

Chapter 5

**Concerns About the Quality and
Appropriateness of Services**

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Concerns About the Quality and Appropriateness of Services

INTRODUCTION

The quality of all kinds of health care, long-term care, social, and other services that may be needed for people with dementia varies greatly from one agency and individual service provider to another.¹ Numerous reports document the poor quality of care provided by some nursing homes (563,759,813,835), board and care facilities (66,166,775,816), and to a lesser extent home care agencies (821,305,852). At the same time, these reports indicate that other nursing homes, board and care facilities, and home care agencies provide excellent care. Differences in quality are typical not only of these types of services, but of all kinds of services that may be needed for people with dementia.

In addition to differences in quality, there are differences in services provided by various agencies and individuals that make the services more or less consistent with the needs of people with dementia. In communities that have more than one nursing home, home care agency, adult day center, physician, lawyer, or any other type of agency or individual service provider, the services offered by one agency or individual may be much more appropriate for people with dementia than the services offered by another agency or individual.

All people who need health care, long-term care, social, or other services are at risk of poor quality or inappropriate care, but people with dementia are particularly vulnerable. Because of their cognitive deficits, they may be unable to identify or articulate their care needs, to evaluate the services they receive, to remember and report instances of poor care, or to be believed. Realizing that people with dementia are so vulnerable, families and other informal caregivers are often extremely concerned about the quality and appropriateness of services they may use for these people.

This chapter focuses on the potential role a federally mandated linking system might play with respect to the quality and appropriateness of services to which it connects people with dementia. The *quality* of a service is defined here as the extent to

which the service increases the probability of desired outcomes and reduces the probability of undesired outcomes, given the constraints of existing knowledge.² The *appropriateness* of a service denotes the aspects of a service that make it consistent with the needs of people with dementia.

In theory, a federally mandated linking system could take any of several different approaches with respect to the quality and appropriateness of services to which it connects people with dementia.

- The linking system could not concern itself with the quality and appropriateness of the services; it could provide no information about the quality and appropriateness of services and rely on families and others who are concerned about quality and appropriateness to obtain for themselves any information they need to evaluate the services.
- The linking system could refer families and others to specific sources of information about the quality and appropriateness of services.
- The linking system could provide families and others with information about the quality and appropriateness of the services.
- The linking system could refer people to or arrange for them only services that met specified standards of quality and appropriateness. (In the case of a linking system that also pays for services, this alternative would mean that the system would only pay for services that met the specified standards.)
- If the linking system provides services, it could assure the quality and appropriateness of those services directly.

In practice, three problems would make it difficult to implement these approaches or would limit their potential effectiveness. First, several of the approaches assume that there are accepted criteria for evaluating the quality and appropriateness of services for people with dementia. In fact, as discussed in this chapter, there is currently no consensus about criteria for evaluating the quality and appropriateness of services for people with dementia.

¹See table 1-2 in chapter 1 for a list of services that may be needed for people with dementia.

²This definition of quality was also used by OTA in its 1988 assessment, *The Quality of Medical Care: Information for Consumers* (832).

Second, several of the approaches assume that accurate information about the quality and appropriateness of services for people with dementia is available from various sources. Although one hears many recommendations about possible sources of such information, the analysis in this chapter indicates that accurate information about quality and appropriateness is not consistently available from any of the recommended sources.

Third, several of the approaches assume that families and other informal caregivers are able to gather information about the quality and appropriateness of services from one or more sources or to use lists of questions and criteria to evaluate services themselves—in short, that families and others are able to function as “informed consumers” in evaluating the quality and appropriateness of services. Although some families and other informal caregivers of people with dementia are certainly able to function as “informed consumers” in this context, others are not for a variety of reasons described in the chapter.

Probably the most important step that could be taken to enable a federally mandated linking system to connect people with dementia to the best available services would be the development of criteria to evaluate services. Certainly, if a federally mandated linking system were going to refer people to or arrange for them only services that met certain standards, the standards would have to be based on accepted criteria. If such criteria were available, some families could use the criteria to evaluate services themselves. Other agencies and organizations could also use the criteria to evaluate services, thus making accurate information about the quality and appropriateness of services available from these sources. The development of criteria for evaluating the quality and appropriateness of services for people with dementia is not the function of a linking system, but ways in which the necessary criteria might be developed and some criteria that might be considered are discussed later in this chapter.

The chapter focuses primarily on *quality assessment* (i.e., the measurement and evaluation of quality) rather than on *quality assurance* (i.e., procedures and activities to safeguard and improve quality by assessing quality and taking action to correct any problems found). The focus on quality assessment reflects the perspective of families and others who are trying to identify good services for a

person with dementia, but who usually are not involved in assuring the quality and appropriateness of services.

Some agencies that link people to services also provide services and therefore can assure (i.e., assess and correct problems in) the quality of those services directly. Other agencies that link people to services contract for some of the services, and some of those agencies have procedures for monitoring and controlling the quality of contracted services. The last section of this chapter describes some of those agencies' procedures for monitoring and controlling quality, including procedures that involve patients and families in monitoring and controlling the quality of the services they receive.

Quality of care and methods of assessing and assuring quality are currently a concern of Congress and the topic of many publicly and privately funded research projects. Interest in quality of care has increased because of widespread concern that cost-containment measures introduced in the past few years may be reducing quality of care (111,831,925). Attention has focused primarily on the quality of hospital and nursing home care, but the focus is expanding now to include in-home and other noninstitutional services (206,216,471,658). In considering the potential role of a federally mandated linking system with respect to the quality and appropriateness of services to which it links people with dementia, this chapter is discussing all types of services that may be needed for these people.

FAMILY CAREGIVERS CONCERNS

Numerous studies and anecdotal reports emphasize the strong commitment of many family caregivers to their relative with dementia. With this commitment comes a deep concern about the quality and appropriateness of any services provided for the person. According to one Office of Technology Assessment (OTA) contractor who studied 500 family caregivers of people with dementia:

What was most impressive from (the) caregiver studies was the emotional investment that caregivers have in their responsibilities. This emotional tone may be reflected in rage at unsympathetic agencies or professionals, fear, grief, advocacy, resignation, humor, but most of all love for and commitment to an impaired older person. With such a strong personal investment, these family caregivers were predictably critical consumers of services and programs in their behalf (291).

A 1986 survey of family caregivers conducted for OTA found that family caregivers were indeed “critical consumers” who were concerned about the quality and appropriateness of services available to their relatives and other people with dementia (926). Other studies report similar findings (145,412). Many of the State task forces and committees that have studied the problem of Alzheimer’s disease and related disorders also note families’ grave concerns about the quality and appropriateness of services (99,143,246,360,396,408,531,541,598,621,870,920).

Some family caregivers are fearful about using services for a person with dementia because they believe that the quality of care provided will be poor and that the service providers will not know how to take care of a person with dementia (88,145,291,396,599). Some family caregivers feel-often realistically-that no one will take as good care of their demented relative as they do. Some fear that their demented relative’s inability to express needs or report inadequate care will cause service providers to neglect the person. Others fear that their demented relative’s troublesome behavior or psychiatric symptoms will cause that person to be physically or verbally abused. Some families are apprehensive about using in-home services for a relative with dementia because they are afraid that the workers will be poorly trained and unreliable. Families who have had problems with one service provider may be afraid to try another one.

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

The concern about insufficient availability of services is legitimate. The important point to be made here, however, is that even when services are

available, there are some situations in which families’ concerns about the quality and appropriateness of the services are the determining factor in their decisions about whether or not to use the services. Some families may choose not to use an available service because they believe that the service is inappropriate for the patient or of poor quality. Likewise, some families who have been reluctant to accept help may decide to use a service if they believe it is appropriate for the patient and of good quality.

OTA does not know how often either of the situations just mentioned occur or whether the frequency of their occurrence varies for different types of services. That there are situations, however, in which considerations of quality and appropriateness are the determining factor in families’ decisions about service use suggests that although some health care and social service professionals, case managers, government planners, policy analysts, and others may regard concerns about the quality and appropriateness of services as secondary to the problem of insufficient availability of services, the families of people with dementia may not always agree. In the view of at least some families in some situations, services that are available but of poor quality or inappropriate for the patient may just as well not exist.³

CONCEPTUAL AND PRACTICAL DIFFICULTIES IN EVALUATING SERVICES

Many people think they know quality when they see it, but they have difficulty defining its components precisely. This predicament is described in a frequently cited passage from *Zen and the Art of Motorcycle Maintenance*:

Quality you know what it is, yet you don’t know what it is. But that’s self-contradictory. But some things **are** better than others, that is, they have more quality. But when you try to say what quality is apart from the things that have it, it all *goes pooff* There’s nothing to talk about. But if you can’t say what Quality is, how do you know what it is, or how do you know it even exists? (663).

³Clearly, considerations of quality and appropriateness do not always play a critical role in family caregivers’ decisions about the use of available services for an individual with dementia. Some caregivers are so severely burdened that they may have to use *any* available service, regardless of its quality and appropriateness. Other families, even severely burdened ones, may choose not to use an available service even though the service is of high quality and appropriate. For a discussion of some of the reasons why families and other caregivers of people with dementia may be reluctant to use available services, see ch. 3.



Photo credit: Peter Carroll

Because of their strong commitment to their relative with dementia families are often deeply concerned about the quality and appropriateness of any services they may use for the person.

People's judgments about quality are often impressionistic. With respect to services for people with dementia, someone might observe something about an agency and decide the agency's services are good or not good without thinking about how he or she reached that conclusion. Likewise, someone might hear from a friend, the family physician, or another source that a certain provider is good or not good and accept that judgment as true without questioning its basis.

Impressionistic judgments about quality may be correct, but quality is not necessarily obvious or easy to judge, and people sometimes differ in their impressions about the quality of a particular service. For judgments about quality to be more than impressionistic, they must be based on criteria that are derived from specified goals or desired outcomes of care and from methods of care that are known to achieve those goals or outcomes (174,385,737,832, 925). At present, however, there is no consensus about the goals or desired outcomes of care for people with dementia, and the efficacy of many methods of care has not been proven (482,510,675).

The lack of a consensus about the goals of some services for people with dementia and the lack of proven methods to achieve those goals is not surprising. Although a few agencies and individuals have focused on providing appropriate services for people with dementia for many years, most health care and social service professionals and other providers have only begun to think about the service needs of people with dementia in the past few years, if at all. Moreover, many treatment methods and service interventions that are used routinely for people with other diseases and conditions have not been evaluated rigorously and are simply assumed to be effective (31,832). Services for people with dementia are not unique in this respect.

A major factor that complicates the development of valid criteria to evaluate the quality of services for people with dementia is the current uncertainty about what distinguishes appropriate services for these individuals from appropriate services for people with other diseases and conditions.⁴ Many service providers who work with people who have dementia believe that such people have special service needs. The difficulty arises in determining exactly what is or should be different about service goals and methods of care for this patient population.

Over the past decade, as awareness of Alzheimer's disease and other diseases that cause dementia has increased, nursing homes, board and care facilities, adult day care centers, and home care agencies have developed some services specifically for people with dementia. Anecdotal evidence indicates that these "special" services vary considerably. To a great degree, this variation reflects the lack of agreement about goals and methods of care for people with dementia. Box 5-A discusses the variation among special nursing home units for people with dementia, often referred to as "special care units," and points out the difficulty families and others may have in evaluating a special care unit and in determining, for example, whether a given special care unit will provide more appropriate care than a regular nursing home unit for an individual with dementia.

Knowledge about what constitutes appropriate care for people with dementia is constantly evolving, and, in fact, special care units and other specialized services for people with dementia provide ideal

⁴The *validity* of criteria to evaluate quality refers to the extent to which the criteria measure what they purport to measure (832).

BOX 5-A—"Special Care Units" for People With Dementia

Over the past decade, some nursing homes have established "special care units" for people with dementia. One might assume that, by definition, these units would provide appropriate care for people with dementia. Many special care units do provide appropriate care, but anecdotal evidence suggests that some special care units do not provide appropriate care (144,317,321,404,425,482,83 1). It is said that some nursing homes use the words "special care" as a marketing tool and actually provide no special services for people with dementia. It is also said that some nursing homes with special care units are misinformed about what is appropriate care for people with dementia.

One study of special care units for people with dementia found that the units differed greatly in their goals and methods of care (624). According to the researchers:

These differences are of such significance that they appear to place special units in direct opposition to each other. Nonetheless, without **exception, their proponents** have hailed the success of the units (624).

It is easy to understand why families and others who are trying to locate a nursing home for a person with dementia could be confused about special care units. They need a way to evaluate special care units and to compare the units with nursing home units that do not claim to provide special care. Otherwise, some families may unwittingly select a special care unit that provides inferior care or is inconveniently located, when a nondementia-specific nursing home is nearby and provides as good or better care. In this context, the director of a regional Alzheimer's center has told OTA that she knows families who feel guilty about not having placed their relative with dementia in a nursing home with a special care unit, even though the nursing home they chose is nearer to their home and provides excellent care, whereas the nursing home with the special care unit is too far from their home to allow them to visit their relative frequently (55).

Determining whether a given special care unit provides appropriate care for people with dementia would require an answer to the question, "What is appropriate care for people with dementia?" Although there is no consensus about the answer yet, two recently published documents may be helpful to families and others who are trying to evaluate special care units. One is an Alzheimer's Association handbook for caregivers on selecting a special care unit (486). The other is a report on "best practices" in special care units produced by the American Association of Homes for the Aging (60).

These two documents and other publications about special care units provide insight into the components of appropriate nursing home care for people with dementia. Some components of care mentioned in these publications are specific to people with dementia (e.g., the need for staff training in the usual symptoms of dementia and in effective responses to behavioral problems that occur often in this patient population). Other components are not specific to people with dementia and would benefit people with other diseases and conditions as well (e.g., adequate staff-to-patient ratios, avoidance of overmedication, and individualization of care). Greater understanding of what distinguishes appropriate nursing home care for people with dementia v. people with other diseases and conditions is needed to develop valid criteria to evaluate special care units.

