



Guidelines for the Determination of Decisional Incapacity

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by the Ethics Committee Consortium of the Center for Practical Bioethics

I. Introduction

An autonomous person is capable of making decisions in relation to self-interests. The principle of respect for the autonomy of persons is central to clinical ethics. Among the rules of ethical conduct, which derive from autonomy, are respect for self-determination, shared decision making, informed consent, truth-telling, and confidentiality. Healthcare professionals ought to endorse these rules and accept the patient as an equal partner in making decisions.

The ideal of shared decision making in healthcare requires a decisionally capable provider with personal beliefs and preferences to negotiate an agreement with a decisionally capable patient holding personal beliefs and preferences. This interaction depends on the open sharing of information through good communication. It is difficult to achieve in the best of relationships and settings, and multiple additional problems arise in a clinical crisis.

Although there are good ethical reasons for the strong assumption that all adults have decisional capacity, healthcare providers must be alert to clues that the patient's decisional capacity may be limited — clues of decisional incapacity. Thus the burden is on the provider to demonstrate a patient's decisional *incapacity* in order to justify the conclusion that an individual has lost self-determination.

There is general agreement that some persons have completely and permanently lost all capacity to participate in healthcare decisions (i.e., those in a persistent vegetative state or end-stage dementia). However, many clinical situations require a careful evaluation of the patient's diminished or intermittent capacity. There is a wide divergence

of opinion as to how much the cognitive and emotive abilities of an adult must be diminished before one can conclude that the adult is decisionally incapable. There are no agreed upon objective standards for measuring the degree of diminished cognitive and emotive abilities. The determination of decisional incapacity is a difficult judgment to make because of its subjective quality, particularly in those instances in which capacity is only slightly or intermittently diminished.

At all levels, healthcare providers have received inadequate training and monitoring in the practice of determining decisional incapacity. Those techniques that have been used traditionally to determine decisional incapacity, such as the minimal status exam or consulting a psychiatrist, are not always adequate to address the subtle complexity of this clinical determination in a critical and open process. There is evidence that the determination of decisional incapacity tends to be made by clinicians without a full appreciation for the possible errors in judgment that may be made in reaching conclusions about incapacity. This document recommends that the healthcare provider who has an ongoing relationship with and historical knowledge of the patient should be the determiner of decisional incapacity. To improve performance of this determination, healthcare providers must be trained to be more self-critical and more open to the patient's perspective.

The central purpose of this guidelines document is to remind healthcare providers of the need to exercise critical reflection of the highest degree in the complex clinical practice of determining decisional incapacity. Further, the document recommends that healthcare providers be particularly open to the subjective aspects of their determination of decisional incapacity. A critical

open process is proposed which facilitates a careful and in-depth evaluation of the multiple factors that interact in decisional capacity and the achievement of an acceptable conclusion.

This document does not provide complete and final answers to the question of how to determine decisional incapacity. It is our hope that it will be used as a tool to stimulate and guide discussion of this topic in healthcare institutions and among healthcare professionals.

II. Project Goal

To enhance respect for the autonomy of persons these guidelines recommend that healthcare providers use a critical open process in determining the decisional incapacity of adults in the clinical setting.

These guidelines promote the respect of patient autonomy in the following ways:

- A. Assuming decisional capacity in adults while recognizing a spectrum of developing, partial, complete, fluctuating, and diminishing decisional capacities;

Assumptions about decisional capacity and the determination of decisional incapacity are an essential foundation for creating an open critical process.

- B. Recognizing and employing ways to enhance decisional capacity;
- C. Appreciating the complex and subjective nature of the process of determining decisional incapacity; and
- D. Developing a critical open process model that can ameliorate the uncertainty of judgment and thus guide the determination of decisional incapacity in the clinical setting.

III. Assumptions

Assumptions about decisional capacity and the determination of decisional incapacity are an essential foundation for creating an open critical process. These assumptions were selected for their importance to the process.

