

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

Promoting Capabilities

Introduction

This tool guides primary care providers in assessing and promoting the decision-making capabilities of adults with intellectual and developmental disabilities (IDD). It promotes health care decision-making capabilities in the context of the patient’s relationships. The tool encourages those who are seeking patient consent to always accommodate patient needs and, if necessary, to involve decision-making supporters. Various formal supported decision-making arrangements are legally recognized in Canada, such as in British Columbia, Alberta, Manitoba, and The Yukon. Elsewhere, a supported decision-making approach can still be incorporated by the patient’s substitute decision maker.

How to use this tool

KNOW YOUR PATIENT: Prior to the health care visit, identify your patient’s vulnerabilities and support needs as they relate to decision making. This could be based on information collected by office staff.^[i;ii]

ACCOMMODATE NEEDS: Determine how best to accommodate your patient’s needs at the beginning of each patient-provider encounter. These are changes to how services are normally delivered to be accessible for a person with a disability (e.g., more time, preferred ways of communicating, quiet environment).^[iii]

ASSESS WHETHER TO INVOLVE DECISION-MAKING SUPPORTERS: This tool provides example questions to determine whether an independent, inter-dependent or dependent decision-making approach should be used with the patient for making the decision at hand (see table 1).

TABLE 1: Continuum of decision-making capabilities and approaches.

INDEPENDENT *(accommodated)*

If needs are accommodated, these patients can exercise their decision-making capabilities. This enables them to make a decision that is informed and aligns with their values and goals.

INTER-DEPENDENT *(accommodated and supported)*

For patients who are not independent decision makers but at least one other person can reliably interpret their values and goals. The decision-making supporters can help the patient to decide which health care options align best with the patient’s values and goals.

DEPENDENT *(substituted)*

Even with available accommodations and decision-making supporter(s), the patient is unable to make this decision and requires a substitute decision maker.

DETERMINE WHO AUTHORIZES THE DECISION: In Canada, apply provincial or territorial laws regarding who authorizes health care decisions.^[iv] Note that the legal status of supported decision making varies among Canadian jurisdictions (see table 2). See supplemental materials for links to provincial laws that specify approaches and parameters.^[iv]

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

<p>BRITISH COLUMBIA, ALBERTA, SASKATCHEWAN, MANITOBA, THE YUKON</p>	<p>These jurisdictions have laws that recognize certain supported decision-making arrangements. Different titles might be used for “supportive decision makers” (e.g., the patient’s representative, associate decision maker, or co-decision maker).</p>
<p>ALL JURISDICTIONS</p>	<p>Substitute decision makers can be encouraged to approximate a supported decision-making process with the patient. The substitute decision maker could involve other persons who might help them interpret and apply the patient’s values and goals. For example, one of the purposes of the Ontario Health Care Consent Act 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)).</p>

AVOID COMMON PRACTICE ERRORS

1. Assuming the patient’s decision-making capability can not be enhanced by their supports or developed through learning.
2. Basing the decision-making approach on the patient’s other decisions in or outside health care.
3. Not recognizing and accommodating needs.
4. Moving too quickly to a substitute decision-making process when a supported decision-making approach could work.
5. Excluding the patient from the decision-making process (e.g.,, not attempting to elicit their values and goals) when the patient can exercise capability independently or inter-dependently.
6. Assuming a paid caregiver is automatically authorized to act as a substitute decision maker, although paid caregivers can often play a supportive role if they know the patient well.

Decision Making:

Promoting the Patient's Capability

1 Patient information *Investigate and complete this part before the health care visit.*

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] or similar health information document(s)		Yes No
Psycho-educational assessment available		Yes No

Level of intellectual disability listed in report(s) Also see Adaptive functioning and communication for adults with IDD ^[ii]	
Mild	Conversational difficulties might exist.
Moderate	Uses phrases and simple sentences to communicate.
Severe	Understanding typically limited to their immediate environment. Limited vocabulary.
Profound	Might appear non-interactive although receptive communication skills might be better than expressive language.
Unknown	

2 Persons accompanying the patient *Note that the legal status of supported decision making varies per Canadian jurisdiction, see introduction and supplemental materials^[iv]*

Full name	Relationship (e.g., friend, parent, partner, paid worker)	Legal role (e.g., substitute or supportive decision maker)

3 Provide accommodations *If possible, investigate and complete this part before the health care visit. [i, iii]*

Accommodations

Accommodations can include providing more time, adjusting sensory input as needed (lights, sounds), ensuring communication supports are in place (devices, translators), scheduling appointments at preferred times of day or across multiple visits as needed, adapting procedures (to manage pain or anxiety) and allowing the person to bring people or items for comfort.

