

Supporting adults with intellectual and developmental disabilities to participate in health care decision making

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Abstract

Objective To discuss what is new in the revised guideline 3 of the “Primary care of adults with intellectual and developmental disabilities [IDD]. 2018 Canadian consensus guidelines” on decision-making capacity, and how to implement the recommendations.

Quality of evidence Integrative review based on a literature search, the framework of the United Nations Convention on the Rights of Persons with Disabilities, and the experience of the authors.

Main message Person-centred health care of adults with IDD should include all possible contributions from the patient in decision making. At present, legal criteria do not address the relational aspects of decision making that are important for adults with IDD. The revised guideline 3 incorporates recent thinking regarding supported and shared decision making. It envisages decision making as a collaborative exercise in which the patient, trusted caregivers, and the family physician all are involved in deciding on medically appropriate interventions that promote the patient’s goals or values.

Conclusion Family physicians and caregivers both play an important role in supporting adults with IDD so that they can participate in health care decision making. Communication, mediation, and advocacy skills, plus the use of tools adapted for adults with IDD, can facilitate the family physician’s role.

Editor’s key points

- ▶ Assess adults with intellectual and developmental disabilities (IDD) regarding their need for accommodation and support in order to participate in health care decision making.
- ▶ Decision making should involve collaboration among the patient, caregivers, and the family physician in deciding on appropriate interventions that will promote the patient’s goals or values.
- ▶ Given the importance of caregiving relationships for the patient with IDD, it is important to identify a common ground among all parties when differences in goals or values arise between the patient and caregivers.
- ▶ Adults with a severe to profound level of IDD can have experiences or relationships that bring them joy and life histories that reveal what their goals or values are.

Points de repère du rédacteur

- ▶ Il importe d’évaluer les besoins d’accommodements et de soutien particuliers qu’ont les adultes ayant des déficiences intellectuelles et développementales (DID) afin qu’ils puissent participer à la prise de décisions sur leurs soins de santé.
- ▶ La prise de décisions devrait s’appuyer sur la collaboration entre le patient, les aidants et le médecin de famille pour le choix des interventions appropriées qui tiennent compte des objectifs ou des valeurs du patient.
- ▶ Étant donné l’importance que revêtent les relations avec ses aidants pour le patient ayant des DID, il importe de trouver un terrain d’entente entre toutes les parties lorsque survient entre elles un différend quant aux objectifs ou aux valeurs.
- ▶ Les adultes ayant des DID de graves à profondes, peuvent vivre des expériences ou des relations qui les rendent heureux, et leur vécu peut révéler leurs objectifs ou leurs valeurs.

Aider les adultes ayant des déficiences intellectuelles et développementales à participer aux décisions en matière de santé

Résumé

Objectif Présenter les nouveaux éléments de la ligne directrice 3 révisée des «Lignes directrices consensuelles canadiennes sur les soins primaires aux adultes ayant des déficiences intellectuelles et développementales (DID) de 2018» sur l'aptitude à prendre des décisions, de même que les façons de mettre les recommandations en pratique.

Source de l'information Une revue qui intègre une recherche documentaire, le cadre conceptuel de la *Convention relative aux droits des personnes handicapées* de l'Organisation des Nations Unies et l'expérience des auteurs.

Message principal Les soins de santé centrés sur la personne aux adultes ayant des DID devraient tenir compte de toutes les contributions possibles du patient à la prise de décisions. À l'heure actuelle, les critères du droit ne prennent pas en compte les aspects relationnels de la prise de décisions qui sont importants pour les adultes ayant des DID. La ligne directrice 3 révisée incorpore de récentes notions entourant une prise de décisions conjointe et soutenue. Elle envisage la prise de décisions comme un exercice en collaboration dans lequel le patient, ses aidants dignes de confiance et le médecin de famille participent tous au choix des interventions médicalement appropriées qui prennent en considération les objectifs ou les valeurs du patient.

Conclusion Les médecins de famille et les aidants jouent un rôle important dans le soutien aux adultes ayant des DID de manière à ce qu'ils puissent participer aux décisions sur leurs soins de santé. Des habiletés en communication, en médiation et en plaidoirie, de même que le recours à des outils adaptés aux adultes ayant des DID, peuvent faciliter le rôle du médecin de famille.

This article discusses guideline 3 on capacity for decision making in the "Primary care of adults with intellectual and developmental disabilities [IDD]. 2018 Canadian consensus guidelines" (hereafter referred to as *guideline 3*).¹ It discusses what has changed from the last such guideline in 2011,² and the basis for these changes. It suggests how family physicians can apply guideline 3 to their practices.