- A. Healthcare providers have an obligation to respect the autonomy of persons by assuming they have decisional capacity.
- B. The essential elements of decisional capacity are as follows:
 - 1. The ability to communicate choices,
 - 2. The cognitive process of understanding information relevant to the decision, and
 - 3. The ability to make choices consistent with personal values.
- C. While assuming decisional capacity, healthcare providers should be attentive to clues of decisional incapacity. However, disagreement with the healthcare provider's recommendation is not in itself a clue to diminished capacity.
- D. Persons diagnosed as having a mental illness, physical disability, or those who have been adjudicated incompetent should be assumed to have decisional capacity until good reasons are evident to doubt decisional capacity.
- E. Decisional capacity is task specific, that is, a person has or lacks capacity for a particular decision at a particular time and under a particular set of circumstances.
- F. Determination of decisional incapacity is not based on fixed objective standards, but on the careful judgment of those who best know the person.
- G. Decisional capacity may fluctuate; therefore:
 - 1. Attention must be given to enhancing capacity before reaching a determination of incapacity.

2. The factors that diminish decisional capacity may include physiological dysfunction, psychological disorders, and medication effects.
 3. Evaluations for decisional capacity must be repeated over time and in varying circumstances to reach a confident conclusion.
- H. The provider's need to trust a person's decisional capacity tends to increase with the severity of the potential consequences of the decision.
- I. The fact that persons hold idiosyncratic or unusual beliefs or values does not invalidate decisional capacity.
- J. Persons may, however, have irrational goals, beliefs, or values that are so extreme as to invalidate their decisional capacity.
- K. The assessment of a person's cognitive and emotive processes and their interaction is important for the determination of decisional incapacity.
- L. The determination of decisional incapacity may be described as an "art form" or a "clarifying conversation." A clarifying conversation involves a balanced assessment of both cognitive and emotive processes and an estimate of the coherence of the self-structure as expressed in the person's own story.
- M. There are selected clinical situations (e.g., traumatic head injury) in which cognitive neuropsychological testing may be the primary means of determining decisional incapacity.

IV. Critical Open Process of Determining Decisional Incapacity

In most clinical situations, shared decision making can proceed on the assumption of the patient's decisional capacity. The following process can be used when the patient's decisional capacity is

questionable. This process is more an artful conversation on the quality of the dialogic relationship and a values-sensitive perspective than an objective measure of specific cognitive abilities.

A. Assume decisional capacity in all.

Approach all patients with respect and attention to the communication process, assuming that they are fully capable of making their own healthcare decisions. Be especially attuned to language or sensory deficits or differences that may interfere with communication.

B. Identify yourself and your role.

To assume decisional capacity in all patients requires that you treat them with dignity as full partners in the conversation. If you are intending to determine decisional incapacity, you should openly state your intention.

C. Listen carefully to the patient's story for confirmation that the patient is making choices consistent with his or her personal values.

Listen for any of the following clues to capacity:

1. Preferences, values, and beliefs that are congruent with the patient's life story.
2. Preferences, values, and beliefs that would be plausible or possible from any frame of reference. Providers must be careful not to impose their frame of reference as the standard of what is plausible. It is helpful to ask whether any "plausible person" could make this judgment.
3. Coherence, congruence, or consistency over time and in different circumstances while allowing for appropriate ambivalence.
4. Expressions of a sense of humor.
5. The ability to ask relevant questions.
6. Evidence of self-reflection.

- 7. The ability to express meaning.
- 8. The ability to express concern.
- 9. Evidence of appropriate affect.

D. Recognize that decision making is a synthesis of cognitive and emotive acts and processes.

Both cognitive and emotional processes and their interaction need to be considered. Mood and emotions are important indicators of a person's ability to express value and meaning. Functioning on a "feeling" level does not invalidate decisions.

E. Ask yourself the central question: "Is the patient able, in his or her own terms or frame of reference, to share an understanding of the clinical issues involved in this decision?"

Evaluating the answer to this central question is at the core of determining decisional incapacity, and the provider should return to it frequently as a check on the openness of the process. This question requires that the conversation be framed in terms that are intentionally accommodating to the patient's perspective.

F. Offer the patient the option of having assistance or an advocate and an opportunity to challenge the determination or to refuse to participate in the process.

