The Right to Decide.

Assessing the legal, regulatory and policy basis for supported decision-making among people who have an intellectual disability in Ontario

Community Living Ontario

Intégration communautaire Ontario

“States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.”

- Convention on the Rights of Persons with Disabilities (CRPD), Article 12 (4)

“Under article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity.”

- United Nations Committee on the Rights of Persons with Disabilities

“Nothing About Us Without Us.”

a. Introduction

Far too often, people who have intellectual, developmental, cognitive, and mental health disabilities in Ontario are prevented from guiding their own lives and making their own decisions.

This is happening despite the fact that the Province of Ontario is governed by a range of legal frameworks that recognize the legal capacity and decision-making rights of people with disabilities.[1] Disabled people in Ontario consistently have their rights trampled and removed because legislation, policies, programs, and practices do not live up to the targets set by the legal frameworks that are supposed to guide them.

In the simplest sense, disabled people continue to be stereotyped based on the label of 'disability,' rather than being treated as individuals with unique abilities, personalities, histories, preferences, and life goals. They face constant bias, stigma and discrimination in education, health care, social services, employment, legal affairs, financial systems, housing, government programs and everyday life. Their capacity to direct their own lives and make their own decisions is constantly questioned.

Barriers to decision-making and control are particularly salient for people labelled as having an intellectual disability, because of pervasive stereotypes and beliefs about their mental capacity. People who have an intellectual disability are much more capable of making decisions and directing their own lives than is commonly believed.

Ontario's Substitute Decisions Act (the "SDA") and *Health Care Consent Act* (the "HCCA") (and, in particular, interpretations of these acts) are two important documents where biases and stereotypes about people who have an intellectual disability are enacted. In our view, these two pieces of legislation, and interpretations of this legislation, fall far short of meeting the requirements of the *Convention on the Rights of Persons with Disabilities* (the "CRPD"), the *Canadian Charter of Rights and Freedoms* (the "Charter"), the *Ontario Human Rights Code*, the *Accessibility for Ontarians with Disabilities Act*, and the disabled persons' mantra of "Nothing About Us Without Us." As a result, people who have an intellectual disability continue to experience serious barriers to health, well-being, and quality of life.

While other jurisdictions have been inspired by the Convention on the Rights of Persons with Disabilities to enact new approaches to legal capacity and decision-making, and despite consistent advocacy from people who have an intellectual disability and their families, Ontario continues to be stuck in the past.

[1] In order to respect and honour different perspectives on language, this document uses a variety of 'people first' and 'identity first' terms to describe people, including 'people with disabilities,' 'disabled people,' 'people labelled as having an intellectual disability,' 'people who have an intellectual disability, etc.

b. Definitions: Understanding the language of 'legal capacity,' 'mental capacity,' 'will and preference,' and 'supports for decision-making'

Discussions about decision-making and control among people who have an intellectual disability can be complex and sometimes confusing. It is important to define a few key words and phrases that are commonly used: 'legal capacity,' 'mental capacity,' 'will and preference,' and 'supports for decision-making.'

What is 'legal capacity'?

'Legal capacity' refers to people's right to be recognized as persons before the law, exercise rights, access the civil and judicial system, enter contracts, make decisions about their own life, and speak on their own behalf.[2, 3]

In many situations (e.g., 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 medical decisions, and deciding where and with whom they live.

What is 'mental capacity'?

In Ontario's Substitute Decisions Act, 'mental capacity' is defined as the ability to understand information that is relevant to making a decision, and the ability to appreciate the reasonably foreseeable consequences of a decision or lack of a decision.

What is 'will and preference'?

Article 12 of the CRPD refers to the "rights, will and preferences of the person." While a broad range of articles have been written about the definition of 'will and preference,' Community Living Ontario is informed by the realities of the past in thinking about these concepts. For example:

- People with disabilities have an overwhelming *preference* not to be sterilized against their will.
- People with disabilities have an overwhelming *preference* not to be forced into large, controlled-access facilities against their will.
- People with disabilities have an overwhelming *preference* to not be physically touched, abused, or restrained against their will.