4 Assess and support capability*

Decision at Issue

Proposed Procedure

Procedure	Investigation	Treatment
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Description:

Benefit / Risk / Burden:

Alternative Procedure (Add other options as needed)

Procedure	Investigation	Treatment
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Description:

Benefit / Risk / Burden:

Patient's Values and Goals

E.g., what the patient enjoys, what or whom patient cares about most, cultural and religious values, the patient's hopes for the future. Provide accommodations and supports in communication with the patient about these as needed.

HOW TO COMPLETE THIS SECTION

- Tell your patient that you will be asking some questions that will help him or her to take part as much as possible in making this decision. Use the suggested questions for your discussion with the patient. Let the patient know they can invite someone they trust to be present.
- **IF YOUR ANSWER IS NO OR UNSURE TO ANY OF THE STATEMENTS** → ask the patient whether he or she wants to be assisted by anyone. Then, with this assistance, reassess.
- **IF YOU HAVE PROVIDED ACCOMMODATIONS AND SUPPORTS, BUT YOUR ANSWER IS STILL NO OR UNSURE TO ANY OF THESE STATEMENTS** → find the appropriate substitute decision maker (SDM). Encourage the SDM to discuss the decision with the patient and someone who knows the patient well and is trusted by the patient → proceed to step 5 : authorization.

DISCUSS THE HEALTH PROBLEM

ASK THE PATIENT: *Can you explain why you are here today? Can you explain what is bothering you most?*

1. The patient understands his or her specific health problem

Yes No Unsure

* Adapted from: Etchells, E., Darzins, P., Silberfeld, M., Singer, P. A., McKenny, J., Nagli.e., G.,... & Strang, D. (1999). Assessment of patient capacity to consent to treatment. Journal of general internal medicine, 14(1), 27-34.

EXPLAIN THE PROPOSED PROCEDURE(S) i.e., investigation or treatment and its risks, benefits, burdens. If needed, use accommodations (see STEP 3).

ASK THE PATIENT: *Do you understand that this could (help us to find out how to) make you feel better?*

2. The patient understands the purpose of the proposed investigations or treatments

Yes No Unsure

DISCUSS THE PATIENT'S PREFERENCES If needed, use accommodations (see STEP 3).

ASK THE PATIENT: *Let's talk about this option. Can you tell me something you like about it? Can you tell me something you don't like about it?*

EXPLAIN ALTERNATIVE PROCEDURES i.e., investigation or treatment option 2 and its risks and benefits. If needed, use accommodations (see STEP 3).

ASK THE PATIENT: *Let's talk about another option. Can you tell me something you like about it? Can you tell me something you don't like about it? Is this option better than the other one or ones for you?*

3. The patient understands alternative ways of investigating or treating, and the expected consequences of each (i.e., benefits, risks, and burdens) and has selected an option based on their values and goals.

Yes No Unsure

FOR PATIENTS WHO REFUSE

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

4. If the patient indicates refuses all options for investigating or treating, he or she understands the likely effects.

Yes No Unsure N/A

CONFIRM THAT THE PATIENT'S PREFERRED OPTION IS CHOSEN FREELY

ASK THE PATIENT: *Do you think this is the only choice you have? Is anyone telling you to choose (or not choose) to do this?*

5. I am free of concerns about factors in the patient's life that could be unduly inducing or compelling the patient to make this decision.

Yes No Unsure

5 Conclusion and authorization

Note: the legal status of supportive decision makers varies among Canadian jurisdictions (see table 2 and supplemental materials for legislations^{iv}).

If you answered YES or N/A to all of the statements in step 4 :

The patient can exercise capability for making this decision.

If you answered NO to any of the statements in step 4 :

The patient is unable to exercise capability for making this decision and is dependent on a substitute decision maker.

