

Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities:

Promoting Capabilities

Introduction

This tool is for healthcare providers 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*^[vi], it offers a person-centred approach that considers the rights of persons to be accommodated to demonstrate their capacity to make a certain healthcare decision. Such accommodations can include the help of decision-making supporters who know the patient well. Laws recognize decision-making supporters in British Columbia, Alberta, Manitoba, and The Yukon. In Ontario, and elsewhere in Canada where the law does not yet recognize decision-making supporters, these individuals 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 healthcare provider who is performing the assessment.

How To Use This Tool

SECTIONS 1 AND 2: Complete information about your patient before the visit.^[i,ii]

SECTION 3: Plan how to accommodate your patient, guided by the patient and patient's caregivers if you are unfamiliar with the patient or uncertain how to accommodate.^[iii,iv] Consistent with Ontario's human rights laws, healthcare providers should consider what accommodations people with disabilities need, and should comply with their duty to accommodate them to the point of undue hardship.^[vii]

SECTIONS 4 AND 5: Determine the patient's capacity, including the patient's need for someone to help them respond to assessment questions (Table 1). Laws vary across Canada regarding the legal role of decision-making supporters (see Table 2 and Supporting Materials).^[ix]

TABLE 1: Healthcare decision-making approaches involving adults with IDD



 PATIENT IS CAPABLE OF MAKING THE DECISION		 PATIENT IS INCAPABLE OF MAKING THE DECISION
INDEPENDENT The patient can provide appropriate information to the healthcare provider performing the capacity assessment without the assistance of a decision-making supporter to meet the capacity test.	INTER-DEPENDENT 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 healthcare provider performing the capacity assessment.	SUBSTITUTED 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.

TABLE 2: Legal status of decision-making supporters in various Canadian jurisdictions.

<p>BRITISH COLUMBIA, ALBERTA, MANITOBA, & THE YUKON</p>	<p>These jurisdictions have laws that recognize certain decision-making supporter arrangements. Different terms might be used, such as, “representative” (British Columbia); “supporter” (Alberta); “support network” (Manitoba), and “associate decision-maker” (Yukon).</p>
<p>ONTARIO</p>	<p>Where the patient has been found capable to make a treatment decision, the ultimate decision about treatment is theirs to make. However, it is consistent for healthcare providers to accommodate the patient’s need for help from decision-making supporters in order to reach their healthcare decision.</p> <p>In Ontario, the law does not yet recognize decision-making supporters. One of the purposes of Ontario’s <i>Health Care Consent Act</i> ^[vi], however, is “to ensure a significant role for supportive family members when a person lacks the capacity to make a decision about a treatment” (s.1.(e)). It is consistent with this Act for healthcare providers to accommodate the patient’s need for help from such supporters to make healthcare decisions.</p> <p>When a substitute decision-maker is required, in addition to the significant role the Act sets out for supportive family members, substitute decision-makers should be encouraged to include decision-making supporters of the patient. The supporters may be able to help the substitute decision-maker to interpret the patient’s prior capable wishes, which is a critical role of the substitute decision-maker. If there are no prior capable wishes that apply to the decision, the substitute decision-maker must make the decision in the patient’s ‘best interests’, which the supporters can also assist to help determine. Under the Act, ‘best interests’ includes considering the patient’s values and beliefs.</p>

AVOID COMMON PRACTICE ERRORS

1. Assuming the process to determine the patient’s capacity to consent to treatment would not be enhanced by accommodating needs, such as the presence of decision-making supporters.
2. Not taking steps to determine, or failing to address, the patient’s need to be accommodated as part of the process of assessing capacity.
3. Presuming that the decision-making approach for the capacity assessment process or as it relates to a specific treatment decision should be the same as that used by the patient for other decisions in or outside health care.
4. Not checking whether the patient is able to understand, and does understand, that he or she has options and can make the decision freely.
5. Moving 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. Assuming that paid caregivers are legally permitted to assume, and 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.

