

Chapter 2

The Need for Public Education and Information and Referral

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The Need for Public Education and Information and Referral

INTRODUCTION

Many factors determine whether people with dementia and their caregivers ultimately are linked to the services they need.¹ Clearly, people cannot be linked to services or sources of funding for services that do not exist. The lack of sufficient services and funding for services for people with dementia is a major public policy concern that was emphasized in OTA's 1987 assessment *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias* (831). Unfortunately, the ideal of having sufficient services and funding for services is not the current reality.

To avail themselves of whatever services do exist, families and others who are caring for people with dementia need accurate information about what services and funding for services are available. To plan realistically and to make informed decisions about a patient's care, these caregivers also need to know what services and funding are *not* available. Evidence reviewed in this chapter suggests that in many cases, accurate information about the availability of services and funding for services is extremely difficult to obtain. Moreover, many caregivers are unaware of potentially helpful resources.

Physicians, other health care and social service professionals, service providers, and others who work with people with dementia and their caregivers are frequently called on to advise the caregivers about services and to select and arrange services for people with dementia who have no informal caregiver to help them. In order to provide that assistance, these individuals who work with dementia patients and their caregivers also need accurate information about services and funding for services. Like families, however, they may have difficulty obtaining that information.

This chapter focuses on the informational aspects of the process by which people with dementia and their caregivers are linked to services. The first section below presents information on caregivers' views concerning the need for accurate information about services and funding for services. A subse-

quent section discusses deficiencies in caregivers' knowledge about services and notes the relationship between caregivers' knowledge about services and their use of services. Another section describes the information and referral process for people with dementia in a specific locality (Cuyahoga County, Ohio) and suggests seven reasons why accurate information about services and funding for services is often not available. The last three sections of this chapter address what is special about the information and referral needs of people with dementia and their caregivers, what is special about the information and referral needs of ethnic minority people with dementia, and the role of physicians in linking demented patients and their caregivers to services. At the conclusion of each major section, OTA draws implications for an effective system to link people with dementia and their caregivers to services.

On some of the topics addressed in this chapter, there is little information in the general literature. As noted in chapter 1, OTA commissioned several small, exploratory studies for this assessment in order to learn more about how people with dementia are linked to services and about problems that may arise in that process. Although the findings of these studies cannot be generalized with certainty, they do provide insights into the linking process that are useful in thinking about the characteristics of a system that would effectively connect people with dementia to services. Two of the OTA-commissioned studies—one in Cuyahoga County, Ohio (186) and the other in two counties in southern California (866)—pertain particularly to the informational aspects of the linking process and are discussed in some detail.²

An important conclusion that OTA draws from the analysis in this chapter is that public education and information and referral are two essential components of an effective system to link people with dementia and their caregivers to services. *Public education* in this context means providing general information to help people understand dementia and the kinds of services that may be helpful for individuals with dementia. *Information and referral* in this context means providing infor-

¹See table I-2 inch. 1 for a list of the services that may be needed for people with dementia.

²Complete reports on the OTA-commissioned studies in Cuyahoga County and in southern California are available from the National Technical Information Service in Springfield, VA (see app. A).

mation about and referrals to specific services and sources of funding for services in the community.

Although this chapter focuses on the informational aspects of the linking process, it is important to note that some people with dementia and their caregivers are unlikely to respond to public education programs and may be unable or unwilling to contact an information and referral source on their own. OTA's analysis in chapter 3 suggests that to link some people to services, active outreach and case management are necessary. Thus, outreach and case management are also essential components of an effective system to link people with dementia to services.

Accurate information about services for people with dementia includes information about the quality of services, as well as about the availability of services and funding. Families and other caregivers want the services they may use for a person with dementia to be of acceptable quality, and their perceptions about quality may influence their decisions about using the services. Because of the importance of information about quality and because of the complexity of issues involved in evaluating the quality of services for people with dementia, a full chapter of this report (ch. 5) focuses specifically on problems in obtaining information about quality.

CAREGIVERS' VIEWS ON THE NEED FOR INFORMATION

Families and other informal caregivers of people with dementia often view the lack of accurate information about services and funding for services with frustration and consider it an important aspect of the difficulty of caring for a person with dementia. Numerous State task forces and committees that have focused on the problems of Alzheimer's disease and related dementias have noted caregivers' concerns about the lack of accurate information about services and funding (37,142,246,360,396,408,497,500,530,537,592,599,870,920).³ The Alzheimer's and Related Diseases Task Force in Kansas reported, for example:

Family members and caregivers pleaded at the public hearings for information about Alzheimer's and related diseases. They pleaded for reliable

referrals to services and easily accessible and up-to-date information so they could properly plan and care for their loved ones (396).

The Wisconsin Task Force on Alzheimer's Disease and Other Irreversible Dementias similarly reported:

Alzheimer's family members often tell distressing stories about not knowing where to go for help, going from one service provider to another in a vain search for assistance, and being misinformed about availability of services or eligibility for programs (920).

Echoing similar concerns, the New Jersey Alzheimer's Disease Study Commission reported that the caregivers of people with dementia were 'all too often passed from one potential information source to another without obtaining answers and/or help in identifying specific local resources' (599).

One of the specific concerns that caregivers expressed to some State task forces and committees on Alzheimer's and other dementias was that accurate information on eligibility for publicly funded programs such as Medicaid was lacking. The task forces in Maryland and Michigan noted that some caregivers had been given incorrect information about Medicaid eligibility (497,530).

Another specific concern that caregivers expressed was the lack of information about legal and financial matters related to patient care and the difficulty of finding anyone to advise them on these matters (37,99,142,246,408,497,500,530,599). One son told the Kansas Alzheimer's and Related Diseases Task Force, for example:

We talked to 17 attorneys to find one who would accept the case. There is no one place or phone number that can answer specific questions. I have been told I am asking questions that no one has ever asked before (396).

Lastly, families and informal caregivers told State task forces and committees that many physicians were not knowledgeable about services that might benefit people with dementia and their families and did not refer them to such services (412,479,497,500,531,592,599). Despite the fact that some caregivers told State task forces and committees about physicians who had been helpful in referring them to support groups and other services (497,500,599), many caregivers' experiences were negative. One

³App. C lists reports of the State task forces and committees that have studied or are studying the problem of Alzheimer's disease and related dementias.



Photo credit: M.P. Cordero-Aranda

The difficulty of obtaining accurate information about services and funding for services is extremely frustrating for many family caregivers.

woman in Michigan said her husband's physician gave her no referrals or other advice except to "accept the fact that the patient would never be any better than he was at that time and would probably get progressively worse" and "take him home and learn to live with it" (531). A caregiver in Massachusetts said that the demented person's physician "offered no advice or any alternative other than nursing home care" (500).

In 1986, in conjunction with OTA's 1987 assessment of Alzheimer's and other dementias, a mail survey of individuals drawn from the mailing list of the national Alzheimer's Association was performed (926).⁴ Survey questionnaires were mailed to a

sample of 2,400 individuals, and responses were received from 569 family caregivers of people with dementia from 49 States and the District of Columbia. The responses from these 569 caregivers indicate the importance to family caregivers of information and assistance in locating services and sources of funding for services.

Part of the survey questionnaire asked respondents how important they considered 11 different types of assistance in the care of people with dementia (926). The three types of assistance considered 'essential' by the largest percentages of the 569 responding family caregivers are listed below. Two of the three (those in *italics*) had to do with information and assistance in locating services and funding for services:

1. A paid companion who could come to the home a few hours each week to give them a rest (68 percent said that a paid companion was essential, and 96 percent indicated that it was either essential, very important, or important).
2. *Assistance in locating people or organization that provide care for the patient* (56 percent said that such assistance was essential, and 97 percent said it was either essential, very important, or important).
3. *Assistance in applying for Medicaid, Social Security, Supplemental Security Income, etc.* (54 percent said that such assistance was essential, and 94 percent said it was either essential, very important, or important) (926).

Another study of 59 black family caregivers of people with dementia in Cleveland, Ohio, had similar findings (750). Asked what help they needed to care for their relative with dementia, the caregivers in this study said they needed the three things listed below. One of these (the item in *italics*) had to do with information about services and funding for services:

1. Affordable respite services.
2. Counseling to help resolve family conflicts about the patient's care.
3. *Information about Alzheimer's disease, available community resources, and sources of legal and financial assistance.*

⁴A complete report on the 1986 mail survey conducted in conjunction with OTA's assessment is available from the National Technical Information Service in Springfield, VA (see app. A).

DEFICIENCIES IN CAREGIVERS' KNOWLEDGE ABOUT SERVICES

Many caregivers of people with dementia have limited knowledge about the availability of services that may benefit a person with dementia. One of the questions in the 1986 mail survey just mentioned pertained to caregivers' knowledge of services in their communities (926). As shown in table 2-1, the percentage of the 569 family caregivers who said a service was available or not available varied, depending on the service in question. The important finding for the discussion here, however, is that, *depending on the particular service in question, between 31 and 55 percent of the responding caregivers said they did not know whether the service was available.*

Another survey of family caregivers in 16 States asked the caregivers if they knew of any services (excluding support groups) for people with dementia in their community (117). Although 43 percent of the 597 responding caregivers said they knew of at least one community service and 21 percent said they were certain that no services were available in their area, *36 percent of the responding caregivers said they did not know whether any services were available. Since the sample of family caregivers for this survey was drawn from the mailing lists of family support groups and family support groups often provide caregivers with information about services (245,256,294)—the fact that more than one-third of the survey respondents did not know whether services were available in their community is surprising and indicates the extent of the problem of caregivers' lack of knowledge about services.*

A third study of 93 family caregivers of people with dementia in Michigan also asked the caregivers about the availability of services in their communities (138). *Depending on the particular service in question, 14 to 58 percent of the responding caregivers said they did not know whether the service was available.* Older caregivers were more likely than younger caregivers to say they did not know whether services were available. Caregivers who were depressed (as shown by responses to a widely used depression questionnaire) were less likely than other caregivers to know whether services were available.

Table 2-1—Family Caregivers' Knowledge of Six Types of services, 1986 (N = 569)

"As far as you know, is it possible where you live to obtain the services of"			
Service	Yes	No	Don't know
Paid companion/ home health aide	52%	17% ²	31%
Visiting nurse	55	11	34
Nursing home care	23	36	41
Adult day care	31	26	43
Respite care	23	26	51
Domiciliary/boarding care	16	29	55

SOURCE: Yankelovich, Skelly and White/Clancy, Shulman, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, April 1986.

