



LAW COMMISSION OF ONTARIO  
COMMISSION DU DROIT DE L'ONTARIO

# **UNDERSTANDING THE LIVED EXPERIENCES OF SUPPORTED DECISION-MAKING IN CANADA**

**Legal Capacity, Decision-Making and Guardianship**

**March 2014**

Commissioned by the Law Commission of Ontario

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The LCO commissioned this paper to provide background research for its Legal Capacity, Decision-Making and Guardianship project. The views expressed in this paper do not necessarily reflect the views of the LCO.

**CCEL Study Paper No. 7  
March 2014**

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## I. INTRODUCTION

### A. Research Question

The right of a person to make her own decisions has been characterized as an essential aspect of citizenship in a liberal democratic country.<sup>1</sup> However, disability—and sometimes, more importantly, public perception of the mental capacity of people with cognitive, mental and developmental disabilities—can present limitations on their ability to make decisions that reflect their true values and wishes. Supported decision-making legislation provides a framework for formal legal recognition of one or more of the people who are crucial to an adult's decision-making processes, sometimes allowing them to speak on behalf of the adult. The approach is valued for significantly enhancing the self-determination and dignity of people with disabilities, 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.

Internationally, British Columbia's *Representation Agreement Act*<sup>2</sup> is recognized as pioneering legislation, being one of the first legal regimes for supported decision-making. The Act was proclaimed in 2000, and since that time there has been little research published on the experience of using supported decision-making in British Columbia or the other Canadian jurisdictions which followed suit in creating legislation that recognized supported decision-making relationships.<sup>3</sup> This paper summarizes our findings from a short research initiative on supported decision-making. The research engages people who have participated in supported decision-making—both professionally and personally—in order to enhance our understanding of how supported decision-making occurs in practice, within diverse communities. The goal of this research project is to share strategies and practices that enable supported decision-making to be an appropriate, effective and empowering tool. Many factors—such as the vulnerability of many of the people who make use of supported-decision-making in their daily lives, and the importance of protecting the right to self-determination—suggest a need for this inquiry.

This paper explores the lived experience of supported decision-making in Canada. Diverse communities have wisdom to offer that can help us to understand how supported decision-making can be best utilized, and how various programs and practices can be enhanced to make the approach more accessible, if not also safer, for different communities.

## B. Research Scope

This research initiative involved three levels of inquiry:

1. A review of legislation in Canada that addresses supported decision-making;
2. Telephone interviews with key informants from British Columbia, Yukon, Alberta, Manitoba and Saskatchewan who have professional or practice expertise in relation to the use of supported decision-making in those jurisdictions; and
3. Interviews with people in British Columbia who have participated in supported decision-making personally, using representation agreements, including:
  - a. Supported decision makers—ie, individuals using supported decision-making to make their own decisions, and
  - b. Supportive decision-makers designated under representation agreements—including representatives and family caregivers

The time constraints of the funder required the research to be conducted in four months. As a result, this paper must be understood as an initial scoping of the issues involving some key practitioners and a small number of individuals with personal experience using supported decision-making. Our hope was to explore a number of issues in order to ascertain whether further inquiry is warranted, and to interview a much greater and broader sample of informants with personal experience using supported decision-making in a subsequent inquiry.

## C. Overview of Findings

This section contains a brief summary of findings. More thorough discussion can be found in sections II to IV of this paper.

### 1. Review of Legislation

Five Canadian jurisdictions were included in this research: British Columbia, Yukon, Alberta, Saskatchewan and Manitoba. These provinces and territories have all passed legislation that references supported decision-making. On review, while the *Vulnerable Persons Living with a Mental Disability Act*<sup>4</sup> of Manitoba references support networks and supportive decision-making, there is no statutory regime for supported decision-making created through this Act. Research indicates, however, that supported decision-making occurs informally in the province, without statutory protection.

British Columbia is the only jurisdiction that has passed a self-contained statute addressing supported decision-making; in the three other jurisdictions supported decision-making is recognized in legislation that addresses both guardianship and supported decision-making.

Although supported decision-making is statutorily recognized in British Columbia, Yukon, Alberta and Saskatchewan, there is significant variety across jurisdictions. The three key differences are:

- a. *How arrangements are put in place*—particularly as to the extent to which court processes are required;
- b. *Terminology*—different terminology is used to refer to the supportive decision-makers, and sometimes the same term is used in different jurisdictions to denote a very different kind of relationship; and
- c. *Scope of powers*—particularly as to whether personal, health care and/or financial decisions may be included in the arrangement.

This brief summary covers these three issues. Greater detail on each jurisdiction is found in section II of this paper.

*a. How Supported Decision-making Arrangements are Put in Place*

In British Columbia and the Yukon supported decision-making relationships are exclusively created by agreement, without court intervention. In Alberta a kind of supportive decision-making is possible through either agreement or court order. In Saskatchewan formal supported decision-making is only possible with court intervention.

*b. Terminology around Supported Decision-making in Canada*

In British Columbia the supportive decision-maker is called a **representative**; however, the same statute allows an adult to appoint a substitute decision-maker by agreement. Both decision-makers are called representatives, so strictly speaking a representative may be a substitute or supportive decision-maker, depending on the terms of the agreement. In the Yukon, the supportive decision-maker is called an **associate decision-maker**; however, the same statute allows an adult to appoint a substitute decision-maker by agreement and this decision-maker is also called a representative. So in Canada a representative could be a substitute or supportive decision-maker.

Under the *Adult Guardianship and Trusteeship Act*<sup>5</sup> of Alberta, there are arguably two different kinds of supportive decision-makers: a **supporter** or a **co-decision-maker**. A supporter relationship is created by agreement via a document called a supported decision-making authorization, and appears on the face of the statute to create a relationship similar to the approach taken in British Columbia and the Yukon.

In Alberta and Saskatchewan there is generally greater court involvement in supported decision-making. In Alberta, a **co-decision-maker** may be appointed by the court in circumstances where the adult's decision-making capacity is

significantly impaired, and the adult would have capacity to make the personal decisions at issue if provided with support and guidance.<sup>6</sup> The court must be satisfied that the adult consents to the order and appointed decision-maker. Capacity is determined by a court appointed capacity assessor.

In Saskatchewan the supportive decision-maker is called a **co-decision-maker** as well. However, on review of the legislation it is questionable to characterize the approach as creating an authentic supported decision-making relationship: the arrangement can only be put in place by order of the court, on application, and it is not clear that the adult whose autonomy is at issue may even be an applicant.

### *c. Scope of Powers*

In terms of scope of powers, in British Columbia the supportive decision-maker may be granted the power to make decisions regarding personal care, routine management of the adult's financial affairs, instructing counsel, and some health care decisions. There are specific exclusions in the statute regarding health care consent, including the use of physical restraints.<sup>7</sup> In Yukon the statute is silent regarding the types of decisions that may be included in a supported decision-making agreement. In Alberta the authority of a co-decision maker is limited to personal decisions, but the meaning of "personal" appears to capture health care decision-making<sup>8</sup>—only financial decisions seem to be excluded. In contrast the scope of powers covered by a supported decision-making authorization in Alberta is not limited by statute. In Saskatchewan powers are extremely broad, specifically including chemical and physical restraints.

## *2. Summary of Interviews with Key Expert Informants*

We interviewed 20 key informants from Manitoba, Saskatchewan, Alberta, British Columbia and the Yukon. Experts from government, offices of the Public Guardian and/or Trustees, lawyers, advocates and members of non-profit organizations which support persons with intellectual disabilities were included in the process. A minimum of three interviews was held in each jurisdiction, with cross-representation. Interviews were conducted on a confidential basis and were very frank in nature. Below are some themes that emerged from the discussions. Underlying many of the themes is a lack of awareness of supported decision-making across sectors and communities.

*a. There is a tension between people who understand supported decision-making as a system that supports and enables "everyday" or familial decision-making practices, and those who understand supportive decision-making as a specific legal framework.* The former is well-acknowledged and agreed upon. The latter is a source of struggle and some difficulty. This philosophical difference appears to be the root of much of the confusion and worry about supported decision-making. On the whole, people who view supported decision-making as a formalization of everyday decisions seem less likely to worry about

abuse or liability. For people who view it as a specific legal framework, implications of abuse, fiduciary obligation, liability and “what ifs” are more pervasive.

*b. People do not even understand substitute decision-making, let alone supported decision-making.* Supported decision-making is a good idea, but without focused, ongoing and excellent public and professional education, the systems matter little. Every single expert informant identified the lack of training and education across the professional and community spectrum about decision-making in general to be of primary concern.

*c. Even if it is not well understood, or very often adopted, supported decision-making is an important option for self-determination, dignity and rights.* Informants had nearly unanimous agreement that even if supported decision-making had low uptake and presented some practical challenges, the legislative option was an important avenue for persons with cognitive impairment to express personhood and to maintain dignity. There is a difference which can be drawn between “good law” and “good uptake” or understanding of the law. Experts agreed that the challenges inherent in the “roll-out” of these laws, the steep learning curve required to understand them and the challenges inherent in decision-making in general, should not be conflated with the rightness of the law itself.

*d. Supported decision-making currently works for a limited number of people—predominately younger adults with “mild to moderate” intellectual disabilities, who have actively engaged circles of support.* The practice of supported decision-making can be an important part of self-determination. Where supported decision-making works is where very active and committed families are engaged in a circle of support, and use this legal arrangement to empower the adult with intellectual disabilities. Only two informants suggested that supportive decision-making would have robust use for older adults who had cognitive impairment due to dementia. Informants suggested that supported decision-making did not yet have much uptake amongst other groups who might benefit, such as those with psycho-social challenges, people with drug or alcohol addictions, people with post-traumatic stress or persons living with brain injury.

*e. Despite supported decision-making regimes in place, people still seek plenary guardianship over people with capacity challenges, or “make do” with nothing at all.* Because of practicalities—including significant cost and dealing with third party institutions—supporters of persons with capacity challenges still often seek the broadest possible plenary powers provided by guardianship (or, where an adult has capacity, to make a power of attorney). Alternatively, because of the high cost of guardianship orders, informants indicated that a lot of supported decision-making is done on a very informal basis; consequently, supportive decision-making is untracked and difficult to research conclusively.



*f. Just having a supported decision-making regime in law is not enough—education across the continuum of decision-making is required.* Uptake of supported decision-making is higher when the system is easy, low-cost and a great deal of education surrounds the regime. There was consensus that both non-profit organizations and government need to work together in a focused way to ensure that supported decision-making, substitute decision-making and guardianship are understandable concepts, with workable and accessible entry points. Supported decision-making is most understandable as part of a continuum of decision-making by, and for, adults with cognitive impairment.

*g. Third parties, such as financial institutions, often feel uncomfortable dealing with supported decision-making documents, unless there are strong relationships between the family and the financial institution.* Supported decision-making documents work best when the individual and corporate third parties know and trust each other. Otherwise, third party institutions are likely to be confused or untrusting of these documents—this is often the reason that guardianship orders are sought. If the supported decision-making document is not understood, or the perceived risk to the financial institution is too high or uncomfortable; then the family or supporters are often placed in a situation where they must choose between not accessing the third party services or products, or going to court to get a guardianship order. The latter approach means declaring the person with cognitive impairment, incapable of making decisions. This outcome is often the very one which the person with cognitive impairment and their supporters was trying assiduously to avoid.

*h. In some cases, it is too early to tell how supported decision-making will work in practice.* In Alberta, in particular, the supported decision-making regime seems to be working well. Tracking is taking place where possible. However, it is too early in the process to see exactly what uptake or roadblocks will result.

*i. Individuals and third party institutions need practical training to help people understand how to do supported decision-making.* Two separate issues were expressed here. First, the large majority of informants indicated that the concept of supported decision-making was compelling, but there are no training materials or programs which are widely available. Such training would help supported decision-makers understand how to ask questions, and how to be supportive rather than substituting their decisions onto the person with the agreement. Skill development opportunities were identified as an important next step. Further, members of organizations which support persons with intellectual disabilities expressed the related concern of “slippage”—which was to use supported decision-making systems to actually engage in substituted decision-making. It was noted that in a way, this was a more insidious version of substitute decision-making, in that it claimed to be the will of the person with intellectual disabilities, but was in fact, the will of the other person imposed and rebranded.

*j. The promise and concept of supported decision-making is very appealing and should be promoted in accordance with Art. 12 of the UN Convention on the Rights of Persons with Disabilities.* There was unanimous agreement that the ideals of supported decision-making were the way of the future. There was broad agreement that even if supportive decision-making agreements did not work for many people, it remained important to make supported decision-making available for those who did and could use the practice in their lives. There was broad agreement that offering the choice of supported decision-making in law hurt nearly no one and provided important empowerment for those who could take advantage of the regime. Further about half the informants suggested that having supported decision-making on the decision-making continuum, helped to re-enforce the notion of “most effective, least intrusive”. In short, there was a thought, although none which was verifiable, that there might be a positive spill-over effect of restraint into the more substituted types of decision-making realms. Overall, however, there was agreement that having supported decision-making systems available was a good thing, even if supported decision-making was not well understood and not well adopted as of yet.

### *3. Summary of Experiential Supported Decision-making Research (British Columbia)*

For this project we interviewed a mix of supported decision-makers (one), representatives (supportive decision-makers, seven) and caregivers of adults with supported decision-making agreements (two). The goal had been to interview a greater number of supported decision-makers. Various challenges to recruitment emerged, which are discussed in the methodology section of this paper (III.A). However, in spite of these limitations in the research some useful findings can be documented. Below are some themes that emerged from the discussions.