Decision Making in Health Care: Promoting Capabilities

1 Patient information

Name		DOB
First	Last	

Additional information (email ahead of appointment or ask to bring it in)	Date Completed	Status (Y / N)
About my Health ⁽ⁱ⁾ , My Health Care Visit ⁽ⁱⁱⁱ⁾ or similar health information document(s) is available.		Yes No
Psycho-educational assessment is available.		Yes No

Level of intellectual disability ⁽ⁱⁱⁱ⁾ Psycho-educational assessments contain valuable information about what strategies will best help your patient with IDD to learn and process new information. Generally, patients with IDD benefit from plain language, additional time, repetition, and visuals.	
Mild	Gear explanations to Grade 2 to Grade 6 level.
Moderate	Gear explanations to Grade 1 to Grade 4 level.
Severe	Gear explanations at preschool to Grade 1 level (ages 3-6 years). Include caregivers who know the patient well to assist.
Profound	Use simple language and one-step directions (age up to 3 years). Include caregivers who know the patient well to assist.
Unknown	

2 Persons accompanying the patient

Full name	Relationship (e.g., friend; parent; partner; paid worker)	Role (e.g., future substitute decision-maker; supporter)

3 Plan to accommodate the patient's needs

Accommodating needs
<p>Accommodating needs can include providing sufficient time for discussion and making decisions, adjusting sensory inputs (lights, sounds), ensuring typical supports to communicate are in place (devices, translators), scheduling appointments at preferred times of day or across multiple visits, adapting procedures to manage pain or anxiety, allowing the person to bring items or people to enhance comfort and security, offering coaching in decision-making skills or engaging one or more decision-making supporters. If uncertain about how to provide accommodations for this patient, seek input from professionals experienced in working with adults with IDD (e.g. speech-language pathologist, occupational therapist).</p>

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 following treatment 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?*

1. 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?*

2. 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 more sick. 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.*

3. 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?)*

4. 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?*

5. 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:

6. 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

This section applies the legal test for *capacity* in Ontario's *Health Care Consent Act* (s. 4).^[vi] 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 Ontario, to be capable to give or refuse consent to the proposed treatment, the patient must be able to:

1. understand the information that is relevant to this specific decision, AND
2. appreciate the reasonably foreseeable consequences of this specific treatment decision or lack of a decision.

There are two scenarios which might result in determining that the patient is capable: the patient might be independently capable or inter-dependently capable with the help of a decision-making supporter (See Table 1.) Under the Health Care Consent Act, decisions regarding any treatment must: 1. relate to the treatment; 2. be informed; 3. be given voluntarily; 4. not be obtained through misrepresentation or fraud.

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 (where this is legal, i.e. not in Ontario) Substitute decision-maker

Supporting materials

Practice tools

- i. **About My Health**
Developmental Disabilities Primary Care Program of Surrey Place, Ontario
ddprimarycare.surreyplace.ca/tools-2/general-health/about-my-health/
- ii. **My Health Care Visit**
Developmental Disabilities Primary Care Program of Surrey Place, Ontario
ddprimarycare.surreyplace.ca/tools-2/general-health/todays-visit/
- iii. **Adaptive Functioning and Communication Associated With Different Levels of Developmental Disabilities**
Developmental Disabilities Primary Care Program of Surrey Place, Ontario
ddprimarycare.surreyplace.ca/tools-2/general-health/adaptive-functioning/
- iv. **Communicate CARE**
Guidance for person-centred care of adults with intellectual and developmental disabilities, Developmental Disabilities Primary Care Program of Surrey Place, Ontario
ddprimarycare.surreyplace.ca/tools-2/general-health/communicating-effectively/