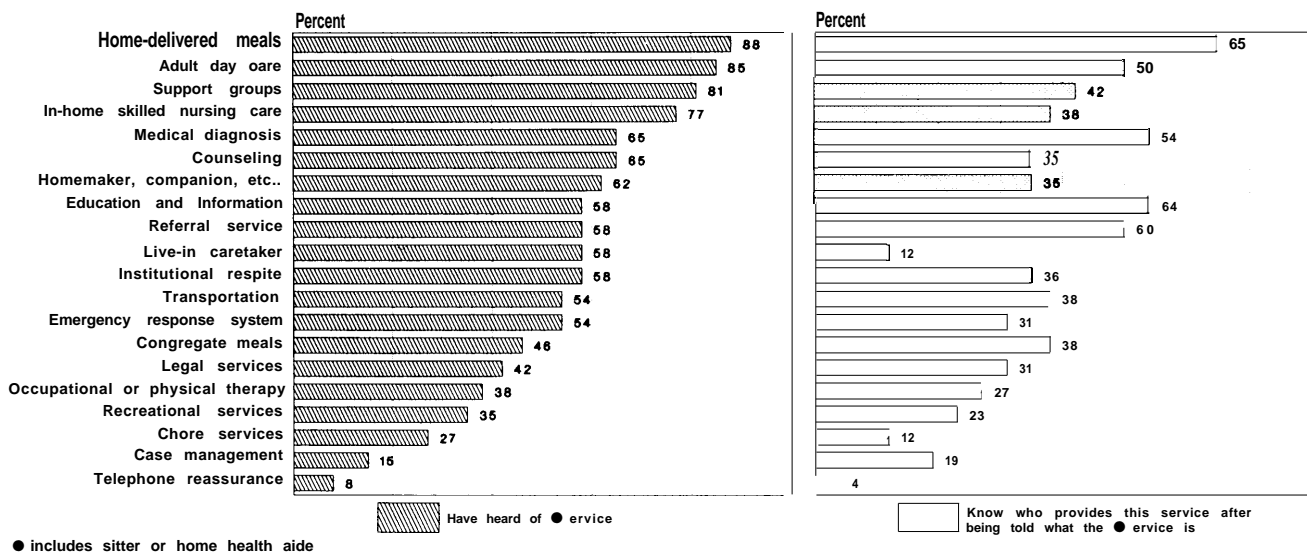
As mentioned earlier, OTA commissioned an exploratory study in Cuyahoga County, Ohio, to shed light on the process by which people with dementia are linked to services and the problems that may arise in that process (186).⁵ That study in Cuyahoga County included in-depth interviews with 26 caregivers who contacted the telephone helpline of the Cleveland Alzheimer's Association Chapter between April and July 1988-6 spouses, 14 adult children, 4 other relatives, and 2 friends of a person with dementia. As part of the interview conducted for OTA, each of the 26 caregivers was read a list of 20 services that might be needed for a person with dementia and asked two questions with respect to each service: 1) whether he or she had heard of the service, and 2) whether he or she knew who provided it in Cuyahoga County.

As shown in figure 2-1, the only services that more than 75 percent of the 26 caregivers had heard of were home-delivered meals, adult day care, support groups, and in-home skilled nursing care (186). The remaining 25 percent of the caregivers were not familiar with these four services, and even more caregivers were not familiar with other services such as counseling, referral services, home-maker services, and case management.

For many of the services on the list, a majority of the 26 caregivers interviewed could not identify specific providers. There were no services for which more than 65 percent of the caregivers could identify a specific provider. Only half of the caregivers said they could identify a specific provider of referrals or education and information programs on dementia. Only one-third said they could identify a specific

⁵All of the components of the study in Cuyahoga County, Ohio, are described in app. A.

Figure 2-1-Caregivers' Knowledge of Services in Cuyahoga County, Ohio, 1988



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

provider of homemaker, companion, sitter, or home health aide services.

The caregivers of people with dementia who were interviewed in the exploratory study in Cuyahoga County may not be representative of caregivers of people with dementia across the country or even caregivers in Cuyahoga County. That all 26 of them were in contact with an Alzheimer's Association chapter suggests that these caregivers may be more knowledgeable about services than caregivers in general. Nevertheless, the fact that many of these 26 caregivers were unaware of services suggests that lack of knowledge about potentially helpful services is a significant problem among caregivers.

The Relationship Between Caregivers' Knowledge of Services and the Use of Services

Not all families and other informal caregivers who know about services use them. The 1986 mail survey of family caregivers that was commissioned by OTA as part of its 1987 assessment of Alzheimer's and other dementias found that, depending on the service in question, 32 to 61 percent of the family caregivers who knew about a service had used or were using the service (926). The previously mentioned survey of 597 family caregivers of people with dementia in 16

States found that 58 percent of the caregivers who knew about any community services had used at least one of them (117).

To learn more about what factors determine whether caregivers of people with dementia use services and how caregivers' knowledge of services affects their use of services, the contractors who conducted the study in Cuyahoga County asked the 26 caregivers they interviewed to give their opinions about why people do not use services (186). Each caregiver was read a list of 14 possible reasons why people might not use services and asked: 1) whether and how often each was a reason why people in general did not use a service; and 2) whether it was a reason why they themselves did not use the service.

As shown in table 2-2, the reason for not using services that was identified most frequently by the 26 caregivers in Cuyahoga County-both for people in general and for themselves-was *lack of knowledge about what services are available* (186). The reason second most frequently identified by the caregivers for themselves was inability to afford the services. The reason second most frequently identified by the caregivers for people in general was lack

of knowledge about how to make arrangements to use services.

In addition to including interviews with caregivers, the study conducted for OTA in Cuyahoga County, Ohio, included in-depth interviews with representatives of 24 agencies in the county that provide information and referrals for people with dementia--4 hospitals, 2 home care agencies, 4 county and city government offices on aging, the county human service agency, 3 private social service agencies, 5 senior centers, 2 multiservice agencies, the county public library, the county information and referral agency, and a community mental health center (186). Each of the agency representatives was given a list of 15 possible reasons why people might not use services and asked to give his or her views on how often each reason keeps people with dementia and their caregivers from using services.

As shown in table 2-3, clients' *lack of knowledge about the availability of services* was identified as often or occasionally a barrier to service use by all 24 agency representatives in Cuyahoga County, Ohio (186).

There are many reasons why people do not use services. Barriers to the use of services that pertain to the personal characteristics or perceptions of people with dementia and their caregivers are discussed in chapter 3. The main point here is that the 26 informal caregivers and 24 agency representatives interviewed in the study in Cuyahoga County, Ohio, identified people's lack of knowledge about services as the single most important barrier to the use of available services. Lack of knowledge about services was identified as a barrier to the use of services more often than any other factor, including the ability to pay for services. Although the results of the study in Cuyahoga County cannot be generalized with any certainty given the small sample sizes and other aspects of the study, they do suggest that lack of knowledge about services among the caregivers of people with dementia is an important barrier to the use of available services.

The Distinction Between Service Consciousness and Service Knowledge

In thinking about the problem of caregivers' lack of knowledge about services, it is useful to distinguish between:

- . general awareness of services, which some researchers call *service consciousness*; and
- . knowledge about a specific service, including who provides it in a community, which some researchers call *service knowledge* (431).

As shown in figure 2-1, the study conducted for OTA in Cuyahoga County, Ohio, made that distinction explicitly and found that many of the 26 caregivers interviewed there not only lacked service knowledge (i.e., did not know of specific providers of services in the community) but also lacked service consciousness (i.e., had never even heard of some types of services) (186). Most of the other studies that have investigated caregivers' knowledge of services have not drawn any distinction between service consciousness and service knowledge; and the questions they have asked seem to pertain more to service knowledge than to service consciousness.

Despite the fact that most studies have not focused on it, caregivers' lack of service consciousness is an important aspect of the overall problem of caregivers' lack of knowledge about services. People who are generally aware of potentially beneficial services are likely to search for information about the availability of a specific service in their community when the need arises (431); people who are not generally aware of services are unlikely to search for that information.

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

Since caregivers' lack of knowledge about services is at least one of the major reasons that people with dementia and their caregivers do not use services, an effective system to link people with dementia to services must find ways of increasing caregivers' knowledge about services. In order to increase caregivers' knowledge of services, a linking system must seek to enhance both caregivers' general awareness of the kinds of services that may be helpful (i.e., service consciousness) and their knowledge of specific service providers (i.e., service knowledge) (186).

Caregivers' service consciousness can be increased by *public education programs* and materials such as those that have been developed by the Alzheimer's Association, other voluntary associations that represent people with Alzheimer's, Huntington's, or Parkinson's disease, or stroke, and some State and local government agencies. Public educa-

Table 2-2-Caregivers' Opinions About Why People Do Not Use Services,
Cuyahoga County, Ohio, 1988 (N = 26)

Possible reasons why people do not use services	How often is it true for people in general? usually	Is this a reason you did not use services? Yes
People don't know what services are available	73%	81%
People know what services are available but don't know how to make arrangements to use them	42	50
People can't afford to pay for services	38	73
People don't think they need the services recommended to them	38	50
People don't use the services because they do not want to lose their independence	38	19
The system of services for people with dementia and their families is too complicated for people to figure out	35	46
People don't recognize the fact that they need services	33	42
The kinds of services needed by people with dementia and their families aren't available in the areas where some people live	31	50
Some services needed by people with dementia and their families just aren't available	31	54
People don't have transportation to services.	27	35
Using services makes people feel uncomfortable	27	31
Agencies that provide information about services and make referrals don't know enough about what services are available	27	42
People are afraid others will not approve if they use services.	19	19
People have money but are not willing to pay for services	3	8

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

Table 2-3-Agency Representatives' Opinions About Why People Do Not Use Services,
Cuyahoga County, Ohio, 1988 (N = 24)

Possible barriers	How frequently does each barrier keep potential clients from using services?	
	Often	Occasionally
Clients don't know that services are available	75%	25%
Clients do not have adequate financial resources to pay for the service.	71	16
Clients desire to remain independent of the formal care system	58	33
Services aren't available in some geographic areas	58	29
Clients don't recognize they need formal services	54	42
Clients don't have transportation to the service	54	25
The service system is too complex or fragmented for people to use	48	30
Clients don't know how to access services once they've found they're available	42	46
Clients feel the recommended service is not needed	38	46
Clients are uncomfortable using recommended services*.	38	38
Needed services aren't offered for dementia clients	33	29
Persons providing information and referral don't have comprehensive knowledge about what services are available	28	42
Clients are judged to have adequate financial resources but are unwilling to pay for services	16	42
Clients think others will disapprove of their using the recommended service	12	29
Clients' schedules or competing demands prevent their use of services.	4	29

*One respondent (4 percent) did not answer this question.

bhreer@ondents(12 percent) did not answer this question.

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

tion programs and materials inform people about dementia and about the kinds of services that maybe helpful for people with dementia; they generally do not give detailed information about specific agencies or individual service providers, although they frequently do give a telephone number to call for such information.

The detailed information that people need in order to select and arrange a particular service can be made available through *information and referral programs*. Information and referral programs can only assist people who contact them, however, and people who are unaware of services are unlikely to call. This observation underscores the point made

earlier that an effective linking system must include public education as well as information and referral.

WHY ACCURATE INFORMATION ABOUT SERVICES AND FUNDING FOR SERVICES IS OFTEN NOT AVAILABLE

There are many anecdotes about the difficulty of obtaining accurate information about services and funding for services for people with dementia. To OTA's knowledge, however, the only research on the number and types of agencies that provide information and referrals for people with dementia and their referral procedures is the exploratory study conducted for OTA in Cuyahoga County, Ohio (186).⁶

The following discussion presents the Cuyahoga County study's findings about the information and referral process for people with dementia in the county, identifies seven reasons why accurate information about services and funding for services is often not available, and discusses the implications of those findings and reasons for an effective system to link people with dementia to services.

Although the findings in Cuyahoga County are not necessarily generalizable to other localities, they do provide a context and a basis for thinking about the problem of lack of accurate information about services and funding for services. OTA would like to emphasize that no criticism of Cuyahoga County is intended by any part of the discussion in this report. In fact, Cuyahoga County is known for its commitment to aging and human services and for the recent efforts of many organizations and individuals there to improve services and service delivery for people with dementia. Whatever problems in linking people with dementia to services can be noted in Cuyahoga County, therefore, are likely to be worse in other parts of the country. OTA is grateful to the agencies in Cuyahoga County for their participation in its study, which provides the only available data on some aspects of the information and referral process for people with dementia.