Independent Decision

the patient authorizes

Supported Decision

The supportive decision maker authorizes with or without the patient. At present (i.e., February 2019) British Columbia is the only province in which a decision-making supporter can authorize a decision on behalf of the patient.^[iv]

The patient authorizes. Only in Alberta, Manitoba, and the Yukon Territories the patient can authorize in a supported decision making arrangement.^[iv]

Substituted Decision

Consent must be obtained from the highest ranking eligible person stipulated in the hierarchy of substitute decision makers set out in the provincial regulations.^[iv]

If the substitute decision maker does not know the patient well facilitate discussion between the SDM, the patient and caregivers familiar with the patient.¹ In jurisdictions where supported decision making is not legally recognized, advise the substitute decision maker (if different than the person the patient requests for assistance) of the patient's supported decision to guide determining patient's best interest.

Patient's assent or dissent and his/her wishes:

Decision authorized by:

First

Last

The patient

Patient and/or Decision-making supporter

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. 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/

iii. 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 regarding health care consent or supported decision making across Canadian jurisdictions

iv. Legislations

Federal

Supreme Court of Canada Re Eve [1986] 2 S.C.R.
 388 <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/170/index.do>

Alberta

Adult Guardianship and Trusteeship Act, SA
 2008, c A-4.2 <http://www.qp.alberta.ca/documents/Acts/A04P2.pdf>
 Personal Directives Act, RSA 2000, c P-6, <http://www.qp.alberta.ca/documents/Acts/p06.pdf>
 Powers of Attorney Act, RSA 2000, c P-20 <http://www.qp.alberta.ca/documents/Acts/p20.pdf>

British Columbia

Representation Agreement Act, RSBC 1996, c
 405 http://www.bclaws.ca/civix/document/id/complete/statreg/96405_01
 Health Care (Consent) and Care Facility
 (Admission) Act, RSBC 1996, c 181 http://www.bclaws.ca/Recon/document/ID/freeside/00_96181_01

Manitoba

The Health Care Directives Act, C.C.S.M. c. H27
<https://web2.gov.mb.ca/laws/statutes/ccsm/>

p033-5e.php

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>

The Mental Health Act, C.C.S.M. c. M110
<https://web2.gov.mb.ca/laws/statutes/ccsm/m110e.php>

The Public Trustee Act, C.C.S.M. c. P205
<https://web2.gov.mb.ca/laws/statutes/ccsm/p205e.php>

New Brunswick

Infirm Persons Act, RSNB 1973, c I-8
<http://laws.gnb.ca/en/showfulldoc/cs/I-8//20181230>

Advance Health Care Directives Act, RSNB 2016,
 c 46 <https://www.gnb.ca/0062/acts/BBA-2016/Chap-46.pdf>

Trustees Act, SNB 2015, c 21
<https://www.gnb.ca/legis/bill/FILE/58/1/Bill-30-e.htm>

Newfoundland and Labrador

Advance Health Care Directives Act, S.N.L.
 1995, c. 4-41 www.assembly.nl.ca/legislation/sr/annualstatutes/1995/A04-1.c95.htm

Adult Protection Act, S.N.L. 2011, c 4.01
<https://assembly.nl.ca/Legislation/sr/statutes/a04-01.htm>

Nova Scotia

Personal Directives Act 2008, c.8,s.1.
<https://novascotia.ca/just/regulations/regs/pdpersdir.htm>
 Adult Capacity and Decision-making Act 2017,
 c. 4 <https://nslegislature.ca/legislative-business/bills-statutes/consolidated-public-statutes>

Northwest Territories and Nunavut

Guardianship and Trusteeship Act, S.N.W.T. 1994,
 c. 29 <https://www.nunavutlegislation.ca/>

Ontario

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>
 Trillium Gift of Life Network Act, R.S.O.
 1990, c. H.20 <https://www.ontario.ca/laws/statute/90h20>

Prince Edward Island

Consent Treatment and Health Care Directives
 Act, S.P.H.I. 1996, c. C-17.2 <http://www.gov.pe.ca/>

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.

