Informed Consent in Adults with Developmental Disabilities (DD)

Primary care providers initiate the consent process for a person with DD when:

(1) A new treatment or a change in treatment is proposed, unless it had been accepted through a previously agreed-to 'plan of care.' Consent should be obtained not only for treatment/management but also for assessment/investigation, especially if invasive. The health care provider who proposes a treatment/investigation has the obligation to obtain consent to administer it from the patient, if capable, or from his/her legally authorized Substitute Decision-Maker (SDM).

(2) There is a change in the patient's ability to understand the nature and effect of the treatment. This change can be positive as well as negative (e.g., the patient may develop new skills that facilitate their giving consent, or his/her function may deteriorate and thus require a SDM.)

STEPS INVOLVED IN THE CONSENT PROCESS

A. Determine Capacity (see Checklist C)

- **Capacity** refers to the mental ability to make a *particular* decision at a *particular* time; it is question- and decision-specific and should be documented relative to each decision. Assess capacity to consent for each treatment or plan of treatment. Even when a Power of Attorney (POA) for Personal Care exists, capacity for consent to the particular treatment at this time should be assessed.
- **Capacity is not static** but can change over time or require distinct abilities depending on the nature and complexity of the specific treatment decision. Specific capabilities may be lost or gained at different times during the life of a patient with DD. Situations may arise where consent to a treatment has been given or refused on a patient's behalf. However, if that patient then becomes capable of consenting to the treatment in the opinion of the health care practitioner, the patient's own decision would take precedence over that of the SDM.
- **Assessed capacity can vary according to the supports provided.** Involve the patient wherever possible by adapting the level and means of communicating to him/her; patients require functionally appropriate means of communication and support to realize their capacity for informed consent to, or refusal of, treatment. Offer information in a form you believe the patient will understand (e.g., pictures, symbols, gestures, vignettes). (See also *Communicating Effectively with People with Developmental Disabilities*.)
- **Involve others who know the patient best**, such as family members or paid care givers, to obtain information or to facilitate the patient's understanding and communication. Note that although paid care givers may provide valuable support for decision making, *they are not legally permitted to consent to or refuse treatment on behalf of a patient* in Ontario and in various other jurisdictions.
- **If the patient is incapable of giving consent**, or if there is uncertainty in this regard, follow appropriate legal procedures and ethical guidelines for assessing capacity. If incapable, delegate authority for decision making, which should be based on the patient's best interests in the circumstances. Generally, only patients with mild to moderate DD will be capable of consenting, whereas those with severe to profound DD will not have that capability but may be able to assent to a proposed treatment. Whenever possible, even when consent is obtained from a SDM, assent should be sought from the patient and be documented.

B. Obtain and Document Consent

- **Consent must be given voluntarily:** Allow sufficient time for the patient to understand, consider the information, and ask questions. If the patient requests additional information, provide a timely response.
- **Consent must be related to a proposed investigation or treatment and be informed by adequate disclosure:** The person obtaining consent should be knowledgeable and well-informed about the condition and proposed intervention.
- **Consent must not be obtained through fraud, coercion or misrepresentation:** The patient should not be under any duress or pain. It is important to be familiar with how the individual with DD usually exhibits pain (e.g., normal or unique pain responses), which may unduly affect decisions.

Name: DOB:

C. Informed, Voluntary Consent Checklist and Sample Questions [a]

Inform the patient that you will be doing a capacity assessment with him/her. Do not assume that the patient will understand the connection between the illness and some consequent intervention.

Use the categories below to guide your assessment, and the examples below them if helpful.

- For each category of question, check **Yes**, **No** or **Unsure**.
- If the answer is No to any of these questions, the patient is not capable.

1. Does the patient understand that you are offering an intervention for a health problem? ☐ **Yes** ☐ **No** ☐ **Unsure**

e.g., What problems are you having right now?
What problem is bothering you most?
Do you know why you are in the hospital/clinic?