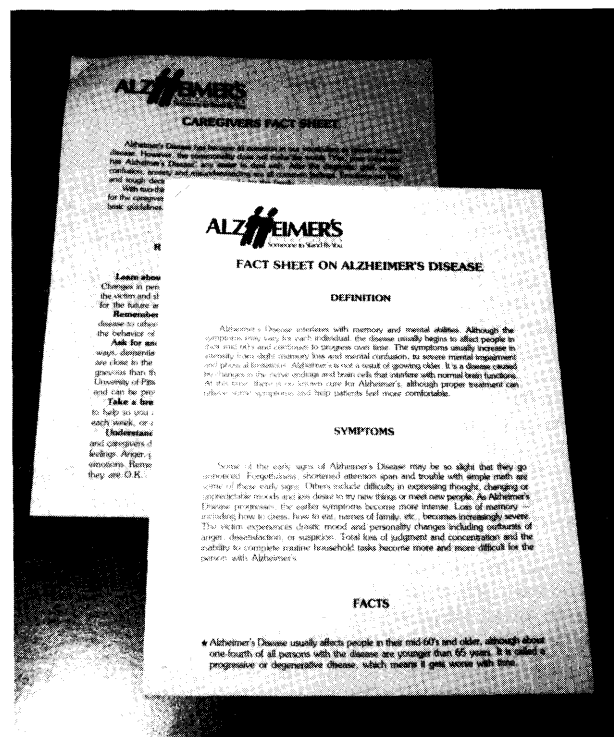


Photo credit: Bill Adams

Public education materials such as these fact sheets on Alzheimer's disease and caregiving can increase caregivers' knowledge about dementia and about the kinds of services that maybe helpful for a person with dementia.

The Information and Referral Process in Cuyahoga County, Ohio

In 1987, OTA's contractors mailed a survey questionnaire to 324 public and private agencies in Cuyahoga County, Ohio, that the contractors thought might provide information and referrals or services of any kind for people with dementia (186). Ninety-seven (30 percent) of the 324 agencies responded. OTA's contractors did not make any attempt to obtain information about the 227 agencies that did not respond to the survey questionnaire.

Of the 97 agencies that responded to the survey in Cuyahoga County, 84 indicated that they did in fact provide information and referrals and/or services for people with dementia—8 hospitals, 9 nursing homes, 11 home care agencies, 2 adult day centers, 10 local government agencies, 3 social service agencies, 21 senior centers or programs, 2 multiservice agencies, 10 referral agencies, and 8 other types of agencies (186).

⁶A complete report on the study in Cuyahoga County is available from the National Technical Information Service in Springfield, VA (see app. A).

Of these 84,75 agencies (including agencies of all the types just listed) indicated that they do provide information and referrals for people with dementia in Cuyahoga County. Some of the 75 agencies (e.g., referral agencies) provide information and referrals as their primary function, and others (e.g., hospitals, nursing homes, senior centers) provide information and referrals as a secondary function. Sixty-three of the 75 agencies said that they provide information and referrals for people with dementia who are not receiving any services from the agency; presumably, the other agencies provide information and referrals only for people with dementia who are receiving services from the agency.

As noted earlier, OTA's contractors conducted in-depth interviews with representatives of 24 of the 75 agencies that said they provide information and referrals for people with dementia (186). According to these agency representatives, many of the 24 agencies provide information and referrals for people with dementia both over the telephone and in person. They tell people about available services and give them the names and telephone numbers of specific service providers. Many of the agencies also hand out or mail printed educational materials, including Alzheimer's Association brochures, other pamphlets and articles on dementia, lists of nursing homes and other types of agencies, and the names and telephone numbers of agencies and contact people within those agencies. One agency representative noted, "We send them anything we can think of to get the information across."

Only about half the 24 agency representatives interviewed in Cuyahoga County said that their agencies provide information about funding for services (186). With a few exceptions, the agencies that provide it furnish information pertaining only to *funding* for their own agency's services.

Only 1 of the 24 agency representatives was from an information and referral agency per se (186). The other 23 agencies do not provide information and referrals as a primary function but often provide information and referrals as a byproduct of intake for their own services—that is, if a person who contacts the agency is not eligible for the agency's services or needs services the agency does not provide, he or she is referred to another agency.

Other than the information and referral agency, most of the 24 agencies do not consider a person for whom they provide telephone information and

referrals to be their client (186). Thus, a person does not become a 'client' of the agency until he or she is linked to a service provided by the agency. Most of the 24 agency representatives said their agencies will provide information and referrals to anyone, even if the person needing assistance is not a "client" in this sense, but they seem to regard the information and referrals they provide for people they do not consider "clients" as an informal community service rather than a formal function of the agency.

The 24 agency representatives were asked what criteria their agency used to select a provider once the agency had determined that a person needed a particular service (186). The criteria named most frequently were the person's financial situation and the location of the service (8 mentions each). Other criteria mentioned were the provider's reputation and past performance (7 mentions); the patient's or family's needs, characteristics, and/or willingness to accept a provider (6 mentions); and the agency's informal affiliations with various providers (4 mentions).

Eighteen (75 percent) of the 24 agency representatives indicated that their agencies sometimes refer potential clients to other agencies for a service even though their own agency provides the service (186). Among the reasons for interagency referrals, geographic location was the most frequently cited. Other reasons included the referring agency's inability to accept new clients; patient or family preference; the patient's ineligibility for services from the referring agency (e.g., too young); agency rules or interagency agreements that certain categories of people (e.g., those in need of protective services) should be referred automatically to another agency; and financial considerations.

Some of the agency representatives said that clients are referred from one agency to another when third-party reimbursement for a client's care is no longer available to the first agency (186). They said that this practice is common when a client of a home care agency is hospitalized: when the person is discharged from the hospital, the hospital's home health care agency often provides care until third-party reimbursement runs out; then the person is referred back to the original agency for ongoing care.

One item of particular interest in this OTA assessment is how agencies that provide information and referrals for people with dementia keep current

on what services are available. In the study in Cuyahoga County, OTA's contractors gave all of the 24 agency representatives a list of ways in which one might stay up-to-date and asked them which ways were used in their agency (186). The largest number of agency representatives (19 agencies or 79 percent) reported that their agencies use the Cleveland Alzheimer's Association Chapter to keep current on what services are available for people with dementia. (Interestingly, the perception of the staff of Cleveland Alzheimer's Association Chapter office is that very few agencies call the chapter for service information. Since the study in Cuyahoga County was conducted under the auspices of the Cleveland Alzheimer's Association Chapter, it is difficult to know how many agencies actually use the chapter to keep current and how many just gave the answer they thought the researchers wanted to hear.)

The majority of the 24 agency representatives interviewed in Cuyahoga County reported that their agencies use the countywide information and referral agency, local government offices on aging, Cleveland's Federation for Community Planning, and information supplied by other service providers to keep current on what services are available for people with dementia (186). Some of the agency representatives said that staff of their agencies keep current by attending health fairs, seminars, workshops, and committee and board meetings or through newsletters and published directories.

All 24 agency representatives reported that staff of their agencies use "informal friendships or association with other agency staff" to keep current on what services are available for people with dementia (186). On the basis of agency representatives' comments during the interviews, OTA's contractors concluded that informal networking is probably the primary way that agency staff members keep current on services for people with dementia. Staff members not only learn about specific services that way, but they also establish relationships with staff of other agencies that are invaluable later when they are trying to arrange services for a client.

All 24 agency representatives said their agencies initiate contacts with other service providers for at least some of the people for whom they provide information and referrals, but only 1 of the agencies initiates such contacts routinely (186). Other agencies encourage people to make their own contacts with agencies to which they are referred. Some

agencies only initiate contact with other agencies if the person needing assistance is considered a client. Often, a decision about who should make the contact is based on staff judgment about the patient's or family's ability and willingness to make the contact. One of the 24 agency representatives referred to the process of agency-to-agency contact as "babying" people who are afraid of making their own contacts.

Finally, although most of the 24 agency representatives interviewed in Cuyahoga County said their agencies follow-up on some referrals to ensure that needed services are obtained, few agencies have systematic followup procedures. Some agencies ask the patient or family and the other provider to report back on the success or failure of a referral, but if these individuals do not report back, they are not contacted systematically by the agency.

Seven Reasons Why Accurate Information About Services and Funding for Services for People With Dementia Is Often Not Available

OTA's analysis of information and referral procedures and agencies in Cuyahoga County, Ohio, suggests that there are at least seven reasons why accurate information about services and funding for services for people with dementia is often not available. The seven reasons are highlighted in the discussion that follows. OTA's informal discussions with members of the advisory panel for this assessment and with numerous other people who work with dementia patients and their families in different communities suggest that the same reasons are applicable in many areas of the country beyond Cuyahoga County.

At the start of this assessment, OTA staff expected that the biggest problem families and others confront in trying to obtain accurate information about services and about funding for services for people with dementia would be the lack of information. In the course of the assessment, however, OTA found that ***wrong information and partial information may be at least as big a problem as the lack of information.*** Caregivers or others who contact an information and referral source and receive no information may continue to search for assistance from other information sources. People who receive wrong information—for example, those who are told, "There are no services," when, in fact, there are services—may just accept the information as correct and not even try to contact another source of

information. Likewise, people who receive partial information—for example, those who are told, “There is an adult day care center 30 miles from here,” when, in fact, there is another center much closer—may accept what they have been told, only to discover much later that there were other options. The origins of wrong and partial information about services and funding for services are identified in the following discussion.

1. Because there are many potential providers of services for people with dementia and because the services they offer change from time to time, it is difficult for anyone to maintain an up-to-date list of available services.

In the exploratory study in Cuyahoga County, Ohio, OTA’s contractor sent a questionnaire to 324 agencies that they thought might provide information and referrals or services of any kind for people with dementia (186). Of the 97 agencies that completed survey questionnaires, 84 agencies said they did in fact provide information and referrals and/or services for people with dementia. It is likely, given the diverse needs of people with dementia and their caregivers, that a good number of the 227 agencies that did not respond to the survey are also potential sources of assistance. In addition, many voluntary associations and individual professionals to whom the questionnaire was not sent are potential service providers for people with dementia.

The fact that there are many potential service providers does not mean that enough services are available or that dementia patients’ needs can be met. The study in Cuyahoga County did not address the many details about an agency’s services that determine whether the services are really available to a particular patient and whether they meet his or her needs. Those details, which affect the availability of services from agencies in all parts of the country, not just Cuyahoga County, include:

- an agency’s general eligibility criteria and any additional eligibility criteria for a specific service;
- the exact nature of the service;
- when and where the service is provided and for how long;
- what the service costs; and
- whether there is any source of funding for the service other than client fees.

These kinds of details often reflect regulations and requirements associated with the agency’s funding source (e.g., Medicare, Medicaid, State programs). They may also reflect State or local government licensing or certification requirements and the mission, objectives, and history of the agency (391,481,641,821,83 1).

The details of an agency’s services change from time to time, often in response to changes in the requirements of the agency’s funding sources (641, 821,922). Federal, State, and local governments and private associations and foundations initiate new services and terminate others. Publicly and privately funded research and demonstration projects that provide services also begin and end. These changes may increase or decrease the availability of services. Since they also affect an agency’s overall budget, these changes may also determine the total volume of services an agency can provide.