There may be situations in which a patient's decisional capacity might be improved by assistance from another person. For example, if a patient has usually functioned in partnership with another, it may be appropriate for the partner to be included in the conversation. If a patient objects to the conclusion reached in a determination, there should be a process by which to challenge the conclusion and ask for another opinion. There is no consensus on the question of seeking consent to do a determination of decisional incapacity.

However, if a patient consistently and persistently refuses to cooperate in the process, the determination cannot be done. A surrogate decision maker may be required.

G. Do everything possible to enhance decisional capacity.

The person determining decisional incapacity should maximize the patient's ability to participate in this decision. This process will take time, sensitivity, patience, and persistence. In order to enhance decisional capacity, the provider should:

1. Identify times and environmental conditions that enhance capacity.
2. Ameliorate the effects of
 - medication,
 - psychological stress factors,
 - physiological stress factors (e.g., oxygen desaturation, inadequate blood pressure, severe pain), and

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- hearing, vision, and speech deficits.

H. Be especially alert for clues of decisional incapacity in the following clinical situations:

1. extended ICU stay,
2. postoperative state,
3. medication effects,
4. illness with central nervous system effects,
5. persistent, distracting pain, and/or
6. loss, grief, or devastating news.

I. Do everything possible to enhance the patient's ability to participate in the determination process; for example,

1. plan to take adequate time,
2. prepare to be empathic,
3. recruit the person best able to conduct the determination process,
4. determine whether or not a translator is needed, and
5. determine whether or not the patient needs a support person.

J. Identify the behavioral clues suggesting that the patient may not have decisional capacity.

At various points in a conversation you may begin to suspect that the patient does not understand the relevant clinical information. Patient behaviors that may raise doubts about one's decisional capacity include the following:

1. Patient does not appear to understand the provider's analysis of the clinical situation.
2. Patient does not engage in conversational give and take or ignores the provider (closes eyes or turns away).
3. Patient's affect is inappropriate.
4. Patient makes statements that appear to be irrational, incoherent, or delusional.
5. Patient makes contradictory statements.

K. Do everything possible to minimize provider bias in interpreting clues about decisional incapacity.

Do a sensitive reassessment to ensure that these clues are not the result of provider bias. The questionable responses may be based on some language, culture, gender, age, class, or educational differences, or other set of values or beliefs that may be

meaningful to the patient, but may not be meaningful (or may have a different meaning) to the provider. Be prepared to recognize your own value judgments, biases, and prejudices.

L. Providers making the determination ought to check their concerns about the patient's decisional capacity with others who are knowledgeable about the patient.

Inquire of diverse members of the healthcare team, family members, and friends of the patient and when possible check concerns with a peer of the patient (e.g., someone of the same race, age, gender, culture, or economic class) to minimize imposing your values on the patient.

M. Openly share your concerns with the patient about his or her decisional capacity.

If it appears capacity is very questionable, openly share your concerns with the patient. An example of sharing is: "What we've talked about thus far suggests to me that you don't completely understand what is happening and that you can't make this decision all by yourself. What can you tell me that would help me to understand your point of view?"

N. Document your conclusion by referring to your justification for the determination.

Documentation should reveal the salient content of the determination process. What ultimately persuaded you that this patient does or does not have capacity for this decision at this time under these circumstances? Be specific. Use the patient's language when possible.

O. If you feel unable to reach a justifiable determination about decisional incapacity, continue to assume decisional capacity and consider calling in a consultant to assist with the determination.

Although it is desirable for those who know the patient best to complete the deter-

mination of decisional incapacity, there are instances in which a conclusion cannot be confidently made. In such instances, other members of the healthcare team can provide another perspective. There is little or no evidence that a specialist who has no history of knowing the patient can make a determination of decisional incapacity with any more validity than a provider of the healthcare team who is familiar with the patient.

P. Determine the patient's capacity to designate a surrogate.

In instances where the determination of the patient's decisional capacity is uncertain, consider whether or not the patient is at least capable of designating a surrogate decision maker. Selecting the appropriate surrogate may require a lesser degree of decisional capacity than clinical decision making.