2. Does the patient understand the nature of the proposed investigation or treatment and the expected benefits, burdens, and risks? ☐ **Yes** ☐ **No** ☐ **Unsure**

e.g., What could be done to help you with your (specify health problem)?
Do you think you are able to have this treatment?
Do you know what might happen to you if you have this treatment?
Do you know if this treatment can cause problems? Can it help you live longer?

3. Does the patient understand possible alternative treatment options and their expected benefits, burdens, and risks? ☐ **Yes** ☐ **No** ☐ **Unsure**

e.g., Do you know different ways that might make you better?

4. Does the patient understand the likely effects of not having the proposed investigation or treatment? ☐ **Yes** ☐ **No** ☐ **Unsure**

e.g., Do you know what could happen to you if you don't have this (*specify*) done?
Could you get sicker or die if you don't have this (*specify treatment*)?
Do you know what could happen if you have this (*specify treatment*)?

5. Is the patient free from any duress (e.g., illness, family pressure) or pain or distress that might impair his/her capacity regarding the particular decision? (Note that a relatively minor illness can cause significant anxiety.) ☐ **Yes** ☐ **No** ☐ **Unsure**

e.g., Can you help me understand why you've decided to accept/refuse this treatment?
Do you feel that you're being punished? Do you think you're a bad person?
Is anyone telling you that you should or should not get this treatment?

6. Is the patient free from a mental health condition (e.g., mood disturbance or psychiatric illness) that may influence his/her capacity to give consent? (Note that having mental illness is not in itself an indicator of permanent incapacity. This factor may change once the mental health condition is treated.) ☐ **Yes** ☐ **No** ☐ **Unsure**

e.g., Are you hopeful about the future?
Do you think you deserve to be treated?
Do you think anyone is trying to hurt and/or harm you?
Do you trust your doctor and nurse?

Assessment:

DATE: _____ PRINT NAME: _____ SIGNATURE: _____

a. Questions adapted from: Etchells E. Joint Centre for Bioethics-Aid to Capacity Evaluation **www.utoronto.ca/jcb**

CAPABLE	NOT CAPABLE	UNSURE
If "YES" to ALL of the above, and the patient can remember the information long enough to make a decision (verify by asking him/her to explain the information to you), then consider that capability exists to consent to or refuse the proposed treatment.	**If "NO" to ANY of the above,** then repeat the questions; you may need to repeat this process several times to ensure that the patient understands. **If the patient still does not understand**, he/she is incapable and a legal Substitute Decision Maker (SDM) should be assigned (see below).	**Consult family, if not already done** **Consider seeking a second opinion from:** • **Designated "capacity assessor"** (e.g., for admission to long-term care and/or personal assistance services) **www.ccboard.on.ca** • **Hospital ethicist/bioethics committee** if available • **Provincial regulatory College or Medical Association**, especially if the decision is related to reproduction, genetic testing, chemical restraints, procedures, or end-of-life issues

D. Identify the Current Substitute Decision Maker (SDM)

If a patient is incapable of providing voluntary and informed consent, then consent must be obtained from the highest ranked eligible person identified in the hierarchy set out in the provincial regulations. That person is the Substitute Decision Maker (SDM).

The hierarchy in Ontario is as follows:

1. Guardian of the patient (under the Substitute Decision Act) with authority to provide consent to treatment
2. Power of Attorney (POA) for Personal Care (this individual may be a different person than POA for Property)
3. Representative appointed by the Consent and Capacity Board
4. Spouse/partner
5. Child older than 16 years of age/custodial parent or Children's Aid Society
6. Parent with right of access
7. Sibling
8. Any other relative (related by blood, marriage or adoption)

Note: In Ontario, **a paid care provider cannot function as a SDM,** although he/she can come to appointments and convey information.