SOURCE: Office of Technology Assessment, 1990.

settings for research on alternate methods of care. Nevertheless, the development of criteria to assess quality cannot await final, indisputable evidence about effective methods of care or a consensus about the goals of care for these people. As is true of criteria to evaluate the quality of treatment methods and services for people with other diseases and conditions, criteria to evaluate the quality of services for people with dementia must be developed on the basis of the best available information from research and provider experience, leaving open the option to change the criteria as new knowledge develops.

The following section presents some of the ideas and issues involved in defining and measuring quality. It provides a conceptual framework that

could be used to develop criteria for evaluating the quality of services for people with dementia. The subsequent section discusses the potential role of patients and families in defining quality and specifying goals and methods of care.

Defining and Measuring the Quality of Services for People With Dementia

Quality has been defined and its components identified to a greater extent for hospital care, acute medical care, and nursing home care than for home care or social services. It is generally agreed, however, that quality is multidimensional for all these types of services and for all kinds of people who use the services (173,385,83 1,832). The quality

of services for people with chronic physical or cognitive impairments has been defined within the dimensions of the person's physical and mental health, functional ability, safety, emotional and social well-being, autonomy, and quality of life (385,563,831). Other dimensions in which quality might be defined are caregivers' well-being and the financial security of the person and his or her family.

To evaluate the quality of a service in other than an impressionistic reamer, it is necessary to identify goals or desired outcomes of care within each of those dimensions and to identify methods of care that lead to the specified goals or outcomes. The criteria that are used to measure quality must be derived from the specified goals and methods (174,385,737,832,925).

Specifying Goals of Care

Patients, families, service providers, and others have different goals in the care of people with dementia. The differences reflect their varying backgrounds, values, experiences, and knowledge, their current responsibilities, and their perceptions of the patient's condition. Some people emphasize the importance of maintaining the patient's physical health and safety. Others emphasize autonomy, freedom from fear, or reduced anxiety and agitation. Achieving the best possible quality of life for the patient is probably the overriding goal in the view of many families and some service providers, but the meaning of 'quality of life' in this context is highly idiosyncratic (735).

Different goals imply different methods of care and different criteria to evaluate quality. Sometimes legitimate goals of care conflict (385,735). For example, a person with dementia may enjoy walking unattended, valuing control and autonomy in this one area of her life, yet be unsteady on her feet and prone to falls. To ensure her physical safety, her caregivers could prevent her from walking unattended by physically restraining her in a chair, but this decision would conflict with the goal of maintaining her autonomy (831).

Service providers and others often have several goals in caring for a person with dementia. When those goals imply different methods of care in a given situation, priorities must be set, either implicitly or explicitly, in order to determine what good care is in that situation (385). A list of goals in which priorities are not clear is not sufficient to resolve

questions about appropriate methods of care in a given situation; nor is such a list sufficient to develop meaningful criteria to evaluate quality.

Identifying Effective Methods of Care

Effective methods of care must be identified in the context of agreed-on goals. In the past few years, many books and articles have been published describing what the author or authors believe are effective methods of care for people with dementia. The goals of these methods of care are sometimes explicit, but often they are not. Moreover, few of the recommended methods have been subjected to rigorous testing (932). Thus, belief in their effectiveness rests primarily on anecdotal evidence. Research to evaluate the effectiveness of alternate methods of care for people with dementia is essential, both to improve services for these people and to develop valid criteria to measure quality.

Developing Criteria To Measure Quality

Criteria for evaluating quality generally pertain to the structure, process, or outcomes of care. *Structural criteria* pertain to the resources available for care (e.g., the number and qualifications of staff, physical plant, and financial resources). *Process criteria* pertain to the activities involved in care (e.g., care planning, medication procedures, and procedures for handling difficult patient behaviors). *Outcome criteria* pertain to aspects of the patient's condition that are attributable to the process of care (e.g., functional ability, participation in activities, and patient satisfaction) (172).

Many commentators use structural, process, and/or outcome criteria to express their answers to the question, "What are good services for people with dementia?" Sometimes, these criteria are presented in the context of goals and methods of care, but often they are not. Families and others may latch onto a single criterion or Criteria relevant to only one aspect of care and assume that any service that meets those criteria is good. Thus, for example, some families might believe that a specified physical design ensures that a nursing home will provide high-quality care. Although physical design is an important component of quality, it does not guarantee good care (486).

The structure, process, and outcomes of care are related. Structural criteria are indicators of quality only insofar as the factors they reflect influence the process and outcome of care. Process criteria are

indicators of quality only to the extent that the factors they reflect influence outcome, and outcomes are an indicator of quality only if they are attributable to the structure and process of care. It is widely agreed that, by itself, no single structural, process, or outcome indicator is an adequate measure of quality and that all three types of indicators are needed for a valid assessment (173,392,470,755, 832,925).

Information about structure, process, and outcomes may be more or less difficult for families and others to obtain and more or less valuable to them. Information about structural characteristics of a given agency or service provider--e.g., the training and experience of the staff--may be relatively easy to obtain. The exclusive reliance on structural criteria to evaluate quality has been criticized, though, because structural characteristics indicate only the *capacity* of the agency or provider, not the services that are actually given (173,734).

Accurate information about the process of care--i.e., the activities involved in care--maybe difficult for families and other outsiders to obtain, in part because they may not have an opportunity to observe the process of care directly before they make a decision to use the service. Survey procedures for government regulation of nursing homes and other agencies and for voluntary accreditation programs include process criteria and may produce findings that are useful for families and others who are trying to evaluate the quality of services for a person with dementia. Some processes that are selected for observation or regulation for these purposes are not linked or are only indirectly linked to the goals or desired outcomes of services (563,831). Thus, they may not be valid indicators of quality. A later section of the chapter discusses the availability of findings from regulatory and accreditation programs and their potential value for people who are trying to evaluate services.

Recognition of the limitations of structural and process criteria and concern about the impact of cost containment on the quality of many types of services have spurred new interest in outcome criteria (392,470,925). Accurate information about the outcomes of services provided by different agencies and individuals might be valuable to families and others who are trying to select the best service provider. For

most of the types of services that maybe needed for people with dementia, outcome measures are only beginning to be used. Thus, information about patient outcomes is not generally available.

Moreover, information about patient outcomes, like information about structural and process indicators, may be difficult for families and others to interpret correctly. The use of outcome criteria to measure quality of care assumes a direct link between the process and outcomes of care, but that link is seldom simple or clear. Obviously, outcomes that are not attributable to the process of care should not be used to assess its quality (174,311,471).

Many factors other than the process of care can affect patient outcome. These include the severity of the person's condition, the course of his or her disease(s), and the ability and willingness of the patient and family to cooperate with the process of care. Because these factors affect outcome independently of any service, high-quality care does not always produce good outcomes (392,755). Likewise, good outcomes may occur even if the quality of care is poor.

Lastly, the use of outcome criteria to assess quality requires a comparison between expected outcomes and achieved outcomes. At present, very little is known about the course of many diseases that cause dementia, and people with dementia vary greatly in the progression of their symptoms.⁵ As a result, it is often difficult to judge whether observed changes in a patient's condition over time are the result of services the patient received or an inevitable consequence of his or her underlying disease. As more is learned about the normal course of diseases that cause dementia, it will become easier to identify valid outcome criteria to evaluate the quality of services.

What Role Should Patients and Families Play in Defining Quality and Specifying Goals and Methods of Care?

Historically, what constitutes good care has been defined by the providers of care (471,831,832). Goals, methods of care, and criteria for evaluating quality have been established by health care and social service professionals and other service providers and reflect their point of view. Some commentators argue that patients should play a greater

⁵This topic was discussed at greater length in ch. 1.

role in defining quality (130,737). Opinions on this issue vary and may depend on the kinds of patients and services that are being considered.

For many people, the need for medical care and other health-related services is episodic and distinct from their daily lives, and the services they receive are intended to cure specific illnesses or solve other health-related problems. For people with dementia and other chronic debilitating conditions for which medical cures and complete solutions frequently are not possible, health-related and social services may be needed over a prolonged period and may become interwoven with the life of the patient and patient's family (if there is one). Services provided in a patient's home often involve intimate details of the patient's life (386). At the extreme, in a nursing home, the care and the life of a patient may almost merge (120,385).

In such situations, the quality of care and the quality of the patient's life may be barely separable--and enhancing the quality of the patient's life may become the most appropriate goal of services. People's views about quality of life differ, however. If enhancing the patient's quality of life is the Primary goal of care, some commentators suggest, then patients' values and preferences should be reflected in the definition of quality of care (392). Many commentators go further, suggesting that patients' values and preferences should be reflected in the definition of quality of care even if quality of life is not the primary goal of services (174,471,768). In fact, some commentators would probably consider the responsiveness of a service provider to patients' values and preferences itself to be an important indicator of the quality of care.

Patients' values and preferences can be reflected in the definition of quality of care in a number of ways. They can be taken into account in establishing the goals of care, in setting priorities among the goals, or in selecting among alternative methods of care (74). Criteria for evaluating quality can also be chosen to reflect patients' values and preferences (470). One outcome indicator that measures quality in relation to the patient's values and preferences is patient satisfaction. The importance given to other outcome criteria can be adjusted to reflect patients' values and preferences (130).

If a person is severely cognitively impaired or unable to communicate, ascertaining that person's values and preferences may be difficult or even impossible. In some cases, the best way of ascertaining the person's values and preferences is to consult his or her family and friends about what the person would have considered good care. Some commentators would probably want to limit the role of a demented person's family in defining good care to representing the person's values and preferences. Other observers might argue that the values and preferences of a demented person's family are relevant to determining what constitutes good care.⁶

An underlying assumption of this OTA study is the importance of supporting family caregivers. In some cases, supporting family caregivers means giving them the information they need to evaluate different care options (919). Supporting family caregivers also may mean giving them a greater role in defining quality and specifying goals and methods of care. Several approaches for expanding families' role in monitoring and controlling the quality of services provided for their relative with dementia are discussed later in this chapter.

Apart from consulting a person's family and friends, another way of ascertaining the values and preferences of a person with dementia is to use a "values history." A values history is a document that expresses a person's wishes, values, and preferences with respect to his or her care. The Institute of Public Law at the University of New Mexico has developed a values history document for elderly people as part of its "National Values History Project" (252). The document is currently being tested in hospitals, nursing homes, home care agencies, and other sites. Recently, the Institute of Public Law completed a project in which volunteer "temporary treatment guardians" successfully used values histories to ascertain the wishes and preferences of hospitalized elderly people who were too cognitively impaired to make decisions about their own care and had no relative or friend to make the decisions for them (802). Although the values history document focuses on medical treatment decisions, it does include questions about a person's attitudes about independence, self sufficiency, and control and about his or her living situation, finances, and relationships with relatives and friends

⁶Some of the issues that arise in balancing the values and preferences of a demented person and the person's family are discussed at greater length in ch. 4.

who might be involved in decisions about the person's care.

LIMITATIONS OF POSSIBLE SOURCES OF INFORMATION

Given the complexity of the issues involved in evaluating the quality and appropriateness of services for people with dementia, just discussed, it would certainly be easiest for a federally mandated linking system *not* to concern itself with the quality and appropriateness of services to which it connects people with dementia and instead to rely on families and other informal caregivers to obtain for themselves the information they need to evaluate services. Many books, pamphlets, and articles that offer advice to families and other informal caregivers about how to obtain services for a person with dementia suggest that caregivers are responsible for selecting good services. The publications point out that identifying good services takes time and that caregivers may have to make many calls to find someone who can help them identify good services. Many of these publications recommend that caregivers of people with dementia start looking for services and visiting facilities before they need them (15,133,319,517,767).

The publications suggest that information about the quality and appropriateness of serviceman which caregivers could base their selection of services-may be available from one or more of the following sources:

- relatives, friends, and acquaintances who have used a service;
- physicians, nurses, social workers, and other health care and social service professionals;
- professional and provider associations (e.g., the State or local medical society, or nurses, hospital, or nursing home associations);
- the Alzheimer's Association;
- caregiver support groups;
- "dementia experts"
- agencies that provide telephone information and referrals;
- hospital discharge planners and case managers;
- State long-term care ombudsmen;

- aging network agencies (e.g., the State office on aging, area agency on aging (AAA), or a senior center);
- other State and local government agencies (e.g., offices of the State departments of health, mental health, human services, social services, or public welfare);
- government regulatory agencies;
- voluntary accreditation programs;
- internal quality assurance programs; and
- other possible sources of information (15,38,133,464,527,767).⁷

OTA's review in this section considers each of the potential information sources listed above in terms of two questions:

- whether information about the quality and appropriateness of services for people with dementia is likely to be available from the source, and
- if so, whether the information is likely to be accurate and/or helpful to families and others who are trying to locate good services for a person with dementia.

Many people whom OTA asked about how families and others can obtain information about the quality and appropriateness of services for people with dementia said that families and other informal caregivers should not be expected to obtain the information themselves, and that such an expectation places too great a burden on many families. Whether expecting families and other informal caregivers to obtain information about the quality and appropriateness of services places too great a burden on them depends partly on how difficult it is to obtain the information and partly on characteristics of the family or other caregiver and the circumstances in which they are trying to locate and arrange services. For some families and other informal caregivers, the approach to obtaining information about quality and appropriateness that is recommended in most advice books and pamphlets--contacting a variety of people and agencies, asking questions, and visiting potential service providers-may work reasonably well. It is easy to imagine numerous reasons why this approach would not work well for many other families and informal caregivers, however, and these reasons are discussed

⁷It is not always clear whether the publications that recommend some of these sources are suggesting them as sources of information about what services are *available* or about what services *are good*. Readers of these publications probably assume, however, that at least some of the recommended sources of information will be able to provide information about quality and appropriateness.

in the section of this chapter that considers limitations on caregivers' abilities to obtain information about quality and appropriateness. This section focuses only on the availability and accuracy of information about quality and appropriateness from specific sources.

The information about quality and appropriateness that families and other informal caregivers need to make informed decisions about services should also guide decisions about services for people with dementia who have no informal caregiver. It is unclear, however, who would use the information and what would happen to people with dementia for whom no acceptable services could be found. These questions are discussed later in this chapter.

