

# Decision-Making in Health Care of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities



## Introduction

This tool is for health care clinicians who assess legal capacity of adults with intellectual and developmental disabilities (IDD). In light of the United Nations' *Convention on the Rights of Persons with Disabilities*, it offers a person-centered approach that considers the rights of persons to be accommodated to demonstrate their capacity to make a certain health care decision. Such accommodations can include the help of decision-making supporters who know the patient well. Currently 19 states have laws recognizing decision-making supporters. See <https://supporteddecisions.org/resources-on-sdm/state-supported-decision-making-laws-and-court-decisions/> for a list of states and their laws. In states where laws do not yet recognize decision-making supporters, including Tennessee, such supporters can and should be included as much as possible within existing legal structures to help the patient, as much as needed, to respond to the health care clinician who is performing the assessment.

## How To Use This Tool

<b>Sections 1 and 2</b>	Complete information about your patient before the visit
<b>Section 3</b>	Plan how to accommodate your patient, guided by the patient and patient's family/support person if you are unfamiliar with the patient or uncertain how to accommodate.
<b>Sections 4 and 5</b>	Determine the patient's capacity, including the patient's need for someone to help them respond to assessment questions (Table 1).

**Table 1:** Health care decision-making approaches involving adults with IDD

 <b>PATIENT IS CAPABLE OF MAKING THE DECISION</b>		 <b>PATIENT IS INCAPABLE OF MAKING THE DECISION</b>
<b>INDEPENDENT</b> The patient can provide appropriate information to the health care clinician performing the capacity assessment without the assistance of a decision-making supporter to meet the capacity test.	<b>INTER-DEPENDENT</b> In order to optimize the patient's ability to best demonstrate that they meet the test for legal capacity, the patient requires the accommodation of having a decision-making supporter present to help the patient respond to the health care clinician performing the capacity assessment.	<b>SUBSTITUTED</b> Even with help from a decision-making supporter and other supports, the patient is unable to respond to assessment questions to meet the capacity test. The patient will require a substitute decision-maker.

---

## Important Practice Points

1. Presume the process to determine the patient's capacity to consent to treatment would be enhanced by accommodating needs, such as the presence of decision-making supporters.
2. Make sure to determine the patient's need to be accommodated as part of the process of assessing capacity.
3. Do not presume that the decision-making approach for the capacity assessment should be the same as that used by the patient for other decisions in or outside health care.
4. Always check whether the patient is able to understand, and does understand, that he or she has options and can make the decision freely.
5. Do not move too quickly to a finding of incapacity and seeking consent of a substitute decision-maker before assessing whether, with help from a decision-making supporter, the patient is better able to demonstrate capacity to make the treatment decision.
6. Do not assume that paid support persons are legally permitted to assume or have assumed the role of a substitute decision-maker for the incapable patient, and are permitted to give consent to treatment for a patient. They may not, although in some instances they may support the patient to elicit further and better information for a capacity assessment.



#### 4. ASSESS THE PATIENT'S CAPACITY AND NEED FOR A DECISION-MAKING SUPPORTER\*

##### Describe treatment options

##### Relative health benefits to the patient of treatment options

##### Risks of likely harm or need for additional supports for each treatment option

##### Patient's goals and values relevant to this decision

###### Explore and discuss with the patient and, with their permission, others of their choice:

- ▶ What does the patient hope for from this treatment? (e.g., comfort, to get better, to live longer)
- ▶ How can treatment be delivered to restore or prioritize what matters to the patient?
- ▶ Is there anything about the patient's family relationships, culture, or religion that should be considered?
- ▶ How does the person cope with discomfort or loss? What supports does he or she draw on?

##### ASSESSMENT PROCESS

- ▶ **INFORM THE PATIENT THAT YOU ARE ASSESSING THEIR CAPACITY:** E.g., *"To help you feel better (or get well again or keep you from getting sick), I would like to give you some treatment. I want to make sure first that you are able to understand the treatment. You can ask to stop at any time. I am going to tell you some things and then ask you some questions. You can ask someone to help you answer if you like."*
- ▶ **TIPS FOR ASSESSING:** Examples of questions are given for each statement (1-6) in the assessment. Ask the patient to repeat or show you what he or she understands regarding information that you give.
- ▶ **IF YOUR ANSWER IS YES TO A STATEMENT** → Proceed to the next statement.
- ▶ **IF YOUR ANSWER IS NO OR UNSURE TO ANY OF THE STATEMENTS** → Ask your patient whether he or she wants someone else's help to hear the information again, or other help, in order to answer your questions. Then with this help, reassess.
- ▶ **IF YOU HAVE PROVIDED ALL AVAILABLE ACCOMMODATIONS, BUT YOUR ANSWER REMAINS UNSURE** → Seek advice or reassessment of the patient from an assessor familiar with adults with IDD. You can use this information to assist you to determine whether your patient meets the legal test for capacity.

\*Adapted from: Etchells E, Darzins P, Silberfeld M, Singer PA, McKenny J, Naglie G, et al. Assessment of patient capacity to consent to treatment. *Journal of General Internal Medicine* 1999; 14(1): 27-34.

### Discuss the patient's health issue

**ASK THE PATIENT:** *Can you tell me or show me what is bothering you? Will you let me try to help you feel better?  
Or: Can you tell me why it is important for you to keep from getting sick?*

**The patient is able to and does understand his or her health issue**

Yes

No

Unsure

### Discuss the proposed treatment

Describe or show what you and your patient would have to do in the proposed treatment.

