

Chapter 4

**Questions That Arise in Making
Decisions About Services**

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Questions That Arise in Making Decisions About Services

INTRODUCTION

Linking people with dementia to services involves many important decisions—what services are needed, who will provide them, who will pay for them, and, perhaps most importantly, whether the person will be cared for at home or in a nursing home or other residential care facility. Because of their cognitive impairments, people with dementia generally become less capable of making decisions for themselves. Their diminished decisionmaking capacity raises difficult questions for individuals and agencies involved in linking them to services. This chapter considers two of these questions:

- How should the decisionmaking capacity of people with dementia—in this context, their capacity to make decisions about services—be determined?
- How should decisions about services be made for people with dementia who are not decisionally capable? In other words, who should be the surrogate decisionmaker and what criteria should guide the decisions?

Questions about how to determine whether individuals are capable of making decisions and about how to make decisions for those individuals who are decisionally incapable have been analyzed and debated at length in contexts involving other populations, including mentally ill, unconscious, and terminally ill people, and other decisions, particularly decisions about the use of life-sustaining medical treatments and about participation in research. So far, however, such questions have not received much attention in contexts involving people with dementia and everyday decisions about health care, long-term care, social, and other services that such people may need (93,327).

At the policy level, questions about how to determine demented individuals' decisionmaking

capacity and how to make decisions about services on behalf of those demented individuals who are not capable of making such decisions themselves are often obscured by overriding concerns about the lack of sufficient services and funding for services.² At the level of individual case managers and others who arrange services for people with dementia, the questions are often obscured by the practical difficulties of locating and arranging services in a complex service environment. They may also be obscured by pressures on case managers to complete service arrangements quickly (e.g., because the client is in an unsafe situation, the client's informal support system is overwhelmed, the case manager has many other clients, or the hospital wants the client discharged 'yesterday').

It is important to recognize that although questions about how to determine a demented person's decisionmaking capacity and how to make decisions on behalf of decisionally incapable demented clients are often obscured, such questions are *inherent in* the process of linking people with dementia to services. Whenever the linking process goes beyond public education and information and referral to include the actual arranging of services, these questions are unavoidable.³ Every individual or agency that arranges services for people with dementia necessarily answers the questions in one way or another—either by following explicit procedures for determining decisionmaking capacity and making decisions on behalf of clients who are decisionally incapable or by making implicit judgments. If Congress mandated a system to link people with dementia to services, the agencies that constituted the system would confront the problems of determining decisionmaking capacity and designating surrogate decisionmakers whenever they helped to select or arrange services for people with dementia.

¹As discussed later, this chapter distinguishes between the terms “decisionmaking capacity,” “decisionally capable,” and “decisionally incapable” on the one hand and the terms “competency,” “competent” and “incompetent,” on the other. The terms “competency,” “competent,” and “incompetent” are used only to refer a person's legal status. The term “decisionmaking capacity,” “decisionally capable” and “decisionally incapable” are used to refer to a person's capacity to make decisions in a more general sense. These terms are unfamiliar to many people and their use sometimes results in cumbersome sentence constructions, but OTA believes that these terms are more accurate than other available terms that might be used to represent the concepts being discussed. OTA apologizes to readers who find the terms unfamiliar or their use contorted.

²The lack of sufficient services and funding for services is a topic that was addressed in OTA's 1987 report *Losing a Million Minds: Confronting the Tragedy of Alzheimer's and Other Dementias* (831).

³The need for a linking system to go beyond public education and information and referral in order to serve certain types of dementia patients and their caregivers is discussed in ch. 3.

Most agencies that link people with dementia to services have no explicit policies or procedures for determining their clients' decisionmaking capacity or for making decisions about services on behalf of clients who are decisionally incapable. In the absence of explicit policies and procedures, case managers and others who arrange services in these agencies must act on their own judgments about whether their clients are capable of making decisions about services and about how such decisions should be made for clients who are not decisionally capable. Some of these case managers and others may not be aware of the implications of these judgments, and some of them may not even be conscious of making the judgments.

Judgments about a person's decisionmaking capacity and about how decisions should be made for people who are decisionally incapable involve fundamental legal rights and complex legal and ethical issues, some of which are discussed in this chapter. If an agency, case manager, or other individual that arranges services for people with dementia is not aware of the legal rights and legal and ethical issues involved in decisionmaking, there is little likelihood that those rights and issues will be adequately considered when decisions about services are made.

In the context of linking people with dementia to services, one major objective in determining decisionmaking capacity is to ensure that people who are decisionally capable will be given the opportunity to make decisions about services themselves and that people who are not decisionally capable will be protected from decisions that may be harmful to them. The ultimate objective in designating a surrogate decisionmaker and establishing criteria to guide surrogate decisions is to ensure that the best possible decisions are made for people who are not decisionally capable. Establishing explicit agency policies and procedures for determining decisionmaking capacity and for making surrogate decisions would not guarantee the achievement of these objectives. Nevertheless, establishing explicit policies and procedures could help focus agencies' and case managers' attention on the important legal rights and legal and ethical issues at stake in

decisionmaking and thereby increase the likelihood that those rights and issues would be considered when decisions about services are made.

This chapter discusses certain concepts and distinctions that are important in thinking about how to determine people's decisionmaking capacity and how to make decisions on behalf of people who are not capable of making decisions themselves. The chapter also discusses some approaches that agencies and individuals that arrange services for people with dementia might use to determine their clients' decisionmaking capacity and to make decisions about services for clients who are decisionally incapable. Some of the concepts, distinctions, and approaches discussed here are derived from analysis and debate about other types of decisions (e.g., decisions about the use of life-sustaining medical treatments and participation in research) and about other client populations (e.g., mentally ill, unconscious, or terminally ill people), and they may or may not be directly applicable to decisions about services for people with dementia. Other concepts, distinctions, and approaches discussed here are derived from recently completed and ongoing research and demonstration projects that address the problems of decisionmaking for people with dementia more directly.⁴

The chapter discusses many unresolved issues. For some of the issues, there is, as yet, no agreement about the correct theoretical resolution. For other issues, there is agreement about the correct theoretical resolution but little understanding about how to apply it in the context of linking people with dementia to services.

If Congress mandated a national system to link people with dementia to services, it could require that the agencies that constitute the system have explicit policies and procedures for determining their clients' decisionmaking capacity and for making decisions for people who are not capable making decisions themselves. The concepts, approaches, and issues discussed in this chapter are relevant to the content of such policies and procedures and the questions that would have to be answered in developing them.

⁴These projects include: 1) studies on the "Personal Autonomy in Long-Term Care Initiative" funded by the Retirement Research Foundation (327); 2) a study of hospital discharge planning for elderly people with diminished decisionmaking capacity, funded by the Florence V. Burden Foundation and the Retirement Research Foundation (181,241); and 3) a project funded by the Littleton Foundation and the Retirement Research Foundation to train "temporary treatment guardians" and to refine and disseminate a "values history questionnaire" that allows individuals to document their preferences and values so that if surrogate decisionmaking becomes necessary in the future, it will reflect the individual's wishes (252,802).