The reader should bear in mind that the conceptual and practical difficulties in defining and evaluating quality that were discussed in the previous section of this chapter are applicable to any information about quality that may be provided by the sources discussed here. In the following discussion, those difficulties are assumed to exist and are not repeated for each source.

Relatives, Friends, and Acquaintances Who Have Used a Service

Relatives, friends, or acquaintances who have used a service are a possible source of information about its quality. They have first-hand experience with the provider, and to the extent that their needs are or were similar to those of the patient for whom services are being sought, their judgments about quality may be accurate and helpful.

The story of Mrs. D in chapter 1 includes an instance in which advice about the quality of a service provider that was offered by a chance acquaintance proved helpful. One of Mrs. D's sons who called the local AAA happened to talk to a secretary there whose mother had Alzheimer's disease. The secretary had used a local adult day program for her mother and recommended it highly. Mrs. D's sons visited the center and agreed with her assessment.

Although the advice of a chance acquaintance proved helpful in Mrs. D's case, there are several drawbacks to relying on relatives, friends, or acquaintances for judgments about the quality of services. One is that relatives, friends, and acquaintances may not know anyone who has used a

provider of the type that is needed. Another is that the judgments of friends and acquaintances may reflect values and preferences of one family or patient that are not shared by another family or patient (767). A patient's condition and care needs and specific aspects of the patient's caregiving situation differ from one patient and family to the next, so that what is good for one patient and family may not be equally good for another patient and family.

Another drawback to relying on judgments about the quality of services that are made by relatives, friends, and acquaintances is that such judgments may be based on observations of a single aspect of an agency's services or an isolated incident that does not reflect the quality of the services in general. A family may think highly of a nursing home, for example, because they feel close to one staff member who has been friendly or kind, even though the care provided by the nursing home is not particularly good overall.

Another drawback is that information about quality that is obtained from relatives, friends, or acquaintances may be based on outcomes that are not attributable to the process of care and thus not valid indicators of quality. The physical and mental deterioration of a person with dementia is distressing to everyone involved, and families may have difficulty separating their feelings about the patient's condition from their feelings about the service provider. A family whose relative dies in a nursing home after a long, difficult illness, for example, may have negative feelings about the facility, even though the patient's deterioration and death were caused by his or her illness, not poor care.

A final drawback to relying on the opinions of relatives, friends, or acquaintances about the quality of services is that such individuals are likely to have had experience with only one or two service providers. Although they may offer correct information about those providers, they are unable to assist the caregiver in comparing the quality of services offered by other providers.

Physicians, Nurses, Social Workers, and Other Health Care and Social Service Professionals

People are used to relying on their physician for referrals to medical and health-related services (832). For many people, relying on a physician may be the easiest and most comfortable way to get the

name of a good service provider. Ideally, a physician who has a long-standing relationship with a patient and family can match what he or she knows about them and what he or she knows about service providers in the community and recommend the best provider for them.

This ideal often does not work in practice. Families report that many physicians are not knowledgeable about the kinds of services that dementia patients are likely to need and that some physicians are not willing to spend time talking about services (125,257,412,531).⁸ Physicians' knowledge of community services is derived in part from feedback they receive from patients and families they refer to various providers. Physicians who have many patients with dementia may be more likely than those with few demented patients to know about the quality of relevant services.

Some people have a tie to a nurse, social worker, psychologist, or other health care or social service professional who might be knowledgeable about the quality and appropriateness of services. Like physicians, these professionals have different areas of expertise and serve different kinds of clients. Some have extensive experience with community agencies and providers who serve people with dementia, whereas others may have never even visited a nursing home, adult day center, or other agency (390).

Health care and social service professionals usually have professional contacts that are a potential source of information about quality that generally is not available to families or other informal caregivers. In addition, because of their training, health care and social service professionals have a frame of reference for evaluating quality of care that most families do not have. On the other hand, individual physicians, nurses, social workers, or other health care and social service professionals are unlikely to have a systematic method for evaluating quality. As a result, their judgments about quality, although grounded in professional training and experience, still are impressionistic.

It takes time for anyone to become familiar with community agencies and service providers. Health care and social service professionals who are new to a community may know very little about the quality of available services.

Lastly, some health care and social service professionals are affiliated with service providers in such a way that they benefit financially from referrals, and some of them routinely refer patients or clients to those providers even if they know that better services are available from other providers. It is not known how often this practice occurs.

For all the reasons just mentioned, health care and social service professionals are likely to differ greatly in their ability to provide helpful information about the quality of services. In light of this difference, a question that arises is: How can patients, families, and others know which professionals are most likely to be helpful? Another question that arises is: When a specific physician or other health care or social service professional gives a caregiver the name of, say, a home care agency for a person with dementia, how should the family interpret the referral?:

- Does the referral mean that the agency is one that the professional recommends on the basis of his or her extensive knowledge about the quality of care provided by various home care agencies in the community?
- Does it mean that the agency is one that the professional knows about and regards as good, although he or she is not familiar with other agencies in the community?
- Does it mean that the agency is one that the professional knows very little about?
- Does it mean that the agency is one with which the professional has some financial affiliation?
- Does it mean that the professional is referring the patient to the agency not because of the quality of its care but because he or she knows the agency will accept the patient's source of payment?
- Does it mean that the professional is referring the patient to the agency not because of the quality of its care but because he or she knows that the patient will be difficult to care for, and, for the sake of future referrals, he or she wants to maintain a good relationship with agencies that provide better care?

Patients, families, and others may very well assume that a referral from a physician or another health care or social service professional implies at least some endorsement of the agency or provider,

⁸For further discussion of this topic, see ch. 2.

and therefore they may not question the basis for the referral. They also may not question referrals because they think it would be disrespectful to the professional or because they do not know what to ask.

Some health care and social service professionals routinely give patients or families the names of three service providers in order to give them a choice. Given the different knowledge and motivation of professionals, the meaning of three referrals is no more clear than the meaning of one referral:

- Should the patient or family assume the first name on the list is the one the professional really recommends?
- Might all three choices be good, or all three poor?
- Does a list of three providers imply anything about quality?

In summary, referrals to service providers by individual health care and social service professionals may or may not indicate that the providers offer good care. Patients, families, and others are unlikely to know this, and without knowing it, they cannot function as informed consumers in selecting services.

Professional and Provider Associations

Medical societies, nurses' associations, and associations of other professionals and providers maybe good sources of information about what services are *available*. These organizations can often provide lists of their members in a certain area or members who say that they specialize in caring for certain types of patients. Some also refer patients and families to individual association members.

These lists and referrals generally are not evaluative however. They simply indicate that the individual provider or agency belongs to the association. Except to the extent that belonging to a given association or having been certified by such an association is evidence of quality, the lists and referrals do not provide information about quality.

The Alzheimer's Association

Advice books and pamphlets for caregivers of people with dementia often advise caregivers to contact the Alzheimer's Association for information about services. Many of these publications imply that the Alzheimer's Association—or more likely

one of its local chapters—will be able to provide information about quality. One Alzheimer's Association pamphlet says, for example:

Once you have located a service, you will want to evaluate its quality and appropriateness to your needs. Here again, your local [Alzheimer's Association] chapter, whose members have gone through this experience before you, can be of great help (15).

As discussed in chapter 8 of this report, information and referral is one of the primary functions of Alzheimer's Association chapters, but chapters vary in the manner in which they perform it. In 1988, an OTA contractor surveyed 10 Alzheimer's Association chapters by telephone to learn about their information and referral services (484). The chapters were chosen to represent a range of sizes, urban/suburban/rural location, and the use of professional v. volunteer staff. Among other questions, the chapters were asked, "How do you determine the quality of services to which you refer patients and families?" Chapter respondents reported that they use three methods to determine quality:

- informal communication with other agencies;
- advice from professionals on their board; and
- feedback from families.

One chapter respondent said, "This is a small town. I know most of those places" (484).

None of the 10 chapters had a systematic way of collecting information about the quality of services. Most of the chapters reported that if they receive negative feedback from a family about an agency or provider, they "check it out" and remove the agency or provider from their referral list if they conclude that the services are inadequate (484). One chapter keeps a file box of families' comments about service providers and makes the box available to other families (485). None of the chapters reported routinely asking families about the quality or appropriateness of services they had used. Two of the chapters reported that they ask service providers if they have a license and whether their staff is trained to work with dementia patients. One chapter has a list of nursing homes that have failed government inspections (484).

In the opinion of the OTA contractor who conducted the survey and who has visited many Alzheimer's Association chapters in addition to those surveyed, the informal methods that chapters use to evaluate quality usually work well and

chapters generally know which agencies and individuals provide good care for people with dementia (484). She concludes that relying on an informal process works as long as the network of providers and users remains small and the chapter knows the providers and the families and professionals who give it information and feedback. As the network of providers and users expands, however, it becomes more difficult for chapters to maintain accurate information about quality (484).

The Southeastern Wisconsin Alzheimer's Association Chapter is currently under contract to the State of Wisconsin to provide statewide information and referral services for Alzheimer's patients through the Alzheimer's Information and Training Center.⁹ It has created a computerized database of service providers that is used to give callers information about services in their geographic area (410). According to the Southeastern Wisconsin chapter's education coordinator, how to provide information about quality is "a big question" (263). Callers are given three choices of service providers, if there are three choices. They are told that there are important differences in the quality of services offered by different providers, and they are urged to visit agencies and talk to providers before choosing one. Callers are not told which agencies or providers give good care. The chapter believes that it must be "unbiased," partly because of concerns about legal liability. It believes, for example, that callers must be given the names of all the nursing homes in a locality that have a "special care unit," not just the name of one facility that the professional staff or volunteers think is good.

Some Alzheimer's Association chapters give out printed materials with advice on selecting a particular kind of provider. Figure 5-1 is a list of questions for evaluating an adult day care center distributed by the Cleveland Alzheimer's Association Chapter.

The Greater Washington, DC Alzheimer's Association Chapter has a video for families to watch about how to select a nursing home (232). The chapter also has a list of members who have a relative in a local nursing home or board and care facility and are willing to talk to other families about the facility.

Caregiver Support Groups

Caregivers who attend support groups sponsored by the Alzheimer's Association and other public and private agencies often obtain first-hand information from other caregivers about the quality and appropriateness of services they have used. Research indicates that participation in a support group leads to increased knowledge about community services (245) and that this aspect of participation in a support group is valued by group members (294).

Many caregiver support groups devote meetings or parts of meetings to discussions about community resources (377). In relatively informal support group meetings, outside experts may share their observations about the quality and appropriateness of services offered by community agencies and providers more freely than they would in a more formal or public situation. The leaders of support groups may also be knowledgeable about community services and willing to share their judgments about quality and appropriateness, either during meetings or in personal discussions later on (256).

The primary drawback to relying on caregiver support groups as a source of information about the quality and appropriateness of services is that many caregivers do not belong to support groups. Male caregivers, ethnic minority group caregivers, and caregivers who have no one to care for the patient while they attend a meeting are particularly unlikely to belong (158,314).

"Dementia Experts"

"Dementia experts"—individuals who develop or work in programs designed for people with dementia or who serve many people with dementia—are likely to have opinions about the quality and appropriateness of community services based on information from their own clients who use, or have used, the services. Furthermore, in those communities with only a few agencies providing services specifically for people with dementia, the service providers are likely to know each other, to participate in planning any new service for people with dementia, to be on the board of the local Alzheimer's Association chapter, to run support groups, and/or to provide training about dementia for the staff of nursing homes and other community agencies.

⁹For more information about the Alzheimer's Information and Training Center operated by the Southeastern Wisconsin Alzheimer's Association Chapter, see box 8-G inch. 8. Additional information is provided in the section on State information and referral programs in ch. 7.

Figure 5-1-List of Questions for Evaluating an Adult Day Care Center,
Distributed by the Cleveland Alzheimer's Association Chapter

A. D. Alzheimer's Disease

and Related Disease Association, Inc.

Cleveland Chapter

1801 Chestnut Hills Drive

Cleveland Heights, Ohio 44106

Phone: 216-721-8457

E V A L U A T I N G D A Y C A R E S E R V I C E S

Here is a handy checklist of questions to help you ascertain how well a facility is equipped to fill its goal of providing respite for caregivers:

- Is it convenient and accessible?
- Does it provide or arrange for transportation?
- Does it provide or arrange for companion/aid assistants to help the care-receiver get up bathed, dressed and ready?
- Are its service hours appropriate for your situation?
- Do its services include family-supportive programming such as caregiver support groups or referral services?
- How expensive is it?
- Is there financial assistance available?
- Are there any hidden expenses, such as lunch fees, craft supply fees, fees for outings?
- Are there any hidden benefits, such as the availability of regular professional testing for blood pressure, annual immunizations, hair styling services, dental check-ups, etc. ? (Although such benefits will typically require additional fees, they may be invaluable time-savers for caregivers,)
- Must you commit to a minimum amount of service, i.e., at least 2 days/week?
- What is the notification policy for absence due to illness or scheduling problems?
- What is the policy concerning late arrival or late pick-up?
- What are the notification policy and conditions for terminating service?

**Figure 5-I-List of Questions for Evaluating an Adult Day Care Center,
Distributed by the Cleveland Alzheimer's Association Chapter-Continued**

Here is a handy checklist for ascertaining how well a facility is equipped to meet the needs of your loved one:

- Does it perform a comprehensive assessment prior to placement, including an evaluation of the client's medical needs, social and family history, cognitive functioning, and social skills?
- Does it restrict or segregate its population by types of impairment or by level of care required?
- What is the ratio of staff to client? (Remember, a new facility is likely to increase its participants over time; ask for the existing ratio, as well as the worst case ratio.)
- What training, education, and practical experience does the staff have in dealing with care-receivers whose needs are comparable to those of your loved one?
- Is there a formal process for reviewing a client's needs and evaluating a client's participation on a regular basis?
- Is there an accessible and easy-to-talk-to person available to discuss your loved one's special needs, level of participation, etc., when problems or questions arise?
- Can the facility accommodate the special physical or medical requirements of your loved one, i.e., can it:
 - dispense medicine?
 - give reminders about taking pills?
 - assist with toileting?
 - provide total access and participation to wheelchair-restricted client?
 - effectively communicate with hearing impaired participants?
- Does the client population appear to be compatible with your loved one's social history? (Some men are uncomfortable with an overwhelming female group; some people are intolerant of racial and ethnic differences. Unless you are honest about the realities of your loved one's social history, a lasting and effective placement will be impossible.)