*a. The process of creating an agreement was difficult, expensive and confusing.* This was one of the most common themes to emerge from interviews. Most participants had developed an agreement with the assistance of a lawyer. Informants emphasized a need for additional community agencies and resources available to assist people to understand supported decision-making and create representation agreements.

*b. Supported decision-making is not generally a two-person relationship but rather a network of three or more people, not all of who are named in the agreement.* Most informants were part of a relationship involving more than one representative named in the agreement, with the most common number being three supportive decision-makers. Some informants indicated their support network was larger but only three were named in the agreement. That said, none of the agreements discussed in our interviews included a monitor.

*c. Participants found giving authority to a supportive decision-maker to be scary but empowering.* The process was a part of a larger journey of taking control over their own lives and planning for the future.

*d. Many informants expressed frustration about dealing with social services, hospitals and health care staff because representation agreements are not universally understood or consistently recognized.* Participants said that the Ministry of Social Development often requires separate documentation of the relationship and the authority, utilizing their own forms. A number of supportive decision-makers said that their ability to support their supported decision-maker was undermined because health care staff were unwilling or unable to take the time to provide them with enough information on health conditions and treatment options. Recognition of representation agreements varied widely from person to person and sector to sector. In some instances service providers did not ask to see the document and accepted the representative's statement that he or she was a representative for the adult. In many instances the informant had to "educate" someone as to what a representation agreement or a supportive decision-maker was, almost always resulting in a great deal of delay.

*e. Being a supportive decision-maker can be a challenging, pressure-filled responsibility.* Supportive decision-makers feel they require a lot of guidance and information in order to assist them act in a manner that honours the wishes of the supported decision-maker. In particular, informants wanted to know more about what mechanisms existed to prevent abuse of, and pressure on, the supported decision-maker.

*f. Supported decision-making and substitute decision-making are not distinct practices in BC.* It appears that a number of people with disabilities are planning for their supportive decision-maker to become their substitute decision-maker in the event that they lose capacity to participate in decisions about their own lives. In this sense supported decision-making operates as a kind of training ground for substitute decision-makers. It also appears that a number of adults are acting as both supportive decision-makers (through a representation agreement) and substitute decision-makers for property or finance (through a power of attorney) for the same adult concurrently. In other cases, based on discussions with informants, there seems to be a bit of slippage between the practices of supported and substitute decision-making, with representatives being engaged in both substitute and supported decision-making utilizing the same representation agreement, yet strongly characterizing their relationship as supportive in nature.

## II. BACKGROUND

### A. Rationale for Research

#### 1. *The Law Commission of Ontario Project on Legal Capacity, Decision-making and Guardianship*

In 2012 the Law Commission of Ontario (LCO) commenced a two to three year law reform project on legal capacity, decision-making and guardianship in Ontario. The law reform inquiry considers the existing legal framework that applies to circumstances where adults may have challenges that impact on their ability to make decisions, including the experiences of people with cognitive, intellectual, mental health or other disabilities. The LCO project explores current mechanisms and standards for assessing capacity, legal processes and legislation concerning the designation of substitute decision-makers, and the regime governing powers of attorneys in Ontario, including provisions concerning advance planning. The project will examine Ontario legislation such as the *Health Care Consent Act*<sup>9</sup>, the *Substitute Decisions Act*<sup>10</sup> and the *Mental Health Act*<sup>11</sup>. In undertaking this inquiry the LCO project applies its recently developed *A Framework for the Law as it Affects Persons with Disabilities*<sup>12</sup> and *A Framework for the Law as it Affects Older Adults*<sup>13</sup>, with the goal of considering the issues in a manner that recognizes the experiences of, and the barriers negotiated by, both people with diverse disabilities and older adults, including the evolving experiences of people with disabilities as they age.

The principles of both of the LCO Frameworks emphasize the importance of understanding the “implementation gap between the law as drafted and the law as applied.”<sup>14</sup> The Frameworks also endorse a “person-centred approach” that considers how people experience the law, given their unique and evolving abilities and disabilities, and the different ways systemic barriers connected to identity and privilege impact on access and experience.<sup>15</sup> This research initiative on supported decision-making, which explores the lived experience of supported decision-making by talking to both experiential and professional experts, seeks to apply both these principles.

This research initiative on supported decision-making was commissioned as part of the LCO project on legal capacity, decision-making and guardianship. In total six research papers were commissioned. The full list of researchers and topics can be found on the Legal Capacity, Decision-making and Guardianship project webpage.<sup>16</sup>

#### 2. *The International Context: UN Convention on the Rights of Persons with Disabilities*

The *Convention on the Rights of Persons with Disabilities* (CRPD),<sup>17</sup> adopted by the United Nations on December 13, 2006, and ratified by Canada on March 11, 2010, signaled the creation of a comprehensive international human rights treaty

focused specifically on promoting, protecting, and ensuring the full and equal enjoyment of all human rights and fundamental freedoms by all people with disabilities, and promoting respect for their inherent dignity.<sup>18</sup>

The CRPD not only promotes human rights equality and non-discrimination, but requires that party states create a framework ensuring accessibility for, and independence of, people with disabilities. The sections of Article 9 dealing with physical accessibility have been largely adopted in Canada's provincial and federal human rights acts and codes. One clause in particular, section 2(f) of Article 9, which requires ensuring people with disabilities access to their personal information, is an issue with implications for Canadian supported decision-making legislation.

Article 19 of the CRPD focuses on ensuring people with disabilities have the ability to live independently and be included in the community. It reads:

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.<sup>19</sup>

Based on the guiding principles of dignity and freedom, the Convention seeks to protect a person's right to have the opportunity to choose where they live, with whom they live, which community services and recreational activities they take part in, and make other fundamental life decisions. For the most part, the clauses of Article 19 have since been included in Canadian supported decision-making legislation to assure a supportive decision-maker's ability to assist the supported adult with these types of decisions and assure their independence.

*a. Article 12 of the CRPD*

Upon originally signing the treaty in 2007, Canada declared reservations with respect to the Convention's Article 12, which requires equal recognition of people with disabilities before the law. The language of the article encompasses mental capacity and decision-making rights. It states:

**Article 12 – Equal recognition before the law**

States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

States Parties shall recognize that *persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.*

States Parties shall take appropriate measures to provide access by persons with disabilities to support they may require in exercising their legal capacity.

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.

Subject to the provisions of this article, States Parties shall take all appropriate and effective 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, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.<sup>20</sup>

In effect, the article requires that all people, regardless of disability, be accorded the right to make their own decisions, and be provided the support required to exercise their decision-making autonomy. Canada anticipated that this section could be interpreted in a manner that required the elimination of substitute decision-making. As a result, it reserved the right to continue the use of substitute decision-making arrangements in appropriate circumstances and subject to their existing regulations and safeguards.

The recent passage of the CRPD, ratified by Canada in March 2010, has thus increased the attention on the BC approach to supported decision-making. The Convention prioritizes the promotion and protection of the dignity and respect of persons with disabilities, including the removal of barriers that impede on the full

and effective participation in society. The language of the CRPD raises the question of whether the notion of guardianship is fundamentally and inherently a form of discrimination based on intellectual or mental disability, and highlights the need to consider alternative approaches that allow people with cognitive and other challenges to participate, and take leadership, in decisions that impact their lives.

### *3. The Canadian Context: A Brief History of Supported Decision-making in Canada*

Canada is internationally recognized for its leadership in implementing supported decision-making legislation. Many Canadian jurisdictions have enacted legislation that recognizes supported decision-making in a variety of forms, with the British Columbian *Representation Agreement Act*<sup>21</sup> being one of the first in the world to address supported decision-making in a self-contained statute, outside of a guardianship context. For that reason, the law is considered to create a pioneering model for supported decision-making. The Act took effect in 2000.

The British Columbia model allows a person to designate a supported decision-maker by agreement, formalizing the ability of a trusted individual to assist another adult in making basic decisions. The legislation is designed to allow any person who meets the capacity threshold to enter into a representation agreement; in other words, the legislation does not reference disability, a factor which has been identified as a strength of the legislation:

... many disability rights activists view [the Act] as “normalizing” insofar as it neither singles out nor excludes [people with disabilities] as a group. For many members of the disability rights community, part of the advantage of representation agreements is that they are not disability-specific, and they do not marginalize persons with challenges. They are broad documents that any adult can use in order to nominate a substitute [or supportive] decision-maker and to make their wishes known. An empowerment and normalization theory underlies representation agreements.<sup>22</sup>

In British Columbia (and some other jurisdictions), these agreements are made privately between the parties, and require no involvement of the courts, being initiated by the adult needing support. The *Representation Agreement Act* allows an adult to appoint substitute or supported decision-makers provided the adult can meet the capacity standards set out in the legislation. The Act imposes lower capacity standards than appear in other statutes, standards that can be met by adults who would not likely meet the capacity requirements to create other personal planning documents, such as powers of attorney.

The creation of the *Representation Agreement Act* owes much to the advocacy of community organizations who sought legal recognition for existing helpers who

provide crucial support to adults with disabilities, and an alternative to the existing guardianship regime. The guardianship model in British Columbia (under the *Patients Property Act*)<sup>23</sup> requires a legal determination that a person lacks capacity in order for a decision-maker, called a Committee, to be legally recognized (as a substitute decision-maker). The Act does not recognize supported decision-making. This committee process instigates an often intrusive evaluation of the adult's capacity, and results in a loss of decision-making rights.

Since the *Representation Agreement Act* became law in British Columbia, Alberta (2008), Saskatchewan (2001), and the Yukon (2003) have all adopted their own styles of supported decision-making legislation. Manitoba legislation also references supported decision-making (since 1993). Each of these jurisdictions has approached the issue from a unique direction: some provinces, like British Columbia, emphasize the preservation of independence by allowing vulnerable adults to enter into representation agreements privately; other jurisdictions prioritize the safety of vulnerable adults and require judicial or quasi-judicial intervention before an appointed supported or substitute decision-maker can be named and legally recognized.

While there are nuances between jurisdictions, the principles underlying the legislation remain consistent. Supported decision-making legislation seeks to provide adults with a framework, complete with regulatory safeguards, through which to choose and rely on the assistance of a trusted individual for making certain categories of decisions, providing vulnerable adults and their families and friends with the resources necessary to preserve dignity, autonomy and the right to self-determination.

#### *a. Ideological Tensions in British Columbia around the Representation Agreement Regime*

It has been argued that the *Representation Agreement Act* created a schism between the disability community and the legal community, with seniors' groups being caught in between.<sup>24</sup> A number of the key advocates from the developmental disabilities community strongly pushed for the abolition of powers of attorney. Madam Justice Marion Allan and Laura Watts explore this schism in a Study Paper published by the Canadian Centre for Elder Law in 2006.<sup>25</sup> They characterized representation agreements as a legislative outflow of the disability movement at the time, noting "the central focus was on incapacity as a disability or challenge, rather than on incapacity as a seniors' rights issue".<sup>26</sup> They identify a tension emerging as a function of the then new and controversial push towards a less formal, and less protective, approach to advance planning and decision-making, with undefined concepts of capacity. They write:

There is no question that BC's disability advocates were pivotal in the campaign for the development of proxy-style representation agreements in the 1990s. The disability community sought an empowering,



normalizing tool that would enable adults with challenges to make their own decisions to the greatest extent possible. Accordingly, advocates pressed for an extremely low threshold of capacity necessary to make section 7 representation agreements, sometimes referred to as “standard” or “limited” agreements. However, the legal and health care communities were reluctant to rely on a planning document with such a low, undefined and nebulous capacity threshold. As a result, certain higher-level decisions were placed in a separate class of section 9 representation agreement provisions, sometimes referred to as “enhanced” or “general” agreements. These section representation agreement provisions require a higher, although still undefined and nebulous, level of capacity. They also require the assistance of a lawyer.

Although the *Representation Agreement Act* came into force in 2000, it remains a contentious document, often criticized for its vague drafting.<sup>27</sup>

The wording of the *Representation Agreement Act* spells out a conception of capacity to appoint a representative very different from the more traditional threshold for appointing an attorney. The statutory language for the test of capacity to make a standard-form representation agreement is as follows:

#### **Test of incapability for standard provisions**

8 (1) An adult may make a representation agreement consisting of one or more of the standard provisions authorized by section 7 even though the adult is incapable of

- (a) making a contract,
- (b) managing his or her health care, personal care or legal matters, or
- (c) the routine management of his or her financial affairs.

(2) In deciding whether an adult is incapable of making a representation agreement consisting of one or more of the standard provisions authorized by section 7, or of changing or revoking any of those provisions, all relevant factors must be considered, for example:

- (a) whether the adult communicates a desire to have a representative make, help make, or stop making decisions;
- (b) whether the adult demonstrates choices and preferences and can express feelings of approval or disapproval of others;
- (c) whether the adult is aware that making the representation agreement or changing or revoking any of the provisions means that the representative may make, or stop making, decisions or choices that affect the adult;
- (d) whether the adult has a relationship with the representative that is characterized by trust.<sup>28</sup>

This very explicit list of functional capacities to make a representation agreement caused joy and relief to some supporters of the regime, and trepidation and rejection by others.

The consultation period around the legislation was lengthy, but many from the legal community felt that their experiences around the practicalities of legal decision-making were not well understood. The conflict seemed to centre between the hope of empowerment for persons with disabilities to organize their affairs on the one side, and the concrete concern that any system which is put into place legislatively must be usable, and understandable, to the both the legal community and the users of the legislation. The *Representation Agreement Act*, as drafted, contained very unclear language, and was based on a concept of capacity that was novel in law.

