

Agencies That Might Constitute a Uniform National Linking System

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Agencies That Might Constitute a Uniform National Linking System

INTRODUCTION

As described in chapter 7, all States have linking programs, and some States and local communities have service systems that help families and others locate and arrange services and sources of funding for services for people with dementia. These State and community programs and systems are extremely diverse and are administered by a great variety of agencies. Some of the programs and systems are dementia-specific, and others are not. If Congress established a national system to link people with dementia to services, it could allow States to decide which agencies should constitute the linking system in their jurisdiction. Under this option, each State could be given the choice of either: 1) selecting a single category of agencies to constitute the linking system statewide, or 2) selecting agencies of different types or a consortium of agencies to constitute the linking system in different local communities.

An alternate approach that Congress might consider would be to establish a national linking system in which the Federal Government would select a single category of agencies to constitute the system nationwide. Whether Congress should establish a national linking system composed of a single category of agencies designated by the Federal Government or one composed of agencies designated by individual States is an important policy issue discussed in chapter 1. A system composed of a single category of agencies nationwide might be more recognizable to the public than a system composed of different types of agencies in different States and might be better suited to helping long-distance caregivers of people with dementia find services. One of the major drawbacks to this approach is that the designation of a single category of agencies to constitute the linking system nationwide would disrupt some existing State programs and service systems, particularly programs and systems that utilize agencies that are not selected or that are unique to a particular State or locality.

This chapter analyzes 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 nationwide:

1. area agencies on aging,
2. community mental health centers,
3. community health centers,
4. Alzheimer's Association chapters,
5. Family Survival Project,
6. States' regional Alzheimer's diagnostic and assessment centers,
7. hospital-based geriatric assessment programs,
8. home health agencies,
9. social health maintenance organizations,
10. On Lok Senior Health Services, and
11. adult day centers.

The Office of Technology Assessment (OTA) compiled this list by identifying categories of agencies that met the following criteria:

- agencies in the category are currently engaged in linking at least some people with dementia to services;
- agencies in the category are discrete entities that could be identified and funded directly from the Federal level; and
- agencies in the category are currently part of a nationwide "system" of agencies (e.g., area agencies on aging, Alzheimer's Association chapters) or could conceivably be expanded to serve the entire country (e.g., On Lok, Family Survival Project).

OTA believes that the 11 categories of agencies analyzed in this chapter include all the categories of agencies that meet these criteria. Inclusion of a category of agencies in this analysis does not mean that OTA considers the category of agencies currently capable of constituting a national linking system for people with dementia, but only that the category of agencies meets the criteria for inclusion in the analysis.

State and local government agencies, such as State or local departments of health and social services, are not included in the analysis in this chapter; the reason is that States and local governments determine the functions of their own agencies, and specific State and local government agencies could not be designated by the Federal Government

to perform the linking functions. If Congress allowed States to designate the agencies that would constitute the linking system, States could designate any State or local government agency they chose. Some of the State and local government agencies that are currently involved in linking people with dementia to services are described in chapter 7.

Each subsequent section of this chapter provides a brief overview of a single category of agencies and presents the available information about who is served by that category of agencies and the extent to which the agencies serve people with dementia. Each section then analyzes its particular category of agencies in terms of its current performance of the four functions OTA deems critical to an effective system to link people with dementia to services:

1. public education,
2. information and referral,
3. outreach, and
4. case management.

As defined in this report, *public education* means providing general information to help people understand dementia and the kinds of services that maybe helpful for individuals with dementia. *Information and referral* means providing information about and referrals to specific services and sources of funding for services in the community. *Outreach* means using an active method to identify people 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. *Case management* means assessing a client's needs, developing a plan of care for the client, arranging and coordinating services for the client, monitoring and evaluating services the client receives, and reassessing the client's situation as the need arises.

An important policy question raised in chapter 1 of this report is whether the agencies that constitute a national system to link people with dementia to services should be agencies that allocate services and funding for services. In the analysis that follows, the extent to which each category of agencies allocates services and funding for services is indicated.

OTA does not select any single category of agencies as the category that should be designated to constitute a national linking system. In fact, OTA's main conclusion from the analysis in this chapter is

that no single category of agencies is currently capable of functioning effectively as a national linking system for people with dementia and their caregivers. As discussed in the following sections, each of the 11 categories of agencies has positive features that would contribute to its ability to serve as the basis of a national linking system, but each category also has one or more features that would have to be modified for agencies in the category to function effectively as such a system.

The identification of features of each of the 11 categories of agencies that would have to be modified for agencies in the category to function effectively as a national system to link people with dementia to services is not intended to be critical of the agencies. Linking people with dementia to services is not the primary objective or even one of the primary objectives of some of the 11 categories of agencies, and each category of agencies has other important objectives. Moreover, all of the agencies operate within resource constraints. In the case of some of the categories of agencies, it would take a significant redirection of the agencies' mission and resources to function effectively as a national system to link people with dementia to services. Such a redirection of those agencies' mission and resources would compromise their ability to fulfill other objectives, including the provision of services for other client populations.

The congressional committees that requested this study asked OTA to identify particular agencies that are doing a good job of linking people with dementia and their caregivers to services, and OTA found at least one "model" agency in each of the 11 categories of agencies. In the case of Family Survival Project, On Lok Senior Health Services, and social health maintenance organizations, the original agencies are themselves models. The "model" agencies in the other categories are highlighted in the shaded boxes in this chapter. The agencies in each of these categories differ from one another in many ways that affect their capacity to link people with dementia to services, however; and it is important to emphasize that the "model" agencies are often the exception rather than the rule.

It is by no means clear that Congress should designate a single category of agencies to constitute a national linking system for people with dementia. If Congress decided instead to allow States to designate the agencies that would constitute the

linking system in their jurisdiction, the analysis in this chapter might be useful to individual States in selecting those agencies and in determining how the agencies they selected might have to be modified to function effectively in linking people with dementia and their caregivers to services.

AREA AGENCIES ON AGING

Area agencies on aging (AAAs) are public or private nonprofit agencies that are designated to receive Federal Older Americans Act funds to plan, coordinate, and arrange services for elderly people. AAAs are part of a nationwide network of agencies developed since the enactment of the Older Americans Act (Public Law 89-73) in 1965. This network, often referred to as the "aging network," includes:

- the Administration on Aging within the U.S. Department of Health and Human Services,
- 57 State units on aging,
- 670 AAAs, and
- thousands of local agencies and individuals that provide services for elderly people through contracts or other agreements with AAAs (69,575).

OTA has included AAAs in its analysis of agencies that might constitute a national system to link people with dementia to services for several reasons. One reason is that some AAAs provide public education, information and referral, outreach, and case management for elderly people, including some people with dementia. In addition, AAAs are mandated by the Older Americans Act to provide for the establishment of information and referral services for elderly people and to ensure that an 'adequate proportion' of the Older Americans Act funds allocated to the AAA are spent for 'services associated with access to services,' including information and referral and outreach for elderly people (818). The great majority of people with Alzheimer's disease and other diseases that cause dementia are elderly,¹ and these provisions of the Older Americans Act would seem to include them.

Another reason that OTA has included AAAs in its analysis of agencies that might constitute a national system to link people with dementia to services is that AAAs already exist in many parts of the country. Also since AAAs are part of a nation-

wide network, they may be able to help long-distance caregivers locate and arrange services for a person with dementia who lives in a different area of the country.

One observer has suggested using AAAs and other aging network agencies to create a nationwide network of highly visible and easily accessible "Aging Resource Centers for Help" to which elderly people and their families could turn for assistance:

Perhaps the most pressing need in our aging society is for a highly visible distinctive site in every community—that is part of a nationwide, inter-community network of such sites—to which older people and their families can turn for beginning the process of getting help, reliably. The Title III network is ideally situated to fulfill this need, if it can become more visible, in a uniform fashion, in communities nationwide. It has already evolved into an infrastructure of agencies throughout the country (68).

If there were such a nationwide network of resource centers for elderly people, it probably could be adapted to meet the needs of people with dementia and their caregivers as well.

Overview of the Agencies

As originally enacted in 1965, Title III of the Older Americans Act established a program of Federal grants to States for the development of "a comprehensive and coordinated system" of services to help elderly people live independently in their communities and in their homes (818). The Older Americans Act established the Administration on Aging as the Federal agency responsible for carrying out all of its provisions, including the administration of the Title III program of Federal grants to States.

The Older Americans Act of 1965 required each State to designate a single State agency--commonly referred to as a 'State unit on aging'--to formulate a plan for developing the system of community services envisioned in the act and to oversee the use of Title III funds in the State (818). Currently, there is a State unit on aging in each of the 50 States and in the District of Columbia, Puerto Rico, the Virgin Islands, Guam, American Samoa, the Northern Mariana Islands, and the Trust Territory of the

¹An analysis of available & on the prevalence of dementia that was conducted for OTA in 1985 found that individuals under age 65 accounted for less than 1 percent of all people with severe dementia and less than 10 percent of all people with mild or moderate dementia (152).

Pacific Islands (566). The names of State units on aging vary from State-to-State (e.g., the Michigan Office of Services to the Aging, the Nebraska Department on Aging, the Mississippi Council on Aging, the New Mexico State Agency on Aging, the New Jersey Division on Aging) (566). State units on aging operate not only as the agencies required by the Older Americans Act, but also as components of State and territorial government, and as a result, their functions vary greatly in different States and territories.

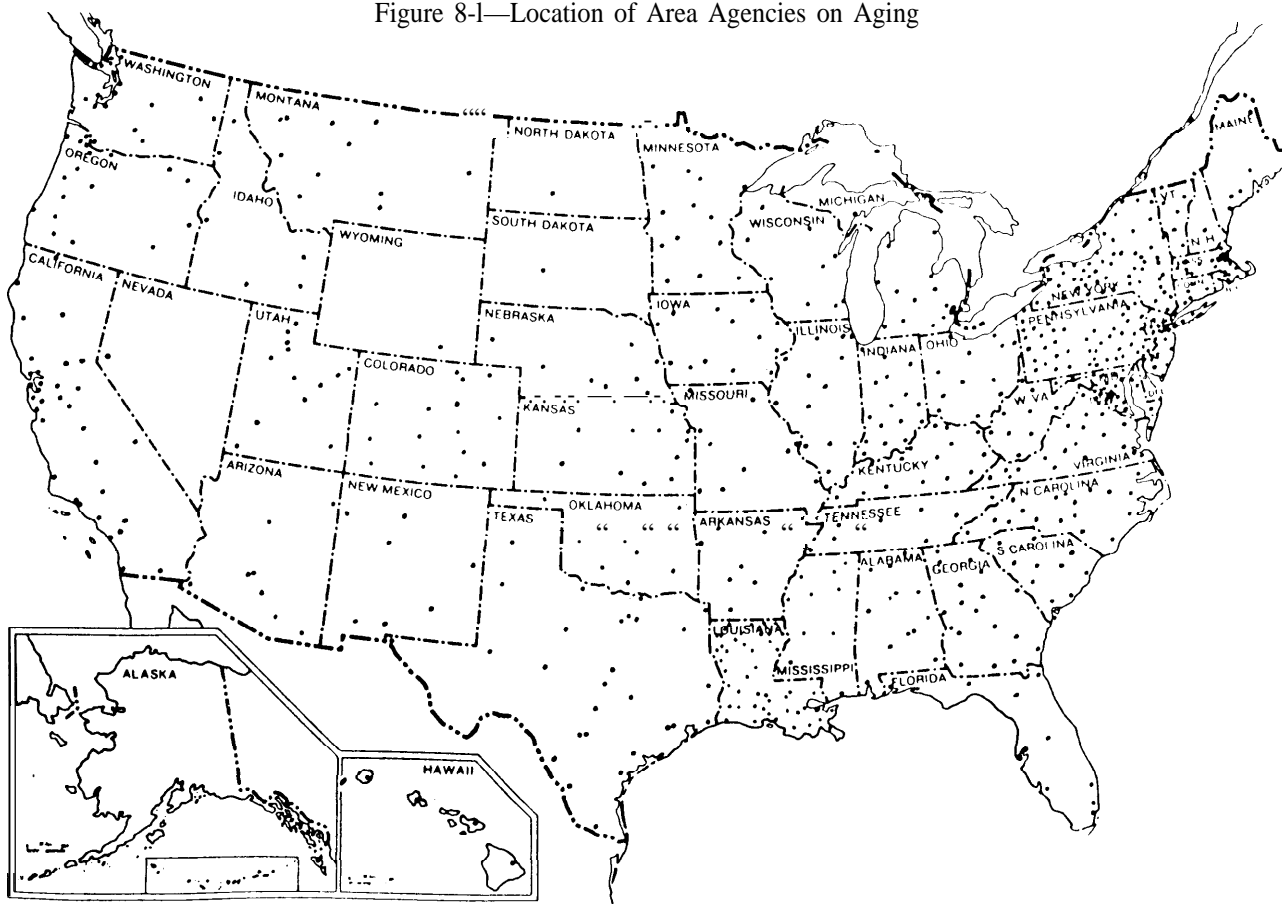
The Older Americans Act has been amended 11 times since 1965. In 1973, the act was amended to require each State or territory seeking Title III grants to divide its jurisdiction into "planning and service areas" and to designate an AAA to plan, coordinate, and arrange services for elderly people in each area. Sparsely populated States or territories are allowed to treat their jurisdictions as one planning and service area and to designate only a single AAA, and

13 States and territories have chosen to do so; in those areas, the State unit on aging serves as the AAA (374,575). All but a few States have designated more than one AAA. New York, with 58 AAAs, has the most (575). Figure 8-1 shows the distribution of AAAs throughout the country.

States with a similar number of residents over age 60 do not necessarily have the same number of AAAs. For example, Georgia, Virginia, and Wisconsin, each of which has about 850,000 residents over age 60, have 18, 26, and 6 AAAs respectively (566). Likewise, South Dakota and Minnesota, each of which has about 130,000 residents over age 60, have 1 and 11 AAAs respectively. In terms of the number of elderly people in their planning and service area, AAAs are not uniform nationally.

About two-thirds of AAAs are public agencies, including county or city government agencies and council of government, regional planning, and economic development agencies. The remaining

Figure 8-1—Location of Area Agencies on Aging



SOURCE: National Association of Area Agencies on Aging, *A Directory of State and Area Agencies on Aging, 1987-1989* (Washington, DC: 1988).

one-third of the AAAs are private, nonprofit agencies (575). The term “area agency on aging” is a generic one; the names of specific AAAs vary (e.g., Active Aging, Inc., Community Council of Greater Dallas, District 5 AAA, Western Reserve AAA) (566). Like State units on aging, many AAAs operate not only as agencies required by the Older Americans Act, but also as components of county or city government or private agencies that have many functions other than those mandated by the act. This fact explains some of the differences among AAAs that are discussed in this section.

Each AAA is required by the Older Americans Act to prepare annually and submit to the State unit on aging a plan for the development of a comprehensive and coordinated system of services for elderly people in the AAA’s planning and service area (818). The plan developed by an AAA must ensure that elderly people in the AAA’s area have access to the following services:

- nutrition services, including congregate and home-delivered meals;
- access services, including transportation, outreach, and information and referral;
- in-home services, including homemaker and home health aides, visiting and telephone reassurance, chore maintenance, in-home respite care, minor modification of homes to accommodate frail, older individuals, and supportive services for families caring for older people; and
- community services, including adult day care, senior centers, legal assistance, and adult protective services (374,566,818).

To implement its area plan, each AAA is required by the Older Americans Act to arrange for the provision of services with local providers and to coordinate the services it provides or pays for with the services of other community agencies and voluntary organizations (818). AAAs often contract with other agencies and individuals to provide Title III-funded services. The Older Americans Act specifically forbids AAAs to provide, rather than to contract for, a Title III-funded service unless the service:

1. is directly related to an AAA’s administrative functions,
2. can be provided at less cost by the AAA than any other provider, or
3. in the judgment of the State unit on aging, must be provided by an AAA to ensure an adequate supply (818).

It has been estimated that in 1986, AAAs throughout the country contracted with more than 26,000 service providers (212).

It is important to note that, in general, AAAs are not required by the Older Americans Act to *provide* services, but rather to plan and arrange for their provision. Many AAAs do provide a variety of services, sometimes for the three reasons just cited and sometimes because, as mentioned earlier, AAAs are public and private agencies that have many functions other than those mandated by the Older Americans Act. On the other hand, some AAAs operate almost exclusively as planning agencies and provide few, if any, services. Relevant to this point, a 1987 study of 25 AAAs by the Office of the Inspector General of the U.S. Department of Health and Human Services found that all the AAAs considered the development of a comprehensive and coordinated system of community services for elderly people—not the provision of services—to be their highest priority (853).

For fiscal year 1989, Congress appropriated \$858 million for Title III programs.² About two-thirds of this was for nutrition services (mainly congregate meals), and the remaining one-third was for all other services authorized under Title III (829). Title III funds are allocated to State units on aging according to a formula that is based in part on each State’s portion of the national population over age 60 (818). Although State units on aging derive a significant portion of their budgets from Title III funds, they also receive funds from other sources, including the Federal Social Services Block Grant program, the Medicaid 2176 Home and Community-Based Waiver program, and State general revenues (374,575).

State units on aging allocate most of the Title III funds they receive to AAAs (374,575). To allocate the funds, State units are required by the Older Americans Act to develop and apply a formula that

²The amount of Federal funding for programs under Title III of the Older Americans Act has always been small in comparison to the amount for other Federal programs that serve elderly people (828). For fiscal year 1987, for example, the \$700 million appropriated for Title III programs represented less than 0.25 percent of the \$270 billion annual Federal outlays for benefits for elderly people (68).

takes into account the geographic distribution in the State of elderly people with the greatest economic and social need (818). The amount of Title III funds received by individual AAAs varies, depending primarily on the overall Title III funds available to a State and the formula used by the State for allocating the funds (69,575). In addition to Title III funds, many AAAs receive funds from other sources, including Federal, State, and local government agencies and programs, foundation grants, and voluntary contributions from elderly service users (65,170,605).

Who Is Served

People over age 60 are eligible for services paid for with Title III Older Americans Act funds. Some AAAs use non-Title III funds (e.g., funds from other Federal, State, and local government programs, private contributions, and other sources) to serve younger people (170,605,756). If an AAA uses only Title III funds to pay for a specific service, however, people who are under age 60 generally are not eligible for the service.

AAAs are prohibited from using means testing to determine elderly people's eligibility for services paid for with Title III funds, and they may not charge fees for these services, although they may request voluntary contributions.³ Because Title III-tided services are not means tested, AAAs are sometimes able to provide or pay for services for elderly people who do not meet the financial eligibility criteria for other programs (575,828).

The Older Americans Act requires that AAAs give priority to ensuring that the service needs of elderly people with the greatest economic or social need are met. Economic need is defined as having an income level at or below the federally established poverty levels. In 1985, 43 percent of all elderly people who received Title III-tided services had incomes below these levels (266). Social need is defined in terms of noneconomic factors, including physical and mental disabilities, language barriers, and cultural, social, or geographic isolation. OTA is not aware of any information about the percent of elderly people who received Title III-funded services who have physical or mental disabilities or were socially or geographically isolated. In 1987, minor-

ity elderly people constituted 16 percent of all people who received Title III-funded services (454).

The extent to which AAAs serve people with dementia is unclear. The results of several studies indicate that some, and perhaps many, people with dementia receive services of various kinds through AAAs (193,605,756,934), but no data are available on the total number of people with dementia who receive services through AAAs. Moreover, as noted later in this section, some people with dementia who receive services through AAAs may not be identified as having dementia.

In 1986, the New York City Department for the Aging surveyed all State units on aging and all AAAs to determine what services they provided—either directly or through arrangements with other providers—for people with Alzheimer's disease and their families (605). Forty-six State units on aging and more than 200 AAAs responded to the survey. Some of the AAAs that responded said that they were providing the same services for people with Alzheimer's disease as for other elderly people, but many of the AAAs reported that they were providing or paying for some special services for people with Alzheimer's disease and their families. The special services mentioned most frequently were caregiver support groups, educational programs and materials, respite care, and adult day care. Many of the AAAs reported that they had sponsored training programs about Alzheimer's disease and dementia for professionals and other service providers. Many of the AAAs also said that they had formed cooperative alliances with Alzheimer's Association chapters and other agencies in an effort to meet the needs of Alzheimer's patients and their families.

A 1987 mail survey of AAAs in Virginia had similar findings (193). Information was obtained about services that were provided or paid for by 25 Virginia AAAs for people with Alzheimer's disease and their caregivers. Caregiver support groups—provided or sponsored by 22 of the AAAs—were by far the most frequently mentioned service. Other services that were mentioned by about one-third of the AAAs were information and referral, congregate meals, adult day care, respite care, and other in-home services. A few of the AAAs said they had provided or paid for an Alzheimer's disease newsletter,

³As discussed later in this section, some AAAs do use means testing to determine people's eligibility for services paid for with non-Title III funds, and some AAAs charge fees for such services (353,462).

brochure, or videotape, and a few had included information about Alzheimer's disease in their AAA newsletter. Most of the AAAs reported that they had sponsored or co-sponsored workshops, educational programs, or community meetings on Alzheimer's disease for caregivers, service providers, and/or the general public, and most of the AAAs (20 of the 25 AAAs that responded to the survey) considered these educational programs to be their most successful dementia-specific services.

In contrast to the findings of these surveys, OTA has heard from many people, including Alzheimer's caregivers, Alzheimer's advocates, health care and social service professionals, and others, that AAAs are not providing adequate services for people with dementia. In part, these complaints may reflect some people's lack of awareness of the services provided by AAAs, especially their lack of awareness that some of the services provided by other agencies or organizations are, in fact, funded in whole or in part by an AAA. The complaints probably also reflect some people's expectation that AAAs *should* provide services for people with dementia—an expectation they may not have for some of the other categories of agencies discussed in this chapter. Nevertheless, the complaints are clear and pervasive. Given these complaints, OTA has been surprised by the number of AAAs that report that they offer special services for people with dementia.

In addition to hearing complaints about the lack of sufficient AAA services for people with dementia, OTA has been told that some AAA staff members are uninformed about Alzheimer's disease, dementia, and potentially beneficial services for people with dementia and/or unresponsive to the needs of people with dementia and their caregivers (see, e.g., the case study of Mrs. D in ch. 1). No data are available to determine whether these allegations reflect isolated incidents or a more general problem.

The Administration on Aging has funded many initiatives to provide training for the staff of aging network agencies about Alzheimer's disease and dementia and to encourage aging network agencies to provide or pay for services for people with dementia. These initiatives include:

- the publication in 1983 and 1984 of four handbooks on Alzheimer's disease and how to work with Alzheimer's patients and their families (851);

- training sessions on Alzheimer's disease for State unit on aging and AAA personnel, as required by the 1984 amendments to the Older Americans Act;
- a multiyear initiative to encourage AAAs and other aging network agencies to develop support groups for caregivers of people with dementia;
- many research and demonstration projects on various kinds of services and methods of working with people with dementia and their caregivers (605); and
- the designation in 1989 of a "National Resource Center on Alzheimer's Disease" at the University of Southern Florida.

The Older American's Act contains several specific references to services for people with Alzheimer's disease and their caregivers. The act requires that an AAA's annual plan ensure that an adequate proportion of Title III funds allocated to the AAA will be spent for in-home services, including "supportive services for families of elderly victims of Alzheimer's disease and related disorders" (818). The act also requires that an AAA's annual plan show how Title III-funded services will be coordinated with the activities of community organizations established to help people with Alzheimer's disease and their families (818). In addition, in 1987, Congress created a new section of Title III specifically to authorize in-home services for "frail older individuals" (818). "Frail" is defined in the new section of the law as "having a physical or mental disability, including Alzheimer's disease or a related disorder with neurological or organic brain dysfunction, that restricts an elderly person's ability to perform daily tasks or threatens his/her capacity to live independently" (818). It is too soon to know what effect this new program will have.

Linking Functions

Information and Referral



The Older Americans Act requires that each AAA's area plan "provide for the establishment and maintenance of information and referral services in sufficient numbers to assure that all older individuals within the planning and service area covered by the plan will have reasonably convenient access to such services" (818). Some AAAs contract with other

agencies to provide information and referrals for elderly people, and some AAAs provide information and referrals themselves (756). A 1988 survey of State units on aging conducted by the National Association of State Units on Aging found that AAAs in the 41 States that responded to the survey were operating 320 information and referral programs and contracting for an additional 697 information and referral programs (577).⁴ In some planning and service areas, the AAA was operating or contracting for more than one information and referral program. The most frequently reported reasons for this practice were geography and language or nationality (577).

It is clear that many AAAs provide or contract for information and referral programs for elderly people, but for the purpose of this OTA study, it is important to emphasize that some AAAs do not provide information and referrals themselves. A member of the advisory panel for this OTA study who contacted many AAAs in the course of setting up IBM's Eldercare Referral Service reported that some of the AAAs she contacted said that they were not appropriate agencies to provide the kind of individualized referrals that are part of the IBM Eldercare program (659).⁵ These AAAs pointed out that they are primarily planning agencies and that they do not provide information and referrals for individuals.

No data are available on the number of people with dementia and their caregivers who are currently served by information and referral programs provided or funded by AAAs. In 1985, the Eastern Massachusetts Alzheimer's Association Chapter conducted a mail survey of Massachusetts AAAs and a few other agencies in the State (756). All of the 24 agencies that responded to the survey, including 22 AAAs, indicated that they provided information and referrals for people with dementia, but about one-quarter of the agencies were unable even to estimate the number of people with dementia they had served because they did not keep records of the diagnoses or conditions of the people for whom they provided information and referrals. An exploratory study conducted for OTA in Cuyahoga County, OH, which is described in detail in chapter 2, found that

many types of agencies that said they provided information and referrals for people with dementia in the county did not keep records on the people they served by either diagnosis or condition (186). The fact that an agency does not keep records on the people it serves by their diagnosis or condition does not prove that the agency staff member who provides information and referrals is unaware of clients' diagnoses or conditions. It suggests that this could be the case, however. If a person with dementia is not identified as such by an information and referral source, the person may not be referred to appropriate services.

Another concern about the referrals provided by some AAAs for people with dementia is the accuracy and comprehensiveness of the AAAs' lists of services. AAAs in many communities maintain lists of services for elderly people, but anecdotal evidence indicates that these resource lists vary in the extent to which they are accurate and comprehensive with respect to services that may be needed for people with dementia (246).

In order to improve information and referral for people with dementia, some States have established statewide dementia-specific information and referral programs. Chapter 7 discusses 13 such programs, six of which are administered by the State agency that also functions as the State unit on aging. Some AAAs have also established dementia-specific information and referral programs. The New York City Alzheimer's Resource Center, which was established in 1984 by the New York City Department for the Aging—a department of municipal government and the largest AAA in the country, is probably the most ambitious of these programs (see box 8-A). The resource center maintains up-to-date information on all services available to Alzheimer's patients and their families in the area and functions as an information clearinghouse, answering 125,000 inquiries a year (605). It also provides public education and a variety of direct services for people with dementia and their caregivers.

Because AAAs are part of a nationwide network, they have the potential to connect long-distance caregivers to sources of information about services for elderly people who are living in other areas of the

⁴The 1988 survey also found that 32 States had toll-free statewide information and referral programs; 18 of these statewide programs were specifically for elderly people, and many of them were operated by the State agency that functions as the State unit on aging (577). State information and referral programs for elderly people and for people with dementia are discussed in ch. 7.

⁵IBM's Eldercare Referral Service is discussed in ch. 1.

Box 8-A—The New York City Alzheimer's Resource Center

The New York City Department for the Aging, a department of municipal government and *the* largest area agency on aging in the country, offers assistance to Alzheimer's disease patients, caregivers, and professionals through the New York City Alzheimer's Resource Center. Established in 1984 with funds from the Brookdale Foundation and the City of New York, the Alzheimer's Resource Center is the first municipally sponsored comprehensive information, referral, and counseling service in the Nation.

Information and Referral--The Alzheimer's Resource Center operates a comprehensive information and referral program and works with a variety of other organizations to link Alzheimer's patients, their families, and others to appropriate programs and services in the city. The Alzheimer's Resource Center maintains current information on all services available to Alzheimer's patients and their families in New York City and functions as an information clearinghouse, responding to over 125,000 inquiries a year. The center has an interdisciplinary staff of professionals who provide guidance to families and caregivers on public benefits and entitlement programs, nursing home placement, home care services, respite, and adult day care. The center is open from 9:00 a.m. to 5:00 p.m. Monday through Friday.

Public Education--Public education efforts to help people understand the nature of Alzheimer's disease and learn about available resources have been a major activity of the Alzheimer's Resource Center. The center reaches the public in a variety of ways, including publications, mass transit advertising, radio and television public service announcements, press releases from the mayor's office, and direct mailings. The center has found that publications are a valuable method of providing help to caregivers and others in understanding Alzheimer's disease and the resources available to them. Several editions of a 100-page" resource guide, *Alzheimer's Disease: Where To Go for Help in New York City*, have been prepared by the Alzheimer's Resource Center in cooperation with the New York City Chapter of the Alzheimer's Association. Cooperative activities with other organizations are an important aspect of the center's public education and other activities. Each year, the Alzheimer's Resource Center and the New York City Chapter of the Alzheimer's Association sponsor a citywide mayoral conference, with over 1,000 participants, to educate people about Alzheimer's disease, draw attention to Alzheimer's programs in the New York City area, and promote new Alzheimer's programs. The center also works with private sector companies and unions to conduct health fairs and lunchtime training and support groups for caregivers.

Provision of Services---In addition to providing educational programs and materials and information and referrals, the Alzheimer's Resource Center has undertaken several efforts to provide services not available elsewhere.

- A family counselor provides free one-on-one *professional counseling* to family members who are in crisis.
- The center operates a free *in-home respite* program for families who are ineligible for Medicaid but unable to afford the purchase of private home care. The program provides for a maximum of 16 hours of in-home respite to allow family members to attend to medical appointments, run errands, or attend family support group meetings. The center also provides time-limited round the clock emergency care in the home in situations where the family caregiver must be away from home or is ill and unable to continue providing care.
- The center offers *legal and financial guidance* to help caregivers deal with issues pertaining to incompetency and surrogate decisionmaking, property, planning for long-term care costs, etc. Funding for legal and financial assistance was initially provided through the center's Alzheimer's Legal Support Project, a demonstration project funded by the Administration on Aging.

SOURCES: R. Goldstein, director, New York City Alzheimer's Resource Center, New York, NY, personal communication, June 1988; New York City Department for the Aging, "Caregiver Training and Support Resource Center," proposal for the New York State Office for the Aging, New York, NY, 1988; New York City Department for the Aging and the Brookdale Foundation, *Agendas for Action: The Aging Network Responds to Alzheimer's Disease*, compiled and written by F. Tanner (New York, NY: August 1986); and New York City Department for the Aging Alzheimer's Resource Center and the New York City Chapter of the Alzheimer's Association *Alzheimer's Disease: Where To Go for Help in New York City* (New York, NY: November 1987).

country. Currently, the National Association of State Units on Aging is trying to create a national access system that would connect the information and referral programs of aging network agencies across the country (577). This system, called "Elderlink,"

was initiated in Illinois in **1989 (148)**. Of the **49** State units on aging that responded to a survey conducted by the National Association of State Units on Aging, 16 State units said that AAAs would be the most appropriate referral point for the national access

system for information and referrals; 9 State units said that a single statewide telephone number would be the most appropriate referral point for the access system; 7 said that a combination of AAAs and a single statewide telephone number would be the most appropriate referral point; 13 advocated options that involved other community agencies; and 4 did not specify an opinion (577).

This OTA report identifies visibility in the community as an important criterion for designating the agencies that should constitute a system to link people with dementia to services. Visibility in the community is particularly important for the information and referral component of a linking system because families and others must initiate contacts with information and referral sources themselves. Because the specific names of AAAs vary and because some AAAs are located within multipurpose agencies, some families and others may not be aware of the AAA as a source of help in finding services.

The 1987 study of 25 AAAs by the Office of the Inspector General of the U.S. Department of Health and Human Services concluded that within their service areas, the 25 AAAs were generally better known to service providers than to elderly people (853). The vast majority (nearly 90 percent) of 179 local service providers contacted for the Inspector General's study knew the local AAA existed, but only about half of the 122 elderly people interviewed for the study knew of the local AAA.

One commentator has noted that although some elderly people are aware of their local AAA, many millions of older people and their families do not know that AAAs exist or do not know the names of the agencies, where they are located, or how to get in touch with them (68). On the other hand, people may be more aware of the AAA in their area than of some of the other categories of agencies discussed in this chapter.

Case Management



Some AAAs provide case management directly; some AAAs contract with other agencies to provide case management; and some AAAs do neither. A 1987 survey of 144 AAAs conducted by the National Association of AAAs found that 60 of these AAAs (about 40 percent) provided case management di-

rectly (462). According to the association, as of 1989, some AAAs in more than half of all States were providing case management—also called ‘care management’ or ‘care coordination’—and additional AAAs were planning to offer it (568). Box 8-B describes the care management program of the Region IV AAA in St. Joseph, Michigan. The care management program, which began as a pilot project in a three-county area of the State in 1983, has since been expanded to other parts of the State.

Despite the significant number of AAAs that are providing case management, there is considerable controversy about whether AAAs *should* provide case management. In connection with their planning function, AAAs are mandated by the Older Americans Act to “conduct efforts to facilitate the coordination of community-based, long-term care services. . . designed to emphasize the development of client-centered case management as a component of such services” (818). Thus, AAAs are mandated to encourage the development of case management in the community, but there is no mandate in the act for AAAs to provide case management.

The Administration on Aging and some AAAs view case management as a “direct service” that AAAs are, and should be, prohibited from providing (627). Having AAAs provide case management, the Administration on Aging argues, could detract from AAAs’ ability to plan and coordinate comprehensive and coordinated systems of community services for elderly people (853). In contrast, the National Association of AAAs and some AAAs consider case management an “administrative function” that AAAs are not prohibited from providing (568). The National Association of AAAs argues that case management is a function that complements AAAs’ mandated functions of coordinating community services for elderly people and ensuring access to the services.

The director of the Region IV AAA in St. Joseph, Michigan (see box 8-B) refers to the view that providing case management detracts from an AAA’s planning and coordinating functions as “a phantom issue” and argues that:

Far from detracting, [providing case management] *enhances the* comprehensive planning process. The additional valuable data on the needs of frail persons give an AAA additional guidance in changing priorities and developing services. Since the inception of our case management activities, we

have developed financial management services for those not needing full guardianship, funded respite care, focused on the development of housing alternatives, and devised formal training programs for agencies serving Alzheimer's victims and their families (170).

In the opinion of the National Association of AAAs, AAAs are an appropriate setting for case management for several reasons: 1) AAAs are already connected to a range of formal and informal service providers and systems; 2) AAAs generally do not provide services or, if they do provide services, they do not charge for them, and therefore they have no financial or other incentives to overuse services; and 3) AAAs are not in competition with other community service providers (568,627). With regard to the competition among community service providers, the director of the Region IV AAA in St. Joseph, Michigan (see box 8-B) points out:

When our AAA launched its case management project, we pulled together as many service providers as we could find to inform them of our intentions. Almost every provider felt it could do a better job than we. We were, however, practically every agency's second choice because of the vested interest of their competitors (170).