Q. Solicit assent.

Despite full use of this process, there may be instances in which decisional capacity is determined to be inadequate for informed consent. In those cases of incomplete capacity, it may be appropriate

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to obtain the *assent* of the patient. Assent is the free, uncoerced expression of a patient's willingness to undergo a specific healthcare treatment based on the patient's level of knowledge and understanding. In addition to the patient's assent, to satisfy legal requirements, a surrogate should be asked to consent.

V. Sample Cases Illustrating Issues in Determining Decisional Incapacity

A. Case of the Woman Unwilling to Consent to Surgery

A fifty-one-year-old woman was found unresponsive at home by police after the mail carrier reported that mail had not been picked up for seven days. The patient appeared to have been on the floor for several days. She was admitted with severe dehydration, sepsis, respiratory failure, and encephalopathy of unknown origin.

The patient has no relatives in this area. An estranged daughter and son live in California. Siblings living in another city filed for guardianship, and the County Public Administrator was appointed legal guardian. Over the following three weeks, several surgeries and procedures were completed with consent of the guardian.

Six weeks later the patient was weaned from the ventilator. There were times when the patient had a "wild look in her eyes." She communicated little except to express her wish to die. After being transferred to a skilled nursing facility, she began to communicate with a social worker who had gained her confidence.

A plastic surgeon requested permission to close an extensive sacral decubitus ulcer. A case worker with the Public Administrator's office gave permission and the surgery was scheduled. The patient was told by the nursing staff about the planned surgery. She spoke with the social worker and vigorously protested the surgery stating that she was afraid that she would die during the procedure. The surgery was cancelled by the surgeon. After a week of conversation, the patient continued to refuse the surgery while at the same time the surgeon and guardian agreed that the surgery was necessary to heal the decubitus ulcer. The surgeon and

guardian planned to sedate the patient before surgery and complete the procedure without her consent.

The social worker became an advocate for the patient and raised a question about doing the surgery against the patient's wishes. The Public Administrator personally interviewed the patient and agreed that the patient had a "better grasp of her surroundings and should be heard with regard to her wishes."

The surgeon decided to take pictures of the sacral decubitus as a way to persuade the patient to consent to surgery. Despite the attempts at persuasion, the patient continued to refuse to have surgery. □

B. Case of the Man Who Accepted the Risk of Heart Disease

A fifty-year-old widower had been flown by emergency helicopter from a rural hospital to a city hospital with a diagnosis of "myocardial infarction in process." In the emergency department, he presented with an abnormally irritable mood, pressured speech, flight of ideas, and made rambling references to multiple activities he needed to attend to. His cardiac condition was thought to be life threatening. Therefore, he was sedated and moved to the Intensive Care Unit.

Psychiatric evaluation and history of previous psychiatric hospitalization (supplied by an uncle) supported the diagnosis of Bipolar Disorder with Manic Episode. The psychiatric team assessed the patient daily, provided supportive psychotherapy, and collaborated with other healthcare providers to determine whether or not the patient had decisional capacity.

Of particular concern was the patient's daily demand to leave the hospital, which he based on his belief that "there is nothing

wrong with my heart." He insisted that he needed to pursue his various activities. Some improvement of his mood occurred during the five days of his hospitalization, and he did consent to noninvasive heart studies. On the sixth day, the patient was presented with the cardiology team's conclusion that he had sustained an inferior myocardial infarction and that there was high risk of extension of the infarction as a result of residual ischemia. Angioplasty was recommended immediately.

The patient had been refusing psychotropic medication during the past twenty-four hours calling them "knockout pills," and the irritable and aggressive mood returned. He refused cardiac treatment and demanded to leave. At this point, the psychiatric team was asked to make a determination of the patient's decisional capacity.

What follows is a summary of the conversation between the patient and clinical nurse specialist (CNS) from the psychiatric team.

CNS — "JR, I'm here now because your cardiologist has asked me to let him know if you're capable of making the decision to leave against medical advice. The psychiatrist and I think . . ."

JR — "Yes, I know that psychiatrist, and he's a nice fellow and all, but he and I are going to part ways."