Laws

- 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. **Ontario - Legal Sources and Policies - Health Care Consent and Related Resources**
Health Care Consent Act, 1996
<https://www.ontario.ca/laws/statute/96h02>
Substitute Decisions Act, 1992, S.O. 1992, c. 30 <https://www.ontario.ca/laws/statute/92s30>
Mental Health Act, R.S.O., 1990, c.M.7
<https://www.ontario.ca/laws/statute/90m07>
Personal Health Information Protection Act, 2004, S.O. 2004, c.3, Sched. A
<https://www.ontario.ca/laws/statute/04p03>
D'Arcy Hiltz and Anita Szigeti, A Guide to Consent and Capacity Law in Ontario, 2020 edition. Toronto: LexisNexis, 2019.
Starson v. Swayze, [2003] 1 S.C.R. 722 (Supreme Court of Canada)
<https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/2064/index.do>
College of Physicians and Surgeons of Ontario, Policy:

- "Consent to Treatment"**, February 2001
<https://www.cpso.o.ca/Physicians/Policies-Guidance/Policies/Consent-to-Treatment>
College of Nurses of Ontario, Practice Guideline, "Consent", 2017
https://www.cno.org/globalassets/doc/policy/41020_consent.pdf
College of Occupational Therapists of Ontario, "Standards for Consent, 2017"
<https://www.coto.org/resources/details/standards-for-consent-2017>
Ontario Human Rights Commission, Policy: "Policy on preventing discrimination based on mental health disabilities and addictions", Chapter 16 -Consent and Capacity, January 2014.
<https://www.ohrc.on.ca/en/policy-preventing-discrimination-based-mental-health-disabilities-and-addictions>
Ontario Consent and Capacity Board
<https://www.ccboard.on.ca/scripts/english/index.asp>
- vii. **Ontario - Legal Sources and Policies - Human Rights and Duty to Accommodate**
Human Rights Code, R.S.O. 1990, c. H.19
<https://www.ontario.ca/laws/statute/90h19>
Eldridge v. British Columbia (Attorney General) [1997] 3 S.C.R. 624 (Supreme Court of Canada)
<https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/1552/index.do>
College of Physicians and Surgeons of Ontario, Policy: "Professional Obligations and Human Rights", September, 2008.
<https://www.cpso.on.ca/Physicians/Policies-Guidance/Policies/Professional-Obligations-and-Human-Rights>
Ontario Human Rights Commission, Policy: "Policy on ableism and discrimination based on disability", June, 2016
<https://www.ohrc.on.ca/en/policy-ableism-and-discrimination-based-disability>
 - viii. **Canada - Provincial/Territorial Jurisdictions - Legal Sources on Health Care Consent**
Borden Ladner Gervais LLP (General Editor), Canadian Health Law Practice Manual, LexisNexis, Looseleaf
Mona Pare, "Of Minors and the Mentally Ill: Re-Positioning Perspectives on Consent to Health Care", 2011, 29 Windsor Yearbook of Access to Justice, 107-125.
 - ix. **Canada - Legal Sources on Supported Decision Making**
Legislation in Canada that contains formal legal recognition of a role for supports in decision making
British Columbia

Representation Agreement Act, R.S.B.C. 1996,
Chapter 405

http://www.bclaws.ca/civix/document/id/complete/statreg/96405_01

Alberta

Adult Guardianship and Trusteeship Act, S.A.
2008, Chapter A-4.2

<https://www.qp.alberta.ca/documents/Acts/A04P2.pdf>

Saskatchewan

The Adult Guardianship and Co-decision-making Act, S.S. 2000, c. A-5.3

<https://www.qp.gov.sk.ca/documents/english/statutes/statutes/a5-3.pdf>

Manitoba

The Vulnerable Persons Living with a Mental Disability Act, C.C.S.M. c. V90

<http://web2.gov.mb.ca/laws/statutes/ccsm/v090e.php>

Yukon

The Adult Protection and Decision Making Act, being Schedule A to the Decision-Making Support and Protection to Adults Act, S.Y. 2003, c.21

<http://www.gov.yk.ca/legislation/acts/dmspa.pdf>

of the CRPD's right to legal capacity and supported decision-making: A Canadian perspective. Prepared for a Symposium at the University of British Columbia "In from the margins: New foundations for personhood and legal capacity in the 21st century", April 2011
<http://supporteddecisionmaking.org/legal-resource/paving-way-full-realization-crpds-rights-legal-capacity-and-supported-decision-making>

James K, Watts L. Understanding the lived experiences of supported decision-making in Canada. Prepared for the Law Commission of Ontario, March, 2014.

