

Informed Consent

Informed consent means whether a person agrees to do something or have something happen to them. It often describes the ability to make decisions with more risk and greater consequences. For example, decisions about health care, where to live, and how to spend money may require informed consent. If an individual is using Supported Decision-Making a Supporter cannot make decisions or give consent for the individual. Always identify legal decision-makers.

To obtain valid informed consent three elements are necessary:

- 1 Capacity
- 2 Information
- 3 Voluntariness

Capacity

Capacity considers the individual's ability to communicate, understand, and logically work with the information being presented. 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. Knowledge of an individual's disability and how it affects their abilities is important. Assess what parts of the decision-making process may need support.

Capacity should be assessed on a decision-by-decision basis. Incapacity to make one decision does not equal incapacity to make other decisions. Capacity can change over time and varies according to supports provided. A risky decision does not mean the individual lacks capacity. Checking for capacity:

- Ask the individual to communicate the decision back to you or to another person. Do not fill in any blanks or provide prompts.
- See if the individual has a consistent decision when asked repeatedly.
- Check comprehension by asking open ended questions.

Individuals should be presumed to have capacity



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Do Ask:

- What did we just talk about?
- What am I asking you to decide?
- Can you tell me about ____?

Don't Ask:

- Do you understand?
- Do you want to ____?

Information

Information includes the facts provided to the individual to help them understand. Look at information through the lens of the person receiving it, not whether you feel the information being presented is adequate. Make sure the mode of communication is appropriate for the situation as there may not be the same opportunities to freely ask questions or observe social cues.

Ways to effectively communicate information:

- Consider the environment, the individual and their specific needs, including accommodations or alternative formats.
- Introduce yourself and identify your area of expertise.
- Be prepared to communicate verbally or in writing.
- Use visual aids and written material.
- Help take notes.
- Show the individual by drawing a diagram or sketch, taking them 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 they choose to do nothing.

Ask:

- Do you want to know anything else?
- How much time would you like to make the decision?
- Do you want to talk about the decision with someone else?

Voluntariness

Voluntariness means the person is acting freely. 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.