Clearly, however, providing case management places AAAs in competition with other agencies and individuals that provide case management, including agencies that provide case management in conjunction with other services such as home health care.

Some AAAs that provide or contract for case management do so with Title III Older Americans Act funds, and some use public funds from other sources, such as State general revenues, Medicaid, and the Federal Social Services Block Grant (354, 587). In addition, some AAAs provide fee-for-service case management that is paid for by individual clients, and some AAAs have contracts with private companies to provide case management for their employees or, in the case of insurance companies, their policyholders. In 1987, for example, 11 AAAs in Washington State contracted with Blue Cross of Washington and Alaska to provide case management for holders of the company's long-term care insurance policies (416).

Very little information is available about the capability of AAA case managers to work with people with dementia. In the 1985 survey of the AAAs and other agencies in Massachusetts mentioned previously, 14 of the 24 responding agencies, all but two of which were AAAs, reported that they provided case management for people with Alzheimer's disease (756). Five of the 14 agencies reported that all of their case managers had special training about Alzheimer's disease, and 10 of the 14 agencies reported that their case management supervisors had special Alzheimer's training (typically received at workshops sponsored by the Alzheimer's Association).

An exploratory study conducted for OTA in 1988 involved interviews with case managers in five Pennsylvania AAAs to determine what they perceived to be the unique aspects of working with people with dementia and their families (934). The findings of the study, which are discussed at length in chapter 3, provide some insight into the difficulties involved in providing case management for individuals with dementia and the capability of case managers in those AAAs to work with individuals with dementia and their families.⁶On the basis of the interviews with these case managers, OTA's contractors concluded that some of the case managers dealt with clients with dementia and their families in very skillful ways. None of the case managers had received any special training for this ability, however (934).

Public Education



As discussed earlier, the results of the 1986 survey of AAAs and State units on aging conducted by the New York City Department for the Aging (605) and the 1987 mail survey of AAAs in Virginia (193) indicate that many AAAs have sponsored a variety of programs and developed or paid for the development of materials to educate the public about Alzheimer's disease, dementia, and services for people with dementia. Often agencies of various types conduct public education efforts on a one-shot basis, and it is unclear from the results of the surveys whether this is the case with the AAAs that responded to the two surveys.

⁶A full report on this OTA contract is available from the National Technical Information Service in Springfield, VA (see app. A).

Box 8-B—The Care Management Program of the Region IV Area Agency on Aging in St. Joseph, Michigan

Michigan's Region IV area agency on aging (AAA) in St. Joseph, Michigan, operates a care (or case) management program for people of all ages who live in the AAA's three-county service area and are at risk of nursing home placement. The AAA's program began in 1983 as a case management program for people over age 60 who were at risk of nursing home placement and had exhausted all other community long-term care resources. In 1987, the program was expanded with funds from the Michigan Department of Social Services to include nursing home preadmission screening and case management for people of all ages who are eligible or potentially eligible for Medicaid-funded nursing home care.

Funding for the AAA's care management and screening program comes from both the Michigan Office of Services to the Aging, which is the State unit on aging, and from the Michigan Department of Social Services, which is the State Medicaid agency. Funds from the Office of Services to the Aging are used to provide case management and a variety of services for medically qualified clients who are over age 60. Funds from the Department of Social Services are used to provide case management and services for medically qualified clients of all ages who meet specified financial eligibility criteria. By using funding from whichever source accommodates the eligibility characteristics of a client, the program enables any person medically qualified for nursing home care to participate.

Potential clients are referred to the AAA's care management and screening program by various sources. About 30 percent of referrals come from hospitals and physicians; 20 percent from home health agencies; 20 percent from family and friends; and the rest from a variety of other sources. The AAA publicizes its program through the Alzheimer's Association and other community organizations, and about 20 percent of its clients are people with dementia.

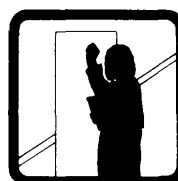
Each client referral received on the phone is screened by an intake specialist. If the intake specialist believes that the person is at risk of nursing home placement, the intake specialist refers the person to the care management team for a comprehensive assessment. From November 1987 to November 1988, intake specialists interviewed 509 individuals; 395 of them were referred for a comprehensive assessment, and the rest were referred to service providers in the community.

The AAA's program has five care management teams, each consisting of a social worker and a registered nurse. These teams conduct comprehensive assessments of the health status, functional ability, and informal support system of people referred to them. After conducting this assessment, the team discusses care options with the client

AAAs that sponsor public education programs or develop materials about dementia and services for people with dementia often do so in collaboration with an Alzheimer's Association chapter or other voluntary organizations that assist people with dementia and their families. On their own or in collaboration with these other organizations, some AAAs have published and disseminated service directories and brochures, books, videotapes, newsletters, and other educational materials about Alzheimer's disease (605). Some AAAs have sponsored public service announcements on the radio, television, or in newspapers to inform the public about Alzheimer's disease, and some have provided speakers for community programs about dementia. OTA is not aware of any data on the percent of AAAs that have conducted any of these activities.

The Geriatric Authority of Holyoke, Massachusetts operates an Alzheimer's Resource and Referral Center with Older Americans Act funds provided by the local AAA, Holyoke/Chicopee Regional Senior

Services. The Alzheimer's Resource and Referral Center maintains a resource library with books, videotapes, and training materials related to Alzheimer's disease. In addition, the center offers educational programs, publishes a monthly newsletter about Alzheimer's disease and services for people with dementia, and conducts nursing home tours for caregivers who are looking for a nursing home for a person with dementia. The center also provides support groups for caregivers and a support group for patients who are in the early stages of their disease. The center's director regularly telephones some family caregivers who are unable to attend **support group** meetings to provide emotional **support and reduce** the caregivers' sense of isolation (494).



Outreach

In conjunction with their planning function, AAAs are mandated by the Older Americans Act to:

and family members and develops a plan of care. If a client is capable of remaining in the community with in-home supportive services, the care managers determine which services are needed and arrange for their provision either by agencies that have cooperative, nonfinancial agreements with the AAA's program or by providers who bid competitively to serve the program's clientele. Each care management team handles a caseload of about 40 clients.

Care managers may purchase services for clients only if no other payment options (e.g., Medicare or private resources) exist. To resolve service payment issues, care managers rely on the program's consultation staff, consisting of an eligibility specialist and nurse consultant. For clients who cannot afford to pay privately for services and initially are not eligible for Medicaid, the program provides financial management services. If it is determined that Medicaid and other payment options are not available for a client, care managers may pay up to \$975 per month for services for the client. The program uses a system of "priority groups" based on need for services and ability to pay for them to ensure that care managers purchase services for clients in the greatest need.

To make sure that clients and caregivers are satisfied with the services they are receiving and to monitor any changes in their situation that may necessitate a change in the plan of care, a member of a care management team makes regular followup visits at least every 3 months to the client home. If the situation warrants it (e.g., a client's condition is unstable), followup is more frequent. Care managers use verbal reports from clients and caregivers to monitor the quality of services provided (529).

In fiscal year 1988, the Region IV AAA's care management and screening program provided comprehensive assessments to 319 clients, at an average cost per client of \$100, and care management services to 386 clients, at an average cost per client of \$895. These services were funded with \$199,200 from the Michigan Department of Social Services and \$186,000 from the Michigan Office of Services to the Aging.

In addition, the program directly purchased services costing \$42,794 which includes \$37,284 to provide 88 clients with long-term services such as personal care, home-delivered meals, homemaker, respite, financial management, and counseling services, and \$5,510 to provide 36 clients with one-time or short-term services such as environmental aids (e.g., grab bars, safety rails), medications or personal hygiene items (e.g., adult diapers), and immediate response services (e.g., ambulance trips).

SOURCES: LB. Kellogg, associate director, Region IV AAA, Inc., St. Joseph MI, personal communication, Nov. 2, 1989; and Michigan Region IV Area Agency on Aging, Inc., "Michigan Department of Social Services: Preadmission Screening Program Annual Report," St. Joseph, MI, Feb. 15, 1989.

... assure the use of outreach efforts that will identify individuals eligible for assistance under the act, with special emphasis on rural elderly, older individuals who have greatest economic need (with particular attention to low-income minority individuals), older individuals who have greatest social need (with particular attention to low-income minority individuals), and older individuals with severe disabilities, and inform such individuals of the availability of such assistance (818).

In addition, the Act authorizes the use of Title III funds for 'services designed to encourage and assist older individuals to use the facilities and services available to them' (818).

The extent to which AAAs ensure the provision of outreach and the mechanisms by which they do so vary. In some areas, senior centers that have been designated by local AAAs as focal points for service delivery attempt to seek out and serve isolated elderly people (240). In addition, some AAAs provide outreach through door-to-door canvassing

to identify homebound or isolated people in need of services (575). OTA is unaware of any data on the extent of these activities. One commentator has concluded, however, that many AAAs serve a disproportionate number of people who are already connected to the formal service system (240). Several individuals have told OTA that demented elderly people without family caregivers are unlikely to come to the attention of most AAAs unless they are referred by another community agency (69,261).

An increasing number of AAAs are becoming involved in various ways in 'gatekeeper' programs that could help them identify isolated people with dementia and isolated caregivers. As discussed in chapter 3, gatekeeper programs recruit individuals such as utility meter readers and mail carriers who come into contact with many people in the course of their regular daily activities and train them to identify elderly people who may need assistance and refer such people to a central agency. The first

gatekeeper program in this country was established in 1978 by a community mental health center in Spokane, Washington, with funding and technical assistance from the Eastern Washington AAA.⁷ The New York City Alzheimer's Resource Center (see box 8-A) receives referrals from a gatekeeper program sponsored by a local utility company (261).

A 1988 survey of AAAs, State units on aging, and State public utility commissions found that 146 AAAs in 46 States and the District of Columbia were involved in gatekeeper programs, most of which had been developed during 1987-88 (320). The "gatekeepers" for these programs are employees of 164 companies or organizations, including electric, gas, telephone, and water companies, post offices, social service organizations, pharmacies, groceries, banks, libraries, and cable television companies.

According to the results of the 1988 survey, AAAs play a variety of different roles in gatekeeper programs, including helping to start up the programs, developing training programs for the gatekeepers, training the company trainers, training the actual gatekeepers, training agency personnel to receive referrals from the gatekeepers, keeping records of referrals, and monitoring the program (320). Referrals from the gatekeepers generally are received either by the AAA or by an information and referral agency. The AAAs that were involved in the programs identified by the 1988 survey reported receiving an average of 4 to 5 referrals a month. Many of the programs were so new at the time of the survey, however, that they could not provide any information about average number of referrals.

It is unclear to what extent these gatekeeper programs will help AAAs identify isolated people with dementia and isolated caregivers. Many of the programs are run by utility companies, and the primary focus in some of those programs is bill payment problems (320). Nevertheless, the programs provide a mechanism by which some people who need assistance, but would not contact an AAA or any other agency on their own, can be referred for help.

Role in Allocating Services and Funding

AAAs allocate services that are paid for with Title III Older Americans Act funds. Eligibility for these services is generally limited to people over age 60.

As noted earlier, AAAs are prohibited from using means testing to determine elderly people's eligibility for services funded with Title III money, and they may not charge fees for these services (although they may request voluntary contributions).

Many AAAs also allocate services paid for by other public and private funds. The Region IV AAA in St. Joseph, Michigan (see box 8-B) allocates services paid for by Medicaid and by Michigan's Alternate Care Program, a program funded entirely with State money. Likewise, the New York City Alzheimer's Resource Center (see box 8-A) allocates services paid for with city funds and private foundation grants, in addition to other sources. When an AAA allocates services paid for with public or private funds other than Federal Older Americans Act funds, it does so on the basis of the eligibility criteria set by those other funding sources --criteria that may be very different from the eligibility criteria for services paid for with Older Americans Act funds.

Probably the best examples of AAAs allocating services on the basis of eligibility criteria that are different from the eligibility criteria for services paid for with Older Americans Act funds are the AAAs that have been designated by States to administer State nursing home preadmission screening programs and Medicaid 2176 Home and Community-Based Waiver programs. In administering these programs, some of which are discussed in chapter 7, AAAs use means testing and strict functional and medical criteria to determine people's eligibility for services. It is important to keep in mind that AAAs that administer these programs are operating not only as agencies mandated by Title III of the Older Americans Act, but also as public or private agencies that have many functions other than those mandated by the act.

Summary

As agencies that might be designated to constitute a national system to link people with dementia to services, AAAs offer many advantages:

- . AAAs exist in every State.
- . AAAs already have connections to many different agencies and individuals that provide services that may be needed for people with dementia.

⁷The gatekeeper program in Spokane, Washington, is described in box 8-C in the following section of this chapter.

- Some AAAs provide information and referrals and case management for elderly people, including some people with dementia.
- Some AAAs have sponsored public education programs and developed or paid for the development of public education materials about Alzheimer's disease, dementia, and services for people with dementia.
- Some AAAs are involved in outreach programs that may help them to identify isolated people with dementia and isolated caregivers who would not contact the AAA or any other agency on their own.
- AAAs probably have more visibility in their communities than some of the other categories of agencies discussed in this chapter.
- AAAs are part of a nationwide network of agencies and therefore have the potential to serve long-distance caregivers who need help in locating and arranging services for an elderly person with dementia.

Despite these considerable advantages, there would be several drawbacks to designating AAAs as the basis for a national system to link people with dementia to services. The most important drawback relates to questions that have been raised about the capacity of AAAs to work effectively with people with dementia and their caregivers. As discussed in this section, OTA has heard complaints that some AAAs' resource lists are not accurate or comprehensive with respect to the services that may be needed for people with dementia, that some AAAs' staff are not informed about dementia or services for people with dementia, and that some AAAs' staff are not responsive to the needs of people with dementia. OTA does not know how widespread any of these problems are. AAAs have many mandated functions and serve many different client groups, so it is to be expected that some AAA staff members are not knowledgeable about dementia or services for people with dementia. Moreover, this section has cited numerous ways in which some AAAs are serving people with dementia effectively. Nevertheless, the perception of family caregivers, Alzheimer's advocates, and others that AAAs are uninformed about dementia and/or unresponsive to people with dementia and their caregivers is a major drawback to designating AAAs to constitute a linking system for people with dementia.

A second drawback to designating AAAs as the basis for a national system to link people with dementia to services is the diversity of AAAs. What may appear from the Federal level and in the context of the Older Americans Act as 670 agencies with similar functions are, in fact, 670 agencies that differ from each other in virtually all respects except that they receive Title III Older Americans Act funds. Some AAAs are essentially planning agencies that provide few, if any, programs for individuals. Without significant changes, those AAAs could not function effectively as linking agencies for people with dementia. Moreover, many of the most impressive programs provided by AAAs for people with dementia are programs that are paid for primarily by public funds other than Older Americans Act funds or by private funds. That one AAA or AAAs in one State provide such programs does not indicate that other AAAs in other States could also do so, because the other AAAs may not have access to funding for the programs.

A third drawback to designating AAAs as the basis for a national linking system for people with dementia is that services and programs paid for with Older Americans Act funds are generally limited to people over age 60, whereas some people with dementia are under age 60. This problem would appear to be easily resolved by legislation that lowered the age limit generally or for certain programs.

A final drawback is the lack of outreach in some AAAs. People with dementia who live alone and have no informal caregiver are unlikely to contact an AAA or any other agency on their own. If AAAs were designated to establish a national system to link people with dementia to services, effective outreach methods would have to be implemented by all AAAs.

Lastly, it should be noted that although the analysis in this section has focused primarily on AAAs, the discussion in chapter 7 about State programs and systems that link people to services shows that State units on aging are generally involved in and often initiate aging network programs that link elderly people to services. If AAAs were designated to establish a national system to link people with dementia to services, State units on aging should be included in that designation.

COMMUNITY MENTAL HEALTH CENTERS

Community mental health centers (CMHCs) are local agencies that provide mental health services for people of all ages who have mental and emotional problems. CMHC services include diagnosis and assessment of mental health problems; psychotherapy; individual, group, marital, and family counseling; pharmacological treatment for mental health problems; and other mental health services. All CMHCs provide mental health services on an outpatient basis, and some CMHCs also offer inpatient mental health services.

There is no generally accepted figure for the number of CMHCs in the United States, in part, because of a lack of agreement about which agencies should be counted as CMHCs. The 1987 National Registry of Community Mental Health Services, published by the National Council of Community Mental Health Centers, listed 1,800 agencies that provided community mental health services, and an additional 2,800 "satellite" service locations associated with the 1,800 agencies (583). The 1,800 agencies and their satellite locations existed in all 50 States, the District of Columbia, Puerto Rico, Guam, and the Virgin Islands. By 1990, the Council's list of agencies that provide community mental health services had grown to 2,300 agencies, not including satellite locations (207). The council believes that its 1990 list probably includes almost all agencies that could be considered CMHCs (207).

OTA has included CMHCs in its analysis of agencies that might constitute a national system to link people with dementia to services for several reasons. One reason is that many CMHCs provide public education, information and referral, case management, and outreach for mentally ill people, and at least a few CMHCs provide these linking functions for people with dementia. In addition, CMHCs' expertise in assessing and treating mental, emotional, and behavioral problems is relevant to identifying the service needs of people with dementia and their caregivers and linking them to appropriate services. Although the diseases that cause dementia are physical conditions, their manifestations often include mental, emotional, and behavioral problems, and these problems are frequently

the most difficult aspect of a patient's illness for families and others to manage (681,705). If the problems are assessed and treated effectively, a patient's overall functioning may be improved. Even if no fundamental changes can be made in a patient's functioning, the family or other caregivers can be taught ways of managing the patient's problems so that the burden of caregiving is reduced. In either case, the patient's service needs are likely to be changed and decreased. The expertise of CMHCs' staff in assessing and treating emotional problems may also benefit people with dementia and caregivers who have feelings and perceptions that make them reluctant to use needed services.⁸

Overview of the Agencies

Outpatient mental health services have been available on a limited basis from various kinds of community agencies and from individual psychiatrists, psychologists, and other mental health professionals for along time. Federal support for "community mental health centers" was initiated in 1963 with passage of the Community Mental Health Services Act (Title II of Public Law 88-164) that authorized Federal grants to local groups to establish CMHCs (766,808). The 1963 act funded CMHC construction and required CMHCs to provide five types of mental health services: 1) inpatient services, 2) outpatient services, 3) partial (day or night) hospitalization, 4) emergency services, and 5) consultation and education (766). In subsequent years, Congress added funds for planning and staffing and expanded the types of mental health services CMHCs were required to provide.

In 1981, Federal funding for the CMHC program and nine other programs was consolidated into a block grant-the Alcohol, Drug Abuse, and Mental Health Services (ADMs) block grant (766,808). States were given the authority, within certain legislated limits, to set priorities for the use of the block grant funds and to allocate the funds. In order to receive Federal ADMs block grant funds, CMHCs were required to provide five types of mental health services: 1) outpatient services, 2) 24-hour emergency care, 3) day treatment or partial hospitalization, 4) screening of potential State institution residents, and 5) consultation and education. Inpatient services were not included.

⁸The kinds of feelings and perceptions of people with dementia and their caregivers that make them reluctant to use needed services are discussed in ch. 3.

At the Federal level, the ADMS block grant is administered by the Alcohol, Drug Abuse, and Mental Health Administration in the U.S. Department of Health and Human Services. This agency has certain oversight responsibilities and assesses each State's compliance with legislative mandates through the block grant application process, annual reports, audits, and compliance reviews. At the State level, the ADMS block grant is administered by a designated State agency—usually the State department of health, human services, or mental health.

By 1981, when the ADMS block grant was established, more than 700 CMHCs had received Federal funds under the Community Mental Health Services Act of 1963 (625,766,806,808), and about 500 of these CMHCs were still receiving Federal funds under the act (806). For some years after the establishment of the ADMS block grant, States were required to allocate some of their block grant funds to those CMHCs that received Federal funds under the 1963 act in 1981, and would have been eligible to receive funds under the act in subsequent years. This requirement is no longer in effect, but some, and perhaps many, CMHCs that were funded under the 1963 act do receive ADMS block grant funds (207). The number of such agencies is not known because the data system that was in place under the 1963 act to collect information about CMHCs was discontinued when the block grant was established, and no alternate system was created to collect the information.

In addition to CMHCs that were funded under the Community Mental Health Services Act of 1963, there are many other agencies that provide community mental health services, but never received Federal funding under the 1963 act. As noted earlier, the National Council of Community Mental Health Centers has a list of 2,300 agencies that provide community mental health services. That number includes agencies that were funded under the 1963 act and agencies that were not. Some agencies that provide community mental health services but were not funded under the 1963 act currently receive ADMS block grant funds, but the number of such agencies is not known (207).

Although CMHCs are sometimes discussed as if they were a clearly defined group of agencies, there is no agreement about precisely which agencies should be considered CMHCs. The term ‘community mental health center’ is a generic one that was

used in the 1963 act, but many agencies that provide community mental health services are not called ‘community mental health centers’ and have a variety of other names. The agencies that received funding under the Community Mental Health Services Act of 1963 can be identified and are identified, for example, in the 1987 National Registry of Community Mental Health Centers (583). The characteristic that made those agencies a clearly defined group—receipt of Federal funds under the 1963 act—ceased to exist almost a decade ago. Agencies that provide community mental health services but did not receive funding under the 1963 act, have never been a clearly defined group.

In the national inventory of mental health organizations conducted in 1986 by the Alcohol, Drug Abuse, and Mental Health Administration, agencies that provide community mental health services were subsumed under four categories:

1. freestanding psychiatric outpatient clinics (of which there were 780),
2. freestanding psychiatric day/night (partial hospitalization) organizations (of which there were 97),
3. multiservice mental health organizations (of which there were 1,363), and
4. general hospitals with separate psychiatric outpatient services (of which there were 1,354) (489).

These four categories included both agencies that did and did not receive funding under the 1963 act.

OTA is not aware of any research on agencies that provide community mental health services that compares agencies that received funding under the 1963 act and agencies that did not. One commentator believes that there are probably very few differences between the two groups of agencies, but that agencies that received funding under the 1963 act may tend to be larger, to provide more comprehensive mental health services, and to be more focused on caring for the indigent than agencies that did not receive funding under the act (207). If Congress chose to designate CMHCs to constitute a national system to link people with dementia to services and if, as has been suggested, the two groups of agencies are quite similar, Congress would probably want to include both groups of agencies in the system. It should be recognized, however, that determining exactly which agencies are CMHCs for this purpose may be difficult.

More importantly, the mechanism by which the Federal Government could designate CMHCs to constitute a national linking system for people with dementia is unclear. States determine which agencies receive ADMS block grant funds; thus block grant funding does not create a direct link between the Federal Government and CMHCs. Moreover, some agencies that provide community mental health services and could be part of a national linking system may not receive ADMS block grant funds, and there is no obvious connection between the Federal Government and those agencies. Lastly, States operate many mental health facilities, including outpatient mental health clinics, some of which are on the grounds of State mental hospitals (207,719). These clinics are considered CMHCs by some States and are included in some lists of CMHCs. As State agencies, their functions are determined by State government; whether they could be part of a national linking system for people with dementia would be the decision of each State.

In fiscal year 1989, \$246 million of the Federal appropriation for the ADMS block grant was targeted for mental health (520), and much of this amount funded CMHCs. ADMS block grant funds make up only 6 percent or less of the budget of the average CMHC, however (207,441,489,584,719). A 1987 survey of agencies that are members of the National Council of Community Mental Health Centers found that in addition to the 6 percent from the ADMS block grant, the average CMHC received 43 percent of its budget from State government, 13 percent from local government, 11 percent from Medicaid, 9 percent from client fees, 8 percent from private insurers, and 11 percent from other sources, such as the Social Services Block Grant, charitable contributions, and Medicare (584).⁹

Who Is Served

CMHCs provide mental health services for people of all ages. CMHCs that receive ADMS block grant funds are specifically required to serve seriously mentally ill adults, emotionally disturbed children, mentally ill elderly people, and other undeserved populations in their service areas, regardless of the individuals' ability to pay for the services, current or past health condition, age, handicap, race, or sex.

In the years since the establishment of the ADMS block grant, the influence of the Federal Government has given way to the expanded role of State governments in planning and directing community mental health services, and CMHCs have modified their programs and services to reflect State Priorities. Most States give highest priority to serving seriously mentally ill people, and CMHCs have increasingly targeted their programs to serve this client population (370,441,585,719). The term "seriously mentally ill" (previously "chronically mentally ill") usually refers to adults with a diagnosis of schizophrenia, a major affective disorder, psychosis, or a personality disorder, and a recent history of psychiatric care that required more than voluntary outpatient treatment (585). The term "seriously mentally ill" is not usually used to refer to people with Alzheimer's disease or other diseases that cause dementia.

The extent to which CMHCs serve people with dementia is not known. Data from the national inventory of mental health organizations conducted in 1986 by the Alcohol, Drug Abuse, and Mental Health Administration showed that among the clients of the four types of agencies included in the survey (freestanding psychiatric outpatient clinics, freestanding psychiatric day/night organizations, multiservice mental health organizations, and general hospitals with separate psychiatric outpatient services), only 4 percent had a diagnosis of organic brain syndrome (489), a diagnosis that often includes Alzheimer's disease and other diseases that cause dementia. Since CMHCs were subsumed under these four categories of agencies, the data suggest that CMHCs were serving very few people with dementia.

A 1984 survey of agencies that were members of the National Council of Community Mental Health Centers found that one-third of the 281 responding agencies reported that they had special services for people with Alzheimer's disease and their families. How representative these findings were for all CMHCs is not known. In the 6 years since the data were collected, awareness of Alzheimer's disease and the special service needs of people with Alzheimer's and other dementing diseases has increased greatly in this country, and more CMHCs may have special services for people with dementia now than

⁹ADMS block grant funds are a very small part of all funds allocated by States for mental health services—less than 3 percent in fiscal year 1986 (573). Most funds allocated by States for mental health services are used to pay for inpatient services.

in 1984. On the other hand, the fact that a CMHC has special services for people with Alzheimer's disease says almost nothing about how many people with Alzheimer's or other dementing diseases the agency serves.

The 1984 survey found that agencies that reported that they had special services for elderly people were much more likely than other agencies to also report having special services for people with Alzheimer's disease (458). Although OTA is not aware of any research to this effect, it is logical that there could also be an association between the number of elderly people served by agencies that provide community mental health services and the number of people with dementia served by these agencies, especially since the great majority of people with dementia are elderly. If the latter association exists, then people with dementia are probably underserved by CMHCs since CMHCs have historically underserved elderly people (6,7,419,458,766,806).

Beginning in 1975, Congress has repeatedly mandated more services for elderly people through CMHCs, and some progress has been made in increasing the number of elderly people served by these agencies (6,7). Since the establishment of the ADMS block grant, however, CMHCs' emphasis on serving seriously mentally ill people has resulted in fewer services for other client groups, including elderly people (6,7,441,458,585,806,808). OTA is not aware of any current national data on the number of elderly people served by CMHCs, but a 1987 survey of 335 CMHCs by the National Council of Community Mental Health Centers found that elderly people constituted only 8 percent of the agencies' clientele (584), even though elderly people make up 12 percent of the U.S. population.

Many reasons have been cited to explain the underrepresentation of elderly people in the clientele of agencies that provide community mental health services. These reasons include:

- negative attitudes of mental health professionals about elderly people and their potential to benefit from mental health treatment,
- limitations on reimbursement for mental health services through Medicare,
- lack of transportation,
- lack of awareness of mental health services among elderly people, and

- resistance to the use of mental health services among elderly people (238,419,445,451,692,766,%08,889).

Most important for this assessment is the fact that some, and perhaps many, elderly people and some younger people perceive a stigma associated with the use of mental health services (272,419,445,889).

Notwithstanding these problems, a few CMHCs have been very successful in developing comprehensive elderly service programs that target and serve elderly people with dementia (97,419,688). One such program, developed in the State of Washington by the Spokane CMHC with support from the Eastern Washington AAA, is described in box 8-C. This program provides public education about mental health problems in elderly people, including mental and emotional problems associated with dementia; information and referrals for elderly people with mild cognitive impairments; case management for elderly people with more serious mental problems; and outreach to identify elderly people who need services, but are not willing or able to contact service providers on their own (688,689).

Another program operated by a CMHC in Ventura County, California, also serves elderly people with dementia and provides all four functions that OTA concludes are essential to link people with dementia to appropriate services: public education, information and referral, case management, and outreach. That program is described in detail in a recently published book, *Outreach With the Elderly: Community Education, Assessment, and Therapy* (418).

Linking Functions

Information and Referral



CMHCs provide information and referrals for their own clients. CMHCs are also capable of providing information and referrals for the general public, but the extent to which they do so is not known. Likewise, CMHCs are capable of providing information and referrals for long-distance caregivers who need help locating services for a relative who lives in the CMHCs' service area, but the number of long-distance caregivers who are served by CMHCs is not known.

Box 8-C—The Spokane Community Mental Health Center's Elderly Services Program, Spokane, Washington

In 1978, the Spokane Community Mental Health Center (CMHC) established an Elderly Services Program to provide mental health and other services for elderly people, especially frail, vulnerable, and moderately to severely impaired elderly people. The program receives 60 percent of its funding from the Eastern Washington AAA (Older Americans Act and Washington State aging funds). Other program funds come from the State mental health grant-in-aid program, the ADMS block grant, and the National Institute on Drug Abuse.

The Spokane CMHC's Elderly Services Program has two components:

- * a telephone information and referral component for elderly people who have mild psychiatric and/or cognitive impairments and who have a caregiver or other support system that is willing and able to act on their behalf; and
- a multidisciplinary assessment, treatment, and case management component that offers elderly people believed to be at high risk of institutionalization a comprehensive in-home assessment, a variety of preventive, rehabilitative and supportive services, and case management.

The information and referral component is staffed by three telephone screeners. The case management component is staffed by a program manager and 5 multidisciplinary teams which include 5 team leaders (4 are nurses), 15 case managers, 1 psychiatrist (36 hours/week), and resident physicians.

Elderly people are sometimes referred to the case management program by their families. Other referrals come from volunteer 'gatekeepers.' Volunteer gatekeepers are individuals who interact with many people in the course of their regular activities—e. g., mail carriers, meter readers, and other utility workers; property appraisers; apartment and mobile home court managers; fuel oil dealers; employees of police, ambulance, and fire departments; grocery clerks; and pharmacists—and are specially trained to identify individuals who are confused, ill, or otherwise at risk. Training for gatekeepers is provided by the CMHC in cooperation with the corporations and businesses that employ the volunteers.

In 1987, gatekeeper referrals accounted for 37 percent of all clients admitted to the Elderly Services Program's case management program. Gatekeepers' outreach efforts were especially useful in identifying demented elderly people living alone. In 1987, 46 percent of the demented elderly people living alone who were referred to the program were referred by the gatekeepers.

The comprehensive in-home assessment that is given to each elderly person referred to the case management program is coordinated by a case manager who is accompanied on home visits by members of the multidisciplinary team. Following the assessment, the team develops a detailed plan of care. This plan seeks to make use of the potential of family and other support systems, and family conferences are held when needed. Caregiver support groups are also available.

The Spokane Elderly Services Program can deliver a variety of preventive, supportive, and rehabilitative in-home services via 14 agencies with which it has written agreements. Most of these agencies are AAA-funded. The most frequently used services are homemaker/chore services, visiting nurses and nurse aides, adult day health care, home-delivered meals, and respite. The Elderly Services Program is dependent on these other agencies to implement much of the treatment plan, and all agencies are involved in weekly case staffing meetings. The Elderly Services Program also provides at least 20 hours of training for the service providers (e.g., chore workers) on topics such as dementia and depression.

The Spokane CMHC's Elderly Services Program has been very successful in reaching elderly people. Whereas clients over age 60 represent between 4 to 8 percent of the CMHC population nationally, the Elderly Services Program's clients account for 22 percent of the Spokane CMHC's client population. Minority elders, who constitute only 2 percent of Spokane's elderly population, make up 6 percent of the case management program.

SOURCE: R. Raschko, "Spokane Community Mental Health Center Elderly Services," unpublished mimeo, Spokane Community Mental Health Center, Spokane, WA, May 25, 1988.

Some CMHCs provide referrals to all kinds of health care, long-term care, social, and other services, as well as to mental health services (97,419,688).

Anecdotal evidence suggests that other CMHCs only provide referrals to mental health services (746).

Very little information is available about whether CMHCs generally have lists of community services to which they refer people, and if so, how they obtain the lists. One OTA panelist believes that some CMHCs generate their own resource lists and that other CMHCs use resource lists from a local United Way information and referral program, an AAA, or another source (689).

Case Management



The Community Mental Health Center Amendments of 1975 required CMHCs to provide case management for their elderly clients (766), but until the establishment of the ADMS block grant in 1981, CMHCs provided relatively little case management. Since then, most CMHCs have increased the case management they provide (370,441). One study of 54 CMHCs in 15 States found that in the 3 years after the establishment of the ADMS block grant:

Most centers reported substantial improvements in their case management programs. Examples include conducting better assessments, more inter-agency collaboration, greater cooperation among staff from different services, more coordination, closer monitoring, specific staff assignments, more home visits and work with families, and better liaison with hospitals. Along with expanded services, most centers reported increased staff time devoted to case management, and in some States, increased funding as well (441).

CMHCs provide case management primarily for people with serious mental illness (207,370,441, 466,585). According to one source, the majority of CMHC clients who receive case management are either young adults or previously deinstitutionalized adults—many of who are now in their forties (207). A 1987 membership survey by the National Council of Community Mental Health Centers found that 86 percent of 595 responding CMHCs provided case management for their clients with serious mental illness (585).

The percentage of CMHCs that provide case management for people with dementia is not known but is probably small, given the targeting of most CMHCs' case management to people with serious mental illness. An official from one State has told

OTA he believes that the case management technology used by CMHCs in his State for seriously mentally ill people could be adapted to serve people with dementia, but that the CMHCs' case management programs would have to be greatly expanded to serve the additional clients (466). OTA is aware of several CMHCs, however, that provide case management for many people with dementia (97, 419,688). One example is the CMHC in Spokane, Washington, that is described in box 8-C.

CMHCs vary with respect to the personnel they use to provide case management. Some, and perhaps many, CMHCs use a multidisciplinary team to provide the initial client assessment and care plan, and some CMHCs include a psychiatrist and/or a psychologist on the team.¹⁰ Social workers, nurses, and psychologists provide ongoing case management in some CMHCs, but most CMHCs probably use personnel without these credentials. According to one source, many CMHCs assign the lowest ranking personnel with limited training and experience to provide case management for people with serious mental illness (523). To address this problem, one State, Rhode Island, has developed a voluntary formal training and certification program for CMHC case managers (905).