For the supporters of the new system, moving to a functional capacity test that enumerates such subjective terms as “feelings of approval” or a relationship “characterized by trust” bring the legislative system into the circles of support and the reality of engaging with some members of the community of persons with intellectual disabilities. For critics, these terms are unquantifiable, easy to say but nearly impossible to interpret in reality, and represent such a “low” level of capacity that representation agreements might put people with capacity challenges at greater risk of abuse.

In many ways, this was one of the first legal conversations taking an entirely new approach to issues of substitute decision-making—and the dialogue occurred in a period of well-developed and passionate disabilities advocacy. At the time, however, the legal community and the seniors’ rights community was not yet as engaged in the discussion in British Columbia. It is likely now, particularly in light of the passage on the *Convention on the Rights of Persons with Disabilities*<sup>29</sup> (Art. 12) that these concepts of more fluid and modern understandings of capacity and social vulnerability would raise far fewer eyebrows in 2014, than they did in the early 1990s, when many of these concepts were still under early development. Indeed, criticism for the functional test of capacity at the foundation of the *Representation Agreement Act* appears to have generally quieted down, as the principles of Art. 12 of the CRPD have become more commonly accepted, and as other Canadian jurisdictions have moved to embed a supportive decision-making regime of their own.

## **B. Key Concepts**

### *1. What is Supported Decision-making?*

#### *a. The Difference Between Supported Decision-making and Guardianship*

*Mary has a twenty-year-old son named Chris. Friends describe Chris as lighthearted, generous and easy to get along with. Chris has a developmental disability and Mary is worried that someone may try to*

*take advantage of his good nature. In the past, a door to door sales person had approached Chris and convinced him to hand over a signed cheque without Chris fully understanding the consequences of that action.*

*Chris and Mary discuss good money sense and conclude it would be best if Chris discussed large expenditures with Mary and she helped him with this financial decision-making. She does not acquire veto power, but Chris agrees to contact her when appropriate, to get her input, and the Credit Union agrees to notify Mary if Chris seeks to withdraw more than \$500 from his account on a single day. Given that Mary is already named as a representative in Chris's representation agreement, and the credit union knows Chris and Mary well, the financial institution agrees to this arrangement. Chris is happy that he still has control over his finances and feels more secure knowing that he is less likely to be taken advantage now.*

Supported decision-making is often considered an alternative to substitute decision-making, and in particular to guardianship. Guardianship is a form of substitute decision-making where an individual's legal right to make all or some of their personal, health care or financial decisions is removed, and a separate person, sometimes but not always a family member, is given the legal authority to make decisions on the adult's behalf. The guardian becomes empowered to make significant decisions on behalf of the adult, and communicate directly with individuals such as physicians, lawyers, teachers, social workers, landlords, and staff at financial institutions regarding decision-making and implementation of decisions. Guardians also acquire access to an adult's personal information.

Each province and territory in Canada has legislation governing guardianship in place. Although there is variety in terms of legal processes and key factors, such as the opportunity for the adult to have input in the choice of guardian and the development of the plan for guardianship, many of the principles underlying guardianship are consistent across Canada. In particular, in guardianship and health care consent law there is a presumption of mental capacity.<sup>30</sup>

Guardianship and other substitute decision-making systems ostensibly exist to assist people unable to make their own decisions—for example, a person in a coma at the extreme, but more commonly people with cognitive issues or dementias. The legislation exists to protect individuals liable to injure themselves or undermine their assets as a result of compromised decision-making. These laws also purport to protect vulnerable adults from being taken advantage of by individuals or institutions that do not have the adult's best interests at heart. The statutes are protectionist in orientation.

However, in the interests of protection, guardianship also strips people with disabilities of fundamental rights, and can result in their complete exclusion from decision-making in relation to their own lives. Guardianship can also be a tool for controlling an adult and her assets, and misuse and abuse of guardianship authority is not uncommon.<sup>31</sup> Supported decision-making provides a less

intrusive legal alternative to guardianship. The model maintains some protection for a vulnerable adult while honouring an individual's right to choose who participates in making decisions about issues that impact them, and reinforces the right to be part of that decision-making process as well.

*b. Principles and Values underlying Supported Decision-making*

*Elliot is the supported decision-maker for his much younger brother, Max, who has a foetal alcohol spectrum disorder. In the past, Max's parents, their grandmother, and their aunt were the supported decision-makers in Max's life. Over the years, other people were brought into Max's circle of decision-making, such as a favorite school teacher and a soccer coach Max worked with for many years. When the Representation Agreement Act came into effect Max's informal and undocumented supported decision-making circle was formalized through a representation agreement. When Elliot became an adult he too became a supportive decision-maker for his brother. Max's supportive decision-makers all cared deeply for him and sometimes got together as a group to talk with Max about decisions he was thinking about.*

*Over the years Max and Elliot's parents passed away and soon Elliot found himself the only supportive decision-maker in his brother's life, with no one to consult with about Max's life, other than Max himself. Everyone else in Max's life was essentially paid to support Max through community organization programming. Elliot also found that no one in his own social circles understood or had any personal experience with supported decision-making. He felt quite isolated in understanding how best to support his brother.*

*When Elliot spoke to Max's health care providers, financial institution staff and educators, he found everyone expected, and pressured, him to make decisions for—not with—Max. People would call him into meetings about Max without even notifying Max about an issue. Elliot found it increasingly difficult to make decisions with, not for, Max, in spite of his own good intentions.*

The Mental Disability Advocacy Centre (MDAC) articulates the following principles as being at the heart of supported decision-making:

- The person retains their full legal capacity;
- The person himself/herself makes the decision. The role of supporters is to assist this person to reaching his/her own decisions;
- There is a relationship of trust between the person making the decision and the supporters;
- Such a system must be borne of the free agreement of the adult and the supporter(s);
- There is usually a supporting group or network around the person making the decision;

- The role of supporters is to assist the person making the decision to communicate his/her intentions to others and help him/her understand the choices at hand;
- Supporters are usually unpaid and could include friends, family, and/or members of the community.<sup>32</sup>

Although conceptually and legally supported decision-making is often characterized as an alternative to guardianship (and we must appreciate the impact of guardianship on individual autonomy to understand some of the strengths of a supported decision-making approach), strictly appreciating supported decision-making in terms of this contrast ignores some of the key principles underlying supported decision making ideology. MDAC explains that “autonomous decision-making and supported decision-making are [not] necessarily contradictory.” They argue “that these models can actually be used in together... highlight[ing] that **interdependence** is a normal method of decision-making for everyone.”<sup>33</sup> As they explain in more detail:

Everybody needs support from others in making important as well as less important decisions concerning different areas of life. Indeed this is obvious; we all need the knowledge and expertise of people around us because we do not have all the talents and skills which are relevant to make every kind of decision possible in life... The type and amount of assistance which we all, as individuals, need when making decisions and choices can be different, but in reality we all make choices and decisions based on the supported decision-making model.<sup>34</sup>

In this sense decision-making is an inherently social activity, and some form of supported decision-making is the norm. Treating supported decision-making as an option required because of disability pathologizes the decision-making processes of people with disabilities and is potentially an inherently discriminatory perspective on decision-making. The need for additional support in order for people with certain disabilities to participate in decision-making is not necessarily or exclusively a function of a lack of ability. Rather, the need for support or assistance results of systemic barriers to inclusion people with disabilities face; they require supports to surmount challenges associated with discrimination. As is written in the CRPD, which is grounded in a social model of disability,<sup>35</sup> “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.”<sup>36</sup>

Canadian legislation uses various terminology to denote the supportive decision-maker, such as representative, supportive decision-maker, co-decision maker and associate decision-maker. These distinctions are explored in section II.C of this paper.

## 2. What is Capacity?

*Indira is a 56-year old woman with capacity challenges pursuant to early onset-dementia. Indira's doctor informs her that while her mental capacity is mildly impaired and fluctuating now, it will likely deteriorate significantly in the short-term. Indira is surrounded by family and friends, but each has their own idea of what Indira should do and why.*

*Indira wants to make a supported decision-making agreement naming her adult sons Anil and Rafique as her supporters. She wants to make her own decisions for as long as possible, although the supported decision-making regime will not allow for decision-making in respect of the more sophisticated financial arrangements that will assuredly be needed in her situation. Her daughter, Lakhi, wants her mother to get a power of attorney made quickly—one which would continue past any incapacity her mother seems sure to experience very soon. In contrast, her husband does not want to put any documents in place. He believes that it is disrespectful to his wife, family and culture to create a power of attorney or supportive decision-making authorization; the family has always made decisions as a group—picking certain family members to make decisions is against their family culture.*

*The family agrees to go Indira's lawyer, Ms. Price, for advice on what to do. The lawyer advises that supportive decision-making documents will be of short-lived use in Indira's case. Ms. Price notes with concern that Indira may not have the capacity to make powers of attorney right now, and that guardianship will be costly and take away Indira's current legal rights to make decisions, labeling her "incapable". However, the lawyer advises, doing nothing is a recipe for problems and may result in the Public Guardian and Trustee becoming eventually involved if no financial decision-making system is established.*

At its core, capacity (also known as capability) is about decision-making.<sup>37</sup> Although grounded in medical and other information about a person, capacity is a legal concept. As we have written elsewhere:

Definitions of capacity vary across jurisdiction and have evolved over the years. The key to many recently revised definitions is the notion that a capable adult must be able to understand information, evaluate data, and appreciate the consequences of decisions. In this sense capability is about a person's decision-making process, and it is neutral as to the outcome of that process.<sup>38</sup>

As noted above, definitions vary in terms of whether a determination is global (also called plenary), or decision-specific.<sup>39</sup> A finding of incapability may, for example, be limited to financial matters or to particular personal care decisions. The table below summarizes capacity definitions and standards found in the five Canadian jurisdictions which reference supported decision-making in legislation.

Each of the statutes discussed in the following table is discussed in greater detail in section C of this paper.

**TABLE 1—DEFINITIONS AND STANDARDS OF CAPACITY IN SUPPORTED DECISION-MAKING LEGISLATION IN CANADA**

<p>British Columbia</p> <p><i>Representation Agreement Act</i></p> <p>Section 8</p>	<p>(1) An adult may make a representation agreement... even though the adult is incapable of:</p> <ul style="list-style-type: none"> <li>(a) making a contract,</li> <li>(b) managing his or her health care, personal care or legal matters, or</li> <li>(c) the routine management of his or her financial affairs.</li> </ul> <p>Capacity is determined by taking into account all relevant factors, including whether the adult:</p> <ul style="list-style-type: none"> <li>(a) Communicated a desire to have a supported decision-maker</li> <li>(b) Demonstrated choice and preference, or express approval or disapproval</li> <li>(c) Awareness that making representation agreement will affect them</li> <li>(d) Has a relationship with the proposed supported decision-maker that is characterized by trust.</li> </ul> <p>Capacity is presumed unless proven otherwise (section 3).</p>
<p>Yukon</p> <p><i>Decision Making Support and Protection to Adults Act</i> (Part 1, Sch A)</p>	<p>An adult may enter into a supported decision-making agreement if they understand the nature and effect of the agreement (section 6).</p> <p>Capacity (called capability) is presumed unless proven otherwise (section 3).</p>
<p>Alberta</p> <p><i>Adult Guardianship and Trusteeship Act</i></p>	<p>An adult is considered 'capable' to authorize a supported decision-maker if they understand the nature and effect of a supported decision-making authorization (section 4(1)).</p> <p>Capacity is defined as the ability to understand the information that is relevant to the decision, and to appreciate the reasonably foreseeable consequences of making a decision, or of not making a decision (section 1(d))</p> <p>Capacity is presumed unless proven otherwise (section 2).</p>
<p>Saskatchewan</p> <p><i>The Adult Guardianship and Co-decision-making Act</i></p>	<p>Capacity is determined by assessing the vulnerable adult's ability to both:</p> <ul style="list-style-type: none"> <li>Understand information relevant to making a decision, and</li> <li>Appreciate the reasonably foreseeable consequences of making a decision, or of not making a decision (decision 2(d)).</li> </ul> <p>Capacity is presumed unless the contrary is demonstrated (section 3).</p>
<p>Manitoba</p> <p>-</p> <p><i>Vulnerable</i></p>	<p>Capacity is presumed unless proven otherwise (Preamble).</p>

<p><i>Persons Living with a Mental Disability Act (Part 4)</i></p>	<p>There is no definition or standard for entering supported decision relationships but rather an assumption that all vulnerable adults living with a mental disability benefit from support and that this should be encouraged.</p>
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### C. Supported Decision-making Legislation in Canada

Five jurisdictions in Canada currently address supported decision-making in legislation: British Columbia, Yukon, Alberta, Saskatchewan and, to a very limited degree, Manitoba. Although some of the guiding principles, where articulated in the legislation, are consistent, the details of the regimes are quite varied. This section of this paper provides a comparative summary of the five approaches, including a narrative description of each section and a comparative table.

#### 1. British Columbia – Representation Agreement Act

The supportive decision-maker is called a **representative**.

British Columbia's *Representation Agreement Act*<sup>40</sup> is considered to be pioneering legislation in the area of supported decision-making. It is the first self-contained supported decision-making legislation that specifically addresses the appointment, duties, and oversight of supportive decision-makers (known as “representatives” in the *Act*), as well as the mental capacity required of adults in order to enter into a formal supported decision-making relationship.

The *Act* arguably approaches the issue in a less intrusive way than other jurisdictions. While some other provinces create complex judicial structures to ensure proper execution, appointment, and assessments, British Columbia's approach is to allow the vulnerable person and their chosen representative to do much of the work themselves without governmental intrusion. For example, capacity to enter into a representative agreement is not determined by a formalistic legal test, but rather a subjective examination of a vulnerable person's wishes along with a presumption of capacity.<sup>41</sup> Likewise, a representation agreement does not require approval from a court. Rather, parties are only required to properly draft and execute the agreement.