E. Documentation

Document and Update Power of Attorney (POA) for Personal Care

- Even if a POA for Personal Care document exists, the physician should first assess present capacity of the patient before seeking the consent of the POA for Personal Care.
- Make sure to document and update the delegated POA for Personal Care, including specifying who (e.g., from social services) needs to initiate Power of Attorney delegation.
- If the parents have delegated SDM power to another caregiver, this should be documented.
- Document Plan of Care for Ongoing Treatment.
- Consent for treatment can apply over a period of time with a specified renewal period and may include items such as adjustment of medications. Having this consent and a documented plan of care is also useful for anticipated health problems, given the patient's current health status.

Document 'Circle of Care' [b, c]

- Consists of all health care providers and support personnel who are permitted to rely on a patient's implied consent to collect, use or disclose his/her health care information for the purposes of providing health care. In a physician's office this includes physicians, nurses, specialists or other health care providers to whom the physician refers the patient, and health professionals selected by the patient (e.g., pharmacist, physiotherapist). In a hospital it includes the attending physician and members of the health care team who have direct health care responsibilities to the patient.

Advance Care Planning

- Discuss with patient and his/her caregivers and record (e.g., patient's preference for SDM, Advance Directives or a Living Will).

Cross-Cultural Sensitivity

- Be respectful of cross-cultural differences in communication styles.
- Seek consultation and input from members of the patient's cultural community, as necessary, to enhance communication.

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[b] **www.mcmasterchildrenshospital.ca/body.cfm?id=209**

[c] **www.ipc.on.ca/images/Resources/circle-care.pdf**

F. Consent Required for Incapable Patients in Various Medical Situations in Ontario (HCCA[1], CPSO[2]) Note: In Ontario, The Mental Health Care Act supersedes the Health Care Act.

EMERGENCY SITUATIONS	• Patient is experiencing severe suffering or is at risk of sustaining serious bodily harm if the treatment is not administered promptly. • To save life or prevent serious damage to health.
↓ ACTION IF CONSENT NOT AVAILABLE	• Treatment [d] may be given **without consent** to an incapable patient if, in the opinion of a physician, there is an emergency and the delay required to obtain consent or refusal on the patient's behalf will prolong that patient's suffering or will put him/her at risk of sustaining serious bodily harm or death. • Inquire if the patient has Advance Directives.
NON-EMERGENCY MAJOR	• Administering medications, or certain procedures (e.g., long-acting injectable hormonal substances for contraception, IUD insertion, draining an abscess). • Testing for HIV. • Providing treatment(s) for situations that pose substantial risk to the patient. • Providing procedural sedation and analgesia in the Emergency Department.
↓ ACTION IF CONSENT NOT AVAILABLE	• If there is no SDM or he/she cannot be contacted, only the Consent and Capacity Board can give consent.
NON-EMERGENCY MINOR	• Providing routine medical or dental treatments (e.g., check-up, ear syringe, nail cutting). • Administering routine medications or adjusting doses. • Providing topical anaesthetics or mild analgesia for minor procedures (e.g., laceration repair).
↓ ACTION IF CONSENT NOT AVAILABLE	• If there is no SDM or he/she cannot be contacted then treat if patient assents or does not object, and treatment is necessary. • Make a note in the patient record that he/she is assenting or not objecting and that treatment is necessary. Obtain consent from SDM as soon as possible. • Defer or re-book.

[d] **Treatment includes:** anything performed for a therapeutic, cosmetic or other health-related purpose, treatment plan, adjustments in the treatment, and continuation of the same treatment in a different setting.

Treatment does not include: assessing the patient's capacity to make decisions about treatment, admission to a care facility or personal assistance services, assessing the patient's capacity to manage property, taking a health history, assessing or examining a patient to determine the general nature of the patient's condition, communicating an assessment or a diagnosis, admitting a patient to a hospital or other facility, providing a personal assistance service, providing a treatment that in the circumstances poses little or no risk of harm or performing anything prescribed by the regulations.

References

1. Health Care Consent Act of Ontario, 1996. Chapter 2, Schedule A Ontario Regulation 856/93, as amended 2007 (made under the Medicine Act, 1991).

