
Decisionmaking Incapacity

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This Report deals primarily with decisionmaking about health care when patients possess the capacity to make their own decisions. Since adults typically are able to decide among most medical alternatives most of the time—a fact reflected in the legal presumption of competence—treatment decisions are usually made with little if any attention to whether or not a patient is incapacitated. When the patient is not incapacitated, there are no signals to raise the issue, which is as it should be. Although data do not exist about the prevalence of decisional incapacity, there is reason to believe that the problem is quite small. Yet when the issue does arise it can greatly complicate decisionmaking, especially when the consequences of a decision are significant.

In the final Part of this Report, the Commission turns briefly to a number of important issues raised by the problem of decisional incapacity: Who is incapacitated? What principles should govern decisionmaking or incapacitated patients? Who should make decisions for incapacitated patients? And what review of such decisions is necessary and appropriate?

Who Is Incapacitated and How Is It To Be Determined?

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One of the conditions for health care decisionmaking is the capacity to make such decisions, as described in Chapter Three. The components of decisional capacity were delineated there as possession of a set of values and goals, the ability to communicate and understand information, and the ability to reason and deliberate. This Chapter goes beyond that conceptual framework to discuss more fully three aspects of incapacity: the identification of those who are incapacitated,¹ the means for making such assessments, and the relationship between professionals, institutions, and the state in this process.

Identification of Incapacity

In light of the presumption that most patients have the capacity to make health care decisions, on what grounds might a person be found to lack such a capacity? Three general criteria have been followed: the outcome of the decision, the status or category of the patient, and the patient's functional ability as a decisionmaker.

¹ The terms "incapacity" and "incapacitated" as used in this Report are shorthand labels for patients who lack the capacity to make a particular health care decision, as described in Chapter Three. These terms are not synonymous with either mental or physical incapacity. Though decisional incapacity ordinarily results from mental or physical infirmity, all persons with such infirmities are not *ipso facto* "incapacitated" as that term is used here.

The outcome approach—which the Commission expressly rejects²—bases a determination of incapacity primarily on the content of a patient's decision. Under this standard, a patient who makes a health care decision that reflects values not widely held or that rejects conventional wisdom about proper health care is found to be incapacitated.

Using the status approach, certain categories of patients have traditionally been deemed incapable of making treatment decisions without regard to their actual capabilities.³ Some of these categories of patients—such as the unconscious—correspond closely with actual incapacity. But other patients who are presumed to be incapacitated on the basis of their status may actually be capable of making particular health care decisions. Many older children, for example, can make at least some health care decisions,⁴ mildly or moderately retarded individuals hold understandable preferences about health care, and the same may be true in varying degrees among psychotic persons.

The third approach to the determination of incapacity focuses on an individual's actual functioning in decisionmaking situations rather than on the individual's status. This approach is particularly germane for children above a certain age (variously described as from seven to mid-teens).⁵ For example, rather than considering children under the age of majority incompetent to decide unless they come within one of the exceptions created by the statutory and common law, these patients could be regarded as competent unless shown to lack decisionmaking capacity.⁶ Similarly, a senile person may have

² See p. 61 *supra*.

³ See Loren H. Roth, Alan Meisel, and Charles W. Lidz, *Tests of Competency to Consent to Treatment*, 134 AM. J. PSYCHIATRY 279 (1977).

⁴ See Lois A. Weithorn and Susan B. Campbell, *The Competency of Children and Adolescents to Make Informed Treatment Decisions*, 53 CHILD DEVELOPMENT (in press); Sanford L. Leiken, *Minors' Assent or Dissent to Medical Treatment* (1982), Appendix K, in Volume Three of this Report; Barbara Mishkin, *The Report and Recommendations of the National Commission for the Protection of Human Subjects: Research Involving Children*, 1 ADVANCES IN LAW & CHILD DEVELOPMENT 63, 76 (1982).

⁵ Weithorn and Campbell, *supra* note 4. See also Thomas Grisso, JUVENILES' WAIVER OF RIGHTS—LEGAL AND PSYCHOLOGICAL COMPETENCE, Plenum Press, New York (1981).

⁶ Law has traditionally viewed people under a specified age—long set at 21 years and more recently at 18—as precluded from making decisions about any contractual matters, including their own health care. In effect, there has been a presumption of *incompetency*, contrary to the usual presumption of competency accorded adults. Some exceptions of a loosely functional nature have been created for “emancipated” or “mature” minors, in recognition that some children under some circumstances in fact have the capacity to make health

been declared incompetent by a court and a guardian may have been appointed to manage the person's financial affairs, but the functional standard would not foreclose the need to determine whether the senility also negated the individual's capacity to make health care decisions. What is relevant is whether someone is in fact capable of making a particular decision as judged by the consistency between the person's choice and that individual's underlying values and by the extent to which the choice promotes the individual's well-being as he or she sees it.