<https://www.lco-cdo.org/wp-content/uploads/2014/03/capcity-guardianship-commissioned-paper-ccl.pdf>

Kerzner L. Supported decision-making innovations: The Canadian experience. In: Disability law and policy: An analysis of the UN Convention (O'Mahony C, Quinn G, eds.). Dublin: Clarus Press Ltd, 2017.

Sullivan WF, Heng J. Supporting adults with intellectual and developmental disabilities to participate in health care decision making. Can Fam Physician. 2018;64(Suppl 2):S32-S36.

x. **Secondary Sources**

Kerzner L. Paving the way to full realization

Some of these supporting materials are hosted by external organizations and the accessibility of these links cannot be guaranteed. The DDPCP will make every effort to keep these links up to date.

Frequently Asked Questions (Ontario)

Q: Can my patient engage in a supported decision-making process in Ontario?

A: Decision-making supporters do not have legal status in Ontario, however, they can play an important role for your patients. Decision-making supporters may assist a patient to meet the test of capacity to allow them to make their own treatment decisions. When the patient is capable of making their own decision, the patient might still wish to involve decision-making supporters to discuss the decision and talk through the options. If the patient, after using supporters and other accommodations, still cannot meet the test of capacity, Ontario's law stipulates that substitute decision-maker can give or refuse consent to treatment on the patient's behalf. The substitute decision-maker might wish to discuss the decision with the patient, supporters and other people who know the patient well.

Q: WHAT IF I CANNOT FIND A SUBSTITUTE DECISION-MAKER (SDM) FOR THE PATIENT, AND THE PATIENT IS DETERMINED TO BE INCAPABLE TO MAKE THE DECISION(S) AT ISSUE?

A: Call the Office of the Public Guardian and Trustee Treatment Decisions Unit toll-free at 1-800-387-2127. In Ontario, the Public Guardian and Trustee is the substitute decision-maker of last resort if no other substitute decision-maker can be located.

Q: Sometimes my patient wants privacy and, at other times, wants support from her parents. How can I respect her privacy and maintain trust if I suspect, for some decisions, it is unlikely she will be capable, either independently or inter-dependently, of making the decision(s)?

A: Ask your patient whom she might like to include in healthcare decisions and explore her concerns around sharing information with others. Explain where and how information is documented in the chart and who may access it. Also clearly explain the limits of privacy and confidentiality. Information might need to be shared if the patient has been found incapable of making the treatment decision. At that time, only information relevant to the decision will be provided to the substitute decision-maker.

Q: My patient does not want the automatic family member specified in the hierarchy of substitute decision-makers in the Health Care Consent Act involved in making decisions regarding her health care. What are the options?

A: The hierarchy ensures that everyone has an automatic family member as substitute decision-maker for treatment decisions if they do not have a legally appointed substitute decision-maker. A patient can decide on a preferred substitute decision-maker who is different from the one set out in the hierarchy by naming their attorney for personal care. The patient can do this by making a Power of Attorney for Personal Care and might wish to consult a lawyer to do so. Note that, to make a Power of Attorney, the patient must meet a test of capacity, which is less stringent than for treatment decisions (Ontario's *Substitute Decisions Act*, s. 47).

Q: I don't believe that my patient's substitute decision-maker is acting in accordance with the legislation, which sets out the principles that must be followed for giving or refusing consent. What can I do to help my patient?

A: You can make an application to Ontario's Consent and Capacity Board (called a Form G application) to ask the Board to determine whether the patient's substitute decision-maker is acting in accordance with the principles they must follow. These principles require that the substitute decision-maker follow wishes that the patient expressed while capable, if possible and applicable in the situation. If there are not any such wishes, or it is impossible to comply with the wishes, the decision is made in the patient's best interests. The Consent and Capacity Board can be reached toll-free at 1-866-777-7391, and the website is www.ccboard.on.ca.

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