CNS — "Like we've told you before, we think you need treatment for a psychiatric problem which at times interferes with your ability to make decisions and to run your life in a way that doesn't get you hurt."

JR — (slamming a glass of water down on the bedside table and yelling), "There is nothing wrong with my mind, and there is nothing wrong with my heart."

CNS — “JR, it is understandable that you’re upset, but I need you to control yourself and to demonstrate to me that you are making the decision to leave with a sound mind. We would like you to stay here and have the necessary treatment for your heart and psychiatric problem. If it’s not clear you understand the risks you are taking by leaving, then I will need to petition the court for you to be treated against your will.”

JR — (becoming noticeably calmer and demonstrating to the CNS his ability to control his behavior) “We had a deal — I took the tests but I was leaving today no matter what. Do you have any idea how much antiques are worth? Well, I have some that would knock your socks off. I’ve already wasted all this time here. If I don’t get my stuff out pretty soon, I’m going to be on the street. You know how landlords are. He wants to rent to a relative so he’s kicking me out.”

CNS — “JR, I have a hunch part of you believes you have a heart problem. What does that part of you think about the risk the cardiologist says you’ll be taking if you leave now?”

JR — (beginning to cry, which the CNS interprets as an appropriate response for someone struggling with the decision he had been asked to make)

“I’ve taken risks before.”

Conclusion of the CNS. “I believed that he had taken risks before and that he knew he was taking a risk now. He had ‘enough’ insight and judgment.” □

C. Case of the Unpersuaded Patient

RW is a seventy-four-year-old male who suffered a stroke four years ago involving the right cerebral hemisphere. He has left hemiparesis, speaks clearly, and is fully

oriented. During the three years that he has been in the nursing home, he has been conversant, shows judgment, and expresses his own decisional capacity. The one area of psychological distortion is his frequent imaginary accounts of his wife’s unfaithfulness. Depression with paranoid features caused him to be hospitalized eighteen months ago in a psychiatric facility for two weeks. One year ago, he was hospitalized for pneumonia and congestive heart failure with good recovery.

On this occasion, pneumonia has again made hospitalization necessary. On the third day, a repeat chest x-ray showed complete opacification of the left hemithorax. This was a marked change from the localized left lower lobe infiltrate seen on the first day. The likelihood of left main stem bronchial mucus plugging made it reasonable to ask for a therapeutic bronchoscopy to remove the probable plug and restore ventilation to the left lung.

RW had been less communicative than usual during this hospitalization. He spoke in short phrases and after much prompting and waiting for a response. He refused consent on the grounds that he knew that his pneumonia was caused by “gold dust in the room.” Furthermore, since his previous pneumonia was cured by medication, he believed this episode would resolve without a bronchoscopy. Neither his wife nor the physician could persuade him to the point of view of consenting to the bronchoscopy.

His wife raised the issue of decisional incapacity by saying that “he is not right in his mind.” The physician began a process of determining decisional incapacity. The physician had made a special effort throughout his relationship to RW to give him attention and assume his capacity to make decisions, in spite of his somewhat flawed interpretation of some elements of his life situation (i.e., his wife’s unfaith-

fulness). He was asked about his belief about the cause of his pneumonia. He was consistent in his belief that the gold dust caused it and that the best way to treat his pneumonia was to counteract that dust.

RW never did agree that he might be afraid of the bronchoscopy procedure, but insisted that he simply did not need it. While the patient indicated he trusted the physician, he turned the conversation around and protested that the physician didn't trust him to know about the dust. He controlled the conversation by intermittent silence and refusal to respond.

At the time of the determination, he was on oxygen and his oxygen saturation was above 90 percent. He was taking Ativan 1 mgm q. eight hours as he had been for several months. The conversations were held in a private room, on two occasions, and lasted ten minutes each time.

As a result of the physician's ambivalence about the determination of decisional incapacity, a psychiatric consultation was requested. The psychiatrist, who also serves on the hospital ethics committee, was uncertain about decisional capacity but favored a determination of incapacity. An experienced intensive care nurse, also from the hospital ethics committee, was confident that RW had decisional capacity.