The Commission recommends that determinations of incapacity be guided largely by the functional approach, that individuals not in certain basic categories (such as under the age of 14, grossly retarded, or comatose) should be assumed to possess decisionmaking capacity until they demonstrate otherwise, and that incapacity should be found to exist only when people lack the ability to make decisions that promote their well-being in conformity with their own previously expressed values and preferences.⁷ The fact that a patient belongs to a category of people who are often unable to make general

care decisions and that for reasons of social policy such decisions ought to be sufficient. This system, based .on a general rule of incompetence with an ever-expanding number of statutory exceptions, has meant that children are more often presumed competent to make health care decisions, or has at least brought about an implicit lowering of the age of presumed incompetence. See A. M. Capron, *The Competence of Children as Self-Deciders in Biomedical Interventions*, in Willard Gaylin and Ruth Macklin, eds., WHO SPEAKS FOR THE CHILD, Plenum Press, New York (1982) at 57-114.

The Commission endorses this general trend, recognizing that there is an age, below about 14 years old, at which the traditional presumption of incompetence still ought to govern. The presumption, however, is merely a starting point for inquiry. Even when children lack the capacity to make decisions, their involvement in the decisionmaking process not only acknowledges their individual status but also may enhance their cooperation in and compliance with therapeutic procedures. The variations in children's capabilities could appropriately be recognized by providing that for certain interventions, a practitioner should obtain both the *consent* of a child's legal guardian and the *assent* of the child. The latter would be insufficient by itself to authorize the intervention, but the intervention could not go ahead without it. Cf. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, REPORT AND RECOMMENDATIONS: RESEARCH INVOLVING CHILDREN, Government Printing Office, Washington (1977) at 5-19.

⁷ When efforts to communicate with a patient and learn his or her preferences would jeopardize the patient's well-being because of an urgent need for treatment, it is appropriate for health care providers to treat the patient as incapacitated and to turn to a surrogate decisionmaker or, when none is available, to care for the patient without consent, as permitted by the "emergency" exception. See generally

decisions for their own well-being or that an individual makes a highly idiosyncratic decision should alert health care professionals to the greater possibility of decisional incapacity. But it does not conclusively resolve the matter.

Rarely—again, the unconscious patient is the main exception—will incapacity be absolute. Even people with impaired capacity usually still possess some ability to comprehend, to communicate, and to form and express a preference. In such cases, even when ultimate decisional authority is not left with a patient, reasonable efforts should be made to give the person relevant information about the situation and the available options and to solicit and accommodate his or her preferences.

Assessments of Incapacity

The objective of any assessment of decisional incapacity is to diminish errors of mistakenly preventing competent persons from directing the course of their own treatment or of failing to protect the incapacitated from the harmful effects of their decisions. Health care professionals will probably play a substantial role, if not the entire one, in the initial assessment and the finding may never be reviewed by outside authorities. Nonetheless, since assessment of an individual's capacity is largely a matter of common sense, there is no inherent reason why a health care professional must play this role.

“Decisionmaking incapacity” is not a medical or a psychiatric diagnostic category; it rests on a judgment of the type that an informed layperson might make—that a patient lacks the ability to understand a situation and to make a choice in light of that understanding. Indeed, if a dispute arises or a legal determination of a patient’s competence is required, the judge empowered to make the determination will consider the situation not as a medical expert but as a layperson. On the basis of the testimony of health care personnel and others who know the individual well, and possibly from personal observation of the patient, the judge must decide whether the patient is capable of making informed decisions that adequately protect his or her own interests.

Health care professionals are called upon to make these assessments because the question of incapacity to make health care decisions usually arises while a person is under their care. Particularly within institutions such as hospitals, a treating physician often involves colleagues from psychiatry, psychology, and neurology who have ways to accumulate, organize, and analyze information relevant to such assessments.⁸ These

Alan Meisel, *The “Exceptions” to the Informed Consent Doctrine: Striking a Balance Between Competing Values in Medical Decisionmaking*, 1979 WIS. L. REV. 413, 436, 476.

⁸ The “mental status examination” is perhaps the best example of how

examinations can yield considerable information about the patient's capabilities. The sources of useful information to be collected include discussions of the situation with relatives and other care-givers, particularly those in close contact with the patient, such as nurses. Ultimately, whether a patient's capabilities are sufficiently limited and the inadequacies sufficiently extensive for the person to be considered incapacitated is a matter for careful judgment in light of the demands of the situation. If the patient improves (or worsens) or if the decision to be made has different consequences, a reassessment of the individual's capacity may be required.

Finally, in any assessment of capacity due care should be paid to the reasons for a particular patient's impaired capacity, not because the reasons play any role in determining whether the patient's judgment is to be honored but because identification of the causes of incapacity may assist in their remedy or removal.⁹ The Commission urges that those responsible for assessing capacity not be content with providing an answer to the question of whether or not a particular patient is incapacitated. Rather, in conjunction with the patient's health care team (of which the assessor may be a member), they should to the extent feasible attempt to remove barriers to decisional capacity.