Whether CMHCs can provide effective case management for people with dementia depends in part on whether they have a working relationship with other community agencies that furnish the kinds of services that maybe needed by people with dementia. Beginning in 1975, CMHCs were required by the 1975 amendments to the Community Mental Health Services Act of 1963 to coordinate their services with the services of other health care and social services agencies (766). In 1981, the law establishing the ADMS block grant reemphasized the need for CMHCs to coordinate services with other agencies.

Although some CMHCs have developed strong working relationships with other community agencies, many CMHCs have not (6,7,203,418,451). A 1983 survey of 233 CMHCs found almost no coordination and little routine interaction between CMHCs and AAAs (6). A followup survey 2 years later indicated that interactions between these types of agencies had increased, and 18 percent of the CMHCs reported having a formal agreement with

¹⁰CMHCs also use psychiatrists to make initial diagnoses, and some use psychologists to provide testing and other information needed for diagnosis.

the local AAA (7). Another survey in 1984 found that 23 percent of 281 responding CMHCs had a formal agreement with an AAA, and 66 percent had an informal affiliation (451). Interestingly, this survey found that CMHCs that were affiliated with AAAs—whether through formal or informal agreements—were twice as likely as other CMHCs to provide special services for people with Alzheimer's disease, respite care, and family support services.

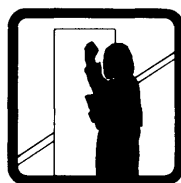
Public Education



The Community Mental Health Services Act of 1963 and the law that established the ADMS block grant required CMHCs to provide “consultation and education” services. In response to a 1987 survey of 335 agencies that are members of the National Council of Community Mental Health Centers, 89 percent of the agencies reported that they were providing such services (584). Although no data are available, it is likely that many CMHCs provide public education programs and materials as part of their consultation and education services. The programs and materials may not pertain to dementia, however.

Some CMHCs that have special programs for elderly people provide public education programs and materials about dementia and about services for people with dementia (418,689). These programs and materials include community meetings, workshops, public service advertisements, brochures, and other printed materials. Some experts believe that vigorous public education efforts are essential in overcoming the stigma associated by some people with mental health services and that such efforts can be successful in getting elderly people, including people with dementia, and their caregivers to use the services provided by a CMHC (95,418).

Outreach



People with serious mental illnesses often are unable or unwilling to contact service providers on their own. For this reason, many CMHCs have developed outreach programs (585), but most of these programs probably do not target people with dementia.

The director of elderly services at the CMHC in Spokane, Washington, maintains that outreach is essential to serving demented elderly people who



Photo credit: Bill Adams, Northwest Images

The Eastern Washington Area Agency on Aging recently sponsored a public education campaign to inform people about the telephone information and referral program of the Community Mental Health Center in Spokane, Washington. Billboards like the one pictured here were displayed in early 1990 and are scheduled for use again in the fall of 1990.

live alone (688). Some CMHCs that have special programs for elderly people have outreach programs that target these people. The Spokane CMHC's “gatekeeper” program (see box 8-C) is particularly effective in reaching demented elderly people who live alone; in 1987, 46 percent of the demented people living alone who were referred to the Spokane CMHC program were referred by the volunteer “gatekeepers.”

Another CMHC serving two rural counties in Iowa also has a gatekeeper program that has been effective in identifying elderly people with dementia who need services but are unwilling or unable to contact service providers on their own (97,763). The gatekeeper program uses mail carriers, utility workers, and others to refer elderly individuals who needed assistance to an outreach team from the CMHC; the team then contacts the individuals, evaluates their service needs, refers them for medical and social services, and provides ongoing mental health services in the home, if needed.

Role in Allocating Services and Funding

CMHCs generally do not allocate services or funding for services other than those they provide.

Summary

As agencies that might be designated to constitute a national system to link people with dementia to services, CMHCs offer several advantages:

- There are more than 2,000 CMHCs nationwide.

- CMHCs typically employ a wide range of professionals, including psychiatrists, psychologists, nurses, social workers, and others who have expertise in the assessment and treatment of mental and emotional problems.
- CMHCs serve individuals of all ages.
- Many CMHCs have experience in providing case management.
- A few CMHCs provide public education, information and referral, case management, and outreach for people with dementia, thus suggesting that other CMHCs could also do so.

Despite these advantages, there are several important drawbacks to designating CMHCs as the basis of a system for linking people with dementia to services. The primary drawback is that many CMHCs serve relatively few people with dementia. CMHCs have historically underserved elderly people, and the great majority of people with dementia are elderly. Moreover, since the inception of the ADMS block grant, most CMHCs have focused increasingly on serving seriously mentally ill adults, a category that usually does not include people with dementia. Although these CMHCs provide information and referral, case management, and outreach for their clients who are seriously mentally ill, it would require a considerable change in direction and either a reallocation of agency resources or a significant increase in resources for these CMHCs to provide similar assistance for people with dementia. Obviously, a large-scale reallocation of CMHCs' resources from people who are seriously mentally ill to people with dementia would create a major gap in services for people who are seriously mentally ill.

A second drawback to designating CMHCs as the basis of a system for linking people with dementia to services is that some CMHCs do not have effective working relationships with other community agencies that provide the kinds of services that may be needed for people with dementia.

A third drawback is that CMHCs are not a clearly defined group of agencies that could be designated by the Federal Government to constitute the linking system nationwide. The generic term "community mental health center" is used to refer to agencies that received funding under the Community Mental Health Services Act of 1963—a group of agencies

that can be identified precisely—and to other agencies that provide community mental health services but did not receive funding under the 1963 act—a group of agencies that cannot be identified precisely. Since there is no current source of direct Federal funding that is unique to either or both of these groups of agencies, it is unclear what mechanism the Federal Government could use to designate the agencies as the basis of a national linking system.

A final drawback is that some people with dementia and their families and other informal caregivers may not be willing to contact a CMHC for help in locating and arranging services because they perceive a stigma associated with mental health services. As indicated earlier, however, some experts believe that public education efforts by CMHCs can be successful in overcoming this stigma.

COMMUNITY HEALTH CENTERS

Community health centers (CHCs) are organizations that provide primary health care and other health-related services to individuals in a local community. Their clients include people who tend not to be adequately served by other health care providers: poor and low-income people, members of ethnic minority groups, and people who live in medically underserved areas. As of 1989, there were about 1,200 CHCs delivering care at more than 2,000 sites throughout the country.

OTA has included CHCs in its analysis of agencies that might constitute a national system to link people with dementia to services because CHCs reach population groups that often are not served by the other categories of agencies discussed in this chapter—notably, poor people and ethnic minorities.

Overview of the Agencies

Some CHCs receive Federal funding under Section 330 of the Public Health Service Act, which authorizes grants to public and private nonprofit organizations that provide primary health care to populations or areas that are "medically underserved."¹¹ To be eligible for Section 330 grants, CHCs must have a governing board with a majority of members who are users of the CHC's services.

¹¹A medically underserved population or area is one with a shortage of health care services. Among the factors the U.S. Department of Health and Human Services considers in determining whether an area or population is medically underserved are the accessibility of health services and people's ability to pay for health services (825).

Section 330 CHCs also must adjust their fees to their clients' ability to pay (578).

As of 1987, nearly 600 CHCs nationwide were receiving Section 330 grants (664). These CHCs provided health care services at approximately 1,600 different sites, including their primary location and satellite sites that ranged in size from full-service community clinics to outposts of single health professionals (664). At least some Section 330 CHCs exist in every State except Wyoming and in all U.S. territories (578). Because of their emphasis on serving medically underserved areas and populations, however, Section 330 CHCs typically are not uniformly distributed throughout a State.

Section 330 CHCs are required to provide the following primary health care services, either directly or through contracts or cooperative agreements with other agencies (825):

- physician and physician extender services,
- diagnostic laboratory and radiologic services,
- preventive health services,
- emergency medical services,
- transportation services,
- preventive dental services, and
- pharmaceutical services.

The decision about whether to provide other services—e.g., hospital, home health, mental health, dental, and vision services—rests with an individual CHC's governing board (693).

Section 330 CHCs supplement their Section 330 grants with funds from other sources. In fiscal year 1985, Section 330 CHCs received 48 percent of their total revenue from Federal grants, 16 percent from Medicaid, 5 percent from Medicare, 6 percent from other third party payers, 11 percent from patient fees, and 14 percent from State, local, and other sources (578). Federal Section 330 grants have been declining in recent years, so alternative sources of revenues are becoming increasingly important to CHCs.

In addition to Section 330 CHCs, there are an estimated 500 to 750 other CHCs that do not receive Section 330 grants (381,664). These CHCs do not receive Section 330 grants for a variety of reasons. Sometimes they do not apply for a grant because they either cannot meet or choose not to meet one or more Federal eligibility requirements—e. g., the requirement that more than half the members of the CHC's governing board be users of the CHC's services (381,664).

Very little information is available about CHCs that do not receive Section 330 grants. Anecdotal evidence suggests that Section 330 CHCs and other CHCs are similar in many ways, but that Section 330 CHCs tend to be larger and to provide a more comprehensive range of services (381,664). Some CHCs that do not receive Section 330 grants are affiliated with hospitals and are funded in part through the hospitals. Such CHCs also may receive funds from State and local governments, foundations, churches, and other philanthropic sources.

Many Section 330 CHCs, particularly the larger ones, have a full complement of health care professionals, including physicians, physician assistants, nurses, therapists, dentists, health educators, social workers, and others. No information is available about the number and type of staff in CHCs that do not receive Section 330 grants. Nor is it known how many CHCs of either type have staff who are knowledgeable about dementia. A 1986-87 study of 10 Section 330 CHCs identified by the La Jolla Management Corp. as having good programs for elderly people (693) found that only 1 of the physicians in the 10 CHCs had specialized geriatric training, although some of the other staff members in the 10 CHCs had attended geriatric training workshops and seminars. No information is available about the extent to which CHC staff members have specific training in dementia.

Who Is Served

In 1985, Section 330 CHCs served over 5 million individuals, many of whom might not have received health care services otherwise (578). Half of the CHC users resided in high-poverty urban communities, and half resided in rural areas. Sixty-five percent of the users were either black, Hispanic, or members of other ethnic minority groups.

Section 330 CHCs are intended to serve the poor, and 60 percent of the 5 million individuals who received health care services from Section 330 CHCs in 1985 had family incomes below the Federal poverty level; 85 percent had family incomes below 200 percent of the poverty level. Section 330 CHCs also serve some individuals who are able to pay for part or all of their care. Individuals whose family incomes are below the Federal poverty level are charged nominal fees, if any, for services. Individuals whose family income falls between 100 and 200 percent of the poverty level are charged a

reduced fee based on their family income and family size. Individuals with family incomes above 200 percent of the poverty level are charged the full fee for CHC services.

The emphasis in many CHCs has been on providing care for mothers and children. In 1985, 45 percent of Section 330 CHCs' clients were children. Only 9 percent were people over age 65 (578).

The extent to which CHCs serve people with dementia is not known. As comprehensive health centers, Section 330 CHCs diagnose and treat people with a variety of conditions. In 1982, the most commonly observed diagnoses, in descending order, were vaginitis, otitis media, urinary tract infection, dermatitis, obesity, diabetes mellitus, abdominal pain, adjustment disorder, bronchitis, and trauma (118). This list suggests that the centers were not seeing a large number of people with dementia at that time. A current list, if one were available, might include other diagnoses. It is also possible that CHCs are providing primary health care for some people with dementia but not identifying their dementia. The 1986-87 La Jolla study mentioned earlier found that some CHCs lacked specific means to detect mental disorders, including dementia. The reason was that many of them used adult, rather than geriatric, screening criteria. The adult criteria miss dementia and other problems that are prevalent among the elderly (693).

As discussed later in this section, some CHCs provide case management for the clients of State-funded long-term care programs that serve elderly and disabled people, including people with dementia. In addition, at least one CHC, Eastern Shore Rural Health System, Inc., in Virginia, has a special Alzheimer's Disease Project that provides public education about Alzheimer's disease as well as caregiver support groups and respite services (see box 8-D).

Although the extent to which CHCs serve people with dementia is not known, it is reasonable to assume that CHCs that serve large numbers of elderly people are more likely than other CHCs to serve people with dementia. As noted earlier, in 1985, only 9 percent of Section 330 CHCs' clients were over age 65. The percentage of elderly clients varies greatly among CHCs. The 1986-87 La Jolla study found that depending on the CHC, elderly people made up from 2 to 46 percent of its client population (693). According to the National Associ-

ation of Community Health Centers, the percentage of elderly CHC clients is generally lower in urban than in rural areas; in some large cities, elderly people make up only 5 percent of all CHC users (569).

The Health Resources and Services Administration (HRSA), which administers Section 330 grants at the Federal level, has initiated several efforts over the years to increase Section 330 CHCs' services for elderly people. In 1984, for example, it awarded \$1.7 million in supplemental Federal funds to 57 Section 330 CHCs to pay for new or expanded programs for the elderly that might later be replicated by other CHCs (693).

HRSA has also sponsored joint initiatives with the Administration on Aging to increase collaboration among CHCs, State units on aging, AAAs, State and local health departments, and voluntary organizations that provide services for elderly people (420). In 1987, for example, HRSA and the Administration on Aging conducted regional workshops for personnel of State units on aging and associations representing CHCs at the State level (420,648). One intended outcome of the workshops was to help participating agencies overcome "turf" problems that often interfere with the coordination of services for elderly people.

As a result of the 1987 initiative, collaborative projects involving aging network agencies and CHCs were established in many States. In Kentucky, the State Community Health Center Association and the State Division on Aging developed a joint plan that included the goal of training case managers in the CHC and AAA systems to improve elderly people's access to both CHC and AAA resources (420). In Utah, four health education fact sheets—including a fact sheet on dementia—were developed for distribution to elderly people through CHCs, senior centers, and other elderly services agencies (420).

Some CHCs that have implemented successful programs to serve elderly people did this in collaboration with AAAs and other aging network agencies even before the 1987 initiative. The Shawnee Health Services and Development Corp., which operates three CHCs in southern Illinois that provide many services for elderly people, credits the success of its elderly services programs in part to coordination with the local AAA, senior centers, and other aging network agencies (631). Over the last 6 years, the

number of elderly clients served by Shawnee's three CHCs has quadrupled, and the ratio of elderly clients to total CHC clients has tripled. The local AAA has paid for several programs implemented by Shawnee (648).

Linking Functions

Information and Referral



CHCs provide their clients with information about services and referrals to community service providers. OTA has no data on the types of referrals provided by CHCs, and these undoubtedly vary depending on a CHC's clientele and the training and experience of its staff. The purpose of CHCs is to furnish primary health care, however, and anecdotal evidence suggests that the referrals provided by CHCs are more often to other health care services than to the long-term care, social, or other services that also are needed for people with dementia.

OTA does not know how many CHCs maintain comprehensive lists of community resources that include the kinds of services that maybe needed for people with dementia. Nor does OTA know how many, if any, CHCs serve caregivers at a distance.

Case Management



According to the National Association of Community Health Centers, CHCs pioneered and developed the concept of managed care (578). The focus of care management or case management in CHCs is generally on health care needs. If clients need hospital, nursing home, or acute home health care, or special medical services, CHC staff often arrange and monitor the provision of these services. In contrast, the findings of the few small studies that addressed the question of case management in CHCs suggest that CHCs generally do not provide the kind of comprehensive, ongoing case management that is needed by some dementia patients (478,693).

Most of the 10 CHCs in the 1986-87 La Jolla study did not provide their elderly clients with a comprehensive assessment that included social and environmental as well as health status (693). The professional staff of the 10 CHCs typically functioned individually and rarely came together as a team to develop a multidisciplinary plan of care for

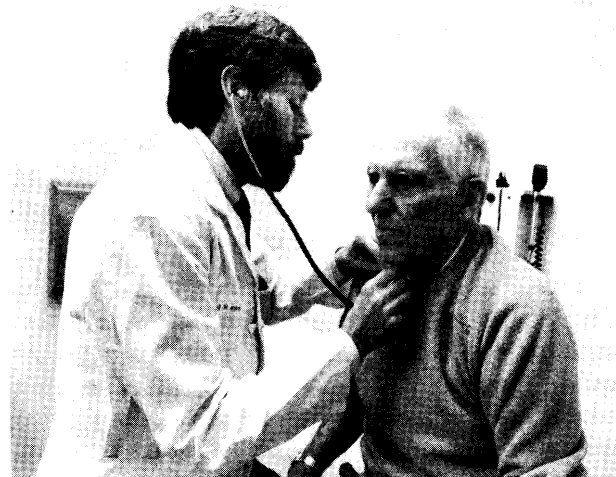


Photo credit: Alzheimer's Association and Rush-Presbyterian/St. Luke's Medical Center.

The main function of community health centers is to provide primary health care. Consequently, the information and referrals and case management provided by community health centers generally focus on the health care needs of their clients.

a client. Nor did they generally provide followup or ongoing monitoring of services other than health care services. Families frequently were not involved in a client's clinical evaluation, although they were involved in support groups, respite care, and home care programs in CHCs that provided these programs. A study of seven CHCs in New York found that "CHCs frequently lacked the social workers and/or community health aides necessary to make referrals and act as liaisons to the myriad of other agencies which may be involved with an elderly individual" (478).

The amount of contact a CHC has with other community organizations is relevant to its ability to perform case management. According to the National Association of Community Health Centers, most CHCs have contact with many different agencies—social service agencies, community action programs, local government offices, and other medical and dental providers—that allows for extensive referrals between CHCs and other agencies (569). A 1984 study of 32 communities showed that CHC coordination with other agencies was increasing (924), but the 1986-87 La Jolla study concluded that even some of the 10 CHCs that were identified by La Jolla as having good programs for elderly people had not established relationships with some of the types of agencies that are most likely to provide services for elderly people (693).

Box 8-D-The Alzheimer's Disease Project of Eastern Shore Rural Health System, a Community Health Center in Virginia

Eastern Shore Rural Health System (ESRHS) is a community health center that provides medical and other services at three clinic sites in two Virginia counties on the southern tip of the Delmarva Peninsula, which lies between the Chesapeake Bay and the Atlantic Ocean. ESRHS serves a rural area with a population of 50,000 people, half of whom have incomes below the Federal poverty level and half of whom are black. Since 1982, ESRHS has established a variety of programs for elderly people, often with encouragement and funding from the Eastern Shore Area Agency on Aging/Community Action Agency, which is the local AAA. From 1983 to 1986, the percentage of EMU-IS'S clients who were elderly increased from 13 to 18 percent.

ESRHS's Alzheimer's Disease Project was initiated in 1984, when the local AAA gave ESRHS a \$1,000 grant to establish and run support groups for family caregivers of Alzheimer's patients. In 1985, the project was expanded to provide in-home respite services for Alzheimer's family caregivers with a \$7,000 grant from the Dementia Center of Hampton Roads (Virginia). Currently, family caregivers of people with dementia can receive up to 20 hours of respite care a week. Since 1986, funding for such services has been provided via an annual grant from the Hampton Roads Alzheimer's Association Chapter, and fees to caregivers for respite services are based on a sliding scale. The Alzheimer's Disease Project generally provides respite services to about 10 families at a time. To assess how the patients and families who are receiving the respite services are managing, the project coordinator and a geriatric nurse practitioner make home visits every 4 to 6 weeks.

In addition to offering support groups and respite services for the caregivers, ESRHS's Alzheimer's Disease Project provides public education about dementia and about ESRHS's services for people with dementia and their families. Public education is provided through brochures, a quarterly newsletter, articles and advertisements in the met@ and community meetings. The Alzheimer's Disease Project also provides training related to dementia and the care of dementia patients for the staff of local nursing homes and home health agencies and for other people who work with dementia patients and their families. Lastly, the Alzheimer's Disease Project furnishes families with home health care supplies, including wheel chairs; incontinence supplies; skin care products, such as alternating pressure pads; plate guards and special cups for feeding; and other assistive devices.

SOURCES: S. Ray, N. List, R. Clinkscale, et al., La Jolla Management Corp., Columbia, MD, "Assessment of the Current Utilization of C/MHCs by the Elderly and an Assessment of the Capability of C/MHCs To Develop Comprehensive Community-Based Primary Care Health Service Systems for the Elderly," prepared for the Bureau of Health Care Delivery and Assistance, Health Resources and Services Administration, Public Health Service, U.S. Department of Health and Human Services, Rockville, MD, July 1987; C.D. Rienerth, executive director, Eastern Shore Rural Health Services, Inc., Onancock, VA personal communication, Aug. 1, 1989; G.V. Podelo, executive director, Eastern Shore Area Agency on Aging/Community Action Group, Onancock, VA, letter to the Office of Technology Assessment, U.S. Congress, Washington, DC, Aug. 16, 1989; and C. Dever, development director, Eastern Shore Rural Health Services, Inc., Onancock, VA personal communications, Aug. 2, 1989, and Sept. 9, 1989, and quarterly reports on ESRH's Alzheimer's Disease Project for June 14, 1984, Jan. 25, 1985, Oct. 25, 1985, Apr. 25, 1986, July 25, 1986, Oct. 24, 1986, Jan. 27, 1988, July 27, 1988, and for the period January to May 1989.

On the other hand, at least a few CHCs provide comprehensive, ongoing case management, often in connection with a State-funded long-term care program. Shawnee Health Services and Development Corp. in Illinois, described earlier in this section, has a contract with the State of Illinois to function as a "Care Coordination Unit" to provide case management for people who are eligible for Illinois' Community Care Program--i.e., people who are over age 60 and fictionally impaired enough to be eligible for Medicaid-funded nursing home care (631,648,693).¹² The case managers for this program are based in Shawnee's CHCs. AltaMed Health Services Corp., a CHC in Los Angeles, also provides comprehensive case manage-

ment for some of its clients through two programs (see box 8-E).

Public Education



As noted in box 8-D, the Eastern Shore Rural Health System's Alzheimer's Disease Project uses brochures; newsletters; articles and advertisements in the media; and community meetings to inform the public about dementia and services for people with dementia. The CHCS in the 1986-87 La Jolla study used presentations to other community agencies, neighborhood groups, and participants in church meal programs to inform the people about their

¹²See ch. 7 for further information about Illinois' Community Care Program.

services for elderly people (693). Presumably, other CHCs use similar methods. The focus of their public education efforts probably reflects their main interests, however, which often do not include caring for elderly people or people with dementia.

CHCs have the opportunity to provide patient and family education in conjunction with their health screening and primary health care services, and many do so. Once in the community to screen for high blood pressure or diabetes, for example, CHCs can furnish people with information about any of a variety of health problems and about services of the CHC and other community agencies that may be available to address the problems. OTA does not know how often CHCs use such opportunities to provide patient and family education about dementia and services for people with dementia.

Outreach



CHCs conduct outreach programs of various kinds, but no information is available about how successful they are in identifying people with dementia or people who live alone and otherwise might not seek care.

A 1986 study of 10 CHCs conducted by the National Association of Community Health Centers found that all 10 centers studied provided services in many locations, including senior centers, adult day care and congregate meal sites, and other locations where the elderly frequently convene (569). Still, lack of outreach services beyond these locations was identified as a barrier to the use of CHCs' services by elderly people.

Role in Allocating Services and Funding

Some CHCs that provide case management under contract with State long-term care programs—e. g., AltaMed, described in box 8-E—also determine clients' eligibility for services paid for by the programs. In general, however, CHCs do not control people's access to services other than the CHCs' own services.

Summary

As agencies that might be designated to constitute a national system to link people with dementia to services, CHCs offer several advantages:

- . CHCs exist at more than 2,000 sites across the country.

- CHCs reach low-income people and members of minority groups who often are not reached by other health care delivery systems.
- CHCs are located in many areas where other service agencies are absent, including rural and other medically underserved areas.
- CHCs usually provide medically focused case management for their clients.
- Many CHCs employ a full complement of health care professionals, including physicians, physicians' assistants, nurses, social workers, therapists, dentists, health educators, and others who might be able to provide multidisciplinary assessments and care plans for people with dementia.

Despite these advantages, most CHCs are not currently well equipped to link people with dementia to services for several reasons. CHCs' main purpose is to provide primary health care services. The type of case management performed by CHCs is typically medical in orientation, and most CHCs do not provide or routinely link people to the full range of long-term care, social, legal, financial, and other services that may be needed for people with dementia.

Many CHCs serve mostly mothers and children. Such CHCs are unlikely to have staff with training, expertise, or interest in working with people with dementia. Over the years, CHCs have tended to underserve elderly people. Moreover, even when CHCs do see elderly people, they often do not use screening criteria that can identify dementia in older people. In addition, many CHCs do not have relationships with the types of community agencies that are most likely to serve people with dementia.

As noted earlier, some CHCs have programs specifically for people with dementia, and some provide public education, information and referrals, outreach, and case management for elderly and disabled people, including people with dementia. The existence of these programs in some CHCs suggests that they could also be implemented in other CHCs. Implementing them without a large infusion of funds for new programs, however, would require a significant redirection of many CHCs' efforts, which would adversely affect other CHC programs and client populations.

Lastly, a national linking system composed of CHCs could be directly funded by the Federal Government through the approximately 600 CHCs

Box 8-E—The Linking Programs of AltaMed Health Services, a Community Health Center in Los Angeles, California

AltaMed Health Services Corp. operates a community health center (CHC) with several locations in an economically depressed, medically underserved area of East Los Angeles that has a predominantly Hispanic population. AltaMed began developing programs for elderly people in 1981, and subsequently became the first CHC in California to be licensed to provide adult day health care and the first Hispanic program to receive such licensure.

In addition to providing adult day health care, AltaMed currently operates two programs that link people to services:

- . the Linkages program, and
- . the Multi-Purpose Senior Services Program (MSSP).

The Linkages Program is a program operated by AltaMed under contract with the State of California. The Linkages Program provides assistance in locating and arranging services for elderly and disabled people who are at risk of nursing home placement, but not necessarily impaired enough to be eligible for nursing home care paid for by Medi-Cal (California's Medicaid program). Some Linkages clients only need telephone referrals or help with arranging services on a one-time basis. Others need and receive short-or long-term case management. As of 1987, AltaMed's Linkages Program was serving about 200 clients, 70 percent of whom were over age 60. The Linkages Program does serve individuals with dementia, but OTA does not know how many.

MSSP is a Medicaid 2176 waiver program that AltaMed has operated under contract to the State of California since 1986. The program provides comprehensive, ongoing case management for elderly people who are eligible for nursing home care according to Me&Cal requirements but choose to remain at home. MSSP's clients receive an initial in-home assessment, referrals and assistance in arranging and monitoring needed services, monthly followup either by phone or in person, and reassessment at 6-month intervals by a nurse/social worker team. MSSP also pays for in-home and other services for clients if other funding for the services is not available. AltaMed's MSSP program serves individuals with dementia, although OTA does not know how many.

SOURCE: S. Ray, N. List, R. Clinkscale, et al., La Jolla Management Corp., Columbia, MD, 'Assessment of the Current Utilization of C/MHCs by the Elderly and an Assessment of the Capability of C/MHCs To Develop Comprehensive Community-Based Primary Care Health Service Systems For the Elderly,' prepared for the Bureau of Health Care Delivery and Assistance, Health Resources and Services Administration, Public Health Service, U.S. Department of Health and Human Services, Rockville, MD, July 1987.

that currently receive Section 330 grant funds. To include in the linking system the other 500 to 750 CHCs that do not receive Section 330 grants would require the development of new criteria for identifying CHCs that would encompass these CHCs.

ALZHEIMER'S ASSOCIATION CHAPTERS

The Alzheimer's Association, also known as the Alzheimer's Disease and Related Disorders Association (ADRDA), is a national, privately funded, voluntary association of families, service providers, scientists, health care professionals, and other concerned individuals, founded in 1980 to confront the problems of Alzheimer's disease and related disorders. The association has five primary goals:

- . to support research into the cause, treatment, cure, and prevention of Alzheimer's disease and related disorders;

- . to stimulate awareness of Alzheimer's disease among the public and professionals;
- . to encourage the formation of Alzheimer's Association chapters to create a nationwide support network for families of people with Alzheimer's disease;
- . to advocate for Federal, State, and local public policies and legislation to assist Alzheimer's patients and their families; and
- . to provide community programs and services for people with Alzheimer's disease and their families (16).

As of May 1990, the Alzheimer's Association had 210 chapters in 49 States (every State except Alaska) (461).

OTA has included Alzheimer's Associations chapters in its analysis of agencies that might constitute a national system to link people with dementia to services because the Alzheimer's Association specializes in educating the public about dementia and

Box 8-F—The Wisconsin Alzheimer's Information and Training Center

In 1985, the Wisconsin legislature passed a bill to establish the Wisconsin Alzheimer's Information and Training Center. Following competitive bidding, the southeastern Wisconsin Chapter of the Alzheimer's Association was chosen to develop and operate the center.

The goals of center areas follows:

- . to disseminate information about Alzheimer's disease and related disorders through printed and audiovisual materials, training, technical assistance, and a telephone hot line;
- . to increase service providers' knowledge about Alzheimer's disease and related disorders;
- . to identify the needs of Wisconsin's Alzheimer's patients and their families; and
- to link families and other caregivers of Alzheimer's patients to appropriate services.

During 1984 and 1985, a statewide needs assessment was conducted to gather information about services in Wisconsin. This and other available information was computerized and has since been updated regularly for use in providing information and referrals and in advocating for new services.

The Wisconsin Alzheimer's Information and Training Center provides information free of charge to anyone who calls, including families, health care and social service professionals, community agencies, and voluntary organizations. Most requests for information are made through the center's toll-free 800 telephone line. Staff members and trained volunteers, most of whom are Alzheimer's family members, respond to the calls. Callers are given information about State-funded respite care and other community services and up-to-date information on Alzheimer's disease, caregiving, and legal issues. Some family caregivers require telephone counseling, and their calls often last between 30 to 45 minutes.

Out-of-State callers who are seeking services for a relative with Alzheimer's disease living in Wisconsin are generally referred to local service providers. Wisconsin residents seeking services for a relative with Alzheimer's living in another State are referred to an Alzheimer's Association chapter in that State.

The center maintains a lending library of Alzheimer's books, videos, slides, pamphlets, and brochures, and publishes original pamphlets, brochures, slides, and audio/video cassettes with Alzheimer's information. The center provides caregiver training and offers physicians and other health care professionals a program to familiarize them with available specialized Alzheimer's medical services and care facilities. The center also offers technical assistance to county agencies, service providers, and other organizations that are providing or are interested in developing services, such as support groups, adult day care, in-home respite care, specialized residential care, and assessment units for Alzheimer's patients. In 1989, the center sponsored its third annual statewide conference on Alzheimer's disease that involved family members, professionals, paraprofessionals, and volunteers. It has conducted over 100 workshops throughout the State on various facets of Alzheimer's disease.

The day-to-day activities of the center are managed by its paid staff (including a social worker, a nurse, and 2 recreation therapists) and about 12 volunteers. The center has an advisory council of 18 people who are family caregivers or representatives of community organizations such as the American Association of Retired Persons, county agencies on aging, nursing homes, adult day centers, and home care agencies. Other Wisconsin Alzheimer's Association chapters participate in an advisory capacity.

SOURCE: B. Keyes, "Wisconsin Alzheimer's Information and Training Center," program description, Milwaukee, WI, December 1987.

in providing information and referrals for people with dementia and their families. The association's national office develops and distributes many different types of public education programs and materials about dementia. The national office also has a toll-free 800 telephone line to give callers information about Alzheimer's disease and to refer them to local chapters for help. Alzheimer's Association chapters distribute the public education materials

developed by the national office, and many chapters also develop and distribute their own public education materials. In addition, chapters sponsor meetings, conferences, and other events to educate the public about dementia. Lastly, Alzheimer's Association chapters are required by the national association to have a newsletter and a telephone information and referral service, usually referred to as a "helpline" (461).

Overview of the Agencies

The Alzheimer's Association's national headquarters is in Chicago, Illinois. In addition to developing and distributing public education programs and materials and operating the toll-free 800 telephone line, the national office raises and allocates funds for biomedical research on Alzheimer's disease and, to a lesser extent, for research on the care of people with Alzheimer's disease and related disorders.¹³ The national office coordinates the activities of the association's national board and the chapters, provides technical consultation to service providers and other organizations, and coordinates the association's advocacy efforts at the Federal level. In 1987, the association's national office had a paid staff of 100 people and a budget of \$11 million funded with contributions from individuals, foundations, and corporations (313, 325).

The Alzheimer's Association's 200 chapters are diverse, ranging from large chapters run by both paid staff and volunteers to small chapters run entirely by volunteers. Each chapter is a separate corporation and generates its own funds through private contributions. The amount and kinds of services a chapter can afford to offer depend largely on the funds it can generate locally (484). The association's national office estimated that in 1988 the annual budgets of individual chapters ranged from \$10,000 to \$500,000, depending on chapter size and fundraising ability (484).

Most chapters use only private funds to finance their programs, but some chapters receive public funds for various programs. One example is the Southeastern Wisconsin Chapter, which was selected by the State of Wisconsin in 1985 to operate the Wisconsin Alzheimer's Information and Training Center. The center's public education, information and referral, and other programs are described in box 8-F. Funds for the center are provided by the State. The operating cost is \$150,000 a year (410).

In addition to the chapters' public education and information and referral programs, which are discussed at greater length later in this section, the chapters provide many other types of programs and services. Many chapters provide training about

dementia and caregiving techniques for family caregivers, service providers, and others. In addition, all Alzheimer's Association chapters offer caregiver support groups. As of 1988, chapters throughout the United States were sponsoring a total of 1,500 caregiver support groups, all of which were free and open to the public (313). These groups provide their attendees with peer support, informal counseling, and information about local service providers.¹⁴ Some chapters also provide short-term counseling for some family caregivers.

As of 1988, about 70 Alzheimer's Association chapters were providing some form of respite services for Alzheimer's patients and their caregivers (313, 325). Some chapters use trained volunteers to provide respite care; some use paid respite providers; and some use both. When paid respite providers are used, chapters typically charge a fee based on the family's ability to pay and subsidize the remaining cost of the services from chapter resources. A few chapters have a training program for respite workers and maintain a list of trained respite workers to whom they can refer families and others (183).

Advocacy on behalf of Alzheimer's victims and their families is one of the key functions of the Alzheimer's Association and its chapters. At the national level, the Alzheimer's Association testifies at congressional hearings and advocates for public policies to meet the unique needs of people with dementia and their caregivers. The association also joins coalitions of national groups to support legislation and regulatory measures of importance to people with dementia and their families. Alzheimer's Association chapters conduct public awareness campaigns to draw public and legislative attention to the problems of Alzheimer's disease. Many of the chapters advocate with State and local government officials and legislators for programs to benefit people with dementia and their families. The association develops materials, conducts workshops, and sponsors public policy forums to help chapter members become more effective advocates. As a result of all these activities, it is probably correct to say that over the past 10 years, the Alzheimer's Association has been the driving force responsible

¹³In addition to its sponsorship of research, the Alzheimer's Association has sponsored several demonstration projects and is currently co-sponsoring with the Robert Wood Johnson Foundation a demonstration project in which 19 adult day centers have received funding to create comprehensive systems of care for people with dementia (712). The project is described in the last section of this chapter.