The legislation allows an adult to designate a supportive or substitute decision-maker, stating that “an adult may authorize his or her representative to help the adult make decisions, or to make decisions on behalf of the adult.”<sup>42</sup> The powers granted to representatives can be quite broad, and allow the representative to assist in a wide range of the vulnerable person's daily living activities—including nearly all decisions about physical care and routine financial affairs. The *Act* notes decisions regarding any of any of the following matters may be included:



- (a) the adult's personal care;
- (b) routine management of the adult's financial affairs, including, subject to the regulations,
  - (i) payment of bills,
  - (ii) receipt and deposit of pension and other income,
  - (iii) purchases of food, accommodation and other services necessary for personal care, and
  - (iv) the making of investments;
- (c) major health care and minor health care, as defined in the *Health Care (Consent) and Care Facility (Admission) Act*, but not including the kinds of health care prescribed under section 34 (2) (f) of that Act;
- (d) obtaining legal services for the adult and instructing counsel to commence proceedings, except divorce proceedings, or to continue, compromise, defend or settle any legal proceedings on the adult's behalf.<sup>43</sup>

The representative may “accept a facility care proposal under the *Health Care (Consent) and Care Facility (Admission) Act* for the adult's admission to a care facility, but only if the facility is:

- (a) a family care home,
- (b) a group home for the mentally handicapped, or
- (c) a mental health boarding home.<sup>44</sup>

The *Act* notes the following exclusion:

- A representative may not be authorized under this section:
- (a) to help make, or to make on the adult's behalf, a decision to refuse health care necessary to preserve life, or
  - (b) despite the objection of the adult, to physically restrain, move or manage the adult, or authorize another person to do these things.

The legislation requires representatives to act honestly, in good faith, and with the care, skill, and diligence of a reasonably prudent person.<sup>45</sup>

Oversight takes the form of a “monitor”, which is an individual named in the representation agreement to ensure that the representative is acting honestly, in good faith, and with the care, skill, and diligence of a reasonably prudent person.<sup>46</sup> The monitor may visit and speak with the represented adult at any time and inquire about the assistance they are receiving. If, as a result of their monitoring, the monitor has reason to believe the representative is serving inappropriately, the monitor may require the representative to produce documents justifying his or her actions, and to report regularly to the monitor. If all other steps have failed, the monitor must inform the Public Guardian and Trustee, who will investigate the issues.

Under the *Act*, representation agreements appear before court only when a representative applies to the court for directions about the interpretation of a provision in the agreement,<sup>47</sup> or where the Public Guardian and Trustee pursues

an objection by a party.<sup>48</sup> Otherwise, a representation agreement under the *Act* remains an entirely private contract.

## 2. Yukon – *Decision-Making Support and Protection to Adults Act*

The supportive decision-maker is called an **associate decision-maker**. Unlike the legislation in British Columbia, the Yukon *Decision-Making Support and Protection to Adults Act*<sup>49</sup> is not a stand-alone statute for supported decision-making. Instead, it regulates the appointment of associate decision-makers, representatives, and guardians in a single statute, and distinguishes the roles, duties, and responsibilities of each kind of decision-maker.

The purpose of Part 1 of the Act (Supported Decision-making Agreements) is described in the Act as:

- (a) to enable trusted friends and relatives to help adults who do not need guardianship and are substantially able to manage their affairs, but whose ability to make or communicate decisions with respect to some or all of those affairs is impaired; and
- (b) to give persons providing support to adults under paragraph (a) legal status to be with the adult and participate in discussions with others when the adult is making decisions or attempting to obtain information.<sup>50</sup>

The role of associate decision-makers is similar to that of representatives under the British Columbia model. The statute characterizes the role as being to assist a vulnerable adult by obtaining and explaining relevant information to them, as well as helping them make and express decisions in a manner that communicates the vulnerable adult's wishes.<sup>51</sup>

The *Act* outlines the requirements for appointing an associate decision-maker with a supported decision-making agreement. As in British Columbia, a court order is not necessary to appoint an associate decision-maker. The statute requires the agreement must be properly executed and witnessed.<sup>52</sup> Once a decision has been made with the help of an associate decision-maker, the *Act* deems that that decision shall be recognized as being the adult's decision, unless a court determines the presence of fraud, misrepresentation, and undue influence.<sup>53</sup> The agreement must detail both the types of decisions within the scope of authority of the associate decision-maker and the types of decisions excluded from the authority.<sup>54</sup>

As compared with the *Representation Agreement Act*, the Yukon *Act* does not set out the types of decisions that may be covered by a supported decision-making agreement. If disagreement or concerns arise from the associate decision-making agreement, the Yukon *Act* does not create oversight procedures like that of BC's legislation. Although the *Act* is intended to protect vulnerable adults from undue influence by associate decision-makers, it does not specify the means by which relief can be obtained or the role monitored. Conversely, an

associate decision-maker may apply to the Supreme Court to have an associate decision-making agreement voided where the vulnerable adult enters into a decision without consulting with the associate decision-maker in relation to a type of decision covered by the agreement.<sup>55</sup>

The *Act* also establishes the framework for designating “representatives” and “guardians”. Like the associate decision-maker, the representative derives authority from a voluntary agreement. However, the representative is a substitute, not a supported decision-maker. There appears to be a slight difference in the potential scope of authority: the decisions that may be covered by a representative agreement are set out in the *Act*, and include decisions prescribed by the regulations with respect to matters of a non-financial nature that relate to the adult’s person, including where and with whom the adult is to reside; and managing the financial affairs of the adult prescribed by the regulations.<sup>56</sup> The potential scope of authority is quite broad and similar to the BC *Representation Agreement Act* regime, though does not extend to health care decisions.

Appointing a representative is done in the same way as an associate decision-maker, requiring only proper form and execution.

### *3. Alberta – Adult Guardianship and Trusteeship Act*

The supportive decision-maker is called a **supporter**.

As is the case with the Yukon legislation, the *Adult Guardianship and Trusteeship Act*<sup>57</sup> outlines a three-tiered approach to supported and substitute decision-making in an integrated statute. The *Act* allows any adult who understands the nature and effect of a supported decision-making authorization to appoint a supporter.<sup>58</sup> It also allows the court to appoint a “co-decision maker” or a guardian where necessary.

On the face of the statute, the role of an Albertan supporter is identical to that of a representative in British Columbia and an associate decision-maker in the Yukon: the supporter is authorized to access, collect, obtain, or assist the appointing adult in accessing, collecting, or obtaining information relevant to making a decision. Supporters are also responsible for assisting the adult in understanding the information, and making decisions with that information. The supporter may communicate on behalf of the adult, or assist him or her in communicating decisions to other people.<sup>59</sup>

As in British Columbia and the Yukon, only form and proper execution is required to create a supported decision-making authorization. Afterwards, the supported-decision-maker is required to act in the adult's best interests, and act diligently and in good faith.

A co-decision-maker, by comparison, may be appointed by the court under the same statute to assist an adult in circumstances where the following four conditions are met:

- (i) the adult's capacity to make decisions about the personal matters that are to be referred to in the order is significantly impaired,
- (ii) the adult would have the capacity to make decisions about the personal matters that are to be referred to in the order if the adult were provided with appropriate guidance and support,
- (iii) less intrusive and less restrictive alternative measures than the appointment of a co-decision-maker for providing assistance to the adult in making decisions about the personal matters that are to be referred to in the order, including the making of a supported decision-making authorization, have been considered or implemented and would not likely be or have not been effective to meet the needs of the adult, and
- (iv) it is in the adult's best interests to make the order.<sup>60</sup>

The criteria to be considered in assessing best interests are set out in the *Act*.<sup>61</sup> In order to make the appointment the court must be satisfied that the adult consents to both the proposed co-decision-maker and to the order itself.<sup>62</sup> The appointment of a co-decision-maker nullifies any existing supported decision-making authorization, replacing it instead with the resulting court order. Both supported decision-making authorizations and co-decision-making orders may only apply to personal matters, and thus do not apply to decision-making regarding financial matters—in this sense the potential scope of authority is more limited than that of a representative under the BC regime for supported decision-making. However, the meaning of personal matters appears to capture health care decisions, for the *Act* states that the order must set out the personal matters to be covered by the order and may include any of the following:

- (a) the adult's health care;
- (b) where, with whom and under what conditions the adult is to live, either permanently or temporarily, or temporarily;
- (c) the persons with whom the adult may associate;
- (d) the adult's participation in social activities;
- (e) the adult's participation in any educational, vocational or other training;
- (f) the adult's employment;
- (g) the carrying on of any legal proceeding that does not relate primarily to the financial matters of the adult;
- (h) any other personal matter the Court considers necessary.<sup>63</sup>

If the co-decision-maker does not act in good faith, the adult may bring an action against him or her in court.<sup>64</sup> Unique to the Albertan statute, the *Act* contains a specific section outlining a range of offences that may be committed by co-decision makers, guardians, and trustees, including fines up to \$10,000. These offences include causing mental or physical harm to the vulnerable adult, and causing damage or loss of property of the vulnerable adult.<sup>65</sup>

Also unique to the *Albertan Act* is a framework for determining capacity. Capacity is determined by a capacity assessor, who conducts a court-ordered assessment if capacity is at issue in an application.<sup>66</sup> The assessor must determine whether or not the adult understands the information that is relevant to making a decision, and whether or not the adult is capable of appreciating the reasonably foreseeable consequences of a decision (or a failure to make a decision). If the adult does not have the capacity to make decisions about personal matters, the court may appoint a guardian to fully take over decision-making responsibilities.

#### 4. Saskatchewan – *The Adult Guardianship and Co-decision-making Act*

The supportive decision-maker is called a **co-decision-maker**.

Unlike the other provincial statutes previously discussed, *The Adult Guardianship and Co-decision-making Act*<sup>67</sup> addresses supported decision-making through the court system. While British Columbia, Alberta, and the Yukon allow adults to enter into supported decision-making agreements as private individuals, in Saskatchewan a co-decision-maker derives her authority by a court appointment, following an application and hearing. It is not clear on the face of the legislation whether the adult whose decision-making autonomy is at issue may be the applicant; it appears rather that the wishes of the adult are but one of many factors that should be considered by the court, applying a best interests test. The court must specify which decisions are included in the order, and the *Act* distinguishes between personal and property decision-makers. With respect to a personal co-decision-maker, the authority may include:

- (a) decisions respecting where, with whom and under what conditions the adult is to live, whether permanently or temporarily;
- (b) decisions respecting with whom the adult is to associate and who may have access to the adult;
- (c) decisions respecting whether the adult should engage in social activities and, if so, the nature and extent of those activities and related matters;
- (d) decisions respecting whether the adult should work and, if so, the nature or type of work, for whom he or she is to work and related matters;
- (e) decisions respecting whether the adult should participate in any educational, vocational or other training and, if so, the nature and extent of that training and related matters;
- (f) decisions respecting whether the adult should apply for any licence, permit, approval or other consent or authorization required by law that does not relate to the estate of the adult;
- (g) subject to the powers of any litigation guardian, decisions respecting the carrying on of any legal proceeding that does not relate to the estate of the adult;
- (h) subject to *The Health Care Directives and Substitute Health Care Decision Makers Act*, decisions respecting the adult's health care, including decisions respecting admission to a health care facility or respecting treatment of the adult;

- (i) subject to the regulations, decisions respecting the restraint of the adult's movement or behaviour by the use of a device, medication or physical force, where necessary to protect the health or safety of the adult or others;
- (j) decisions respecting the adult's diet, dress, grooming, hygiene and other matters of daily living;
- (k) decisions respecting any other matters specified by the court and required to be made by the personal co-decision-maker or personal guardian in the best interests of the adult.<sup>68</sup>

As compared other legislation discussed above, these powers are extremely broad, including the use of physical restraints. The *Act* notes that authority is shared, and documents requiring signature must be signed by both the adult and her co-decision-maker; however, the co-decision-maker must:

...acquiesce in a decision made by the adult and shall not refuse to sign a document mentioned in section 16 if a reasonable person could have made the decision in question and no harm to the adult is likely to result from the decision."<sup>69</sup>

In *Saskatchewan's Adult Guardianship and Co-decision-making Act* the term "co-decision-maker" is used differently than in Alberta, denoting a kind of supported decision-making. However, the process of creating the arrangement is intrusive and not directed by the adult, and in this sense the regime parallels a guardianship model. Based strictly on the language of the legislation, the *Act* appears to create a hybrid between supported decision-making and guardianship.

The process set out in the *Act* is as follows. First, a notice of application must be served in accordance with the *Act*, and notice must be given to all parties that may have an interest. This includes the adult who may require a co-decision-maker, the nearest relatives (unless they consent), and any existing co-decision-maker, attorney (empowered by a power of attorney), proxy (empowered by a health care directive), trustee, or supporter.<sup>70</sup> Then, a preliminary assessment is performed which determines the level of the adult's capacity regarding certain matters. Capacity is determined by a statutory test, which considers whether the adult (a) has the ability to both understand information relevant to making a decision, and (b) appreciates the reasonably foreseeable consequences of making or not making a decision.<sup>71</sup> The adult is presumed to have capacity unless the contrary is demonstrated. A hearing is conducted in Chambers,<sup>72</sup> on affidavit evidence, with the onus on the applicant to prove on balance of probabilities that the adult needs a co-decision-maker.<sup>73</sup>

To come to its decision, the court will look at a range of factors, such as:<sup>74</sup>

- the preliminary assessment;
- the types of decisions the adult will, or will likely, need help with;

- the supportive resources currently available to the adult to help them make decisions;
- the wishes of the adult; and
- the suitability of the proposed co-decision-maker.