[2]https://www.un.org/esa/socdev/enable/rights/ahc8docs/ahc8idc1218ex.doc
[3]https://inclusioncanada.ca/2017/11/15/what-is-legal-capacity/

We know this because people with disabilities are people, and no person wants these things. All people, including disabled people, have an overwhelming *preference* to control their own lives and make their own decisions.

As we know, disabled people have been sterilized against their will, forced into locked residential wards, and physically and sexually abused on a disturbingly massive scale. These experiences inform the way we currently approach decisions about related things like sexual and reproductive health, housing, and medical care. They translate into how we understand people's desire to control and manage their own money, who they choose to provide support and care, who they choose to hang out with, which foods they like to eat, and what substances they want to put into their body.

Decades of experience have taught us that all people can express will and preference, even if they don't use spoken, written, or signed language to communicate. Therefore – and this is a central tenet of the CRPD – all people are presumed to be capable of exercising their legal capacity. Unfortunately, current Ontario legislation, including the *Substitute Decisions Act* and *Health Care Consent Act*, raises barriers to the exercise of legal capacity. Supported decision-making can act as a bridge that brings Ontario closer to the ideal set out in the CRPD.

What is 'supported decision-making'?

In much of the literature about legal capacity, there is a close connection between mental capacity and the idea of 'supports for decision-making,' or 'supported decision-making' (as opposed to substitute decision-making) – where people with intellectual disabilities get help with understanding information, weighing options, considering benefits and risks, thinking through consequences, and communicating decisions.

While the idea is often seen as applying only to people who have an intellectual disability, supported decision-making is just another way of describing how we all make decisions. For example, when we fill in our tax returns, get our car fixed, or choose to undergo a health procedure, we turn to experts and the people around us to help make informed decisions.

Recently, the Institute for Research and Development on Inclusion and Society (IRIS) put forward the *decision-making capability approach* to legal capacity, which is instructive:

> "Unlike the usual approaches to recognizing the right to decide, which require that a person must demonstrate a certain level of ability to understand information about a decision and appreciate the consequences of a decision or non-decision, the decision-making capability approach recognizes that we all need support to make decisions."

"The foundational, and universal, decision-making ability in this approach is that a person manifests an intention and expresses their will and preference to achieve it. This is the basis for decision-making in a particular circumstance. As needed, others can, to a lesser or greater extent, bring the understanding and appreciation needed to interpret a person's intentions, will, and preferences and apply them to a decision at hand."

"There are two main ways a person's decision-making capability can be constituted:

- Independent decision-making capability – a person can carry out the understanding and appreciation needed for a valid decision, with only minimal support from others.

- Interdependent decision-making capability – a person requires significant or total support of others in interpreting and translating their will and preferences into a particular decision."

In simpler terms, this approach revolves around the idea that disabled and non-disabled people alike are able to understand information, and are able to think about the consequences of decisions, with assistance from people that they know and trust, and who know them well. Further, the argument is that this approach is safer for people who have an intellectual disability, and produces greater health and well-being, than substitute decision-making arrangements like guardianship.

c. Ontario is not meeting its legal and human rights commitments to people who have an intellectual disability

Too often, people with intellectual, developmental, cognitive, and mental health disabilities in Ontario are prevented from guiding their own lives and implementing decisions that follow from their will and preferences. This can happen informally within families, communities, and systems like schools, hospitals, and social programs. It can also happen procedurally through forms of substitute decision-making like guardianship.

This problem is to a large extent the result of negative and ableist stereotypes about the mental capacity and decision-making capabilities of people with disabilities. People with disabilities and their family members are told from a very early age that they should have limited or no expectations with respect to education, employment, relationships, and control over their own lives. They are given few opportunities to make decisions, take risks, and learn from mistakes – experiences that are the norm for nondisabled children and youth, and that are crucial to personal and social development.