¹⁴The role of caregiver support groups in providing their attendees with information about the quality of available services is discussed in ch. 5.



Photo credit: Alzheimer's Association

The Alzheimer's Association has been an effective advocate for increased Federal funding for biomedical research and improved services for people with dementia.

for a 10-fold increase in Federal spending for biomedical research on Alzheimer's disease in that period and for many of the other changes in Federal, State, and local laws and regulations that affect the availability of appropriate services for people with dementia.

The Alzheimer's Association has grown rapidly since its establishment in 1980. New chapters are constantly being formed, and the functions of the national office and the chapters are expanding. As this growth has occurred, the number of paid staff in the national office and the number of chapters that have paid staff has increased. Although some chapters still operate without any paid staff, it is clear that the association is becoming less an organization operated by volunteers and more an organization directed by volunteers but operated on a day-to-day basis by paid staff and volunteers.

To learn about the capacity of Alzheimer's Association chapters to function as the basis of a national system to link people with dementia and their caregivers to services, OTA contracted for a survey of Alzheimer's Association chapters (484).¹⁵ A questionnaire was developed and mailed to 10

chapters. The chapters were selected to reflect diversity in size, in services provided, in composition of staff (i.e., volunteer or paid), in type of area served (i.e., urban, suburban, or rural), and in other characteristics. The 10 chapters surveyed by OTA's contractor were:

- . the Palm Beach County Chapter,
- . the Detroit Area Chapter,
- . the New York City Chapter,
- . the Honolulu Chapter,
- . the Albuquerque Chapter,
- the Central Virginia-Lynchburg Chapter,
- . the Eastern Massachusetts Chapter,
- . the Western North Carolina Chapter,
- . the North Central Montana Chapter, and
- . the Greater Kansas City Chapter (484).

OTA's contractor interviewed each chapter's president or executive director by telephone to obtain answers to the questions. Some of the survey findings are presented in the following discussion.

For several reasons, caution must be used in generalizing from the results of the survey. The number of chapters surveyed was small, and the individual chapters surveyed were not randomly selected. Moreover, the survey was conducted in early 1988, and, as noted above, many Alzheimer's Association chapters have expanded their programs and services since then (461). Nevertheless, the main conclusion of the survey—that Alzheimer's Association chapters vary greatly in the extent and sophistication of their programs to link people with dementia to services—is undoubtedly still true in 1990.

Who Is Served

Family members are the primary users of Alzheimer's Association chapters' services, but friends and neighbors of people with Alzheimer's disease, health care and social service professionals, other service providers, staff of State and local government agencies, researchers, journalists, students, and some people who have Alzheimer's disease also contact the chapters for various reasons (186,484). Family members are the primary users of the chapters' telephone helplines and support groups and the sole users of chapters' short-term counseling and respite services.

¹⁵A complete report on the survey of chapters conducted for OTA is available from the National Technical Information Service in Springfield, VA (see app. A).

Alzheimer's Association chapters respond to requests for information and assistance from anyone who calls, but particularly from family members of people with dementia. Certain types of family caregivers—notably ethnic minority caregivers, poor caregivers, and caregivers who live in remote areas—have been less likely than other types of family caregivers to seek help from Alzheimer's Association chapters. The 10 Alzheimer's Association chapters surveyed for OTA in 1988 reported that few ethnic minority individuals were participating in their programs (484). Nine of the 10 chapters reported that they were not reaching particular groups, including blacks, Hispanics, Native Americans, and Asian Americans.

Currently, the Alzheimer's Association's national office and some chapters are expanding their efforts to reach ethnic minority caregivers of people with dementia (183,461). The national office has made available to chapters training and support materials to encourage minority participation and set apart a half-day of the association's annual meeting, held in October 1989, to discuss minority issues (461). Some chapters have established support groups specifically intended for ethnic minority caregivers (461,484).

Some of the 10 chapters surveyed for OTA in 1988 reported that they were not reaching low-income dementia patients and their caregivers or patients and caregivers who live in remote areas (484). Three of the 10 chapters reported problems in reaching low-income people. Interestingly, three chapters said they were not reaching people with high incomes. Five of the 10 chapters reported problems in reaching people with dementia and their caregivers who live in rural areas; one chapter indicated that it has a toll-free telephone line to be more accessible to these caregivers.

Only one of the 10 surveyed chapters specified a problem in reaching people with dementia who live alone and have no family members or other informal caregiver to help them. Anecdotal evidence indicates, however, that Alzheimer's Association chapters generally focus on serving family caregivers of people with dementia and may not expect to serve many individuals with dementia who live alone and have no caregiver (183,461,485). The available data on who is served by chapters indicate that chapters serve very few such individuals (186,484).

Linking Functions

Information and Referrals



As noted earlier, each Alzheimer's Association chapter is required by the national association to have a telephone "helpline" to provide callers with information about Alzheimer's disease and to refer them to local service providers (461). The number of calls handled by chapter helplines and the sophistication of their information and referral procedures vary greatly from one chapter to another. Larger chapters with paid staff generally handle larger numbers of calls. The Cleveland Chapter's helpline (see box 8-G) received more than 3,200 calls in the 4-month period from April through July 1988 (186). Over the past 3 years, the Detroit Area Chapter's helpline received 2,000 to 3,000 calls a year (484). In contrast, some small chapters offering strictly "volunteers serving neighbors" programs report as few as 3 to 4 calls a week (484).

Most calls received by chapter helplines are from family caregivers. As noted in box 8-G, 80 percent of the documented calls received by the Cleveland Chapter's helpline were from family caregivers (186). In 1988, the New York City Chapter reported that 70 percent of the 35 to 50 calls received daily by its helpline were from family caregivers living in the area; the other 30 percent were from out-of-State families seeking help for a relative living locally, fiends, neighbors, sitters, individual service providers, agencies, clergy, students, nursing homes, lawyers, a few physicians, and people who feared that they might have Alzheimer's disease (484).

All 10 of the Alzheimer's Association chapters surveyed for OTA in 1988 reported using trained volunteers to respond to helpline inquiries (484). Many of these helpline volunteers were family caregivers of people with Alzheimer's disease. Seven of the 10 chapters surveyed for OTA in 1988 had a paid professional on staff, usually a social worker or nurse, who trained and supervised the helpline volunteers, served as a helpline consultant, and answered some helpline calls.

People call chapter helplines for various reasons and receive many different kinds of responses. Box 8-G discusses the reasons given by callers to the Cleveland Chapter's helpline. Table 8-1 lists the needs expressed by people who called the Detroit

Box 8-G-The Cleveland Alzheimer's Association Chapter's Helpline

The Cleveland Chapter of the Alzheimer's Association has a telephone helpline operated by both volunteers and paid staff. In a typical month, the helpline receives more than 800 calls. If a caller requests copies of printed materials or referrals to services, a form is completed to document the call. In the 4-month period from April through July 1988, the helpline received 3,251 calls, 446 of which (about 1 out of 7) resulted in the completion of a helpline form.

Sixty percent of the 446 documented helpline calls received in that period were either requests for general information about Alzheimer's disease or requests to be placed on the chapter's mailing list; 25 percent were requests for specific information from the chapter's bibliography or about particular services. Eighty percent of the 446 calls were from family members of a person with dementia, and 13 percent were from professionals requesting information for their clients. Ten calls during the 4 months were from students working on class projects; 4 were from people interested in volunteer opportunities; and 6 were from individuals who were worried about their own memory loss. Twelve calls were from local people concerned about a person with Alzheimer's disease who lived outside of the Cleveland area and 7 calls were from people out-of-town who were concerned about someone living locally.

From April 1988 through July 1988, the helpline referred 40 callers to specific service providers. As part of a study conducted for OTA in 1988 (see app. A), 26 of these 40 callers were subsequently interviewed. All 26 were caregivers of a person with dementia. When asked why they had called the helpline, 20 of the 26 caregivers said they had called to get the names of people or organizations offering services for people with dementia; 13 said they had wanted help deciding what types of services would be best for the person; 8 said they had wanted to know what kinds of tasks an agency or professional caregiver could be expected to do; 8 said they had called to find out the usual cost of hiring someone to provide in-home services; 6 said they had sought information about what types of services are paid for by Medicare or Medicaid; and 4 said they had called to discuss a problem the patient or the caregiver had with a service provider.

Some of the 26 caregivers said they had called for general information in order to understand a demented person's behavior and to figure out what to expect and how to respond. A woman concerned about her sister's forgetfulness explained, "I wanted to know what could be done if she had Alzheimer's disease." A daughter who stayed with her 80-year old mother on weekends noted "I wanted to find out if mom could stay alone; I didn't know when I called that it was dementia or what dementia was. A few caregivers said they had called the helpline just because they needed someone to talk to. As one spouse put it, "I quit work and now that I'm home all day, I'm always thinking about our problem. I get lonely sometimes. Brothers and sisters are out of the country, and our son doesn't want to be bothered. You know-I had to talk about it."

When asked why they had called the helpline instead of another source of information, several of the 26 caregivers indicated that the Alzheimer's Association seemed the most appropriate place to call considering what they were dealing with. The wife of a 76-year-old man with dementia noted, "You know, people talk-you hear about things. Sounded like my husband so I thought I could talk to someone there." Many of the caregivers reported reading an article or hearing something on television that gave them the idea to call the helpline. A nurse helping a friend obtain services for her spouse observed that "since they are specific in dealing with Alzheimer's disease they would have the most information and resources. Three caregivers were referred to the helpline by a professional. Nine caregivers had contacted other community agencies before calling the helpline.

When asked whether they had found any aspect of the helpline particularly helpful, some of the 26 caregivers noted the caring attitude and attempts to facilitate service use on the part of the helpline's staff. Individual professionals were described as "very helpful," "very nice," and "gentle." Some caregivers particularly appreciated the thoroughness, promptness, or evidence of extra effort by the staff. One woman who called the helpline in desperation after calls to other agencies and hospitals explained, "I'm very pleased with the help I received from the Alzheimer's Association and the social worker. The social worker agreed to come to Dad's home to talk about Mother's problem.

SOURCE: S.K. Eckert, and K. Smyth, "A Case Study of Methods of Beating and Arranging Health and Long-Term Care for Persons With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington DC, May 1988.

Table 8-1—Expressed Needs of People Who Called the Detroit Alzheimer's Association Chapter's Helpline and Responses Given by the Helpline, 1987

What did Helpline callers say they needed?	Percent of callers who expressed this need
General information	36 %
Referral for adult day care or respite care.	23
Referral for medical care	11
Referral for nursing home	9
Help with patient management	5
Tributes.	2
Referral for legal information or services.	2
Referral to adult foster care	1
Autopsy	0.6
Financial information	0.4
Request for a speaker	0.3
Helpline responses	Percent of callers who received this response
Sent information	31 %
Referred to in-home respite	13
Referred to medical care	11
Referred to a support group	11
Referred to adult day care	9
Referred to nursing home	8
Telephone counseling	5
Onsite counseling	4
Arranged a speaker.	0.3

SOURCE: N.L. Mace, "The Role of ADRDA Chapters in Providing Information and Referral Services for Persons With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1988.

Alzheimer's Association chapter's helpline in 1987 and the responses given by the helpline. These figures are typical of the estimates given by the other chapters surveyed for OTA in 1988 (484).

Despite differences in the helplines operated by different Alzheimer's Association chapters, helplines have in common that they are informal and ask few questions before responding to inquiries; thus they pose minimal barriers to family caregivers in obtaining information and referrals (484). Responses to helpline inquiries are immediate and personal. The 10 chapters surveyed for OTA in 1988 consistently reported using an empathetic approach to callers: "We listen, and the caregivers tell us what they need" (484). Because many of the helpline volunteers have been caregivers themselves, and because the volunteers and paid staff members spend so much time talking to callers, families feel understood and supported. In the view of OTA's contractor, this listening/supporting function may be as valuable to families as the information and referrals they receive.

The information about available services that Alzheimer's Association chapters use to provide information and referrals comes from various sources. Some chapters, including the Greater Washington, DC Chapter, have compiled directories of community services that may be needed for Alzheimer's patients and their caregivers (267). For the most part, however, the methods used by chapters to obtain information about community services are less thorough. Some chapters use directories produced by other agencies. Many obtain information about community services through word-of-mouth reports from families or professionals on the chapters' board or through informal networking with other community agencies (484). Some chapters refer callers to other agencies for information about services (e.g., AAAs and family service agencies).

Two of the 10 chapters surveyed for OTA in 1988 were using computers to maintain information about community resources (484). The other eight chapters were using files, but three of them had plans to computerize their resource lists. One of the chapters was not using a computer to maintain its list of community resources because the chapter's volunteers were not comfortable with using a computer (484).

As noted in boxes 8-F and 8-G, at least some Alzheimer's Association chapters provide information and referrals for long-distance caregivers. The Cleveland Chapter, for example, serves both local families requesting information for a relative with dementia living outside the chapter's service area and families calling from out of town about a relative with dementia living in the Cleveland area (186).

Clearly, the capacity of Alzheimer's Association chapters to meet the information and referral needs of people with dementia and their families varies from one chapter to another. Some chapters have well-developed information and referral procedures and systematic methods for obtaining information about available services. Other chapters are still in the process of developing their information and referral helplines and do not have systematic methods of collecting information about available services (484). Anecdotal evidence and the findings of the survey conducted for OTA in 1988 indicate that most chapters do not have formal followup procedures to determine whether helpline callers for whom they provide referrals are successfully linked to the services they need, although some chapters do

Box 8-H—The Alzheimer's Family Consultants Program of the Palm Beach County, Florida Alzheimer's Association Chapter

The Palm Beach County Chapter of the Alzheimer's Association offers care management for people with dementia through its Alzheimer's Family Consultants Program. From October 1988 to June 1989, the program provided care management for 361 people with dementia and 392 caregivers.

The Alzheimer's Family Consultants program provides care management free of charge, according to need, regardless of age or income. Most of the program's clients are Alzheimer's patients who live with a caregiver, but the program also serves patients who live alone. The local sheriff, police department, and community businesses refer people with dementia who live alone to the program.

The program has three full-time paid staff members: two registered nurses who serve as Alzheimer's family consultants, and a nurse supervisor. The program has received grants from two local government agencies: \$11,000 from the City of Boca Raton in 1987, and \$48,000 from the Palm Beach County Commissioners in 1988.

When a person with dementia enters the program, an Alzheimer's family consultant makes sure the person has had a thorough diagnostic evaluation, meets with the patient and family to discuss various care options, and then arranges services for them. The family consultant discusses with the family the patient's potential eligibility for Medicare, Medicaid and other sources of funding for services and makes certain the family gets an attorney's advice about legal and financial issues related to the care of the person with dementia.

The Alzheimer's family consultants frequently arrange for clients to attend a specialized Alzheimer's adult day program sponsored by the Palm Beach County Chapter. They may also arrange in-home respite care. If the family wishes, the family consultant will schedule the respite visits and negotiate prices with the respite care agency.

The Alzheimer's family consultants follow-up regularly with phone calls or home visits to be sure their clients are satisfied with the services they are receiving. The family consultants work with their clients throughout the course of the dementia or until the person with dementia enters a nursing home.

The Alzheimer's family consultants offer caregiving training to families and refer families to local support groups. They also educate other community organizations about Alzheimer's disease and provide technical assistance to service providers who are developing programs for people with dementia. In 1989, Alzheimer's family consultants provided training for Palm Beach police officers about how to recognize and manage people with dementia and participated in a program sponsored by the Palm Beach County Chapter to make available locator identification bracelets to help the sheriff's office identify lost and confused people and return them to their homes.

As the Family Consultants program has become better known in the county, it has received an increasing number of requests from the community for help in crises involving people with dementia. The requests include calls from neighbors of people with dementia who believe the people are at immediate risk and calls from the police and other local officials who have identified a person with dementia who has no one to help him or her. Recently, the Family Consultants program has been asked to provide expert testimony in several guardianship cases involving individuals with dementia.

SOURCE: M.M. Barnes, executive director, Alzheimer's Association Palm Beach Chapter, Palm Beach, FL, personal communication, Sept. 8, 1989.

have such procedures. Several years ago, the association's national office put together a Helpline manual to assist chapters in developing their helplines.

Case Management



Few Alzheimer's Association chapters report that they provide case management, but many chapters perform certain case management functions, including helping caregivers define the kind of services they need and contacting service providers for some

caregivers who are unable to do so themselves (461,484). OTA is aware of several Alzheimer's Association chapters that provide all five functions that OTA has defined as core case management functions, although the chapters may not call what **they** provide "case management." One example is the Palm Beach County Chapter, which provides what it calls 'care management' through its Family Consultants Program (see box 8-H). It should be noted that the Palm Beach County Chapter's care management program serves people with dementia who live alone and have no informal caregiver to help them (54).

There is some discussion, at present, among Alzheimer's Association members about whether providing case management is a priority function for chapters. The discussion often flounders, however, on different definitions of what case management is. Some association members believe that providing case management (as they define it) is an essential part of the chapters' role in helping people with dementia and their families. Other members believe that chapters should concentrate their efforts on public education, information and referral, and other functions, such as training caregivers and providing respite services. Anecdotal evidence suggests, in the meantime, that the number of chapters that provide case management is increasing.

Public Education

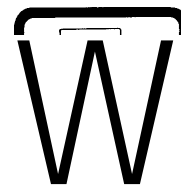


As noted earlier, the Alzheimer's Association has an extensive public education program. The association's national office sponsors public service announcements and publishes and distributes books, articles, and brochures about all aspects of Alzheimer's disease and the care of people with dementia. These publications are available from the national office and from the chapters. The national office publishes a newsletter that is received by a half million people nationwide (473) and develops and circulates audiovisual materials to educate the public about Alzheimer's disease. Through its toll-free 800 telephone line, the national office answers questions from anyone about any aspect of the disease.

Alzheimer's Association chapters also develop and distribute many kinds of publications and audiovisual materials about Alzheimer's disease and the care of people with dementia. Some chapters have lending libraries with printed and audiovisual materials on these topics (473,484). Some chapters sponsor programs and public service announcements on radio and television. The chapters also participate in health fairs, community meetings, and conferences that provide opportunities to educate the public about Alzheimer's disease. As mentioned earlier, all chapters are required by the association to publish a newsletter, and the chapter newsletters are a source of information about Alzheimer's disease and the care of people with dementia for all who read them (461).

The national office supports the chapters' public education efforts in various ways, including the provision of up-to-date information about Alzheimer's disease and related issues. One objective of the national office is to encourage consistency among chapters in the information they provide for the public, particularly information about new scientific findings and potential treatments for Alzheimer's disease (461).

Outreach



Some Alzheimer's Association chapters have developed certain procedures to identify people with dementia who need assistance but are unlikely to contact a chapter or to seek help on their own. These procedures generally involve training individuals, such as police and bank employees, to identify people with dementia who may need assistance and to notify the chapter or someone else who can help. Alzheimer's Association chapters also approach physicians who may be treating people with dementia and encourage them to refer these people to the chapter for help. The 10 Alzheimer's Association chapters surveyed for OTA in 1988 said they rely on their public education programs and materials, including newsletters, other publications, and public service advertising, to reach people who may need their services. Of the 10 surveyed chapters, 6 reported that other agencies referred clients to them; 4 said they were listed in the yellow pages; and 4 said they were listed in handbooks published by other agencies. For the most part, the chapters said that they were successful in reaching white, middle-class families (484).

Role in Allocating Services and Funding

Alzheimer's Association chapters do not control access to or funding for services other than those they provide.

Summary

As agencies that might be designated to constitute a national system to link people with dementia to services, Alzheimer's Association chapters have many advantages:

- The Alzheimer's Association and its chapters provide many public education programs and materials about Alzheimer's disease, dementia and the care of people with dementia.

- Alzheimer's Association chapters provide information and referrals for people with dementia and their caregivers.
- The public education, information and referral, and other programs and services provided by the Alzheimer's Association and its chapters are intended specifically to meet the needs of people with dementia and their caregivers.
- Alzheimer's Association chapters respond to inquiries from families and other informal caregivers in a flexible, personal, and non-bureaucratic way. Because of this and because of their focus on Alzheimer's disease and related disorders, families of people with dementia often experience a sense of being understood and supported.
- Some Alzheimer's Association chapters provide case management.

Despite these advantages, there would be certain drawbacks to designating Alzheimer's Association chapters as the basis of a national system to link people with dementia to services. First, the capacity of individual chapters to meet the information and referral needs of people with dementia and their caregivers varies. Some chapters have systematic procedures for developing and maintaining an accurate list of available services and sufficient paid staff and/or volunteers to operate an information and referral program that would meet the needs of all people with dementia and their caregivers in the chapters' service areas. Other chapters—particularly some of the small, volunteer-run chapters that rely on informal methods of gathering and dispensing information about services—might have difficulty operating a program that would meet those needs.

Another drawback to designating Alzheimer's Association chapters as the basis for a national system to link people with dementia to services is that many chapters do not have outreach procedures to identify people with dementia who live alone and have no informal caregiver to help them or people with dementia whose informal caregiver is unable for any reason to seek services for the person. In addition, although many chapters assist some caregivers in defining their service needs and contacting service providers, most chapters do not provide the comprehensive case management that would be necessary to locate, arrange, and monitor services for individuals with dementia who do not have an informal caregiver or for those that have a caregiver

who is unable to follow through on arranging and monitoring services.

As discussed earlier, low-income and ethnic minority caregivers have been less likely than other caregivers to seek help from Alzheimer's Association chapters. The Alzheimer's Association's national office and some chapters have recently initiated special efforts to reach ethnic minority patients and caregivers. Such efforts require a substantial investment of chapters' limited resources, however, and it is unclear how many chapters will be able to commit the necessary resources.

With additional funds, many of the drawbacks cited above could be overcome. On the other hand, some existing Alzheimer's Association chapters might not want to change their current operating procedures to provide outreach and case management for all people with dementia, even if additional funds were available.

In considering the drawbacks to designating Alzheimer's Association chapters to constitute a national system to link people with dementia to services, it is important to note that some caregivers of individuals with dementia may be unlikely to contact an Alzheimer's Association chapter for assistance because they do not identify the individual's problem as Alzheimer's disease. This is probably especially likely to occur if the individual has serious physical impairments in addition to his or her dementia and has not been diagnosed as having Alzheimer's disease; it might also occur in some instances in which the individual has Parkinson's or Huntington's disease or any dementing disease or condition other than Alzheimer's disease. Additionally, anecdotal evidence indicates that some caregivers perceive a stigma associated with the diagnosis of Alzheimer's disease; they might not want to contact an Alzheimer's Association chapter for assistance. OTA does not know how many caregivers would be unlikely to contact an Alzheimer's Association chapter for any of these reasons. Certainly, as public awareness of Alzheimer's disease increases, any stigma associated with the diagnosis is likely to be reduced, and caregivers are more likely to identify the condition, even in an individual with serious physical impairments.

Finally, it is clear that if Congress designated a category of agencies other than Alzheimer's Association chapters to constitute the national linking

system, the association and its chapters should be involved in planning the system, training the staff of the agencies that constitute the system, and monitoring its performance on an ongoing basis. Several examples of linking programs and systems in which Alzheimer's Association chapters function in this way have been described in this report (see, e.g., the description of Missouri's Alzheimer's helpline in box 7-A in ch. 7). As discussed in chapter 1, it is essential to involve the Alzheimer's Association and its chapters in planning the linking system and monitoring its performance in order to assure that the system is *dementia-friendly* and *dementia-capable*.

FAMILY SURVIVAL PROJECT

The Family Survival Project (FSP) has evolved from a task force of concerned families and community leaders who organized in the San Francisco Bay area in 1976 to assist caregivers of adults with progressive or irreversible brain impairment (199). Its first efforts included documenting the problems of caring for adults with irreversible brain impairment and advocating State and Federal laws to develop services for brain-impaired adults and their caregivers. In 1979, FSP received funding from the State of California to develop a community program of supportive services and training for the caregivers of brain-impaired adults. In 1984, the State of California decided to use FSP as the model for a statewide system. Since then, FSP has functioned in two capacities:

- As California's Statewide Resources Consultant, FSP helped establish a statewide network of 11 regional resource centers for families and caregivers of brain-impaired adults (3 in 1986, 3 in 1987, and 4 in 1988) and currently helps coordinate the network and performs a number of other statewide functions.¹⁶
- As the Bay Area Regional Resource Center, FSP serves as a regional resource center for the families and caregivers of brain-impaired adults in a 6-county area with about 5 million people (405).

FSP's clients include the families and caregivers of individuals with dementia, stroke, traumatic brain injury, brain tumor, and other diseases and conditions that cause brain impairment. The majority of its clients are caregivers of people with Alzheimer's

disease and other diseases that cause dementia (200,235).

OTA has included FSP in its analysis of agencies that might constitute a national system to link people with dementia to services because FSP's functions as California's Statewide Resources Consultant and as the Bay Area Regional Resource Center closely parallel those OTA considers essential to an effective system for linking people with dementia to services. In addition, FSP's program has been duplicated throughout the State of California and might be duplicated elsewhere.

Overview of the Agency

In its capacity as California's Statewide Resources Consultant, FSP currently performs a number of functions:

- It operates a statewide information clearinghouse on topics related to brain impairment and the needs of caregivers.
- It publishes regular information letters and bulletins about regulatory changes, new programs, model programs, and research related to brain disorders and services for brain-impaired adults and their caregivers.
- It provides technical training and consultation to government agencies, service providers, and volunteer organizations interested in developing new programs for brain-impaired adults and their caregivers.
- It coordinates the activities of government agencies, service providers, and community organizations to develop programs and services for brain-impaired adults and their caregivers.
- It offers personnel at California's regional resource centers an initial orientation, inservice training sessions, and annual staff development conferences.
- It encourages public and private participation in the financing and provision of services for brain-impaired adults and their caregivers.
- It conducts social policy research on the extent and consequences of brain impairment for individuals and their families.
- It advocates public policy reforms to encourage the development of services for brain-impaired adults and their caregivers (102).

¹⁶For information about California's statewide network of regional resource centers, see the discussion of California's linking programs in ch. 7.

As the Bay Area Regional Resource Center, FSP performs several additional functions:

- It provides information and referrals to programs and services to meet the needs of family caregivers of brain-impaired adults living in its service area.
- It conducts 3 support groups for caregivers of brain-impaired adults and regularly refers caregivers to over 100 other support groups in the region.
- It evaluates family caregivers' needs for supportive services and provides some supportive services directly (e.g., short-term counseling, family consultation, long-term care planning, and training on caregiving techniques) and other services via providers operating under contract (e.g., respite, transportation, legal and financial consultations, and neuropsychological evaluations) (199).

FSP derives the bulk of its funding from contracts with California's Department of Mental Health (200). For fiscal year 1987-88, FSP received \$1,047,619, including \$440,664 to function as the Statewide Resources Consultant, and \$606,955 to function as the Bay Area Regional Resource Center; each of the 10 other regional resource centers received about \$200,000. For fiscal year 1989, the California legislature appropriated \$5.2 million for both FSP and the 10 other regional resource centers (14). FSP also receives funds from foundation grants, private donations, and fees or donations for services from caregivers.

FSP's staff serves both the Bay Area Regional Resource Center and the Statewide Resources Consultant (199). All of these individuals are knowledgeable about dementia, and most hold bachelor's and/or master's degrees in human services or social work. Some of FSP's staff serve as "resource persons" for the Statewide Resources Consultant. FSP's Research and Information Program's three staff members operate the statewide information clearinghouse and conduct social policy research related to brain impairment (200). FSP's Education and Service Program's three staff people educate the public about brain impairment and offer technical assistance to professionals and organizations interested in developing programs and services for brain-impaired adults and their caregivers (405).

FSP's Bay Area Regional Resource Center staff members include two intake and resource specialists, who respond to initial inquiries and maintain regional resource files; a family consultant, who counsels caregivers about legal concerns, appropriate respite care, and other issues related to caregiving; two social workers, who perform in-depth assessments of individual families' needs, develop plans of care, provide short-term counseling, arrange for respite and other services made available by providers under contract to FSP, and make home visits if and when respite services are initiated; and a regional training specialist, who offers family training on patient management and organizes family support groups (405).

Public advocacy in support of programs and services for brain-impaired adults and their caregivers has been a primary function of FSP since its inception (199). In 1979 and 1983, FSP advocated California legislation that led to the establishment of the Statewide Resources Consultant and the statewide system of regional resource centers. FSP currently organizes conferences and prepares testimony and reports for use in developing services for brain-impaired adults and their caregivers throughout California. FSP also distributes information to over 1,200 "key contacts" that it uses to coordinate advocacy activities and promote cooperation among local, State, and national organizations.

Who Is Served

FSP's primary focus is on serving the families and other caregivers of brain-impaired adults, including individuals with dementia. Anyone who calls, visits, or writes FSP, however, can receive information about brain impairment and related programs and services. In 1987, the Statewide Resources Consultant responded to about 700 initial inquiries from callers in other States or in regions of California without an operating regional resource center (200). The Bay Area Regional Resource Center responded to about 1,500 initial requests for information and referrals from callers in the more immediate area: 1,001 from families and other informal caregivers of brain-impaired adults, 473 from service providers and members of the general public, and 2 from brain-impaired adults.

All the caregivers of brain-impaired adults who want to participate in training events and support groups offered by FSP at the Bay Area Regional

Resource Center are able to do so. In 1987, 1,287 people attended FSP-sponsored training events and 99 caregivers attended an FSP-sponsored support group (405). Caregivers of brain-impaired adults living in a six-county service area are eligible for counseling, respite care, and other supportive services provided by or through the Bay Area Regional Resource Center, but not all caregivers receive such services. In order to receive them, caregivers must first be referred by FSP's intake and resource specialist to the family consultant or social workers for an indepth needs assessment. In 1987, 636 of the 1,001 caregivers who contacted the Bay Area Regional Resource Center for the first time chose to go through the intake screening process, and 251 of them were referred for an indepth needs assessment. Of the 251 referred for assessment, 106 received respite care, 90 received consultation/planning, 39 received legal/financial consultation, 8 received counseling, and 8 received neuropsychological patient evaluations (405).

The majority (62 percent) of the 636 caregivers who chose to go through FSP's intake screening process in 1987 were taking care of an individual with dementia. The remaining caregivers were taking care of individuals with stroke (18 percent), traumatic brain injury (16 percent), a brain tumor (4 percent), and other diseases and conditions that cause brain impairment (4 percent) (200).

For consultation/planning, legal/financial consultations, counseling, and family support groups, FSP generally solicits a "suggested donation" from the brain-impaired adult's family. For respite care, FSP charges a copayment based on the family's income. In 1987, 75 percent of the 106 families who used FSP's respite services contributed to the cost of respite care; the average cost for FSP to provide a family with respite services for a month was \$327, and on average, \$27 of this was paid by the family, and \$300 was paid for with State funds (200).

Linking Functions

Information and Referral



Providing information and referrals to the family caregivers of brain-impaired adults is a principal function of FSP, both as California's Statewide Resources Consultant and as the Bay Area Regional Resource Center. As noted earlier, in its capacity as

the Statewide Resources Consultant, FSP maintains a statewide database of information about brain impairment, related caregiving problems, and services for brain-impaired adults and their caregivers. FSP collects data from regional resource centers on caregivers, patients, services, and costs of services in their regions for use in the statewide database, and it analyzes these data to identify unmet needs (200). FSP also refers callers to regional, State, and national programs and services for brain-impaired adults and their caregivers.

In its capacity as the Bay Area Regional Resource Center, FSP maintains comprehensive lists of formal and informal in-home and community services for brain-impaired adults and their caregivers in each county of its six-county service area. It also maintains a resource library that distributes information packets and lends books, videotapes, and reference materials about brain impairment and related issues. FSP can respond to requests for information made by telephone, in writing, or in person. It has a toll-free telephone number to serve long-distance caregivers seeking information and referrals to services for a brain-impaired relative living in the San Francisco Bay area.

The Bay Area Regional Resource Center's intake and resource specialists maintain regional resource files and take most calls from first-time callers. When someone calls FSP, these staff members listen and then try to assist the caller in determining what he or she needs so they can refer the caller to appropriate resources. Some callers are referred directly to other community agencies that provide specific services. Other callers are referred to FSP's family consultant or to social workers for followup assistance with legal concerns, respite care, and a variety of other issues related to caregiving. FSP's intake and resource specialists can handle as many as 30 calls a day.

First-time callers who do not wish to go through the intake screening process are sent packets of written material detailing FSP's programs and other community programs and services for brain-impaired adults and their caregivers. In 1987, the Bay Area Regional Resource Center sent about 900 packets of written materials to first-time callers. All of the packets include the telephone number of FSP's family consultant in case an inquirer wants more information or assistance (200).

Case Management



Although the organization does not say that it provides case management, FSP provides all five functions that are included in OTA's definition of case management for some of the people it serves as the Bay Area Regional Resource Center. If an intake and resource specialist at FSP believes that a family caregiver or other caller needs assistance beyond information and referral, he or she refers the caller for an in-depth needs assessment (405). The assessment of the caregiver's and brain-impaired adult's needs is conducted either by FSP's family consultant or by one of FSP's social workers, who gathers information through an interview with the caregiver on the telephone, at FSP's office, or at the caregiver's home. The purpose of the assessment is four-fold:

1. to determine what functional problems of the brain-impaired adult necessitate additional services,
2. to determine how the caregiver perceives the caregiving situation,
3. to determine what impact caregiving has had on the caregiver's physical and/or mental health, and
4. to collect demographic data to assist in developing a statewide database on caregivers of brain-impaired adults.

After FSP's family consultant or social worker assesses the caregiver's and brain-impaired adult's needs and starts a case file, he or she recommends services. The recommended services are usually provided either directly by FSP (e.g., short-term counseling, family consultation, long-term care planning, and training on caregiving techniques) or by service providers under contract to FSP (e.g., respite, transportation, legal and financial consultation services, neuropsychological evaluations). Some services are provided by community agencies or service providers with which FSP does not have contracts. In 1987, FSP contracted for 25,510 hours of in-home respite, 1,946 days of day care, 59 hours of legal or financial consultation, 74 hours of neuropsychological patient evaluation, and 16 one-way transports (200).

An FSP staff member, usually the family consultant or social worker who originally assessed the family's needs, maintains ongoing contact with a

family using FSP-recommended services (405). If respite services are involved, the contact person is the social worker who arranges the respite services and monitors the services at monthly intervals. An FSP staff member gives caregivers verbal and written instructions on how to use the services, and FSP's staff coordinates information about the caregiver's situation with the service provider. An FSP staff member telephones to make sure that families have been linked successfully with community agencies or services with which FSP does not have contracts.

At 6-month intervals, families receiving services are reassessed by the family consultant or social worker to determine what, if any, changes in their situation may warrant revising the plan of care and to measure the effectiveness of service interventions on the caregiver's well-being (405). If there is a significant change in the caregiver's or brain-impaired person's situation or if a major crisis occurs, families may be reassessed before the 6-month period has elapsed.