#### 5. *Manitoba – Vulnerable Persons Living with a Mental Disability Act*

The *Vulnerable Persons Living with a Mental Disability Act*<sup>75</sup> contains a number of references to decision-making support and support networks, but does not truly create a regime for supported decision-making, providing no statutory authority for entering into a supported decision-making relationship.

The *Act* defines supported decision-making as:

The process whereby a vulnerable person is enabled to make and communicate decisions with respect to personal care and/or their property and in which advice, support, or assistance is provided to the vulnerable person by their support network.”<sup>76</sup>

The preamble emphasizes the importance of decision-making support and support networks, stating:

WHEREAS Manitobans recognize that vulnerable persons are presumed to have the capacity to make decisions affecting themselves, unless demonstrated otherwise;  
AND WHEREAS it is recognized that vulnerable persons should be encouraged to make their own decisions;  
AND WHEREAS it is recognized that the vulnerable person's support network should be encouraged to assist the vulnerable person in making decisions so as to enhance his or her independence and self-determination;  
AND WHEREAS it is recognized that any assistance with decision making that is provided to a vulnerable person should be provided in a manner which respects the privacy and dignity of the person and should be the least restrictive and least intrusive form of assistance that is appropriate in the circumstances;  
AND WHEREAS it is recognized that substitute decision making should be invoked only as a last resort when a vulnerable person needs decisions to be made and is unable to make these decisions by himself or herself or with the involvement of members of his or her support network;<sup>77</sup>

A support network is defined as “one or more persons who provide advice, support or assistance to a vulnerable person” and may include:

- (a) the vulnerable person's spouse or common-law partner,
- (b) other members of the vulnerable person's family, and
- (c) others chosen by the vulnerable person<sup>78</sup>

The Act states that, “supported decision making by a vulnerable person with members of his or her support network should be respected and recognized as an important means of enhancing the self-determination, independence and dignity of a vulnerable person.”<sup>79</sup>

There is no other reference to supported decision-making in the Act. On its face, the Act does not create a regime for supported decision-making.



**TABLE 2—COMPARISON OF KEY PROVISIONS RELATED TO SUPPORTED DECISION-MAKING IN CANADIAN LEGISLATION**

<b>WHO CAN BE APPOINTED AS A SUPPORTIVE DECISION-MAKER?</b>	
<b>British Columbia</b>	Any consenting adult (19 years or older), other than an individual who provides (or is an employee of a facility that provides) personal care or health care services for compensation to the vulnerable adult, can be appointed as a representative. <b>(s.5(1)(a))</b>
	The Public Guardian and Trustee, or a credit union or trust company (as long as their authority does not extend to health or personal care) may also be appointed. <b>(s.5(1)(b)-(c))</b>
<b>Yukon</b>	An adult can appoint any adult as an associate decision-maker <i>except</i> a person who is an employee or employer of the adult, or a person against whom an order has been made under the <i>Family Violence Prevention Act</i> or under the adult protection section of the <i>Decision-Making Support and Protection to Adults Act</i> . <b>(s.7)</b>
<b>Alberta</b>	Any 1 to 3 consenting adults (18 years or older) that are themselves not being represented by a supported decision-maker, co-decision-maker, guardian, or attorney under an enduring power of attorney, can be supported decision-makers. <b>(s.4(1))</b>
<b>Saskatchewan</b>	Any adult (16 years or older – <b>s.2(a)</b> ) who, in the opinion of the court, has a sufficient interest in the personal welfare of the vulnerable adult may apply to be appointed as co-decision-maker for personal care or property. <b>(s.6(a))</b>
	The Public Guardian and Trustee or any individual, corporation, or agency (or category of such) designated by the minister in accordance with the regulations, may also apply. <b>(s.6(b)-(c))</b>

<b>WHAT MUST A PERSON KNOW AND UNDERSTAND IN ORDER TO APPOINT A SUPPORTIVE DECISION-MAKER?</b>	
<b>British Columbia</b>	An adult must have the capacity to enter into a representation agreement; they must be able to communicate their desire to appoint a supportive decision-maker, and to demonstrate choice and preference, or express approval or disapproval. The adult must also understand how making a representation agreement will affect them. <b>(s.8(2))</b>
<b>Yukon</b>	An adult must understand the nature and effect of a supported decision-making authorization in order to make a supported decision-making agreement. <b>(s.6)</b>
<b>Alberta</b>	An adult must understand the nature and effect of a supported decision-making authorization in order to make a supported decision-making agreement. <b>(s.4(1))</b>
<b>Saskatchewan</b>	Any person who, in the opinion of the court, has sufficient interest in the personal welfare of the adult may make an application to the court to be appointed as a personal or property co-decision-maker. <b>(ss.6 and 30)</b>

<b>WHAT STEPS ARE NECESSARY TO APPOINT A SUPPORTIVE DECISION-MAKER?</b>	
<b>British Columbia</b>	Proper form and execution of an agreement: written, signed by the adult and supported decision-maker(s), and witnessed by two witnesses (19 years or older; may not be the representative, or an employee, child, spouse, or parent of the representative, must understand the type of communication used by the adult) or one if the witness is a lawyer or notary. <b>(s.13)</b>
	The agreement may be signed by another person on behalf of the adult if (a) the adult is physically incapable of signing the agreement, (b) the adult is present and directs the agreement to be signed, (c) the person signing is not the named representative or a witness, and is witnessed when signing, and – for substitute decision-makers, (d) the person signing completes a monitor's certificate. <b>(s.13(4))</b>
	Under certain circumstances set out in the Act the adult must appoint a monitor (19 years or older, and consenting to the role), unless the representative is the adult's spouse, the Public Guardian and Trustee, or a trust company or credit union; or if there are two or more representatives who must act unanimously. <b>(s.12)</b>
<b>Yukon</b>	Proper form and execution of an agreement: written, dated, signed by the adult and supportive decision-maker(s), and witnessed by two witnesses (19 years or older; may not be the associate decision-maker themselves, an employee, child, spouse, or parent of the associate decision-maker) all in the presence of each other. <b>(s.8)</b>
<b>Alberta</b>	Proper form and execution of an agreement: written, signed by the adult (or person acting on behalf of the adult where the adult shall, in the presence of a witness, instruct another to sign for them) and witnessed by one person (18 years or older; not the named supportive decision-maker nor person who assisted the adult with signing). <b>(ss. 3(1) and 3(5) of <i>Adult Guardianship and Trusteeship (Ministerial) Regulations, Alta Reg 224/2009</i>)</b>
<b>Saskatchewan</b>	Application made to court in proper form, followed by a hearing.

<b>HOW IS CAPACITY DETERMINED?</b>	
<b>British Columbia</b>	<p>Capacity is not determined by whether or not the vulnerable adult can enter into a contract, nor whether they can manage their health, personal, legal, or financial care. <b>(s.8)</b></p> <p>Instead, capacity is determined by taking into account all relevant factors, including:</p> <ul style="list-style-type: none"> <li>• Communicated desire to have a supportive decision-maker</li> <li>• Demonstrated choice and preference, or express approval or disapproval.</li> <li>• Awareness that making representation agreement will affect them.</li> <li>• Whether the adult has a relationship with the proposed supportive decision-maker that is characterized by trust.</li> </ul>
<b>Yukon</b>	<p>An adult may enter into a supported decision-making agreement if they understand the nature and effect of the agreement <b>(s.6)</b></p>
<b>Alberta</b>	<p>An adult is considered 'capable' when they: <b>(s.4(1))</b></p> <ol style="list-style-type: none"> <li>1. Understand the nature and effect of a substitute decision-making authorization,</li> <li>2. Possess the ability to understand the information that is relevant to the decision, and</li> <li>3. Can appreciate the reasonably foreseeable consequences of making a decision, or of not making a decision.</li> </ol>
<b>Saskatchewan</b>	<p>Capacity is determined by assessing the vulnerable adult's ability to both: <b>(s.2(c))</b></p> <ol style="list-style-type: none"> <li>1. Understand information relevant to making a decision, and</li> <li>2. To appreciate the reasonably foreseeable consequences of making a decision, or of not making a decision.</li> </ol>

<b>WHAT LEGAL RIGHTS AND POWERS DO SUPPORTED DECISION-MAKERS POSSESS?</b>	
<b>British Columbia</b>	A representative may help the vulnerable adult they are assisting make decisions affecting their personal care and with the routine management of the adult's financial affairs <b>(s.7(1))</b>
	A representative may authorize the vulnerable adult's admission to a care facility, if the care facility is a family care home, group home for the mentally handicapped, or a mental health boarding home <b>(s.7(2))</b>
	A representative has the right to the adult's records related to their area of granted authority. <b>(s.18)</b>
<b>Yukon</b>	Except when otherwise specified, an associate decision-maker assists a vulnerable adult with: <b>(s.5(1))</b> <ol style="list-style-type: none"> <li>1. making and expressing decisions</li> <li>2. assisting the adult to obtain relevant information</li> <li>3. understanding the relevant information and considerations</li> <li>4. expressing the adult's wishes and decisions, and communicate the decisions</li> <li>5. endeavouring to ensure the adult's decisions are implemented</li> </ol>
<b>Alberta</b>	A supportive decision-maker may do all that is necessary to give effect to decisions of the assisted adult in respect to personal matters (any matter, relating to the personal care of the adult, except financial matters), and may all that is necessary in order to give effect to the decisions made by the adult. <b>(s.9(1))</b>
	A supportive decision-maker has the right to collect information about the adult that is relevant to the decision-making process and to assist the adult in understanding the information. <b>(s.4(2)(a))</b>
<b>Saskatchewan</b>	Duties are assigned by the court according to the needs of the adult – as determined during the initial assessment phase of the application.

<b>WHAT KINDS OF DECISIONS CAN BE COVERED BY A SUPPORTED DECISION-MAKING AGREEMENT?</b>	
<b>British Columbia</b>	<p>A representative may help the adult make decisions, or make decisions for the adult, on: <b>(s.7)</b></p> <ol style="list-style-type: none"> <li>1. the adult's personal care</li> <li>2. the routine management of the adult's financial affairs (payment of bills, receipt of income, purchase of food, accommodations, and other services necessary for personal care, making investments)</li> <li>3. major and minor health care</li> <li>4. obtaining legal services for the adult</li> <li>5. admission to a family care home, group home for the mentally handicapped, or mental health boarding home</li> <li>6. any other issue relating to personal or health care of the adult otherwise specified in the agreement</li> </ol>
<b>Yukon</b>	<p>The scope of the decisions for which an associate decision-maker may assist a vulnerable adult are entirely decided by the contents of the supported decision-making agreement. <b>(s.9(1)(b)-(c))</b></p>
<b>Alberta</b>	<p>A supportive decision-maker may help a vulnerable adult make and communicate decisions with respect to “personal matters”, defined as: <b>(s.1(bb))</b></p> <ul style="list-style-type: none"> <li>• the adult's health care</li> <li>• living arrangements, and decisions about daily living</li> <li>• employment, education, vocational training</li> <li>• social and recreational activities</li> <li>• carrying on legal proceedings that do not primarily relate to the property of the adult</li> </ul>
<b>Saskatchewan</b>	<p>A co-decision-maker may help a vulnerable adult make and communicate decisions with respect to personal care or property, such as: <b>(s.15)</b></p> <ol style="list-style-type: none"> <li>1. living arrangements and decisions about daily living</li> <li>2. consent to health care</li> <li>3. employment, education, vocational training</li> <li>4. social and recreational activities</li> <li>5. anything related to the adult's estate <b>(only property co-decision-maker: s.42)</b></li> </ol>

### III. SUMMARY OF RESEARCH

#### A. Methodology

##### 1. Overview of Methodology

The goal of this project was to capture the experience of what it is like to be ‘*working within*’ a supported decision-making regime in Canada. In order to capture a picture of how the regimes function on the ground, it was necessary to go beyond mere doctrinal analysis of legislation and engage in a more dynamic research methodology to extract information not readily apparent through doctrinal means. Thus, in order to get a more accurate snapshot of how supported decision-making regimes work, researchers adopted a mixed methodological approach. Researchers employed the following research methods:

- Semi-structured interviews with expert interviewees (n=20) with at least 3 informants from each of Manitoba, Saskatchewan, Alberta, British Columbia and the Yukon (the “expert interviews”)
- A series of interviews with adults (n=10) who have been directly engaged with supported decision-making in British Columbia, including both adults with some capacity challenges and people acting as their legal decision-making supporters (the “British Columbia experiential interviews”)<sup>80</sup>
- A brief secondary anonymous survey to expert informants for any additional information or quotes, forming a separate document (the “follow-up survey”)
- Doctrinal legislative research (the “legislative research”)

The research that led to the choice of these particular methodologies is explored below.

##### 2. Interviews with Individuals with Professional Experience with Supported Decision-making—the Expert Interviews

###### a. Background Research into Methodology

A confidential semi-structured interview process was selected for expert interviews in the five designated jurisdictions. This section discusses the methodology for expert interviews with particular attention to study design and relevant research.

*i. Semi-structured Interview: Strengths, Weaknesses and Challenges of this Approach*

Several different methodologies were considered for expert interviews. Given the vast geographical distribution of experts across four provinces and one territory it was not plausible to conduct a focus group, and so this methodology was eliminated from consideration. Fully structured interviews would not provide the appropriate “back and forth” flow required to deeply probe. Further, an unstructured interview is too difficult to analyze and quantify.

