

Issues in Capacity: Balancing Empowerment and Protection

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David Godfrey, ABA Commission on Law and Aging

ABA Commission on Law and Aging

The ABA Commission on Law and Aging is the collaborative and interdisciplinary leader of the American Bar Association's work to strengthen and secure the legal rights, dignity, autonomy, quality of life, and quality of care of aging persons.

The Commission accomplishes its work through research, policy development, advocacy, education, training, and through assistance to lawyers, bar associations, and other groups working on issues of aging.

Key Lessons

1. Capacity is the ability to make an informed choice. This requires understanding the issue, knowing there are options, and making a choice based on personal values.
2. Informal capacity assessments should happen every time an advocate communicates with a client. Initially, this consists of listening for cues that indicates the other person understands the message. When there is a lawyer-client relationship, it is important to also ask follow-up questions that confirm: the client's understanding of the conversation, the client's ability to understand the issue, and the client's ability to make a choice based on their individual values.
3. Formal capacity assessments should be recommended when the lawyer is unsure of the client's ability to understand or when the person's capacity is being challenged. Formal assessments should be done by professionals with specific training in memory and cognitive assessment.
4. Decision supports work to maximize the capacity of the person by helping them to understand the issues and options, and help the person reach a personal choice.
5. Dementia refers to decline in memory or cognitive ability as a result of illnesses such as Alzheimer's disease. Dementia is chronic, currently incurable, and progressive. Clients with dementia will vary significantly in capacity, and capacity will change over time, requiring ongoing reassessment of understanding and varying levels of assistance.

Understanding Capacity

Capacity is the ability to make and communicate an **informed choice**. There is no simple test for capacity. It is important to carefully communicate and assess the person's ability to understand and make a choice. Often, understanding the person's personal values, preferences, or goals can assist in understanding their capacity to make decisions.

Capacity is issue specific, a spectrum, and transient. The first question is: "capacity to decide what?" Different types of decisions require varying levels of memory and distinct cognitive skills. The memory needed depends on how relevant past information is to the choice at hand. For example, very little memory is needed to decide what to wear today. Different decisions require different cognitive skills, such as calculation, comparison, or organizing data.

Capacity is a spectrum. The ability to understand and make choices is not an on-off function. Capacity varies in subtle degrees, from no or very low levels of understanding, to the ability to understand and make decisions on very sophisticated and complex issues.

Capacity is impacted by health, pain, medication, illness, or injury. Capacity can be developed by learning and experience, and it can decrease with illness or injury. As these factors change, capacity can increase, decrease, and return.

PRACTICE TIP

For lawyers, capacity is not defined in the model rules of professional conduct, it is inferred by looking at these rules:

- **Rule 1.4 (b) on Communication:** “A lawyer shall explain a matter to the extent reasonably necessary to permit the client to make informed decisions regarding the representation.” This involves more than talking; it requires recognizing if the client understands the explanation sufficiently to make choices based on the information supplied.
- **Rule 1.2 on Scope of Representation:** This rule allocates to the client the decision on the purpose, goal, or objective of the representation, and to do this, the client needs to understand options and potential outcomes.
- **Rule 1.14 Client with Diminished Capacity:** This rule offers guidance on representing a client with diminished capacity. At the core this is, to the extent possible, maintaining a normal attorney-client relationship. This rule and comments to the rule offer extensive guidance on balancing client autonomy and protection.

Informal Capacity Assessment

With all interactive communication, advocates informally assess capacity by looking for clues in replies that indicate that the person understood the message. This happens in the most casual of conversations when we look for some hint in the feedback of mutual understanding. We really don't think about it, unless we perceive confusion. Informal capacity assessment happens so naturally that we don't even realize we are doing it.

When the informal assessment needs to be expanded upon, it is helpful to ask questions that confirm understanding. This is still informal assessment. Questions should confirm that the person understands. If the initial answer indicates confusion, restate and re-ask. If practical, break the question down into smaller parts that are easier to understand and ask those, looking for understanding. If it still unclear that the person understands, delay action, try again another day, urge evaluation by others, including formal assessment by trained professionals. If you are unsure of the person's ability to understand and make an informed choice, a professional assessment is recommended.

PRACTICE TIP: BETTER COMMUNICATION WITH PERSONS WITH DIMINISHED CAPACITY

- Practice listening skills. Listening is more than hearing. Listening seeks to understand.
- Before you start, make sure the person knows you are talking with them. Make and maintain eye contact if possible.
- Eliminate background noise.
- Watch facial expressions and gestures for added meaning.

- Use a normal voice and short simple sentences. A lower register or tone of voice may be easier to hear. Allow extra time for the person to understand and respond.
- While maintaining a clear conversation, try to be at the person's eye level and face-to-face.
- Communication is a two-way street; just as we try to confirm that the person is understanding our message, we need to assure that we understand what the person is telling us.

Formal Assessment

Formal capacity assessments should be done by physicians, psychologists, social workers, and other professionals with specialized training. A starting point for every assessment is understanding the goal or use of the assessment. The person doing the assessment should be aware of the decisions that need to be decided on, and what others are concerned about. Some assessments can be done quickly, however, a full assessment for a person who has trouble with communication may take several hours. It is best to conduct these over several sessions. Memory and cognition science have advanced rapidly in the past decade. The assessment may include interviews, a standardized psychological test, medical imaging, or lab tests. The scope of the needed testing will vary based on the person's health and should be left up to the professional conducting the assessments.