**ASK THE PATIENT:** *Can you tell me or show me what I am asking you to do?*

**The patient is able to understand and does understand what the proposed treatment involves**

Yes

No

Unsure

### Discuss the treatment benefits for the patient's health

Discuss immediate or short-term discomforts, likely risks of harm, and long-term needs for additional supports as a result of the treatment. For example

*"What I'm asking you to do can help you feel better (get well) or avoid getting sick or sicker. But you might also feel.... or you might need to.... or you might not be able to.... until you start to feel (or get) better (or to stay well). You can always ask for more help or ask to stop."*

**ASK THE PATIENT:** *Can you tell me what will happen with this treatment?*

**ASK THE PATIENT:** *Tell me what you like about this option. Tell me what you don't like about this option.*

### Explore other options as needed

**ASK THE PATIENT:** *Let's talk about another option.*

**The patient is able to and does appreciate the consequences of the treatment for his or her life**

Yes

No

Unsure

**Determine if the patient is capable to decide between treatment options**

**ASK THE PATIENT:** *Can you tell me what you want to do? (Or, can you tell me which option you like the most?)*

**The patient is capable to decide among treatment options** Yes No Unsure

**If the patient refuses all options, determine if he or she is able to appreciate the reasonably foreseeable consequences**

**ASK THE PATIENT:** *Can you tell me what will happen if we don't do anything?*

**The patient is able to appreciate what could likely happen if he or she refuses all treatment options** Yes No Unsure

**Confirm that the patient's preferred option or refusal is chosen freely**

Could there be factors affecting the patient's capacity to make the decision? Consider factors such as learned helplessness, coercion, need for supports to decrease anxiety, fear or other stressors. Explain:

**I am free of concerns about factors affecting the patient's ability to choose or refuse treatment** Yes No Unsure

**5. CONCLUSION AND SEEKING CONSENT**

When considering whether a patient can give informed consent, the legal requirements including capacity and information must be considered.

Using the information you gathered in the previous sections, determine whether the patient meets the test of capacity to make the specific treatment decision in your jurisdiction.

**Is this patient capable with respect to this specific treatment decision?** Yes No

**CONSENT OR REFUSAL OF TREATMENT AUTHORIZED BY:**

Name	Date
Patient (with or without a supporter's help)	
Decision-making supporter (in states where this is legal)	
Substitute decision-maker	

# Supporting materials

## Practice tools

### i. About My Health

Developmental Disabilities Primary Care Program of Surrey Place, Ontario  
<https://ddprimarycare.surreyplace.ca/tools-2/general-health/about-my-health/>

### ii. My Health Care Visit

Health Care for Adults with Intellectual and Developmental Disabilities  
<https://iddtoolkit.vkcsites.org/my-health-care-visit/>

### iii. Adaptive Functioning and Communication Associated With Different Levels of Developmental Disabilities

Health Care for Adults with Intellectual and Developmental Disabilities  
<https://iddtoolkit.vkcsites.org/adaptive-functioning-communication/>

### iv. Communicate CARE

Guidance for person-centered care of adults with intellectual and developmental disabilities  
Health Care for Adults with Intellectual and Developmental Disabilities  
<https://iddtoolkit.vkcsites.org/communicate-care/>

## Resources

### v. International

**UN General Assembly, Convention on the Rights of Persons with Disabilities:**  
resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106, available at:  
<https://www.refworld.org/docid/45f973632.html>. See articles 12, 15, 25, and 26.

### vi. National Resource Center for Supported Decision-Making

offers tools and a searchable database for states' laws and cases.  
<https://supporteddecisionmaking.org/>

### vii. Evaluating Medical Decision-Making Capacity in Practice

<https://www.aafp.org/pubs/afp/issues/2018/0701/p40.html>

### viii. Decision Making and Self-Determination

In: Khemka I, Hickson L (eds.). Decision making in individuals with intellectual and developmental disabilities: Integrating research into practice. New York: Springer Publishing, 2021, pp. 47-64.  
[https://link.springer.com/chapter/10.1007/978-3-030-74675-9\\_1](https://link.springer.com/chapter/10.1007/978-3-030-74675-9_1)

---

## References

Etchells E, Darzins P, Silberfeld M, Singer PA, McKenny J, Naglie G, et al. Assessment of patient capacity to consent to treatment. *Journal of General Internal Medicine* 1999; 14(1): 27-34.

---

## Copyright

This document complements “Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines”, published in *Canadian Family Physician*, Volume 64(4): April 2018, p254-279.

Originally published as: Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities. Sullivan, WF., Bach, M., Heng, J., Henze, M., Kerzner, L., McNeil, K., Perry, A., Vogt, J., Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2020.

Modified with permission of the copyright owner, Surrey Place, Toronto, Canada. This tool was reviewed and adapted for U.S. use by Vanderbilt Kennedy Center, Toolkit Advisory Committee, including primary care providers, self-advocates, and family caregivers.

All rights reserved. The content of this tool may not be reproduced or stored in a retrieval system, or transmitted in any form or by any means without the prior written permission of the copyright owner. All content © Surrey Place, 2023. Contact the IDD Toolkit at [iddtoolkit@vumc.org](mailto:iddtoolkit@vumc.org) for permission to adapt information and tools to your local practice setting.