The College of Family Physicians of Canada affirms the right of patients to participate in decisions regarding their health care.³ Canadian laws on consenting to health care, however, equate decision-making capacity

with an individual's mental capacity to make an independent decision. This legal approach aims to protect patients from being subjected to interventions they do not want; however, it tends to reinforce an informative or consumer model of the patient-physician relationship.⁴ In this model, the physician's role involves formulating the patient's diagnosis and prognosis, and identifying possible interventions. The patient alone is left to decide among these interventions.

The informative or consumer model overlooks the relational aspects of health care decision making that are important for adults with IDD.⁵ They are at a disadvantage when treated as isolated consumers of health care. They need family members and other trusted caregivers, as well as health care professionals, to assist them by eliciting and developing the confidence and skills needed to engage in decisions regarding their health care. Research indicates that the decision-making capacity of adults with IDD depends on factors beyond their intellectual and adaptive functioning—factors such as the extent of their previous experience with health care decisions, the degree and quality of interaction between health care professionals and the patient, and the methods of communication used.⁶⁻⁸ Some adults with IDD who are assessed to lack legal decision-making capacity can contribute to the decision-making process if provided with appropriate accommodation and support from others.⁹⁻¹¹

Many adults with mild IDD (mental age equivalence of 9 to 12 years old) can make simple or familiar decisions regarding health care but might need support to make more complex ones. Most adults with moderate IDD (age equivalence of 6 to 9 years old) need accommodation and support from others to enable them to make even simple or familiar health care decisions. Adults with severe to profound IDD (age equivalence of less than 6 years old) require more extensive accommodation and support. For example, they might be supported to communicate or they might have life histories that indicate their goals or values, all of which can guide decisions regarding their health care.^{12,13}

Guideline 3 incorporates recent thinking regarding supported and shared decision making in health care. It recommends addressing the needs of adult patients with IDD by employing a *collaborative* process in which the patient, trusted caregivers, and the family physician deliberate together to agree on medically sound interventions that best promote the patient's goals or values.

This approach draws on the United Nations' Convention on the Rights of Persons with Disabilities, a document that the federal government and all Canadian provinces and territories have ratified. Article 12 states that "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life" and they should have access to "the support they may require in exercising their legal capacity."¹⁴

Main message

Supported decision making. Supported decision making is an alternative to legal appointment of a guardian or other substitute decision maker for an adult with IDD. Some Canadian provincial and territorial laws recognize this option. British Columbia, Alberta, Manitoba, and Yukon do so.^{15,16} In Ontario, law reform is considering it.¹⁷ In practice, supported decision making means that adults with IDD can enter into an agreement with family members and others whom they trust to be their supporters. Such agreements authorize these supporters to have access to the patient's health records, facilitate the patient's understanding, and interpret and communicate the patient's goals or values. While not yet authorized everywhere in Canada, the general principle that adults with IDD should have accommodation and support to participate in their health care decision making can be applied to some extent.

Shared decision making. Shared decision making is another person-centred approach.^{18,19} While supported decision making engages caregivers of adults with IDD as supporters of patients, shared decision making focuses on the family physician providing support. Shared decision making is a process of mutual engagement that is exploratory and dynamic. It is not about coercing the patient or caregivers to accept the family physician's recommendation, nor is it about leaving patients and caregivers to decide without input and guidance from their family physicians.²⁰

Health care decision making is a multi-step process. The patient, caregivers, and health care professionals all have distinctive roles at each step. These steps, which are familiar to all health care professionals, are as follows:

- assembling information relevant to the patient's health situation,
- formulating a diagnosis and prognosis,
- verifying this, and
- deliberating on possible medical interventions that promote the patient's goals or values.²¹

Decision making is best approached as a collaboration among all parties. Caregivers other than family members and health care professionals beyond the family physician might be involved as needed.²² The family physician takes the lead in the first 3 steps. The input and participation of the patient and caregivers are decisive in the fourth step.

The role of the family physician is to help the patient and caregivers to clarify and discuss the patient's values (eg, life goals or what the patient enjoys) in relation to possible medically appropriate interventions. Shared decision making can be practised in a situation where a substitute decision maker is involved who does not know the patient well. In this case, the guideline stipulates that the family physician should encourage the substitute decision maker to consult trusted caregivers who

know the patient well. Some Canadian laws regulating substitute decision making in Canada already require guardians appointed for adults with IDD by the Office of the Public Guardian and Trustee or the court to do this.