DETERMINING THE DECISIONMAKING CAPACITY OF INDIVIDUALS WITH DEMENTIA

The extent to which individuals with dementia are capable of making decisions about services varies. Some people with dementia, especially in the early stages of their disease, are quite capable of making some or all decisions about services for themselves. Others, in the opinion of everyone who knows them, are incapable of making even simple decisions. Many people with dementia fall somewhere between these extremes.

Under U.S. law, adults are presumed to be competent unless and until factual evidence that refutes the presumption of competency has been presented to a court and the court has declared the person incompetent (945). Adults who have not been adjudicated incompetent have a legal right to make decisions about their medical care, where and how they will live, and how they will manage their own affairs. The vast majority of people with dementia have not been adjudicated incompetent. A 1986 survey of nursing homes in New York State found, for example, that under 3 percent of the homes' residents had been declared legally incompetent (609), even though at least 40 percent of the State's nursing home residents have dementia (217).

Since individuals with dementia who have not been adjudicated incompetent are presumed under U.S. law to be competent, they have a legal right to make their own decisions. Nevertheless, some people with dementia who have not been adjudicated incompetent are, in the opinion of virtually everyone who knows them, incapable of making important decisions about their lives. This chapter uses the terms "competent," "incompetent," and "competency" only to refer to a person's legal status. It uses the terms "decisionally capable," "decisionally incapable," and "decisionmaking capacity" to refer to a person's ability to make decision in a more general sense.

People who make judgments about dementia patients' decisionmaking capacity-physicians, other health care and social service professionals, hospital discharge planners, case managers, service provid-



Photo credit: Bill Adams

Some individuals with dementia are quite capable of making decisions about services for themselves, especially in the early stages of this disease. Surrogate decisions should not be substituted for an individual's own decisions unless it is clear that the individual is incapable of deciding for herself or himself.

ers, and others-often err by automatically assuming that any person with a diagnosis of a dementing disease is incapable of making decisions and by turning immediately to the person's family for a surrogate decisions Many commentators agree that this practice is wrong and that surrogate decisions should not be substituted for a person's own decisions unless it is clear that the person is decisionally incapable (4,27,93,139,210,301,417,671,901,945). On the other hand, some people who make judgments about dementia patients' decisionmaking capacity err in the opposite direction by assuming that a person with dementia is decisionally capable when he or she is not. Many commentators also agree that this practice is wrong because it fails to protect the decisionally incapable person from potentially harmful decisions (93,1 19,176,183,288,671).

Criteria for Determining Decisionmaking Capacity

Legal scholars and others have distinguished three general types of criteria for determining individuals' decisionmaking capacity:

⁵Likewise, many of the State task forces and committees that have studied the problem of dementia begin with a statement that people with dementia gradually lose their decisionmaking capacity, but then jump immediately to a discussion of methods for surrogate decisionmaking, (99,531,713) leaving out any discussion of methods for determining individuals' decisionmaking capacity or supporting their ability to make decisions for themselves.

- status criteria,
- . outcome criteria, and
- . fictional criteria (27,671).

If one uses status criteria to determine a person's decisionmaking capacity, the determination is based on the person's status in a specific category such as diagnosis, consciousness, or age. If one uses outcome criteria to determine a person's decisionmaking capacity, the determination usually is based on the "correctness" or "reasonableness" of the person's decision as judged by other people. If one uses fictional criteria, the determination is based on some aspect of the individual's functioning or potential functioning in a decisionmaking situation (27,671).

Some of the physicians, case managers, and others who make judgments about the decisionmaking capacity of people with dementia are probably not even conscious of making the judgments, and it is very unlikely that many of them consider whether their judgments are based on status, outcome, or functional criteria. Anecdotal evidence suggests, however, that many of these individuals rely more on status and outcome criteria than on functional criteria.

Physicians, case managers, and others who automatically assume that any person with a diagnosis of a dementing disease is unable to make decisions are using a *status criterion*—a diagnosis of a dementing disease. As noted earlier, the use of this criterion to judge a person's decisionmaking capacity is not appropriate, because people with dementing diseases vary greatly in their cognitive abilities, and many of them retain sufficient cognitive abilities to make decisions for themselves, especially in the early stages of their disease.

Physicians, case managers, and others who use the "correctness" or "reasonableness" of an individual's decision to judge the individual's decisionmaking capacity are using *outcome criteria*. If a cognitively impaired person's decision conflicts with a recommendation or decision of the individual's physician, case manager, hospital discharge planner, or some other caregiver, the person's decision may be called "unreasonable" and automatically regarded as evidence that the person is decisionally incapable. If a cognitively impaired person's decision does not conflict with the recommendations or decisions of his or her caregivers, the

issue of the person's decisionmaking capacity may not even arise. (386,901,947).

Two different arguments are made about the appropriateness of using outcome criteria such as the "correctness" or "reasonableness" of a person's decision to judge the person's decisionmaking capacity. On the one hand, some argue, competent adults have a legal right to take risks and make foolish decisions so long as their decisions do not encroach on the rights of others or violate the law (41,93,181,539); people with cognitive impairments should not be deprived of that right. On the other hand, some argue, physicians and other health care and social service professionals have a legal and ethical obligation to protect vulnerable people from danger and neglect; if these professionals think that a cognitively impaired person's decision threatens the person's safety, they are obligated to question it (41,93,181). A middle ground that reconciles these two arguments, in theory at least, is the view that if a cognitively impaired person makes a decision that seems unreasonable to others, the decision should trigger a careful evaluation of the person's decisionmaking capacity but should not result in an automatic judgment that the person is decisionally incapable (945).

Physicians, case managers, and others who use some aspect or aspects of an individual's functioning in a decisionmaking situation to judge the individual's decisionmaking capacity are using *functional criteria*. Two commentators discussing discharge planning for elderly people with diminished decisionmaking capacity have defined functional decisionmaking capacity in terms of a person's ability to comprehend the possible consequences of a plan he or she proposes (181). Other commentators have identified four fictional criteria for determining a person's decisionmaking capacity. Those criteria are listed below in the order of increasing strictness:

1. making a choice;
2. evidencing an understanding of relevant information and issues;
3. rationally manipulating the relevant information; and
4. in addition to 2 and 3 above, appreciating the nature of the situation (29).

The few courts that have considered criteria for determining decisionmaking capacity have generally adopted functional criteria rather than status or



Photo credit: Rush-Presbyterian/St. Luke's Medical Center, Chicago, IL

A person with dementia may be capable of making some decisions but not others.

outcome criteria (27). Most commentators also favor the use of functional criteria to determine a person's decisionmaking capacity, primarily because such criteria pertain directly to the person's actual or potential functioning in a decisionmaking situation (27). Functional criteria for determining a person's decisionmaking capacity are more ambiguous than status or outcome criteria, however. For that reason, a person who uses functional criteria has to exercise more independent judgment than a person who uses status or outcome criteria and may therefore need more training to make these determinations.