**Figure 5-1-List of Questions for Evaluating an Adult Day Care Center,
Distributed by the Cleveland Alzheimer's Association Chapter-Continued**

- Are there specific behaviors or care needs which would enforce your loved one's withdrawal from the program? (Since Alzheimer's disease is a progressive disorder, you need to find out not only how a facility is going to handle existing care needs, but also whether they are prepared and able to handle potential ones, i.e., can they accommodate:
 - incontinence?
 - difficulties in speaking?
 - wandering?
 - special dietary requirements?
- Are the programs and activities adult appropriate?
- Does the programming include activities suitable to your loved one's social history and capabilities, i.e.:
 - gardening?
 - outdoor activities?
 - cultural activities?
 - music therapy?
 - physical therapy?
 - travel movies?
 - joint activities with children?
 - productive work, i.e., social service projects or work-for-pay?
 - homemaker crafts?
- * How does the staff handle a client's unwillingness to actively participate?
- * Are meals nutritious and attractively prepared?
- * Are the staff and facility neat, clean, and orderly in appearance?
- * Are there programs/activities which involve families?



Photo credit: Bill Adams

Caregivers who attend support groups often are able to obtain first-hand information about the quality and appropriateness of services from other support group members.

Anecdotal evidence suggests that these “dementia experts” often provide accurate and helpful information about the quality and appropriateness of services to families and others who are lucky enough or persistent enough to reach them. As the network of service providers and users expands in a community, however, “dementia experts” may become concerned about legal liability and thus increasingly reluctant to recommend specific service providers, especially to people they do not know.

Agencies That Provide Telephone Information and Referrals

Agencies whose primary function is to provide telephone information and referrals generally maintain a list of community agencies and providers that includes the services they offer and sometimes their area of specialization, service hours, eligibility requirements, fees, etc. Telephone information and referral agencies often give callers the names of several agencies or providers from their list, but they usually do not recommend specific providers. If their list, which is usually compiled from information supplied by providers, includes a category of

services for people with dementia, they can give callers information about which providers say they offer such services.

In 1988, OTA contractors surveyed agencies in Cuyahoga County, Ohio, to determine what services they provided for people with dementia and interviewed representatives of 24 agencies that reported providing information and referrals for people with dementia (186).¹⁰ Only 1 of the 24 agencies was primarily an information and referral agency; the others were agencies that provide information and referrals in conjunction with their other functions. None of the agencies had systematic procedures for evaluating the quality of services to which they referred clients. Most of the agency representatives said that agency staff members form opinions about the quality of various services in the process of arranging and monitoring services for their clients and through informal discussions with colleagues both inside and outside the agency (186). When the agencies receive telephone requests for information about services, agency staff members respond on the basis of opinions formed in those ways.

¹⁰Most of the findings of the survey and interviews in Cuyahoga County, Ohio, are discussed in ch. 2. A full report on the study conducted for OTA in Cuyahoga County is available from the National Technical Information Service in Springfield, VA (see app. A).

OTA's contractors concluded that the telephone referral process usually works satisfactorily--i.e., the agencies usually give callers the names of providers they know about and regard as good (186). The criteria agency staff use to evaluate quality are not known, however, and their judgments about quality may or may not be correct. Moreover, some agency staff members believe that the services of for-profit providers are not as good as the services of nonprofit providers and rarely refer callers to for-profit providers. Lastly, some agency staff members do not know about new services. In this regard, OTA's contractors noted that providers of new services for people with dementia often complain that agencies always refer callers to the old providers and it is difficult for a new provider to "break in" regardless of the quality and appropriateness of its services (185).

Hospital Discharge Planners and Case Managers

A major function of all hospital discharge planners and case managers is linking people with services. In the process of performing this function and through feedback from patients and families, discharge planners and case managers form opinions about the quality of services offered by various community agencies and individual providers.

Published practice guidelines for hospital discharge planners and case managers emphasize the importance of identifying high-quality services for clients and of involving clients and families in selecting services. The American Hospital Association's "Guidelines for Discharge Planning," for example, state that hospital discharge planners should identify "resources needed to assure high-quality post-hospital care" and "develop with patients and their families appropriate discharge plans" (20).

The American Nurses' Association's guidelines for nursing case management state that one of the goals of case management is "the provision of quality health care" and that an important function of the case manager is "linking the client with appropriate service providers" (22). The National Association of Social Workers' publication "Standards and Guidelines for Social Work Case Management for the Functionally Impaired" stresses that case managers should support informed client decisionmaking:



Photo credit: Cleveland Chapter of the Alzheimer's Association.

Concerns about legal liability and organizational pressures limit the ability of some hospital discharge planners and case managers to provide families and others with information about the quality and appropriateness of services they may use for a person with dementia.

The case manager must assure that each client receives appropriate assistance by providing the client with accurate and complete information about the extent and nature of the services that are available and by helping the client to decide which services will meet his or her needs (572).

Given their involvement in linking patients to services and practice guidelines such as those just mentioned, one might expect that hospital discharge planners and case managers would be a good source of information about the quality and appropriateness of services. On the other hand, hospital discharge planners and case managers are unlikely to have a systematic method for evaluating quality. Consequently, their judgments about the quality of services may or may not be accurate. Furthermore, some hospital discharge planners and case managers are not knowledgeable about dementia and therefore have no basis for determining whether a given service is appropriate for people with dementia. Even hospital discharge planners and case managers who are knowledgeable about dementia may not be

a good source of information about the quality and appropriateness of services for people with dementia, however, because of the concerns about legal liability and organizational pressures that are discussed below.

Concerns About Legal Liability

A 1987 legal memorandum of the American Hospital Association answered the question, “To what extent, if any, can hospital discharge planning personnel recommend, endorse, or steer discharged patients to particular post-hospital facilities and services?” in the following way:

It is *not the* discharge planner’s responsibility to recommend or endorse particular after-care facilities to patients; indeed, such recommendations or endorsements can expose both the hospital and hospital employees who participate in the discharge planning process to legal risks (21).

According to the 1987 legal memorandum, a hospital can be liable for negligence for referring a patient to a facility or service if the patient is injured in some way there and the possibility of the injury could have been foreseen by hospital staff:

The likelihood of liability is increased when hospital discharge planning personnel go beyond simply advising, notifying, or informing a patient of his options, and affirmatively recommend or endorse a particular option. A recommendation or endorsement suggests that hospital personnel have investigated the facility according to objective, uniform criteria; are in possession of all information necessary to evaluate reasonably foreseeable risks to the patient if the referral is made; and have determined that the particular facility meets the patient’s needs (21).

According to the 1987 legal memorandum, followup telephone calls by discharge planners to patients or families to ensure that their discharge plan is working also expose the hospital to liability for negligence, because such calls may imply that the hospital is still responsible for the patient’s care (21).

To minimize legal risks, the American Hospital Association’s memorandum advises that hospital discharge planners should not decide on their own to make recommendations about post-hospital services or followup calls to discharged patients (21). Rather, hospitals should establish general policies for discharge planners to follow in all but exceptional

cases, and they should designate a person to make decisions about cases in which there may be some reason for deviating from those general policies.

OTA has no information about how often hospital discharge planners recommend specific service providers based on judgments about their quality. Certainly, the concepts expressed in the American Hospital Association’s 1987 legal memorandum would discourage discharge planners from making such recommendations.

That case managers may also be legally constrained from making recommendations about service providers based on judgments about their quality is suggested by the decision in a 1987 Oregon case *Bionic Health Care, Inc. v. State of Oregon Department of Human Resources, et al.* (70). Case managers in a public agency had stopped referring clients to one nursing home that they believed was providing poor care and that was under review by the State licensing and certification agency. The nursing home sued, arguing that it had a valid State license and was certified by Medicare and Medicaid and that the case managers could not refuse to refer clients there. The nursing home won, and the case managers have been instructed not to make recommendations to clients about service providers (435).

Again, OTA has no information about how often case managers recommend certain service providers on the basis of quality. One member of the advisory panel for this OTA assessment, who interviewed case managers who refer people to nursing homes, found that the case managers generally believed that they were legally constrained from making recommendations about nursing homes based on quality. The panelist went on to comment that clients and their families generally don’t know this (389).

People who make nursing home referrals in some other countries may not be so constrained. In Australia, for example, groups of health care and social service professionals “blacklist” nursing homes they believe provide poor care and do not refer clients to these facilities; as a result, the facilities are forced to improve the quality of care they provide or risk going out of business (273). The blacklisting is not capricious, however; grounds for the decisions are identified systematically, in case the decisions are challenged (485).

Organizational Pressures

Organizational pressures also restrict some hospital discharge planners and case managers from making referrals on the basis of quality. Case managers employed by agencies that provide services in addition to information and referral and case management are often expected to refer clients to their own agency's services rather than services provided by other agencies, irrespective of the quality of the services (186,386). Furthermore, some agencies have formal agreements with other service providers, and case managers employed by those agencies are expected to refer clients to those providers, irrespective of the quality or appropriateness of the services.

Organizational pressures to complete care plans quickly also constrain discharge planners and some case managers from making referrals on the basis of quality. Medicare's prospective hospital payment system, instituted in 1983, creates strong financial incentives for hospitals to reduce patients' length of stay. Discharge planners are under pressure to make plans for patients' post-hospital care quickly and may not have time to arrange the best available services (209,947). Moreover, some high-quality services may not be available at the time a patient is discharged from the hospital.

Case managers who are required to arrange services within cost limits may be severely restricted in their ability to make referrals on the basis of quality. The case management literature is replete with discussions of the conflict between the role of the case manager as an advocate for the client, trying to ensure that the client receives good services, and the role of the case manager as an administrator of resources, trying to ensure the cost-effective use of limited services (48,175,230,382,893). In one role, the case manager is seen as the agent of the client and, in the other, the agent of the agency or system.

Some commentators argue that the two roles—client advocate and resource administrator—are not necessarily incompatible if case management is seen as serving an entire population at risk and attempting to meet the needs of that population within available resources (384,892). As noted in chapter 3, a study of 127 case managers in Oregon and Washington State found that the case managers did not perceive the two roles to be in conflict (47). But the theory and practice here are from the point of view of the system, not the client. If there were more than one

provider of a certain type of service in a community, and case managers gave patients and families accurate information about the relative quality of the services, it is hard to imagine why some patients and families would accept poor-quality services, knowing that other patients and families were receiving better services (assuming, of course, that the patients and families were equally able or unable to pay for the services).

Most private geriatric case managers are not subject to the organizational constraints discussed above and may therefore be able to provide information about their perceptions of the quality of services offered by various providers. Some private geriatric case managers visit or interview most of the agencies and providers to whom they refer their clients (357,450). On the other hand, hiring a private geriatric case manager can be costly and thus not a realistic option for many patients and families. In addition, some private geriatric case managers provide certain services themselves and may not give clients information about other providers of these services (390).

OTA's advisory panel and consultants for this study agreed that *at the very least, the staff* of agencies that are designated to constitute a national linking system for people with dementia should disclose to their clients any legal or organizational factors that limit their ability to give clients accurate information about the quality and appropriateness of services or to make referrals on the basis of quality. Beyond that, perhaps ways could be found to enable the staff of agencies that constitute the linking system to provide their clients with information about the quality and appropriateness of services and to connect their clients to what they consider the best available services.

State Long-Term Care Ombudsmen

The Older Americans Act mandates that every State have a long-term care ombudsman to investigate and resolve complaints of residents of nursing homes and other residential care facilities. The long-term care ombudsman program is implemented differently in different States, but it is clear that State long-term care ombudsmen and local paid ombudsman employees and volunteers are knowledgeable about the quality of services provided by long-term care facilities. They generally will talk to families and others about the services provided by different

nursing homes and board and care facilities, and many of them seek opportunities to talk to individuals or groups about steps to take in selecting a facility. They usually do not specifically recommend one facility over another. Some ombudsmen tell callers whether they have had complaints about a facility and, if so, what the subjects of the complaints were and whether the facility cooperated in resolving them (561,629). Other ombudsmen are more cautious about giving out such information.

One drawback to relying on State long-term care ombudsman programs for information about the quality of nursing homes and other residential care facilities is that many people are not aware of their State program, and families may not know how to contact the ombudsman. In addition, ombudsman programs in many States are underfunded and understaffed to take on the job of helping people choose good facilities. Lastly, some ombudsmen may not be knowledgeable about dementia and therefore may have no basis for determining whether a given facility provides good care for people with dementia.

The Robert Wood Johnson Foundation is currently funding an “Ombudservice” for home care clients through the Community Council of Greater New York (140). Like State ombudsman programs, the Ombudservice focuses on resolving client complaints—in this case, complaints of people receiving Medicaid-funded personal care services. In the process of investigating complaints, the program accumulates information about the quality of various personal care providers, but that information is not currently available to the public (561).

Aging Network Agencies

Aging network agencies include State units on aging, area agencies on aging (AAAs), senior centers, and other agencies that receive Older Americans Act funds.¹¹ Books and pamphlets that advise families about how to locate services often recommend that they contact such agencies for assistance. Although aging network agencies vary greatly, most of them will give families a list of service providers. In addition, many aging network agencies distribute written materials on how to select a provider, and some offer case management to help people locate and arrange services.

In any of these agencies, a family might find someone who knows about community services and is willing to share his or her opinions informally about the quality of services offered by different providers. OTA is not aware of aging network agencies that have a systematic method for evaluating service providers or giving families and others information about their relative quality.

Other State and Local Government Agencies

In some States, State and local offices of the departments of health, mental health, human services, social services and/or public welfare, and regional or local health planning agencies have lists of providers, their services, and their practice specialties, which can be requested by anyone. People may also be able to find out from one or more of these agencies whether certain providers are licensed and to obtain the results of government inspections of facilities. The agencies are unlikely to provide other information about the quality of specific service providers. As with aging network agencies, however, families may be able to find someone in any of the agencies who is knowledgeable about providers and willing to talk informally about their quality.