Some of the changes in agencies’ services are small, but their cumulative impact is to create a constantly changing service environment. Agencies may continue to exist with the same name and in the same location, but the services they provide change in ways that make them more or less available, appropriate, accessible, and affordable for different kinds of people. Keeping track of all these changes in order to maintain an up-to-date list of available services is difficult and time-consuming. Yet such a list is an essential component of an effective system for linking people to appropriate services.

Home care services generally change more frequently and are more difficult to keep track of than nursing home services. Most patients and families prefer home care to nursing home care, however, and so it is important to keep lists of home care services up-to-date.

As awareness of Alzheimer’s disease and other diseases that cause dementia has increased in recent years, new services designed specifically for people with dementia have been and continue to be developed in many communities. At the same time, research and demonstration projects established several years ago and other time-limited programs that provide services for some people are ending. Thus, the constant change that characterizes the service environment in general is probably even greater for services designed specifically for people with dementia.



Photo credit: N Winter

To connect people with dementia to appropriate services, a linking system must have an accurate, up-to-date list of available services that includes all the kinds of services that may be needed for a person with dementia.

The number of potential service providers, the many details that determine whether their services are available and appropriate for a particular patient, and the constant change in services contribute to the difficulty families and others face in obtaining accurate information about services. It is easy to understand in this context why people sometimes receive wrong information or partial information about available services (324,641,821,939). The need for an accurate resource list and the difficulty of maintaining it are also clear.

Some areas of the country have fewer service providers than Cuyahoga County, Ohio, and some have more. In areas with fewer providers, maintaining an up-to-date resource list is less difficult but equally important for linking people to appropriate services.

In many communities, one or more agencies compile and update resource lists that may include all available services, certain types of services, or services for certain client groups. In some communi-

ties, the area agency on aging (AAA) or a local government office on aging maintains a list of services for elderly people. Lists compiled by these groups are not always complete or accurate with respect to services that may be needed for people with dementia, however. That observation is illustrated by the fact that in 1985, the Georgia Alzheimer's Disease Study Committee requested that the State's AAAs provide an inventory of services that might be used for people with dementia; the committee subsequently found that the inventories it received from the AAAs "varied widely in their completeness and accuracy to the extent that additional editing, followup, and refinement of responses [were] needed before they could be used" (246). Other State task forces and committees have not commented specifically on the completeness or accuracy of resource lists in their States, but some have noted that an accurate list is needed, and some have attempted to compile such a list, thus suggesting that the lists available to them were not adequate (37,142,360,396,497,500,538,599,713,790).

To maintain an accurate list of services requires a continuing commitment of resources. Computers and available software packages greatly facilitate the task, but whoever is maintaining the list must commit the time needed to keep track of changes, identify new services, and update the database. Government agencies and private groups sometimes pay for the development of a resource list on a one-time basis but fail to commit resources for updating it (259). As time passes, families and others that contact providers on the list find that some services have changed or are no longer available. New services may not be on the list at all. Without continual updating, the list itself can become a source of wrong or partial information.

2. A large number of agencies and individuals provide information and referrals for people with dementia, but many of them do not have an accurate resource list or other effective methods for keeping up to date on available services.

The study conducted for OTA in Cuyahoga County, Ohio, illustrates that a given area may have many sources of information and referrals for people with dementia (186). Of the 97 agencies that responded to the survey questionnaire that OTA's contractors sent to public and private agencies in the county, 75 indicated that they provide information and referrals for people with dementia. It is possible that some of the 227 agencies that did not respond to the survey also provide information and referrals. Furthermore, some of the voluntary associations and individual professionals who were not included in the agency survey may also provide information and referrals for people with dementia in Cuyahoga county.

From their interviews with 24 agency representatives in Cuyahoga County, OTA's contractors determined that, in general, agency staff keep up to date on available services through informal contacts and active networking—a process one agency representative called “hustle” (186). In the view of these contractors, the reliance of agency staff on informal contacts and relationships to keep current cannot be overstated. OTA's contractors found, however, that many of the agency representatives lacked a broad knowledge of available services, and the contractors concluded that although informal networking may be a valuable source of information about services,

it is not sufficient by itself in a complex service environment, such as that found in Cuyahoga County and many other parts of the country.

To maintain an accurate list of services for people with dementia and their caregivers is difficult, as discussed earlier, and many agencies that provide information and referrals for people with dementia are unlikely to be able to commit sufficient staff time to maintain such a list. Individual physicians, other health care and social service professionals, and service providers who refer dementia patients and their families to services are also unlikely to be able to maintain an accurate resource list. A survey of 10 Alzheimer's Association chapters conducted for OTA in 1988 found that the chapters generally did not have systematic procedures for maintaining a comprehensive resource list (484).⁷

The large number of agencies and individuals that provide information and referrals for people with dementia, often without an accurate resource list, increases the likelihood that patients, families, and others will receive wrong information or partial information about available services. Given this problem, it would seem desirable to have a single agency in each community designated to maintain a list of available services and to allow other agencies and individuals easy access to the list. For such a system to function effectively, all agencies and individual service providers would have to be committed to it. Ideally, agencies and individual providers would share a database that they could access by telephone or through periodic receipt of updates on a magnetic storage medium (186).

3. Many agencies do not track the people they serve by either diagnosis or condition and therefore do not identify people with dementia; people with dementia who are not identified as such are unlikely to receive appropriate information or referrals.

People with dementia must be identified as such if they and/or their caregivers are to receive appropriate information and referrals. Very few of the agencies in Cuyahoga County that responded to the initial questionnaire or were interviewed keep records on the people they serve by either diagnosis or condition (186). Most of these agencies do not keep such records either on people for whom they provide

⁷See ch. 8 for a discussion of the survey of 10 Alzheimer's Association chapters.

telephone information and referrals or on people who receive services from the agency. A study of Massachusetts agencies that offer information and referrals and home care services found that these agencies also did not track the people they serve by either diagnosis or condition (756).

The fact that an agency does not track people it serves by their diagnosis or condition does not prove that the individual social worker, nurse, or other information and referral agent at the agency is unaware of the person's diagnosis or condition. It suggests that this could be the case, however. If a person with dementia is not identified as such by an information and referral agent, the person will not be referred for specialized services even if the services are available and appropriate for his or her needs. Furthermore, printed materials about dementia and caregiving techniques that could be helpful to the person's caregiver are unlikely to be provided; and common characteristics and care needs of people with dementia that influence the kinds of services they need may not be recognized.

It is important to note that some agencies do identify clients by their diagnosis or condition. Examples are Alzheimer's Association chapters, other voluntary associations that serve people with Alzheimer's, Huntington's, or Parkinson's diseases or stroke, and Alzheimer's diagnostic and assessment centers.⁸

4. The location of services is often an important factor in caregivers' decisions about service use, but agencies making referrals do not always consider location.

Many of the 26 caregivers of people with dementia who were interviewed by OTA's contractors in Cuyahoga County indicated that the location of a service influenced their decision about using the service (186). Many of the 24 agency representatives interviewed in Cuyahoga County also identified the location of services as a factor that affects use. For some patients and families, location is of concern because they do not have a car or other means of transportation. For others, location is of concern because there is a possibility that the person with dementia may become agitated on a long ride, and this prospect may discourage families from using services (488).

Some communities are so small that the location of services may not significantly affect caregivers' decisions about their use. In other communities, there is no choice of service providers because only one provider exists. In communities where there is a choice, however, it would be helpful to patients and caregivers if the referrals they got included the names of providers near their homes. Making such referrals requires the availability of a comprehensive resource list and may require special formatting of the list to identify providers in specific locations.

5. There are many potential sources of funding for services. Complex rules for each source make it difficult for anyone to provide accurate information about funding in general and even more difficult to provide information that is relevant to the service needs of a particular patient.

About half of the 97 agencies that responded to the initial survey questionnaire in Cuyahoga County indicated that they do provide information about funding for services, but the information that most of them provide pertains only to funding for their own agency's services (186). Few of the agencies responding to the survey indicated that they offer benefits counseling (i.e., information about various sources of funding for services and how and where to apply for benefits).

The OTA contractors who conducted the study in Cuyahoga County concluded that benefits counseling is difficult to provide (186). One of the reasons it is difficult is that there are many potential sources of funding for services. Many Federal, State, and local government programs, private agencies, and voluntary and charitable organizations pay for some services that may be needed for people with dementia. Furthermore, some people have private insurance that covers some services.

It is important to emphasize that the fact that there are many potential sources of funding for services does not mean that adequate funding is available. Each funding source has rules that limit the availability of funds by restricting who is eligible and what services are covered. Eligibility may be restricted on the basis of a person's age, income, assets, diagnosis, physical or mental condition, residence, family composition, and other factors. Coverage may be restricted by rules about the type of service that can

⁸Regional Alzheimer's diagnostic and assessment centers are discussed in ch.8.

be paid for; the profession, training, and licensure of a person who can be reimbursed for providing the service; the setting in which it can be provided, and its duration and frequency (124,391,641,831). The rules in each of these areas are interrelated, so that a particular service is paid for only if it is provided to a patient with a certain diagnosis or condition, by a certain provider, in a certain setting, for a given time period.

It is often unclear whether a person with dementia will be eligible for services paid for by certain programs—especially programs like Medicare and Medicaid that have eligibility and coverage requirements related to a person’s physical condition and physical care needs. Although many people with dementia are determined to be ineligible for funding for services through these programs (124,186,831), other people with dementia do receive services paid for by these programs. This situation may arise because of real differences in the physical condition and physical care needs of different patients. On the other hand, it may arise because of differences in the way a patient’s condition and care needs are described on an application or billing form or because of different interpretations of a program’s regulations by its administrators. The eligibility and coverage requirements for services paid for or provided by the U.S. Department of Veterans Affairs (VA) are particularly complex and difficult for non-VA information and referral sources to understand or explain to caregivers.⁹

To further complicate an already confusing situation, the eligibility and coverage requirements of all finding sources change from time to time. Overall funding levels also change, and so the total amount of available assistance varies over time.

The large number of potential sources of funding for services, the complexity of their eligibility and coverage requirements, changes in the rules and overall funding levels, and uncertainty about whether a person with dementia fits within the eligibility and coverage requirements make it extremely difficult for anyone to provide accurate information about available funding (186,641,790). It is easy to understand in this context why families and others receive wrong, partial, or no information about potentially beneficial funding sources.

United Seniors Health Cooperative, a nonprofit organization in Washington, DC, has developed a computerized service that identifies an elderly person’s potential eligibility for more than 50 local, State, and Federal funding programs (799). This service, called the “Benefits Outreach and Screening Service,” is a promising approach to making available accurate information about funding for services. To use the Benefits Outreach and Screening Service, an individual completes a questionnaire about his or her finances, medical condition, and other information. That information is then fed into a computer, which reviews the available funding programs, identifies benefits the person may be eligible for, and prints out a list of those benefits and instructions on how and where to apply for them. The software package for the service has been purchased by a consortium of human service agencies in Buffalo, New York, and by agencies in 15 other areas of the country, including AAAs in Virginia and county government agencies in Wisconsin. As of late 1989, the software was being adapted for use in New York State, where it will not only identify benefits the person maybe eligible for but also print out completed applications for six publicly funded programs (799).

6. The terms used for many services that may be needed for people with dementia are new to families and others. If families and other caregivers do not understand what the services are, information about the availability of these services is meaningless to them.