Despite these low expectations and the barriers that result, people with disabilities have fought for decades for the right to obtain a proper education, access employment for decent pay, make decisions about their own health, have social and romantic relationships, and generally control their

own lives. This fight is reflected in international, national, and provincial legal frameworks and legislation that support the right to decide. The following section lays out the substantial (if imperfect and incomplete) basis for the right to decide in our province.

d. The legal basis of the Right to Decide in Ontario: Equality, dignity, and accommodation

There are well-established legal frameworks and clear legislation that support self-determination among disabled people internationally, nationally, and provincially in Ontario, though these are often misunderstood or ignored. We will review each of these, moving from the international level, to national, and lastly to the provincial context.

International Provisions:

Convention on the Rights of Persons with Disabilities (CRPD)

The CRPD, ratified by Canada in 2010, includes Article 12, "Equal recognition before the law," which directs nations to:

- Reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
- Take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
- Ensure that all measures that relate to the exercise of legal capacity respect the rights, will and preferences of the person.
- Take measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit.
- Ensure that persons with disabilities are not arbitrarily deprived of their property.

Notably, the Government of Canada has formally stated that "Canada recognizes that persons with disabilities are presumed to have legal capacity on an equal basis with others in all aspects of their lives."[4]

The CRPD also includes Article 5, "Equality and non-discrimination," which directs nations to:

- Recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

[4]http://www.bayefsky.com/html/canada_t2_disability.php

- Prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.

- Take all appropriate steps to ensure that reasonable accommodation is provided, to promote equality and eliminate discrimination.

The first principle of the CRPD is "respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons." There is a crucially important link between equality, equal recognition before the law, accommodation, and dignity that will be woven through the rest of this document.

National Provisions:

Accessible Canada Act

While the *Accessible Canada Act* (passed into law in 2019) only applies to federally-regulated entities, it offers useful language and guidance with respect to disability. The Act's list of principles is informative:

- All persons must be treated with dignity regardless of their disabilities;

- All persons must have the same opportunity to make for themselves the lives that they are able and wish to have regardless of their disabilities;

- All persons must have barrier-free access to full and equal participation in society, regardless of their disabilities;

- All persons must have meaningful options and be free to make their own choices, with support if they desire, regardless of their disabilities;

- Laws, policies, programs, services and structures must take into account the disabilities of persons, the different ways that persons interact with their environments and the multiple and intersecting forms of marginalization and discrimination faced by persons;

- Persons with disabilities must be involved in the development and design of laws, policies, programs, services and structures; and

- The development and revision of accessibility standards and the making of regulations must be done with the objective of achieving the highest level of accessibility for persons with disabilities."

[2]https://www.un.org/esa/socdev/enable/rights/ahc8docs/ahc8idc1218ex.doc
[3]https://inclusioncanada.ca/2017/11/15/what-is-legal-capacity/

The Canadian Charter of Rights and Freedoms

Section 15 (1) of the Charter states that "Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability."

This section of the Charter is an important basis of the presumption of mental capacity and the right to legal capacity among people who have an intellectual disability.

Additionally, section 7 of the Charter states that "everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice." The Supreme Court of Canada has interpreted this as meaning that "liberty protects the right to make fundamental personal choices free from state interference. Security of the person encompasses a notion of personal autonomy involving control over one's bodily integrity free from state interference."[5]

Supreme Court of Canada Decisions

The Supreme Court of Canada has made several important decisions related to the concept of dignity. These decisions, and the central role of dignity in Canadian jurisprudence, have concrete implications for the duty to accommodate people with disabilities, including accommodations related to the exercise of legal capacity.

For example, the Supreme Court has stated that "human dignity means that an individual or group feels self-respect and self-worth," and that "human dignity is harmed when individuals and groups are marginalized, ignored, or devalued, and is enhanced when laws recognize the full place of all individuals and groups within Canadian society."[6]

Further, the Supreme Court has noted that the purpose of section 15 of the Charter is to "prevent the violation of essential human dignity and freedom through the imposition of disadvantage, stereotyping, or political or social prejudice, and to promote a society in which all persons enjoy equal recognition at law as human beings or as members of Canadian society, equally capable and equally deserving of concern, respect and consideration."[7]

In simpler terms, for the Supreme Court the purpose of section 15 is "the protection of human dignity," and "to prevent the violation of human dignity and freedom" that often follows the imposition of "limitations, disadvantages or burdens through the stereotypical application of presumed group characteristics rather than on the basis of merit, capacity, or circumstance."[8] The link between dignity and disability-related accommodations has concrete implications for human rights policy at the provincial level.