FSP uses various means to try to ensure the quality of services provided by or through the Bay Area Regional Resource Center (405). In addition to holding regular case conferences and performing 6-month reassessments, FSP sends family caregivers a client satisfaction survey. Respite providers—including home care agencies, day care programs, and inpatient respite facilities—are required to submit with their bid package information on licensing, staff qualifications, program services, internal quality assurance procedures, and insurance verification. FSP staff members visit respite providers to meet their staff and observe their programs before signing a contract. Similarly, FSP staff members screen attorneys and neuropsychologists for their expertise and sensitivity to the needs of caregivers of brain-impaired adults before FSP contracts for their services.

Public Education



FSP provides extensive public education to increase public and professional awareness of the needs of brain-impaired people and their caregivers (200). In its capacity as the Statewide Resources Consultant, FSP regularly distributes information letters and bulletins to a general mailing list of more than 15,000 individuals and groups throughout California

and provides information and technical assistance to California's regional resource centers. It also distributes a quarterly newsletter with updated information on services, public policy, research, and available resources for brain-impaired adults and their caregivers. FSP maintains an updated speakers file of professionals and consumer advocates (200).

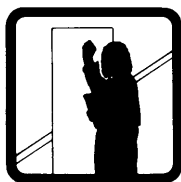
For professionals who deal with brain-impaired adults, including individuals with dementia, FSP offers training programs that cover topics ranging from patient management to legal and financial matters. FSP also publishes a bimonthly "Training Events Calendar," which includes information about training opportunities and upcoming State and national conferences (200).

For government agencies, service providers, and volunteer groups interested in developing new programs and services for brain-impaired adults and their families, FSP often provides technical assistance—e.g., training, consultation, and information. The organizations that FSP has helped include the Brain Damage Coalition of California, as well as local chapters of the Alzheimer's Association and the National Head Injury Foundation (199).

As noted earlier, in its capacity as the Statewide Resources Consultant, FSP conducts social policy research. Among the studies FSP has conducted are a study of publicly funded and third-party programs available to brain-impaired adults and their caregivers, a study of the cost of care of brain-impaired adults, and a study of employed caregivers of brain-impaired adults (200).

FSP also seeks to educate the public about brain impairment and related issues in its capacity as the Bay Area Regional Resource Center (199). The primary way it does this is through community forums and fact sheets, handbooks, and brochures.

Outreach



Although FSP conducts extensive public education programs, it does not have specific outreach procedures to identify brain-impaired adults or caregivers who need assistance but are unlikely to seek help on their own or to be referred to FSP by someone else. Brain-impaired adults who live alone and have no relative or friend to help them and overburdened caregivers who are not connected to a

community agency or individual health or social service provider are unlikely to be reached by FSP.

To assist caregivers in rural areas, some of California's regional resource centers use an "outstationed" family consultant. For some rural families, the outstationed family consultant may be the only source of information and patient management assistance in the community (405).

Role in Allocating Services and Funding

FSP does not control access to, or funding for, services other than those (e.g., respite services) it makes available.

Summary

As an agency that might be designated to serve as the basis of a national system to link people with dementia to services, FSP offers many advantages:

- FSP is part of a well-developed, easily accessible statewide system that provides information and referrals to services for brain-impaired adults and their caregivers in California. As California's Statewide Resources Consultant, FSP maintains a statewide database of information about brain impairment, related caregiving problems, and service options for brain-impaired adults and their caregivers. As the Bay Area Regional Resource Center, it maintains comprehensive lists of services in each of the counties in its service area.
- FSP assesses the needs of some caregivers of brain-impaired adults who call the agency and recommends services that are provided either directly by FSP (e.g., short-term counseling, family consultation, long-term care planning, and caregiver support groups), by service providers under contract to FSP (e.g., legal and financial consultation, transportation, and respite services), or by other providers in the community.
- FSP follows up to ensure that brain-impaired adults and their caregivers receive the recommended services.
- FSP provides education and training for caregivers, professionals, and other individuals who deal with brain-impaired adults.

FSP is currently established only in California. If FSP were to be designated as the basis of a nationwide system to link people with dementia to services, it would have to be replicated throughout

the country. FSP's programs have been imitated throughout California and informally by organizations that are developing services for people with dementia and their caregivers in other States, so replication throughout the country might be accomplished fairly easily.

Although FSP's functions and goals closely parallel those OTA finds essential for an effective system to locate and arrange services for people with dementia, most of the services provided by FSP focus on the needs of the caregivers of brain-impaired adults. In the absence of outreach procedures, people with dementia who live alone and have no caregiver to help them may not be identified by FSP and, as a result, may not be connected to the services they need.

REGIONAL ALZHEIMER'S DIAGNOSTIC AND ASSESSMENT CENTERS

In the past few years, some States have established regional Alzheimer's diagnostic and assessment centers. Although the names and functions of these centers vary from State-to-State, all the centers have certain things in common. They are all associated with medical centers. They all offer individuals suspected of having Alzheimer's disease or a related disorder a diagnosis and a comprehensive assessment by a multidisciplinary team that is knowledgeable about dementia, and they all develop a plan of care for each individual that typically includes recommendations regarding appropriate health care, long-term care, social, and other services. Some regional Alzheimer's diagnostic and assessment centers provide services such as medical treatment, psychiatric treatment, adult day care, caregiver education and training, and caregiver support groups, and some centers assist in locating and arranging services for their clients. Many of the centers also conduct biomedical and clinical research.

OTA has included regional Alzheimer's diagnostic and assessment centers in its analysis of agencies that might constitute a national system to link people with dementia to services for several reasons. One reason is that such centers are currently serving people with dementia. More importantly, however, the centers provide people who are suspected of having Alzheimer's or another dementing illness an accurate diagnosis and a comprehensive multidimensional assessment.

Many diseases that cause dementia cannot be cured at present, but some can be cured or ameliorated if they are diagnosed accurately and treated correctly. Identifying these curable diseases is the first step in caring for people with dementia. Individuals who have a dementing disease that is not curable still may have other treatable conditions that exacerbate their dementia and make them less able to function independently and more difficult for their families and others to manage. A comprehensive evaluation can help to identify these potentially remediable conditions. Lastly, a comprehensive evaluation provides the information that is needed to match an individual with appropriate services.

Overview of the Agencies

At least 10 States have one or more regional Alzheimer's diagnostic and assessment centers (513). The regional Alzheimer's diagnostic and assessment centers in five States—California, Florida, Illinois, New Jersey, and Pennsylvania—are described in this section. Connecticut, Kentucky, Maryland, New York, and Ohio also have regional Alzheimer's diagnostic and assessment centers, and other States may have such centers as well. Detailed information about the centers in California, Florida, Illinois, New Jersey, and Pennsylvania is presented in this section to give a sense of some of the similarities and differences among existing centers. No implication is intended about the relative merits of the centers in these five States v. the centers in other States.

All the centers are quite new. California began developing its centers in 1984 (227), and the centers in other States have been established since then.

The regional Alzheimer's diagnostic and assessment centers in California, Florida, Illinois, New Jersey, and Pennsylvania all use a multidisciplinary team to provide diagnosis, comprehensive assessments, and other services for their clients. The composition of the team varies from center to center, but typically includes a physician (e.g., geriatric internist, neurologist, psychiatrist) and other professionals (e.g., clinical psychologist, social worker, nurse) (55,222,227,306,522).

In all five States, startup funding for the regional diagnostic and assessment centers came from a combination of State funds and public and private grants (55,220,225,364,599). Medicare, Medicaid, and private insurance cover some of the costs of

diagnosis, assessment, and medical or psychiatric treatment provided by some of the centers. In addition, all of the centers derive some of their funding from client fees. All of the States but Pennsylvania have continued to provide funds for their centers' operating costs (14,364).

California's Alzheimer's Disease Diagnostic and Treatment Centers: California has a statewide system of nine centers called "Alzheimer's Disease Diagnostic and Treatment Centers." The nine centers and their locations are:

- Program for Alzheimer's Disease Care and Education, University of California/Langley Porter Psychiatric Institute in San Francisco;
- University of California, Davis-Northern California Alzheimer's Disease Center, Alta Bates-Hernck Hospital in Berkeley;
- Alzheimer's Disease Diagnostic and Treatment Center, University of California/Davis Medical Center in Sacramento;
- Alzheimer's Disease Diagnostic and Treatment Center, University of Southern California/St. Barnabas Senior Center in Los Angeles;
- Southern California Alzheimer's Disease Diagnostic and Treatment Center, University of Southern California/Rancho Los Amigos Medical Center in Downey;
- Alzheimer's Disease Diagnostic and Treatment Center, University of California/San Diego Medical Center in San Diego;
- Alzheimer's Disease Center, Stanford University/Palo Alto Veterans Administration Medical Center in Palo Alto;
- Alzheimer's Disease Diagnostic and Treatment Center, University of California, San Francisco/Fresno Veterans Administration Medical Center in Fresno; and
- Alzheimer's Disease Diagnostic and Treatment Center, University of California, California College of Medicine/Valley Medical Center in Irvine (335).

The functions of the nine California centers are described in box 8-I. In 1984, the California legislature appropriated \$1 million to initiate the statewide system of diagnostic and treatment centers (225). The legislature has provided funding for the centers' operation each year since then. In fiscal year 1988-89, \$2.9 million was appropriated for this purpose (14).

Florida's Memory Disorder Clinics: Florida has four regional Alzheimer's diagnostic and assessment centers called "Memory Disorder Clinics." The clinics were established as part of the Florida Alzheimer's Initiative enacted in 1985 (214). The memory disorder clinics are located at the following sites:

- Suncoast Gerontology Center at the University of South Florida Medical School in Tampa,
- Center on Adult Development and Aging at the University of Miami Medical School in Miami,
- Wein Center at the Mount Sinai Medical Center in Miami, and
- Shands Teaching Hospital at the University of Florida Medical School in Gainesville (222).

The clinics in Tampa and Miami have multilingual staff and print their publications in both English and Spanish (222).

All of Florida's memory disorder clinics offer individuals with memory impairment a diagnosis and assessment by a multidisciplinary team, a plan of care that includes recommendations about needed medical, psychiatric, and other treatment, and referrals to community service providers (222). With the patient's and/or family's permission, the clinics forward a report of the diagnosis and recommended plan of care to the patient's primary care physician and consult with the primary care physician regarding ongoing medical management.

Florida's memory disorder clinics provide extended medical and psychiatric treatment for some of their patients (222). The clinics also provide caregiver support groups and counseling for families about caregiving and legal and financial issues.

In 1985, the Florida legislature appropriated \$500,000 to establish the four Memory Disorder Clinics (220). In fiscal year 1988-89, the legislature provided nearly \$0.9 million to operate the clinics (14). The clinics are eventually supposed to support themselves through an Alzheimer's Disease Trust Fund consisting of monies from gifts, grants, and other sources; as of 1988, however, Florida was having difficulty expanding its system of memory disorder clinics statewide because of funding limitations (302).

Illinois' Regional Alzheimer's Disease Assistance Centers: Illinois has two regional diagnostic and assessment centers called "Regional Alzheimer's Disease Assistance Centers." These centers (see

Box 8-I--California's Alzheimer's Disease Diagnostic and Treatment Centers

In 1984, the California legislature passed a law mandating the establishment of Alzheimer's disease diagnostic and treatment centers. Subsequently, contracts for the development of the centers were awarded to nine university schools of medicine in various parts of the State. Six centers were established in 1985, and three more began operating in 1989.

California's nine Alzheimer's Disease Diagnostic and Treatment Centers are currently required by the State:

1. to provide diagnostic and treatment services for Alzheimer's patients, including those under age 65;
2. to conduct research to discover the cause of, and treatment for, Alzheimer's disease;
3. to provide training, consultation, and education to caregivers of Alzheimer's disease patients;
4. to increase the training of health care professionals about Alzheimer's disease;
5. to develop a uniform data system to compile demographic, medical, and service use information for each patient seen at the centers; and
6. to reevaluate all of their Alzheimer's patients annually.

The nine centers offer their patients a comprehensive evaluation that typically includes a medical, neurological, psychiatric, psychological, and social assessment and may also include a dental, audiological, and podiatric examination and a nutritional evaluation. If there are concerns about whether a patient can be cared for effectively at home, a social worker or nurse practitioner assesses the person's home environment. Following the assessment, members of the center's multidisciplinary team discuss options for the patient care and meet with the patient and/or the patient's family to develop a plan of care. The services the centers offer their patients vary but can include nursing, social work, pharmacy, occupational therapy, and physical therapy. Three centers (in Downey, San Diego, and Berkeley) have adult day care programs.

California's Alzheimer's Disease Diagnostic and Treatment Centers refer their patients to community services, but they generally do not provide case management unless the staff believe that a patient and his or her family require special assistance. An exception is the St. Barnabas Senior Center in Los Angeles, which provides extensive case management for some of its clients.¹

In addition to conducting research on Alzheimer's disease, the staff at California's Alzheimer's Disease Diagnostic and Treatment Centers give lectures and presentations to community groups to educate them about Alzheimer's disease and related issues. In addition, the centers offer caregiver training and support groups for family caregivers and education and training programs for health care and social service professionals and other service providers. The centers offer academic courses and residency internships to physicians, postdoctoral students, and graduate students in social work, nursing, psychology, public health, dentistry, and associated fields.

Some of the Alzheimer's Disease Diagnostic and Treatment Centers have adapted their programs to meet the special needs of individuals with dementia in their service area. For instance, the center in San Diego is developing culturally and linguistically appropriate neuropsychological tests to more effectively serve the large Spanish-speaking population in San Diego County. The center in Sacramento has worked with community agencies and area physicians to develop services that can be accessed locally because of its rural service area.

¹The case management provided by the Alzheimer's Disease Diagnostic and Treatment Center at the St. Barnabas Senior Center in Los Angeles is discussed later in this section.

SOURCES: P.J. Fox, D.A. Lindeman, and A.E. Benjamin, *Status of Alzheimer's Disease Diagnostic and Treatment Centers and Alzheimer's Disease Research Grants in California* (San Francisco, CA: University of California Institute for Health and Aging, January 1986); P.J. Fox, D.A. Lindeman, and A.E. Benjamin, *Evaluation of Alzheimer's Disease Diagnostic and Treatment Centers in California: 1987 Project Year* (San Francisco, CA: University of California Institute for Health and Aging, January, 1988); D.A. Lindeman, administrative director, Northern California Alzheimer's Disease Center, personal communication Nov. 20, 1989.

box 8-J) provide a comprehensive medical evaluation for individuals who are thought to have Alzheimer's disease, develop a plan of care for each individual, and assist the individuals and their caregivers in locating and arranging services in their communities (349). One center at Rush-Presbyterian-St. Luke's Medical Center serves the Chicago

metropolitan area. The other center at Southern Illinois University School of Medicine serves the predominately rural, downstate counties (349).

The Illinois legislature appropriated \$170,000 to cover startup costs for the two centers in 1987 (55). In fiscal year 1989, the legislature appropriated \$1.2 million for the operating costs of the centers (14).

Box 8-J—Illinois' Alzheimer's Disease Assistance Centers

Illinois has two Alzheimer's Disease Assistance Centers associated with medical schools--one in Chicago and one in Springfield--that provide diagnosis and assessment for people with Alzheimer's disease and other dementing illnesses. The centers provide their patients comprehensive evaluations consisting of a general physical and neurological examination, neuropsychological testing, laboratory tests, and psychiatric and psychosocial evaluation. After a consultation with the patient, the patient family, and the evaluation team, the team's social worker assists the family in arranging medical and social services for the patient and helps the family find a support group and/or family counseling services.

Medical followup generally consists of consultation with each patient's primary care physician and the provision of semi-annual reevaluations. As the number of clients served by the southern Illinois University Center has increased, the center has devoted more resources to providing ongoing case management: the center's social worker and other staff members maintain at least monthly contact with patients who require special attention.

In addition to its current services, each of the Alzheimer's Disease Assistance Centers is developing a system of hospitals or medical centers (known as "primary providers" to function as local sites for diagnosis and treatment for Alzheimer's patients. Each center is also developing a system of community health care, mental health, and social service providers to which Alzheimer's patients and their families can be referred. Each center has compiled a county- by-county database of available community services for its region.

SOURCE: M. Barringer, clinical coordinator, Southern Illinois University School of Medicine, Alzheimer's Center, Springfield, IL, personal communications, Feb. 2, 1988, Aug. 19, 1988, and Nov. 5, 1988.

New Jersey's Regional Alzheimer's Diagnostic and Assessment Centers: New Jersey has two regional Alzheimer's diagnostic and assessment centers:

- . Institute for Alzheimer's Disease and Related Disorders, established in 1985 at the Robert Wood Johnson Medical School in Piscataway; and
- Alzheimer's Evaluation Program, established in 1986 at the University of Medicine and Dentistry of New Jersey, School of Osteopathic Medicine, in Stratford.

New Jersey's two Alzheimer's diagnostic and assessment centers work in conjunction with eight State-funded geriatric assessment programs located in medical centers throughout the State to provide a coordinated system of diagnosis and assessment for people suspected of having Alzheimer's disease (272). The centers rely on their patients' primary care physicians to provide ongoing medical treatment (599). Both of the centers provide their patients with referrals to community services, and both centers offer consultation, education, and training for family caregivers and service providers.

One of New Jersey's centers, the Institute for Alzheimer's Disease and Related Disorders in Piscataway, provides long-term case management for its clients, if they need it (272). The center in Piscataway also provides caregiver support groups

and dementia-specific adult day care and serves as a clearinghouse for information about Alzheimer's disease for the general public (599). The center maintains a statewide directory of services for Alzheimer's patients (599).

In 1986, the New Jersey legislature appropriated \$500,000 to fund the two centers' startup costs (599). In fiscal year 1989-90, the New Jersey legislature appropriated \$615,000 for their operating costs (14).

Pennsylvania's Diagnostic and Evaluation Centers for Alzheimer's Disease: Pennsylvania has 11 regional Alzheimer's diagnostic and assessment centers called "Diagnostic and Evaluation Centers for Alzheimer's Disease" that replicate a model program developed by the Harrisburg Institute of Psychiatry under a contract with the Pennsylvania Department of Aging (306). These 11 centers, all established since 1985, augment the services provided by 21 geriatric assessment programs in the State. Pennsylvania's 11 Diagnostic and Evaluation Centers are located at the following sites:

- Sharon General Hospital in Sharon,
- Altoona Hospital in Altoona,
- Medical Center of Beaver County in Beaver,
- Soldiers and Sailors Memorial Hospital in Wellsboro,
- Wilkes-Barre General Hospital, in Wilkes-Barre,

- . Western Pennsylvania Hospital in Pittsburgh,
- . Community Health Services in Quakertown,
- Hamot Medical Center in Erie,
- . Franklin Regional Medical Center in Franklin,
- . Divine Providence Hospital in Williamsport, and
- . Moses Taylor Hospital in Scranton (306).

At any of the 11 centers, a patient suspected of having Alzheimer's disease can get a comprehensive evaluation by a multidisciplinary team that typically consists of a psychiatrist, physician, clinical psychologist, social worker, and registered nurse (306). The team submits its findings and a recommended plan of care to the patient's primary physician who retains responsibility for the patient's ongoing medical care. If a patient has no primary care physician, the team's social worker assists the patient in obtaining one. The team's physician may monitor a patient for a short period of time (weeks to months) to supervise the patient's medications. The team's social worker educates family caregivers about Alzheimer's disease and related issues, trains caregivers to care for the patient, provides family therapy, and refers families to Alzheimer's support groups and health care and social services in the community.

The Pennsylvania legislature appropriated \$500,000 in fiscal year 1985 for an Alzheimer's disease initiative. Included as 1 of the initiative's 10 components was provision for technical assistance by the Harrisburg Institute of Psychiatry for the development of the Diagnostic and Evaluation Centers for Alzheimer's Disease (650). Now that the 11 centers are established, they are expected to operate without State funding (364).

Who Is Served

The regional Alzheimer's diagnostic and assessment centers in California, Florida, Illinois, New Jersey, and Pennsylvania serve anyone suspected of having Alzheimer's disease or a related disorder. Most clients are referred to the regional centers by hospitals, primary care physicians, family members, and community organizations, but some clients are self-referred (222,349,364,522,227). The number of people served by individual centers varies; Pennsylv-

vania's centers evaluate an average of three new patients a month (364), whereas Illinois' centers evaluate an average of 30 patients a month (349). Because dementing disorders are most prevalent among elderly people, the majority of people served by the centers are elderly, but they also serve younger people.

Linking Functions

Information and Referral



All of the regional Alzheimer's diagnostic and assessment centers in California, Florida, Illinois, New Jersey, and Pennsylvania provide their clients with information and referrals to health care, long-term care, social, and other services and have a social worker on their multidisciplinary team to do this (55,222,227,306,599). Some regional centers follow-up with a phone call or postcard to see whether their clients obtained the services to which they were referred (55). California's centers are gathering data now to determine whether their clients use the services to which they are referred (334,460).

All of the Alzheimer's diagnostic and assessment centers in the five States are capable of providing information and referrals for people other than their own clients, but most of the centers do not consider providing information and referrals to the general public as one of their primary functions. The exceptions are Illinois' center in Springfield and New Jersey's center in Piscataway, each of which operates an Alzheimer's-specific information and referral program with a toll-free number for the general public (600,347).¹⁷

The centers in California, Florida, Illinois, New Jersey, and Pennsylvania either have access to or are currently developing comprehensive lists of community resources for Alzheimer's patients and their caregivers. California's centers have a uniform data system to compile information about their clients, including information about the types of services the clients use. This data system is compatible with that of California's regional resource centers for brain-impaired adults (225).¹⁸ New Jersey's Institute for

¹⁷In California and Pennsylvania, agencies other than the regional Alzheimer's diagnostic and assessment centers are the primary sources of Alzheimer-specific information and referrals and operate statewide telephone information and referral programs.

¹⁸California's regional resource centers for brain-impaired adults patterned after the Family Survival Project are discussed in the section on the Family Survival Project in this chapter and in the section on California's linking programs in ch. 7.

Alzheimer's Disease and Related Disorders in Piscataway is developing a similar database (272).

Illinois' Regional Alzheimer's Disease Assistance Centers are in the process of developing a catalog of service providers in each county of their regions (349). In Pennsylvania, the Department of Aging did a survey by county of hospitals, State agencies, and community service providers, and the survey results are being used to develop a database of statewide services to be used by Pennsylvania's Diagnostic and Evaluation Centers for Alzheimer's Disease (616).

Case Management

All of the regional Alzheimer's diagnostic and assessment centers provide their clients with a multidisciplinary assessment and develop a plan of care for them. The extent to which regional centers perform the other core functions of case management (e.g., arrange and coordinate needed services, monitor and evaluate the services delivered, and reassess the client's situation as the need arises) varies greatly among individual centers. Moreover, some regional centers limit their case management activities to arranging medical services.

California's Alzheimer's Disease Diagnostic and Treatment Centers typically do not arrange and coordinate nonmedical services for their clients unless a client or his/her family requires special assistance (334). The center at St. Barnabas Senior Center in Los Angeles is the exception to this rule; it provides many of its clients with extensive case management (225,227). The majority of St. Barnabas Senior Center's clients are isolated, poor, elderly people, many of whom have no family caregiver. St. Barnabas' five social workers select individuals with dementia from the senior center's clientele and screen them for admission to the Alzheimer's Disease Diagnostic and Treatment Center's program. Following a comprehensive assessment, the social workers arrange and coordinate in-home and other community services for the individuals. The Alzheimer's Disease Diagnostic and Treatment Center also operates a home care program that provides shopping, transportation, and companion services for elderly dementia patients. St. Barnabas Senior Center has a money management program, which is available to individuals in the Alzheimer's Disease Diagnostic and Treatment Center's pro-

gram, and provides help in bill paying or acts as power of attorney or conservator for individuals incapable of managing their own funds (227).

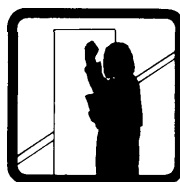
Florida's Memory Disorder Clinics develop a plan of care and refer their clients to services in the community, but they generally do not arrange the services (222). Ongoing contact with a client is limited to a formal medical reassessment every 6 months. The reassessment includes a follow-up family conference, where unmet needs can be identified and referrals to appropriate services can be made.

Illinois' two regional Alzheimer's disease assistance centers use social workers and nurses to help clients and their families arrange and coordinate community services (55). The social workers and nurses follow-up by postcard or phone call to see that clients are satisfied with the services and maintain at least monthly contact with patients who require special attention. Clients receive semiannual or annual medical reevaluations that include a family conference where it can be determined whether the client and family are receiving the services they need.

New Jersey's Institute for Alzheimer's Disease and Related Disorders in Piscataway offers ongoing case management for all of its clients who need it (272). New Jersey's Alzheimer's Evaluation Program in Stratford, which serves a predominately rural southern part of the State where families must travel a long distance to the center, refers its clients to local agencies for case management.

Pennsylvania's Regional Diagnostic and Evaluation Centers for Alzheimer's Disease rely on a patient's primary physician to carry out the recommended plan of medical care. As noted earlier, if a patient has no primary physician, the center's social worker assists the patient in obtaining one. The center's social worker also refers patients and their families who need social services to agencies in the community, but the social workers rely on the community agencies to provide extended case management for patients and their families who need it.

Public Education



To inform the public about the availability of their services, the five States' regional Alzheimer's diagnostic and assessment centers distribute written materials about dementia and the services they offer

for people with Alzheimer's disease and their caregivers. The staff of some of the centers also participate in community meetings and other public forums to educate people about dementia and about potentially helpful services for people with dementia.

Outreach



Most regional Alzheimer's diagnostic and assessment centers do not have outreach procedures to identify people with dementia who need assistance but are unlikely to contact a center on their own or to be referred. At least some of the centers do serve people with dementia who live alone and have no family caregiver, however. In the period from June 1985 to June 1987, 22 percent of the 452 people with dementia who were seen by California's Alzheimer's Disease Diagnostic and Treatment Centers lived alone, and 10 percent had no caregiver (227). Of those seen by the center at St. Barnabas Senior Center, 80 percent lived alone, and more than 20 percent had no caregiver. Individuals who live alone and have no caregiver may be referred to an Alzheimer's diagnostic and assessment center by a physician, another health care or social service professional, a community agency, or another source.

Some regional Alzheimer's diagnostic and assessment centers have mobile assessment units to reach patients who live in remote areas. New Jersey's Alzheimer's Evaluation Program in Stratford operates a mobile assessment van that travels throughout the predominately rural southern part of the State to minimize transportation difficulties for the families of Alzheimer's patients. Likewise, one of the regional Alzheimer's Diagnostic and Evaluation Centers in Pennsylvania has developed a "Project Concern" program in which health care professionals travel in a specially equipped mobile van to rural areas of the State to provide health education and diagnostic screening tests. California's Alzheimer's Disease Diagnostic and Treatment Centers are developing mobile geriatric assessment units to reach patients living in remote areas of the State.

Role in Allocating Services and Funding

The regional Alzheimer's diagnostic and assessment centers in California, Florida, Illinois, New Jersey, and Pennsylvania do not control access to

services or funding for services other than those they provide.

Summary

As agencies that might be designated to constitute a national system to link people with dementia to services, regional Alzheimer's diagnostic and assessment centers offer the following advantages:

- Regional Alzheimer's diagnostic and assessment centers have a multidisciplinary staff that includes professionals who are specifically knowledgeable about dementia.
- Regional Alzheimer's diagnostic and assessment centers provide individuals suspected of having Alzheimer's disease a comprehensive evaluation that may reveal a treatable cause for their dementia or other treatable conditions that are exacerbating their dementia and reducing their functional ability.
- Regional Alzheimer's diagnostic and assessment centers provide comprehensive assessments that may help match individuals with appropriate services.
- Regional Alzheimer's diagnostic and assessment centers provide their clients with referrals to community services, and some centers function as formal sources of Alzheimer-specific information and referrals for the general public.
- Some regional Alzheimer's diagnostic and assessment centers provide short-term case management to arrange and coordinate services for their clients, and a few centers provide extended case management.
- Since regional Alzheimer's diagnostic and assessment centers provide diagnosis, they are the first point at which some people with dementia and their families come in contact with the so-called service system; as such, the centers help these patients and their families identify appropriate services relatively early in the patient's disease. Similarly, since many of the centers reevaluate patients at regular intervals, they can be sites for intermittent referrals and assistance in arranging services for patients and families.
- Regional Alzheimer's diagnostic and assessment centers are already established in some States.

Despite these advantages, designating regional Alzheimer's diagnostic and assessment centers as the basis of a national system for linking people with dementia to services would have several drawbacks. One obvious drawback is that most States do not have such centers. A second drawback is that most of the existing centers do not consider providing information and referrals to the general public as one of their primary functions. Furthermore, although all the centers refer their clients to services, many of them do not follow-up to make sure that the clients obtain the services.

At least some regional Alzheimer's diagnostic and assessment centers have clients who live alone and have no family member or other informal caregiver. On the other hand, most of the existing centers do not have outreach procedures to identify people with dementia who are unable to seek help on their own and have no one to help them. Likewise, most of the existing centers do not provide the extended case management that may be needed to arrange, coordinate, and monitor services for such people. If regional Alzheimer's diagnostic and assessment centers were designated to constitute a national linking system for people with dementia, most of the existing centers would have to expand their information and referral, case management, and outreach programs significantly.

Finally, it should be noted that some families of individuals with dementia do not think of the individual as a "person with dementia;" this is probably especially likely if the individual has physical impairments in addition to his or her dementia. These families are unlikely to contact a regional Alzheimer's diagnostic and assessment center for help. Likewise, people who perceive a stigma associated with a diagnosis of Alzheimer's disease may be unwilling to contact a regional Alzheimer's diagnostic and assessment center.

HOSPITAL-BASED GERIATRIC ASSESSMENT PROGRAMS

Hospital-based geriatric assessment programs are special hospital programs that use a multidisciplinary team to evaluate elderly patients with complicated medical or psychiatric problems and to develop a coordinated plan of care (848). Although hospital-based geriatric assessment programs differ from one another, they are all designed to provide a comprehensive assessment of a patient's physical,

mental, emotional, behavioral, functional, social, and financial status and to identify both problems and strengths of the patient (723). Some hospital-based geriatric assessment programs also provide medical and psychiatric treatment and rehabilitative services, and many link their patients to other services in the community. A nationwide survey of nearly 7,000 hospitals conducted in 1987 by the American Hospital Association found that about 1,400 hospitals had a geriatric assessment program (532).

OTA has included hospital-based geriatric assessment programs in its analysis of agencies that might constitute a national system to link people with dementia to services for two reasons. The most important reason is that these programs provide comprehensive, multidimensional patient assessments that can improve diagnostic accuracy, identify potentially treatable diseases and conditions, and help to define a patient's service needs. As noted in the previous section, many diseases that cause dementia cannot be cured at present, but some can be cured or ameliorated if they are diagnosed accurately and treated correctly. Identifying these curable diseases is the first step in caring for people with dementia. Individuals who have dementing diseases that are not curable still may have other treatable illnesses and conditions that exacerbate their dementia and make them less able to function independently and more difficult for their families and others to manage. If these illnesses and conditions are detected and treated effectively, an individual's overall functioning may improve, and his or her service needs may be reduced. Lastly, even if an individual has an incurable dementing disease and no treatable illnesses or conditions that are exacerbating his or her dementia, a comprehensive, multidimensional assessment provides information that is needed to match the individual with appropriate services.

The second reason that OTA has included hospital-based geriatric assessment programs in its analysis of agencies that might constitute a national system to link people with dementia to services is that the programs are associated with hospitals. Hospitals exist in most communities. Many people are familiar with hospitals and accustomed to relying on hospitals for help with medical problems (89). Moreover, hospitals are available on a round-the-clock basis, 7 days a week, and they are usually centrally located and accessible by public transportation. Not all

hospitals have a geriatric assessment program, but it is likely that if reimbursement were available through Medicare or other funding sources, many more hospitals would establish such programs.

Overview of the Agencies

Hospital-based geriatric assessment programs include both inpatient and outpatient programs. The inpatient programs typically provide more intensive evaluation and treatment and serve elderly patients with illnesses that necessitate hospitalization (726). The outpatient programs typically serve elderly patients who do not need hospitalization or inpatient testing and who can be evaluated and treated on an outpatient basis.

Both inpatient and outpatient geriatric assessment programs use multidisciplinary teams to perform comprehensive patient assessments. The teams typically include a physician, a nurse, and a social worker, and, if not included on the core team, a wide variety of other health care professionals (e.g., psychiatrists, psychologists, dietitians, pharmacists, occupational therapists, and physical therapists) who are available for consultation (272,394,907). Although the size and composition of geriatric assessment teams vary, the teams typically have staff who are knowledgeable about dementia (12,701,726,907).

Rubenstein has identified four major types of inpatient and outpatient hospital-based geriatric assessment programs:

- inpatient geriatric specialty units,
- inpatient geriatric consultation services,
- outpatient geriatric services, and
- inpatient and outpatient geropsychiatry services (723).

Inpatient geriatric specialty units are the most common type of geriatric assessment program (723). They generally offer hospitalized patients a comprehensive assessment by a multidisciplinary team, a comprehensive plan of care, treatment, and recommendations for care following hospital discharge. Inpatient geriatric specialty units are of three main kinds: 1) subacute geriatric assessment units, 2) geriatric rehabilitation units, and 3) special-emphasis acute care units. The first kind, subacute geriatric assessment units, typically provide subacute treatment and rehabilitation for a carefully targeted group of frail elderly patients (723). Most

subacute geriatric assessment units are part of the Veterans Administration (VA) system, which, as of 1989, had 87 such units (917). A subacute geriatric assessment unit at the VA medical center in Sepulveda, CA, is described in box 8-K.

The second kind of inpatient geriatric specialty unit—geriatric rehabilitation units—provide intensive rehabilitative services to hospitalized patients (723). Some units of this type exclude people with dementia on the grounds that they are incapable of benefiting from rehabilitative services (35).

The third kind of inpatient geriatric specialty unit (special-emphasis acute care units) are acute care hospital wards that specialize in treating certain physical and mental problems that are common in elderly people (723). Such units have a multidisciplinary team trained to identify and treat these problems.

The second major type of hospital-based geriatric assessment program, *inpatient geriatric consultation services*, consist of freestanding teams of health care professionals who visit hospitalized patients and perform comprehensive assessments to identify the patients' medical and psychiatric impairments (328,455,723). Staffing patterns of inpatient geriatric consultation teams reflect the goals and the resources of the hospital in which the team functions; most have physicians (house staff and/or faculty geriatricians), nurses, and social workers, but they usually do not have all the disciplines represented on the staff of an inpatient geriatric specialty unit (723,914). Ordinarily, an assessment by a geriatric consultation team is performed at the request of a patient's primary physician (328, 723,914). The consultation team makes recommendations and works with the primary physician and other hospital staff to implement the recommendations, but the team has no control over patient management, nursing, or rehabilitative services (107,914).