For various reasons, the terms used for many services that could benefit people with dementia may not be understood by families and others (324). Terms such as “respite care,” “congregate meals,” “case management,” and “telephone reassurance” are new to many families. Interestingly, OTA’s contractors in Cuyahoga County found that even some caregivers who had used case management did not recognize the term (186).

The terms used for some services reflect the requirements of their funding source, and not necessarily the needs of patients or the actual services provided. Examples are ‘homemaker’ and ‘home health aide’ (299,303). Medicare pays for “home health aides” in certain circumstances but rarely pays for “homemakers; the difference

⁹The complexity of the VA’s eligibility and coverage requirements is described in ch. 6.

between the two is defined in Medicare regulations. Many caregivers who need someone to help them take care of a dementia patient at home are not familiar with the Medicare regulations and do not define their service needs in terms of those regulations. Such caregivers are not likely to understand the difference between a “homemaker” and a “home health aide” without a clear explanation, and as illustrated in the case of Mrs. Din chapter 1, some service providers have difficulty explaining the difference clearly. The biggest difference often is who pays for the service, not what is provided.

Information and referral agencies often categorize services according to the terms providers use for the service. If someone calls an information and referral agency for information about a service but uses a different term for it than the provider uses, the person may not be told about a potentially helpful provider. Instead, the person may be told about providers who call their service what the person said he or she wants but may not offer what the person actually needs.

Information about services is meaningless to families and others who do not understand what the services are. To make the information meaningful, the service must be described and categorized in terms relevant to patients' and caregivers' needs. Categorizing services in a way that is relevant to the needs of patients and families, however, is a difficult task for information and referral agencies (183).

7. Proprietary concerns and agency turf issues sometimes deter staff in one agency from giving people information about another agency's services.

Although nearly 75 percent of the 24 agency representatives interviewed in Cuyahoga County said their agencies sometimes refer people to other agencies for a service even if their own agency provides it, OTA's contractors concluded that most of the agencies refer people to their own services (186). This practice is to be expected because the staff of a particular agency are most familiar with their own agency's services and because the services of one's own agency are often easiest to arrange. On the other hand, referring a patient to the services of an agency other than one's own may be more appropriate if the other agency is closer to the patient's home or offers services that are more appropriate for the patient's needs.

To say that proprietary concerns deter one agency's staff from giving people information about another agency's services implies that the first agency is aware of the other agency's services, knows they are appropriate for the patient, and still does not refer the patient or family to that agency. That was the implication in some agency representatives' complaints about hospitals that provide home care for patients through their own home health care agency until the patients' third-party reimbursement runs out and then refer the patients to another home care agency (186).

A different problem occurs when one agency's staff members do not give people information about another agency's services because they are not aware of the other agency's services or do not consider those services appropriate for a patient's needs. This situation is particularly likely to occur when the two agencies are in different “systems.”

As discussed in chapter 1, most services for people with dementia are provided in one of several broad systems: the medical care system, the aging services system, the mental health system, the social service system, the public health system, and the public assistance system. These systems are delineated by the Federal programs that fund them, the training of people who work in them, and historical divisions among State and local government agencies that administer the services. Although not rigidly differentiated, the systems generally are not integrated with one another.

For several reasons, referrals are more likely to occur within a system than from one system to another. One reason is that informal networking between agencies often occurs only within a given system, and service providers in one system may not be aware of services in other systems. Another reason is that service providers in the same system tend to have a common perspective on dementia and the appropriate care for people with dementia. Thus, they may have greater understanding of and confidence in services provided by other agencies and individuals in their system than in services provided by other systems. Consequently, agencies in one system, say the mental health or social service system, may not refer people to services provided by agencies in another system, say the aging services system; and conversely, agencies in the aging services system may not refer people to services

provided in the mental health or social service systems.

Proprietary concerns and agency turf issues sometimes interfere with the development of an accurate list of available services. A list developed by someone in one system may not include services provided by agencies in other systems. In addition, anecdotal evidence suggests that some agencies do not want an accurate list to be developed because they are afraid they will lose clients to other agencies (611).

At the time of the study in Cuyahoga County, proprietary agencies were not included in the resource list of the countywide information and referral agency (185). OTA does not know whether proprietary and nonproprietary agencies constitute separate systems in other areas of the country. Clearly, beneficial services for persons with dementia are provided by both proprietary and nonproprietary agencies, and caregivers and others need to know about services provided by both types of agencies in order to make informed decisions about the patient's care.

The first steps in overcoming turf problems that interfere with the availability of accurate information about services are to include all providers in the resource list and to foster a sense of joint ownership of the list. As discussed elsewhere in this report, there is a general need for integration of services, service providers, and systems.

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

Given the large number of potential services, service providers, and sources of funding and the complex and changing rules that restrict their availability, it is not surprising that families and others sometimes receive wrong, partial, or no information about services and funding for services for people with dementia. The many agencies and individuals that provide information and referrals for people with dementia compound the potential for error. Although some agency staff members, individual health care and social service professionals, and service providers are undoubtedly more knowledgeable about available services than others, families and others who need help in locating appropriate services have no way to tell the difference.

The discussion in this section has turned repeatedly to the importance of an accurate, comprehensive resource list. Without such a list, agency staff, individual health care and social service professionals, service providers, voluntary associations, and others that refer patients and families to services must rely on informal networking and "hustle" to keep current on available services. These methods are helpful, but they are not sufficient in complex service environments.

Most areas of the country have fewer agencies and individual service providers than Cuyahoga County, Ohio, and some communities may have so few that a formal resource list is not necessary. In the course of this assessment, however, OTA has been told by many individuals that there are no services in a given community, but later has been told by other sources that there are some services, either in that community or readily available to its residents from a nearby community. This situation has occurred most often when, for example, the available services are provided by a mental health agency and the individual is familiar with social service or aging network agencies. OTA does not intend to suggest here that sufficient services are available if all systems are considered, but only to point out that even people who are concerned about services for people with dementia and think they know what is available in their community may not be aware of some services.

Maintaining an accurate resource list is difficult and requires a continuing commitment of resources. Ideally, one agency in a community should maintain the list and other agencies and individuals should have access to it. To address caregivers' concerns about the location of services, lists for other than very small communities should be formatted to allow easy retrieval of information about service providers in a given geographic area. To begin to address some of the turf problems that interfere with the availability of accurate information about services, the list should include all service providers and be readily available for their use.

Computers make it easier now than in the past for an agency to compile and update a resource list and to make the updated version of the list available to other agencies and individual service providers. Special computer software, such as that used for the previously described Benefits Outreach and Screening Service created by United Seniors Health Cooperative (799), may be the only effective way to

keep track of the large number of funding sources and the complex and changing eligibility and coverage requirements that determine whether benefits are available to an individual.

The availability of an accurate and comprehensive resource list would neither change the inherent complexity of the service environment at the community level nor make up for lack of services. It would improve access, however, and, by letting people know what services exist, it would allow for more appropriate use of services. Likewise, the availability of accurate information about funding for services would neither change the inherent complexity and fragmentation of public and private programs that pay for services nor make more funding available. It would increase the likelihood that people receive benefits for which they are eligible, and it would allow families and others to plan realistically for the care of people with dementia. The process of compiling and maintaining an accurate resource list also could aid in efforts to identify gaps in services and funding for services for people with dementia.

If a single agency in a community were designated to maintain an accurate resource list, the designated agency would not have to be the source of all referrals or the single access point for services. The desirability of establishing a single access point for services in each community has been debated by many investigators (see, e.g., Callahan, 1981 (104), and Piktialis and Callahan, 1986 (661)). Some service providers fear that if a single agency is designated to maintain the resource list, that agency will control referrals and may discriminate against certain providers (61 1). If the single agency were required to make the resource list widely available, however, other agencies, individual health care and social service professionals, voluntary associations, and others could use it themselves to make referrals.

The findings from Cuyahoga County, Ohio, and elsewhere suggest that people with dementia are not always identified as such by agencies that provide information and referrals (186,756). In the past decade, the awareness of Alzheimer's and other dementias has increased greatly among health care and social service professionals and service providers. Nevertheless, some people who provide information and referrals are not trained or predisposed to identify dementia in their clients. A system to link people with dementia to services must include

mechanisms for identifying people with dementia if it is to provide appropriate information to such people or refer them to appropriate services.

Lastly, OTA's contractors found that most of the agencies that responded to the survey in Cuyahoga County do not have systematic procedures to follow-up on referrals to make sure patients receive needed services (186). The lack of followup procedures does not pertain to the availability of accurate information about services, the topic of this section, but it is relevant to a different question: If accurate information about services for people with dementia is available, can patients, families, and others use it to locate and arrange the services they need? That question is touched on in the following section and discussed in detail in chapter 3. OTA's contractors in Cuyahoga County noted a difference between the kind of referral support, including followup, received by people who are considered clients of an agency and the referral support received by people who just get information and referrals over the telephone (186). Patients and families who need assistance to follow through on a referral are more likely to receive it if they are considered clients of the referring agency. In either case, however, without systematic followup procedures, an agency that provides information and referrals is unlikely even to know which of the people it has referred to services actually needed more help to follow through on the referrals. Systematic follow-up procedures are essential to keep such people from "falling through the cracks."

WHAT IS SPECIAL ABOUT THE INFORMATION AND REFERRAL NEEDS OF PEOPLE WITH DEMENTIA

Many aspects of the information and referral process are similar for individuals with dementia and individuals with other conditions, but there are some differences that are relevant to developing an effective system to link people with dementia to services. Several of these differences are identified in the following discussion, which draws on the observations of administrators of State information and referral programs, an analysis of data on callers to the "Home Help Line" of the Benjamin Rose Institute in Cleveland, and some findings from the caregiver interviews that were part of the study conducted for OTA in Cuyahoga County, Ohio.

Comments by Administrators of State Information and Referral Programs

Comments to OTA by the administrators of some State information and referral programs suggest that calls made about services for people with dementia often require more time than calls about services for other people. The director of Alzheimer's Information Services in Massachusetts, for example, has told OTA that calls received by the State's Alzheimer's telephone information and referral program usually last much longer than calls received by the State's general information and referral program for elderly people (121). He estimates that whereas calls to the State's general information and referral program for elderly people usually last only a few minutes, calls to the Alzheimer's information and referral program typically last about 20 minutes and sometimes last as long as an hour and a half.

An administrator in the Oklahoma Special Unit on Aging that has a telephone information and referral program for elderly people has told OTA that people who call the program for a person with dementia usually want more than information and referrals (544). He says that people calling for a person with dementia are much more likely than people calling for a nondemented elderly person to "want to talk."

The director of the North Carolina Alzheimer's telephone information and referral program also says that people who call that program often want more than information and referrals (290). Her perception is that many callers want help in understanding dementia and defining the patient's service needs, as well as information and referrals.

An Analysis of Data on Callers to the Benjamin Rose Institute's Telephone Information and Referral Program

OTA is not aware of any research that specifically compares the process of information and referral for people with dementia to the process for nondemented people. In the absence of such research, the OTA contractors who performed the study in Cuyahoga County, Ohio, analyzed data that was collected in 1984 and 1985 on people who had called the Benjamin Rose Institute's telephone information and referral 'Home Help Line' in those years (186).

The Benjamin Rose Institute is a nonprofit agency in Cleveland, Ohio, that conducts research and provides health care, social services, and residential care for elderly people.