Semi-structured interviews were then considered. The advantages of semi-structured interviews are myriad. A semi-structured interview can:

Help to define the areas to be explored, but also allows the interviewer or interviewee to diverge in order to pursue an idea or response in more detail. This interview format is used most frequently in healthcare, as it provides participants with some guidance on what to talk about, which many find helpful. The flexibility of this approach, particularly compared to structured interviews, also allows for the discovery or elaboration of information that is important to participants but may not have previously been thought of as pertinent by the research team.<sup>81</sup>

The strengths of semi-structured interviews include:

- The depth of the information able to be extracted;
- The fact that the respondent can influence the topic so that unexpected issues and topics emerge;
- The researcher can probe to understand perspectives and experiences; and
- The topic guide [of questions] ensures that a core list of questions is asked in each interview, and because the order of questions is not fixed the flow and sharing of views can be more natural.<sup>82</sup>

The weaknesses or challenges of semi-structured interviews are:

- Trained interviewers are needed to probe without being directive or judgmental;
- The analysis of findings is more difficult as it must be done by the person or people who conducted the interviews;
- The researcher has to try to avoid bias in analysis;
- The researcher needs to know something of the local culture to capture the interviewees’ real meaning;
- The analysis can be time-consuming; and
- In some cases it can be difficult to generalize findings.<sup>83</sup>

The weaknesses were mitigated by using a trained social science researcher experienced in interview research, having all findings analyzed by the



researcher, ensuring that the researcher did have familiarity with each of the jurisdictions,<sup>84</sup> ensuring that the interview schedule was planned as far as practical in advance, and using conscious “checks” to reduce bias.

As the strengths significantly outweighed any weaknesses, and a plan was established to reduce weaknesses, the semi-structured interview format was adopted.

### *ii. Informant Selection, Confidentiality, and Research Questions*

Semi-structured interviews depend not only on skilled researchers, but also on having “good informants”. A “good informant” for a semi-structured expert interview must have the following attributes:

- Be knowledgeable about the topic—an expert by virtue of involvement in specific life events
- Be able to reflect and provide detailed experiential information about the area under investigation
- Be willing to talk<sup>85</sup>

This 3-step model of a “good informant” was adopted for the research methodology and applied in the selection of interviewees.

This research initiative follows the World Health Organization model (WHO guide), for group selection and recommended sample size for semi-structured interviews.<sup>86</sup> In particular, guidelines for a semi-structured interview methodology in community research is explained in s. 3.4 of this WHO guide as follows:

You will need to limit the number of interviews, as semi-structured interviews are quite time-consuming to conduct and analyse. The aim is not to get a representative sample of the various categories of informants, but to gather a substantial body of information from them. Try to limit the list of the people you will interview to around 20-30 who are likely to give you most information on the problem and can choose from a variety of perspectives. You usually only need to interview 3-5 people from each of the identified groups.

While the research proposal only called for 15 total respondents initially, this number was increased to 20 in accordance with the WHO recommendations. Identified groups were also considered, and 3-4 “types” of experts were grouped across jurisdictions. Further discussion of these groups is found under Qualitative Techniques below.

Hardon, Hodgkin and Fresle describe well the semi-structured interview approach:

When conducting semi-structured interviews, the interviewer is prepared with a list of questions and topics to be discussed. The order of the questions and topics parameters are left undefined and are adapted to the flow of the discussion. It is best to start with a topic that is not sensitive and is important to the respondent. Thus, an informal, friendly atmosphere can be created, facilitating a 'natural' flow of ideas and opinions. The researcher acts as a moderator, guiding the respondent from one topic to another. Conducting such interviews requires a skilled moderator.<sup>87</sup>

The WHO guide suggests that a foundational step of successful semi-structured interviews is to have a checklist of questions to ask each participant. Moreover, having broader "prompt questions" also helps to shape the scope of the discussion.<sup>88</sup> Prompt questions are useful to ensure that:

...key issues are addressed and the flow of the interview is maintained. The planned order of the prompt questions does not need to be strictly adhered to...for this style of interviewing. Consideration should be given to the phrasing of prompt questions to avoid leading the participant. This is crucial because the interviewer's expectations can affect the participant's response.<sup>89</sup>

As such, a checklist of five questions was developed, with ten prompt questions for the expert interviews.

Expert interviewees feel safest providing frank information if they are freed from fear of being quoted and if the interviewer assures the expert interviewee that they will not be identified by their revealed experiences. Confidentiality was thus built into the interview process. One of the findings of a significant literature review on ethical issues and concerns on the part of interviewees suggests that interviewee worry over confidentiality is an inhibiting factor for semi-structured interviews. Further, the "most common threat" felt by interviewees, was that they would be "identified...in writing up of reports and, particularly, the use of quotes. Whilst individuals may not be identifiable to the general public, they may well be identifiable to...the peers also involved in the study".<sup>90</sup>

In order to confirm whether the issue of confidentiality was valid in this research study, a short series of key informant discussions (n=5) was held. Of these key informant discussions, all agreed that confidential interviews would provide the most candid and frank results.

The semi-structured interviews were thus designed to be confidential, with explanations to interviewees that their name and organizations would be cited as having participated, but that no quotations would be used, and that while institutions may be cited, no reference to "who said what" would be included in the study.

The literature review of best techniques in semi-structured interviews noted above suggested that use of stories and hypotheticals was also encouraged as a method of animating the information garnered through the confidential interviews.<sup>91</sup>

Cases or examples were solicited from expert interviewees wherever possible. Also, stories of people with disabilities were included in the analysis portion of the research project.

### *iii. Expert Interviewee Recruitment and Process*

Key informants who would be “good interviewees” were identified on issues relating to supported decision-making in each jurisdiction. Each of the appropriate offices of the Public Guardians (PG) and Trustees (in Alberta the PG, in Manitoba, the Vulnerable Persons’ Commissioner) was contacted and representatives from each agreed to participate. Existing relationships were of significant assistance in recruitment, due to a higher knowledge of the research organization and pre-existing trust.

Each of the associations for Community Living was contacted as well, with introductions from a known leader in the disability community. Due to the compressed time of this study, there was limited time to build trust in this community and it took somewhat longer than ideal to recruit participants. However, once a relationship was established participants from different organizations dedicated to issues of Community Living were willing to be interviewed. Additionally, leading professors who had been involved with community engaged research and law reform in elder and disability law were canvassed.

Members of capacity or rights-related tribunals or non-profit organizations were also approached to participate in this study. Several members who were recruited were very engaged in this issue and willing to participate. Last, members of the legal profession in the different jurisdictions were approached in order to garner those viewpoints.

In order to ensure full frankness, expert interviewees were assured that while their names would be credited, no specific quotes would be attributed to them, and the resulting research paper would focus on the content of their observations, rather than the positions of the people giving them. In many cases, experts were pleased to be able to provide a frank report with the appropriate assurances.

The interviewees were provided with a Backgrounder to the Project, an email explaining the purpose of the interview, and the five questions that would be central to the interview. They were also provided with the ten “prompt” questions in advance.

Two interviews took as little as fifteen minutes to complete. Two interviews took 90 minutes or longer due to the interest on the part of the interviewee to continue discussing the topic. On average the interviews lasted 20-30 minutes.

The questions were designed to capture a rounded picture of supported decision-making relationships, including instances where they have been used successfully, barriers and how people navigated challenges effectively. A strength-based perspective in this approach was key. Due attention was given to identifying issues that require clarification in the process of supported decision-making. A full list of questions asked in the semi-structured expert interviews can be found in the Section V Appendix.

### 3. *Experiential Experts*

#### a. *Background Research on Methodology*

For people with disabilities, the goal of the experiential methodology was to ensure the greatest level of inclusion and accessibility possible, taking into consideration the time limitations of the study. Significant research into best research practices was undertaken before designing the experiential interview portion of this study.

The importance of including people with a disability in research on disability issues was notably underscored in the *Report of the Commission on the Status of People with Disabilities*<sup>92</sup>, and the *United Nation's Convention on the Rights of Persons with Disability*<sup>93</sup>, adopted in December 2006. Significant literature supporting these foundational declarations suggest a need for research methodology which respects that individuals who have a disability are considered experts in their own experience. Use of stories<sup>94</sup> and sharing of experience is foundational to good research methods in this field, particularly on how to overcome challenges uniquely faced by people with disability or cognitive impairment.<sup>95</sup>

To understand the lived experience of people with disabilities, significant attention was given to the methodological process of involving people with disabilities in the research—specifically in identifying what research methods can best accommodate people with disabilities in communicating their experiences of supported decision-making in British Columbia. Background research in exploring disability research ideals, realities and qualitative methodology was undertaken.

Inherent in this focus is the core philosophical question: is the research *on* or *with* people with a disability. Participatory action and emancipatory research show promise because they explore practical solutions to the issues of pressing concern to people with disabilities.<sup>96</sup> Action within the lens of social research is addressed well by Oliver:

The development of such a paradigm stems from the gradual rejection of the positivist view of social research as the pursuit of absolute knowledge through the scientific method and the gradual disillusionment with the interpretative view of such research as the generation of socially useful knowledge within particular historical and social contexts. The emancipatory paradigm, as the name implies, is about the facilitating of a politics of the possible by confronting social oppression at whatever level it occurs.<sup>97</sup>

More recently, researchers have restated the emancipatory paradigm as central to research on disability policy.<sup>98</sup> The agenda has become one where research highlights multiple and significant social inequalities while aiding people with impairment in politicizing and mobilizing, pointing hopefully to some better future.<sup>99</sup>

Alternatively, a critical realist approach skirts the discussion of disability as a social construction or creation and instead focuses on the experimental basis of impairment and an exploration of the day-to-day problems associated with living with a disability.<sup>100</sup> Research to date has embraced the idea of changing and removing the barriers faced by people with disabilities largely in an ideological way. The principles guiding disability research, while conceptually well grounded, in practice often remain broad in scope and are seldom mapped out in plain, practical terms. A number of concerns have been raised regarding research involving people with disabilities.<sup>101</sup> It is important to question the extent that a research project can empower participants or result in positive impacts on their lives.

It may be more challenging for people with profound intellectual or communication skills to participate in research and caution is needed when determining how to include people with diverse abilities in research. Notably, there is a concern that if persons are only partially included in the research, it may also be understood as partially rejecting or excluding them.<sup>102</sup> Setting the criteria for research and obtaining consensus from the disability community is a difficult task, in which there is an inherent danger of priorities being lost in the focus on a desire to define what constitutes disability research and how it should be conducted.<sup>103</sup> With this balance in mind, we set to investigate potential methodological approaches that can accommodate, empower and include people not only ranging in mental and physical abilities, but also from diverse backgrounds, including gender, ethnicity, class and sexuality.

#### *b. Qualitative Techniques*

The most prevalent methods for conducting research with individuals with impairment include semi-structured interviews, photographic techniques and proxy responses.<sup>104</sup> The majority of disability research to date follows a semi-structured interview approach. Less popular methods include focus groups, questionnaires and surveys, narratives and ethnography. Many researchers

agree that there needs to be flexibility in methods for data collection in response to the changing needs of disabled people. Most researchers favour a mixed methods approach.<sup>105</sup>

People with learning disabilities need to believe that their views are valid and important in order to feel the research process is relevant and worthwhile. Semi-structured interviews provide the opportunity to develop a relationship with the participant and assure them that they will be listened to and understood. This requires sensitivity from the interviewer. It may also be helpful to offer the accompaniment of a familiar, valued person in the interview process.<sup>106</sup>

Generally, open-ended questions or the use of narrative yield more data than the use of statements. Narrative methods enable people with learning difficulties to recall, recount and review their lives, valuing them as experts.

Questionnaires can be interpreted as limiting the respondents' flexibility in answering questions, leading to limited responses. Questions asked outside a meaningful context that have no relevance to the individual being interviewed would likely be dismissed. The challenge here is that people with emotional, learning or communication difficulties may require highly structured support in answering questions. Yet, such support may skew results through the nature and phrasing of questions.<sup>107</sup> Ottmann and Crosbie explore this concept further and suggest methods that elicit a person's view may produce a number of biases including: recency effects, a tendency to agree with the viewpoint of the interviewer, providing information that is not factual, and positive response bias.<sup>108</sup>

A powerful approach to help develop trust and respect is to check back in a process of participant validation. This "checking back" stage becomes even more important when the individual's communication difficulties may pose barriers to understanding what the participant is trying to communicate with words.<sup>109</sup>

For individuals with profound learning or communication difficulties, the whole interview may rely on interpretation by a representative who is emotionally and communicatively involved. Often this person is a caregiver or relative who is emotionally connected to the person with a disability who is being interviewed. The support person can act as a proxy, answering questions as if they were the other person. Research suggests that approximately half the time proxy responses matched with those provided by people with a disability in an interview setting.<sup>110</sup> Inherent in this gap is the tendency for proxies to address issues of importance *for* the individual with a disability rather than issues important *to* them. This is particularly complex, and ironic, when the focus of the research itself involves discussion of substitute, "proxy", and supportive decision-makers. This may place the experiential research interviewee with a disability in a conflicted position, and may create confirmation bias or "interpretative filtering".

Nonetheless, additional emotional support of a familiar, valued person involved in the interview process can provide comfort to a participant that helps empower them to express their views. Focus groups have also successfully been used to help build confidence among participants by providing safe, non-threatening environments.<sup>111</sup> Unfortunately, focus groups can be difficult to organize and produce uneven outcomes.<sup>112</sup>

The research methodology comparative study by Ottmann and Crosbie suggest a combination of qualitative techniques which can be helpful when conducting disability research.<sup>113</sup> Visual cues can accompany interviews as useful prompts. When time permits, using programs such as “Photovoice”<sup>114</sup> may also be a useful tool to use in conjunction with interviews.<sup>115</sup> Photovoice, however, can be somewhat less appropriate for people with an intellectual disability, particularly those with obsessive tendencies.<sup>116</sup>

In conclusion, it is likely that the most appropriate mix of methods will depend on the time, budget and focus of the research to be conducted. Flexibility is key. Rigid assumptions about individuals who have a disability requiring a particular methodology may be a more significant constraint on the research than anything the individual brings to the situation.