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[5]Carter v Canada (Attorney General), 2015 SCC 5 at para 64. https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do.

[6]Law v Canada (Minister of Employment and Immigration) [1999] 1 SCR 497. https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/1691/index.do?q=law+v+canada.

[7]Law v Canada.

[8]Law v Canada.

Provincial Provisions:

Ontario Human Rights Commission

Continuing on the theme of dignity, the Ontario Human Rights Commission (OHRC) has stated that:

> "The duty to accommodate people with disabilities means accommodation must be provided in the way that most respects the dignity of the person, if doing so does not cause undue hardship. Human dignity encompasses individual self-respect, self-worth and inherent worth as a human being. It includes physical and psychological integrity and empowerment. It is harmed when people are marginalized, stigmatized, ignored or devalued. Privacy, confidentiality, comfort, individuality and self-esteem are all important factors.
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> "Respect and support for a person's autonomy is also crucial. It reflects a person's right to self-determination, to be treated without paternalism, and means subjecting people to minimal interference in their choices. Consideration needs to be given to how accommodation is provided and the person's own participation in the process.
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> "Respect for dignity includes being considered as a whole person, not merely in relation to one's disability. It includes respecting and valuing the perspectives of people with disabilities, particularly when people speak about their own experiences."[9]

Additionally, in its *Policy on preventing discrimination based on mental health disabilities* and addictions, the OHRC states that "The power to make decisions about matters that affect one's own life and to have them respected by law is a fundamental part of realizing one's rights as an autonomous adult, and indeed, is fundamental to personhood itself." This policy directs organizations to:

- Offer plain-language self-help resources to help people with disabilities make their own decisions about taking part;
- "Establish an accessibility office, or trained staff that act as a resource for people with capacity issues to seek information or assistance;
- "Make sure that everyone can provide informed consent – that is, make sure everyone has the information they need to make a decision, including possible outcomes flowing from that decision;
- "Involve a support network or circle of support (such as family or friends) to help the person make decisions, or interpret what a person wants when they need to make a decision."

[9]https://www.ohrc.on.ca/en/policy-ableism-and-discrimination-based-disability.

Ontario Health Care Consent Act

Ontario's Health Care Consent Act (HCCA) holds that "a person is presumed to be capable with respect to treatment, admission to a care facility and personal assistance services." This language mirrors the Substitute Decisions Act, which is addressed in detail below.

Additionally, the HCCA states that "a person may be incapable with respect to some treatments and capable with respect to others" and that "a person may be incapable with respect to a treatment at one time and capable at another." Again, this mirrors an underlying provision of the Substitute Decisions Act, i.e., that capacity and incapacity are decision-specific.

Ontario Substitute Decisions Act

Ontario's Substitute Decisions Act contains language that is meant to protect people from the loss of dignity and rights that results from a finding of incapacity. Section 22 (3) of the Act states:

> "The court shall not appoint a guardian if it is satisfied that the need for decisions to be made will be met by an alternative course of action that, (a) does not require the court to find the person to be incapable of managing property; and (b) is less restrictive of the person's decision-making rights than the appointment of a guardian."

The Ontario Ministry of the Attorney General has published G*uidelines for Conducting Assessments of Capacity*,[10] which is a crucial document in the interpretation of the Substitute Decisions Act. This document stresses the importance of avoiding findings of incapacity, and of avoiding substitute decision making wherever possible. For example, the document acknowledges that people "can make unpopular, unwise or eccentric choices in the absence of incapacity," and that "risky or even foolish decisions must be respected."