The third major type of hospital-based geriatric assessment program, *outpatient geriatric services*, are hospital-affiliated clinics that use a multidisciplinary team to provide a comprehensive assessment to elderly people who come or are referred to the clinic (723). Some outpatient geriatric services also provide other services, depending on their staff's expertise and the needs of their clientele. An outpatient geriatric clinic associated with a hospital in Rochester, New York, is described in box 8-L.

Box 8-K—An Inpatient Subacute Geriatric Assessment Unit: The Geriatric Evaluation Unit at the Sepulveda VA Medical Center in Sepulveda, California

In June 1979, the VA Medical Center in Sepulveda, California, opened an inpatient Geriatric Evaluation Unit with 15 beds on a 29-bed subacute care hospital ward. The unit is staffed full time by a multidisciplinary team consisting of a faculty geriatrician, a physician's assistant, a geriatric fellow, a medical intern, and geriatric nurses; part-time staff include a social worker, psychologist, dietitian, pharmacist, occupational therapist, and physical therapist.

The Geriatric Evaluation Unit's goals are to provide elderly patients with:

1. a comprehensive assessment by a multidisciplinary team;
2. short-term, goal-oriented therapy and rehabilitation; and
3. arrangements for follow-up care after hospital discharge.

Patients are admitted to the Geriatric Evaluation Unit from an acute inpatient ward or from the outpatient department of the Sepulveda VA Medical Center. To be eligible for admission to the unit, patients must be over age 65 and have medical, functional, or psychosocial problems that interfere with living at home. Patients are denied admission to the unit if they are in the terminal phase of a disease (e.g., cancer), require acute care, or have end-stage dementia and no social support system to prevent their placement in a nursing home.

The focus of the first week of a patient's stay in the Geriatric Evaluation Unit is typically on assessing the patient needs and planning treatment. The focus of the subsequent 3 or 4 weeks is usually on providing treatment and rehabilitation. Taking into account the nature and extent of the patient's therapeutic progress, the multidisciplinary team develops a plan for the medical care of the patient following discharge from the hospital. Patients who have been discharged are eligible to be seen regularly in the geriatric followup clinic, usually by the same physician or physician's assistant who cared for them on the Geriatric Evaluation Unit.

SOURCE: L.Z. Rubenstein, K. Josephson, G.D. Wieland, et al., "Geriatric Assessment on a Subacute Hospital Ward" *Clinics in Geriatric Medicine*, L.Z. Rubenstein, L.J. Campbell, and R.L. Kane (eds.) (Philadelphia, PA: W.B. Saunders Co., 1987).

Patients of outpatient geriatric services are generally self-referred or referred by family members, community agencies, or physicians (549,907). Patients who are referred by their primary physician typically remain under the direct care of the physician. Some observers have noted that physicians are more likely to refer patients to outpatient geriatric services for psychosocial problems than for medical problems (549,909). These observers stress that geriatric assessment includes the evaluation of both medical and psychosocial problems and that there is a need to educate physicians to this effect (549,909).

The fourth major type of hospital-based geriatric assessment program, *geropsychiatry services*, exist specifically to serve elderly people with psychiatric problems. Geropsychiatry services are found in both inpatient and outpatient settings. An outpatient geropsychiatric clinic that serves elderly people in Seattle, Washington, is described in box 8-M.

Inpatient and outpatient geropsychiatry services provide elderly people with a comprehensive assessment by a multidisciplinary team that usually includes a psychiatrist and may include a psychologist (12,706). Inpatient units offer pharmacologic,

psychotherapeutic, and behavioral interventions in a hospital setting where the patient's physical and mental condition can be closely monitored. The professionals on the multidisciplinary team usually participate actively in discharge planning for the patients they evaluate. Outpatient geropsychiatric clinics typically provide their clients with a comprehensive, multidimensional assessment and case management and link the clients and their caregivers to community services (706).

The costs of a hospital-based geriatric assessment vary, depending in part on the setting and composition of the assessment team. The average cost of an assessment is often much less in an outpatient program than an inpatient program (703,910). The inclusion of psychiatrists or other specialists as core members of an outpatient geriatric assessment team raises the cost of some outpatient programs, however (493,703).

The costs of a hospital-based inpatient or outpatient geriatric assessment per se are not covered by most third-party payers (379,722). Typically, Medicare, Medicaid, and private insurers cover physicians' services and lab tests associated with diagno-

Box 8-L--An Outpatient Geriatric Service: The Geriatric Ambulatory Consultation Service at Monroe Community Hospital in Rochester, New York

The Geriatric Ambulatory Consultation Service affiliated with **Monroe Community** Hospital in Rochester, New York, is an outpatient clinic that provides comprehensive geriatric assessments. About one-third of the 131 elderly patients who received geriatric evaluations at the clinic between May 1983 and April 1984, had a dementing illness.

When someone calls the Geriatric Ambulatory Consultation Service, he or she is interviewed on the phone by a specially trained registered nurse. The nurse determines how urgent the situation is and what consultative expertise is necessary to address the problem and then arranges the necessary clinic appointments. The nurse is familiar with services provided by other professionals and agencies in the community and, in some cases, refers callers to these services.

At the initial clinic visit, a patient receives either a simple geriatric assessment or a full-team comprehensive assessment. Members of the multidisciplinary consultation team include a physician, a nurse, and a social worker. A psychiatrist is available two times a week to assess patients with psychiatric or behavioral problems. After the initial evaluation, the team may call on additional health care specialists for consultations, if needed.

After each clinic session, the members of the consultation team hold a conference to discuss each new patient. A plan of care is developed to meet the needs of each patient and the patient's family. The consultation team's social worker often contacts community agencies to arrange services for the patient or the patient's family and, when necessary, accompanies the family to case conferences with community agencies to discuss the patient and family's needs.

Followup visits at the clinic are scheduled as necessary to complete additional diagnostic procedures, to reevaluate the plan of care, and to review the patient progress. Most patients require four followup visits. Conferences are often held with family members to refine and modify the plan of care. Home visits are provided to individuals who require such visits because of the complexity of their health care needs or questions about their home environment.

SOURCES: M-E. Williams, "Outpatient Geriatric Evaluation" *Clinics in Geriatric Medicine*, L.Z. Rubenstein, L.J. Campbell, and R.L. Kane (eds.) (Philadelphia, PA: W.B. Saunders Co., 1987); M.E. Williams and T.F. Williams, "Evaluation of Older Persons in the Ambulatory Setting," *Journal of the American Geriatrics Society* 34(1):37-43, 1986.

sis, but do not cover the services provided by nonphysician professionals (e.g., nurses and social workers) involved in the assessment process (493,701,703,722). Whatever costs are not covered by insurance are borne either by the patient or by the hospital with which the geriatric assessment program is affiliated (379,493).

Hospital-based geriatric assessment programs of various types are an established part of the health care systems of several countries (e.g., Great Britain, Sweden, and Israel) (722). Although such programs have been developing in the United States for the past 15 years, growth in the number of geriatric assessment programs has been slower here than in countries that have a national health care system to coordinate their financing and development (722).

Who Is Served

Geriatric assessment programs generally target elderly people with potentially remediable medical or psychiatric problems who may be at risk of

premature or inappropriate institutionalization (394, 848). **One** commentator estimates that these "at-risk" elderly people constitute between 5 and 10 percent of hospitalized elderly patients and an undetermined percentage (perhaps 2 to 5 percent) of unhospitalized elderly people (722).

Some hospital-based geriatric assessment programs accept only elderly people who are considered to be at risk of nursing home placement (727). Other programs accept people primarily with psychiatric problems. Some programs exclude elderly people with acute illnesses; some exclude elderly people who are terminally or chronically ill (726); and some exclude people who are disruptive or who do not have the potential to be rehabilitated (35,726).

Very little information is available about the number of people with dementia who are served by geriatric assessment programs, but some types of geriatric assessment programs appear to be more likely than other types to serve people with dement-

Box 8-M—An Outpatient Geropsychiatric Clinic: The Geriatric and Family Services Clinic at the University of Washington Hospital in Seattle, Washington

The Geriatric and Family Services Clinic, located at the University of Washington Hospital Medicine Clinic, is an outpatient clinic that provides psychiatric, medical, and social evaluation of mentally impaired older persons, recommends appropriate treatment for them, and provides support and practical advice to their families. The evaluation generally entails a minimum of three, but typically four, visits to the clinic.

At the initial clinic visit, a psychiatrist or psychologist meets with the patient and family members (separately and together) to observe family dynamics, obtain the patient psychiatric history, and formulate a diagnosis; a nurse and/or occupational therapist assesses the patient's day-to-day functioning and suggests ways to strengthen the patient's capabilities. At subsequent clinic visits, an internist or family physician examines the patient to identify and treat reversible causes of dementia, and, when needed, a psychologist administers additional tests to assess the patient's memory and intellectual functioning. Infeasible, a social worker makes a home visit to gather information on the patient's home environment, family, etc. An architect may accompany the social worker on the home visit to inspect the patient's home and suggest physical changes to help the patient function better at home.

Following the elderly patient's visits to the clinic and the home visit, the multidisciplinary team holds a conference to consolidate findings and develop recommendations in 11 specified areas:

- . housing and living situation,
- . food and nutrition,
- self care,
- physical health,
- . household tasks,
- emotional and mental factors,
- financial matters,
- transportation,
- day-to-day routine,
- family stress caused by a patient, and
- * patient's interference with family members' work or other activities.

Using the notes from this conference, the staff prepares treatment recommendations and discusses them with the patient and the patient's family. The suggestions may include strategies such as starting medication; stopping medication; counseling for the patient, family, or both; use of community resources; behavior modification; and environmental manipulation. The clinic provides followup medical treatment as needed. The multidisciplinary team attempts to coordinate care with the patient primary physician and other health care and social service professionals. Generally, one-quarter to one-half of the patients receive ongoing medical case management from the clinic.

At least four times a year, the clinic offers families of patients structured group sessions, at which members of the multidisciplinary team discuss various aspects of mental impairment, and families are given the opportunity to express feelings and discuss caregiving problems. The multidisciplinary team is also available for 10- to 15-minute telephone consultations whenever the family needs practical advice or help in warding off a crisis.

SOURCE: B. V. Reifler, E.B. Larson, and L. Teri, "An Outpatient Geriatric Psychiatry Assessment and Treatment Service," *Clinics in Geriatric Medicine*, L.Z. Rubenstein, L.J. Campbell, and R.L. Kane (eds.) (Philadelphia, PA: W.B. Saunders Co., 1987).

tia. Of the three kinds of inpatient geriatric specialty units, subacute geriatric assessment units probably serve the most patients with dementia. Some of these units do not serve people with severe dementia, however (394).

Inpatient geriatric consultation teams can visit elderly patients on acute medical, surgical, and psychiatric wards throughout a hospital and so have the potential to reach large numbers of hospitalized patients who may have dementia. As consultants,

however, the team can evaluate only those patients referred to them by a patient's primary physician (328,723,914). In some cases, differences of opinion about what type of patient will benefit from geriatric assessment or "turf" issues may prevent some patients, including those suspected of having dementia, from receiving an assessment (914).

Information from several sources indicates that many of the clients of *outpatient geriatric services* are elderly people with dementia (272,493,909).

About one-third of the 1,373 elderly people who received assessments from New Jersey's eight geriatric assessment centers from January 1987 to June 1989 had a diagnosis of Alzheimer's disease or a related disorder (272). Likewise, one-third of the 131 elderly people who received assessments from May 1983 to April 1984 at the Geriatric Ambulatory Consultation Service in Rochester, New York, had a dementing disease (909) (see box 8-L).

Elderly people with dementia also constitute a significant proportion of the clients of many inpatient and outpatient *geropsychiatry services* (12, 493,705). The Geriatric and Family Services Clinic in Seattle, Washington (described in box 8-M) generally evaluates about 250 elderly people with dementia a year (706).

Linking Functions

Information and Referral



The primary functions of all hospital-based geriatric assessment programs are to provide elderly people with a comprehensive multidimensional assessment and to develop an appropriate plan of care. When discussing a patient's plan of care with the patient and his or her family or other informal caregiver, the staff of geriatric assessment programs usually provide information about community services and referrals to specific service providers. In some cases, this occurs only once, however, immediately following the patient's assessment. The referrals provided by many inpatient geriatric assessment programs pertain primarily to a patient's medical needs (723), and some inpatient geriatric assessment programs refer their patients to other information and referral sources in the community for referrals to social and other nonmedical services (724). In contrast, most outpatient geriatric assessment programs provide their patients with referrals to a range of medical and nonmedical services (703, 909).

Although all hospital-based geriatric assessment programs provide their patients with information and referrals to at least some types of community services, most programs are unequipped to provide the general public with information and referrals to community services. Although no definitive data are available, information from several sources suggests that many geriatric assessment programs do not

maintain a comprehensive list of community resources for use in referrals (379,699,724).

Case Management



Case management includes five core functions: assessing a client's needs, developing a plan of care, arranging and coordinating services, monitoring and evaluating the services delivered, and reassessing the client's situation as the need arises. The extent to which hospital-based geriatric assessment programs perform functions that go beyond assessing a client's needs and developing a plan of care varies.

One commentator has noted that many inpatient geriatric assessment programs have limited knowledge about nonmedical community services and do not emphasize coordinating such services for their patients or providing followup (746). Outpatient geriatric assessment programs tend to have a closer working relationship with community service providers and are more likely than inpatient programs to arrange and coordinate community services for their patients and to provide followup (493, 549,722,907). Some outpatient geriatric assessment programs provide only limited followup after patients are initially linked to services, however (907).

Participants in the 1987 Geriatric Assessment Consensus Development Conference sponsored by the National Institutes of Health agreed that successful implementation of a comprehensive plan of care for an elderly person depends on the availability of case management to link the person to needed services (848). Many participants in the conference recommended that geriatric assessment programs place more emphasis on providing case management. Likewise, some commentators have recommended that all geriatric assessment programs should take a more active role in coordinating social and other nonmedical services for their patients (108,722,907).

Public Education



Some hospital-based geriatric assessment programs distribute brochures and sponsor meetings and other community forums to inform the public about their services (272). Geriatric assessment programs generally do not provide public education about dementia or about services other than their own for people

with dementia. Frequently, however, members of geriatric assessment teams give speeches or publish articles that explain the potential value of comprehensive geriatric assessment in accurately diagnosing a patient's medical and psychiatric condition and in developing an appropriate plan of care.

outreach



Hospital-based geriatric assessment programs do not routinely engage in outreach to identify potential clients (724). Typically, they deal only with patients who are referred to them. The programs sometimes serve patients without families who are referred by a physician, another hospital staff member, or a community agency such as Adult Protective Services.

Role in Allocating Services and Funding

Hospital-based geriatric assessment programs do not control access to, or finding for, services other than those they provide.

Summary

As agencies that might be designated to constitute a national system to link people with dementia to services, hospital-based geriatric assessment programs offer the following advantages:

- Hospital-based geriatric assessment programs provide elderly people with a comprehensive multidimensional assessment that may reveal a treatable cause for their dementia or other treatable diseases and conditions that are exacerbating their dementia and reducing their functional ability.
- Hospital-based geriatric assessment programs provide elderly people with a comprehensive multidimensional assessment that may help match individuals with appropriate services.
- Hospital-based geriatric assessment programs typically have staff who are knowledgeable about dementia.

Despite these advantages, designating hospital-based geriatric assessment programs as the basis of a national system to link people with dementia to services would have several drawbacks. One drawback is that hospital-based geriatric assessment programs generally are not equipped to provide information and referrals to the general public. To do

so would require a major redirection of their efforts and resources. A second drawback is that hospital-based geriatric assessment programs generally do not provide outreach to identify people with dementia who would benefit from their services but are unlikely to contact a geriatric assessment program on their own or be referred to the program. A third drawback is that although some hospital-based geriatric assessment programs link their patients to all kinds of community services, inpatient geriatric assessment programs, in particular, often refer their patients primarily to medical services and do not emphasize referrals to or coordination of social and other nonmedical services.

There are several other possible drawbacks to designating hospital-based geriatric assessment programs as the basis of a national system to link people with dementia to services. One of these is that some hospital-based geriatric assessment programs focus primarily on the needs of patients and pay less attention to the needs of family caregivers. Another is that geriatric assessment programs are intended to serve people who want or are willing to accept a comprehensive assessment by a multidisciplinary team; by design, therefore, they may exclude people who do not want or are unwilling to accept a comprehensive assessment. It is unclear how many, if any, people with dementia or their caregivers would be unwilling to accept such an assessment.

Lastly, hospital-based geriatric assessment programs are more expensive than some of the other categories of agencies discussed in this chapter. On the other hand, to the extent that hospital-based geriatric assessment programs can identify and treat diseases and conditions that exacerbate patients' dementia and thus help them to function more independently, these programs can decrease the patients' service needs and thus reduce the overall cost of their care to all payers.

Whether the association of geriatric assessment programs with hospitals is primarily an advantage or a drawback to designating such programs as the basis of a national linking system for people with dementia is unclear. Certainly, many people are comfortable with hospitals as settings for medical care. On the other hand, the patient assessment and care planning provided by hospital-based geriatric assessment programs, particularly inpatient programs, sometimes focuses too greatly on the medical aspects of a person's condition and on referrals to

medical services to the exclusion of nonmedical problems and referrals to social and other supportive services.

If hospital-based geriatric assessment programs were designated as the basis of a national system to link people with dementia to services, the programs would have to place more emphasis on coordinating a range of services for their patients. Since outpatient programs tend to do this and are also less expensive than inpatient programs, outpatient programs would generally be more appropriate than inpatient programs as settings for a national linking system. Clearly, however, inpatient programs would be needed for some people with dementia.

HOME HEALTH AGENCIES

Home health agencies are local organizations that provide in-home health care and health-related services that may include any of the following:

- skilled nursing services;
- physical, occupational, and speech therapy;
- social work services;
- homemaker, home health aide, companion, and chore services;
- respite care;
- nutritional services; and
- in-home hospice care.

Some people use the term "home health agency" narrowly to include only agencies that provide the more medically oriented in-home services (e.g., skilled nursing services and physical therapy). As used in this report, however, the term refers to agencies that provide any of the in-home services listed above. According to the National Association for Home Care, in 1989, there were about 12,800 home health agencies in the United States—a figure that includes both Medicare-certified home health agencies and other agencies that provide in-home services but are not Medicare-certified (337).

OTA is including home health agencies in its analysis of agencies that might constitute a national system to link people with dementia to services for several reasons. First, case management is an integral component of the care provided by home health agencies for many of their clients. Second, at least two States, Illinois and New York, are using home health agencies to provide case management for a State-funded, long-term care program. Third, home health agencies are a major player in the

delivery of health care and long-term care services in this country. Lastly, home health agencies provide many of the services that maybe needed for a person with dementia.

Overview of the Agencies

Home health agencies include many different types of public and private organizations. The public organizations typically are units of State, county, or other local government departments of health or public health. The private organizations include both for-profit and nonprofit agencies. Some home health agencies are independent entities; some are operated by another organization, such as a hospital; and some are part of a multiagency chain (224,773).

Some home health agencies of each of the above-mentioned types are Medicare-certified: that is, they meet the Federal requirements for participation in the Medicare program, including a requirement that they provide skilled nursing services. As of April 1989, 5,681 home health agencies were Medicare-certified (337). Other home health agencies of each of the above-mentioned types are not Medicare-certified, either because they do not meet the requirements for participation in the Medicare program or because they choose not to participate in the program. No precise data are available on the number of home health agencies that are not Medicare-certified, but the National Association for Home Care has estimated that in 1989, more than 7,100 home health agencies (55 percent of all home health agencies) were not Medicare-certified (337). Only Medicare-certified home health agencies can receive Medicare reimbursement for home health services.

The Federal Government collects many different kinds of information in connection with the certification of home health agencies for Medicare and the payment of Medicare home health claims. Thus, as illustrated in the following discussion, much more is known about Medicare-certified home health agencies than about non-Medicare-certified home health agencies (224,340).

The proportion of home health agencies that are Medicare-certified varies among States. In 1987, for example, 85 percent of the 194 home health agencies in Arkansas were Medicare-certified, compared to only 21 percent of the 821 home health agencies in New York (340,570).

Table 8-2-Services Provided by Medicare-certified Home Health Agencies, 1986,
N = 5922

Service	Percentage of agencies that provide the service	Percentage of agencies that provide the service using agency staff
Nursing services	100%	99 %
Home health aide or homemaker	97	88
Physical therapy	89	53
Speech therapy	61	37
Medical social work services		45
Occupational therapy	59	32
Nutritional guidance	28	21
Medical appliances or equipment	21	9
Pharmaceutical services	10	5
Physicians' services	1	0.8

SOURCES: Foundation for Hospice and Home Care, Basic *Home Care Statistics: The Industry 1988*, Washington DC, 1988; S.L. Hughes, Center for Health Services and Policy Research, Northwestern University, Evanston, Illinois, "Home Care: Where We Are and Where We Need To Go," draft prepared for the National Institute on Aging In-Home Community and Supportive Services Advisory Group, Bethesda, MD, Apr. 19, 1990.

As of April 1989, 18 percent of the Medicare-certified home health agencies were public agencies; 32 percent were private, for-profit agencies; 13 percent were private, nonprofit agencies; 9 percent were visiting nurse associations (VNAs); 26 percent were hospital-based agencies; and the remaining 2 percent were nursing home or rehabilitation-based agencies or agencies under combined auspices (337). No similar information is available about non-Medicare-certified home health agencies.

Medicare-certified home health agencies are permitted to provide in-home services directly-i. e., using the agency's staff, or through contracts with other providers. Data on the services provided by Medicare-certified home health agencies in 1986 show that all or the great majority of these agencies were providing nursing, home health aide, and homemaker services and were using agency staff to provide these services (see table 8-2). Fewer agencies were providing other types of in-home services, and the agencies that were providing the other types of services were more likely to be using contractors to provide them (224,340). No similar data are available on the services provided by non-Medicare-certified home health agencies.

Home health agencies generally employ registered nurses, licensed practical nurses, home health aides, homemakers, and social workers (224). Some home health agencies also employ physical therapists, speech therapists, occupational therapists, and a variety of other service providers, whereas other home health agencies contract with these types of service providers (224,822). A 1987 analysis of the

employment patterns in Medicare-certified home health agencies indicates that the average home health agency employed 7 registered nurses and 5 home health aides (337). Again, no similar figures are available for non-Medicare-certified home health agencies.

Home health agencies are licensed by some States and territories, but not by others. OTA's tabulation of the results of a survey by the National Association for Home Care (571) shows that, as of March 1989, 35 States and territories licensed Medicare-certified home health agencies, and 30 States and territories licensed non-Medicare-certified home health agencies.

The number of home health agencies increased greatly in the past 25 years, from an estimated 1,200 agencies in 1965 to more than 12,800 in 1989 (224,337). The number of Medicare-certified home health agencies increased from 1,753 in 1967 (the second year in which there was Medicare certification for home health agencies) to more than 6,000 in 1986, and then decreased to 5,681 by April 1989 (224,337,773). OTA is not aware of any data on the number of non-Medicare-certified agencies in the late 1960s, but recent estimates suggest that in the past few years, the number of non-Medicare-certified agencies continued to increase, even though the number of Medicare-certified agencies dropped somewhat.

The predominant types of home health agencies also changed over time. In 1967, 37 percent of all Medicare-certified home health agencies were VNAs, and 54 percent were public agencies (224). By 1972,

a smaller percentage of Medicare-certified home health agencies (24 percent) were VNAs, but public agencies still constituted more than half (57 percent) of all such agencies (773). By 1989, however, only 9 percent of all Medicare-certified home health agencies were VNAs, and only 18 percent were public agencies (337).

As the proportion of VNAs and public agencies decreased, the proportion of other types of home health agencies increased. During the 1970s, private, nonprofit agencies were the fastest growing type of Medicare-certified home health agency, increasing from less than 1 percent of all such agencies in 1972 to 14 percent in 1982 (773). From 1982 to 1986, private, for-profit home health agencies were the fastest growing type of Medicare-certified home health agency, increasing from 17 percent of all Medicare-certified home health agencies in 1982 to 32 percent of all such agencies in 1986 (453,773)¹⁹. For the past few years, hospital-based home health agencies have been increasing faster than any other type of Medicare-certified home health agency (453,773).²⁰

No information is available about the proportion of various types of home health agencies among non-Medicare-certified agencies, but the National Association for Home Care believes that for-profit agencies that serve only private pay clients are increasing (224). Durable medical equipment supply agencies, which are not usually classified as home health agencies even though they provide in-home medical therapies (e.g., mechanical ventilation, IV antibiotics, and chemotherapy) are also increasing (773).

In-home services are paid for by Medicare, Medicaid, other Federal, State, and local government health care and long-term care programs, patients, patients' families, charitable organizations, and other sources (469,81 1,821). Many private insurers pay for in-home services, and at least 17 States require private insurers to include home health benefits in their plans (773). As of May 1989,

73 of the 90 Blue Cross and Blue Shield plans offered home health benefits (401).

Medicare is the largest third-party payer for home health care. As noted earlier, Medicare pays only for in-home services that are provided or contracted for by Medicare-certified home health agencies. Medicare expenditures for in-home services for 1989 were estimated to be \$2.9 billion (3 percent of total Medicare expenditures) (337,837). Data for fiscal year 1984 show that Medicare payments accounted for almost three-quarters of the revenues of Medicare-certified home health agencies in that year (224), but anecdotal evidence suggests that proportion may have decreased since then.

Non-Medicare certified home health agencies receive funds from all the sources listed above, except Medicare. OTA is not aware of any information about the proportion of funds from various sources that are received by non-Medicare-certified home health agencies. Nor is OTA aware of any information about the proportion of funds from sources other than Medicare that are received by Medicare-certified home health agencies.

Medicaid expenditures for in-home services amounted to nearly \$1.4 billion in 1986 (224). It should be noted, however, that Medicaid and all sources of funding for in-home services other than Medicare pay for services that are provided not only by Medicare-certified and non-Medicare-certified home health agencies, but also by individual providers who are not connected with a home health agency (298,821). Thus, expenditures for in-home services by sources other than Medicare are not necessarily payments to home health agencies.

Who Is Served

The question of who is served by home health agencies is particularly important in considering the capacity of home health agencies to link people with dementia to services because, as discussed later in this section, the case management that is provided by home health agencies generally is "service-centered" —i.e., it is usually provided only for

¹⁹Before 1981, for-profit home health agencies could not be Medicare-certified in States that did not have licensure laws for such agencies. The Omnibus Budget Reconciliation Act of 1980 (Public Law 96-499) (effective July 1981) allowed those agencies to participate in the Medicare program, thereby spurring a dramatic increase in the number and percentage of Medicare-certified private, for-profit agencies.

²⁰The recent increase in hospital-based home health agencies reflects, in large part, the attempt by hospitals to expand their services in other areas to compensate for decreases in the use of inpatient care following the implementation of the Medicare Prospective Payment System in 1983, and of other similar government and nongovernment initiatives that have been implemented in the past few years to control the use and cost of inpatient hospital care (453,773).

people who are receiving other services from the agencies.

Virtually all the available information about who is served by home health agencies pertains to individuals who receive Medicare-funded services from Medicare-certified home health agencies. In 1986, 1.6 million individuals received Medicare-funded services from such agencies; 94 percent of the individuals were over age 65, and 64 percent were women (733). The 10 most frequent diagnoses for these 1.6 million individuals were: cerebrovascular disease, congestive heart failure, hip fracture, chronic airway obstruction, hypertension, diabetes, pneumonia, other pulmonary conditions, heart attack, and urinary incontinence.

These diagnoses accounted for only one-fourth of the individuals. Medicare enrollees over age 85 were 4 times more likely than Medicare enrollees age 65 or 66 to receive Medicare-funded in-home services.

It has been estimated that people who receive Medicare-funded in-home services constitute 60 to 100 percent of the clients of individual Medicare-certified home health agencies (538). If that estimate is correct, then up to 40 percent of the clients of some Medicare-certified home health agencies receive in-home services that are not Medicare-funded. Very little information is available about those people or about people who receive in-home services from non-Medicare-certified home health agencies.

The 1982 National Long-Term Care Survey—a large-scale study of a nationally representative sample of elderly people who had at least one limitation in activities of daily living (ADLs) or instrumental activities of daily living (IADLs)—gathered information on the subjects' use of in-home services. Data from the survey show that only 26 percent of the subjects received any paid in-home services, including 20 percent who received both paid and unpaid (informal) in-home services and 6 percent who received only paid in-home services (469).

The extent to which the paid in-home services received by subjects of the 1982 National Long-Term Care Survey were provided by home health agencies is unclear. Among the subjects who received any paid in-home services, 14 percent re-

ceived services that were paid for by Medicare (469); these services were undoubtedly provided by Medicare-certified home health agencies. Seven percent of the survey subjects received in-home services that were paid for in whole or in part by Medicaid; 2 percent received services paid for in whole or in part by private insurance, and more than 40 percent received in-home services they paid for themselves. The in-home services paid for by Medicaid, private insurance, and individuals for themselves may or may not have been provided by home health agencies. Evidence from various sources suggests that families and other informal caregivers of people with dementia who use paid in-home services often hire maids, sitters, and other individuals who are not employed by or under contract to a home health agency to provide the services (291,934).

Although little comprehensive information is available about people who are served by home health agencies, much has been written about factors that influence who is served by these agencies. Probably the major factor that influences who is served by home health agencies is the availability of reimbursement—particularly reimbursement from Medicare. The Medicare home health services benefit is medical in orientation, and eligibility for the benefit is restricted to “homebound” individuals who need part-time or “intermittent” skilled nursing services and/or physical therapy or speech therapy. A physician must certify that one of these three services is “medically necessary” for an individual. Medicare also pays for home health aide services, occupational therapy, and social work services, but only for individuals who are eligible for Medicare-funded skilled nursing services, physical therapy, or speech therapy.

Like the Medicare home health services benefit, private insurance benefits for in-home services generally are medically oriented,²¹ as are the in-home services that States are required to provide in their Medicaid programs. The Federal Medicaid program also gives States the option to provide health-related personal care services, but funding for these less medically oriented in-home services and for similar in-home services paid for with Older Americans Act and Social Services Block Grant funds is significantly less than the funding for the

²¹Blue Cross and Blue Shield coverage extends, much as Medicare's coverage does, only to home care that has been certified by a physician as being medically necessary. The company's “long-term care benefit,” which permits the provision of nonmedical “custodial” (or supportive) care, is currently being marketed by only 15 of the 73 plans (401).

medically oriented services paid for by Medicare, private insurance, and the required Medicaid program. Thus, there are strong financial incentives for home health agencies to serve people who need medically oriented in-home services.

Another factor that influences who is served by home health agencies is technological advances that allow the provision at home of sophisticated medical treatments, such as mechanical ventilation, IV antibiotics, and chemotherapy, previously available only in hospitals (340,821,830). To the extent that reimbursement is available for the use of these treatments at home, there is an incentive for home health agencies to serve people who need those treatments.

A third factor that influences who is served by home health agencies is the Medicare Prospective Payment System and other government and non-government programs that have created financial incentives for shorter hospital stays. As a result of these programs, more people are discharged from hospitals in a medically unstable condition and are in need of short-term, post-hospital acute care. Since the needs of these individuals generally correspond to the eligibility criteria for Medicare-funded in-home services, there are financial incentives for home health agencies to serve them.

When the Prospective Payment System was implemented in 1983, many analysts suggested that there would be a large increase in the number of people who received Medicare-funded in-home services (449,822). That increase did not materialize. In fact, the annual rate of increase in the number of people who received Medicare-funded in-home services for the years 1983-86 was smaller than it had been for the preceding 4 years (1980-83) (733). Instead, there was an increase in Medicare denials of reimbursement for in-home services (449,836). These denials generally were explained on the grounds that the in-home services had been provided for individuals who were not "homebound," that the services were not "medically necessary" or "intermittent," or that they did not constitute "skilled nursing care" as defined in the Medicare regulations. Anecdotal evidence suggests that the impact of the denials has been to push Medicare-certified home health agencies further in the direction of serving individuals who need medically oriented in-home services, particularly short-term, post-hospital acute care services, and individuals

who are so severely impaired that they cannot leave their homes. This effect has been exacerbated by the growth in the overall number of home health agencies, the resulting competition among agencies for limited funds, and cuts in Federal funding for programs that pay for nonmedical in-home services (776,922).

Some researchers who have studied the changes in the home care field in recent years have noted a shift in the field "from providing services to a concern with providing *profitable services*" (922). They comment:

The national focus on cost containment . . . has increased the competition not only between proprietary [for-profit] and nonprofit agencies, but also among nonprofit agencies themselves. It is an interesting dilemma for nonprofit agencies that have operated on an ideology of providing services as opposed to competing in an economic marketplace and especially for those that do not offer clearly defined medical services. Agencies that provide supportive services have been faced not only with the need to become more competitive in general but also to alter their service structure to at least appear as if they are quasi-medical. This is necessary if they are to either recapture some of their lost government funding or become more competitive in the open market (922).

Some people who work in home health agencies and are knowledgeable about the changes that have occurred in the home health care field in recent years have told OTA that although they recognize the importance of medically oriented in-home services and short-term, post-hospital acute care services, they regret the shift away from the public health or community health model of home care that was the norm when VNAs and government agencies were the predominant types of home health agencies. That model of home health care, which may be best characterized as a nursing rather than a medical model, focuses on the family, not just the individual patient, and stresses preventive health services, health education, coordination of services, and long-term, supportive services for people with chronic conditions (42). Although many VNAs, government agencies, and to a lesser degree, other types of home health agencies continue to provide these types of services and to serve individuals who need these types of services, it is probably becoming increasingly difficult for them to do so because of the pressures discussed earlier.

The extent to which home health agencies serve people with dementia is unclear. The preceding discussion of factors that influence who is served by home health agencies suggests several reasons why home health agencies might not be serving many people with dementia. In addition, family caregivers and advocates for people with dementia often complain that the eligibility requirements for Medicare-funded in-home services discriminate against people with dementia and that the medically oriented services provided by many home health agencies are not appropriate for the needs of people with dementia. Data from the 1982 National Long-Term Care Survey indicate that survey subjects who were said to be "senile" by the proxy respondents who answered the survey questions for them and survey subjects who had characteristics that suggested they might have dementia (e.g., they needed help in taking medicines), were more likely than other survey subjects to have unmet needs for in-home services and to be paying for their own in-home services (469,811).

On the other hand, OTA's informal discussions with individuals who work for home health agencies suggest that these agencies are serving many people with dementia. Individuals who work for home health agencies often express frustration about the lack of adequate funding for in-home services for people with dementia and concern about the difficulty of providing in-home services for dementia patients who frequently are not aware of their need for services and may not be capable of making decisions about services for themselves. It is clear, however, that many of their clients are people with dementia.