OTA's contractors compared data on two groups of people who had called Benjamin Rose Institute's Home Help Line:

- 30 individuals who had called the Home Help Line for an elderly person with a mental impairment (e.g., Alzheimer's disease, mental illness, brain damage, forgetfulness, confusion, or senility¹⁰); and
- 116 individuals who had called the Home Help Line for an elderly person with a physical health condition and no mental impairment (186).

OTA's contractors found several differences between the two groups of callers that point to special aspects of the information and referral process for people with dementia (186). First, more than one-third (36 percent) of the physically impaired people called the Home Help Line themselves, but none of the mentally impaired people did. This finding illustrates the limited capacity of people with a mental impairments to contact an information and referral source for themselves and supports the conclusion of this OTA assessment that an information and referral program is not itself sufficient to link people with dementia to services; as discussed in chapter 3, people with dementia who have no family member or other informal caregiver to help them may require outreach and case management.¹¹

People who had called the Home Help Line for a mentally impaired person were more likely than people who had called for a physically impaired person to have previously contacted another agency that could not provide the needed assistance. The two groups of callers also differed in their reasons for calling the Home Help Line. People who had called for a mentally impaired person were more likely than people who had called for a physically impaired person to say:

- that they needed help in deciding what types of services would be most helpful;
- that they needed to know what services Medicare and Medicaid cover; and

¹⁰The definition of mental impairment in the Benjamin Rose Institute's data set included mental illness as well as dementia, so the findings do not pertain only to people with dementia.

¹¹For OTA's analysis in support of this conclusion, see ch. 3.

- . that they needed help in knowing what tasks they could expect someone they hired to do (186).

Another difference between the two groups was in the percentage of people in each group who made it through various steps in the process of getting services. OTA's contractors identified five steps in that process:

1. contacting an information source to obtain a referral;
2. receiving the name of a service provider;
3. contacting the provider;
4. finding that the provider actually offers the needed service; and
5. using the service (186).

When OTA's contractors compared people who had called the Home Help Line for a mentally impaired person and people who had called for a physically impaired person in relation to these steps, they found two differences (186). First, the percentage of people who received a referral was smaller for people who had called for a mentally impaired person (79 percent) than for people who had called for a physically impaired person (86 percent). Second, the percentage of people who ended up using the service to which they were referred was smaller among the mentally impaired people (11 percent) than among the physically impaired people (19 percent).

OTA's contractors also found that the people who had called the Home Help Line for a mentally impaired person were more likely than people who had called for a physically impaired person to say that they were having difficulty providing care (e.g., were not able to continue giving the same amount of assistance they had been giving or did not have enough time or energy to provide the care needed) (186). Research indicates that the caregivers of cognitively impaired people are generally more stressed than caregivers of physically impaired people (161,296,415,612). The finding that people who called the Home Help Line for a mentally impaired person were more likely to have problems providing care suggests that providers of information and referral for people with dementia must be especially attentive to the needs of caregivers.

Findings From Interviews With Caregivers in Cuyahoga County, Ohio

As noted earlier, the OTA-commissioned study in Cuyahoga County, Ohio, included interviews with 26 caregivers who called the Cleveland Alzheimer's Association Chapter's telephone helpline between April and July 1988 (186). Many of the 26 caregivers said they had been unsure at the time they called the helpline about what service they needed, and half of them said they had called the helpline for assistance in deciding what types of services would be most helpful. Six caregivers (23 percent) said they had called to find out what services Medicare or Medicaid cover. Several caregivers said they had called the Alzheimer's helpline just to talk, and many seemed to be reaching out for emotional support and reassurance.

Eleven (42 percent) of the 26 caregivers had previously contacted other agencies, including information and referral agencies, diagnostic centers, social service agencies, hospitals, and nursing homes. One spouse who was looking for day care said, "I was not able to find anything out." A daughter said she had called hospitals and other agencies and that her call to the helpline was motivated by "complete frustration." Another daughter said, "I called numbers from the telephone book—it was a waste of time."

Although not all of the 26 caregivers had called the Alzheimer's helpline for a referral, 23 caregivers received the name of one or more service providers (186). Of these 23 caregivers, almost half (11 caregivers) did not subsequently contact the service provider(s) recommended. The caregivers who did not contact the recommended service provider(s) gave a variety of reasons. Two of them cited the anticipated cost of the service; a third decided she did not need the service yet; and a fourth said she did not contact the recommended provider because "the phones at the agencies were not answered or the line was busy." In one case, a granddaughter had received referrals for day care and nursing homes for her grandmother, but her parents were not willing to act on the recommendations she received. In another case, a son caring for his 83-year-old mother felt that the referral he received did not go far enough: "I was told to find a doctor on my own and was sent a list of hospitals. I didn't contact any of them because no one recommended a specific doctor."

Of the 12 caregivers who did contact the recommended service provider(s), 9 caregivers reported that the provider(s) actually offered the needed service, and all 9 used the service (186). The other three caregivers who contacted the recommended service provider found that the provider did not have the service they needed. Two of the three said the hours that services were offered by the provider did not meet their needs. The third caregiver who was caring for her mother who had both dementia and cancer felt that no agency she contacted provided the kind of care her mother needed.

The percentage of caregivers who advanced through the five steps in the process of getting services and actually used the service(s) to which they were referred was larger among the caregivers who got a referral from the Cleveland Alzheimer's Association Chapter's helpline (35 percent) than among people who contacted the Benjamin Rose Institute's Home Help Line (11 percent) (186). Although the reasons for this difference are unclear, it maybe attributable to one or more of the following factors: 1) as a helpline operated by a dementia-specific organization, the helpline operated by the Cleveland Alzheimer's Association Chapter may attract callers with more clearly defined needs than the Home Help Line of the Benjamin Rose Institute; 2) caregivers who contact the Alzheimer's Association helpline may be in more immediate need of services than caregivers who call the Benjamin Rose Institute; 3) the person who staffs the Alzheimer's Association helpline may provide comparatively more support to callers, thus encouraging them to follow through on referrals; 4) the service providers to which Alzheimer's Association helpline callers are referred may be more appropriate for the needs of people with dementia; or 5) the callers to the Alzheimer's Association's helpline may regard the helpline as a source of expertise about the special needs of a person with dementia, thus adding to the credibility of the referral.

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

The preceding discussion of special aspects of the information and referral process for people with dementia suggests that the information and referral component of a system to link people with dementia to services must meet certain requirements in order to function effectively. In particular, the staff of the information and referral program must be able to

spend enough time to understand the individual caregiving situation and to help the caregiver define the patient's care needs and determine what types of services would be helpful. In addition, the staff must be:

- knowledgeable about dementia and the care needs of people with dementia;
- knowledgeable about services for people with dementia;
- able to provide accurate information about eligibility and coverage for services that may be needed for people with dementia through Medicare, Medicaid, and other funding sources; and
- attuned to the stresses associated with caring for a person with dementia and the difficulties dementia caregivers may have already encountered in trying to obtain accurate information about services and funding for services.

These requirements define what it would mean for an information and referral program to be ***dementia-capable***. Some people believe that only a dementia-specific information and referral program, i.e., a program that serves only people with dementia and their caregivers, could meet the requirements. Most of the members of the advisory panel for this OTA assessment concluded that an information and referral program that serves other elderly and disabled people as well as people with dementia could meet the requirements, but only with explicit recognition of the special information and referral needs of people with dementia, a commitment to serve such people, and special training for the staff.

WHAT IS SPECIAL ABOUT THE INFORMATION AND REFERRAL NEEDS OF ETHNIC MINORITY PEOPLE WITH DEMENTIA

Ethnic minority people with dementia and their families face all the same problems in obtaining accurate information about services and about funding for services as other people, but they also face additional problems due to language and cultural differences and demographic factors. At the start of this assessment, OTA could not find any research on information needs or information and referral procedures for ethnic minority people with dementia. Several studies of ethnic minority people in general have found that lack of information interferes with

their use of services (see, e.g., Guttman, 1980 (284); and Holmes, et al., 1979 (329)). On the other hand, a telephone survey of 1,608 black, Puerto Rican, Mexican-American, and other white people found little difference among three of these groups (blacks, Mexican-Americans, and other whites) in their knowledge about services and funding for services (330). Only the Puerto Rican group was significantly less likely to know about services and funding for services.

In 1988, to determine how ethnic minority people with dementia are linked to services and to identify any special problems that may arise in the linking process for them, OTA commissioned an exploratory study in California (866). That study is described in the next section and its implications for an effective system to link ethnic minority people with dementia to services are discussed.

Findings From a Study of Four Ethnic Minority Groups in Two California Counties

The OTA-commissioned study of how ethnic minority people with dementia are linked to services was conducted in two counties in California (Los Angeles and San Diego Counties) (866). OTA's contractors conducted interviews with families and other informal caregivers of black, Hispanic, Japanese, and American Indian people with dementia and with staff members of agencies that provide services for people in the four ethnic groups. After they compiled the results of the interviews, the contractors and OTA staff met with some of the interviewers and service providers from three of the four groups—blacks, Hispanics, and Japanese—in order to discuss the findings and their policy implications. Unfortunately, they were unable to arrange a meeting with the American Indian service providers in the time available for the study.

Several limitations of the study in California should be noted. First, the study sample does not represent all ethnic minority groups. OTA's contractors had hoped to include Chinese and Korean caregivers to broaden the Asian-American sample, but the necessary interviews could not be arranged. Many other groups also could have been included, since there are more than 100 ethnic groups in the United States (491,792). Second, even for the groups that were studied, the sample is not representative. People with dementia who have no informal caregiver were not included in the study, for example.

Lastly, the sample is composed largely of patients and caregivers who were successfully linked to services. Patients and caregivers who are not receiving services are underrepresented (866). Thus, the findings of the study in California depict a "best case scenario" with respect to linking ethnic minority people with dementia to services. The study did identify many problems, though, and it provides useful insights into the information needs of ethnic minority people with dementia and their caregivers. To OTA's knowledge, it is the only source of data on this topic.

OTA's contractors interviewed 88 ethnic minority caregivers, including 35 blacks, 25 Hispanics, 18 Japanese, and 10 American Indians (866). The study questionnaires were translated into Spanish and Japanese, and the interviewers for the Hispanic and Japanese caregivers were bilingual. Even though most of those caregivers were bilingual, they generally preferred to be interviewed in their native language. The black and American Indian caregivers were interviewed in English.

As shown in table 2-4, when asked if they knew about specific services, the majority of the ethnic minority caregivers said they knew about the following services: diagnosis and other physicians' services, transportation, home health care, home-delivered meals, nursing homes, chore services, information and referral, financial counseling, and mental health services (866). Less than half of the caregivers said they knew about adult day care, paid companion, protective services, and legal services. The results of in-depth interviews with the caregivers indicate that these responses reflect service consciousness (i.e., general awareness of services) rather than service knowledge (i.e., knowledge of a specific provider in the community) (865).

OTA's contractors found considerable variation among the four ethnic groups with respect to the percentage of caregivers who said they knew about each service (866). Some of the variation may have been due to differences in the types of services provided by the agencies from which the individuals were receiving services. Quite possibly caregivers know more about services of agencies to which they are connected than about services of other agencies. Moreover, some services are more readily available to some groups than to others.

