

The Right
to **Decide.**

Intellectual Disability and the Right to Decide

Discussion Paper: Recommendations to Reduce
Substitute Decision-Making and Increase Access
to Supports for Decision-Making in Ontario

This document offers legislative and policy recommendations to increase choice, control, and decision-making among people who have an intellectual disability.



The Right to Decide Project – Overview

‘Legal capacity’ refers to people’s experience of being recognized as persons before the law, exercising rights, accessing the civil and judicial system, entering into contracts, making decisions about their own life and property, and communicating on their own behalf.

In many situations (for example, in the case of guardianship) substitute decision-making removes people’s legal capacity, i.e., the right to direct their own lives, including managing their money, making health-related decisions, and deciding where and with whom they live.

From 2018 to 2023, Community Living Ontario worked with five front line service organizations to understand how people who have an intellectual disability exercise their right to legal capacity – that is, how they make choices and decisions, and the barriers they face in doing so.

Our collaborative work uncovered many enablers of legal capacity, as well as many barriers. This resource is part of a series of documents that address this important issue.

Our local partners in the project were Community Living Dryden & Sioux Lookout, Brockville & District Association for Community Involvement, Durham Family Resources, and Community Living Windsor in partnership with Windsor Essex Brokerage for Personal Supports.

Special thanks to the Institute for Research and Development on Inclusion and Society (IRIS), PooranLaw, and Inclusion Canada.

For more information and resources related to this project, please visit our Right to Decide resource page.



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Introduction

In a 1995 discussion paper funded by the Ontario Ministry of Citizenship, the Coalition on Alternatives to Guardianship wrote that, “if we refuse to permit an individual to be designated ‘incapable,’ that person has a chance to become more capable. If [they are] labelled incapable (especially in a solemn and official manner), then increased levels of capability are extremely unlikely to be reached.”

The Coalition also wrote that “not only does a designation of incompetence or incapacity have a devastating negative impact on those who are forced into that classification, the reality is that there are enormous problems in attempting to devise reliable and realistic means of making such a distinction.”¹

There is great irony in the fact that Ontario-based advocates were ahead of their time in thinking about mental and legal capacity, yet the province of Ontario has fallen behind other jurisdictions (including four Canadian provinces and one territory,² nineteen U.S. states,³ and Australia⁴) in recognizing the legal capacity and right to decide of people who have an intellectual disability.

The recommendations put forward in the following sections of this document build on legislation, regulations, and policy that have already been implemented in other jurisdictions, and that were significantly inspired by work produced in Ontario.

Legal capacity and decision-making: Combining a long-term vision with short-term changes

The recommendations offered below are separated into two streams:

- a. A long-term stream that envisions the implementation of supported decision-making legislation in Ontario.
- b. A short-term stream that foresees better use of existing provisions that require legal, health, financial, and social service system actors to implement and support decision-making arrangements that are less restrictive than guardianship.

This document draws on our critiques of guardianship, the capacity assessment process, the court system, and the Ontario Public Guardian and Trustee, which can be found on our Right to Decide resource page.

Defining Supported Decision-Making

Supported decision-making allows people with disabilities to make choices about their own lives with support from a team of people they choose. Decision supporters can help a person seek out and understand information, weigh options, make decisions, and communicate those decisions. They can also help to increase a person’s ability to make decisions without support.

Supported decision-making is an alternative to guardianship that preserves a person's human rights. Instead of having a guardian make a decision for the person with the disability, supported decision-making allows the person with the disability to make their own decisions and preserve their legal status as a person under the law.

For more than thirty years, Community Living Ontario has urged governments in Ontario and across Canada to implement alternatives to guardianship. This advocacy is based in our profound belief that guardianship represents a violation of the right to autonomy and self-determination on the basis of mental disability, a prohibited ground of discrimination under section 15 of the *Canadian Charter of Rights and Freedoms*. Moreover, we believe that placing people under guardianship (which vests their legal agency and personhood in another authority) undermines their right to equal respect and dignity, which are cherished values in Canadian society.

Legal scholar Sheila Wildeman has made the case that:

“... extending supported decision-making across sectors and services, in a manner integrated with access to other resources, will strengthen disabled persons' agency and community participation in ways preventive of intensive crisis- and conflict-based interventions as well as long-term institutionalized control and thereby reduce the social, economic and personal costs of such interventions and systems over time.”⁵

This paragraph encapsulates several decades of disabled persons' advocacy, and rightfully positions control and decision-making as the

central factors around which health and quality of life revolve. In simpler terms, the logic goes as follows:

If we respect and support people's right to exercise legal capacity, and increase access to services and supports that enhance self-determination and control, quality of life will increase and costs will decrease.

In the recommendations that follow, we are calling on the Government of Ontario to engage in two key action streams that will advance the right to exercise legal capacity (in other words, the right to decide), and that will lead to increases in quality of life and reduced costs among people who have an intellectual disability:

1. Implement a proactive, evidence-based system of supports for decision-making for people who have an intellectual disability in Ontario, underwritten by changes to the *Substitute Decisions Act* and the *Health Care Consent Act*.
2. Increase oversight and make changes to ensure that service providers, health care practitioners, substitute decision-makers, and legal system stakeholders are following the principles and directives set out in the *Ontario Substitute Decisions Act*, with particular attention to (a) the presumption of mental capacity, and (b) decision-making supports that are less restrictive than guardianship.