At least one observer has suggested that cognitive assessment tests, such as the Mini-Mental State Examination (218), could be used as an objective measure of decisionmaking capacity (613). That idea has intuitive appeal, but OTA is not aware of any research that compares people's cognitive ability as measured by their scores on a cognitive

assessment test and their decisionmaking capacity as measured by some other standard, and anecdotal evidence suggests that such scores and decisionmaking capacity may not be highly correlated. Moreover, in some cases, people's scores on cognitive assessment tests are not even an accurate indicator of their cognitive abilities. Sometimes, the tests incorrectly identify people as cognitively impaired who are cognitively normal; this situation is particularly likely to occur when the tests are used for ethnic minority people and people with very little formal education (831,865).

Although commentaries on criteria for determining people's decisionmaking capacity favor the use of functional criteria over status or outcome criteria as a general principle, it is important to note that most of the discussion on this topic has occurred in the context of decisions about life-sustaining medical treatments and about participation in research.

Moreover, discussion has often focused on people other than those with dementia (e.g., mentally ill and terminally ill people). The implications of using functional rather than status or outcome criteria to determine dementia patients' capacity to make everyday decisions about health care, long-term care, social, and other services have received very little attention. Thus, it is unclear whether there are any special considerations in the use of functional criteria for this purpose and whether there may be certain functional criteria that are especially appropriate for this population.

The Concept of Decision-Specific Decisionmaking Capacity

A concept that has emerged in the legal and ethical debate about determining decisionmaking capacity is the concept of decision-specific capacity. That concept is that a person's capacity to make a decision may differ for each decision. A person may be capable of making a simple decision carrying little risk but not capable of making a more complex decision carrying significant risks (176,178,945). Furthermore, "a person maybe [capable of making] a particular decision at a particular time, under certain circumstances, but [incapable of making] another decision, or even the same decision, under different conditions" (93).

The concept of decision-specific decisionmaking capacity is widely advocated and accepted (27,93, 177,671,672), but discussion about the application of the concept has occurred in the context of single decisions about the use of life-sustaining medical treatments or participation in research. So far, very little has been written about the application of this concept in the context of situations that call for making multiple interrelated decisions about a person's living arrangements and the use of various health care, long-term care, social, and other services over time.

Applying the concept of decision-specific capacity in situations involving multiple interrelated decisions over time may be considerably more difficult than applying the concept in situations where a single decision is needed. As an example, consider the dilemma raised in the following instance. A cognitively impaired man who requires supervision and personal care decides that he wants to remain at home with homemaker assistance instead of entering a nursing home. The man's

physician, the case manager, and others agree that the man is capable of making that decision, and so the case manager arranges for homemaker services. Subsequently, however, the man refuses to pay or repeatedly fires the homemakers who are sent to help him. What should be done in a case like this-when a cognitively impaired person refuses to implement his or her own decision?

Several commentators have pointed out that some people who are capable of *making* a decision are not necessarily capable of *implementing* it (i.e., they have decisional autonomy but not executional autonomy), and that such people need assistance in implementing their decisions (139,179,384). The application of that principle is clear with respect to people who *are physically* unable to implement their decisions, but it is less clear in the case of a cognitively impaired person who refuses to implement his or her own decision. Does it make sense to conclude that such a person is decisionally capable with respect to one decision and decisionally incapable with respect to other decisions that are needed to implement that decision? Raising this dilemma is not intended to dispute the validity of the concept of decision-specific decisionmaking capacity. Rather, it is intended to illustrate the difficulty that a case manager or other arranger of services might encounter in seeking to apply the concept to decisions about services for people with dementia.

Who Should Determine Decisionmaking Capacity?

Many commentators believe that a person's decisionmaking capacity should be determined without court involvement whenever possible and that the courts should be called on as a last resort only if an irreconcilable disagreement about a person's decisionmaking capacity arises among those who are caring for the person (177,253,539,945). Such determinations are better made without court involvement, they say, in part because court proceedings tend to be expensive, time-consuming, and emotionally stressful for everyone involved. In addition, many months may pass before a court hears a case and issues a decision, and applying the concept of decision-specific decisionmaking capacity would be virtually impossible if many decisions about a person's care had to be made over time, and a court hearing had to be held to determine the person's capacity to make each decision.

If, as a general practice, determinations of people's decisionmaking capacity are to be made without court involvement, some person or body other than the courts has to make them. Some hospitals and nursing homes have established explicit institutional policies that delineate procedures to be followed in making decisions about the use of life-sustaining medical treatments, and their policies often include procedures for determining patients' decisionmaking capacity (475,833). In addition, some hospitals and nursing homes have an ethics committee--a multidisciplinary group established to address ethical dilemmas that arise within the facility and advise staff about difficult treatment decisions. Hospital and nursing home ethics committees sometimes assist facility staff in determining whether patients are capable of making decisions about their medical care (833).

Agencies that arrange services for people with dementia could establish explicit policies, not unlike the institutional policies just mentioned, that would delineate procedures to be followed when decisions about services are needed for clients of questionable decisionmaking capacity. The agency policies could specify procedures for determining such individuals' decisionmaking capacity, including instructions about who should be involved in making the determinations.

Some agencies that arrange services for people with dementia might be able to adapt the model of a hospital or nursing home ethics committee for determining their clients' decisionmaking capacity (179). OTA knows of one community mental health center in Spokane, Washington, that has established a multidisciplinary team consisting of a psychiatrist, a nurse, and a social worker to determine its clients' decisionmaking capacity (689).⁶ Other agencies could use a similar approach.

In judging individuals' legal competency, courts frequently rely on the opinions of psychiatrists and psychologists. Some of the agencies OTA studied that arrange services for people with dementia—e.g., community mental health centers—have psychiatrists and psychologists as employees or consultants. These agencies might assign a psychiatrist or psychologist the primary responsibility for determining their clients' decisionmaking capacity.

Agencies that arrange services for people with dementia also might assign case managers the primary responsibility for determining their clients' decisionmaking capacity. OTA has heard different opinions about the wisdom of this approach, and some people's opinions depend on the educational background, experience, and training of the case managers who would be performing the function. Citing the important legal rights and legal and ethical issues involved in judgments about an individual's decisionmaking capacity, some people argue that only those case managers who have received special training in determining decisionmaking capacity--either in addition to or irrespective of their having a certain educational background and/or experience--are qualified to determine their clients' decisionmaking capacity. Other people argue that case managers with certain types of educational background and experience (e.g., those with a master's degree in nursing or social work and some amount of experience) are qualified to determine their clients' decisionmaking capacity. Still other people argue that case managers are not qualified to determine individuals' decisionmaking capacity regardless of the case managers' educational background, experience, and/or any special training they may have received.

It is important to note in this context that in many and perhaps most agencies that arrange services for people with dementia, case managers are the ones who determine their clients' decisionmaking capacity, even though there may be no explicit agency recognition that they are performing that function and some of the case managers may not be aware that they are doing so. Some people might argue that the current situation is satisfactory, although OTA has not heard that opinion expressed (except with respect to case managers with certain educational background and/or experience).