The person may be able to consent to an assessment, or if the health care providers believe it is appropriate, a health care surrogate may consent. Courts can also order assessments with cause, provided the assessment meets the statutory requirements in the state (commonly in guardianship, conservatorship, mental health, or criminal cases). Simple assessments where there is little question of the capacity are commonly completed by health care providers as part of a routine office call. Complex assessments, which take more time, are only covered by insurance or benefits if they are part of a diagnosis or treatment. In cases where capacity is harder to determine, assessments can be time consuming and finding a source of payment can be difficult. Some community mental health programs, local health departments, and community-based public services programs can provide formal assessments.

A formal assessment looks at long- and short-term memory; orientation to place, self, and time; the ability to organize facts and information; the ability to make reasoned choices; calculation abilities; and visual-spatial issues. Administering and interpreting standardized testing requires specialized training that is far beyond the scope of this chapter summary. Failing the simplest of the standardized tests is an indicator of impairment—and merits caution. A passing score on the simplest of the standardized tests does not address the critical question of understanding the issue under consideration.

PRACTICE TIPS: COMMON MISPERCEPTIONS IN CAPACITY

- Failure to follow advice is not proof of lack of capacity.
- Failing to act in one's "best interest" is not proof of lack of capacity.
- Agreeing with one family member, and not others, is not proof of lack of capacity.
- Making gifts or spending "foolishly" are not proof of lack of capacity.
- The capacity to decide one issue does not assure capacity to decide a different question.
- A diagnosis with dementia does not revoke an adult's legal capacity.

Decision Supports

The goal of decision supports is to leverage capacity by providing assistance with understanding, in order to maximize the person's decision-making and autonomy. In decision supports, the person selects trusted supporters, or technical supports, to help them. The support spectrum ranges from enrolling in direct deposit, where the payor and financial institution support the person's choice, to working with trusted advisors on complex personal, medical, or business issues. The supporter's purpose is to carefully communicate with the person. The supporter does everything possible to help the person understand the issue, the risks, and the benefits of options, so that the person can make an informed choice. Then the supporter helps the person as needed or requested to carry out that choice.

For decision supports to be effective, the person needs some ability to communicate, to understand basic concepts, and to make at least simple choices. The objective of decision supports is to make the most of the person's abilities—decision supports focus on abilities, not limitations. It is important to remember that people communicate in different ways and to explore all of the ways the person may be able to communicate.

Dementia and Capacity

Dementia describes declines in memory and cognition (the ability to make decisions) as a result of illness or disease. Dementia is a decline that exceeds normal age-related changes in memory and cognition. The most widely known cause of dementia is Alzheimer's disease, however there are many diseases that manifest symptoms of dementia. The impact on memory and decision-making varies significantly based on the cause of the dementia. One of the keys to diagnosing different underlying causes of dementia is to assess the ways that the person's memory, cognition, or behavior have changed.

A dementia diagnosis does not have a legal impact on a person's legal ability to make decisions, choices, or participate in life. It is important to assess the understanding of a person experiencing dementia on an ongoing basis. Dementia, and the related decline in memory and cognition, are chronic and progressive. The best therapies available today can slow the progression of symptoms, and relieve some of the collateral impacts for some persons with dementia, but there is currently no cure. The symptoms progression varies significantly from person to person and from underlying cause to underlying cause. Early diagnosis offers the greatest hope for effective treatment.

The earlier the diagnosis, the greater the opportunity for the person to put into place trusted supports, and the greater opportunity to make others aware of the person's values, goals, and preferences. A person with early to mid-stage dementia can do most things with modest supports and help. As the illness progresses, the need for support and help will increase. In the later stages, a person with dementia may become unable to communicate with others.

Balancing Empowerment and Protection

Some choices in our lives can be made without consideration of options or consequences. There is little consequence to the choice between wearing a blue t-shirt or a red t-shirt. The only ability needed is selecting an option. Yet, we see persons with diminished capacity denied the dignity of even the simplest of choices in the name of protection.

Some decisions have life or death consequences, or drastic financial consequences. People should be empowered to make these choices, and at the same time, as a society, we want assurance that people making choices which have the potential for bad outcomes do so knowing that there are consequences and options. Empowerment is not an assurance that the person is going to make the choice that is "best for them" or "what others think the person should do." Empowerment is honoring the choice that the person finds is the best "choice for them" while knowing the potential outcomes and all the options.

Conclusion

Capacity is the ability to make an informed choice. We informally assess capacity when we communicate with others by confirming understanding. Capacity is issue specific and is a spectrum from low to high ability of understanding. It is transient, and it can increase and decrease. We support decision making by practicing effective communication skills to make the most of people's ability to understand and make a choice. When we are truly unsure of a person's ability to understand risks and options, we should urge a formal assessment before proceeding with important choices. Formal capacity assessment is complex and should be done by experts with specialized training. Dementia is a decline in memory and cognition caused by illness or disease. Persons living with dementia are often able to make informed choices, with help. We empower and protect people by helping them make the choice that they want to make, and should only try to protect persons from their choices if it is clear that the person is unable to understand the potential negative consequences and that they have other options.

Additional Resources

- [ABA handbooks and guides for understanding and assessing capacity](#)
- [The PRACTICAL tool describes options to support decision making.](#)
- [ABA Model Rules of Professional Conduct describe a lawyer's obligation of competence, communication, allocation of authority and working with a client with diminished capacity. The commentary provides in depth guidance on several points.](#)
- [Supporting Decision Making Across the Age Spectrum is a report describing the application of decision supports to empower adults.](#)

Case consultation assistance is available for attorneys and professionals seeking more information to help older adults. Contact NCLER at ConsultNCLER@acl.hhs.gov.

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