[law/statutes/pdf/c-17_2.pdf](#)

Quebec

Civil Code of Québec (C.C.Q.), S.Q. 1991, c. 64 (Articles, 11-13, 15, 20 and 22)

<http://legisquebec.gouv.qc.ca/en/showdoc/cs/CCQ-1991/20120101>

Saskatchewan

The Adult Guardianship and Co-decision-making Act <http://publications.gov.sk.ca/details.cfm?p=91019>

Yukon

Decision Making, Support and Protection to Adults Act, SY 2003, c.21 www.gov.yk.ca/legislation/acts/dmspa.pdf#page=30

Regulations, policies, guidelines, and legal aid (Ontario).

- v. **Consent and Capacity Board (CCB)**
www.ccbboard.on.ca
- vi. **Office of the Public Guardian and Trustee (OPGT)**
www.attorneygeneral.jus.gov.on.ca/english/family/pgt/
- vii. **Legal Aid Ontario**
www.legalaid.on.ca
- viii. **Consent to Treatment, College of Physicians and Surgeons of Ontario**
<https://www.cpso.on.ca/Policies-Publications/Policy/Consent-to-Treatment>
- ix. **Practice Guideline: Consent, College of Nurses of Ontario**
http://www.cno.org/globalassets/docs/policy/41020_consent.pdf
- x. **Standards for Consent, College of Occupational Therapists of Ontario (COTO)**
www.coto.org/resources/standards-for-consent-2017

Easy-to-read resources

- xi. **Substitute decision makers (Who decides if you cannot), Ontario Medical Association**
https://www.oma.org/wp-content/uploads/eolc_sdm.pdf
- xii. **Practical guide to health care consent and advance care planning in Ontario, Speak Up Ontario campaign, Hospice Palliative Care Ontario**
<http://www.speakupontario.ca/resource-guide>
- xiii. **Making health care decisions for others: A guide for substitute decision makers, Speak Up Ontario campaign, Hospice Palliative Care Ontario**
https://www.speakupontario.ca/wp-content/uploads/2018/07/A_SDM_guide_to_substituted_decision_making_March_23_20161.pdf
- xiv. **Substitute decision maker wallet cards, Speak Up Ontario campaign, Hospice Palliative Care Ontario**
<https://www.speakupontario.ca/resource/wallet-cards-en/>
- xv. **Supported Decision-Making Agreements – Could this help me?, Yukon Government Department of Health and Social Services**
http://www.hss.gov.yk.ca/pdf/supported_dm_booklet.pdf

NOTE: Always consider provincial laws and regulations similar to those listed for the province of Ontario.

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Frequently Asked Questions (Ontario)

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

A: The patient's substitute decision maker can authorize a supported decision-making approach with the patient as needed, provided that: your patient with IDD requests help from one or more supportive decision makers, or is capable of communicating values and goals to such a person or persons who can reliably interpret and help the patient decide on health care options. If uncertain, seek legal advice.

Q: What if I cannot find a substitute decision maker (SDM) for my patient after reasonable efforts, and the patient needs one?

A: Call the Office of the Public Guardian and Trustee to advise: 1-800-366-0335.

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, she will be unlikely to exercise decision-making capability for making the decision independently?

A: Clearly explain the limits of privacy and confidentiality. Information might need to be shared if:

- the patient cannot exercise decision-making capability for making a specific decision. At that time, only information relevant to the decision will be provided to the substitute decision maker. If they disagree that they cannot exercise capability, patients can

contest with the Consent and Capacity Board.

- harm to self or others could occur without disclosure to relevant individuals or organizations (e.g., abuse, suicidality).

Explain where and how information is documented in the chart, and who may access it.

Ask your patient whom she might like to include in health care decisions and explore her concerns around sharing information with others.

Q: My patient does not want the designated substitute decision maker involved in making decisions regarding her health care. What are her options?

A: If your patient can understand the implications of signing a Power of Attorney document, she can select a substitute decision maker with the help of a lawyer. If your patient is not capable of assigning a Power of Attorney and cannot independently exercise her decision-making capability with respect to the decision in question, the patient can apply to the Consent and Capacity Board to have another substitute decision maker appointed. In such circumstances, legal aid services might be helpful for your patient (www.legalaid.on.ca).

Q: I don't believe that my patient's substitute decision maker is acting in her best interest. What can I do to help my patient?

A: You can apply to the Consent and Capacity Board for directions and to ask that they assess whether these persons are acting in accordance with the legislation guiding their role and responsibilities.

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- United Nations Convention on the rights of people with disabilities*. New York, NY: United Nations; 2006. Available from: <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

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