The educational background and experience of individuals who function as case managers in agencies that arrange services for people with dementia varies greatly, but to OTA's knowledge, the question of how education and experience affect case managers' ability to determine people's decisionmaking capacity has not been systematically investigated. It is reasonable to believe, though, that whatever their background, case managers and others who arrange services for people with demen-

⁶The Elderly Services Program of the Spokane Community Mental Health Center is described in box 8-C in ch. 8.



Photo credit: Eastern Area Agency on Aging, Brewer, ME

In many agencies that arrange services for people with dementia case managers are the ones who determine their clients' decisionmaking capacity, even though there may be no explicit agency recognition that they are performing that function.

tia would benefit from training in determining decisionmaking capacity. The form such training should take and who should provide it are unclear, however.

A resource center established at the University of Minnesota in 1988 might be able to develop training materials about determining decisionmaking capacity for case managers and others who arrange services for people with dementia. This center, the Long-Term Care Decisions Resource Center, was established by the Federal Administration on Aging to conduct research and to provide State units on aging and area agencies on aging (AAAs) with training and technical assistance related to decisionmaking in long-term care. The Minnesota center is addressing a variety of topics related to long-term care decisionmaking, including client assessment, care planning, and other case management functions. In relation to its work on these topics, the center might be able to develop training materials about methods of determining decisionmaking capacity and about legal and ethical issues involved in judgments about an individual's decisionmaking capacity. Such materials could be used to train case managers in AAAs and then be disseminated to other agencies.

Methods of Enhancing Decisionmaking Capacity

Several commentators believe that physicians, other health care and social service professionals, hospital discharge planners, case managers, and

others have an obligation to support and enhance the decisionmaking capacity of people with dementia (93,177,945). They also have an obligation to make the most of the variability in such individuals' decisionmaking capacity to allow individuals to make decisions for themselves to the greatest extent possible (93,177,945).

The decisionmaking capacity of a person with dementia is diminished first and foremost by cognitive deficits caused by the person's dementing disease. Since the cognitive abilities of a person with a dementing illness typically vary from day to day and even in the course of the same day, the person's decisionmaking capacity may be greater at some times than others. To allow the person to make his or her own decisions about services to the greatest extent possible, physicians and other health care and social service professionals must be available and willing to make the most of periods of relative lucidity (93,181).

In addition to being affected by the person's dementing disease, the decisionmaking capacity of a person with a dementing disease may be diminished by a variety of other factors that are more or less susceptible to interventions by physicians or others who are caring for the person. Such factors include medications, coexisting illnesses, stress, and unfamiliar environments that exacerbate the person's cognitive deficits, as well as sensory impairments that interfere with the person's ability to receive information relevant to decisions (93,414,945). Other factors include language barriers that interfere with communication; the lack of information about possible living arrangements and services, the form in which information about services is presented, and the ways in which questions about services and living arrangements are framed (4,179,386,798). Eliminating or compensating for factors that adversely affect decisionmaking capacity is one way to enhance a person's decisionmaking capacity and support the person's autonomy.

Unfortunately, the decisionmaking capacity of most individuals with dementia deteriorates over time. Another way to enhance the decisionmaking capacity and support the autonomy of such individuals, therefore, is by anticipating their mental deterioration and encouraging them to take advantage of legal arrangements that allow them to document their wishes or preferences with respect to certain types of decisions, so these wishes and preferences

can inform future decisions by surrogate decision-makers. Such legal arrangements include the following:

- trust agreements, which allow individuals to document their wishes for the management of their financial affairs in the event that they become decisionally incapable;
- living wills, which allow individuals to document their preferences about the use of life-sustaining medical treatments in the event that they become decisionally incapable; and
- durable powers of attorney, which allow individuals to designate someone to make health care and/or financial decisions for them (i.e., a surrogate decisionmaker) if the individual becomes decisionally incapable.

Many commentators have noted the importance of these legal arrangements and have emphasized that physicians, other health care and social service professionals, service providers, hospital discharge planners, case managers, and others who work with people with dementia and their families have a responsibility to encourage the patients and their families to have the necessary documents executed while the person is still decisionally capable (38,137,180,253,539,644,945).

If agencies that arrange services for people with dementia had explicit policies and procedures for determining their clients' decisionmaking capacity, they could incorporate available methods for enhancing decisionmaking capacity into their procedures. Implementing methods for enhancing decisionmaking capacity may be difficult, however, because the methods are often time-consuming; they do not fit easily into the time constraints of the typical hospital discharge planning process or situations in which services must be arranged quickly because the patient and family are in crisis by the time they come to the attention of the case manager (4,139,179,417,901).

The reason for enhancing individuals' decisionmaking capacity is to allow people to make decisions for themselves to the greatest extent that they are able. Efforts to preserve the autonomy of individuals with dementia have to be balanced, however, with a recognition that such individuals are often decisionally incapable and therefore may need

protection from decisions that may be harmful to them (119, 183,288). Designating someone to make decisions about services for a person who is decisionally incapable is not depriving that person of autonomy. In fact, allowing such a person to make decisions for himself or herself may be more correctly construed as abandonment than as supporting autonomy (41,417,547).

A full discussion of the difficult legal and ethical considerations involved in supporting the autonomy of a person with questionable decisionmaking capacity v. protecting the person from potentially harmful decisions is beyond the scope of this report.⁷ The main point here is that those seeking to support autonomy must balance their efforts with the recognition of realistic limits on autonomy caused by the person's dementing disease (41,178,546). Striking a balance between supporting a decisionally capable individual's autonomy and protecting a decisionally incapable person from potentially harmful decisions often requires subtle judgments on the part of whoever is determining the person's decisionmaking capacity—an observation that again suggests the need for training of the individuals who have to make these judgments.

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

As the preceding discussion points out, physicians, other health care and social service professionals, hospital discharge planners, case managers, and others who are involved in arranging services for people with dementia sometimes simply assume that anyone with a diagnosis of a dementing disease is decisionally incapable, without carefully evaluating the person's decisionmaking capacity. Furthermore, most agencies that arrange services for people with dementia do not have explicit policies and procedures for determining their clients' decisionmaking capacity. Judgments about clients' decisionmaking capacity in these agencies are frequently made by case managers and others who may or may not be knowledgeable about methods for determining decisionmaking capacity or about the complex legal and ethical issues involved in such judgments. (Some of these individuals may not even be aware that they are making the determinations.)

⁷For further discussion of these issues and considerations as they relate to decisions about services for people with dementia, the reader is referred to the summer 1987 issue of *Generations*, "Coercive Placement of the Elderly: Protection or Choice?" and the June 1988 supplement to *The Gerontologist*, "Autonomy in Long-Term Care" (241,251).

If Congress mandated a national system to link people with dementia to services, Congress could require the agencies that were designated to constitute the system to have explicit policies and procedures for determining clients' decisionmaking capacity. The questions that would have to be addressed by agencies in establishing such policies and procedures include the following:

- What criteria should be used to determine decisionmaking capacity?
- Who should be involved in determining client's decisionmaking capacity?
- What procedures should be used to enhance clients' decisionmaking capacity while at the same time protecting decisionally incapable people from potentially harmful decisions?

