



CANADIAN CENTRE FOR
ELDER LAW

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Understanding the Lived Experience of Assisted and Supported Decision-making in Canada

BACKGROUND

1. What is Supported Decision-making?

Supported and assisted decision-making is valued for significantly enhancing the self-determination and dignity of people with compromised mental capacity, allowing them to participate in decisions that impact their lives in circumstances where they might not otherwise have the legal or cognitive capacity to make decisions independently. Supported decision-making legislation creates a legal framework for supported decision-making, addressing matters such as:

- What kinds of decisions can be covered by supported decision-making relationships?
- What must a person be able to know and understand in order to appoint a supported decision-maker? (the capacity standard)
- Who can be a supported decision-maker?
- What steps must be undertaken to create a supported decision-making relationship?
- What are the duties and responsibilities of a supported decision-maker?
- What legal rights and powers does a supported decision-maker possess?

In this background, at the early stages of this project, we use the expression “supported decision-making” to refer to both supported and assisted decision-making, recognizing that our research may reveal that the two expressions denote slightly different practices or relationships.

The recent passage of the United Nations Convention on the Rights of Persons with Disabilities, ratified by Canada in March 2010, has increased the focus on legal models of supported decision-making. Article 12 of the Convention, entitled Equal Protection before the Law, states that “States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life,” and “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”¹ The language of the Convention raises the question of whether the notion of guardianship (legally imposed substitute decision making for adults who do not meet a mental capacity threshold) is fundamentally and inherently a form of discrimination based on intellectual or mental disability, and highlights the need to consider alter-

¹ United Nations, Convention on the Rights of Persons with Disabilities, in force May 2008, online: <http://www.un.org/disabilities/default.asp?id=259>

native approaches to decision-making that allow people with cognitive challenges to participate in, and take leadership in, decisions that impact their lives.

2. Supported Decision-making Legislation in Canada

Canada is internationally recognized for leadership in legislated supported decision-making. British Columbia's *Representation Agreement Act*² is considered pioneer legislation, being one of the first self-contained supported decision-making legal regimes in the world. Other Canadian jurisdictions have also enacted legislation that recognizes supported or assisted decision-making to some degree, using different language and legal frameworks, generally as part of adult guardianship and adult protection legislation. Although BC is unique for creating a stand alone supported decision-making regime, different models of supported decision-making now exist in Manitoba (*Vulnerable Persons Living with a Mental Disability Act*³), Yukon (*Decision-Making Support and Protection to Adults Act*⁴), Alberta (*Adult Guardianship and Trusteeship Act*⁵), and possibly, Saskatchewan, through court appointed co-decision-making (*Adult Guardianship and Co-decision-making Act*⁶).

For the developmental disability community, the creation of the representation agreement framework was a huge victory, and the use of supported decision-making within that community is generally considered a success story. In BC, the *Representation Agreement Act* allows adults to enter into an agreement to appoint a supported or substitute decision-maker. Section 7 of the Act grants legal recognition to the family and community members who provide supported and assisted decision-making for adults with mental capacity issues. Section 7 and 9 of the Act also allow an adult to appoint substitute decision-makers provided they meet the capacity standards set out in the legislation—lower capacity standards that could be met by adults who would not likely meet the capacity requirements to create other personal planning documents, such as powers of attorney.

Although the *Representation Agreement Act* was developed in response to the experience of the community living or developmental disability community, the legislation is disability-neutral, and through the *Representation Agreement Act* supported decision-making is potentially available to other populations of adults with cognitive limitations or compromised capacity, including survivors of a traumatic brain injury, people with conditions such as Parkinson's Disease, and older people with Alzheimer's and other dementias. However, such populations are not necessarily characterized by the rich communities of support that often surround people who grew up with developmental disabilities, and provide some insulation against abuse, exploitation or negative influence. Representation agreements are now being used for supported and substitute decision-making, as an incapacity planning tool, in other populations of vulnerable adults, raising the question of whether representation agreements specifically, and supported decision-making more generally, are an ideal tool for adults facing progressive neurological decline, particularly in a social context in which elder abuse is increasingly prevalent. A single legal tool may not be the right fit for different vulnerable populations; however, supported decision-making remains an option being considered by diverse communities with mental capacity issues, and much can be learned by successful use of supported decision-making in BC and the rest of Canada.

² *Representation Agreement Act*, RSBC 1996, c 405.