### *c. Recruitment Strategies and Questions*

Finding experiential experts—people who were engaged in supported decision-making in British Columbia—was a significant challenge. Many representation agreements are done informally and within a family structure. While there is an opportunity for people to register their representation agreement, this is not required, nor is the register easily accessible by researchers. Nidus (the Representation Agreement Resource Centre) indicated that it was under significant funding strain and was not willing to participate in the research initiative. Different relationship strategies including offering honoraria to non-profit organizations to act as research partners in the recruitment process were somewhat successful.

Discussions with Community Living BC suggested interest and willingness to support contact with their community members. Outreach was also undertaken to a variety of non-profit organizations, the BC Adult Abuse and Neglect Collaborative, and to lawyers who work in the fields of capacity and planning, with the goal of encouraging these groups to reach within their own networks to help find users of supported decision-making to participate in the group research.

Materials were posted on the CCEL website and distributed by email to existing contacts. Overall, while research recruitment was initially slow, as trust relationships increased, so did the ability to connect with potential experiential

interviewees. The information provided for outreach is included in the Section V Appendix.

The majority of interviewed experiential experts were affiliated with the Planned Lifetime Advocacy Network and the Family Caregivers Network Society, and all interviews were conducted in Vancouver and Victoria, British Columbia.

#### *4. Rationale for Methodological Approaches—Summary*

A mixed methodological approach was used to access information about how supported decision-making is functioning “on the ground” in the five jurisdictions. Doctrinal legislative research on the legislation provides the starting framework of the legal models. Both a narrative set of descriptions and comparative chart formats allows for readers to access often difficult to compare legislation in a clearer fashion. Chart formats also allow for increased accessibility by providing a visual comparator model.

Semi-structured confidential expert interviews were chosen as the best methodology to create a horizontal review of how, in practice, people in the five jurisdictions found the supported decision-making regimes to be working. The WHO methodological format, plus research gained from extensive literature reviews, provide strong rationale for this methodological choice.

Semi-structured interviews with people who used or were using supported decision-making in the jurisdiction where this legislative option has been available longest (British Columbia) was undertaken. The semi-structured interview process was augmented to ensure accessibility and to increase trust. Research partners were used to access participants and to create a discourse framework for the experience. Study design methodology was adaptive to the needs of participants.

A survey of ten questions was distributed to people who have been engaged in the research. This survey acts as both a research “follow up” and a secondary data source. Research participants were invited to distribute the survey electronically to their networks. By using this mixed methodological approach, the researchers were able to access significant data results.

##### *a. Challenges and Limitations*

The original design was to significantly limit the expert interviews, with a minimum of three experts per jurisdiction to a total of fifteen interviews (n=15). This data set was expanded to twenty at the design stage in accordance with the WHO methodology adopted, detailed above.

While nearly all of the experts were very well connected to community experience and very sensitive to the needs to persons with intellectual, psycho-social or other disabilities including cognitive impairment due to age-related



illness, predominately they were not speaking from lived experience.<sup>117</sup> While the interview numbers were appropriate, a larger pool of experts to choose from would be additionally helpful. As expert interviewers became more confident that they were part of a cohort of colleagues being interviewed, their willingness to be involved in this project increased.

Finding research participants in British Columbia who were actively involved in supported decision-making was challenging. There is no one central data set to access. Working from trusting relationships is critical when researching a group of potentially vulnerable adults; a high level of research comfort and trust was required before the research team was able to access experiential interviewees. Working with community partners to conduct research requires a high degree of transparency, organization and bridge-building. Working within such a compressed research period, some of this relationship support had to be expedited. Ultimately, we conducted most of the interviews in December, more than two months later than hoped, because it took so long to build trust with stakeholder organizations who could link us to experiential experts, and because the key organization which we had expected to link us to interview subjects, Community Living BC, was not able to connect us with participants.

Attempts were made to engage an appropriate representative group in the knowledge that such groups are sometimes not appropriately diverse or representative. For this project we interviewed a mix of supported decision-makers (one), representatives (supportive decision-makers, seven) and caregivers of adults with supported decision-making agreements (two). The research team took thoughtful steps to try and mitigate this limitation, but the inclusion of only one supported decision-maker remains a limitation of the research.

## **B. Findings**

### *1. Expert Interviews*

*Genevieve is a 23-year old woman with Down's Syndrome. She has a part-time job at a local library shelving books. She has never had the legal capacity to make a power of attorney to deal with her property and financial matters. Her 55-year old parents are active in encouraging her community engagement and development but are also highly concerned with their daughter's inability to manage finances. They are both financially protective of her, and want her to have as much independence as possible. They give their daughter a routine allowance for spending money, but they pay her bills directly.*

*There is a supported decision-making document in place, naming her parents the joint supportive decision-makers. However, recently Genevieve inherited \$40,000 from her aunt. Her parents took Genevieve to their financial institution to open a Registered Disability Saving Plan (RDSP) in their daughter's name. Because Genevieve did not have the*

*legal capacity to make financial decisions, she could not open an RDSP account herself. She cannot make a power of attorney due to her capacity challenges not meeting the standards required.*

*Her current supportive decision-making arrangement does not allow someone to make complex higher lever decisions for Genevieve on a substituted basis; rather, her supportive decision-making agreement only has the scope to support Genevieve in making her own decisions. She needs a legal substitute decision-maker to legally “stand in her shoes” and act as her full decision-maker. In short, Genevieve will need a guardianship in place in order to open an RDSP account.*

*In the end, her parents have to choose between making a costly guardianship application that would have the effect of declaring Genevieve incapable (something which the family has always specifically avoided doing), and not having an RDSP for their daughter.*

#### *a. British Columbia*

*i. Functionally, how is it all working in your jurisdiction? What is the “on the ground” experience in your expert opinion?*

Representation agreements in British Columbia were one of the first legal and social experiments in trying to find ways to formalize an inherently informal type of decision-making. The representation agreement regime was predominately designed in response to the disability community’s desire to ensure that people with intellectual disabilities have the highest degree of choice in maintaining their own legal autonomy over decisions. There was widespread agreement across those interviewed that this innovative model has been embraced predominately by this community, and was not seen as particularly helpful to older adults or to people with other types of fluctuating cognitive impairment, such as people with traumatic brain injury. People in the “community living movement” seem generally appreciative of both the framework and the innovative atmosphere that British Columbia has around it.

As a mechanism to organize supported decision-making, the representative agreement system is seen by some as problematic. One respondent agreed to go on the record as saying that:

The lawyers didn’t like [representation agreements] because they thought that representation agreements were too open to abuse, and too unclear. The folks in the intellectual disabilities movement wanted to get rid of all the powers of attorneys and to replace the entire thing. But of course it takes time to understand new systems. The goal of representation agreements was to formalize what was already happening informally. They might not work for everyone but they work well for some.<sup>118</sup>

British Columbia experts whom we interviewed raised questions about the level of capacity that an adult would have to possess to sign such a document. In particular, the representation agreement's movement away from the common law test for capacity, based on the ability to "understand and appreciate", was difficult for many to accept.

There is a sense that British Columbia has some of the most progressive practice and service models for delivery, which can strongly support persons with intellectual disabilities. However, concerns remain that in practice there is "slippage". The concern is that instead of using representation agreements for supported decision-making, in some people's hands they are a more palatably branded version of substitute decision-making. They may, in some cases, be used to overprotect within a nearly plenary guardianship-type purview, under the guise of a supported decision-making system.

Two British Columbia experts indicated that they knew of instances where parties have moved ahead with representation agreements knowing that the person that they are supporting has a very limited understanding of the document or the framework. Within certain circles this concern is discussed openly. However, the concern about possible liability or negative effect remains low. When queried about why concerns about this are low, both responded that most people who are using supported decision-making documents in British Columbia are members of a small community where representatives are highly engaged in the lives of the person they are supporting.

The spirit of the supported decision-making arrangement is not one which people challenge; rather, the practice is easily circumnavigated, particularly in times of stress. In British Columbia, the system appears to be more about formalizing an inherently private, pre-existing type of decision-making, rather than imposing benchmarks or protective regimes. At this point, there is no evidence that this system has any markedly increased outcome of abuse, and people we interviewed suggested no particularly different level of concern about abuse in supportive decision-making systems versus substitute decision-making systems.

In British Columbia, the supported decision-making provisions in s.7 of the *Representation Agreement Act*<sup>19</sup> appear to be more an opportunity to provide dignity, accessibility and personhood with the increased comfort of a document for third parties. It seems less a system designed to regulate personal activities step-by-step.

Overall, supported decision-making pursuant to British Columbia representation agreements have not had a wide adoption. People outside of the disability community, particularly seniors and people with psycho-social or brain injury, prefer an easier-to-understand and perhaps a more "legal" framework. There is

a sense that the philosophy of supported decision-making is a good one to have imbued in law, but that the system is not yet one which people can yet execute with ease or confidence. For people who are not overly worried about abuse, formalities and liabilities, supported decision-making occurs “off the books” in terms of legal documentation. It is a practice that occurs in families and circles of supporters on an everyday basis.

Supported decision-making is working in some environments. Lawyers and third parties struggle with what the agreements mean in terms of liability and who is responsible for the decision. Third parties, in particular, emphasize the need for clarity and responsibility, when they are uncomfortable or not well trained in the decision-making continuum. It is not surprising then, that the findings support that supportive decision-making arrangements work best with third parties who know the vulnerable adult and the supporter.

Monitors, which are permitted in section 12 of the *Representation Agreement Act*, are generally seen as a positive option. Having a monitor allows more easily for more than one person to be involved, which can better support making difficult decisions in the “grey zone.” Monitors are seen as acting as a sober second thought and a further check or balance before having to go to court.

There is a tension between people who understand supported decision-making as a system that supports and enables an everyday or familial practices, and those who understand supported decision-making as a specific legal framework. The former is well-acknowledged and agreed upon. The latter is a source of struggle and some difficulty.

The supported decision-making arrangement can work well if there is a supporter who cares, but there are numbers of people who do not have anyone close in their life that would be an appropriate “supporter”.

Generally there was a sanguine sense that third parties within health care often do not seek consent appropriately regardless of the legal decision-making framework.

There is very little litigation around representation agreements and essentially none around supported decision-making pursuant to a representation agreement. However, there is also very little litigation around capacity and guardianship issues in general. As there are relatively few supported decision-making agreements in comparison to powers of attorney or guardianship, it would be unlikely that many cases would surface. Further there may be issues of self-selection at play. Families who are more prone to paternalism or are shy about liability will still seek a court ordered committee (guardianship); families who are actively involved in supported decision-making circles and networks may be more naturally comfortable with the informal and the grey areas. Overall, however, it is notable that the court-based processes are difficult

for people with capacity issues to access, and there are nearly no legal aid systems available to support substitute decision-making cases.

Representation agreements with supported decision-making are sometimes used when the more vulnerable adult wants to make decisions that “push back” against their family. Supported decision-making via a representation agreement can be a declaration of difference. It can be a way that more vulnerable adults can formalize their values, wishes and beliefs as different from those of their families.

There was a concern that supported decision-making is not particularly appropriate for people with psycho-social / psychiatric disorders. The concern lies particularly in the inability of the person who may be experiencing a mental break to understand and appreciate their own situation. It is inappropriate to try to reason within a supported decision-making framework with someone who is in a psychotic state, for instance.

Older adults who have degenerative diseases of aging can also benefit from supported decision-making in the early stages of their disease; however, there is a strong tendency to move to substitute decision-making for this group. Substitute decision-making is easier and more convenient for many in the older adult cohort. For older people with degenerating capacity issues, timeliness of decisions is often of the essence. There is evidence to suggest that there are different types of issues being dealt with at different stages of the lifecourse. For instance, younger people with intellectual disabilities may be building functional capacities and looking to support positive ways of increasingly ability to manage money, engage with employment opportunities and consider future options for marriage or children. By contrast, older people with dementia may be most concerned about health and personal care planning, financial arrangements such as wills or use of life-long saved assets, and quality of life / end of life decision. While there are certainly cross-over areas, it remains that lifecourse can have an important impact on the type of decisions being made, and as a result, the appropriateness of supported decision-making. Further, a good substitute decision-maker will, in practice and by legislative requirement, include the vulnerable adult as much as possible in decision-making.

Indeed, while there may be value in the early months or years for older people with diseases like dementia, that value deteriorates with their condition and actually can become a tool of abuse. The question remains unresolved as to whether a certain minimum level of capacity is required to enjoy the possible benefits of supported decision-making.

There are some concerns about the effect of the lifecourse. While people with intellectual disabilities have not historically lived long lives, this is changing. It is expected to see entirely new socio-medical issues arise in the next decade, as people with Down Syndrome are living longer lives with dementia<sup>120</sup>.

There was a moderate concern that there would not be enough people to volunteer to be supported decision-makers. There was a sense that the farther away one went from a close familial relationship, the harder it is to recruit supported decision-makers and engage in supported decision-making. In other fields, such as in criminal law circles of support, some evidence suggests that the idea of surrounding, supporting and monitoring another adult is good in theory, but unless it is underpinned by strong relationship bonds, that volunteer enthusiasm soon wanes<sup>121</sup>.