None of these questions is easily answered. Some of the possible answers discussed in the preceding sections were developed in discussion and debate about determining decisionmaking capacity for other client populations and other types of decisions. More research and analysis is needed about procedures for determining decisionmaking capacity in people with dementia and in the context of decisions about the health care, long-term care, social, and other services that may be needed for them. Training about determining decisionmaking capacity could benefit case managers and others who arrange services for people with dementia. Such training is especially needed for case managers or other individuals who have primary responsibility for determining their clients' decisionmaking capacity.

MAKING SURROGATE DECISIONS ABOUT SERVICES FOR INDIVIDUALS WITH DEMENTIA

If an individual with dementia is decisionally incapable, decisions about services must be made for the individual. It is important to reemphasize, however, that making decisions for such a person is the *second* step. The process of making decisions about services should begin with a presumption that the individual is decisionally capable. Only after that presumption is refuted should other people make decisions for the person (946).

When decisions are made on behalf of an individual who is decisionally incapable, someone or some group of people is chosen as the surrogate decisionmaker, whether that choice is made explicitly or

implicitly. Furthermore, the surrogate decisions are based on some criteria, whether those criteria are explicit or implicit. When decisions about services are made for an individual with dementia, the choice of a surrogate decisionmaker and the criteria for surrogate decisions are probably more often implicit than explicit. Nevertheless, who is chosen as the surrogate decisionmaker and what criteria are used for surrogate decisions can have a profound impact on the life of the individual with dementia.

Who Should Make Surrogate Decisions About Services?

As mentioned earlier, people who are decisionally capable can designate someone to make decisions on their behalf through the legal mechanism of a durable power of attorney. In some States, people who are decisionally capable also can designate someone to make decisions for them through another legal mechanism—a living will. Very few people have executed either a durable power of attorney or a living will. Moreover, the types of decisions that can be made with a durable power of attorney vary from State to State, and it is often unclear whether or to what extent a durable power of attorney authorizes the designated surrogate to make decisions about the kinds of health care, long-term care, social, and other services that may be needed for a person with dementia. State living will laws that allow the designation of a surrogate decisionmaker generally only authorize surrogate decisions about the use of life-sustaining medical treatments and, in some States, only for terminally ill individuals.

If a decision about services is needed for a decisionally incapable person with dementia and the person has not formally designated a surrogate decisionmaker, physicians, other health care and social service professionals, service providers, hospital discharge planners, case managers, and others usually turn to the person's family (if the person has one). Available evidence, including a 1982 Harris poll and a more recent study, indicates that most people want a family member **to make** decisions for **them if they are not** able to make the decisions themselves. The 1982 Harris poll found that 57 percent of the 1,251 people interviewed nationwide said they wanted a family member **to make important** medical decisions for them if they were not capable of **doing so themselves**; about one-third wanted their doctor **to make** such decisions (476). In another, more recent study, 90 percent of the 40

elderly persons interviewed said they **wanted a family member or family members to make health care decisions for them if they were not capable of doing so themselves**; the remaining 10 percent wanted their doctor, a lawyer, or a close friend to make the decisions (322).

The 1982 Harris poll and the more recent study both focused on health care decisions, and although the majority of respondents in both studies said they wanted family members to make surrogate decisions for them, the next largest number of respondents said they wanted their physician to make the decisions (322,476). Physicians are probably perceived by most people as more qualified to make decisions about health care than about some of the other kinds of services that may be needed for individuals with dementia. No data are available, but it is likely that if the studies had focused on decisions about social and other nonmedical services, the preference for family members as surrogate decisionmakers would have been even stronger.

Despite the fact that most people prefer to have family members make decisions for them if they become decisionally incapable, many States provide no legal authority for family members to make the decisions unless the family member is designated as a surrogate decisionmaker by a durable power of attorney or a living will, as just described (36,531,945).

As of April 1987, only 15 States had “family consent laws” (i.e., statutes that authorize family members to make decisions for relatives who are decisionally incapable), although courts in 5 additional States had ruled that family members could make such decisions (539,540). These family consent laws and court rulings generally only apply to certain types of patients and certain types of decisions. The laws and court rulings in some States authorize families to make decisions for a decisionally incapable relative only if a physician has certified that the person is terminally ill (540). Many existing family consent laws and court rulings only address decisions about life-sustaining medical treatments, and it is not clear whether they apply to decisions about the other kinds of health care, long-term care, social, and other services that maybe needed for people with dementia.

In States that do not have family consent laws, the legal rights and responsibilities of family members and others in making decisions for decisionally



Photo credit: Maria P. Cordero-Aranda

Most people want family members to make decisions for them if they are not capable of making the decisions themselves.

incapable people are unclear. In these States and in many of the States that already have family consent laws, legislation is needed to clearly delineate the extent of, and limitations on, the decisionmaking authority that is granted to family members and others, including any limitations on the types of decisions that the law authorizes them to make. The designation of surrogate decisionmakers, including family members, for decisionally incapable people with dementia will continue even in the absence of such legislation, but State statutes that clearly define the rights and responsibilities of family members and others in making decisions for decisionally incapable people and also delineate the types of decisions that a designated surrogate is and is not authorized to make would create a firm legal basis for determining who should make decisions about services for decisionally incapable people with dementia.

Several problems complicate the practice of using family members as surrogate decisionmakers. One is that a person's relatives may disagree about which one(s) should make the necessary decisions. Such disagreements may arise between the demented person's adult children, between adult children and the spouse, or between siblings and other relatives who have been involved in caring for the person (85,137,186,514,670,936). Some States' family consent laws address this problem by specifying the order in which certain family members (e.g., the spouse and the adult children) are authorized to make surrogate decisions (539). OTA has not analyzed the pros and cons of this approach.

Some of the other problems that complicate the practice of using family members as surrogate decisionmakers probably would persist even if all States had clear, comprehensive statutes on designating surrogate decisionmakers. One such problem, as discussed in chapter 3, is that some family members are not comfortable making decisions for a relative with dementia (307,487,533,669,936). Despite their concern about their relative's welfare and knowledge about his or her wishes, some family members are reluctant to take control. Such reluctance is evident in following statement of a 74-year-old woman whose husband had dementia:

My husband refuses to believe that there is anything wrong with him. Sometimes he does seem to be better than others, so how do I tell him that he needs help? (669)

A study of 15 spouses of people with dementia found that wives were much more likely than husbands to have difficulty making decisions for their demented spouses (533). The researcher concluded:

The males' assumption of authority over their wives was. . . a natural extension of their authoritative role in the family. For the wives, assuming an authority position over another adult, especially a man who had probably been the authority figure in the marriage, was one of the hardest aspects of the caregiving role (533).

Another problem that complicates the practice of using family members as surrogate decisionmakers is that some families are not appropriate surrogate decisionmakers. The practice of turning to a person's family for surrogate decisions assumes that family members are more likely than other people to know the patient's values and preferences and to be concerned about his or her interests. That assumption is valid in many cases, and perhaps most, but certainly not in all (93,945). Furthermore, even family members who know a patient's values and preferences and are concerned about the patient's interests, do not always make decisions on the basis of those values, preferences, and interests.

