decisions for themselves?

Option A: *Congress could require the agencies that constitute the linking system to have explicit procedures for determining their clients' decisionmaking capacity and making decisions about services for clients who are incapable of making decisions for themselves.*

Option B: *Congress could make no requirements with respect to procedures for determining clients' decisionmaking capacity and making decisions about services for clients who are incapable of making decisions for themselves.*

Option C: *Congress could direct the U.S. Department of Health and Human Services to fund research to develop model agency procedures for determining clients' decisionmaking capacity and making decisions about services for clients who are incapable of making decisions for themselves.*

Option D: *Congress could direct the U.S. Department of Health and Human Services to develop methods for training case managers and others about the legal and ethical issues involved in the way decisions about services are made and procedures for determining clients' decisionmaking capacity and making decisions about services for clients who are incapable of making decisions for themselves.*

Option E: *Congress could direct the U.S. Department of Health and Human Services to organize and support forums for analysis and debate about unresolved issues in how decisions about services for people with dementia are and should be made.*

Fundamental legal rights and complex legal and ethical issues are involved in the way decisions about services for people with dementia are made. Yet most agencies that link people with dementia to services do not have explicit procedures for how those decisions should be

made. Chapter 4 emphasizes the need for explicit agency procedures for determining clients' decisionmaking capacity and making decisions (or designating someone to make decisions) for people who are not capable of making decisions for themselves. Federal legislation to create a linking system for people with dementia could require that any agency that is part of the system have such procedures (option A). Option B would not require explicit procedures. Option C would direct the U.S. Department of Health and Human Services to fund research to develop model procedures.

Some case managers and others who participate in making decisions about services for people with dementia are not knowledgeable about the legal and ethical issues involved in how these decisions are made. Option D would direct the U.S. Department of Health and Human Services to develop appropriate methods for training case managers and others about these issues.

Some unresolved questions about decision-making practices, particularly the question of the relative weight to be given to the needs, preferences, and interests of the patient v. the family in decisions about services, require further analysis (see ch. 4). Option E would require the U.S. Department of Health and Human Services to organize and support forums for analysis and debate about those issues.

ISSUE 6: Should the linking system concern itself with the quality of services to which it links people with dementia, and if so, how?

Option A: *Congress could mandate that the system not concern itself with the quality of services to which it refers people, leaving that issue to clients, families, and others.*

Option B: *Congress could mandate that the system inform clients and their families about what, if any, information it will provide about the quality of available services.*

Option C: *Congress could mandate that the system inform clients and their families about*

which agencies and individuals that provide services are licensed, certified, and/or accredited.

Option D: *Congress could mandate that the system refer clients only to licensed, certified, and/or accredited agencies or individual service providers.*

Option E: *Congress could mandate that the system provide clients and their families any available information about the quality of services.*

Option F: *Congress could mandate that the system control the quality of services to which it refers clients by contracting with providers that will meet certain standards and monitoring provider compliance with the standards.*

Option G: *Congress could require the U.S. Department of Health and Human Services to study the legal issues involved in providing information about the quality of services to clients of a system that links people to services. This study could determine whether there is a difference in liability incurred by a public v. private agency that provides such information and whether the form or source of the information affects liability.*

Option H: *Congress could immunize the linking system from legal liability for good faith efforts to disseminate information about the quality of services.*

As discussed in chapter 5, accurate information about the quality and appropriateness of services is not consistently available to families and others who are selecting services for people with dementia. For a variety of reasons discussed in that chapter, agencies and individual health care and social service professionals and others who refer people with dementia to services and select and arrange services for them frequently do not and/or cannot either provide information about the quality of the services or select services on the basis of quality. Option A would mandate that the linking system not concern itself with the quality and appropriateness of services it refers people to or arranges for

them. Options B through F suggest various ways in which a linking system could address the question of the quality and appropriateness of services. Option G would require the Department of Health and Human Services to study the legal issues that arise when a linking system provides its clients with information about the quality and appropriateness of services. Option H would immunize the linking system from legal liability for measures it takes to inform its clients about the quality and appropriateness of services. Options B-H are not mutually exclusive.

ISSUE 7: Who should have responsibility for linking veterans with dementia to services?

Option A: *Congress could inundate that the VA have primary responsibility for linking veterans with dementia to non-VA services.*

Option B: *Congress could mandate that the non-VA linking system have primary responsibility for linking veterans with dementia to non-VA services.*

The VA provides many services that may be helpful for veterans with dementia. The complexity of the eligibility criteria for VA services, especially as they interact with the factor of space availability, means that only the VA can finally link veterans with dementia to VA services however. A non-VA linking system could not perform that function effectively, and this OTA report does not consider that possibility.

Since not all services that are needed for veterans with dementia are available through the VA, and since some veterans with dementia are not eligible for VA services, many veterans with dementia need help in locating and arranging non-VA services. Option A would assign the VA primary responsibility for linking veterans with dementia to non-VA services. Option A option would require the VA, probably through the Social Work Service at each VA medical center, to provide information and referrals to non-VA services and assistance in locating and

arranging non-VA services for all veterans with dementia, including veterans who are not receiving VA services.

Since the VA Social Work Service is currently able to provide case management for certain “at risk” veterans who are not eligible for or currently receiving VA services, it is unlikely that Option A would require statutory changes. On the other hand, Option A would undoubtedly require the addition of staff to the Social Work Service at each VA medical center. In addition, each VA medical center that does not have a comprehensive list of available non-VA services would have to develop such a list and all VA medical centers would have to adopt procedures to ensure that the list is kept up-to-date.

It is also likely that VA medical centers with large catchment areas would have to assign some VA social workers to geographic areas distant from the medical center, as has been done by the Minneapolis VA Medical Center in connection with its rural case management program (see ch. 7). Lastly, the VA would have to develop outreach procedures to identify veterans with dementia who need help but are unlikely to contact the VA on their own and have no one to contact the VA for them.

Under option B, the VA would be responsible for linking veterans with dementia to VA services, and the non-VA linking system would have primary responsibility for linking veterans with dementia to non-VA services. This option would probably be easier to implement than option A, since the non-VA linking system would, once established, have the capability to serve people in all areas of the country and would have to maintain an accurate resource list to serve nonveterans anyway. The drawback to Option B is the possible duplication of case management and information and referral functions for some veterans who are receiving VA services. Procedures for minimizing such duplication of effort could probably be worked out between the VA Social Work Service and the non-VA linking system.