Government Regulatory Agencies

Various government agencies regulate health care, long-term care, and other services that may be needed for people with dementia:

- State agencies license individual professionals and nonprofessional service providers (e.g., physicians and home health aides).
- State and local government agencies license health care and long-term care agencies (e.g., nursing homes and home health care agencies).
- Federal and State Medicare and Medicaid agencies certify facilities and service providers that receive reimbursement from Medicare and Medicaid, and they contract with peer review organizations (PROS) to review the hospital care and some nursing home and home health care provided to Medicare and Medicaid beneficiaries.

Each of these regulatory agencies has several purposes, one of which is to safeguard quality of care.

¹¹For more information on aging network agencies, in particular AAAs, see ch. 8.

If government regulation guaranteed that all services were at least adequate, families and others would not have to worry about basic aspects of quality and could concentrate instead on finding services that matched the individual needs of the patient. Government regulation does not prevent inadequate care, however. A range of quality, from excellent to poor, is found in agencies subject to extensive regulation, and inadequate care is given by regulated and unregulated providers and in regulated and unregulated settings (305,524,563,816,821,836,875).

Many factors contribute to the persistence of poor-quality care despite government regulation. The factor cited most often is inadequate funding for services (87,205,331,376,392,563). A related factor is the shortage of qualified personnel—especially, nurse's aides, home health aides, and homemakers who provide much of the paid personal care for people with dementia (109,305,331,563,821,852). The shortage of qualified aides and homemakers is due in large part to inadequate funding. These individuals are paid very little. They are often poorly trained. Turnover is high, and those who receive training do not necessarily stay with the job. It is said that nursing homes and home care agencies compete for workers with McDonalds and other fast food restaurants—and often lose (747).

A third factor that is cited as contributing to the persistence of poor-quality care despite government regulation is deficiencies in regulatory procedures (17,305,392,563,814,821,831,852). Deficiencies in regulatory procedures include the use of inappropriate standards for evaluating quality, infrequent monitoring of care, and lack of credible sanctions for poor care. Many regulatory programs are underfunded and do not have sufficient staff for inspections and enforcement proceedings. This weakens the regulatory effort.

Government and nongovernment agencies and voluntary associations are working to improve regulatory procedures. A description of their efforts and analysis of the potential for their success would require another full study. Suffice it to say that efforts to improve regulatory procedures for nursing homes and board and care facilities have been under way for more than 10 years, with some but certainly not full success. Efforts to improve regulatory procedures for in-home services are only beginning. Many people will have to select services long before

government regulatory programs are improved sufficiently to guarantee that all available services are at least of adequate quality.

In the meantime, the question posed here is whether the results of existing regulatory procedures would be helpful to people who are trying to select good services. If a provider has a State license, can families assume the provider will give good care? If a nursing home is certified by Medicare, does that mean it provides good care? Is there information from government inspections of nursing homes and home health care agencies that is available to families and is or could be valuable to them in selecting services?

The answers to these questions vary from one State and locality to another, for different types of providers, and for services paid for by different funding sources. Much of the information needed to answer the questions is not available. It is probably correct to conclude, however, that the results of existing regulatory procedures could be useful to some people who are trying to select services, with the following important qualifications:

- ***Not all services that might be needed for people with dementia are regulated.*** Although all States regulate some types of board and care facilities, they do not regulate other types. Adult day centers are not regulated in some States. Home health care agencies must be certified by Medicare and Medicaid in order to receive reimbursement from those funding sources, but many agencies that provide in-home services are not eligible for or do not seek Medicare or Medicaid certification. Many States license agencies that provide some kinds of in-home services, but agencies that provide other kinds of in-home services are not required to be licensed, and some States do not license any home care agencies (305,821,852). Moreover, individual in-home workers employed by home care agencies differ in their abilities and motivation; the agency's license, if any, does not reflect these differences. Lastly, individual in-home workers who are not employed by an agency and are hired from a newspaper ad or other such source are not regulated in most States.
- ***Information from licensing, certification, and PRO review procedures may be difficult for families and others to obtain.*** In 1988, for the

first time, the U.S. Department of Health and Human Services released information from Medicare and Medicaid nursing home surveys. To get information about other types of agencies and service providers, one would have to know that the information exists; find out which State or local government office keeps the information; obtain permission to see it; and probably go there to do so. Some agencies require a prior written request for information and charge a fee. OTA does not know how many people attempt this process or succeed in getting the information they want.

- *Regulatory procedures are often based on minimum standards and/or standards that are not directly related to people's primary concerns about quality.* State licensing requirements for professionals and service providers often set minimum standards for training and experience. Licensing requirements for some types of agencies focus only on fire and safety standards. The criteria used in some survey and certification procedures translate only indirectly into quality of care. Thus, the information about quality that families and others are looking for may not be contained in the findings of regulatory procedures.
- *People may have difficulty interpreting information from regulatory procedures.* Some regulatory procedures are lengthy and complex. Reports of their findings are not written for the layperson. Moreover, people who are not familiar with the procedures and the agencies being surveyed may not know which findings are noteworthy. In support of this observation, one OTA advisory panelist commented, "There are violations, and then there are violations!" (390).
- *Information from existing regulatory procedures is not dementia-specific.* OTA is not aware of any State or locality that regulates services for people with dementia using different criteria or procedures than it uses to regulate services for people with other diseases and conditions, although some States now are developing criteria to evaluate "special care units" in nursing homes. Since dementia-specific criteria have not been used in regulatory procedures (and generally have not been available), information about aspects of agencies' services that might make one agency's services more appropriate than another agency's

services for a person with dementia may not be collected in the regulatory process or included in regulatory reports.

- *Information derived from regulatory procedures may not be correct.* Some regulatory procedures rely on notes in patients' medical records and the agency's written policies to evaluate quality of care rather than on direct observations of the process of care. This approach can lead to what is called "paper compliance"—i.e., agencies meet quality standards on the basis of documentation in patients' medical records and written policies rather than actual care they provide (385,925). Even when inspectors do observe the process of care, what they see may not be the ordinary process of care, but rather a special show put on to impress them (120).

All these factors limit the usefulness of findings from government regulatory procedures for families who are trying to select good services.

It is not clear to what extent individuals and agencies that refer people to services use the findings from government regulatory procedures as indicators of the quality of services. OTA informally asked about 20 individuals and agencies that make referrals for people with dementia: 1) whether they check to see that service providers to whom they refer patients have required licenses or certification, and 2) whether they review government inspection reports on agencies to which they refer patients. The majority answered "no" to both questions. State long-term care ombudsmen do often use reports of nursing home inspections in their discussions with people who are trying to select a good nursing home.

Government regulatory programs could be designed to produce information about quality that would be helpful for people who are trying to select good services (385,738), but existing programs are not designed for this purpose. The Omnibus Budget Reconciliation Act of 1987 mandated changes in many requirements for Medicare and Medicaid certification of nursing homes and home health care agencies, including a new survey protocol for home health care agencies and changes in nursing home regulations that also will result in issuance of a new survey protocol. These new protocols should be designed so that the information they collect is useful to families and others who are trying to select good services, and the resulting information should

be presented in a format and written in language that a layperson can understand.

Voluntary Accreditation Programs

Some agencies that provide services for people with dementia voluntarily comply with requirements of independent associations, such as the Joint Commission on Accreditation of Health care Organizations (JCAHO), the National League for Nursing (NLN), and the National Home Caring Council of the Foundation for Hospice and Home Care (FHHC). JCAHO accredits hospitals, nursing homes, hospital-affiliated home health care agencies, and beginning in 1988, other home health care agencies. Most hospitals in the United States are JCAHO-accredited, as are more than half of all hospital-affiliated home health care agencies (628) and a small proportion of nursing homes (about 1,400 in 1986) (563).

NLN, in conjunction with the American Public Health Association, accredits home health care agencies. FHHC, a sister organization of the National Association for Home Care, accredits homemaker-home health aide agencies. Very few agencies are accredited by either group: as of 1986, about 100 agencies had NLN accreditation, and about 140 had FHHC accreditation (734).

Agencies that seek JCAHO, NLN, or FHHC accreditation choose to be evaluated and pay for the survey process that leads to accreditation. One might assume, therefore, that it is important to these agencies to provide high-quality care and to be recognized for doing so. If that is true, accreditation might be a useful indicator of quality for people who are trying to locate good services.

There have been very few attempts to compare the quality of care provided by accredited and nonaccredited agencies, however (832). In addition, although the outcome of an accreditation survey is public information, the full report of an evaluation usually is not, so one cannot review findings of the survey with respect to specific standards.

Families and others who are trying to select good services probably are not aware of accreditation. Most books and pamphlets that advise people about locating services for people with dementia do not mention it. Moreover, when OTA informally asked individuals and agencies that make referrals for people with dementia whether they refer people to

home care agencies that are not accredited by JCAHO, NLN, or FHHC, most were unsure, and several acknowledged that they did not know very much about accreditation for home care agencies.

Internal Quality Assurance Programs

Many health care, social service, and other agencies have an internal process to monitor quality of care and correct problems that are found. Internal quality assurance is widely advocated as a way for agencies to maintain acceptable quality of care. Internal quality assurance safeguards quality if monitoring is done systematically by people who have the authority and resources to correct problems (732). Otherwise, quality assurance can deteriorate into a formality that diverts staff from patient care and other important functions.

Although agencies with an effective internal quality assurance program may provide better care than other agencies, families and other outsiders cannot know whether a particular agency's quality assurance program is effective or just a formality. For them, knowing whether an agency has an internal quality assurance program is not a useful indicator of quality.

Other Possible Sources of Information

In some localities, private agencies and voluntary associations collect and publicize information about service providers. In New York City, for example, the United Hospital Fund makes annual nursing home inspections and then publishes information obtained from the inspections (561).

Newspapers and other publications sometimes rate agencies and health care professionals based on the opinions of consumers or other health care professionals. An example is the publication, *Washington Consumers' Checkbook*, which has published ratings of hospitals (885) and recently asked people to evaluate homemaker/home health care agencies they had used. Ratings in commercial publications are likely to appear as a feature item, on a one-time basis, and not to be updated regularly. According to the editor of *Washington Consumers' Checkbook*, *the* time required to conduct surveys and interpret the findings on a regular basis may not be justified from a business standpoint because these features do not attract many additional readers (428).

Changes in ownership, management, or key staff in nursing homes and other agencies can have a dramatic effect on quality of care. Such changes occur frequently in some agencies, so to be accurate, ratings must be updated. Private agencies and voluntary associations may not have the resources to update ratings regularly.

Many books and pamphlets that inform people about the types of health care, long-term care, social, legal, and other services that may be available also contain suggestions about how to evaluate services and lists of questions for families and others to ask service providers. Figure 5-2 is an example of a checklist of questions for families who are trying to select a nursing home.

Several national organizations have developed initiatives to help people become informed consumers of services for themselves or volunteer advocates to help others select good services. The National Council on the Aging's project "Long-Term Care CHOICES," sponsored several community forums in Pennsylvania in 1987 to educate older people and their families about long-term care options. Similar forums were planned for other areas of the country (308). The CHOICES project produced a series of pamphlets about long-term care and a manual for organizing a consumer education campaign on long-term care.

The American Association of Retired Persons (AARP) sponsors many projects to educate people about long-term care and to train them to be informed consumers of long-term care services. One project in Washington, DC, is training volunteers to be "home care advocates" to help other people locate good home care services (791).

Summary

Many of the books and pamphlets that offer advice about obtaining services for people with dementia stress that the final decision about services rests with the demented person's family. These publications urge families to talk to people, ask questions, and visit agencies before choosing one, and they recommend many possible sources of information about the quality and appropriateness of services. OTA's review presented in the preceding section suggests that accurate information about quality and appropriateness is *sometimes* available from some of the recommended sources but is not

consistently available from any of them. The most helpful information often comes from informal discussions rather than from formal referrals or reports. But many telephone calls may be necessary to find the right person to talk to.

Health care and social service professionals and some of the other possible sources of information may or may not be knowledgeable about the quality or appropriateness of available services. With a few exceptions (e.g., government regulatory programs and voluntary accreditation programs), none of the sources of information discussed above has a systematic method for evaluating quality. The validity of the information they provide, therefore, is difficult to judge.

Lastly, concerns about legal liability and organizational pressures may limit the ability of hospital discharge planners, some case managers, and others to make referrals based on considerations of quality. Families are unlikely to know that these individuals are subject to these legal and organizational constraints and may incorrectly assume that the referrals they receive are endorsements of the services.

Some people get helpful advice, but there are no sure sources of evaluative information, and many blind alleys. Sometimes, obtaining accurate information or a referral to a good service provider seems to be a matter of chance. Family caregivers who call a lot of agencies, talk to a lot of people, and ask a lot of questions probably increase the likelihood that they will find the information they need to select good services.

LIMITATIONS ON CAREGIVERS' ABILITY TO OBTAIN INFORMATION

The discussion in the preceding section suggests that obtaining accurate information about the quality and appropriateness of services for people with dementia is often difficult. Some families and other informal caregivers are able to obtain the information they need by contacting a variety of people and agencies, asking questions, and visiting potential service providers, but for a variety of reasons discussed in this section, other families and informal caregivers are not.

