

ND PROTECTION & ADVOCACY PROJECT

INFORMED CONSENT

What is Informed Consent?

Informed consent is a term used when describing a person's agreement with a proposed course of action, usually reserved for decisions with more risk and greater consequences like healthcare decisions, decisions about where to live, and how to spend money.

Elements of Informed Consent

Consent has three elements:

- 1) Capacity
- 2) Information
- 3) Voluntariness

Each element is necessary to obtain valid consent.

What is Capacity?

Capacity considers the individual's ability to communicate, understand, and logically work with the information being presented. If the individual has a disability, knowledge of the disability and how it affects the individual's above abilities is fundamental.

- Does the individual's disability impact his or her ability to communicate?
 - If so, how?
- Does the individual's disability impact his or her ability to understand information?
 - If so, how?
 - Can the information be presented in an alternate format?
- Does the individual's disability impact his or her ability to logically work with the information being presented?
 - If so, how?
 - Does the individual understand the nature of the decision?
 - Are the consequences of making the decision understood?
- Can the individual retain the information long enough to weigh possible outcomes to make the decision?

Factors that influence capacity include resources and support available, situational demands, an individual's physical and mental health,

relationships with other people, and equity issues. Be mindful of these when looking at capacity.

Capacity should be assessed on a decision-by-decision basis. Incapacity to make one decision does not equal incapacity to make others. An individual should never be presumed incapable! Capacity can change over time and can vary according to supports provided. Assess what parts of the decision-making process may need support.

A “risky” or “unwise” decision does not mean the individual lacks capacity.

Check for capacity:

- ✓ By seeing if the individual can communicate the decision back to you or to another person – do not fill in any blanks; (i.e., Do you know ...?)
- ✓ By seeing if the individual has a consistent decision when asked repeatedly.
- ✓ Asking “Do you understand?” does not confirm capacity! Often individuals with disabilities will say “yes” to be agreeable. Open ended questions like “What did we just talk about?” “What am I asking you to decide? Can you tell me about _____?” etc. can help determine capacity.

What is Information?

Information is simply what is being presented to the individual regarding the matter he or she is being asked to consent to. Look at information through the lens of the person receiving it, not whether you feel the information being presented is adequate. Consider the individual and his or her specific needs.

Effectively communicating information:

- Introduce yourself and identify your area of expertise.
- Be prepared to communicate orally and using written materials – have paper and a pencil handy, as the individual may want to write things down or have something drawn out for them.
- Use visual aids in addition to written material, including materials with simple language.
- Show the person. This may mean taking them someplace to see what you are talking about, observe something, or meet someone.
- Present risks and benefits or pros and cons of different choices.

- List possible alternatives.
- Tell the individual what will happen if he or she chooses to do nothing.
- Ask if there is anything else the person wants to know.
- Ask how much time the individual would like to make the decision.
- Ask if there is someone else the individual would like to talk about the decision with.
- Consider the environment in which you are presenting information. Is it accommodating for the individual?

Be very careful using electronic communication as the only method of communication. Make sure the communication form is appropriate for the situation, as there may not be the same opportunities to observe body language, tone of voice, and gestures, or the opportunity to freely ask questions in a timely manner.

What is Voluntariness?

Voluntariness means the person is acting freely. Consent may be withdrawn or withheld at any time. "Freely" must be looked at in the context of the person's life, be aware of coercion or outside pressures! Observe/ask if there is any duress (family pressure, illness, pain, etc.) that might impact the individual's ability to freely consent. Inquire whether anyone is telling the individual how to decide. Explore if there is anything that makes the individual feel like they must make the decision one way or another, or like they must give consent.

If an individual is using Supported Decision-Making, a Supporter cannot make decisions or give consent for an individual. Always identify legal decision-makers!

FOR MORE INFORMATION, CONTACT:

ND PROTECTION & ADVOCACY PROJECT
400 E. BROADWAY, SUITE 409
BISMARCK, ND 58501
1-800-472-2670
(701) 328-2950
www.ndpanda.org
panda_intake@nd.gov



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