These recommendations are not meant to be exhaustive. Rather, they are intended to assist with setting a new path forward that recognizes and enables the exercise of legal capacity among people who have an intellectual disability.

Recommendations

A. Long-view recommendations for the Government of Ontario

1. Ensure that people who have an intellectual disability have a seat at the head of the table in any and all discussions of legal capacity and the right to decide.
2. Perform a comprehensive review of the *Substitute Decisions Act (SDA)*, *Health Care Consent Act (HCCA)*, and other Ontario laws, regulations, and policies that displace the right to the exercise of legal capacity among people who have an intellectual disability. Ground this review in a vision that promotes and protects the ability of people with intellectual disabilities to direct and control their own lives. This includes a definition of ‘legal capacity’ that is consistent with international law and that recognizes that all people have a will and preferences that guide decisions in their lives.
3. Create a formal supported decision-making regime in Ontario, which will update and replace relevant elements of the *Substitute Decisions Act* and *Health Care Consent Act*. This includes a provision for the statutory appointment of decision-making supporters (based in a demonstrated personal relationship of trust, personal knowledge and commitment to people utilizing decision supports), and a recognition of people’s right to accommodations in decision-making processes.

Ontario can build on the work of dozens of jurisdictions around the world that have created administrative and oversight processes for supported decision-making.

The formalization of supported decision-making arrangements as a less restrictive and intrusive alternative to substitute decision-making for adults with intellectual disabilities aligns with the CRPD and the Charter. With appropriate accountability and oversight, new legislation will provide for increased transparency and safety, as compared to current support and substitute decision-making relationships. It will also provide greater direction and certainty to third parties (e.g., financial institutions) when engaging with adults who make use of decision supporters.

4. Support the creation of a Decision Support Hub that is responsible for research and dissemination of best practices in supported decision-making in Ontario.
5. Remove the adjudication of guardianship for people with intellectual disabilities from the Ontario Superior Court of Justice. Create a system of decision support tribunals, with specific knowledge and experience relevant to intellectual disability (including governance oversight from people who have an intellectual disability) that will be responsible for adjudicating applications for guardianship.

This approach has been recommended by the Law Commission of Ontario,⁶ and has been implemented in the province of Manitoba. As the Nova Scotia Department of Justice recently noted:

“Dealing with capacity matters outside court would meaningfully respond to the access to justice issues that we see at the heart of many of the complaints... the complexity and cost of making an application when the matter is relatively straightforward on one hand, and the lack of real opportunity for adults with cognitive disabilities to challenge the conditions imposed on them by a representation order on the other.”⁷

B. Short-view recommendations for the Government of Ontario

1. Recognize and act on the provincial government’s duty to support decision-making arrangements that are less restrictive than guardianship, as provided for in sections 22 (3) and 55 (2) of the *Substitute Decisions Act*.
2. Increase education, training, and resources for judges, legal professionals, capacity assessors, health care practitioners, service providers, family members and other substitute decision-makers engaged in issues of decision-making with people who have an intellectual disability. Perhaps most importantly, increase education about rights, decision supports, and substitute decision-making among people who have an intellectual disability themselves, including those with limited access to the broader community, e.g., those living in long-term care facilities, hospitals, prisons, and psychiatric facilities.

The Ontario Public Guardian and Trustee should identify and make contact with adults who are subject to orders granted under the SDA or HCCA, in order to educate adults and guardians about the significant rights and duties that apply to them under these laws.

The Attorney General of Ontario should engage in education for judges that emphasize efforts to divert applications for substitute decision-making where there are feasible alternatives. This would involve judges working proactively with families and community partners to determine whether substitute decision-making appointments are truly appropriate and necessary.

3. With respect to capacity assessments:
 - Provide funding for the supports (including a person’s decision supporters) required to assist people in demonstrating legal capacity in the context of a capacity assessment, and to enhance participation in decision-making more generally.
 - The Government of Ontario must clearly state that a person can access support and other accommodations in assessments of mental capacity, and update the *Guidelines for Conducting Assessments of Capacity* to reflect this fact.
 - Amend the *Health Care Consent Act* and *Substitute Decisions Act* to clarify that capacity exists where people can meet tests for mental capacity with appropriate accommodations and support.
 - Amend the *Substitute Decisions Act* to include the right to legal counsel as part of capacity assessors’ initial advice to any adult taking part in a capacity assessment. Add this action to the province’s *Guidelines for Conducting Assessments of Capacity*.