It is sometimes assumed that the only thing a case manager has to do with respect to designating a surrogate decisionmaker for a person with dementia who has a family is to note the name and telephone number of one or more family members in the person's medical record or care plan. Sometimes,

however, problems arise—e.g., the person's relatives disagree about who should be the surrogate decisionmaker, or the obvious surrogate is either reluctant to make decisions for the person or unconcerned about the person's well-being—that make designating a surrogate a more difficult task. Such problems suggest a need for agency policies and procedures for designating surrogate decisionmakers (written to comply with existing State laws if there are relevant laws) and training for case managers and others who are involved in selecting surrogate decisionmakers.

Designating a surrogate decisionmaker for a person with dementia who has no family is likely to be even more difficult than doing so for a person who has a family. One unresolved issue is the appropriate role of nonfamily caregivers in making decisions about services for decisionally incapable people with dementia. That issue was brought to OTA's attention by the findings of an exploratory study conducted for OTA in Los Angeles and San Diego Counties, California in 1988 and 1989 (866). One component of the study was interviews with 88 ethnic minority caregivers of ethnic minority people with dementia. The 88 caregivers included 35 black, 25 Hispanic, 18 Japanese, and 10 American Indian caregivers.⁸ The study found that 17 percent of the caregivers were friends or neighbors of the person they were caring for, i.e., not family members, and 34 percent of the black caregivers were not family members.

OTA'S contractors, the individuals who interviewed the black caregivers, and others have pointed out that in many black communities, long-time friends and neighbors are frequently regarded and spoken about as if they were family members (247,866). When it comes to making decisions about services for a decisionally incapable person, however, these "fictive kin" are in the same or perhaps an even more uncertain position legally than family caregivers in States that do not have family consent laws. Although a nonfamily caregiver may know more than anyone else about the wishes and values of the person he or she is caring for—and therefore be the best surrogate decisionmaker for that person—there is no legal authority for the nonfamily caregiver to make the necessary decisions.

⁸All of the components of the study conducted for OTA in California are described in app. A. A complete report on the study is available from the National Technical Information Service in Springfield, VA.

The study conducted for OTA in Los Angeles and San Diego Counties found that the percentage of nonfamily caregivers was higher among the black caregivers than among the Hispanic, Japanese, and American Indian caregivers (866). These findings cannot be generalized with any certainty because of the small size of the samples and the way the samples were recruited. OTA's contractors believe, however, that there is probably a higher percentage of nonfamily caregivers of people with dementia in the black population than in the Hispanic, Japanese, or American Indian populations in the areas studied (865). On the other hand, anecdotal evidence suggests and OTA's contractors believe that the phenomenon of nonfamily caregivers of people with dementia exists in all population groups, including the majority white population. It is likely, therefore, that agencies, case managers, and others that arrange services for people with dementia routinely encounter dementia patients who have nonfamily caregivers. Although the appropriate role of these caregivers in decisions about services for the patients is unclear, it is clear that unless the caregivers are involved in the decisionmaking process in some way, decisions about services for the patients they are caring for will be made without the benefit of their knowledge of the patients' wishes and values.

For individuals with dementia who have no family member or other person to make decisions about services for them and for individuals whose family or nonfamily caregiver is not an appropriate surrogate for any reason, one option would seem to be guardianship--in which a court appoints someone to manage money and make decisions for an individual who has been declared legally incompetent (the ward).⁹ Many commentators regard guardianship as a last resort, however, because it usually entails the drastic deprivation of rights for the ward; because, as discussed earlier, court proceedings are often expensive, time-consuming, and emotionally stressful for everyone involved (177,253,361,945); and because guardianship does not necessarily result in the designation of a reliable surrogate decision-maker.

A full discussion of the many problems with guardianship in this country is beyond the scope of this report. It is sufficient to note some of the

findings of a study conducted by the Associated Press in all 50 States in 1986 and 1987, in which judges, guardians, and others were interviewed and the court files of more than 2,200 individuals who had been declared legally incompetent and assigned a guardian were reviewed (11). That study found that in one-fourth of the cases, no hearing was held to determine whether the person was incompetent. In many cases, once guardianship was established, the court lost track of the paperwork, the guardian, and the ward. Although there are reporting and accounting requirements for court-appointed guardians in all 50 States, the required annual or periodic accountings of the ward's money were missing or incomplete in half the files. Only 16 percent of the files had any kind of report on the status of the ward, and 13 percent of the files were empty except for the original decision that the individual was incompetent and the granting of guardianship powers. One judge interviewed by the Associated Press said:

I don't know where the wards are, who's caring for them, or what they're doing. I have no support staff; I have no welfare workers; I have no aides; I have no assistants; and I have no money (11).

In 1983, Montefiore Hospital in New York added a lawyer to its multidisciplinary geriatric team to resolve legal problems that prevented effective hospital discharge planning for or appropriate placement of elderly patients with diminished cognitive abilities (181). For some patients, the lawyer initiated legal proceedings in order to have a guardian appointed to manage the patient's money so that needed services could be purchased. After several protracted and generally unsatisfactory experiences with the guardianship process, the lawyer concluded that guardianship was an inadequate method of designating a surrogate decisionmaker for the purpose of hospital discharge planning (179). Another lawyer connected to the project described the guardianship process as "a nonexistent alternative" with respect to hospital discharge planning (946). The guardians appointed by the court generally were untrained and unsupervised. Moreover, in at least two cases in which a guardian was appointed after a lengthy court process, the person appointed did not even contact the patient or patient's caregivers for months after the court decision (181).

⁹Some States use the terms "guardian" and "guardianship," other States use the terms "conservator" and "conservatorship," and some States use both terms to refer to the court-appointed person and the mechanism(s) by which that person is appointed to manage the assets and/or make other decisions on behalf of people who are determined to be decisionally incapable (539). In the following discussion, the terms "guardian" and "guardianship" are intended to include both sets of terms.

The American Bar Association has recommended reforms in the guardianship process, and the Center for Social Gerontology in Ann Arbor, Michigan, has developed standards for individuals and agencies that function as guardians for decisionally incapable adults (738). Various other organizations have developed alternatives to guardianship for decisionally incapable people who have no family member or other surrogate decisionmaker.

The University of New Mexico's Institute of Public Law, for example, recently trained 20 volunteers (social workers, lawyers, nurses, and others) to act as "temporary treatment guardians" to make decisions about medical treatment for hospitalized elderly people who are decisionally incapable and have no other surrogate decisionmaker (802). The volunteers underwent a 16-hour training program that involved didactic presentations, case discussions, and role playing. In the course of the 1-year project, the volunteers assisted a total of 50 elderly people. As it turned out, the temporary treatment guardians discovered that some of the elderly people they were called in to assist were decisionally capable after all and that other clients had family members or close friends who could be located with a little "sleuthing" and were able to make decisions for the person.