³ *Vulnerable Persons Living with a Mental Disability Act*, CCSM c V90.

⁴ *Decision-Making Support and Protection to Adults Act*, SY 2003, c 21.

⁵ *Adult Guardianship and Trusteeship Act*, SA 2008, c A-4.2.

⁶ *Adult Guardianship and Co-decision-making Act*, SS 2000, c A-5.3.

3. Proposed Research Initiative

The Canadian Centre for Elder Law is undertaking a quantitative and qualitative research initiative to investigate and document the experiences of using supported decision-making in Canada. The project will involve two levels of inquiry in order to (1) compare experiences across the country, and (2) dig deeper into experiences of using the representative agreement model in BC. This inquiry is focused on the lived experience of using supported decision-making, and an appreciation that people who use the model in their day-to-day lives are experiential experts in supported decision-making.

The original quantitative and qualitative research will involve two components. We will undertake telephone interviews with key informants from BC, Yukon, Alberta, Manitoba and Saskatchewan who have expertise in relation to the use of supported decision-making in those jurisdictions. Interviews will include key stakeholder organizations, such as from the community living sector, and include academics, professionals, practitioners, and volunteers. This research will also include a survey questionnaire. By way of background for this inquiry, we will review relevant legislation and produce a comparative table that highlights the legislative differences between the various legal regimes.

The second phase of research will involve interviews with people who participate personally in supported decision-making, including:

- (a) Individuals using supportive decision making;
- (b) Supported decision-makers designated under representation agreements;
- (c) Individuals acting as monitors under section 12 of the *Representation Agreement Act*; and
- (d) People who form part of an individual's larger community of support.

The aim of this approach is to acquire a rich understanding of the supported decision-making experience.

The interviews conducted in both phases of this research initiative will explore issues such as:

- What are some challenges that have emerged and how have people navigated these challenges effectively?
- What kinds of community supports have empowered the person with capacity challenges to participate as much as possible in decision-making processes?
- What supports are missing?
- How have the decision-making processes been tailored to address and accommodate the unique abilities and communication styles of the adult decision-makers involved?
- What kind of strategies or processes, if any, have been put in place or used to facilitate the supportive decision-making relationship?
- How is the decision-making relationship best characterized in terms of the four categories of people interviewed? Is the relationship a dyad primarily involving decision-maker and supporter, or is there a larger circle of support at issue? Or is there much diversity of approach in this regard?
- Have changes occurring along the life course of the adult using supported decision-making—including factors linked to aging—impacted the supported decision-making experience, and how have people navigated these particular challenges effectively?

This stakeholder research initiative will ascertain how supported decision-making is being used with-in different populations of vulnerable adults and people with different types of disabilities.

In terms of connecting with people to interview, we will rely on community agencies working with people using supported decision-making in BC to forward our call for participation on to their members.

This research initiative will culminate in the publication of a research paper summarizing our findings, which we anticipate will include the following components:

- a) By way of background for the discussion, a comparison of the legal regimes covered by the comparative quantitative and qualitative analysis (in table and narrative format), highlighting key similarities and differences between the existing Canadian legal models that provide a backdrop for supported decision-making;
- b) A summary of feedback from interviews;
- c) Examples of positive use of supported decision-making through narratives developed from stakeholder interviews;
- d) Findings around circumstances where supported decision-making is an appropriate, effective and empowering tool;
- e) Thoughts on circumstances where supported decision making may pose particular challenges, and identify some of those challenges;
- f) Learnings around how barriers such as factors associated with gender, sexual identity, sexual orientation, age, cultural identity, race and racialization, Indigenous identity, language, literacy, type of disability, family status and marital status impact on experiences of using supported decision-making;
- g) A summary of potential additional measures or supports that might enhance accessibility of supported decision-making to various vulnerable populations (or raises concerns that must be addressed in order to make supported decision-making a safer tool);
- h) Comments on the use of the monitor mechanism in BC for enhancing accountability of decision-makers; and
- i) A discussion of legal and ethical issues requiring further exploration by jurisdictions exploring a legal regime for more formally recognizing supported decision-making relationships.

The research paper is being produced for the Law Commission of Ontario, as part of its project on Mental Capacity, Decision-making, and Guardianship. As the paper must be complete by January 2014, this research initiative is, in a sense, an initial scoping project, and only a small, non-representative sample of individuals will be interviewed. This research will help us to determine whether a more lengthy and thorough inquiry is warranted.