



IRIS

Institute for Research and Development on Inclusion and Society
Institut de recherche et de développement sur l'intégration et la société

THE EQUAL RIGHT TO DECIDE IN CANADA CLOSING THE GAP

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IRIS POLICY BRIEFS

APPLYING A DISABILITY RIGHTS LENS TO KEY PUBLIC POLICY ISSUES

THE EQUAL RIGHT TO DECIDE IN CANADA

CLOSING THE GAP

In 2019, IRIS completed a study on how people with developmental, cognitive, and psychosocial disabilities lose the right to make decisions about their lives and what can be done to address this growing problem.

THE ISSUE

More than 50,000 Canadians are currently under guardianship, a system that takes away their power, choice and control over their own lives.

880,000 to 1 million Canadians with disabilities need decision-making assistance and are vulnerable to this assistance being replaced by guardianship because assisted approaches to decision making are not fully recognized or supported in law and public policy.

In addition, untold (and uncounted) numbers of people lose their right to decide when:

- they are involuntarily admitted and treated in mental health facilities;
- adult protection services intervene and remove their right to decide;
- government, health and community service providers and educators urge parents to place their adult children under guardianship in order to access services or 'transition' from the education system;
- a representative acting under a Power of Attorney abuses their power and over-rides the person's wishes and decisions;
- physicians determine a person is "incapable" of giving informed consent;
- financial assistance workers make access to social assistance dependent on having a substitute decision-maker; and,
- residential and social services effectively remove a person's control over their lives.

Disproportionate levels of poverty and unemployment, lack of access to needed disability supports, social isolation, marginalization and segregation and a culture of ableism leave many people with developmental, cognitive, and psychosocial disabilities without real power to direct their own lives.

50,000
CANADIANS
ARE CURRENTLY
UNDER
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THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (CRPD)

PROTECTS THE RIGHT OF
PEOPLE WITH DISABILITIES
TO EXERCISE THEIR LEGAL
CAPACITY - THAT IS, THE
RIGHT TO DIRECT THEIR
PERSONAL, HEALTH CARE,
AND FINANCIAL DECISIONS
- ON AN EQUAL BASIS
WITH OTHERS.

WHY DOES IT MATTER?

- The right to make our own choices and determine the course of our lives is fundamental to our integrity as individuals and in keeping with the values of our democratic society.
- It is discriminatory to deny people the right to exercise power and choice in their lives because of their disability.
- Doing so diminishes their value and contribution in our society, as one group of citizens comes to be seen as less human and less able to have a self-directed authentic life.
- Research shows that many people under guardianship experience financial and other abuse, social isolation, and loss of self-esteem.

HOW DOES IT HAPPEN?

Legal capacity laws: Guardianship, substitute decision making, mental health and other laws restrict people from exercising their right to make decisions if they are found not to have the 'mental capacity' to make decisions by themselves. These laws are based on the outmoded idea that legal capacity is the same as mental capacity. Article 12 of the CRPD breaks that equation, recognizing the universal right to legal capacity with support.

Policies: Public policies in health care, social services, housing and other sectors all reinforce the idea that people need to have certain levels of cognitive ability to be recognized as citizens who can direct their own lives.

Programs: Community programs in health and social services are often empowered by funding from governments to make decisions for the people they support - including where they will live, who they will have relationships with, how they will spend their time, and more.

Daily practice: Often, it is family, friends, community members, health care and social service providers, financial institutions, police, and judges who lack information and awareness about how to support a person to make decisions. Sometimes, out of concern for safety and a person's "best interests," they take away a person's choice and power to direct their own lives.

These barriers amount to discrimination based on disability. The alternative is to provide the right mix of decision-making support a person needs – whether assistance in understanding and communicating, individual advocacy, fostering personal relationships, or interpretive support (helping to translate a person's expression of their will and preferences into decisions) so they can exercise choice and power in their lives.



WHAT CAN BE DONE?

Some of IRIS's recommendations for reform include the following:

- Recognize the integrity of supported decision making – as a non-paid relationship a person chooses to assist them as they make decisions, based on shared understanding, trust and personal commitment.
- Legally recognize “independent” and “interdependent” decision-making capability. Legal definitions of what is required to exercise legal capacity need to change, consistent with the CRPD and the *Canadian Charter of Rights and Freedoms*. People with even the most significant intellectual disabilities can indicate what is important to them. Interpretive support from those who know them can turn their intentions - what matters most to them - into legal decisions. The CRPD requires governments to ensure they have the supports to do so.
- Develop a uniform approach for federal and provincial/territorial legal capacity law, including supported or assisted decision-making. This will help address the growing disparity in decision-making rights across provinces and territories.
- Adopt *Charter*-informed principles to guide the reform.
- Invest in piloting, evaluating, and scaling out community-based initiatives for support in decision-making.
- Closely consult with and actively involve people with disabilities, their families, and their representative organizations at all stages of the reform process.
- Ensure community capacity to support people to exercise legal capacity.
- This includes providing training, information, and assistance to families, the disability community, financial institutions, health care, social services, and justice sectors.
- Reevaluate Canada's reservation on Article 12 considering the study's findings and ensure *Charter* rights to liberty, security and equality, without discrimination based on disability, apply equally to all.



CANADA'S CHARTER OF RIGHTS AND FREEDOMS PROTECTS THE RIGHT TO LIBERTY (SECTION 7) AND EQUALITY (SECTION 15) WITHOUT DISCRIMINATION.

YET GUARDIANSHIP, MENTAL HEALTH, HEALTH CARE CONSENT, CONTRACT, SOCIAL ASSISTANCE, AND OTHER LAWS IN CANADA SYSTEMATICALLY DENY THESE RIGHTS TO PEOPLE WITH INTELLECTUAL, COGNITIVE, AND PSYCHOSOCIAL DISABILITIES BECAUSE OF THEIR DISABILITY.

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