Since 1985, New York State has had a program whereby volunteer surrogate decisionmaking committees make decisions about medical treatments for mentally ill and mentally retarded people who have no other surrogate decisionmaker (777). The committees are composed of at least 12 members who meet in 4-member panels to consider treatment decisions. Each 4-member panel must include a health care professional, a former patient or relative of a patient, a lawyer, and an advocate for the mentally disabled. For each mentally ill or retarded individual, the 4-member panel determines, first, whether the person is decisionally capable and, second, whether there is a family member or a legally appointed guardian who can make the necessary treatment decision. If the answers to both questions are no, the panel makes the treatment decision. In the first year of the program, surrogate decisions about treatment were made in 192 cases. The decisions were made in an average of 14 days from the time the committees received the application—much less time than is required for the typical guardianship proceeding. Some observers feared that it would be difficult to recruit professionals to

serve on the committees, but recruiting volunteers has not been a problem except in some rural areas of the State.

Both the University of New Mexico program and the New York State program provide only a one-time or temporary surrogate decisionmaker and address only decisions about medical treatment. Other guardianship diversion programs provide money management and counseling services for decisionally incapable people, sometimes on a long-term basis (900). All of these programs exemplify methods other than guardianship by which surrogate decisionmakers can be provided for people who are decisionally incapable and have no family member or other surrogate to make decisions for them. To make surrogate decisions for these people, agencies that arrange services for people with dementia could create their own surrogate decisionmaking committee, recruit and train volunteer surrogate decisionmakers, or affiliate themselves with a program that provides surrogate decisionmakers (if such a program is available in the agency's area).

What Criteria Should Guide Surrogate Decisions About Services?

Court rulings and legal analysis of decisions about the use of life-sustaining medical treatments made on behalf of people who are decisionally incapable have identified two standards to guide surrogate decisionmaking:

- the best interest standard, and
- the substituted judgment standard.

The best interest standard requires the surrogate to make decisions from the perspective of a hypothetical reasonable person, using objective, societally shared criteria (945). The substituted judgment standard requires the surrogate to make decisions from the perspective of the patient, using the patient's personal values and preferences (945).

The best interest and substituted judgment standards, respectively, represent two fundamental values in surrogate decisionmaking—patient autonomy and patient well-being (671). The tension between those two values is as central to surrogate decisions about services for people with dementia as it is to surrogate decisions about the use of life-sustaining medical treatments for people who are permanently unconscious or terminally ill. In the context of surrogate decisions about services for people with

dementia, patient well-being as a value is manifested in decisions by physicians, service providers, case managers, or an individual's friends or family that the individual should receive certain services or live in a certain place "for his or her own good," regardless of the individual's wishes. Patient autonomy as a value is manifested in surrogate decisions that an individual with dementia should be allowed to refuse services and live as he or she chooses, even if there is risk associated with those choices. The latter perspective also is reflected in efforts to enhance an individual's decisionmaking capacity, as discussed earlier, and to support the "residual autonomy" of the individual (177).

Some people generally favor surrogate decisions based on patient well-being, whereas others generally favor surrogate decisions based on patient autonomy. Clearly, however, neither value by itself is sufficient for every decision or for every patient. The process of making surrogate decisions about services for people with dementia probably should retain a tension between the two values, but retaining that tension means that in many cases the "right" decision will not be obvious.

When case managers, hospital discharge planners, and others who arrange services for people with dementia make or influence decisions about services, those decisions are likely to reflect their preference for one value or the other, either in general or in the particular situation. Yet some of those individuals may not be aware of the values involved in such decisions or the implications for the patient of decisions that favor one value over the other.

The relationship between patient well-being and autonomy has been discussed and debated extensively with respect to decisions for all kinds of people who are decisionally incapable, and the resulting ideas and principles seem both relevant to and adequate for thinking about criteria for surrogate decisions pertaining to the use of services for people with dementia. In contrast, another issue—how the needs, preferences, and best interests of the patient and of the family should be weighed—has received less attention in discussion and debate about decisions for all kinds of people who are decisionally incapable, and the resulting ideas and principles are less helpful in thinking about decisions about services for people with dementia.



Photo credit: Bill Adams

Agencies that arrange services for people with dementia could create a surrogate decisionmaking committee to make decisions about services for people with dementia who are not capable of making the decisions themselves and have no one else to make the decisions for them.

The members of the advisory panel for this OTA study talked at some length about the question of the relative weight that should be given to the needs, preferences, and best interests of the family v. the patient in decisions about services for persons with dementia. No consensus was reached, but several important points emerged from the discussion. First, it is clear that when family members are necessary participants in a plan of care because the person with dementia lives with them or for any other reason, their needs and preferences must be considered in decisions about services because their interests are at stake in the decisions and because they may not cooperate with the plan of care otherwise. Second, it is sometimes very difficult in practice to separate the needs, preferences, and best interests of the person with dementia and of the family.

Beyond those two points, the OTA advisory panel divided into two groups. Some panelists tended to regard the person with dementia and family as a unit and to consider that unit the appropriate client of the case manager. Those panelists generally were not especially concerned about the difficulty of separating the needs, preferences, and best interests of the patient and those of the family; and they seemed to regard positively the idea of using the needs, preferences, and best interests of the family as criteria for decisions about services. Other panelists tended to regard the person with dementia and family as separate; and they were worried about the potential for conflicts of interest if the needs, preferences, and best interests of the family, rather than those of the patient, were used as criteria for decisions about services.

Both groups of OTA advisory panel members were critical of case managers who represent themselves as advocates for a person with dementia but in fact have their primary allegiance to a relative of the person, a trust officer, or someone else who is paying for their services. This is one of the situations that commentators refer to with the phrase, "Who's the client?" The allegiance of the case manager to the impaired person v. a family member, trust officer, or someone else is in part a question of professional ethics that should be addressed in case management standards and is addressed, to some degree, in the case management standards of the National Association of Social Workers (572) and the National Council on the Aging (581).

A more complex issue is the relationship between the long-term needs, preferences, and best interests of a person with dementia and the needs, preferences, and best interests of his or her primary caregiver, who is usually a family member. Arguably, the long-term best interests of many people with dementia is to remain with a family caregiver even if the care they receive from that person is much less than ideal. It maybe in the demented person's best interest to remain with the family caregiver because the alternative to being cared for by the family caregiver is objectively worse, is worse in the view of the patient, or both; because the person knows the family caregiver; or because families often provide what one commentator has called "substituted memory of shared happenings" -i.e., a knowledge of the patient past (which a formal service provider generally does not have) that is reassuring to the patient and may to some degree compensate for his or her memory loss (177).

On the other hand, there is clearly some point at which the long-term best interests of a patient with dementia are not served by remaining with the family caregiver. Different observers undoubtedly would disagree about when that point has been reached for an individual patient.