Two analyses of data from the 1982 National Long-Term Care Survey and 1982 Medicare billing records—one by the General Accounting Office and the other by researchers at Duke University—shed some light on the question of whether home health agencies serve people with dementia (490a,811). Both analyses were intended to identify distinct categories of individuals who receive Medicare-funded in-home services. Both research groups identified a category of individuals who are chronically ill, have multiple medical problems, including diseases and conditions that cause dementia, and are severely functionally impaired. Moreover, both research groups found that, on average, individuals in this category received more Medicare-funded in-home services than individuals in any of the other

identified categories, including the categories of individuals with severe medical problems such as hip fractures, cancer, and heart attack. The Duke University research group also identified another category of individuals who had cognitive impairments, but few acute or severe medical problems. On average, individuals in the latter category received fewer Medicare-funded in-home services than individuals in any of the other categories. These findings suggest that at least with respect to Medicare-certified agencies, people with dementia who have medical problems in addition to their cognitive impairments are likely to be served, whereas people with dementia who do not have other medical problems may be less likely to be served by the agencies.

In addition to their regular services, some home health agencies have established special programs for people with Alzheimer's and other diseases that cause dementia. Box 8-N describes AL-C*A*R*E*, a joint project of two home health agencies in Washington, DC, that provides in-home respite care and other services for people with dementia and their caregivers. The project is funded primarily by the DC Office on Aging.

Another home health agency that has established a special program for people with dementia is the Visiting Nurse Association of the Valley, a Medicare-certified VNA in Derby, Connecticut (341). The program provides in-home mental health services for people with dementia and their caregivers and for elderly people with medical conditions whose progress is impeded due to psychological problems. Originally established in 1979 with a Federal grant, the program now receives both State funds and some Federal grant funds.

Both AL-C*A*R*E* and the program of the Visiting Nurse Association of the Valley provide special training for the homemakers and home health aides who work for the agencies' dementia programs. Apart from the staff of special Alzheimer's programs, though, it is unclear to what extent the staff of home health agencies are knowledgeable about dementia. In the course of this study, OTA staff heard many complaints about home health agency staff members who were said to be uninformed about dementia and the care of people with dementia. No data are available to determine the extent of this problem.

Box 8-N—AL-C*A*R*E*: A Dementia-Specific Project of Two Home Health Agencies in Washington, DC

AL-C*A*R*E* (Alzheimer's-Coordination, Assessment, Respite, Education) is a joint project of the Visiting Nurse Association of Washington, a Medicare-certified home health agency, and Homemaker Health Aide Services of the National Capital Area, a homemaker-home health aide agency that is not Medicare-certified. **AL-C*A*R*E* serves residents of Washington, DC, who are over age 60, live with a caregiver, and have a dementing illness severe enough to interfere with their daily functioning. The project provides in-home assessments, information and referral, respite care, and caregiver training and support.**

AL-C*A*R*E*'s in-home assessments are done by a nurse practitioner employed by the Visiting Nurse Association of Washington and a social worker employed by Homemaker Health Aide Services of the National Capital Area. Since the primary objective of the project is to support caregivers, the in-home assessments focus as much on the needs of the primary caregiver as on the **needs of the patient. Reassessments are conducted every 3 months. The social worker furnishes referrals to other community service providers, as needed, and the nurse practitioner provides a link to the patient's physician.**

AL-C*A*R*E*'s in-home respite services are provided by specially trained homemakers who are employed by Homemaker Health Aide Services of the National Capital Area and have volunteered to work in the AL-C*A*R*E* project. The specific in-home services provided by the homemakers differ depending on the needs of the patient and caregiver. Less emphasis is placed on the completion of home management tasks than on furnishing whatever assistance will offer relief to the caregiver. Whenever possible, respite services are provided at times selected by the caregiver. As of June 1988, there was no charge for the respite services, but a contribution of \$2 an hour was suggested.

The AL-C*A*R*E* homemakers receive an 8-hour orientation that includes information about Alzheimer's and other diseases that cause dementia and the impact of the diseases on patients and their families and suggestions about caregiving techniques and methods for supporting and assisting caregivers. The homemakers are supervised on an ongoing basis by the project social worker who assists the homemakers in problem-solving and provides emotional support for them. Bimonthly meetings are held for the homemakers to provide additional information about caregiving techniques, and to give the homemakers an opportunity to share feelings about their work in a supportive atmosphere.

One of AL-C*A*R*E*'s major objectives is to provide information and education for caregivers. Caregivers are given a "Family Information Packet" that was developed by AL-C*A*R*E* and contains an overview of Alzheimer's disease; tips on caring for and communicating with people with dementia; suggestions for dealing with problems, such as wandering and incontinence; lists of local support groups, sources of legal services and adult day centers; an "environmental check list" of common safety problems in the home; and a list of publications about dementia. The nurse practitioner provides caregiver education and training about common health problems in people with dementia medications, nutrition, approaches for handling **problem behaviors, and stress** reduction techniques for the caregivers. Caregiver training groups are held about eight times a year. Sometimes guest speakers are invited to discuss issues of special interest to caregivers, but the training groups also provide emotional support for caregivers.

SOURCES: M.Z. Kocin, project director, AL-C*A*R*E*, Washington, DC, personal communications, June 21, 1988; M.Z. Kocin and V. Kendrick, "AL-C*A*R*E*: A Respite Model for Long-Term Care," *Caring* 7(4):39-43, April 1988.

In 1986, the Foundation for Hospice and Home Care published a training manual, *How To Care for the Alzheimer's Disease Patient: A Comprehensive Training Manual for Homemaker-Home Health Aides* (378), and other relevant training materials have also been developed (see, e.g., E.L. Ballard and L.I. Gwyther, *In-Home Respite Care: Guidelines for Training Respite Workers Serving Memory-Impaired Adults* (50)). OTA does not know how widely these training materials are used or what, if any, special training about dementia is available to the staff of home health agencies.

Linking Functions

Information and Referral

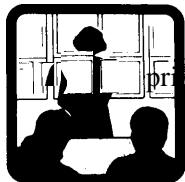
The primary function of home health agencies is to provide in-home services for their clients. People who are already receiving in-home services from a home health agency and need services that are not offered by the home health agency (e.g., home-delivered meals or legal services) are often

referred to other agencies for the needed services. These referrals are usually made by a home health agency nurse or by a home health agency social worker if the client is being seen by a social worker. Anecdotal evidence indicates that other home health agency staff members, including homemakers and home health aides, also sometimes refer agency clients to other community service providers.

Home health agencies generally are not in the business of providing information and referrals for the general public. Nevertheless, people who call a home health agency for services often receive a referral to another community agency or individual service provider if the home health agency does not offer the services they need or if they are not eligible for the home health agency's services. An intake nurse at one home health agency estimates, for example, that she refers an average of one-third of all incoming calls to other agencies or individual service providers (239). OTA is not aware of home health agencies that have followup procedures to determine whether individuals who receive such referrals but are not clients of the agency obtain the services they need.

Home health agencies typically do not develop and maintain comprehensive community resource lists for use in referring their clients and other callers to services (239). Instead, some home health agency nurses and other staff members use resource lists developed by other agencies, and some make referrals on the basis of their own knowledge of agencies and individual service providers in the area. One commentator has suggested that home health agency nurses and other staff members are probably more likely to have the names of community service providers "on their rolodex" than to use a comprehensive resource list (239).

Case Management



Unlike providing information and referrals, case management is a primary function of home health agencies. The home care industry points out that home health agencies "have been acting as case managers for many years, providing those services they can and trying to arrange for other services the patient may need through other community service agencies" (275). Certainly, the five functions that OTA has defined as core case management functions (i.e., assessing a client's needs, developing a plan of



Photo credit: On Lok Senior Health Services

The case management provided by home health agencies generally is service-centered; that is, it is provided for people who are receiving in-home services from the agencies.

care, arranging and coordinating services, monitoring the services, and reassessing the client's situation) have always been part of community health nursing and public health nursing (22,265) and are integral components of the community health or public health model of home care.

The extent to which case management functions are provided by different types of home health agencies and for different types of clients undoubtedly varies, but the results of a 1987 study of home visits by nurses from Medicare-certified home health agencies in five States show that, on average, case management functions constituted almost half of the total nursing time associated with the visits (776). The researcher observed 75 home visits by 26 nurses from 8 home health agencies--one VNA, one public agency, 2 private, for-profit agencies, and 4 hospital-based agencies. The study found that the average nursing time associated with a home visit (not counting travel time) was 73 minutes, of which 41 minutes were spent in the client's home, and 32 minutes were spent before or after the visit on care coordination functions, such as contacting other service providers for the client and documentation. On average, 20 percent of the total nursing time associated with a home visit was spent on client assessment, and 26 percent was spent on care coordination. Psychosocial support, which also might be considered case management, accounted for an additional 9 percent of total nursing time associated with the typical visit. Other components of the visit

were client education, which accounted for 13 percent of the nursing time associated with the typical visit, documentation, which accounted for 19 percent, and physical care, which accounted for 9 percent. Although the small number of home health agencies studied means that the results of the study cannot be generalized with any certainty, its findings tend to support the conclusion that home health agencies are providing case management.

Twenty percent of the 75 home visits observed by the researcher were initial visits to the client, and 80 percent were repeat visits (776). In general, more time was spent on assessment and care coordination in the initial visits than the repeat visits. There were also differences in the average amount of time spent on different functions by nurses from different types of home health agencies. Nurses from the VNA and the public agency spent more time than nurses from the private, for-profit and hospital-based agencies on physical care and care coordination, whereas nurses from hospital-based agencies spent more time on assessment. The important finding of the study for this OTA assessment is not any of the precise percentages or specific differences between types of home health agencies, however, but the large proportion of total nursing time devoted to case management functions.

As noted earlier, the case management provided by home health agencies generally is service-centered; that is, it is furnished in conjunction with the provision of services. Thus, people who receive services from a home health agency may also receive case management, but people who are not receiving services from the agencies are unlikely to receive case management. Some people favor service-centered case management because they think that case management is performed most effectively in conjunction with the provision of services and that patients and families are often more comfortable with case management performed by a service provider, such as a home health nurse, than by someone whose sole function is case management (283,290). Other people are opposed to service-centered case management because they think that service providers tend to over-recommend services and to refer their clients to the agencies' own services even when other, more appropriate services may be available from another agency. These differing contentions are discussed in chapter 1.

With respect to home health agencies' capacity to link people with dementia to services, the important point is that people with dementia may need case management at anytime in the course of their illness, not just at those times when they need the kinds of services provided by home health agencies.

Both Illinois and New York use home health agencies to provide case management for a State-funded long-term care program, and in both States, the home health agencies provide case management for some people who are not receiving in-home services from the agency. In Illinois, one-third of the agencies that furnish case management for the State's Community Care Program are home health agencies. These home health agencies are not permitted to provide in-home services for the program's clients (587). In New York, as of 1986, 46 percent of the 95 local agencies providing case management for the State's Nursing Home Without Walls Program were home health agencies (472). These agencies have the option to provide services for the program's clients but do not always do so (354).²²

In general, the case management provided by home health agencies is paid for only indirectly, if at all, by third-party payers. For many programs that pay for in-home services, some of the costs of case management are included in the reimbursable administrative costs associated with the provision of in-home services. The case management provided by home health agencies in the Illinois and New York programs just described is paid for by Medicaid.

Visiting Nurse and Home Care, Inc., a VNA in Hartford, CT, operates an Alzheimer's Disease Program that provides case management for people with dementia (see box 8-O). Some of the in-home services that the program provides or arranges for its clients are paid for by Medicare. Other services are paid for by Medicaid, private insurance, patients and their families, United Way, or State grant funds. In addition, each of the nine towns served by Visiting Nurse and Home Care, Inc. has a contract with the agency to provide services for its residents who have no other source of funds for needed services (283). The case management provided by the Alzheimer's Disease Program is paid for, generally indirectly, with funds from all these sources.

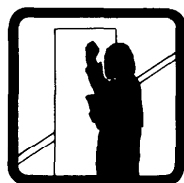
²²Illinois' Community Care Program and New York's Nursing Home Without Walls Program are discussed in ch. 7.

Public Education



Home health agencies perform some public education activities. Home health agency nurses sometimes conduct educational programs at senior centers, adult day centers, nursing homes, and congregate living facilities. Such programs often focus on topics such as nutrition, diabetes, and high blood pressure (239). The programs—while increasing the agency's visibility—also provide a valuable service to the public. In addition, home health agency staff members sometimes distribute pamphlets and other educational materials to their clients. OTA does not know how frequently these programs and educational materials focus on Alzheimer's disease, dementia, or services for people with dementia.

Outreach



Many home health agencies perform various outreach activities. Frequently, a home health agency nurse who is visiting a client in an apartment building or a congregate living facility identifies other people in need of care. The nurse may inform the manager of the facility of the home health agency's services and leave the agency's number. Sometimes, one client of a home health agency informs the agency nurse that another individual needs assistance (239). Home health agency nurses may also be involved in community screening programs and identify people in need of services through such programs. As a result of these activities, home health agencies undoubtedly reach some people with dementia and some caregivers who need help but would not seek services themselves. On the other hand, home health agencies generally do not have systematic procedures for identifying isolated people with dementia and isolated caregivers. In fact, some home health agency staff members would probably consider the implementation of such procedures inappropriate at present because of the insufficient availability of in-home services and funding for in-home services for people with dementia.

Role in Allocating Services and Funding

Most home health agencies do not control access to services other than those they provide. On the other hand, home health agencies provide services funded by many different programs. Consequently,

they are frequently required to determine who will receive services and what services they will receive within the context of the eligibility and coverage regulations of the funding programs. In addition, as noted earlier, at least two States, Illinois and New York, use home health agencies to provide case management in a State-funded long-term care program, and the functions of the agencies that provide case management in these programs include determining people's eligibility for services and allocating services and funding for services. Other States and local governments may also use home health agencies in this capacity.

Summary

As agencies that might be designated to constitute a national system to link people with dementia to services, home health care agencies offer several advantages:

- Home health agencies serve people of all ages and have extensive experience serving elderly people.
- Home health agencies provide case management for many of their clients.
- Home health agencies provide information and referrals for their clients and for some people who are not their clients.
- Home health agencies often regard family members and other informal caregivers as part of the client unit, and conduct an assessment and develop a plan of care that includes the needs of these caregivers as well as the needs of the patient.
- There are more than 12,000 home health agencies across the country.

Despite these considerable advantages, there would be several drawbacks to designating home health agencies as the basis of a national system to link people with dementia to services. One drawback is that home health agencies generally provide case management only for people who are receiving in-home services from the agency. People with dementia may need case management at any time in the course of their illness, not just at times when they need or are receiving in-home services. This section has discussed many factors that are pushing home health agencies more in the direction of serving people who need medically oriented in-home services—particularly short-term, post-hospital, acute care services. Although some individuals with

***Box 8-O-The Alzheimer's Disease Program of Visiting Nurse and Home Care, Inc.,
in Hartford, Connecticut***

Since 1984, the Hartford branch of Visiting Nurse and Home Care, Inc., a Medicare—certified home health agency, has operated an Alzheimer's Disease Program that provides case management and in-home services for people with dementia and their caregivers. Visiting Nurse and Home Care, Inc., serves a nine-town region in **the greater Hartford area. As of 1988, the Alzheimer's Disease Program was serving 40 to 50 people at a time.** According to the program coordinator, the clients of the Alzheimer's Disease Program are generally retained **for longer periods** and require more case management than other clients of Visiting Nurse and Home Care, Inc.

The Alzheimer's Disease Program makes use of all the services offered by Visiting Nurse and Home Care, Inc. Consequently, clients of the program have **access to all the clinical services of the home health agency, including nursing, physical therapy, speech therapy, occupational therapy, medical social work, home health aide, homemaker, and chore services, and home-delivered meals.** In addition, the Alzheimer's Disease Program has **developed relationships with local agencies and individuals that provide a variety of services for people with dementia, and there are many cross referrals between the Alzheimer's program and these other service providers.**

Initial referrals to the Alzheimer's Disease Program come primarily from families or doctors. Since the Alzheimer's Disease Program started, monthly average of 25 to 26 people who are referred to Visiting Nurse and Home Care, Inc. have some problem in mental status that is mentioned at the time of the referral. Those individuals are referred to the Alzheimer's Disease Program. In addition, other clients of Visiting Nurse and Home Care, Inc., who are identified as potentially benefiting from the Alzheimer's Disease Program, are also referred to the program. According to the program coordinator, families of people with dementia often contact the program for information about services several times, often over a period of months or years, before actually deciding to use help.

The Alzheimer's Disease Program is staffed by a geriatric services' group consisting of three registered nurses and a social worker. Both a geriatrician and geriatric psychiatrist are available to the program for consultation,

The Alzheimer's Disease Program provides a professionally led support group for the families and other informal caregivers of its clients. A home visit is required before a caregiver is admitted to the support group. To encourage caregivers to attend the support group, the program arranges for sitters for the dementia patients and/or transportation for the caregivers. The support group meets once a week for 10 weeks. Then, the participants can elect to join a monthly ongoing support group. The program coordinator has noted that participants demonstrate significant changes in their caregiving behavior after attending support group meetings: some elect to use respite care for the first time, others seek necessary institutionalization, and others involve their family members more in caring for the patient.

For the personnel who work with dementia clients, the Alzheimer's Disease Program provides regular in-service education and is developing a support group. Another support group has been organized for professionals who work in isolation in the community with dementia patients. A monthly case conference is held for geriatric nurses and other professionals who have an interest in geriatrics and who are used as "backup" staff as the patient load increases.

SOURCE: Visiting Nurse and Home Care, Inc., VNA Health Resources, Inc., and VNA Fond, Inc., "Annual Report," prepared by L. Preble, and M. Cushman, Plainville, CT, 1987; N. Gustafson, program coordinator, Alzheimer's Disease Program, Visiting Nurse and Home Care, Inc., Hartford, CT, letter to the office of Technology Assessment, U.S. Congress, Washington, DC, Feb. 24, 1988.

dementia need such services, many do not. Individuals **who do** not need the type of services provided by home health agencies are unlikely to receive those services and therefore unlikely to receive case management from the agencies.

A second drawback is that although home health agencies provide information and referrals for their clients and in connection with intake for their own services, they usually do not consider the provision of information and referrals for the general public as one of their primary functions. Many home health

agencies do not maintain a comprehensive resource list **to use in referring callers to community service providers, and most do not have systematic follow-up procedures to determine whether people who are not their clients but for whom they provide referrals actually obtain the services.**

A third drawback is that home health agencies generally do not have systematic outreach procedures to identify isolated people with dementia and isolated caregivers who are not able to seek help for themselves. Lastly, although home health agencies

have extensive experience in providing in-home services for elderly people, including some people with dementia, anecdotal evidence suggests that some home health agency staff members are not knowledgeable about dementia or the care of people with dementia.

In considering the capacity of home health agencies to constitute a national system to link people with dementia to services, the large number of home health agencies is an advantage. It is unclear, however, if Congress designated home health agencies to constitute such a system, whether the system should be made up of: 1) all Medicare-certified home health agencies, 2) only certain types of Medicare-certified home health agencies (e.g., Medicare-certified VNAs, public agencies, and private, nonprofit agencies); 3) certain types of home health agencies regardless of their certification status; or 4) all Medicare-certified and non-Medicare-certified home health agencies. Given the existing link between the Federal Government and Medicare-certified home health agencies, it might be easier to implement a national linking system if only Medicare-certified agencies were included. Moreover, the Federal Medicare regulations create a certain uniformity and some basic standards for Medicare-certified agencies. On the other hand some non-Medicare-certified agencies, particularly some homemaker-home health aide agencies, provide in-home services that closely match the needs of many people with dementia, and these agencies would be valuable components of the linking system. If Congress chose to designate home health agencies to constitute a national linking system, this issue would require further analysis.

SOCIAL HEALTH MAINTENANCE ORGANIZATIONS

A social health maintenance organization (S/HMO) (pronounced shmo) is an innovative organizational entity that offers voluntarily enrolled, elderly Medicare beneficiaries a package of acute and long-term care services and operates on a capitated, prospectively freed budget. In essence, a S/HMO expands the acute care financing and service delivery model of a health maintenance organization (HMO) to include some long-term care services. As of 1990, there are four S/HMOs in the United States,

all of which are part of a congressionally mandated demonstration project—the National S/HMO Demonstration.²³ The four S/HMOs are:

- *Medicare Plus II*, in Portland, Oregon, which is sponsored by a large HMO with more than 280,000 members and extensive experience in providing acute care services to Medicare beneficiaries (Kaiser Permanente);
- *Seniors Plus*, in Minneapolis, Minnesota, which is sponsored by a partnership between a large HMO (Group Health, Inc.) and along-term care agency (the Ebenezer Society);
- *Elderplan*, in Brooklyn, New York, which is sponsored by a comprehensive long-term care agency with no prior experience in administering a prepaid health plan (Metropolitan Jewish Geriatric Center); and
- *SCAN Health Plan*, in Long Beach, California, which is sponsored by a case management agency with no prior experience in administering a prepaid health plan (Senior Care Action Network) (274,841).

OTA has included S/HMOs in its analysis of agencies that might constitute a national system to link people with dementia to services because, in theory at least, the S/HMO model of service delivery in which a single organization provides or contracts for and arranges acute and long-term care services for its members eliminates for those individuals many of the problems in locating and arranging services that are the topic of this OTA report (421). S/HMOs link some of their members to many of the kinds of services that may be needed for a person with dementia, and it is conceivable that S/HMOs could link all of their members with dementia to such services.

Overview of the Agencies

The National S/HMO Demonstration requires the four S/HMOs to offer their members all the acute health care services that Medicare covers (e.g., hospital inpatient and outpatient services, physician and diagnostic services, and specified home health care and skilled nursing home services) (841). In addition, the S/HMOs are required to offer their members certain other services not covered by Medicare, including long-term care services such as personal care, homemaker services, adult day care,

²³The national S/HMO demonstration was mandated by the Deficit Reduction Act of 1984 (Public Law 98-369). It began in 1985, and will continue as a demonstration until September 1992 (2,841).

respite care, transportation, and 2 to 4 months of nursing home care beyond the Medicare benefit (274,452).

To meet the requirements of the National S/HMO Demonstration, the HMO that sponsors Medicare Plus II had to add long-term care services to the acute care services it was already offering its elderly members (841). In contrast, the agencies that sponsor Elderplan and SCAN Health Plan had to add the acute care services required by the demonstration to the case management and long-term care services they were already offering-in effect by setting up new HMOs. Having to start new HMOs was a major challenge for these agencies (269,452). Seniors Plus is cosponsored by an HMO and a long-term care agency, and these agencies were already offering, respectively, the required acute care and long-term care services. According to one commentator, the S/HMOs that are sponsored or cosponsored by HMOs (Medicare Plus II and Seniors Plus) had less difficulty than the other two S/HMOs in enrolling members (half of Medicare Plus II's and more than half of Seniors Plus' S/HMO members were conversions from their affiliated HMOs) (295). The S/HMOs sponsored or cosponsored by HMOs also had more previous experience with controlling health care utilization and processing payments within a managed care system (295).

Although there are currently only four S/HMOs in the United States, existing HMOs could provide a basis for developing more S/HMOs. As of May 1987, there were at least 734 HMOs in this country (279), 214 of which had elected to participate in the Medicare program (588,840). Established HMOs that already serve Medicare beneficiaries, such as "TEFRA HMOs," probably could develop S/HMOs more easily and successfully than other HMOs (841). "TEFRA HMOs" are HMOs participating in Medicare as "risk-contractors" under capitation payment arrangements initiated by the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA). Many TEFRA HMOs already provide more acute and primary care services than Medicare does,²⁴ but they generally do not provide long-term care services. In May 1988, about 137 of the HMOs participating in Medicare were TEFRA HMOs (840).

S/HMOs derive their revenue from three major sources: 1) per capita payments from the Federal Government for Medicare beneficiaries; 2) monthly premiums (ranging from \$29 to \$49), deductibles, and copayments from S/HMO members; and 3) per capita payments from State Medicaid programs for S/HMO members who are eligible for Medicaid (270,841). For each of their Medicare members, S/HMOs receive a fixed per capita payment from the Federal Government equal to 100 percent of the average per capita cost of providing comparable fee-for-service benefits for a Medicare beneficiary living in the S/HMO's service area. For each Medicare member found to be "nursing home certifiable"—i.e., to meet the State's criteria for Medicaid-funded nursing home care—the S/HMOs receive a higher per capita payment (270,841).

In the first years of the S/HMO demonstration, the Federal Government and State Medicaid programs shared financial risk with the S/HMO sponsors (2,841). Now the four S/HMOs are at full financial risk for any losses they incur.

Who Is Served

Each S/HMO serves people over age 65 who are eligible for Medicare and choose to enroll in the S/HMO (2,274). As of December 1987, the four S/HMOs had about 15,000 members:

- . Medicare Plus II had 4,974 members,
- . Seniors Plus had 2,597 members,
- . Elderplan had 4,307 members, and
- . SCAN Health Plan had 2,840 members (2).

In general, S/HMOs have memberships that are proportionately representative of the overall Medicare elderly population in terms of sex, age, living arrangements, and health status (270,841). About one-third of S/HMO members are elderly people who live alone.

In part because S/HMOs are a Medicare demonstration and in part because the per capita payments S/HMOs receive from the Federal Government are based on the average per capita cost of comparable fee-for-service benefits for Medicare beneficiaries, each S/HMO needs to enroll a membership that is no more functionally impaired than a cross-section of the elderly Medicare population (452). To do so, S/HMOs are permitted to screen their applicants and

²⁴Services that are not covered by Medicare but are offered by some TEFRA HMOs include extra hospital days, annual physicals, and prescription drugs (438,439).

to “queue” (put on a waiting list) severely and moderately impaired applicants as necessary. Three S/HMOs (Seniors Plus, ElderPlan, and SCAN Health Plan) include queuing questions on their application forms and sort clients into functional impairment categories based on their responses to two questions concerning mobility and limitations in activities of daily living (ADLs) (452). These three S/HMOs have been able to maintain a member population that is roughly representative of elderly Medicare beneficiaries in terms of distribution of functional impairment:

- 80 percent or more of their members are unimpaired or only mildly impaired,
- 7 to 14 percent of their members are moderately impaired, and
- 5 to 8 percent of their members are severely impaired (274,452).

Medicare Plus II has chosen not to queue but also seems to have been able to maintain such a case mix (452).

OTA is unaware of any data on how many people with dementia are members of the four S/HMOs. It is possible, however, that the queuing mechanisms used by Seniors Plus, SCAN Health Plan, and ElderPlan prevent some moderately or severely impaired people with dementia from enrolling.

Once an individual is enrolled in one of the S/HMOs, decisions about whether the individual will receive specific S/HMO services are made by various different people. Decisions about acute medical care services are generally made by physicians employed by the HMOs and other organizations that provide these services for the S/HMOs (421). At Medicare Plus II, one of the two S/HMOs sponsored by an HMO, decisions about all services ordinarily covered by Medicare are made by hospital discharge planners, home health agency staff, and others who are employed by or work under contract with the sponsoring HMOs; the S/HMO case managers are responsible for decisions about the additional long-term care services required of S/HMOs but not ordinarily covered by Medicare (2). At ElderPlan and SCAN Health Plan, the two S/HMOs not sponsored by HMOs, certain S/HMO case managers are primarily responsible for discharge planning at the hospitals and nursing homes with which the S/HMOs have contracts, and other S/HMO case managers are primarily responsible for decisions

about long-term care services for S/HMO members who are not hospitalized or in a nursing home.

The process by which S/HMO case managers make decisions about which S/HMO members will receive S/HMO long-term care services is described briefly below. Ongoing case management is provided for all S/HMO members who receive long-term care services. Thus, the decisions made by S/HMO case managers about which S/HMO members will receive long-term care services also determine which members will receive ongoing case management. OTA is not aware of any data on how many individuals with dementia who are members of S/HMOs receive S/HMO long-term care services and case management. It is likely, however, that certain aspects of the process by which S/HMO case managers decide which S/HMO members will receive long-term care services prevent some people with dementia from receiving services and case management.

At the time of their enrollment in a S/HMO, all S/HMO members are sent a questionnaire on which they are to report basic social, health, and functional information (452). The completed questionnaires are screened by S/HMO case managers using a set of risk criteria to identify which members may need various types of services. Responses that suggest that a member may need long-term care services automatically trigger a phone call by the case manager (see below).

The questionnaire sent to new members is generally reliable for identifying individuals who are severely impaired as measured by the need for assistance with ADLs, but it does not include questions about mental status (270,452). That shortcoming means that responses to the questionnaire are not very useful in identifying individuals with dementia (452). To identify such individuals from the questionnaire, the S/HMO case managers would have to rely on clues, such as apparent confusion in completing the form or the member's use of psychotropic drugs. A shorter version of the questionnaire is sent to members annually. The shorter version includes a question on severe memory loss.

Based on new members' responses to the questionnaire, S/HMO case managers call all the members who the case managers think may need long-term care services-including all members who case managers think may qualify as “nursing home certifiable” (452). These telephone calls are used by

the case managers to identify individuals with mental impairments, as well as to verify the information on the questionnaires and provide information for new members about S/HMO services. If a S/HMO case manager concludes, based on the call to a member and the member's questionnaire, that the member does not need long-term care services or does not meet the S/HMO's eligibility criteria for such services, but the individual does seem to be at risk, the case manager may decide that the individual should be monitored, as discussed later in this section.

S/HMO members who the case managers think probably need long-term care services and who probably meet the S/HMO's criteria for long-term care services—including all members who case managers think probably qualify as "nursing home certifiable"—receive an in-home assessment by a S/HMO case manager (452,841). The in-home assessment, which usually takes 45 to 90 minutes, includes the member's health status, functional status, mental status, living arrangements, informal supports, and utilization of services. Following the in-home assessment, the case managers decide which members qualify for S/HMO long-term care services, develop service plans for those members, and arrange the services.

The S/HMOs use three different sets of eligibility criteria to determine which members qualify for S/HMO long-term care services—narrow criteria, broad criteria, and implicit criteria (452). Medicare Plus II and ElderPlan have narrow *eligibility criteria*, requiring that their members qualify as "nursing home certifiable" by State standards in order to be eligible for long-term care services (2,452). Different States have different standards for determining who is nursing home certifiable, but in general, the standards identify individuals who are physically or mentally quite disabled (2). In December 1987, 8 percent of Medicare Plus II's enrollees and 4 percent of ElderPlan's enrollees qualified as nursing home certifiable (2).

The narrow eligibility criteria used by Medicare Plus II and ElderPlan would undoubtedly exclude some members with dementia—for example, those in the early stages of a dementing disease. Furthermore, not all Medicare Plus II or ElderPlan S/HMO members who qualify as nursing home certifiable actually receive long-term care services (2). The

S/HMO long-term care benefit is intended to supplement but not replace what a member's family or other informal caregivers can do. If a member who qualifies as nursing home certifiable is judged by the S/HMO case manager to have adequate informal supports, that person will not receive long-term care services.

SCAN Health Plan uses *broad eligibility criteria*, requiring only that a member be determined by a case manager to be either moderately or severely impaired (452). Members in these two categories of impairment make up about 20 percent of SCAN Health Plan's membership but would not necessarily include all of the S/HMO's members with dementia.

Seniors Plus uses *implicit eligibility criteria* to determine its members' eligibility for long-term care services (452). This S/HMO formally limits eligibility to members who are nursing home certifiable (about 8 percent of Seniors Plus members in 1987 [2]) but in practice allows the case manager and the director of its case management unit to extend long-term care benefits to other members if they believe that the members are "at risk" and in need of long-term care services. Thus, a person with dementia at SCAN or Seniors Plus might or might not receive long-term care services.

In addition to limitations on eligibility for S/HMO long-term care services, each S/HMO has imposed the following dollar limits on the amount of long-term care services an eligible member may receive. The S/HMO case managers are responsible for keeping expenditures within these limits:

- Medicare Plus II, \$12,000 per year, with a monthly cap for each member of \$1,000 for community care or 100 days of nursing home care per spell of illness;
- Seniors Plus, \$6,500 per lifetime for nursing home care and \$5,000 per year for community-based care; Seniors Plus has no set monthly budget cap, but the S/HMO case managers must obtain approval of the S/HMO director prior to authorizing any services costing over \$100 per week;
- ElderPlan, \$6,500 annually, with a monthly cap of \$450 per month; and
- SCAN Health Plan, \$7,500 per year, with a monthly cap of \$625 (2,841).

Data from the first **2 years** of the National S/HMO Demonstration show that only a few S/HMO members used enough long-term care services to reach these dollar limits (841).

Linking Functions

Information and Referral



S/HMOs are intended to serve their members, and they do not provide information and referrals to the general public. S/HMO case managers do provide information and referrals for S/HMO members in some instances (2). S/HMO case managers are supposed to refer S/HMO members to free or low-cost community services whenever such services are available and appropriate. For this reason, a S/HMO case manager may refer a S/HMO member to services in the community even if the services are available through the S/HMO. A S/HMO case manager may also refer a member to services in the community if the person needs services that are not included in the S/HMO's benefit package (e.g., legal help, shared housing, home-delivered meals, friendly visitors, senior center) (841). Lastly, if the amount of long-term care services a member receives reaches the dollar limits listed earlier, the S/HMO case manager may refer the member to non-S/HMO services until the benefit renews (usually annually) (2).

Case Management



Case managers play a central role in the S/HMO model of service delivery. As already described, S/HMO case managers determine which S/HMO members will receive long-term care services based on information from a questionnaire completed by each member, a telephone screen conducted by the case managers, and home visits conducted by the case managers. For S/HMO members found to need and be eligible for S/HMO long-term care services, the case managers develop service plans and arrange and coordinate the services. Thus, in the S/HMO model, case managers determine not only which members can receive long-term care services, but also what long-term care services and how much of these services they will receive.

At all four S/HMOs, the case managers are either health professionals, including registered nurses, social workers, and others (e.g., a physical therapist, a speech pathologist), or people with college degrees in human services) (841). As of December 1987, each of the S/HMOs had 5 to 7 case managers with an average caseload of 50 to 71 clients (2).

The case management provided by S/HMOs differs from that provided by many other categories of agencies discussed in this chapter in that it is provided in the context of a service delivery system operating on a capitated, prospectively fixed budget in which there are strong incentives to control the utilization and costs of services (2,270). In such a system, many of the functions of a case manager are essentially administrative tasks related to the operation of the system (e.g., determining an individual's eligibility for services and authorizing the services). S/HMO case managers also perform the five functions that OTA defines as core case management functions—namely: 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. The way they perform these functions is undoubtedly influenced by the focus of the system on controlling the utilization and costs of services, however.

As noted earlier, all S/HMO members who receive long-term care services also receive ongoing case management. In December 1987, the percentage of S/HMO members receiving long-term care services and case management was 5 percent at Medicare Plus II, 10 percent at Seniors Plus, 2 percent at ElderPlan, and 7 percent at SCAN Health Plan (2). OTA does not know what proportion of these individuals had dementia.