Practical suggestions for implementing supported and shared decision making. Applying supported and shared decision making with adults with IDD is not always straightforward and can entail adaptations of normal practice and skills. Best practice and skill in caring for these patients, however, can be learned over time and with experience. The central principles involve always striving to know the patient and caregivers, and to build good relationships based on effective communication and trust. What follow are some practical suggestions.

Determine the patient's decision-making capacity and need for accommodation and support: This approach represents a shift in normal practice. The focus of assessing decision-making capacity should not be on whether the patient lacks legal capacity but on what accommodation and support the patient needs to contribute to decision making. These might include using simply worded or visual materials, involving the caregiver's communication with the patient, and using the results to interpret the patient's goals or values. Such assessments should be conducted for every new patient with IDD and repeated if decisions regarding new interventions are complex or involve substantial risk of harm. Tools for assessing decision-making capacity that have been adapted for adults with IDD should be employed (eg, Decision-Making Checklist²³). When uncertain, refer to a psychologist or other health care professional who is familiar with assessing the decision-making capacity of adults with IDD or people with similar needs.

Family physicians should be aware that a patient with IDD's level of adaptive functioning and the level of support this patient needs can change over time. For instance, the patient's ability to participate in health care decision making can increase as the patient gains confidence and skills, and receives appropriate accommodation and support to do so. Some adults with IDD have had little experience in making their own decisions. They might live in a structured, protective environment in which others make decisions for them without their involvement. Learned helplessness, acquiescence, and suggestibility can predispose a patient with IDD to be compliant with requests from caregivers and health care professionals regarding decisions that do not necessarily promote the patient's goals or values.²⁴

Some patients with IDD might have limited support for decision making or might experience neglectful, abusive, or overprotective relationships. In these situations, the family physician should become an advocate and engage other more suitable supports for the patient.

Enlist the help of caregivers to prepare the patient for visits to the clinic: Supporting a patient with IDD's

participation in health care decision making begins with preparing for visits to the family practice clinic. The patient should be involved in planning for such visits and agree to the goals of the visit.²⁵ Family physicians can encourage caregivers to use tools such as Today's Health Care Visit,²⁶ the Ask (Advocacy Skills Kit) Help Diary,²⁷ Today's Visit,²⁸ and the first part of the Comprehensive Health Assessment Program.²⁹

Promote conditions in the clinic to optimize communication of the patient's and caregiver's perspectives: It is important that the family physician adapt communication to the patient's preferred communication method and involve caregivers. Schedule appointments at an optimal time of day for the patient, book sufficient clinic time, and make the environment appropriate to put the patient at ease (eg, by accommodating any noise or light sensitivities the patient might have).

Family physicians should be aware that some patients with IDD have difficulty expressing emotional distress related to their illness, past traumatic experience with health care, and other negative life events that could affect their response to proposed interventions. When being assessed, the patient's distress might be manifested by resistance or lack of engagement. The underlying causes of such behaviour need to be explored.

Facilitate and support deliberation regarding interventions: Acknowledge and engage the patient and caregivers. Ensure that they understand that there are reasonable options for the patient's care and that a decision does not have to be made during a single visit. It is ethically appropriate for the family physician to explain possible interventions and their potential benefits and risks, but also the goals or values underlying those interventions (eg, prolonging life, improving function, alleviating distress, conserving the integrity of important relationships, minimizing intrusion or inconvenience). Elucidate and clarify expressed preferences of the patient or caregivers in terms of their underlying goals. This is important because the patient and caregivers might not be able to identify or articulate their goals or to distinguish clearly between transient desires and more deeply rooted commitments and hopes. Adults with a severe to profound level of IDD can also have goals (eg, experiences or relationships that bring them joy). Their input, verbally, non-verbally, or through the interpretation of caregivers, and their life histories can indicate what these goals are.

Sometimes, there is incongruence between the patient's expressed preferences and their goals. A discussion of these differences can be helpful. At other times, the goals of the patient and caregiver might be at odds. Given the importance of the caregiving relationship, it is necessary to identify common ground, to facilitate reconciliation of differences, or to find an option for intervention that will be acceptable to all parties.

The family physician ought also to be aware of and accommodate any cultural or religious factors that form

part of the dynamic within family relationships. For example, in certain cultural or religious traditions, deference to those in authority might be common. Be prepared to mediate or advocate on behalf of the patient, however, when the caregiver overlooks or dismisses the patient's perspectives in a way that devalues the person.