If by basing decisions about services on the needs and preferences of the caregiver, one can support the caregiver and prolong the time he or she is willing and able to continue caring for the patient, doing so would seem to be in the patient's long-term best interest, even if it required disregarding the patient's "spoken choice" or short-term best interest. "spoken choice" here refers to a clearly articulated preference of the person which, because of the

person's cognitive impairment, may or may not reflect his or her real needs, preferences, or best interests (18 1).

Consider, for example, a situation in which a person with dementia is placed in a nursing home for 2 weeks against his or her wishes, so that the primary caregiver will be temporarily relieved of caregiving tasks. Even if the placement results in short-term worsening of the impaired person's cognitive and emotional status, some people would say that it is in that person's best interest because it serves the person's presumed long-term interests. Additional situations also might be imagined in which disregarding the spoken choice and short-term best interest of a decisionally incapable person could be regarded as being in that person's best interest.

The point of this discussion is not to resolve the question of the relative weight that should be given to the needs, preferences, and best interests of the person with dementia v. the family in decisions about services but simply to emphasize the complexity of the issue. Three additional considerations further complicate the matter. First, some people with dementia live with and are cared for by a person who is almost as impaired as they are and who might be legitimately regarded as a client. When there are, in effect, two clients in the home, how should their needs, preferences, and best interests be weighed in decisions about services? Second, some, and perhaps many caregivers can be pressured into doing more than they should do for their own good. Are there limits that could or should be applied to what a caregiver is expected, asked, or even allowed to do? **IAN@, as a patient's condition deteriorates, is there a point at which the interests and well-being of the caregiver should take precedence over the interests of the patient?**

There are no simple answers to any of these questions. Case managers and others who arrange services for people with dementia regularly confront situations in which decisions must be made that could favor the needs, preferences, and best interests of the family over those of the patient, or vice versa. They may be more or less aware of the issues involved in those decisions and the implications for the patient and family of decisions that favor the needs, preferences, or best interests of one over the other.

The question of the relative weight that should be given to patients' v. families' needs, preferences,

and best interests in decisions about services requires further analysis. In the meantime, it is unclear what guidelines might be given to case managers and others who arrange services for people with dementia and thus regularly confront situations in which a decision must be made. One approach would be to create within agencies various forums (e.g., multidisciplinary team meetings, formal case conferences, and supervisory conferences) in which those situations could be discussed and deliberated.

Implications for a System To Link People With Dementia to Services

The preceding discussion points out that choosing surrogate decisionmakers for decisionally incapable people with dementia and determining what criteria should guide surrogate decisions about services for them involve complex legal and ethical issues and raise many unanswered questions. State legislation that clearly defined the rights and responsibilities of family members and others in making decisions for decisionally incapable people and delineated the types of decisions that designated surrogates are and are not authorized to make would eliminate many of the existing problems in designating surrogate decisionmakers. Even without such legislation, however, agencies, case managers, and others that arrange services for people with dementia have to turn to someone for surrogate decisions for decisionally incapable clients. Furthermore, it is likely that regardless of the specificity of State legislation, the designation of appropriate surrogate decisionmakers for people with dementia will entail difficult judgments in some and perhaps many cases because of the idiosyncrasies of each patient's situation.

Likewise, although it is generally agreed that patient autonomy and patient well-being are the values that should guide surrogate decisions, the two values often imply different decisions in the same situation, and neither value is appropriate for every situation. Applying the two values in decisions about the use of services for an individual client therefore entails difficult judgments in many cases. Balancing the needs, preferences, and interests of an individual with dementia and the needs, preferences, and interests of the individual's family also requires difficult judgments.

The need for these difficult judgments suggests that agencies that arrange services for people with

dementia should have explicit policies and procedures for designating surrogate decisionmakers and making decisions about services for people with dementia who have no surrogate decisionmaker. It is reasonable to believe that case managers and others who are involved in arranging services for people with dementia would benefit from training about the issues involved in surrogate decisionmaking. To the extent that case managers and others who arrange services for people with dementia actually designate surrogate decisionmakers and/or make decisions about services for their decisionally incapable clients, their need for such training is increased.

If Congress mandated a national system to link people with dementia to services, Congress could require the agencies that were designated to constitute the system to have explicit policies and procedures for designating surrogate decisionmakers (written to comply with existing State laws if there are relevant laws) and for making surrogate decisions in instances where the agency had to make surrogate decisions for any reason. To formulate such policies and procedures, the agencies that constitute the linking system would have to address many of the unresolved questions discussed in this chapter, including questions about what to do when a decisionally incapable client's relatives disagree about which one of them should make the necessary decisions, how nonfamily caregivers should be involved in decisions about services, and when formal guardianship is needed for a client.

To support agencies' efforts to develop policies and procedures for designating surrogate decisionmakers and for making decisions for decisionally incapable clients who have no surrogate, more research and analysis pertaining to many of the questions discussed in the preceding sections is needed. Especially problematic is the question of how to balance the needs, preferences, and interests of an individual with dementia and the needs, preferences, and interests of the individual's family or other informal caregiver. Perhaps it would be useful for government, private agencies that arrange services for people with dementia, and professional associations that represent social workers, nurses, and other professionals who function as case managers to jointly sponsor forums for further discussion of this and related issues.

CONCLUSION

Questions about how to determine the decision-making capacity of people with dementia and how to make surrogate decisions about services for people who lack the capacity to make such decisions themselves are inherent in the process of arranging services for people with dementia. The way such questions are answered involves fundamental legal rights of the patient and raises complex legal and ethical issues. Those rights and issues are at stake regardless of whether the individuals who make or participate in the decisions are aware of them.

In many agencies that arrange services for people with dementia, questions about the methods used to evaluate clients' decisionmaking capacity and to make surrogate decisions about services for clients who cannot make such decisions themselves are obscured by other problems and concerns and by the severe constraints on the time within which decisions about services must be made. In such agencies, concerns about clients' legal rights, and about the legal and ethical issues involved in the way decisions about services are made for people with diminished decisionmaking capacity seem to be second-level concerns to be considered when other problems have been solved.

This chapter has suggested that if Congress mandated a national system to link people with dementia to services, Congress could require that any agency that is part of the system have explicit

policies that delineate the procedures to be followed when decisions about services are needed for clients with diminished decisionmaking capacity. Policies that specify procedures for determining a client's decisionmaking capacity and/or assign responsibility for determining a client's decisionmaking capacity to a person or group of people could help increase the likelihood that clients' rights and the legal and ethical issues involved in decisionmaking are adequately considered.

The chapter has discussed some concepts, distinctions, and approaches that may be useful in developing such agency policies and procedures and in training case managers and others who are involved in arranging services for people with dementia. As noted repeatedly, many of the concepts, distinctions, and approaches that have been discussed were derived from analysis and debate about the use of life-sustaining medical treatments or participation in research, not the kinds of decisions that are the topic of this OTA report. Furthermore, some of the concepts, distinctions, and approaches discussed in the chapter apply more to decisionmaking by and for mentally ill and terminally ill people than to decisionmaking by and for people with dementia. To address the difficult questions and issues that are likely to arise in situations involving decisions about the many kinds of services to which an effective linking system could link people with dementia, further research, discussion, analysis, and debate is needed.