2. College of Physicians and Surgeons on Ontario Consent to Medical Treatment. Policy available at **www.cpso.on.ca/uploadedFiles/policies/policies/policyitems/Consent.pdf**.

Resources

Consent: A Guide for Canadian Physicians, Third Edition, The Canadian Medical Protective Association, 1996.

The Mini Task Force on Capacity Issues, The Dementia Network of Ottawa (2007). Determining capacity to consent: Guiding physicians through capacity and consent to treatment law. *Dialogue*, 3(3) July 2007: 32-38. **www.cpso.on.ca/uploadedFiles/policies/policies/policyitems/capacity_consent_july07dialogue.pdf**

U.K. Web Resource for determining capacity for persons with developmental disabilities: **www.intellectualdisability.info/how-to../consent-and-people-with-intellectual-disabilities-the-basics/**

In Ontario:

Consent and Capacity Board: **www.ccboard.on.ca**
1 800 461-2036; 416 327-4142 Direct Line in Toronto

Legal Aid Ontario: **www.legalaid.on.ca**

Office of the Public Guardian and Trustee 1 800 366-0335

Ontario Partnership on Aging and Developmental Disabilities: **www.opadd.on.ca**

Psychiatric Patient Advocate Office (PPAO): **www.ppao.gov.on.ca**

Federal and Provincial Informed Consent Legislation Websites

Federal	**Supreme Court of Canada Re Eve [1986] 2 S.C.R. 388** http://scc.lexum.org/en/1986/1986scr2-388/1986scr2-388.html
Alberta	**Personal Directives Act, R.S.A. 2000, c. P-6** http://www.qp.gov.ab.ca/Documents/acts/P06.CFM **Dependent Adults Act, R.S.A. 2000, c. D-11** www.qp.alberta.ca/570.cfm?frm_isbn=9780779752935&search_by=link
British Columbia	**Health Care (Consent) and Care Facility (Admission) Act [RSBC 1996]** www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/00_96181_01
Manitoba	**The Health Care Directives Act, C.C.S.M. c. H27** web2.gov.mb.ca/laws/statutes/ccsm/h027e.php
New Brunswick	**Infirm Persons Act, R.S. 1973, c. 1-8** www.gnb.ca/0062/pdf-acts/i-08.pdf
Newfoundland and Labrador	**Advance Health Care Directives, S.N.L. 1995, c. 4-41** www.assembly.nl.ca/legislation/sr/annualstatutes/1995/A04-1.c95.htm
Nova Scotia	**Personal Directives Act 2008, c.8,s.1.** http://nslegislature.ca/legc/statutes/persdir.htm
Northwest Territories and Nunavut	**Guardianship and Trusteeship Act, S.N.W.T. 1994, c. 29, as duplicated for Nunavut by s. 29 of the Nunavut Act.** www.justice.gov.nt.ca/PDF/ACTS/Guardianship%20and%20Trusteeship.pdf
Ontario	**Health Care Consent Act, 1996** www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm **Substitute Decisions Act, 1992, S.O. 1992, c. 30** www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_92s30_e.htm **Trillium Gift of Life Network Act, R.S.O. 1990, c. H.20** www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_90h20_e.htm
Prince Edward Island	**Consent Treatment and Health Care Directives Act, S.P.H.I. 1996, c. C-17.2** www.gov.pe.ca/law/statutes/pdf/c-17_2.pdf
Quebec	**Civil Code of Québec (C.C.Q.), S.Q. 1991, c. 64 (Articles, 12, 15, 20 and 22)** http://www.canlii.org/en/qc/laws/stat/sq-1991-c-64/latest/sq-1991-c-64.html
Saskatchewan	**The Adult Guardianship and Co-decision-making Act, S.S. 2000, c. A-5.3** www.justice.gov.sk.ca/Adult-Guardianship-and-Co-decision-making-Act
Yukon	**Decision Making, Support and Protection to Adults Ac, SY 2003, c.21** www.gov.yk.ca/legislation/acts/dmspa.pdf#page=30