To obtain information about quality, caregivers first have to know which agencies or individuals, if any, provide the services they need. In many

Figure 5-2—List of Questions for Families Trying To Select a Nursing Home

	Yes	No		Yes	No
1. Does the home have a current license from the state?			11. Hallways		
2. Does the administrator have a current license from the state?	—	—	a. Large enough for two wheelchairs to pass with ease?	—	—
3. If you need and are eligible for financial assistance, is the home certified to participate in government or other programs that provide it?			b. Hand-grip railing on the sides?		
4. Does the home provide special services such as a specific diet or therapy that the patient needs?			12. Dining room		
PHYSICAL CONSIDERATIONS			a. Attractive and inviting?	—	—
5. Location			b. Comfortable chairs and tables?	—	—
a. Pleasing to the patients?	—	—	c. Easy to move around in?	—	—
b. Convenient for patient's personal doctor?			d. Tables convenient for those in wheelchairs?	—	—
c. Convenient for frequent visits?	—	—	e. Food tasty and attractively served?	—	—
d. Near a hospital?			f. Meals match posted menu?	—	—
6. Accident prevention			g. Those needing help receiving it?	—	—
a. Well lighted inside?	—	—	13. Kitchen		
b. Free of hazards underfoot?	—	—	a. Food preparation, dishwashing, and garbage areas separated?		
c. Chairs sturdy and not easily tipped?	—	—	b. Food needing refrigeration not standing on counters?	—	—
d. Warning signs posted around freshly waxed floors?			c. Kitchen help observe sanitation rules?	—	—
e. Handrails in hallways and grab bars in bathroom?	—	—	14. Activity rooms		
7. Fire safety			a. Rooms available for patients' activities?	—	—
a. Meets federal and/or state codes?	—	—	b. Equipment (such as games, easels, yam, kiln, etc.) available?		
b. Exits clearly marked and unobstructed?	—	—	c. Residents using equipment?	—	—
c. Written emergency-evacuation plan?	—	—	15. Special-purpose rooms		
d. Frequent fire drills?	—	—	a. Rooms set aside for physical examinations or therapy?		
e. Exit doors not locked on the inside?	—	—	b. Rooms being used for stated purpose?		
f. Stairways enclosed and doors to stairways kept closed?	—	—	16. Isolation room		
8. Bedrooms			a. At least one bed and bathroom available for patients with contagious illness?	—	—
a. Open on to hall?	—	—	17. Toilet facilities		
b. Window?	—	—	a. Convenient to bedrooms?	—	—
c. No more than four beds per room?	—	—	b. Easy for a wheelchair patient to use?	—	—
d. Easy access to each bed?	—	—	c. Sink?	—	—
e. Drapery for each bed?	—	—	d. Nurse call bell?	—	—
f. Nurse call bell by each bed?	—	—	e. Hand grips on or near toilets?	—	—
g. Fresh drinking water at each bed?	—	—	f. Bathtubs and showers with nonslip surfaces?		
h. At least one comfortable chair per patient?	—	—	18. Grounds		
i. Reading lights?	—	—	a. Residents can get fresh air?	—	—
j. Clothes closet and drawers?	—	—	b. Ramps to help handicapped?		
k. Room for a wheelchair to maneuver?	—	—	SERVICES		
l. Care used in selecting roommates			19. Medical		
9. Cleanliness			a. Physician available in emergency?	—	—
a. Generally clean, even though it may have a lived-in look?	—	—	b. Private physician allowed?	—	—
b. Free of unpleasant odors?			c. Regular medical attention assured?	—	—
c. Incontinent patients given prompt attention?			d. Thorough physical immediately before or upon admission?	—	—
10. Lobby			e. Medical records and plan of care kept?	—	—
a. Is the atmosphere welcoming?	—	—	f. Patient involved in developing plans for treatment?	—	—
b. If also a lounge, is it being used by residents?			g. Other medical services (dentists, optometrists, etc.) available regularly?		
c. Furniture attractive and comfortable?			h. Freedom to purchase medicines outside home?	—	—
d. Plants and flowers?					
e. Certificates and licenses on display?					

<p>20 Hospitalization a Arrangement with nearby hospital for transfer when necessary? — .</p> <p>21. Nursing services a. RN responsible for nursing staff in a skilled nursing home? — — b. LPN on duty day and night in a skilled nursing home? — — c. Trained nurse's aides and orderlies on duty in homes providing some nursing care? — —</p> <p>22. Rehabilitation a. Specialists in various therapies available when needed? — —</p> <p>23. Activities program a. Individual patient preferences observed? — — b. Group and individual activities? — — c. Residents encouraged but not forced to participate? — — d. Outside trips for those who can go? — — e. Volunteers from the community work with patients? — .</p> <p>24. Religious observances a. Arrangements made for patient to worship as he or she pleases? — — b. Religious observances a matter of choice? . —</p> <p>25. Social services a. Social worker available to help residents and families? — —</p> <p>26. Food a. Dietitian plans menus for patients on special diets? — — b. Variety from meal to meal? — — c. Meals served at normal times? — — d. Plenty of time for each meal? — — e. Snacks? — — f. Food delivered to patients' rooms? — . g. Help with eating given when needed? — —</p> <p>27. Grooming a. Barbers and beauticians available for men and women? — .</p>	<p>ATTITUDES AND ATMOSPHERE</p> <p>28. General atmosphere friendly and supportive? — —</p> <p>29. Residents retain human rights? a. May participate in planning treatment? — — b. Medical records are held confidential? — — Can veto experimental research? — — c. Have freedom and privacy to attend to personal needs? — — e. Married couples may share room? — — f. All have opportunities to socialize? — — g. May manage own finances if capable or obtain accounting if not? — — h. May decorate their own bedrooms? — — i. May wear their own clothes? — — j. May communicate with anyone without censorship? — — k. Are not transferred or discharged arbitrarily? — —</p> <p>30. Administrator and staff available to discuss problems? a. Patients and relatives can discuss complaints without fear of reprisal? — — b. Staff responds to calls quickly and courteously? — —</p> <p>31. Residents appear alert unless very ill? — —</p> <p>32. Visiting hours accommodate residents and relatives? — .</p> <p>33. Civil-rights regulations observed? — —</p> <p>34. Visitors and volunteers pleased with home? — —</p>
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scoring

Generally, the best home is the one for which you check the most "yes" answers. However, different homes offer different services. You must decide which services are most important to you.

If the answer to any of the first four questions is "no," do not use the home.

SOURCE: L.P. Gwyther, "Nursing-Home-Care Issues," *Understanding Alzheimer's Disease*, M.K. Aronson (ed.) (New York, NY: Charles Scribner & Sons, 1988).

communities, that information is difficult to obtain.¹² To understand why they should investigate different service providers, caregivers need to know that available services are likely to vary considerably in their quality and appropriateness for people with dementia; some caregivers do not know this (57).

In addition, it takes time to evaluate different service providers. Many caregivers delay looking for services until their situation has become desperate. Consequently, they are trying to locate services in an atmosphere of crisis in which there is no time to contact individuals and agencies that might be able

to give advice about the quality and appropriateness of services (289,767).

Even if caregivers have time, some of them do not have anyone to care for their demented relative while they make telephone calls or visit agencies. Some caregivers lack transportation to visit agencies, and some are physically or cognitively impaired themselves. Furthermore, deciding to place a relative or friend in a nursing home is emotionally upsetting to many people (84,517,884), and decisions about other services may be upsetting as well. People who are upset may have difficulty remembering the questions they are supposed to ask providers and

¹²For more information about the difficulty of obtaining information about the availability of services, see ch. 2.

keeping track of what they have heard from various sources about the quality of different services.

Another important point is that some people in this country have never or rarely called a government agency or another source to ask for information or advice. Because of personality, socioeconomic status, educational or cultural background, and/or language differences, some individuals may find asking for information or advice very difficult.

Asking questions of service providers is also difficult for some people. Books and pamphlets for families of people with dementia and for elderly people often include lists of questions they are supposed to ask about agencies and service providers they may use. These lists are often long and all-inclusive. Some questions are for the family to answer, but most are for the service provider. Some families would be uncomfortable asking a service provider all or even a portion of the questions.

For all of these reasons, some families and other informal caregivers may be unable to obtain the information they need to make informed choices about services. A linking system that relied on families and other informal caregivers to function as informed consumers in selecting services for people with dementia would not meet the needs of families and other caregivers who cannot do so.

Finally, although the discussion here has focused solely on the limitations on caregivers' ability to obtain information about the quality and appropriateness of services, the reader should keep in mind that at least 10 percent of people with dementia have no informal caregiver to help them.¹³ Clearly, those individuals are not able to obtain for themselves information about the quality and appropriateness of services. Nor would they be able to use the information, even if they could obtain it.

APPROACHES FOR DEVELOPING CRITERIA TO EVALUATE THE QUALITY OF SERVICES

The development of criteria to evaluate the quality and appropriateness of services for people with dementia is probably the most important step that could be taken to enable a federally mandated linking system to connect people with dementia to the best available services. Certainly if a linking

system were going refer people to or arrange for them only services that met certain standards, the standards would have to be based on accepted criteria. As noted at the beginning of this chapter, it is not the function of a linking system to develop criteria to evaluate services, but this section discusses some of the criteria that might be used, who should develop them, and who could use them.

Criteria to evaluate the quality of services for people with dementia ultimately must be based on agreed-on goals and proven methods of care. Since there is not yet a consensus about the goals of care for people with dementia, and the effectiveness of many methods of care has not been tested, it is premature to establish comprehensive criteria to evaluate quality. Once set, the criteria could become entrenched and discourage the kind of experimentation that has led to innovative services and care methods in the past few years. This outcome would be especially likely if the criteria were adopted for government regulatory purposes.

In developing its "Best Practices for Special Care Programs for People With Alzheimer's Disease and Related Disorders," the American Association of Homes for the Aging (AAHA) has been wary of this possibility. AAHA emphasizes that the "best practices" are not criteria to assess special care units but rather guidelines for nursing homes that may establish such a unit. They are intended to highlight desirable outcomes and examples of good care (793).

The tasks of specifying goals, identifying effective methods of care, and developing criteria to measure quality and effectiveness are interrelated. Conclusions in one area may clarify or resolve issues in other areas. As tentative goals are set, possible methods of achieving them can be identified and tested. At the same time, as methods of care are tested, it becomes clearer what goals are achievable. A major unresolved question with respect to long-term care services for people with dementia, for example, is the extent to which rehabilitation is possible. Is it reasonable to expect improvements in cognitive ability or functioning in this patient population? (390). The answer to that question, which must be derived from research and experimentation with alternate methods of care, will in turn

¹³For the derivation of this estimate, see ch. 1.

determine what goals are realistic for services for people with dementia.

Even though it is premature to establish comprehensive criteria to evaluate the quality of services for people with dementia because of the lack of agreed-on goals and proven methods of care, an attempt to identify possible criteria is helpful in pointing out areas of agreement and disagreement and areas in which further research would be useful. The following discussion is intended in that spirit.

What Criteria Might Be Used?

Two prerequisites for good care that are cited in virtually all books, pamphlets, and articles about services for people with dementia are that the service providers be knowledgeable about dementia and that they be skilled in caring for or responding to the special needs of people with dementia. OTA is not aware of any other factors that are so consistently cited as prerequisites for high-quality, appropriate services for people with dementia.

OTA's 1987 report *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias* discussed the problems involved in attracting and retaining skilled, knowledgeable personnel to work with dementia patients and the education and training needs of professionals, paraprofessionals, and nonprofessionals who care for these patients (831). That report described education and training needs in terms of both factual information and relevant experience.

If there were criteria that accurately measured a service provider's knowledge about dementia and skills in working with people with dementia, those criteria probably also would be valid structural indicators of the quality and appropriateness of the services. In many fields, an individual's knowledge and skills are represented by his or her credentials (e.g., educational degrees, licenses, certificates) or job title. Although some aspects of the knowledge and skills of many professional, paraprofessional, and nonprofessional groups are relevant to the care of people with dementia, OTA is not aware of any group with a uniform credential or job title, in which all or even most of the group members are knowl-

edgeable about dementia and skilled in caring for people with dementia. Some physicians, nurses, social workers, lawyers, and psychologists are knowledgeable about dementia, whereas others are not. The same is true for nursing home aides, home health aides, homemakers, and other paraprofessional and nonprofessional service providers. Thus, neither credentials nor job title are valid criteria to measure service providers' knowledge about dementia and skills in working with people with dementia.

An alternate structural criterion is training. Dementia-related training often encompasses the nature and course of diseases that cause dementia, symptoms, patient care needs, recommended responses to common behavioral problems, and methods for supporting family caregivers. Many public and private agencies and voluntary associations offer training for all kinds of people who work with dementia patients. Training manuals have been developed by Alzheimer's Association chapters, provider associations, and others.¹⁴

Some Alzheimer's Association chapters have or are developing procedures for formally certifying people they have trained (183). At least one chapter certifies in-home respite and personal care workers it has trained. When someone contacts the chapter for information about such workers, he or she is given the names of people the chapter has certified. The director of the Cleveland Alzheimer's Association Chapter points out that chapters also could certify agencies if they have trained the agency's staff. Because of high staff turnover in some nursing homes and home care agencies, however, certification would lose its meaning quickly unless training were repeated frequently (183).

To choose training of service providers as a structural criterion to measure the quality and appropriateness of services assumes that training about dementia and how to care for people with dementia significantly increases the trainee's knowledge and skills in working with people with dementia—an assumption that is widely held but has not been proven in this or related contexts (31,904). The content and duration of the training, who provides it,

¹⁴See, for example: E.L. Ballard and L.P. Gwyther, *In-Home Respite Care: Guidelines for Training Respite Workers Serving Memory-Impaired Adults* (50); C.J. French et al., *Understanding and Caring for the Person With Alzheimer's Disease* (231); L.P. Gwyther, *Care of Alzheimer's Patients: A Manual for Nursing Home Staff* (285); J.T. Harkulich and B.A. Calamita, *A Manual for Caregivers of Alzheimer's Disease Clients in Long-Term Care* (618); and R. Kahn et al., *How To Care for the Alzheimer's Disease Patient: A Comprehensive Training Manual for Homemaker-Home Health Aides* (378).

whether trainees are tested in any way, and whether the training is reinforced over time probably influence its effectiveness. Although some members of the advisory panel for this OTA study considered training a useful structural indicator of quality and appropriateness, others considered it a weak, unproven intervention that generally is not a valid indicator of quality.

Some members of the OTA advisory panel pointed out that it is often easier to obtain agreement about indicators of poor quality than of good quality. They suggested that identifying negative outcomes (e.g., patient agitation and screaming) and clearly undesirable structural and procedural indicators (e.g., lack of staff training and inappropriate use of psychotropic medications to control patient behavior) might make available some information about quality without setting comprehensive criteria. Certainly information about the performance of different service providers with respect to these negative criteria would help families and others to avoid very poor-quality care.