The family physician should gently, but firmly and persistently, focus deliberation on reaching agreement on mutually acceptable goals, and interventions that are means of promoting those goals. It is important, however, that the patient and caregivers feel that they have sufficient time to ask relevant questions and consider options for intervention. At times, when an option involves uncertainty or ambiguity, a trial period for intervention might be an acceptable option. At other times, the family physician might need to address concerns or reservations by adopting a less medically effective option. For example, if the patient has a fear of needles, a flu vaccination via a nasal spray, while possibly less effective, might be an acceptable alternative.

Challenges for implementation. Implementing the above approaches will entail more clinic time and adaptation of normal practice to accommodate and support patients with IDD. It might involve additional training of the family physician (eg, in communicating with and assessing such patients). The family physician's gain in trust and rapport with the patient and caregivers will diminish distress. When the patient and caregivers are treated respectfully as partners in health care, more person-centred decisions result. Adults with IDD have needs because of their disability, and they are entitled to the person-centred care that all patients should receive. The College of Family Physicians of Canada's program committee for IDD and members of the Developmental Disabilities Primary Care Program funded by the Ontario government are some of the groups in Canada that are working to make clinical tools and training available to family physicians in this area. Where resources are unavailable, family physicians can be advocates on behalf of their patients with IDD for such resources.

Conclusion

Family physicians and caregivers play an important role in supporting adults with IDD to make the best decisions possible regarding interventions that promote their health care and life goals. This might involve communicating, understanding, and providing support in deliberating. It might involve helping the patient to develop the confidence and abilities necessary to contribute to health care decision making. Because relationships and support are so important for adults with IDD, the revised guideline 3 on decision-making capacity has incorporated the notions of supported and shared decision making.¹ These approaches are also relevant to patients without IDD with similar needs. Communication, mediation, and advocacy skills, plus the use of tools adapted for adults with IDD, can facilitate family physicians' role in supporting their patients with IDD. 🌿

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Contributors

Both authors contributed to the literature review and interpretation, and to preparing the manuscript for submission.

Competing interests

None declared

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References

1. Sullivan WF, Diepstra H, Heng J, Ally S, Bradley E, Casson I, et al. Primary care of adults with intellectual and developmental disabilities. 2018 Canadian consensus guidelines. *Can Fam Physician* 2018;64:254-79 (Eng), e137-66 (Fr).
2. Sullivan WF, Berg JM, Bradley E, Cheetham T, Denton R, Heng J, et al. Primary care of adults with developmental disabilities. Canadian consensus guidelines. *Can Fam Physician* 2011;57:541-53 (Eng), e154-68 (Fr).
3. College of Family Physicians of Canada. *A vision for Canada. Family practice. The patient's medical home*. Mississauga, ON: College of Family Physicians of Canada; 2011. Available from: www.cfpc.ca/uploadedFiles/Resources/Resource_Items/PMH_A_Vision_for_Canada.pdf. Accessed 2018 Mar 6.
4. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *JAMA* 1992;267(16):2221-6.
5. Reinders H. *The future of the disabled in liberal society: an ethical analysis*. Notre Dame, IN: University of Notre Dame Press; 2000.
6. Cea CD, Fisher CB. Health care decision-making by adults with mental retardation. *Ment Retard* 2003;37(2):78-87.
7. Goldsmith L, Skirton H, Webb C. Informed consent to healthcare interventions in people with learning disabilities: an integrative review. *J Adv Nurs* 2008;64(6):549-63.
8. Wong JG, Clare CH, Holland AJ, Watson PC, Gunn M. The capacity of people with a 'mental disability' to make a health care decision. *Psych Med* 2000;30(2):295-306.
9. Wark S, MacPhail C, McKay K, Müller A. Informed consent in a vulnerable population group: supporting individuals aging with intellectual disability to participate in developing their own health and support programs. *Austral Health Rev* 2017;41(4):436-42.
10. Ferguson L, Murphy GH. The effects of training on the ability of adults with an intellectual disability to give informed consent to medication. *J Intellect Disabil Res* 2014;58(9):864-73.
11. Baumbusch J, Phinney A, Baumbusch S. Practising family medicine for adults with intellectual disabilities. Patient perspectives on helpful interactions. *Can Fam Physician* 2014;60:e356-61. Available from: www.cfp.ca/content/cfp/60/7/e356.full.pdf. Accessed 2018 Mar 6.
12. Heng J, Sullivan WF. Ethics of decision making and consent in people with developmental disabilities. In: Wehmeyer ML, Brown I, Percy M, Shogren KA, Fung WLA, editors. *A comprehensive guide to intellectual and developmental disabilities*. 2nd ed. Baltimore, MD: Brookes; 2017. p. 655-64.
13. Edwards B, Temple V, Dunn L. Adaptive functioning and communication associated with different levels of developmental disability. In: Sullivan WF, Developmental Disabilities Primary Care Initiative Scientific and Editorial Staff, editors. *Tools for the primary care of people with developmental disabilities*. Toronto, ON: Surrey Place Centre, MUMS Guideline Clearinghouse; 2011. p. 6-7. Available from: surreyplace.ca/ddprimarycare/tools/general-health/adaptive-functioning/. Accessed 2018 Mar 6.