The impasse regarding consent led to a delay of five days. During this period, the chest x-ray progressively improved, and the patient became stronger and more expressive. He left the hospital with the pneumonia resolved. He died abruptly at the nursing home two months later while eating his noon meal. □

D. The Case of the Patient Who Said "No" to a Gastric Tube

IR was an eighty-four-year-old woman with a history of dementia, congestive heart failure, and cardiac arrhythmia. She had several hospital admissions for noncompliance with medications and malnutrition. She was able to swallow but did not eat enough to maintain minimal weight. In her apartment, she was said to drink coffee spiked with alcohol all day long. Arrangements were made for the surgical placement of a gastrostomy tube with the consent of the patient's court-appointed temporary guardian.

When the patient was taken to the operating room, she sat up on the table and said, "You're not going to put any tube in me!" The surgeon canceled the case. The patient had told the social worker that she did not want a feeding tube because she believes she eats enough. The judge, who had been involved in the competency hearings, stated that the hospital was putting itself in jeopardy should anything happen to IR since they were not proceeding with the court order for the placement of a feeding tube.

A psychiatrist interviewed IR and concluded that she could be classified as having dementia of Alzheimer's type compounded by alcohol abuse. Her short-term memory was very poor and she was unable to appropriately answer questions on finances. He felt that she was not capable of taking care of herself and recommended guardianship.

The attending physician was reluctant to proceed with placement of a feeding tube against the patient's wishes. The dietetics staff prepared food to the patient's liking, and her intake improved. She did not eat enough to meet nutritional goals but was able to maintain her weight. She was

discharged to a nursing home where she died two months later. □

E. The Case of Surrogates Questioning Capacity

Mrs. C is seventy-six and suffers a progressive neurologic deterioration. Her husband and daughter have cared for the patient in the home with the help of visiting nurses. Because of recurrent aspiration, she is frequently hospitalized for pulmonary infection. The husband and daughter are so concerned about the healthcare decisions regarding Mrs. C. that they have made an appointment with the hospital administrator during one of her hospital admissions. The family claims that they have an advance directive, but the hospital staff have never seen it.

During the current admission, the nurse and social worker discussed with the patient her preferences for resuscitation and being placed on a respirator. Because Mrs. C's speech was very difficult to understand, she was asked to shake her head "yes" or "no." In response to these questions, she vehemently shook her head "no." She correctly identified the hospital she was in, recognized a ceramic pig, and correctly answered questions about other animals and colors.

The patient's attending physician discussed the same issues regarding resuscitation and respirator, and the same negative answers were consistently given. The doctor wrote a DNR order and informed the patient's family of this the next day. The family became upset and said the patient didn't know what she was talking about and she was not able to make such decisions. The doctor asked the patient the questions again in the presence of her family. She continued to say no to resuscitation and respirator but did not

correctly identify the name of the hospital. She did not know the date or the season of the year. At the insistence of the husband, the doctor rescinded the DNR.

A speech pathologist was asked to see the patient and gave the following report:

"Answers yes-no questions with 60-percent accuracy. Yes is a high pitched "uh." No is a low pitched "huh-uh." Does best with one word responses. Names pictures of common objects with 75-percent accuracy. Reads aloud large print."

The speech pathologist set up a communications board to improve interaction with the staff. The family became very angry and demanded that the speech pathologist not see the patient and that the communication board not be used. All decisions were now made by the husband. □

VI. General Suggestions for Using the Guidelines Document

Ethics committees are encouraged to use these guidelines in a full range of applications for designing educational events, initiating or reviewing relevant institutional policies, and for enhancing individual case consultation.

A. Suggestions in Regard to Education

Professional instruction in this area is definitely lacking. Institutional ethics committees could perform a vital function for the clinical professions by facilitating basic and advanced education on how to conduct a determination of decisional incapacity.

B. Suggestions in Regard to Policymaking

There is opportunity to review existing policy for adequacy. Many institutions will not have a policy regarding the determination of decisional incapacity. Each ethics committee working with the appropriate

area of management will need to decide about establishing such a policy. Related policies for informed consent, establishment of guardianship, and other forms of surrogate decision making should also be reviewed.