Ongoing case management is provided for S/HMO members who are receiving long-term care services to make sure they receive prescribed services and to keep the plan of care updated and cost-efficient (2,518). Contact between the S/HMO case manager and the member or the member's family is often frequent during the first 2 to 3 weeks of a care plan until the plan is fully implemented. Once long-term care services are in place and working well, case managers telephone members and/or their families once a month to once every 3 months to monitor their health status and care needs. At Medicare Plus II, case managers do most of their routine monitor-

ing by telephone and make a home visit every 3 months. At Seniors Plus, most monitoring is done by long-term care providers (e.g., home health aides, nursing supervisors, adult day center staff), who alert the S/HMO case manager if changes occur. At SCAN Health Plan, case managers make monthly home visits to all members with service plans. According to one commentator, the S/HMO case managers also maintain telephone contact with families who live at a distance from a S/HMO member receiving long-term care services, to discuss the member's health status and plan of care—especially if the member is severely impaired (422).

Case managers review selected S/HMO members' health status and plans of care at weekly case conferences, which also serve as a quality assurance and utilization review for services provided under the long-term care benefit package. Case managers are also required to provide each member receiving long-term care services with a comprehensive in-home reassessment every 6 months. Many case managers consider the reassessment process unnecessary because their ongoing, frequent contact with members allows them to reassess members' health status and modify plans of care accordingly, without a formal reassessment (841).

Initially, all four S/HMOs chose to provide case management to some "at-risk" members who were not nursing home certifiable or severely impaired and therefore not eligible for long-term care services but were judged by the S/HMO case managers to need "monitoring" due to an unstable medical or social situation (452,841). Over the course of the demonstration, all four S/HMOs have had to cut back on this practice because of the expense. As of December 1987, the percentage of S/HMO members being 'monitored' but not receiving long-term care services was 4 percent at Medicare Plus II, Seniors Plus, and SCAN Health Plan and 3 percent at ElderPlan (2).

What is involved in "monitoring" varies from one client to another and from one S/HMO case manager to another, but anecdotal evidence suggests that some S/HMO members who are being "monitored" are receiving what OTA defines as case management. OTA does not know how many individuals with dementia who are members of S/HMOs are being "monitored." As of December 1987, most Medicare Plus II and Elderplan members who were being monitored were nursing home

certifiable, whereas at Seniors Plus and SCAN Health Plan, most members who were being monitored were not nursing home certifiable.

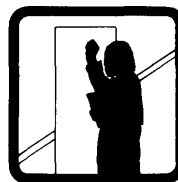
Public Education



Each S/HMO offers health education programs to its membership (422). OTA does not know whether any of these programs include information about dementia or services for people with dementia.

To recruit members, the S/HMOs emphasized that they were designed to keep people healthy and in their own homes. Medicare Plus II, the S/HMO most successful in enrolling new members, combined a direct mail campaign with group presentations and poster displays for the community groups and organizations that supported the S/HMO's development. OTA does not know to what extent, if any, these efforts and similar efforts by the other S/HMOs included information about dementia or about the potential value of the S/HMO model of service delivery for people with dementia and their caregivers.

Outreach



S/HMOs serve only individuals enrolled in their programs. S/HMOs do not have outreach procedures to identify non-S/HMO members with dementia or their caregivers who are in need of assistance but unlikely to seek help on their own.

As discussed previously, S/HMOs use various procedures (e.g., the initial questionnaire and annual followups) to identify S/HMO members who may need services. OTA does not know how often these procedures identify S/HMO members with dementia who need assistance but are unable to seek it on their own. Anecdotal evidence suggests that such individuals would usually come to the attention of a S/HMO case manager via a referral from a physician, a service provider, or a family member or friend of the individual (422).

All four S/HMOs use case-finding mechanisms in hospitals to identify S/HMO members whose conditions may require long-term care services. Medicare Plus II and Seniors Plus train personnel in hospitals, nursing homes, and home care agencies to identify such individuals and refer them to the S/HMO case

managers (452). ElderPlan and SCAN Health Plan involve their case managers in discharge planning at the hospitals with which they have contracts. It is important to note, however, that case-finding mechanisms in hospitals are of little value to people with dementia who are not hospitalized.

Role in Allocating Services and Funding

S/HMOs control the allocation of all the health care and long-term care services included in the *S/HMOs'* benefit package. All allocation decisions are made in the context of the *S/HMOs'* prospectively determined, capitated budget, in which there are incentives to control the utilization and costs of services.

Summary

As agencies that might be designated to constitute a national system to link people with dementia to services, *S/HMOs* offer several advantages:

- By providing or contracting for and arranging many of the acute and long-term care services needed by their members, *S/HMOs* eliminate for their members who receive these services many of the problems in locating and arranging services that are the topic of this OTA report.
- *S/HMOs* provide comprehensive in-home assessments by case managers (typically registered nurses or social workers) to members who case managers think will require long-term care services.
- *S/HMOs* provide their elderly members receiving long-term care services with ongoing case management. This includes care planning, coordinating and arranging services, monitoring services, and periodically reassessing the individual's needs. In addition, *S/HMOs* provide case management in the form of monitoring to some other members who case managers think are at risk.
- *S/HMOs* build on the concept of *HMOs*, and it is possible that some of the-existing *HMOs* in this country could be used as a basis for developing more *S/HMOs*.

Despite these advantages, there are significant drawbacks to designating *S/HMOs*--as they are currently operating--to constitute a national linking system for people with dementia. One obvious drawback is that there are only four *S/HMOs* at present. On the other hand, if reimbursement were

available through Medicare or other funding sources, *HMOs* and other agencies would be likely to establish *S/HMOs*. A second drawback is that *S/HMOs* serve only their members, and some people with dementia might not be able to join a *S/HMO*. All but one of the four existing *S/HMOs* has at various times queued applicants to maintain an acceptable case mix of impaired and unimpaired enrollees. This mechanism may keep some moderately and severely impaired individuals with dementia from joining. Furthermore, *S/HMOs* serve elderly people exclusively, and some people with dementia are not elderly.

Another problem is that although *S/HMOs* provide case management for members who are receiving long-term care services, some *S/HMO* members with dementia--especially members with mild or moderate dementia--are not likely to receive long-term care services and therefore may not receive case management. The process by which *S/HMO* case managers decide which *S/HMO* members will receive long-term care services is intended to target the services to the people who are most impaired and therefore most in need of services. Although targeting services to the most impaired individuals maybe entirely appropriate, an effective system to link people with dementia to services, including the case management component, must be available to patients and their families throughout the course of the patient's illness. The existing *S/HMOs* do "monitor" some members who are not so impaired as to be nursing home certifiable, but these individuals constitute only 1 to 3 percent of all *S/HMO* members.

Lastly, the existing *S/HMOs* provide little, if any, public education about dementia or about potentially beneficial services for people with dementia and little outreach, except case finding procedures for hospitalized *S/HMO* members. The extent to which *S/HMOs* provide their members with information about and referrals to non-*S/HMO* services in the community is unclear, but providing such information and referrals is clearly not one of the primary functions of *S/HMO* case managers. If *S/HMOs* were designated to constitute a national linking system for people with dementia, their public education, outreach, and information and referral activities would have to be expanded.

It is important to keep in mind that the *S/HMO* is an experiment, and components of the *S/HMO* model may hold more promise than the specific

current implementation of the model in meeting the long-term care needs of the elderly, in general, and of people with dementia, in particular. The S/HMO model is an important demonstration of what HMOs might do in the area of long-term care if Medicare reimbursement were increased specifically for long-term care services.

ON LOK SENIOR HEALTH SERVICES

On Lok Senior Health Services is an organization that plans, coordinates, and provides case management and comprehensive health care, long-term care, social, and other services for about 300 very impaired and frail older adults in the Chinatown-North Beach area of San Francisco (639). All of On Lok's clients have been certified by California's Medicaid program, Medi-Cal, as needing intermediate or skilled nursing home care. Without the services provided by On Lok, many of them would be unable to continue residing in the community (28).

OTA has included On Lok in its analysis of agencies that might constitute a national system to link people with dementia to services because On Lok's comprehensive, consolidated service program exemplifies a model of service delivery that eliminates for its clients the problems in locating and arranging services that are the focus of this OTA report.

The On Lok model, in which a single organization provides or contracts for virtually all the health care and health-related services its clients need, can be contrasted with the more traditional model of case management and service delivery in which a case manager refers individuals who need health care, long-term care, social, and other services to agencies and individual service providers in the community (639). The On Lok model is similar to the social health maintenance organization (S/HMO) model discussed in the previous section of this chapter in that it provides services to voluntarily enrolled individuals in exchange for a fixed per capita payment, but On Lok provides a wider range of long-term care, social, and other services than S/HMOs provide. Another difference between On Lok and S/HMOs is that S/HMOs serve a full spectrum of healthy and impaired people over age 65 (3), whereas On Lok serves only severely impaired adults over age 55.

Overview of the Agency

On Lok's program began in 1972 and has expanded over the years. In 1972, On Lok received a 3-year research and demonstration grant from the Administration on Aging to establish an adult day health center (633,940). In 1975, On Lok got another 3-year grant from the Administration on Aging, this time to expand its adult day health program and to provide a variety of other services (e.g., in-home chore services, home-delivered meals, and housing assistance)--all of which were to be delivered or supervised by a multidisciplinary team (634). In 1978, On Lok got a 4-year grant from the Office of Human Development Services in the U.S. Department of Health and Human Services to plan and implement a comprehensive, consolidated, long-term care program for dependent adults (635).

From 1979 to 1983, On Lok operated as a Medicare demonstration program with funding through Medicare waivers; during that time, On Lok received per capita payments for the care of its clients from Medicare, but the payments were based primarily on the costs that On Lok incurred (942). In 1983, On Lok assumed full financial risk for providing all health care and health-related services for its clients in exchange for a fixed per capita payment. On Lok has both Medicare and Medicaid waivers to allow the provision of comprehensive services and for its risk-based financing system.

Currently, On Lok operates three adult day health centers. These adult day health centers are open 7 days a week and are the primary setting in which On Lok's clients receive services. On Lok also has a home health care department that provides in-home services, including home health care, personal care, hospice, and respite care for On Lok clients who need these services (639). Through its adult day health and home care programs, On Lok has the capacity to monitor any client on a 24-hour basis.

About three-quarters of On Lok's clients live alone (28,639). Many of them live in congregate housing provided by organizations affiliated with On Lok. Such housing includes the 54-unit On Lok House, which is subsidized by the U.S. Department of Housing and Urban Development, and a 35-unit single room occupancy hotel, which is privately funded. For some clients, On Lok arranges housing in private residences.

Although On Lok's goal is to enable its clients to continue residing in the community, On Lok arranges and pays for inpatient hospital care or nursing home care for its clients who need either type of care (639,942). On Lok has contracts with local hospitals and nursing homes to provide the needed care, but On Lok retains responsibility for its clients who are hospitalized or in a nursing home. On Lok's physicians manage the care of these clients, and other On Lok staff members visit the clients regularly to monitor their care (639, 942). On Lok clients who are in a nursing home usually continue to attend On Lok's adult day health centers 1 or 2 days a month (639).

As mentioned earlier, On Lok has operated on a risk-based financing model since 1983 (636,639). On Lok receives a fixed, per capita payment for each client. The payment is received from Medicare, Medi-Cal, and/or the client (depending on whether the client is eligible for Medicare and Medi-Cal). When the cost of services is higher than the payment On Lok receives, On Lok absorbs the loss. When the cost of services for an individual client is higher than the payment On Lok receives, On Lok places the excess revenue in a risk reserve fund to pay for cost overruns (28).

For fiscal year 1988, On Lok received an average monthly payment of \$2,156 per client (28). Most of On Lok's clients are eligible for Medicare, and for these clients Medicare pays 36 percent of the per capita payment to On Lok; the remaining 64 percent is paid either by Medi-Cal (for clients who are eligible for Medi-Cal) or by the client. Clients who are unable to pay for part or all of their portion of the payment due to special family circumstances maybe eligible for "scholarships" through a United Way allocation (639). As of the last quarter of fiscal year 1987, Medicaid payments accounted for about two-thirds of On Lok's \$7.2 million annual budget; Medicare payments accounted for just under one-third, and other sources, including clients and the United Way, made up the remainder (640,780).

Efforts to expand On Lok's model of community-based long-term care to other areas of the country are underway. In the Omnibus Budget Reconciliation Act of 1986 (Public Law 99-509), Congress authorized the Health Care Financing Administration to grant On Lok-type waivers to as many as 10 replication sites. In 1987, the Robert Wood Johnson Foundation committed \$4.2 million in startup funds

for six On Lok replication sites and gave On Lok \$1.6 million to provide technical assistance to prospective replication sites (638). In 1987, the Hartford Foundation pledged an additional \$600,000 to On Lok to provide technical assistance in the replication project (637).

Nearly 180 organizations expressed interest in participating in the On Lok replication project. Six replication sites were selected in 1987: the East Boston Neighborhood Health Center in Boston, Massachusetts; Beth Abraham Hospital in Bronx, New York; Providence Medical Center in Portland, Oregon; the Richland Memorial Hospital in Columbia, South Carolina; Bienvivir Senior Health Services in El Paso, Texas; and the Community Care Organization in Milwaukee, Wisconsin.

On Lok continues to work with other sites interested in participating in the replication effort.

Who Is Served

As noted earlier, On Lok currently serves a population of about 300 severely impaired and frail older adults (3). To be eligible for On Lok services, individuals must meet the following criteria:

- . be 55 years or older,
- reside in On Lok's 3.5-square-mile catchment area in northeast San Francisco, and
- . be certified by Medi-Cal as requiring intermediate or skilled nursing home care (639).

During the first 2 years of On Lok's operation as a Medicare demonstration project, the application of these criteria eliminated over 80 percent of all referrals (941), and On Lok had a difficult time securing an adequate number of clients. Other reasons for On Lok's difficulty in securing clients included the inability of many severely impaired elderly people to seek help from On Lok on their own, the unwillingness of some physicians to refer their patients to On Lok and thus relinquish control of the patients, and the reluctance of many elderly people to change their health care arrangements unless motivated to do so by the development of an acute illness (941). On Lok has found that securing an adequate number of clients requires continuing efforts to educate the community about On Lok's services and advantages for potential clients (28).

According to a client profile published in 1988, the average On Lok client is 81 years old and has five serious medical conditions (639). About 58 percent

of On Lok's clients are female, and 42 percent are male. More than 80 percent of On Lok's clients are of Chinese descent; 4 percent are Italian; 2 percent are Filipino; and the rest are of other backgrounds (640). On Lok clients' average monthly income is \$535; 68 percent receive Supplemental Security Income (640). As noted earlier, about 75 percent of On Lok's clients live alone, either in their own homes or in congregate housing. The other 25 percent live with others in the community. About 70 percent of clients require assistance with bathing, 68 percent with home care, 64 percent with cooking, and 51 percent with grooming and hygiene (639).

Many On Lok clients have cognitive impairments. According to On Lok's figures, 85 percent have short-term memory problems, and 80 percent have long-term memory problems (640). Thirty-eight percent have a diagnosis of a mental disorder.

Linking Functions

Information and Referral



On Lok's primary objective is the provision of comprehensive health care, long-term care, social, and other services to its own severely impaired clients. On Lok is not currently oriented toward providing information and referrals for the general public.

Case Management



All of On Lok's clients receive case management. Each person referred to On Lok is assessed by a multidisciplinary team that includes a physician or nurse practitioner, a social worker, a nurse, physical and occupational therapists, and others (942). If warranted, the assessment may also involve a psychiatrist and other medical specialists. Following a comprehensive assessment, a representative from the State Medicaid office certifies or declines to certify the individual as needing intermediate or skilled nursing home care (639).

If an individual is certified as needing intermediate or skilled nursing home care and meets On Lok's other eligibility criteria, he or she is accepted into On Lok's program. On Lok's clients receive ongoing case management by On Lok's multidisciplinary team. The case management includes the development of a plan of care by the multidisciplinary team

that assessed the client, and the subsequent coordination, arrangement, and monitoring of all the health care, long-term care, social, and other services that the client receives (942). It also includes the reassessment of each client at regular intervals. Most clients are reassessed every 3 months, although clients whose conditions are considered stable are reassessed less frequently (e.g., every 6 months).

Public Education



To OTA's knowledge, On Lok does not provide information for the general public about dementia or services for people with dementia. As noted earlier, On Lok has found that securing an adequate number of clients requires continuing-efforts to educate the community about On Lok's services (28). To inform the community about its services, On Lok sponsors public service announcements over the local media, places ads on buses, and participates in an annual health fair in the Chinatown area of San Francisco (940). On Lok's staff also participate in local and national conferences and meetings, where they present information about On Lok's experience with case management, health care financing, and alternative long-term care service delivery systems (28,940).

Outreach



Typically, *On Lok* serves clients who have been referred by various sources, including families, physicians, hospital discharge planners, other community agencies, and family associations (28). A few referrals have resulted from On Lok's participation in a local group called the Coalition of Agencies Serving the Elderly. Recently, On Lok's social workers have been visiting local apartment houses and public housing complexes to reach isolated, elderly people who might benefit from On Lok's services, but are unlikely to learn about the services through On Lok's community education efforts or to be referred to On Lok by other sources.

Role in Allocating Services and Funding

Unlike most of the other agencies discussed in this chapter, On Lok controls the allocation of all health care, long-term care, social, and other services for its clients. All services for each client are planned and



Photo credit: On Lok Senior Health Services

Recently, On Lok's social workers have been visiting local apartment buildings and public housing complexes to reach isolated, elderly people who might benefit from On Lok's services but are unlikely to contact the agency on their own or to be referred to On Lok by another source.

coordinated by On Lok's staff and directly provided by On Lok's multidisciplinary team, by authorized consultants, or by contractors (639).

Summary

As an agency that might be designated to serve as the basis of a national system to link people with dementia to services, On Lok offers several positive features:

- By providing virtually all the health care, long-term care, social, and other services that are needed by its clients, On Lok eliminates problems they might otherwise have in locating and arranging services.

- On Lok provides a comprehensive, multidisciplinary assessment for the individuals who are referred to it.
- On Lok provides ongoing case management, which includes care planning, coordinating and arranging services, monitoring services, and periodically reassessing the individual's needs.
- On Lok has the capacity to serve individuals on a 24-hour basis.

Although On Lok essentially eliminates for its clients the problems in locating and arranging services that are the focus of this OTA report, the On Lok model is not an appropriate model to use as the basis of a national system to link people with dementia to services. As currently structured, the On Lok model is intended to provide case management and comprehensive services to a small population of severely impaired and frail older adults who have been certified as requiring intermediate or skilled nursing care. The On Lok model is not intended to provide information and referrals or case management for people who are less severely impaired (e.g., people in the early and middle stages of dementia) or for their caregivers.

Clearly, On Lok is an effective service system for its clients, and the large number of organizations nationwide that expressed an interest in participating in the On Lok replication program attests to the enthusiasm many service providers feel about this innovative model of service delivery. Moreover, there is little doubt that On Lok's clients with dementia are receiving the care they need. To expand On Lok's functions to include providing information and referrals and case management for people with dementia who are not as severely impaired as On Lok's current clients or who do not need the comprehensive services On Lok provides, would require a significant change in direction and priorities for the organization, possibly to the detriment of the model service system it has created.

ADULT DAY CENTERS

Adult day centers are community organizations that provide a range of health care, social, and other services to small groups of functionally impaired adults in group settings during specified hours of the week. By providing services in a group setting for these functionally impaired adults, adult day centers also give the individuals' primary caregivers a temporary respite from the demands of caregiving.

The National Institute on Adult Daycare, a membership organization composed of professionals in the field of adult day care, has estimated that as of 1989 there were at least 2,500 adult day centers in the 50 States, the District of Columbia, and Puerto Rico (940). Most of the centers are located in cities and other densely populated areas (488).

OTA has included adult day centers in its analysis of agencies that might constitute a national system to link people with dementia to services because many adult day centers serve people with dementia, and anecdotal evidence suggests that the staff of some of these centers have come to be regarded as local experts on what services are beneficial for people with dementia and their caregivers and where such services can be found. As a result, some health care and social service professionals, service providers, and family caregivers turn to them for information and referrals for people with dementia. Furthermore, the Robert Wood Johnson Foundation is currently sponsoring a demonstration project in which the goal is to create a comprehensive system of care for demented people and their caregivers that relies on adult day centers to coordinate the care (717).

Overview of the Agencies

Adult day centers were established in the United States as the result of a grassroots movement to develop services that would enable fictionally impaired adults to remain in their own homes rather than be institutionalized (879). Although a small number of adult day centers were established before 1970, most have been established since then. In part, because of their grassroots origins, adult day centers vary considerably with respect to the organizations with which they are affiliated, the settings in which they operate, the content and structure of their programs, and the clientele they serve (879). Adult day centers are not subject to Federal regulation, although some adult day centers provide services that are reimbursed by Medicaid or Medicare, and those services are subject to Federal regulation (831). The lack of Federal regulation contributes to the variation among centers.

In 1979, the National Council on the Aging established the National Institute on Adult Daycare to open communication among adult day centers

throughout the country and to coordinate activities for the further development of adult day programs and services (879). In 1984, the institute published voluntary national standards for adult day centers, and in 1988, the institute began revising the standards in an effort to reflect the special needs of clients with Alzheimer's disease and other dementing disorders (579).

Adult day centers vary greatly in the services they provide. Some adult day centers provide primarily health care services, and some centers provide primarily social and personal care services. Most provide some combination of social services, nursing, recreational activities, exercise, reality therapy, personal care, and nutrition counseling (879). Although most centers do not provide their clients with a medical evaluation, some centers can arrange for a medical diagnosis or a second opinion for their clients (336,940). Some centers also provide or contract for physical therapy, speech therapy, occupational therapy, psychotherapy, and legal and financial counseling (879). During the time clients are at an adult day center, the center's staff are able to monitor their functional, psychosocial, and general health status on an ongoing basis (336,940). Many centers also offer services for their clients' families and other informal caregivers, such as counseling, caregiving training, caregiver support groups, and information about services and sources of finding for services (606).

Some adult day centers offer services for a few hours a day (e.g., 9 a.m. to 3 p.m. or 10 a.m. to 1 p.m.), 5 days a week (606). Other centers offer services for a few hours a day, 2 or 3 days a week. Still other centers offer services for part of the day only 1 day a week. In some cases, people with dementia who need constant supervision or who may be upset by an interruption in their daily routine attend an adult day program 7 days a week (940),²⁵ but most adult day programs do not operate on a 7-day schedule, so this option is not always available (606).

Most adult day centers are operated by private, nonprofit agencies (879), but some are operated by public agencies, and a few are operated by private, for-profit agencies. Many adult day centers share facilities with other programs. Settings for adult day

²⁵On Lok Senior Health Services, described in the previous section, evolved from an adult day center and offers adult day services 7 days a week (639).

centers include hospitals, churches, senior centers, community centers, elderly housing projects, and nursing homes. Nurses and social workers are the most commonly reported paid professional staff of adult day centers and often serve as a center's director (879). Physicians or psychiatrists may sometimes be available as part-time consultants. Other professionals and laypersons sometimes serve as volunteers.

As of 1986, the average daily cost of providing adult day services was about \$31 per client (879). The two main sources of funding for adult day services are Medicaid and participants' fees. Medicaid reimbursement for adult day services is available at the option of individual States; a nationwide survey by the National Institute on Adult Daycare, completed in 1988, found that 25 States were providing coverage for adult day services under Medicaid (580). People who are not eligible for Medicaid usually pay for adult day services out-of-pocket (879). Some centers allow participants to pay fees based on a sliding fee scale related to their incomes (606). Additional funds may be provided by sources such as foundation grants, individual donations, fundraising projects, and United Way (879). Some funds are also provided by States under the Older Americans Act, the Social Services Block Grant, and Medicaid 2176 waivers.²⁶ As of 1989, proposed Federal legislation to cover adult day services under Medicare had not been enacted (although Medicare does sometimes pay for health care services, e.g., physical therapy, provided by some adult day centers) (606). Most private insurers do not cover adult day services (879).

Who Is Served

In 1987, it was estimated that existing adult day centers served less than 1 percent (about 4,000) of the noninstitutionalized people with dementia in the United States (717). As the demand for adult day services for people with dementia increases, however, some adult day centers are modifying their programs to accommodate clients with dementia. An analysis of a program offered by an adult day center in Gardena, California, that has adapted its program to include people with dementia, concluded that adult day centers can successfully adapt their

programs to meet the needs of adults with dementia (126).

Many adult day centers serve a mixed clientele with both demented and nondemented people. A 1985-86 survey by the National Institute on Adult Daycare did not ask specifically about dementia but did ask about client characteristics that may be related to dementia, such as supervision needs (879). Data from the 847 adult day centers that responded to the survey show that 45 percent of their clients required supervision, and 20 percent required constant supervision.

One example of an adult day center that serves a mixed clientele with some demented patients is the Woodside Senior Assistance Program in Woodside, New York (606). This program serves about 25 persons over the age of 50, approximately 20 percent of whom are 'non-wandering, relatively early stage Alzheimer's patients.' Another example of a center that serves a mixed clientele with some demented patients is the Sea View Hospital and Home Adult Day Services Program in Staten Island, New York. This program serves adults over the age of 21, about 10 percent of whom have Alzheimer's disease and participate in separate as well as combined activities.

Although most adult day centers that serve people with dementia also serve nondemented people, a small but increasing number of adult day centers serve only people with Alzheimer's disease and other dementing illnesses (605,740). Dementia-specific adult day centers usually serve a smaller number of participants than centers with a mixed clientele (717). One dementia-specific center, the Family Respite Center in Virginia, is described in box 8-P.

The number of demented individuals who are able to use adult day services is limited for several reasons. One reason is that existing adult day centers tend to be located in cities or other densely populated areas (488). People with dementia who do not live near a center may be unable to attend because they lack transportation or are unable to commute to the center because of distance. One commentator has noted that some people with dementia become anxious and agitated during long commutes (488).

²⁶Centers that receive Medicaid funds tend to have a health care orientation, whereas centers that rely on Social Services Block Grant funds tend to have a social services orientation (824).

Box 8-P—The Family Respite Center in Falls Church, Virginia

The Family Respite Center is a nonprofit adult day center in Falls Church, Virginia, that has been serving demented people and their caregivers since 1984. The center occupies two large rooms with adjoining bathrooms and kitchen facilities in a local church. It operates from 7:30 a.m. to 5:30 p.m. on weekdays and serves a maximum of 20 clients each day. The center has offered in-home respite care since March 1988 on an hourly and overnight basis.

Funding for the Family Respite Center comes from private donations and clients' fees. Four clients are eligible for Social Services Block Grant funds, and two participants attend on scholarships. The local AAA funds, the meal component of the program and cooperates with other community agencies to provide transportation to the center.

Clients are referred to the Family Respite Center by various sources that include physicians, hospitals, the Department of Social Services, the AAA, community groups such as the Alzheimer's Association, the American Association of Retired Persons, local churches, private home care agencies, and the Madison Adult Day Care Center operated by Arlington County, Virginia.

The Family Respite Center offers a comprehensive program of therapeutic physical and social activities to maintain or improve the physical and mental abilities of demented clients. Each participant is under the care of his or her family doctor, who is kept informed of the patient's status. In addition to informally monitoring each participant's behavior and health, the center reassesses each participant's functional status every 3 months. The center's medical director is a neurologist who is available to consult with both staff and family caregivers. The center also offers education programs for caregivers, volunteers, and service providers and conducts a support group twice a month for family caregivers.

The Family Respite Center does serve people with dementia who are incontinent, who may be disruptive, or who have a history of combativeness. The center also serves people with dementia without immediate family to care for them, providing that they have friends or other individuals who can transport them to the center and provide other services needed to enable them to reside in the community.

Having acquired a reputation via the grapevine as a knowledgeable source of information and referrals, the Family Respite Center receives an average of two inquiries a day from families seeking information about Alzheimer's disease and appropriate services for a family member. Referrals to other services are based on the director's knowledge of local resources and of the experiences of other clients. No formal recommendations are made, and clients are encouraged to evaluate all services before using them.

SOURCE: L.Noyes, director, Family Respite Center, Inc., Falls Church, VA, personal communications, Apr. 12, 1988.

Another reason the number of demented individuals who are able to use adult day centers is limited **is that** most centers have eligibility criteria that exclude certain potential clients. Eligibility criteria vary from center to center (336,606,879,940). Some centers serve all adults over the age of 21 who meet other specified criteria, whereas others serve only those over the age of 55 or 65. Some centers restrict eligibility to people from certain geographic areas; others impose no geographic restrictions. Some centers restrict eligibility on the basis of functional impairment, and other adult day centers serve people with severe functional impairments (304,690).

Eligibility criteria that exclude people who are incontinent, behaviorally disruptive, or combative are likely to exclude some people with dementia. In response to the 1985-86 survey of 847 adult day centers by the National Institute on Adult Daycare, 35 percent of the centers reported that they had

excluded people with unmanageable incontinence; 30 percent reported that they had excluded people who were behaviorally disruptive; and 12 percent reported that they had excluded people who were combative (**879**). Five percent of the 847 centers reported that they had excluded people they considered "too confused," and 5 percent reported that they had excluded people who needed constant supervision. Many of the 847 responding centers indicated that decisions about whether to allow individuals to participate in their programs were often made on a case-by-case basis, depending on factors such as the severity of an individual's functional impairment and the compatibility of an individual's needs with those of other clients.

Even some dementia-specific adult day centers have eligibility criteria that exclude certain people with dementia. The Adult Day Services Program of the Hebrew Home for the Aged in the Bronx, New

York, serves people aged 55 or over with a diagnosis of Alzheimer's, multi-infarct dementia, or Parkinson's disease; the program does not accept people with unmanageable incontinence or wandering behavior (606). In contrast, another dementia-specific program, the Alzheimer's Day Care Program of Morning side House in the Bronx, New York, admits people of all ages and does accept persons who are incontinent (606).

Some adult day centers do not serve people with dementia who live alone and do not have a family or other caregiver to supervise them when the center is closed (488,606). The following anecdote illustrates how the staff of one adult day center worked with a local church to enable a client with Alzheimer's disease who had no family caregiver to remain in the community.

Paul, who suffers from Alzheimer's disease, lives alone and has no immediate family to look after him. He is a member of a local church, however, and church members have taken an interest in his well-being. Some time ago, with the help of church members, Paul was enrolled in an adult day program. Steve, a young man who is a member of Paul's church, agreed to transport Paul from his apartment to the adult day center.

At one point, the local adult protective services agency became concerned about Paul's safety during the hours he wasn't at the adult day center. Adult protective services staff were particularly worried that Paul might wander at night and recommended that he be placed in a nursing home. The adult day center staff objected to this recommendation, because their experience with Paul indicated that once Paul fell asleep, he slept soundly. Steve indicated that he was willing to remain overnight with Paul when Paul was restless, anxious, or unable to fall asleep easily. The staff at the adult day center were convinced that with Steve's assistance, Paul was capable of remaining in the community.

Eventually, the adult protective services agency took Paul's case to court. The adult day center staff were able to convince the court that Paul was capable of functioning safely in the community. The adult day center staff are now trying to find a new apartment for Steve and his family that would also accommodate Paul (617).

As this anecdote suggests, adult day center staff are often highly dedicated people who become very involved in the well-being of their clients and are willing to "go the extra mile" to help their clients get the services they need.

Linking Functions

Information and Referral



Although adult day centers generally have no formal mechanisms for providing their clients and clients' families with information and referrals to other community agencies, many adult day centers do provide clients and their families with information and referrals on an informal basis. Some centers also refer their clients to local AAAs, Alzheimer's Association chapters, or other agencies for information and referrals to community services (485,617,940).

Adult day centers have no formal mechanisms for providing people other than their clients and clients' families with information and referrals to community services, but staff members at some adult day centers that serve people with dementia do provide information and referrals to people other than their clients on an informal basis (485,617,940). These staff members are likely to learn from various sources about services that are used by people with dementia and their caregivers. They may hear about services their clients have used or learn about services through their efforts to help their clients find other sources of assistance. Some staff members at adult day centers come to be perceived as local experts on services for people with dementia, and other health care and social service providers may call them for information and advice. Families of people with dementia may also be referred to them, sometimes for adult day care, but often for information about other community services.

Case Management



Adult day centers generally do not provide their clients with formal case management, but frequent personal contact with clients and their families provides staff members an opportunity to informally assess the needs of clients and their families, suggest appropriate services, and help the family locate and arrange services (485,617,940). Such staff members generally have limited time and resources for formal followup, but clients and their families are likely to report back informally on the success or failures of referrals they have received.

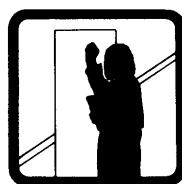
As noted earlier, the Robert Wood Johnson Foundation is sponsoring a \$7.5 million project, the Dementia Care and Respite Services Demonstration, with the goal of creating a comprehensive system of care for demented people and their caregivers in which adult day centers serve as the central coordinating element (717). In 1988, the foundation, in conjunction with the Alzheimer's Association and the Administration on Aging, selected 19 adult day centers nationwide to participate in the demonstration project (712). Each adult day center participating in the project will receive grants of up to \$300,000 over a 4-year period to enhance its services for dementia clients and their caregivers. The Robert Wood Johnson Foundation has found that adult day centers "become 'community centers' for providing and facilitating the range of services needed by people with dementia and their caregivers." Each center participating in the demonstration project is required, among other things, to "develop a case-coordinated plan for each client and caregiver to assure access to requested services through direct provision or referral to other community agencies." The results of the demonstration will have implications for the role of adult day centers in providing case management, respite, and other services for people with dementia and their caregivers.

Public Education



Adult day centers promote their own services and adult day services in general in various ways, including advertising in local newspapers, telephone directories, and community publications and participating in community forums, information fairs, and similar public events. Anecdotal evidence indicates that some dementia-specific adult day centers use similar methods to educate the public about Alzheimer's disease and related dementias and about adult day care as a potentially beneficial service option for people with dementia (485,617).

Outreach



Most adult day centers do not have sufficient staff or resources to conduct active outreach to identify people who might benefit from their services but are unlikely to be referred or to contact an adult day

center on their own (617). On the other hand, some adult day centers send staff to visit elderly housing facilities in the community to seek out people who would benefit from an adult day program (336,940).

Role in Allocating Services and Funding

Adult day centers do not control access to, or funding for, services other than those they provide.

Summary

As agencies that might be designated to constitute a national system to link people with dementia to services, adult day centers offer the following advantages:

- Adult day centers that serve at least some people with dementia may have a nurse, social worker, or other staff member who is knowledgeable about community services for people with dementia and is able to provide information about such services to clients of the center and other people who contact the center.
- Adult day center staff often are highly dedicated people who are very concerned about their clients' well-being and are often willing to "go the extra mile" to help their clients get the services they need.

Although adult day programs are a vital component of community-based, long-term care and provide obvious benefits for some demented adults and their caregivers, it is unlikely that adult day centers could serve as the basis of a national system to link people with dementia and their families to services. The major reason is that although adult day centers provide information and referrals and informal case management for their own clients, such centers currently serve only a small percentage of people with dementia in this country, and most adult day centers do not have the resources to provide information and referrals or case management for people other than their own clients. To have adult day centers take on the task of linking demented people and their caregivers to services would require a significant redefinition of the centers' institutional mission and an infusion of additional resources.