Table 2-4-The Percentage of Ethnic Minority Caregivers Who Said They Know About Certain Services, Los Angeles and San Diego Counties, California, 1988

Service	Total sample (N= 88)	Blacks (N= 35)	Hispanics (N= 25)	Japanese (N= 18)	American Indian (N= 10)
Physicians' services	85%	74%	100%	89%	89%
Diagnosis	64	71	96	33	56
Transportation	80	66	100	72	90
Home health care	77	66	88	78	90
Home-delivered meals	77	63	92	78	90
Nursing home	68	77	100	95	90
Chore services	67	77	84	50	20
Financial counseling	63	43	80	77	78
Information & referral	60	45	64	61	56
Mental health services	55	34	76	61	60
Adult day services	41	26	44	56	60
Paid companion	39	20	68	39	33
Protective services	38	34	56	28	22
Legal services	36	17	52	44	56

SOURCE: R. Vane, L. Birba, J. Yelder, et al., "Linking of Ethnic Minority Elderly With Dementia to Long-Term Care Service," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington DC, 1989.

Many of the ethnic minority caregivers interviewed by OTA's contractors said they needed each of the services mentioned (866). The caregivers were asked in this context how they would find out about and arrange a service they needed. Surprisingly, in this sample of caregivers, most of whom were connected to agencies already, only 17 of the 88 caregivers (19 percent) said they would contact an agency for assistance in locating and arranging the service. Most of the other caregivers said they would try to find out about and arrange the service themselves or ask a family member for help in locating and arranging the service. Some caregivers did not answer the question, thus suggesting that they did not know how they would find out about or arrange the services they needed.

The interviewers concluded that although most of the 88 ethnic minority caregivers were linked to an agency already, they had no concept of a process by which they might obtain help in locating and arranging services (866). Even caregivers who reported knowing about information and referral programs (60 percent of the sample) said they would turn internally to themselves or their families for help in locating and arranging services. The interviewers came away with the impression that these apparently "connected" caregivers were still quite isolated from formal sources of help.

OTA's contractors interviewed 48 individuals who provide services for the 4 ethnic minority groups in the two California counties: 19 black service providers, 8 Hispanic service providers, 7

Japanese service providers, 7 American Indian providers; and 7 other white service providers (866). Sixty-six percent of the 48 service providers had worked for at least 3 years with ethnic minority people with dementia.

The service providers interviewed by OTA's contractors said that many ethnic minority caregivers in their areas have very little knowledge about dementia (866). The service providers also said that with some exceptions, knowledge about dementia is quite limited among the staff of agencies that serve ethnic minority people in the areas studied. Among the 48 service providers who were interviewed by OTA's contractors, 55 percent rated their own knowledge about dementia as moderate, while 40 percent rated their knowledge as high and 6 percent rated their knowledge as low.

The service providers who were interviewed said that dementia frequently is not identified in ethnic minority people for a variety of reasons:

- because families regard patients' cognitive deficits and behavioral problems, if any, as part of normal aging;
- because families feel there is a stigma attached to some symptoms of dementia and hide the patients; and/or
- because health care and social service professionals and service providers who interact with patients are not trained to identify dementia (866).

On the other hand, most of the ethnic minority caregivers interviewed for the study said the person they were caring for had been formally evaluated and diagnosed as having dementia (866). This included 40 percent of the American Indian patients, 60 percent of the black patients, 56 percent of the Japanese patients, and 84 percent of the Hispanic patients. The service providers considered these percentages unusually high for the communities.

The overall impression of the interviewers and OTA's contractors was that the problem of dementia is only one of many problems facing service providers in ethnic minority communities. Available resources are stretched thin, and agencies are overwhelmed by many urgent needs. Understandably, many service providers regard dementia as just one more problem to handle with limited funds and staff capability. In fact, some service providers seemed to regard the available resources for the care of people with dementia as so limited that there was no practical reason for identifying dementia in their frail elderly clients.

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

The interviews with ethnic minority caregivers and service providers in the OTA-commissioned study in California (866) and the interviewers' comments in meetings with OTA staff suggest four areas of consensus about special information needs and information and referral procedures for ethnic minority persons with dementia and their caregivers. Those four points are discussed below.

1. Information about dementia and about services for people with dementia should be available in the native language of patients and caregivers.

As noted earlier, the Hispanic and Japanese caregivers interviewed in the California study were bilingual but they generally preferred to be interviewed in their native language. Many of the people they were caring for spoke Spanish or Japanese exclusively. It was the consensus of the interviewers, service providers, and OTA's contractors that these patients and caregivers and others like them would have much greater difficulty understanding information about services and about funding for services or would be completely unable to under-

stand the information if it were in English rather than in Spanish or Japanese.

An example of the differential impact of information presented in English v. the caregivers' native language occurred in the fall of 1988, at the Little Tokyo Service Center, an agency in Los Angeles that provides services for Japanese people of all ages. Concerned about Japanese caregivers' lack of knowledge about dementia, a social worker at the Little Tokyo Center arranged two informational meetings for caregivers, a week apart, one to be conducted in English and one in Japanese. For both meetings, the main speaker was a Japanese neurologist who is well known in the community. Whereas 10 people attended the meeting conducted in English, 60 attended the meeting conducted in Japanese. During the latter meeting, several caregivers expressed strong interest in setting up a support group for caregivers. The same interest was not expressed in the other meeting (739).

One Hispanic interviewer told OTA about caregivers she interviewed who had gone to a local government agency to apply for public assistance and medical assistance and did not understand why they had been turned down. The interviewer's opinion was that even though the caregivers spoke and understood some English, they did not do so well enough to understand the complex eligibility requirements for these publicly funded programs. Her impression was that the families were very poor and probably eligible for assistance, so she suggested that they appeal. They did not do so, she said, because they did not think they could speak English well enough to present their case effectively to the agency staff (262).

The Los Angeles County Department of Social Services has an Asian unit with case workers who speak Japanese, Chinese, Korean, and Vietnamese to process applications for public assistance and medical assistance (739). OTA does not know whether there is a similar unit with Spanish-speaking case workers, but the department does have Spanish-speaking case workers in some offices (865).

While visiting agencies for the study in California, OTA's contractors noted a lack of printed materials in languages other than English about Alzheimer's disease, dementia, and services for people with dementia—a lack which contrasted with an extensive array of non-English-language printed

materials on other health and mental health problems. In the opinion of OTA's contractors, the lack of non-English-language printed information about dementia is one of the biggest problems preventing access of ethnic minority people with dementia to appropriate services (866).

The Alzheimer's Association has recently translated some of its brochures into Spanish and is distributing them. The social worker at the Little Tokyo Service Center, frustrated by the lack of any information about Alzheimer's disease in Japanese, translated an Alzheimer's Association pamphlet herself in the fall of 1988 (739). Translating these materials into many different languages and promptly distributing the products would appear to be both an achievable objective and a minimum requirement for linking ethnic minority people with dementia and their caregivers to services.

It is not known how many ethnic minority people with dementia or their caregivers need information in a language other than English. Elderly people are more likely than younger people to use their native language (862). Since most patients and many caregivers are elderly, the need for information in other languages may be widespread. In fact, Census Bureau data indicate that among elderly people who speak Japanese at home, 53 percent do not speak English well or do not speak it at all. Likewise, among elderly people who speak Spanish at home, 61 percent do not speak English well or do not speak it at all (863).

2. Information about dementia and about services for people with dementia must be culturally appropriate.

The cultural heritage, traditions, customs, and beliefs of an ethnic group affect how and when members of the group perceive the problem of dementia, who is expected to be the caregiver, what that person's responsibilities are, whether formal services are acceptable, and how and when they are sought (160,315,864). All these factors are relevant to the information needs of ethnic minority people with dementia and their caregivers. In particular, these factors influence what information about dementia, services, and service providers is meaningful and appropriate for them.

It has been suggested, for example, that memory loss and other cognitive deficits associated with dementia are noticed sooner by and are more

troublesome to groups that place high value on cognitive and intellectual functions than to groups that place high value on affective or emotional functions. The latter groups are more likely to be troubled by personality changes associated with dementia or by the failure of the demented person to fulfill his or her accustomed role in the family (237). If information about dementia is to be meaningful to ethnic minority people, it must focus on the aspects of the problem that are troublesome to them. The text of pamphlets and other informational materials should reflect these differences (863).

Cultural factors also are relevant in selecting appropriate service providers for ethnic minority people with dementia. Many of the ethnic minority caregivers interviewed for the study in California were using services from agencies that primarily serve one ethnic minority group (866). Staff of these agencies often are members of the same ethnic group, and the services are adapted in various ways to that group's customs and values.

The ethnic minority service providers who were interviewed in California emphasized the importance of the cultural appropriateness of services (866). Sixty-six percent of the 48 service providers interviewed said that in their experience, an agency's failure to respond to cultural values and concerns was a common barrier to the use of the agency's services by ethnic minority people. In order to refer patients and families to appropriate service providers, an information and referral agent must be aware of their cultural background and knowledgeable about agencies' and individual providers' capacity to serve people of different cultural backgrounds.

3. Information about dementia and about services for people with dementia must be tailored to demographic differences among and within ethnic minority groups.

Demographic factors, such as income and educational background, vary both among and within ethnic minority groups. Although the four ethnic minority groups studied by OTA have lower average incomes than the majority population, not all ethnic minority people have low incomes. The same is true for educational background. Whereas cultural factors are specific to a particular ethnic group, demographic factors cut across ethnic groups (866). The combination of language and cultural differences among ethnic groups and demographic differ-

ences among and within ethnic groups creates a complicated mix of information needs.

Ethnic minority people in groups that have relatively low incomes are likely to be eligible for means-tested services and benefits (492,455). Accurate information about these services and benefits is clearly important for them. On the other hand, information and referral agents cannot assume that individual ethnic minority people have low incomes or that they have a special need for information about means-tested programs.

The educational background of patients and families is relevant to the content, "pitch," and format of printed information about dementia and services for people with dementia (866). Public education messages for radio, television, and other nonprint media also must take into account the formal educational background of the intended audience. OTA's contractors found that educational background varied greatly both among and within the four groups of ethnic minority caregivers interviewed in San Diego and Los Angeles Counties.

To create informational materials that reflect the mix of language, cultural, and demographic differences among ethnic minority people requires extensive knowledge of the intended audience. One Hispanic service provider in Los Angeles has created a Spanish-language "foto novela" (picture book) about Alzheimer's disease and dementia. The picture book format and the pitch of the text are intended for a segment of the Spanish-speaking population that is not reached by Alzheimer's Association pamphlets that have been translated into Spanish. The content of the book, a page of which is shown in figure 2-2, reflects values, customs, and experiences that are common to Mexican-Americans. According to the author, different text and illustrations would be needed for Spanish-speaking Cuban-Americans (146)

4. Information about dementia and services for people with dementia must be available through the existing ethnic minority community infrastructure and ethnic minority agencies, where there are such agencies.

For cultural, demographic, and historical reasons, many ethnic minority people live in communities largely composed of members of the same group. In these communities, there is generally an infrastruc-

ture of individuals and associations that are recognized by the community as sources of information and assistance with a wide range of problems (380,867). Some communities also have agencies that primarily serve one ethnic group in that community. If information about dementia and about services for people with dementia is to reach patients and their caregivers in these communities, it must be available through these individuals, associations, and agencies.

It may not be obvious to outsiders which individuals and associations are recognized by an ethnic minority community as sources of information and assistance. The individuals' occupations and the associations' stated objectives may have no apparent connection with care of people with dementia. Yet information distributed through other, seemingly more appropriate channels, is less likely to reach those that need it or to be accepted by them (862).