C. Suggestions in Regard to Case Review

Although decisional capacity is assumed in every case, some consultations may involve a detailed and careful consideration of decisional incapacity. When that is the case in a clinical situation, the consultant team should

Although decisional capacity is assumed in every case, some consultations may involve a detailed and careful consideration of decisional incapacity.

examine the question of decisional capacity as a preliminary step in evaluation of the case. The team may apply some or all of the guidelines in this document as a method of determining decisional incapacity.

VII. Guide for Ethics Committees to Evaluate and Improve Determinations of Decisional Incapacity within Their Institutions

The Consortium encourages each institutional ethics committee to study the determination of decisional incapacity in the context of actual clinical situations.

1. Review the guidelines document.
2. Review selected articles to broaden the committee's analysis (e.g., see page 12).
3. Use cases to focus on realistic clinical situations.

- a. Use actual cases which your committee has reviewed.
 - b. Use sample cases from this document or published illustrative cases.
4. Clarify practice of providers in your hospital.
 - a. Invite other providers to the discussion.
 - b. Involve all levels of personnel who deal with the issue — physicians, nurses, social workers, chaplains, hospital attorneys, risk managers, patient representatives.
 - c. Describe providers' actual practice.
 5. List the difficulties that providers encounter in actual practice. This task will require sensitive probing and honest reporting. Stress the need to “open up the process” and to be more sensitive to patient values.
 6. Identify the basic problems in ethical terms.
 - a. Principles affirmed or negated
 - b. Virtues followed or ignored
 - c. Goals valued or discredited
 7. Link the determination of decisional incapacity to other ethical issues such as informed consent, advance directives, and respecting patient rights.
 8. Identify and promote agreement among providers about behavioral change(s) needed to improve the practice of determining decisional incapacity. Be aware of ways to improve case review by the committee in regard to decisional incapacity.
 9. Design ways of modifying practice.
 - a. Promote change through educational events.
 - b. Improve guidance policy.

- c. Use other incentives unique to your institution.

If you belong to an Ethics Consortium or network, plan to share your information, including new or revised policies, and recommendations with the Consortium and other ethics committees.

For Further Reading

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Appendix: Guideline Summaries

Three aspects constitute the dynamics of decisional capacity: understanding, deliberation, and communication. These three aspects have been identified in each of the following guidelines, and consensus appears to be growing.

A. *Hasting Center Guidelines*

1. The ability to comprehend information relevant to the decision,
2. The ability to deliberate about the choices in accordance with personal values and goals, and
3. The ability to communicate (verbally and nonverbally) with caregivers.

B. *Cleveland Clinic Guidelines*

1. The ability to understand and communicate relevant information,
2. The ability to reason and deliberate about their choices, and
3. The ability to choose in the light of their goals and values.

C. *Bernard Lo Guidelines*

1. Patients should appreciate that they have choices.
2. Patients appreciate the medical situation and prognosis, the nature of the recommended care, the alternatives, the

risks and benefits of each treatment, and the likely consequences.

3. Patients' decisions should be stable over time and consistent with their values and goals.

D. *Appelbaum and Grisso Guidelines*

1. The ability to communicate choices,
2. The ability to understand information about a treatment decision,
3. The ability to appreciate the situation and its consequences, and
4. The ability to use logical processes to compare the benefits and risks of various treatment options.

In addition to these guidelines, the Consortium recommends the following important documents, which may be used to broaden your understanding regarding decisional incapacity:

- A. *Healthcare Treatment Decision-making Guidelines for Minors*
- B. *Healthcare Treatment Decision-Making Guidelines for Adults with Developmental Disability*

These documents are available through the Center for Practical Bioethics.

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The Center for Practical Bioethics is a freestanding practical bioethics center. Our vision is a society in which ethical discourse and action advance the health and dignity of all persons. Our mission is to raise and respond to ethical issues in health and healthcare. Our core value is respect for human dignity. We believe that all people have intrinsic worth, and we express this belief by promoting both autonomy and social justice in health and healthcare.

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