14. United Nations. *Convention on the rights of persons with disabilities*. New York, NY: United Nations; 2006. Available from: www.un.org/esa/socdev/enable/rights/convtexte.htm#convtext. Accessed 2018 Mar 6.
15. *Representation Agreement Act*. R.S.B.C. 1996 c 405.
16. *Adult Guardianship and Trusteeship Act*. S.A. 2008 c A-4.2.
17. Bach M, Kerczner L. *A new paradigm for promoting autonomy and the right to legal capacity. Advancing substantive equality for persons with disabilities through law, policy and practice*. Toronto, ON: Ontario Law Commission; 2010. Available from: www.lco-cdo.org/wp-content/uploads/2010/11/disabilities-commissioned-paper-bach-kerzner.pdf. Accessed 2018 Mar 6.
18. Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med* 2012;27(10):1361-7. Epub 2012 May 23.
19. King JS, Moulton BW. Rethinking informed consent: the case for shared medical decision-making. *Am J Law Med* 2006;32(4):429-501.
20. Grad R, Légaré F, Bell NR, Dickinson JA, Singh H, Moore AE, et al. Shared decision making in preventive health care. What it is; what it is not. *Can Fam Physician* 2017;63:682-4 (Eng), e377-80 (Fr).
21. Engebretsen E, Vøllestad NK, Wahl AK, Robinson HS, Heggen K. Unpacking the process of interpretation in evidence-based medicine. *J Eval Clin Pract* 2015;21(3):529-31. Epub 2015 Apr 7.
22. Walker P, Lovat T. Dialogic consensus in clinical decision making. *J Bioeth Inq* 2016;13(4):571-80. Epub 2016 Aug 17.
23. Developmental Disabilities Primary Care Initiative. Informed consent in adults with developmental disabilities. In: Sullivan WF, Developmental Disabilities Primary Care Initiative Scientific and Editorial Staff, editors. *Tools for the primary care of people with developmental disabilities*. Toronto, ON: Surrey Place Centre, MUMS Guidelines Clearinghouse; 2011. p. 11-7. Available from: surreyplace.ca/ddprimarycare/tools/general-health/capacity-for-decision-making/. Accessed 2018 Mar 6.
24. Arscott K, Dagnan D, Kroese BS. Assessing the ability of people with a learning disability to give informed consent to treatment. *Psych Med* 1999;29(6):1367-75.
25. Greco-Joseph L. *The situated and dialogical 'nature' of (in)competence: a socio-cultural approach to informed consent treatment decision-making competence in adults diagnosed with intellectual disability* [doctoral thesis]. New York, NY: The City University of New York; 2013.
26. *Today's health care visit*. Toronto, ON: Health Care Access Research and Developmental Disabilities; 2015. Available from: www.porticonetwork.ca/documents/38160/99698/Today%27s+Health+Care+tool_original/0225d60c-faaa-43e5-b8ce-e636bafd1ea9. Accessed 2018 Mar 6.
27. *Ask help diary* [app]. Brisbane, Aust: Queensland Centre for Intellectual and Developmental Disability; 2016. Available from: <https://itunes.apple.com/au/app/ask-diary-advocacy-skills-kit-diary/id1095955087?mt=8>. Accessed 2018 Mar 6.
28. *Today's visit*. In: Sullivan WF, Developmental Disabilities Primary Care Initiative Scientific and Editorial Staff, editors. *Tools for the primary care of people with developmental disabilities*. Toronto, ON: Surrey Place Centre, MUMS Guidelines Clearinghouse; 2011. p. 24-5. Available from: surreyplace.ca/ddprimarycare/tools/general-health/todays-visit/. Accessed 2018 Mar 6.
29. Lennox N. *Comprehensive Health Assessment Program*. Brisbane, Aust: Queensland Centre for Intellectual and Developmental Disability; 2007. Available from: <http://eshop.uniquet.com.au/chap/>. Accessed 2018 Mar 6.

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