Many other criteria for evaluating the quality and appropriateness of services for people with dementia have also been proposed. Some researchers who are conducting a 3-year study that compares nursing homes with "special care units" and nursing homes without such units hope that their findings will allow them to derive indicators of quality (761). Outcome criteria they are considering include:

- measures of acute health care service utilization, such as hospitalization rates and emergency room rates;
- measures of mortality and morbidity, including death, fractures, development of decubiti (bed sores), and medication reactions;
- changes in functional status, including development of contractures, loss of ability to ambulate, and changes in self-care status, socialization, or mental status;
- changes in the number and intensity of behavioral disturbances; and
- changes in overall health (761).

Structural and process criteria they are considering include:

- staff-to-patient ratios;
- staff training;
- facility design;

- environmental characteristics (e.g., noise, lighting, personal items in the patient's room);
- use of medications;
- patient involvement in activities;
- involvement of families; and
- staff morale (761).

Caregiver burden is another outcome criterion that seems particularly relevant for certain services for people with dementia. On the other hand, many factors other than the quality and appropriateness of services affect caregiver burden. Outcomes are valid indicators of quality only if they are attributable to the process of care. In practice, therefore, a measure of caregiver burden may not be a valid indicator of quality.

Patient satisfaction and caregiver satisfaction with services are other outcome criteria that might be used to assess quality and appropriateness. Although people who have used a service maybe a valuable source of information for others who are trying to select good services, OTA is not aware of any organization that routinely collects people's opinions about services they have used for individuals with dementia, analyzes and summarizes the findings, and makes them available to other people. OTA is also not aware of any research on the reliability or validity of patient and/or caregiver satisfaction as indicators of the quality of services for people with dementia.

Research on patient satisfaction as an indicator of the quality of ambulatory and inpatient medical care was reviewed for OTA's 1988 report *The Quality of Medical Care: Information for Consumers* (832). Over 450 relevant publications were screened, and 50 studies were analyzed in depth. The review indicated that:

- patients' ratings of the technical quality of care they received are somewhat inflated but generally in agreement with physicians' ratings of the same care;
- patients' ratings of the interpersonal aspects of care they received are generally in agreement with ratings by trained observers and others;
- patients are generally willing to discuss and rate their medical care;
- older people tend to rate the quality of their care more favorably than younger people, although the reason why is not known; and

- people tend to agree with attitude statements regardless of their content; thus favorably worded statements tend to elicit favorable comments, and negatively worded statements elicit negative comments--and this effect is particularly likely to occur among people of low socioeconomic status (832).

It is sometimes argued that patients' ratings of medical care reflect patients' attitudes about life in general. OTA's literature review suggests that the effect of patients' attitudes about life in general on their ratings of medical care, if an effect exists at all, is weak in the case of ratings of ambulatory and inpatient medical care (832).

Many people with dementia cannot evaluate the services they receive, but their families or other informal caregivers can. Some services are intended primarily to support family caregivers; obtaining caregivers' evaluations of those services, therefore, is clearly appropriate. In some instances, however, a family's evaluation of a service provided for the patient may differ from the evaluation the patient might make if he or she were capable of evaluating the service. For example, families sometimes consider certain activities provided in nursing homes or adult day care centers to be demeaning to their relative with dementia, even though the patient seems to like the activities and the staff believes they are beneficial. In such instances, the family's satisfaction with the services may not be a valid criterion to measure its quality or appropriateness for the patient (764).

Other factors also may affect the validity of patient and caregiver satisfaction as indicators of quality and appropriateness. Patients and families often are afraid to report poor-quality care because they fear retaliation against the patient or loss of the services (33,392). The validity of people's opinions about services also may be affected by the timing of the evaluation in relation to their use of the service (764), sociodemographic characteristics, their expectations for the service, and whether they paid for it. Anecdotal evidence suggests that some people who receive publicly funded services do not report poor-quality care because they think they do not deserve the services and that they should just accept whatever services they get (747)

It could be argued that since patients' and caregivers' opinions about services are, by definition, subjective, they cannot be valid indicators of

quality. If an agency or voluntary association routinely asked patients and caregivers about the quality of services they have used, however, and a large number of responses were collected, idiosyncratic factors that might invalidate one individual's response would become less significant, and common observations and evaluations would emerge. It is these common findings that would be valuable to other people that are trying to select good services.

People's opinions are a particularly appropriate indicator of the quality of services if quality of life is a goal of such services. Other, more objective and more easily quantifiable criteria that frequently are used in regulatory programs and may be more acceptable to service providers do not necessarily reflect the values and preferences of patients and families (877).

Using patient and caregiver satisfaction as indicators of the quality of services for people with dementia has two other advantages, as well. These indicators could be used immediately, even before there is agreement about other criteria to assess quality. In addition, using them would make available some information about quality without setting other criteria that could discourage experimentation with alternate methods of care.

Who Should Develop the Criteria and Who Could Use Them?

Government agencies, private agencies, and voluntary associations each have a role in establishing criteria to evaluate the quality of services for people with dementia. Ultimately, Federal, State, and local government agencies determine what criteria are used in regulatory programs. Government agencies are unlikely to begin developing criteria to evaluate the quality of services for people with dementia, however, until they are required to do so for a dementia-specific program--e.g., a program that pays more for nursing home care in a special care unit than in other nursing home units. If regulations for nursing homes and home health care agencies are any example, it could take a long time for government agencies to develop criteria, and the results might not meet the needs of families and others who are trying to select good services.

The initial steps of setting goals and proposing and evaluating criteria to measure quality might be better accomplished by private agencies and voluntary associations than by government agencies. The

tasks of soliciting, summarizing, and disseminating people's opinions about the quality of services they have used would probably be best accomplished by voluntary associations such as Alzheimer's Association chapters, some of which already perform some of the tasks informally. The most appropriate role for government with respect to developing criteria to evaluate the quality of services for people with dementia might be to fund research to evaluate and compare the effectiveness of alternate methods of care and to sponsor forums for discussion among health care and social service professionals, service providers, families, and others about goals and methods of care and criteria for evaluating quality.

Families and other informal caregivers could use any criteria that were developed and/or any available information about people's opinions about the quality of services to identify service providers who offer high-quality care. Other agencies and organizations could also use the criteria and any available information about people's opinions about the quality of services to evaluate service providers, with the result that information about the quality and appropriateness of services for people with dementia would be available from those sources.

An important, unresolved question is whether case managers and other employees of agencies that constituted a federally mandated linking system could use either the criteria or information about people's opinions about the quality of services to select the best available services for their clients or whether their use of such criteria and information would expose them, their agencies, or the linking system to unacceptable legal risks. To resolve this question will require a thorough analysis of the legal issues raised when an agency or system that links people to services provides its clients with information about the relative quality of available services or selects services for its clients on the basis of information about the quality and appropriateness of the services. The legal risks to the linking system and its employees are likely to be lessened to the extent that any information about quality and appropriateness given out by the linking system is perceived as accurate by service providers and others and to the extent that criteria used by case managers and other employees of the system to select services are seen to reflect the best available information from research and provider experience about what is good care for people with dementia.

Thus far, this chapter has focused primarily on how families and other informal caregivers can select good services and has ignored the problem of people with dementia who have no informal caregiver to help them. Certainly, as noted earlier, the information about quality and appropriateness that families and other informal caregivers need to make informed decisions about services should also guide decisions about services for people with dementia who have no informal caregiver. That can only happen if someone uses the information about quality and appropriateness to select services for these individuals. For that reason, it is particularly important that concerns about legal risks to a linking system and its employees for selecting services for its clients on the basis of information about the quality and appropriateness of the services be resolved expeditiously.

AGENCY PROCEDURES FOR MONITORING & CONTROLLING THE QUALITY OF SERVICES

Some agencies that link people to services have procedures for monitoring and controlling the quality of the services they arrange for their clients. Certain of these agencies provide services and therefore can assure (i.e., assess and correct problems in) the quality of those services directly. Other agencies contract for services; these agencies cannot assure the quality of services provided by any particular agency or individual, but they can use their contracting procedures to select service providers that meet certain standards. The capacity of these types of agencies to control the quality of services to which they link people is an important factor for policymakers to consider in deciding what type of agencies should constitute a system to link people with dementia to services.

This section describes some agencies' procedures for monitoring and controlling the quality of services, including procedures in which patients and families are involved in monitoring and controlling the quality and appropriateness of the services they receive. The potential role of case managers in monitoring and controlling the quality and appropriateness of services for their clients is discussed at the end of the section.

On Lok Senior Health Services, a San Francisco-based service delivery system, is an example of an agency that provides most services directly and has

an internal quality assurance process to monitor and control quality (940).¹⁵ Clients or their families make the decision to receive services from On Lok, but once that choice is made, On Lok assumes responsibility for quality of care.

Pennsylvania's Long-Term Care Assessment and Management Program (LAMP) is an example of a program that contracts with community agencies to provide services for its clients and has procedures for monitoring and controlling the quality of those services (652).¹⁶ LAMP's clients are elderly people who are eligible for Medicaid-funded nursing home care but choose to remain at home. The State of Pennsylvania designates local agencies (primarily AAAs) as LAMP sites to provide a comprehensive assessment, develop of a plan of care, and arrange and monitor services for each client. In turn, the LAMP sites contract with community agencies to provide services.

Contracts between LAMP sites and community agencies that provide services for LAMP clients include many provisions related to quality (872). For example, the fiscal year 1987 contract between the Allegheny County LAMP site and the Visiting Nurse Association (VNA) of Allegheny County specifies services the VNA must provide; that the VNA must be able to respond to emergency requests within 24 hours; and that the VNA must have certain staff, an orientation program, a method for certifying employee participation in continuing education, and an internal quality assurance program. Staff must be licensed or certified as appropriate, and the agency must be certified by Medicare and Medicaid and accredited or eligible to be accredited by JCAHO, NLN, or the FHHC.

Ohio's Pre-Admission Screening System Providing Options and Resources Today (PASSPORT) program is like LAMP in that it provides case management and a package of services for people who are eligible for nursing home care but choose to remain at home (622).¹⁷ The agencies that administer PASSPORT at the local level contract with other agencies to provide services for PASSPORT clients. Their contracts include numerous provisions to ensure the quality of services, including standards

developed for many different kinds of service providers (32,623). The PASSPORT program's standards for homemaker services are shown in figure 5-3.

Illinois' Community Care Program (CCP) funds homemaker, chore, and adult day services for about 25,000 elderly clients through contracts with more than 200 community agencies, called vendors (51).¹⁸ Clients may select a service provider, but it must be one of the vendors. The State of Illinois evaluates the performance of each vendor annually, using a 90-item review instrument that encompasses many aspects of quality and appropriateness. Vendors found to provide inadequate services are terminated from the program.

LAMP, PASSPORT, and CCP are State programs that go far beyond their State's licensing requirements, if any, and any relevant Medicare and Medicaid conditions of participation in their requirements for contractors. People who receive publicly funded services through different programs in the same States may not receive the same quality of care as clients of these programs.

New Jersey has taken a different approach. New Jersey's Medicaid agency requires community agencies that provide personal care or homemaker services to be accredited in order to be reimbursed for services to Medicaid patients. Since 1986, the Commission on Accreditation for Home Care, an organization that is independent of the State has accredited these agencies, based on uniform standards and an on-site inspection (168). As of August 1988, 45 agencies had applied for accreditation: 24 of these received accreditation; six were denied accreditation (primarily because of poor documentation, lack of evidence of appropriate supervision, or inadequate staffing); 10 were deferred and may reapply; and five withdrew their applications (430). New Jersey accepts accreditation by the Foundation for Hospice and Home Care (FHHC) in lieu of accreditation by the Commission, and 9 agencies have been accredited in that way.

In Tulsa, Oklahoma, five local sources of funding for home health aide, homemaker, companion, and chore services have pooled their funds and estab-

¹⁵For more information about On Lok, see ch. 8.

¹⁶For more information about Pennsylvania's LAMP program, see ch. 7.

¹⁷For more information about Ohio's PASSPORT program, see ch. 7.

¹⁸For more information about Illinois' Community Care Program (CCP), see ch. 7.

Figure 5-3-The Ohio PASSPORT Program's Standards for Homemaker Services

Homemaker Services Standards

- I. Homemaking services are provided by a homemaker who has met the education and training requirements for the PASSPORT program.
- II. The homemaker provides timely services, maintains a safe and clean environment and is sensitive to the client and family's needs.
- III. The homemaker performs tasks and duties according to the service care plan. The homemaker prioritizes and organizes tasks to achieve goals outlined on the care plan.
- IV. The homemaker understands that client information is privileged knowledge. The homemaker holds all information in confidence.
- V. Homemaking tasks assigned are performed under the supervision of the homemaker supervisor. The homemaker demonstrates knowledge and skills to perform assigned tasks,
- VI. The homemaker recognizes changes in client conditions and behavior and reports and records according to PASSPORT and agency procedures.
- VII. The homemaker participates as a health care team member and is responsible for communicating with other professional disciplines as appropriate.

SOURCE: R. Applebaum, S.J. Atchley, R. McGinnis, et al., *A Guide To Ensuring the Quality of In-Home Care: Final Report of Ohio's Quality Assurance Project* (Oxford, OH: Miami University, 1988).

lished a joint process to contract for these services.¹⁹ The five funding agencies have formal procedures for monitoring the quality of the services provided by the contractor. Those procedures include sending questionnaires to local hospitals, clinics, and other referral sources to determine their satisfaction with the contractor's services. Client satisfaction with the contractor's services is also assessed by using a standard list of questions (see figure 5-4). This list of questions is used to interview about 10 percent of the agencies' clients annually (556).

In 1987, Senior Care Network, a private hospital-based case management agency in Pasadena, California, began a comprehensive program to monitor and control the quality of services to which it refers clients (795). Senior Care Network combines four

case management programs: two of the programs contract with service providers, and two do not, but all four participate in the quality assurance program. Quality is monitored through quarterly meetings between the service providers and program staff; annual reevaluations; monthly client home visits by case managers; visits by program staff to the provider agencies; and vendor incident reports that often concern "no-shows" or late arrival by home makers and nurse's aides. If service providers accumulate a record of more than 5 percent "no-shows," case managers stop using that provider until the problem is corrected.