- Engage with stakeholders to explore ways of improving the performance of capacity assessments, in the context of both the HCCA and SDA. Education and training should be offered, including the development of a more detailed guide to conducting assessments.
4. With respect to the Ontario Superior Court of Justice:
 - Increase access to independent legal counsel among people with intellectual disabilities facing a guardianship application. While people are entitled to legal counsel in guardianship proceedings, practically speaking in many cases it is very difficult for many to access a lawyer.
 - Require the appointment of a litigation guardian for adults who are unable to instruct counsel in a guardianship proceeding. The litigation guardian must be mindful of the duties to support and represent the adult's will and preference, rather than making decisions on the basis of the litigation guardian's view of the adult's best interests.
 - Increase recourse to alternatives to guardianship by giving adjudicators considering the appointment of a guardian for property or personal care the authority to (a) request submissions from any party regarding the least restrictive alternative, and (b) request decisional- and support-related information regarding individuals whose capacity is in question from parties including the Public Guardian and Trustee, Adult Protective Services Workers, and developmental services staff.
 5. Establish coordinated navigation services to support adults facing SDA proceedings, as well as family members applying to become guardian of property or guardian of the person. This would include referrals to counselling and dispute resolution services, and the connection of adults to independent legal counsel.
 6. Increase funding to Legal Aid Ontario to:
 - Increase access to Section 3 Counsel;
 - Increase access to legal representation for people who want to challenge the appointment or choice of a guardian;
 - Support people to challenge the compliance of substitute decision-makers.

Additionally, implement the Law Commission of Ontario recommendation to “amend the *Substitute Decisions Act* to specify that it is an offence for a person to impede or interfere with the ability of counsel appointed under section 3 to carry out their statutory function, and to codify a right for Section 3 Counsel to meet privately with their clients.”⁸
 7. Empower the Ontario Ombudsman with the authority to conduct ‘spot checks’ of a given number of substitute decision-makers (including family members and the OPGT) each year. This would include attention to the quality of life of the person, substitute decision-makers’ adherence to following and respecting the wishes and instructions of the person, and financial accountability.

8. Significantly increase the number of guardians for property who are required to pass their fiduciary accounts before the Ontario Superior Court of Justice, to root out cases of fraud and increase disincentives to financial mismanagement.

(As the Law Commission of Ontario has noted, “most substitute decision-makers have only a limited understanding of their roles. There are no mechanisms for ensuring that SDMs understand their task: while some will take the initiative to research their responsibilities, many will not. As a result, it is not surprising that these roles are often imperfectly carried out.”)⁹

9. Increase the use of time-limited guardianship orders and increase reviews of existing guardianships. Further, increase the use of limited (as opposed to plenary) guardianships for personal care, and implement partial guardianships for property. As the Law Commission of Ontario has written:

“While the *Substitute Decisions Act* permits the Court, in appointing guardians of property, to impose such conditions as it deems appropriate, there is not the same strong legislative language directing the consideration of and preference for partial guardianships for property. Nor does the legislation specifically address the possibility of partial guardianships for statutory guardians of property.”¹⁰

10. Consider and assess the potential benefits and drawbacks of expanding the ability of the Consent and Capacity Board (CCB) to appoint representatives to make single decisions related to property and personal care. The LCO notes that the CCB has the ability to do this under the HCCA:

“Under Ontario’s regime, decisions for treatment, admission to long-term care and personal assistance services for persons who lack legal capacity are made on a decision-specific basis without the need for a formal, long-term appointment of a substitute decision-maker... The LCO believes that expanding this power to issues related to property management or personal care would increase the flexibility of the system to address those situations where needs for formal decision-making are relatively rare, and even a partial guardianship would unnecessarily restrict the autonomy of the individual.”

11. Honour the promises made in the new strategy for developmental services in Ontario, *Journey to Belonging: Choice and Inclusion*.

Journey to Belonging notes that “People and their families expect to enjoy all the rights and opportunities that other members of society take for granted, like going to school, having a job, receiving healthcare services, and having real choices and control over the decisions that affect them. Significant progress has been made over the years, but we still have work to do.”

Journey to Belonging includes the guiding principle of person-directedness, i.e., “A person is in charge of making important decisions for themselves, based on what they want for their life. People can get help to make decisions for themselves if they would like it.”

If taken seriously, these directives have real implications for how we respond when people request assistance via Developmental Services Ontario. They mean, for example, that:



- Services and supports for transition-aged youth, and for people with intellectual disabilities more broadly, must respond to the pervasive lack of control and decision-making power they have experienced throughout their lives.
- People must have much greater choice as to where they live, and who they live with.
- People must have much greater choice in how they pay for and receive support, and in who provides that support.
- People must be supported to live, age, and die in homes of their choosing.

The Right to Decide project is bringing refocused attention to the ways that people who have an intellectual disability are being stripped and deprived of their rights as persons. Our recommendations, built on decades of research and empirical evidence, as well as lessons learned in other jurisdictions, offer a better way forward that will increase the human rights, health, and quality of life of people who have been marginalized and left behind for far too long.

For more information and resources related to this project, please visit our [Right to Decide resource page](#).



Notes

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Community Living Ontario is a non-profit provincial association that has been advocating with people who have an intellectual disability and their families for 70 years. We proudly work alongside more than 115 local agencies and advocate on behalf of more than 100,000 people across Ontario.

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