The guidelines also clearly state that "in Ontario, a person who is 18 years of age or older is presumed to be capable of making decisions related to property management, unless there are reasonable grounds to believe otherwise."

While we would respectfully question the document's statement that the SDA "was designed to promote personal autonomy," we nevertheless note that the guide puts forward five important provisions:

1. The right to self-determination.

2. The presumption of capacity: "… it is incorrect to assume that all intellectually disabled persons must be incapable by virtue of their disability."

3. People must be assessed on their decisional capacity, not their decisions: "The emphasis is on the quality of the decision-making process, not the actual course of action in which a person engages."

[10]https://www.publications.gov.on.ca/guidelines-for-conducting-assessments-of-capacity

4. Incapacity is domain-specific: “The Substitute Decisions Act rejects the notion of global incapacity and instead recognizes that capacity may be limited only with respect to certain decisions or classes of decisions.”

5. Guardianship as a last resort: “… the SDA specifically prohibits the court appointment of a guardian if less restrictive alternatives exist.”

To provide further clarity, the *Guidelines for Conducting Assessments of Capacity* include a section specific to intellectual disability, which notes that the presence of intellectual or physical disability, difficulties with communication, or institutionalization are not indicators of incapacity. The section also acknowledges that “many people with intellectual disabilities will easily satisfy the cognitive test of mental incapacity.”

While the document does not directly address decisional supports as an accommodation in capacity assessments, assessors are directed to rate people’s capacity (including their capacity to make financial decisions) in a way that accounts for the presence or absence of support, using the following guide:

> Satisfactory = fully independent or compensates for personal limitations (appreciates need for and accepts assistance).
>
> Marginal = could be a problem depending on availability and acceptance of supports.
>
> Unsatisfactory = no assistance available or refusing assistance, resulting in unmet need.
>
> Not applicable = skill is not required to manage property of given size/complexity.

This approach clearly acknowledges the role of supports in decision-making related to property. While the language of ‘accepting assistance’ fails to account for situations where a person seeks out supporters of their own accord, the concept of decisional support is inherent in this approach.

Appropriately (given that the document is an important, if underappreciated, piece in the protection of people’s rights), the Guidelines refer back to the Charter of Rights and Freedoms, which closes the loop in the arguments we are making in this document:

> “Despite the Charter which dictates otherwise, some people (including some parents or other family members) believe that people with intellectual disabilities who are not able to exercise rights independently, should not be entitled to them. Others (including some parents or other family members) spend a lifetime fighting to ensure that those rights are not usurped or violated in any way.”

Koch (Re) (1997)

In 1997, a 35-year-old woman named Linda Koch appealed the result of a capacity assessment that had found her to be incapable. After hearing the evidence, Justice Joseph Quinn wrote a judgement that has been referenced thousands of times in the legal literature. While most of Justice Quinn's response to the evidence is a fairly straightforward review of the *Substitute Decisions Act* (which first came into law in 1992) and the *Health Care Consent Act*, one particular paragraph stands out in the context of our current discussion:

> "It is to be remembered that mental capacity exists if the appellant is able to carry out her decisions with the help of others."

This statement supports our contention that decisional supports are written into the SDA. This view is also supported by the Law Commission of Ontario, which noted in its 2017 report, *Legal Capacity, Decision-making and Guardianship:*

> "… the LCO believes that it should be clearly understood that legal capacity exists where the test for capacity can be met by the individual with the provision of appropriate supports and accommodations short of undue hardship. Accommodations may include alternative methods of communication, extra time, adjustments for time of day or environment, or the assistance of a trusted person who can provide explanations in a manner that the individual can understand."

As a side note, Koch (Re) also essentially amalgamates the HCCA with the SDA, stating that assessments of capacity related to medical decisions must be guided by both the HCCA and SDA. For example, in the decision Justice Quinn states that while the HCCA does not require that assessors inform people that they have a right not to be assessed, they must still offer this information since it is required by the SDA. This has clear implications for the provision of decision-making accommodations under the HCCA.