These models of service delivery, in which the quality of services is monitored and controlled by the agencies that provide, pay for, and/or arrange the

¹⁹The Tulsa Long-Term Care Management Authority, an outgrowth of the five-agency effort described here, is discussed in ch. 7.

Figure 5-4-Questions Used To Evaluate Client Satisfaction in Tulsa, Oklahoma

Client Satisfaction Questionnaire

Read each statement below. Circle the response that is most true. There are no right or wrong answers. No one from (home care agency) will see your responses. Your responses will not affect your services. If you wish, the interviewer will read the statements aloud.

1. I am comfortable with my worker from (home care agency) and I look forward to him or her coming to my house.
NEVER SOMETIMES USUALLY ALWAYS
2. If I have a problem or question about services I would be comfortable talking about it with my worker.
NEVER SOMETIMES USUALLY ALWAYS
3. If I had a problem I could not solve with my worker, I would be comfortable going to the supervisor.
NEVER SOMETIMES USUALLY ALWAYS
4. My worker knows what to do and does it with little or no supervision from me.
NEVER SOMETIMES USUALLY ALWAYS
5. The worker provides the services I expect.
NEVER SOMETIMES USUALLY ALWAYS
6. The worker finishes the job he/she is supposed to do.
NEVER SOMETIMES USUALLY ALWAYS
7. The worker takes longer than necessary to do the job.
NEVER SOMETIMES USUALLY ALWAYS
8. I can depend on my worker to arrive on time.
NEVER SOMETIMES USUALLY ALWAYS
9. The worker does not perform tasks I can do myself.
NEVER SOMETIMES USUALLY ALWAYS
10. I help decide what services I receive in my home.
NEVER SOMETIMES USUALLY ALWAYS
11. I am notified in advance if my worker will be late or cannot come.
NEVER SOMETIMES USUALLY ALWAYS

services, have considerable appeal, given the problems people face in obtaining accurate information about the quality and appropriateness of services otherwise. These models appear to respond to concerns raised in this chapter about families and other informal caregivers who are not able to obtain information about the quality and appropriateness of services themselves and people with dementia who have no informal caregiver to select services for them.

None of the programs described here is dementia-specific. The Medicare Alzheimer's Disease Demonstration that is being implemented at eight sites nationally requires each site to offer clients with Alzheimer's disease a range of in-home and community services (504). The sites are not required to contract for services, but that is an option. OTA does not know whether any of the sites have developed methods for monitoring and controlling the quality of contracted services or what methods of quality assessment and assurance will be used for brokered services.

Procedures for Involving Patients and Families in Monitoring and Controlling the Quality of Services

Giving patients and families greater control over the services they use is an approach that some agencies use to address concerns about the quality and appropriateness of services. This approach can be implemented through a variety of mechanisms, some of which have been discussed earlier:

- involving patients and families in developing the plan of care;
- having patients and families monitor services they receive;
- using patient and family satisfaction as indicators of quality;
- providing an effective grievance mechanism by which complaints from patients and families are received and acted on;
- giving patients and/or families control over the funds to pay for services; and
- involving patients and families in the overall design and evaluation of programs that provide services for them (735,919).

With the exception of patient and family monitoring of services, each of these mechanisms provides a way for patient and family values and preferences to influence the services they receive. In the case of people with dementia, it is probably more often the family than the patient who is actively involved in planning and evaluating services. As discussed earlier, the family can be seen either as representing the values and preferences of the patient in this context and/or as representing its own values and preferences.

Patient monitoring of services has been implemented formally in Ohio's PASSPORT program. Once a client's plan of care is developed, the client is given a checklist that indicates what services are to be provided and tells the client to call the case manager if specific problems arise (see figure 5-5). Whether planned services are actually received—i.e., whether a home health aide or homemaker shows up and does what he or she is supposed to do—is clearly a component of quality. Formal reporting mechanisms like Ohio's checklist offer a promising approach for monitoring it.

Many families informally monitor the quality of services provided for elderly relatives at home or in a nursing home (84,209,928). OTA is not aware of any research on the validity of families' reports about receipt or nonreceipt of services. OTA's literature review on patient satisfaction as an indicator of quality found that patients' reports about what medical services they receive are highly accurate (832).

Having patients and families report on receipt of services transfers only a small amount of control to them. Another approach that has rarely been implemented in publicly funded programs for elderly people but effectively transfers much more control to them, is giving them funds or vouchers to purchase services.

Family Survival Project, a San Francisco-based agency for brain-impaired adults, has implemented this approach in a program that gives family caregivers vouchers to purchase home care services.⁵⁷ The family is regarded as the employer of the service provider. This approach allows families to select home care workers who are acceptable to them, and Family Survival Project has encountered few problems with it (403).

Figure 5-5--Checklist Given to Clients in Ohio's PASSPORT Program

Client: _____ Date: _____
Case manager: _____ Telephone: _____
Instructions: _____

Personal Care

Bath
Oral care
— Shampoo
Shave
Skin care
Foot/nail care
Dress

Elimination

Client to toilet
Client to commode
Client to bedpan
Incontinent care
Ostomy care
Empty commode

Homemaking Tasks

Kitchen cleaning
Bathroom cleaning
Living room cleaning
Bedroom cleaning
Change bed linens
Grocery shopping
Errands
Trash removal
Accompany to doctors

Mobility

Transfers
Walking
Exercise
Assistive device

Nutrition

Meal planning
Breakfast
Lunch
Dinner
Snack
Feed client
Home delivered meals

PLEASE CALL CASE MANAGER IF:

- **WORKER FAILS TO SHOW UP**
- **WORKER FAILS TO PERFORM DUTIES**
- **THEFT OR ABUSIVE CARE**
- **YOU WILL NOT BE HOME FOR SERVICE**

****SIGN SERVICE AUTHORIZATION FORM ONLY FOR THE EXACT HOURS WORKED.**

In 1983 and 1984, the same approach was used in a Wisconsin demonstration project known as the "Consumer-Directed Services Initiative" (CDS) (919). Wisconsin's CDS provided participants or their families with vouchers to purchase services. The 70 participants included individuals of all ages with chronic disabilities who were eligible for nursing home care. Several of them were Alzheimer's patients. Participants had a service coordinator whose role was to ensure consumer direction:

Unlike the traditional case manager who is accountable to a service-providing agency, the service coordinator . . . is directly responsible to the consumer. It is the consumer who decides what services are needed and how they should be provided. The service coordinator uses his or her knowledge of the service system and of the rights and entitlements of the disabled consumer to explore options which the consumer can choose among (919).

Wisconsin's CDS demonstration project concluded that giving people vouchers and the opportunity for choice was an empty gesture unless they were also given information about available service options, training in how to bargain with and influence providers, and support for doing so (919). The underlying assumption of the project was that the client was "the boss," with the power to hire and fire, and the provider was expected to carry out duties according to the client's preferences. Many clients and providers had difficulty with this employer/employee relationship. Expectations differed about what the provider would do; there were personality conflicts; and some providers found it difficult to respect the client's preferences about how he or she wanted services performed.

For most clients with Alzheimer's disease, Wisconsin's CDS demonstration project relied on the family to make decisions about services for the patient (919). The service coordinators who worked with these patients and families frequently had difficulty in deciding when, if ever, the values, preferences, and interests of the family should take precedence over the values, preferences, and interests of the patient and determining, in effect, "who is the client" (919).²¹

Case managers, health care and social service professionals, and others are sometimes ambivalent about giving patients or families control over services, partly because doing so challenges the concept that it is professionals that can and should evaluate client needs and prescribe appropriate treatment (31 1,737). On the other hand, some are justifiably concerned about the possibility that poor care will be provided or that the patient's needs will be neglected in such an arrangement. Family Survival Project monitors intermittently services purchased through the voucher program. In Wisconsin, the CDS service coordinator provided ongoing monitoring.

What Role Can Case Managers Play in Monitoring and Controlling Quality?

Many commentators have suggested that case managers or a case management agency could monitor and control the quality of services generally (48,175,230,386,737,877). In 1987, the Delegate Assembly of the American Bar Association passed a resolution on home care that said, in part:

Experimentation with case management systems is widespread, but the current focus on case management centers largely on its potential to control costs. It may also offer tremendous potential as a tool for quality assurance and monitoring (19).

Case managers and case management systems do not automatically monitor and control quality. Case managers are employed by virtually all the agencies discussed in this report. Their functions vis-a-vis quality vary greatly, depending in large part on the organization, funding, sponsorship, and other characteristics of the agency that employs them. Case management agencies also differ in all these respects, and their current and potential ability to control quality of care also differs.

A recent review of the experiences of case managers in the \$10 million National Long-Term Care Channeling Demonstration illustrates some of these differences (33).²² The Channeling Demonstration, which was funded by the U.S. Department of Health and Human Services from 1980 to 1985, took place in 10 sites: in 5 sites, the case managers had funds to purchase services, and in 5 other sites, they had only very limited funds. Case managers in

²¹ For further discussion of the issue of who is the client of an agency or program that links people with dementia to services, see ch. 4.

²² The Channeling demonstration is discussed further in ch. 7.

both types of sites had difficulty monitoring the quality of homemaker and personal care services received by their clients. Some sites had contracts with homemaker/home health aide agencies, and at those sites, procedures for monitoring quality and responding to inadequate services were detailed in the contracts. At sites that did not have contracts with service providers, procedures for monitoring quality and responding to problems were less structured and less formal. Sites that had funds to purchase services used the threat of withholding payment to pressure providers into improving their services. That option was not available to sites that did not have funds to purchase services.

These findings from the Channeling Demonstration and the discussion earlier in this chapter about case managers' role in providing families and others with information about the quality and appropriateness of services suggest that it is not case managers or case management per se that can monitor and control quality but rather case managers in an agency or service delivery system that has explicit procedures for this purpose. Policymakers should not assume, therefore, that simply involving case managers in a linking system will automatically guarantee that the linking system will monitor and control the quality of services.

CONCLUSION

Families and other informal caregivers need accurate information about the quality and appropriateness of services provided by different agencies and individuals. In the public debate about services for people with dementia, the need for better information about quality and appropriateness has been overshadowed thus far by concerns about insufficient availability of services. Anecdotal evidence indicates, however, that some patients and families who need services do not use them because they are afraid of poor-quality care. For them, availability of services is not the only concern.

Books, pamphlets, and articles about services for people with dementia suggest that caregivers are responsible for selecting good services and that information about quality and appropriateness—on which they could base their selection—is available from a variety of sources. OTA's review of those sources indicates that although the necessary information is sometimes available from many of the sources, it is not consistently available anywhere.

Moreover, referrals to service providers are sometimes misleading. Patients and families who are given the name of a service provider—particularly by a health care or social service professional, hospital discharge planner, or case manager—may assume that the referral is a recommendation based on that individual's knowledge of available service options. That assumption may or may not be correct.

To expect families who are severely stressed by the care of a relative with dementia to call many individuals to ask for information about quality; to locate, read, and understand facility inspection reports; or to correctly guess the basis on which a referral is made by a physician, discharge planner, case manager, or other individual is naive. To expect this of a person with dementia is even more so.

The chapter points out that the development of criteria to evaluate the quality and appropriateness of services for people with dementia is probably the most important step that could be taken to enable a federally mandated linking system to connect people with dementia to the best available services. It is not the function of the linking system to develop such criteria, however.

Developing comprehensive criteria to evaluate the quality and appropriateness of services for people with dementia will take the combined efforts of government agencies, private agencies, and voluntary associations. It will also take time. In the meantime, private agencies and voluntary associations could solicit caregivers' opinions about services they have used for a person with dementia and make that information available to other people who are trying to select good services. In addition, existing regulatory programs could be modified to collect and make available information that would be useful to people who are trying to select good services. Neither of these approaches would result in comprehensive criteria for evaluating the quality and appropriateness of services for people with dementia. These approaches would provide information that is not available now, however, and might lessen the problems families and others face in selecting services.

A federally mandated linking system could not select services for its clients on the basis of the quality and appropriateness of the services without criteria for evaluating quality and appropriateness, but the analysis in this chapter suggests that there are several types of information the system could

provide caregivers of people with dementia to help them select good services. First, and most basic, the linking system could inform caregivers that there are differences in the quality and appropriateness of available services. Second, the system could inform caregivers about what, if any, information it will provide about the quality and appropriateness of services and about any factors that restrict the system and its employees from giving its clients accurate information about the quality and appropriateness of services or making referrals on the basis of quality. Third, the system could inform clients and their families about which service providers are licensed, certified, and/or accredited. Fourth, the system could give caregivers any available information about the quality of services, including, for example, information compiled by a voluntary association about families' and others' opinions about services they have used for a person with dementia. If Congress established a national system to link people with dementia to services, Congress could mandate that the linking system provide its clients with any or all of these types of information.

None of these types of information will solve the problem of how to ensure that people with dementia who are not capable of selecting services for themselves and have no relative or friend to help them are connected to the best available services. To solve that problem would require that the linking system select services for them on the basis of the quality and appropriateness of the services, which, as noted above, would require the development of criteria to evaluate quality and appropriateness. In the absence of the necessary criteria, Congress could mandate that the system refer clients only to

licensed, certified, and/or accredited agencies and service providers; for reasons discussed earlier in this chapter, however, such a requirement would probably have only a very limited impact on the quality and appropriateness of the services these clients would receive. Congress could require that the linking system control the quality of services to which it refers clients by contracting with providers that meet certain specified standards, but the standards do not exist yet.

The chapter has discussed the need for a thorough analysis of the legal issues that are raised when an agency or system that links people to services provides its clients with information about the relative quality of available services or selects services for its clients on the basis of information about the quality and appropriateness of the services. If Congress established a national linking system for people with dementia, Congress could require the U.S. Department of Health and Human Services to conduct or contract for such an analysis. Congress could also immunize the linking system from legal liability for good faith efforts to disseminate information about the quality of services.

Finally, the chapter recognizes the insufficient availability of services in general, and the difficult problems that it creates for anyone trying to arrange good care. On the other hand, there are some good services in almost all communities and important gradations in quality among services that might be considered adequate. Making available information about quality supports the providers of good services and encourages others to improve, even within existing resource constraints.