Policies and Procedures

It is important for the sake of consistency and accuracy—and even more so for the protection of the right to self-determination in the pursuit of well-being—that health care professionals and institutions develop clear policies to assess incompetency. Such policies should acknowledge who within an institution has initial and ultimate responsibility for making such determinations and should, at least in a general way, instruct those who assess capacity about the kinds of inquiries to make, data to collect, and records to keep.

professional expertise can be enlisted in making assessments of incapacity. Such an evaluation is intended, among other things, to elicit the patient's orientation to person, place, time, and situation, the patient's mood and affect, and the content of thought and perception, with an eye to any delusions and hallucinations; to assess intellectual capacity, that is, the patient's ability to comprehend abstract ideas and to make a reasoned judgment based on that ability; to review past history for evidence of any psychiatric disturbance that might affect the patient's current judgment; and to test the patient's recent and remote memory and logical sequencing.

⁹ See Paul S. Appelbaum and Loren H. Roth, *Clinical Issues in the Assessment of Competency*, 138 AM. J. PSYCHIATRY 1462 (1981); Loren H. Roth *et al.*, *The Dilemma of Denial in the Assessment of Competency to Refuse Treatment*, 139 AM. J. PSYCHIATRY 910 (1982).

Patient capacity for decisionmaking will usually be called into question first by attending health care personnel or possibly (though less likely) by the family. Although formal legal procedures exist for determining incompetency, usually such determinations are made extrajudicially; only occasionally are they subsequently subjected to judicial review.¹⁰ The status of nonjudicial determinations of incapacity is therefore uncertain, though there is a growing trend toward requiring formal, judicial proceedings in certain nonroutine situations, such as the termination of life-sustaining treatment¹¹ or the administration of irreversible procedures (for example, sterilization).¹²

¹⁰ The problem of who is to make health care decisions when patients are incapacitated is one that has been the subject of only scant judicial analysis. Evidently this has been recognized for quite some time. At the turn of the century, one legal treatise writer noted that “where an operation is to be performed upon...[a] person *non compos mentis*, who is to give consent is not decided.” Edgar Benton Kinkead, *COMMENTARIES ON THE LAW OF TORTS: A PHILOSOPHIC DISCUSSION OF THE GENERAL PRINCIPLES UNDERLYING CIVIL WRONGS EX DELICTO*, Bancroft Whitney Co., San Francisco (1903) § 376 at 789. One of the leading informed consent cases gives the subject very short shrift: “Where the complaint in suit is unauthorized treatment of a patient legally or factually incapable of giving consent, the established rule is that, absent an emergency, the physician must obtain the necessary authority from a relative.” *Canterbury v. Spence*, 464 F.2d 772, 789 n.92 (D.C.Cir. 1972).

The procedure to be followed in making treatment decisions for incapacitated patients has been appropriately characterized as “haphazard.” See Charles P. Kindregan, *The Court as Forum for Life and Death Decisions: Reflections on Procedures for Substituted Consent*, 11 SUFFOLK U. L. REV. 919, 924 (1977). Rather than comprehensive judicial analysis, there is a conflicting collection of platitudes that fails to address many of the issues that are involved. See, e.g., *Lester v. Aetna Cas. & Sur. Co.*, 240 F.2d 676 (5th Cir. 1957); *Karp v. Cooley*, 493 F.2d 408 (5th Cir. 1974). About the only generalization that can be made is found in the treatises suggesting that the proper practice when the patient cannot give consent is for a close family member to do so if one is available. See, e.g., 2 HOSPITAL LAW MANUAL, *Consents* (1975) paragraph 4-12, at 58; Joseph H. King Jr., *THE LAW OF MEDICAL MALPRACTICE IN A NUTSHELL*, West Publishing Co., St. Paul, Minn. (1977) at 140; Note, 14 CIN. L. REV. 161, 170-72 (1940). The practice of obtaining consent from family members “is so well known in society at large that any individual who finds the prospect particularly odious has ample warning to make other arrangements better suited to protecting his own ends or interests.” A. M. Capron, *Informed Consent to Catastrophic Disease Treatment and Research*, 123 U. PA. L. REV. 340, 424-25 (1974).

¹¹ See the Commission’s forthcoming Report on decisions about life-sustaining treatment.

¹² 44 TENN. L. REV. 879 (1977); 17 NEW ENG. L. REV. 527 (1981-82).

The Commission believes that determinations of incapacity are best made without routine recourse to the courts. Although there is a loose parallel between the criteria for judicial determinations of incompetence and the determination of decisional incapacity, the judicial processes leading to the appointment of a guardian or conservator ordinarily address an individual's incapacity to manage property and financial matters. As a result, guardians are often, though not always, financial institutions or institutional employees such as bankers, who are either ill-suited to or uninterested in the task of managing an individual's personal affairs.

Furthermore, resorting to the courts to adjudicate incompetency—that is, to confirm the patient's lack of decisional capacity—is often so burdensome to both providers and patients or to their families that there is a tremendous reluctance to undertake it. Even when an adjudication of incompetency is sought, the proceedings are in many cases so perfunctory and/or deferential to the professional expertise of providers that the role of the courts amounts to little more than pro forma ratification of what was readily apparent to health professionals. Thus the Commission recommends that, except where state law clearly requires judicial intervention, determinations of decisional incapacity be made at the institutional level and that lawmakers be encouraged to recognize the validity of such determinations. This recognition will require institutions to adopt procedures that merit such deference; in turn, it should reinforce for all participants in the process the importance of reaching a sound decision.

