



AASPIRE

Healthcare Toolkit

Legal and Ethical Considerations

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Legal and Ethical Considerations: Legal and Ethical Concerns

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1 Overview

Physicians have an obligation to obtain informed consent from a patient prior to implementing an assessment or treatment plan. If a patient does not have the capacity to provide a valid consent, informed consent must be obtained from his or her legal representative. For people with disabilities and their caregivers, this process can be fraught with ethical, legal, and logistical challenges. This document provides clinicians with guidance on how to avoid common problems with the informed consent process. Local and state laws may vary; the information contained in this section should not be construed as legal advice.

2 Determining capacity

- For an informed consent decision to be valid, the patient must have the mental ability to understand the risks and benefits of each option, weigh them against each other, and communicate a choice.
- A person's diagnosis of a cognitive, physical, or intellectual disability should not in itself preclude capacity for informed consent.

- Mental capacity is specific to a particular decision. The nature and complexity of decisions vary. Capacity must be assessed and documented separately for each decision to be made.
- Mental capacity is specific to a particular point in time. It is not static and can fluctuate. A capacity determination refers to a specific time.
- Mental capacity can often be improved with adequate supports. Accommodations requested in the patient's tool kit should be arranged prior to assessing mental capacity. Information should be provided in a format and an environment that maximizes the patient's ability to understand (e.g. pictures, videos, demonstrations, field trips, gestures, or vignettes). Adequate time and communication supports should be provided to assist the patient to respond.
- Assume that your patient is competent until proven otherwise. Due to communication challenges, or assumptions about a patient's ability, professionals and caregivers can easily overlook mental capacity. The patient's right to self-determination is frequently violated. Informed consent must be voluntary without coercion, misrepresentation, duress, or pain. People with disabilities may not express pain in a typical fashion and may have sensory sensitivities that distract them.
- After assessment, if there is still uncertainty about mental capacity, the patient's assent should be sought and documented. If the patient does not at least assent to proceed with an important assessment or treatment, consider additional patient protection procedures such as a team meeting with a patient advocate or ethics consultation.

3 Who can substitute decisions?

- Patients who do not have mental capacity to make informed consent decisions can almost always contribute relevant information about their val-

ues, priorities, or degree of distress. This information may be communicated verbally or with other language, facial expressions, gestures, or behavior. This information should be considered by substituted decision-makers.

- Many patients who do not have the mental capacity to provide informed consent do have the mental capacity to decide whom they trust to assist. In this situation, advance directives or power-of-attorney documentation may exist or can be completed. These choices usually take precedence over other legal processes. A power of attorney should not be used for a person who has mental capacity to decide.
- Some patients have legal guardians, conservators, agencies, or caregivers who have been given legal authority to make medical decisions on behalf of a patient when he or she does not have capacity to make a decision. Legal representatives often appreciate input from other sources.
- If no legal representative can be identified, follow state or institutional policies. You can contact your state's [Protection and Advocacy](#) agency for legal advice on how to proceed.
- If still no legal representative can be identified, or if the legal representatives are unable or unwilling to decide, the legal process is unclear. A clinician can attempt to identify everyone in the patient's life who has a stake in the decision. A team meeting can then be held to achieve consensus on how to proceed (e.g., with caregivers, family, supporters, case coordinators, service providers, government agencies, other health professionals serving the patient, client's rights advocates from the state's Protection and Advocacy organization and, if needed, an ethicist).

4 Ethical considerations

- Patients with mental capacity have the right to accept or decline any medical procedure, including intravenous hydration and enteral feeding. Under

the Americans with Disabilities Act, health professionals are responsible for providing access to care, even if it is expensive, complex, costly, or inconvenient. Challenges to providing access should not influence counseling or decision-making.

- Substituted decisions should be made based on the best interests of the patient. Power imbalances always exist. Ask how to structure discussions to minimize power imbalances.
- The lives of people with disabilities are meaningful and valuable. Even people with very significant disabilities tend to rate their quality of life higher than substituted decision-makers and professionals do.
- Clinicians and other team members should avoid dehumanizing language. Clinicians and other team members should be alert for, and challenge, prejudicial assumptions and reasoning during discussions about informed consent.
- People with very significant disabilities can be healthy. Distinguish disability from illness. Clinicians have a tendency to falsely assume that people with complex disabilities are in declining health, even when their health is quite stable and their potential for full recovery from an acute medical event is excellent.
- Medical decisions for people with significant disabilities almost always affect multiple stakeholders, such as caregivers, public agencies, service providers and other funders. Their interests can compete with those of the patient. Though the interests of these other stakeholders are critically important to the overall wellbeing of the patient and to the successful implementation of a health care plan, they should be considered separately.