Gray v. Ontario (2006)

Finally, the 2006 'Gray Decision' of the Ontario Superior Court of Justice is a foundational piece of the puzzle with respect to the right to exercise legal capacity in the province. The decision was connected to the closure of the last three regional centres for people with developmental disabilities, when about 1,000 residents of those facilities were moved into smaller-scale settings including group homes and long-term care facilities.

The Gray Decision includes a reference to "supported decision making" and holds that, where no substitute decision maker has been appointed for a person who might be found to be incapable of managing their property and/or personal care, a substitute decision maker is not necessarily needed:

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[2]https://www.un.org/esa/socdev/enable/rights/ahc8docs/ahc8idc1218ex.doc
[3]https://inclusioncanada.ca/2017/11/15/what-is-legal-capacity/

> "… where alternatives to the appointment of a guardian will allow for decisions to be made concerning an individual's personal care, this is to be preferred to a guardianship order, which requires a finding that the person is incapable of personal care. The Ministry's current process has not required the appointment of a guardian in support of the "supported decision making" process, which in many cases will be consistent with the words and the intention of… [the Substitute Decisions] Act.
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> "As argued by counsel for the Intervenor, Community Living Ontario, a process short of full or partial guardianship is preferable in many cases, as it best recognizes the autonomy and dignity of the individual and the inclusiveness of the decision-making process. There are approximately 1,000 individuals who will be transferred from these three institutions; their capacities and their needs in reference to the decision-making process will differ significantly. It is not possible to dictate a process for obtaining consent to community placements that will apply in every case."

While Gray is problematic in many ways, it is an early example of a court taking seriously the SDA guidance with respect to avoiding substitute decision making where it is not absolutely necessary. The decision is also clear-headed about a central vision of the Charter, i.e., that an understanding of people's capacities and needs cannot be judged from a simplistic label of disability.

What Does This all Mean?

People with disabilities in Ontario consistently face barriers to exercising their right to legal capacity, especially when they are pushed into guardianship. This is happening despite the fact that Ontario is governed by international, national, and provincial guidance that supports people's right to control their lives and make their own decisions, even when their mental capacity has been questioned.

As PooranLaw has written:

> "While the decision-making framework in Ontario reinforces substitute decision-making, we have competing obligations under Article 12 of the CRPD and section 7 and 15 of the Charter to provide supports and accommodations in decision-making, and under the Substitute Decisions Act to seek alternative courses of action to guardianship. Those obligations can often be met through the use of supported decision-making mechanisms, in order to allow individuals to exercise their full legal capacity.
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> … "Other Canadian jurisdictions… have embraced a "decision-making capabilities" approach in Canada that is more consistent with Article 12 of the CRPD and the Charter. Under this approach, the laws recognize and provide access to the full range of supports that may be required to enable all persons to exercise legal capacity, including people with disabilities and the elderly. Provinces and territories such as Alberta, British Columbia, Manitoba, Saskatchewan, and Yukon have incorporated approaches in their laws to include alternative options to guardianship.

[2]https://www.un.org/esa/socdev/enable/rights/ahc8docs/ahc8idc1218ex.doc
[3]https://inclusioncanada.ca/2017/11/15/what-is-legal-capacity/

> "While the laws in Ontario remain steadfast, without any formal recognition of supported decision-making, it is possible for legal practitioners in the province to adopt a range of decision-making options in order to better accommodate clients. Moreover, under the SDA, there is an obligation on lawyers to seek alternative courses of action that are less restrictive than guardianship."[11]

Other jurisdictions have created solutions that support the exercise of legal capacity while maintaining people's safety. And in many respects, Ontario's framework for legal capacity is poised to do the same – but, frustratingly, people in positions of power at all levels fail to understand and appreciate this fact. As a result, they push vulnerable people into situations of ever greater vulnerability, robbing them of power, control, and well-being.

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[11]B. Pooran, S. Dickson & S. Rahman. Guardianship as a last resort. Guardianship-as-a-Last-Resort-PooranLaw-February-2021.pdf.