The importance of the church as a source of support and assistance in black communities is widely recognized (642,770,782), and some commentators have suggested that churches in those communities could provide information about services or refer people with dementia and their caregivers to other sources of information (750). Service providers in Los Angeles County told OTA's contractors that pastors of some black churches are enthusiastic about learning about dementia and making information available to their members. On the other hand, some caregivers cannot leave the person with dementia alone and therefore cannot be involved in church activities (160). Other black caregivers are not connected to a church, and alternate ways of reaching these caregivers also are needed.

Although churches in black communities may play a role in providing information or referring people to sources of information about dementia and services for people with dementia, churches in some ethnic minority communities are unlikely to play such a role. A study of elderly Vietnamese immigrants in two Texas communities found, for example, that 90 percent of the respondents said their church or temple was important to them, but none said they would turn to it for help with a problem (165). They regarded the church or temple as a spiritual and cultural institution and said they would turn to public agencies for information and assistance.

Figure 2-2—Illustrations From a “Foto Novela” (Picture Book) on Alzheimer’s Disease That is Targeted to Mexican Americans



SOURCE: Calmeacac Ed. y i nal Services, Siempre Viva (Los Angeles, CA: Calmeacac Educational Services, 1989).

Clearly, not all ethnic minority people live in communities largely composed of one ethnic group. Making information about dementia and about services for people with dementia available to geographically dispersed ethnic minority people undoubtedly is more difficult than making it available in self-contained minority communities. The study conducted for OTA in Los Angeles and San Diego Counties did not address this problem, and OTA has not looked into methods that have been used successfully to provide information about other health problems for geographically dispersed ethnic minority people.

PHYSICIANS' ROLE IN REFERRING PATIENTS AND CAREGIVERS TO SERVICES

As discussed in the beginning of this chapter, many families and other informal caregivers say that physicians are not knowledgeable about services for people with dementia and do not refer patients and their caregivers to services (125,257,412,497,500, 531,599,934). For example, three-quarters of the 100 family caregivers interviewed for the Connecticut Governor's Task Force on Alzheimer's Disease in 1988 said that at the time of diagnosis, the patient's physician did not refer them to any services (479).

Although other health care and social service professionals also may not be knowledgeable about services for people with dementia and may not provide appropriate referrals, the focus of caregivers' complaints has been on physicians—probably because of caregivers' expectations for physicians. A physician is usually the one who tells the caregivers the patient's diagnosis, and since physicians often refer all kinds of patients for other medical services at the time of diagnosis, caregivers may expect the physician to refer them to services. Similarly, throughout the course of a patient's illness, caregivers are likely to turn to the physician when there are changes in the patients condition and problems they cannot handle (292). They hope and often expect that the physician will be able to provide solutions, including referrals to appropriate services. If that does not happen, the physician may get blamed. Other health care and social service professionals who might provide referrals seem to get blamed less often—probably because patients,

families, and others do not have the same expectations for them.

Physicians are in a difficult position with respect to providing information and referrals for their patients with dementia. The literature identifies many other tasks for physicians who are treating people with dementia, even without considering the task of providing information and referrals. The identified tasks include making a diagnosis; treating any intercurrent illness; managing the patient's medications; offering emotional support for families and other informal caregivers; and providing education and counseling for caregivers about the patient's diagnosis and prognosis and caregiving techniques to reduce patients' behavioral problems and maintain patient functioning (74,154,292,300, 368,679,915). As discussed earlier in this chapter, helping caregivers of people with dementia identify their service needs and select a service provider is often time-consuming. In addition, in many communities, there is no source of accurate, comprehensive information about what services are available, and the service environment is so complex that it is difficult and time-consuming for anyone to keep current on available services. Given existing constraints on physicians' time, it may be unrealistic to expect physicians to provide information about services and referrals to services for their patients with dementia.

On the other hand, many caregivers expect physicians to provide information and referrals. Moreover, given the general feeling of respect for physicians, caregivers are probably more likely to use services if they have been referred to the services by a physician than by someone else. As discussed in chapter 3, some caregivers of people with dementia feel guilty about using services and believe that they should provide all the patient's care themselves. This feeling is compounded for some caregivers by doubts about whether the patient is really "sick" and, therefore, whether the use of services is justifiable. In the eyes of these caregivers, a physician's referral may give legitimacy to their use of services (290,931).

Discussions about physicians' role in providing referrals for dementia patients and their caregivers generally do not distinguish between a physician furnishing information about community services and referrals to specific providers and a physician referring patients and their caregivers to another

source of information and referrals. Some commentators suggest that physicians should act as the coordinator or manager of services for people with dementia. Winograd and Jarvik say, for example:

In addition to providing medical care and psychologic support, the physician can play a pivotal role in developing comprehensive plans for demented patients with the aid of other health professionals (*e.g.*, *discharge* planners and visiting nurses). Social workers can assist with referral to the appropriate resources. . . (915).

This statement implies that the discharge planner, visiting nurse, and social worker should be the sources of information about specific service providers.

Many commentators recommend a multidisciplinary team approach to care of people with dementia (56,257,292,679,915). In that approach, a physician may discuss potentially beneficial services with caregivers and recommend their use, but the task of identifying service providers usually is performed by a social worker, nurse, or another team member. Most physicians do not practice as part of a multidisciplinary team, however. If their patients and the patients' caregivers are to receive information about services and referrals to service providers, the physician must either furnish them or refer the caregivers to another source of information and referrals.

Some and perhaps many physicians may prefer not to be the primary source of information and referrals for their patients with dementia. A study of physicians' roles in treating people with dementia asked 57 physicians to rate the relative difficulty of various tasks involved in caring for these patients (257). The study's findings show that the physicians considered helping patients and their families obtain health care and social services and advising them about nursing home placement among the most difficult and time-consuming tasks in treating these patients. The 47 family caregivers interviewed as part of the study said that physicians were least helpful in these areas. The researchers concluded from the physicians' spontaneous **comments** during the **interviews** that **some** of the physicians made a distinction between coordinating medical services and social services and did **not** regard referrals for social **services as their** responsibility.

It is often said that physicians know less about and refer patients less frequently to social services than to **medical services** (125,133,257,927). It is also said that some physicians are not knowledgeable about home care services and sometimes recommend nursing home placement when the patient could be cared for at home with available services (500,934). The same observations have been made with respect to physicians' knowledge of and referrals to services for elderly people in general, and the findings of some studies support these observations (661,927).

Some AAAs have attempted to increase physicians' awareness of services and encourage physicians to refer elderly people and people with dementia to an AAA for information and assistance with arranging services (934,944). Sometimes these efforts are initially successful. Referrals by physicians to the AAA increase for a time but then drop off. It is not clear why this occurs. Some physicians may not be convinced of the value of certain services for their patients, or their referrals to the AAA may **not** work in some way that leads them to stop referring.

The distinction between service consciousness and service knowledge that was made earlier in this chapter with respect to caregivers' knowledge about services may be helpful in thinking about physicians' knowledge about services and their role in providing information and referrals for people with dementia. If physicians have service consciousness (*i.e.*, they are aware of the types of services that may be useful for people with dementia) but lack service knowledge (*i.e.*, they do not know what specific agencies or individuals provide the services in the community), they still can talk with caregivers about potentially beneficial services and encourage the caregivers **to use** appropriate services. Then they will have **to** refer the patients and caregivers to someone who is knowledgeable about the details of service availability in the community. If, on the other hand, physicians lack service consciousness (*i.e.*, they are not aware of the types of services that may be useful for people with dementia), they will **not** be able to refer **or advise caregivers appropriately**. They may recommend too often the services they know about and fail to recommend others that may be more appropriate for the patient's and family's needs. Anecdotal evidence suggests that some physicians lack service knowledge; others lack both service consciousness and service knowledge; and **still others are well-informed** about services that

may be useful for people with dementia and about the availability of those services in the community.

Physicians play a pivotal role in linking people with dementia to services, and ways must be found to ensure their effectiveness in that role. It may be unrealistic to expect physicians to *stay* up-to-date on available services and funding for services in other than very small communities, and it probably would be undesirable from a societal perspective for physicians to spend their time in that way. A more appropriate objective may be for physicians to be aware of the kinds of services that maybe beneficial for people with dementia, to discuss services in a general way with patients and their caregivers, and then to refer the patients and caregivers to another individual or agency that can provide information about specific service providers and funding for services. Obviously, for this approach to work, a source of accurate information about services and service providers must exist in the community.

CONCLUSION

In many communities, accurate information about services for people with dementia and about funding for such services is not available. Other problems usually receive more attention from policymakers and dementia advocates, but when dementia caregivers are asked, they stress the difficulties they face in trying to obtain information about services and funding. In the view of many caregivers and service providers interviewed for this OTA assessment, caregivers' lack of knowledge about services is the primary barrier to service use.

Knowledge about services has two components, referred to here as service consciousness and service knowledge. The study conducted for OTA in Cuyahoga County, Ohio, found that a significant proportion of caregivers of people with dementia, 12 to 92 percent depending on the service in question, lacked service consciousness—i. e., they had never heard of the service. Again depending on the service, 35 to 96 percent of caregivers lacked service knowledge



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

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i.e., having been told what the service is, they could not identify a specific provider in the community (186).

A caregiver's need for service knowledge probably is greatest at the time(s) when he or she is selecting a specific provider. A caregiver's need for service consciousness, however, is longer lasting and more general. An awareness of different types of services can help a caregiver think realistically about a demented person's care, consider various alternatives, and plan for the future—all of which may increase the caregiver's sense of being in control of the caregiving situation.

Lack of service consciousness is probably addressed most effectively through public education programs. Lack of service knowledge is addressed most effectively through information and referral programs. Neither approach is sufficient by itself because people who lack service consciousness are unlikely to call an information and referral source. Conversely, the kind of information that can be provided through public education programs often is not detailed enough to allow people to locate the services they need or to determine whether they are eligible for various funding programs.

To link people with dementia to appropriate services, an information and referral program must have an up-to-date resource list that includes all agencies and individuals in the community that provide the kinds of services that maybe needed for people with dementia. Whether the information and referral program is dementia-specific or not, it must be dementia-capable. The program's staff must be knowledgeable about dementia, the care needs of people with dementia, and the common problems families and others face in taking care of a person with dementia. The program must be able to provide

accurate information about eligibility and coverage for services through Medicare, Medicaid, and other funding sources. If the program is not dementia-specific, it must have mechanisms for identifying people with dementia so that it can provide appropriate information and referrals. Lastly, it must be responsive to the special information and referral needs of ethnic minority people with dementia.

Even if accurate information about services and funding for services were available, however, it would not mean that there would be enough services or funding. Insufficient availability of services and funding for services is a major public policy concern that cannot be remedied by an accurate resource list or by the best public education and information and referral programs. On the other hand, without an accurate resource list, no one can know with certainty what is and is not available, except in small communities with very few service providers.

In public policy discussions, a single-minded focus on the problem of insufficient availability of services and funding for services for people with dementia precludes awareness of other problems that restrict access to the services and sources of funding that are available. Obviously, one of these problems is the lack of accurate information about services and funding for services. Underlying that problem is the incredible complexity of services and funding at the community level. An accurate resource list and public education and information and referral programs can help caregivers and others locate services and sources of funding but cannot change the inherent complexity of the service environment. If the complexity of the service environment were reduced, obtaining accurate information about services and funding would certainly be less difficult.