Others noted that the positive and enriching relationships which people can have with adults with cognitive impairment or intellectual disabilities is just not well understood yet. Increased education, normalization and better systems can bring about social change which will encourage reciprocal values exchanges between adults with diminished capacity and other adults in the community. However, these positive relationships can be inhibited by the effect of widespread attitudinal barriers, such as ageism or ableism, thus negatively impacting the prospects of effective implementation of supported decision-making.

*ii. What, if any, roadblocks or uncertainties exist which frustrate the process?*

While representation agreements have existed for some time now in British Columbia, they are not widely understood. Pockets of comprehension about the legislative system exist, predominately within intellectual disabilities communities, but this is offset by a more general bewilderment about the law and the practice. The comprehension is highest with people who are fully acquainted with the benefits of supported decision-making and who have family, friends and professionals surrounding them who will provide support. There are roadblocks to accessing or understanding supported decision-making through representation agreements if these conditions are not in place.

There was a mixed sense of which professionals cause roadblocks, and the needs and uncertainties of third parties that often frustrate the process. Some noted that health care providers and lawyers did not trust supported decision-making and that it was awkward and too imprecise a system to “take instructions from”. There was a strong sense that health authorities are involved in highly inappropriate “forced planning” which overrides any supported decision-making opportunity. When one connects with the health authority, there is a push in place for people to declare substitute decision-makers.

Micro-boards are not well understood. However, some systems, which are in place to provide structural safeguards, such as trusts, meet with more comfort from the third party professionals.

There was a general agreement that financial institutions do not feel comfortable with supported decision-making and the “push back” from the financial sector is one reason why supporters often turn to more formal or even court ordered options.

Overall there was a sense that the majority of British Columbians neither know about, nor care about, supported decision-making. The small pockets of passionate advocates are the few who understand the opportunity supported decision-making holds.

Further, there was a general agreement that the sectors supporting adults with cognitive impairment are being squeezed. When services are being cut and when non-profit organizations are fighting for every dollar, there is a slip backwards into congregated services and plenary substitute decision-making.

The costs of putting supported decision-making in place are unclear. The real or perceived cost, can still act as a roadblock.

In summary, the lack of general awareness of supported decision-making is augmented by the general discomfort of third party professionals. There is a general consensus that, no matter the structure in place, people will stop talking to the adult in question and take substituted decision-making from the supported decision-maker instead. Many lawyers in British Columbia have a poor opinion of representation agreements. Their concerns centre around the lack of clarity around who is liable for which types of decisions, the risk of abuse or not being able to take clear instructions from a person with a significantly impaired level of capacity, and the general lack of understanding of how supported decision-making works in practice. Lawyers are still much more familiar with substitute decision-making pursuant to powers of attorney or guardianship and these systems seem more “clear”. They fit the other concepts of decision-making and responsibility found in law, and do not require a nuanced understanding of capacity or rights of personhood to effect legal transactions. However, it is important to note that there are lawyers who specialize in these areas of law who are much more comfortable and familiar with the regime.

### *iii. What issue(s) need clarifying in the process*

Overall the biggest concern requiring clarification is “what does supported decision-making mean in practice?” Many people have ideas of what they think supported decision-making is, but no one really knows how to do it. There is a complete lack of teaching for supported decision-makers around best practices, expectations and pragmatic skills.

*iv. What works really well?*

The opportunity to have supported decision-making is good, but it is quite abstract. There is the positive sense that people's rights and dignity are being respected. Informal arrangements are also working well in British Columbia. However, there is significant importance in having a legal document that can recognize the autonomy and independence of an adult who might otherwise be brushed aside. To some extent, having a supported decision-making legal document can help to overcome third party concerns about privacy issues.

When education is available, it is always a positive. Representation agreements and supported decision-making are better understood when there are educational sessions and a variety of different ways to access information, particularly at the community level.

*v. What thoughts / recommendations do you have?*

There is no real research done on the effectiveness or methods of good supported decision-making. There needs to be a significant amount of work done on this beyond anecdotes. This is especially important now that the CRPD has embedded the concept. People have embraced it at face value because it seems like a "good idea"—and it probably is—but there is no actual evidence to support this notion.

There should be an independent evaluation of the legislation, in Canada at least, along with a review of the practices.

Education and training should particularly be made available to the Public Guardian and Trustee. This group is actively involved in the field, but like everyone else, is struggling with the practicalities of it.

Overwhelmingly there is a need for a focused educational campaign at several levels—both at the community level and the governmental level—but also a strong educational outreach to third parties such as health care providers and financial institutions. Supporters or potential supporters need some type of education that they can access which can help them understand their roles and responsibilities, including how to make decisions.

Some informants believed that there should be no mental competency tests at all in an ideal world, and that the conversation should be all about accommodation.

There was a strong consensus that community-based non-governmental organizations need to have a strong and stable role to engage in this work.



*b. Yukon*

*i. Functionally, how is it all working in your jurisdiction? What is the "on the ground" experience in your expert opinion?*

The Yukon has a very small community, which is very closely connected. Supported decision-making is used, although it is quite often informally done. Because of the strong rural nature of the Yukon, supporting people who need help is very dependent on the family or members of the community. Social services are few and far between and are mostly centred in the capital. Court formalities are not preferred for decision-making, but guardianships often get used in order to more easily access benefits and services. If people are using supported decision-making it is really because they are actively engaged in the strong community living groups, particularly for people with intellectual disabilities or foetal alcohol syndrome. Overall, the supported decision-making legislative regime is a formalization of what has been happening informally for years. The community is close-knit and built on personal relationships, rather than legal ones.

There are few complaints, but then there are very few cases of supported decision-making being formalized either. Uptake of this legal option has not been very strong. People are more concerned about capacity issues within the issues associated with foetal alcohol syndrome or within the criminal justice context.

Overall, supported decision-making is seen as being a good thing to have "on the books", but it has not had significant uptake or impact in the Yukon.

*ii. What, if any, roadblocks or uncertainties exist which frustrate the process?*

In the Yukon, getting information is a challenge. This is particularly true if you are outside of the capital. While government services work and people are trying to help, resources are not well known. The supported decision-making regime is not well understood either, which creates a challenge for people wishing to find alternatives to substitute decision-making. Guardianship orders for people with intellectual disabilities are more often than not required as minors acquire the age of majority, as government and health services often want the comfort and clarity of this type of document.

Overall, supported decision-making utilizing an associate decision-maker is not well understood by citizens, the legal profession or third parties. However, where these supported decision-making arrangements exist, they are not generally challenged.

*iii. What issue(s) need clarifying in the process*

The systems are opaque. While the legislation is innovative and provides multiple choices for people, that knowledge about the innovation is not transmitted to citizens. Very few people have a clear idea on how to navigate the system required to create, foster or maintain supported decision-making circles. In practice, it is also somewhat unclear where the line between substitute and supported decision-making lies.

*iv. What works really well?*

Overwhelmingly, the “small town effect” is what makes supported decision-making work. There is a sense that everyone helps everybody, and people take care of their own.

The existing non-profits who work on issues related to community living and also related to seniors are helpful. While none of them have much in terms of stable funding, the culture in the Yukon is one of collaboration and thrift. People in the community feel that they can do a lot with a little.

*v. What thoughts / recommendations do you have?*

Any project on issues related to supported decision-making, or decision-making in general, needs to seriously consider the issue of sustainability and knowledge transfer in the Yukon. People rotate back to the south and the brain trust related to key social issues can be so easily lost. Other projects in the Yukon are funded as pilots, but then are not followed with appropriate resources to actually sustain or spread the knowledge around supported or other forms of decision-making. It would be helpful if there were clinics to help people fill out forms. It would also be helpful to have a system of advocacy which links the PGT’s office with community groups around the issue of how supported decision-making skills should be developed.

*c. Alberta*

*i. Functionally, how is it all working in your jurisdiction? What is the “on the ground” experience in your expert opinion?*

Alberta is historically shaped by having its *Dependent Adult Act (DDA)*. While the DDA allowed for a “gentler” form of only partial guardianship, the ideals of less restrictive approaches were subverted. People sought nearly plenary guardianship, save and except one area, in order to be able to represent that the adult was only under a partial guardianship. The data in the province, then, seemed to indicate that it was historically a forward thinking jurisdiction, but the practices belied this. When designing the new legislation, there was a strong

desire to overcome this history and to find real and practical ways in which supported decision-making could work.

The new legislation has met with great favour in the province, although is still not very well understood. Albertans now understand that they have three choices: supported decision-making, which is formalized by a free downloadable form and signed by the parties involved; co-decision-making, which is a court-based process and significantly more formalized, and, guardianship, which is the court-based formal substitute decision-making process Albertans have been used to.

When the new legislation was being released there was more information about these supported and co-decision-making options. As that initial push has waned somewhat, so has the level of understanding about these options.

There is a sense that lack of widespread uptake of supported or co-decision-making in Alberta may come from a generational source. Historically, there was a stronger sense that families with adult children with intellectual disabilities should be protected, and that full guardianship was the right course to pursue. As generations shift, the siblings of these adult children are starting to become the supports, rather than the aging parents. This cohort of siblings are much more open to supported and co-decision-making on a principled basis. However, there is strong consensus that in order to help make the shift from a default guardianship model to supported or co-decision-making, there must be structures in place on a paid on-going basis in the field. Dedicated supports from funded NGOs, the Public Guardian and other agencies are necessary to achieve the required shift in culture and knowledge base.

Enquiries from people who have been guardians are now increasing. People are casting about to understand the new regime, but generally feel comfortable with the bifurcated approach.

The supported decision-making form is very easily completed. It is free, easy to use, and can be filed online. While the document is by its nature informal and easy to change, it is seen as having the backing of legislation. The co-decision-making model leans more closely to a substituted decision-making model. Third parties are often more re-assured by the documents made pursuant to this co-decision-making process, as it is viewed as indicating a higher level of both capacity on the part of the vulnerable adult, as well as a higher level of authority on the part of the co-decision-maker.

When one is seeking a supported or co-decision-making formalization, there were differences in advice and reaction. Lawyers, friends and family often encourage the more formal co-decision-making process. There is still an overall comfort with having the “blessing” of the court.

In practice, the interchange with between the individual and the person providing advice and assistance is more person-centred when using the supported decision-making form model. There is a concern that where the co-decision-making model is used there is a shift towards more authority on the part of the co-decision-maker, which feels more like a substitute model of authority.

One of the reasons why people are looking for supported or co-decision-making for people who may “borderline not need it” otherwise, is a fear for what will happen in an emergency health crisis. Without a document allowing inclusion in the decision-making process, family and supporters are concerned about being cut out of health information and decisions. Additionally, there is concern that in emergency situations health care professionals will add a Do Not Resuscitate order to a vulnerable adult’s chart without consultation.

However, it was noted that some health care and financial third parties are becoming increasingly familiar with both supported and co-decision-making models and are not discriminating between them. It was suggested that one alternative explanation for this decrease in anxiety on the part of third parties was their lack of overall understanding of the process of decision-making generally, and their confusion over capacity issues specifically.

There was a general sense that cost was not a significant barrier to supported decision-making. The supported decision-making forms are free for download and no third parties are required in order to formalize the arrangement.

There was a mixed response when asked if cost was a barrier in co-decision-making. For the court-based co-decision-making model people are not required to hire a lawyer, particularly if the matter is a simple and uncontested one. However, in cases where lawyers and expert documents are needed, an adult can apply to have those costs covered by the state. A doctor’s or designated assessor’s report can cost \$500-\$700. For legal fees, families can ask the Crown to pay the costs, or if the matter before the court involves a sizable estate (more often found in cases involving seniors) then the parties can apply to have that estate pay. Full co-decision-making hearings, especially contested ones, could have costs similar to guardianship hearings.

However, community living advocacy groups and other supporters have been active in trying to ensure access to justice. There is a sense that if people are supported by an active community and if there is a reasonable plan to manage the question of cost, then people tend to be eager to move forward.

As the legislation is still quite new, there have been very few challenges to it in the courts. It is still unclear what will happen in a co-decision-making arrangement where either party is no longer capable of functioning in their roles.

Older adults are using the supported decision-making model to avoid privacy issues. It is being used as a justification for allowing family members or friends to attend doctor's appointments or to receive health information in particular.

Liability concerns on the part of supported or co-decision-makers are low. There is little concern about being held to a standard of support or co-decision-making, as the adult remains the one in control. This holding of the final veto allows the adult to revoke the arrangement. It does little, however, to address undue influence or emotional abuse.

The people best suited to supported or co-decision-making include: people with language barriers, especially older adults with language barriers; and high functioning adults with intellectual disabilities, where their families are pushing the adult's rights forward in a positive way—but are still interested in being kept in the loop regarding a few key issues. The approach can be helpful for people with brain injury or learning disabilities. Supported and co-decision-making are not viewed as viable longer-term options for people with dementia. Use of a supported decision-making document may help in early stages, but after that, these adults should be supported to make their advance directives or plan for a substituted decision-making model in future.

As the legislation was only brought into force in 2009, there has been an adjustment period while people work out appropriate checks and balances. For instance, there is no formal review process in the co-decision-making model similar to the guardianship six-year review process, which gave rise to some concerns. However, getting rid of that review process has considerably assisted some families, for the cost of the review process was significant. Instead, there is a much stronger front-end system of vetting put in place, including criminal records checks for co-decision-makers, notifications to interested parties, and the ability to have anyone complain. There is a sense that abuse will happen in all systems, as it is a societal issue. However, the delicate balance of accessibility, appropriate formality and cost seems better with the new legislation overall.

*ii. What, if any, roadblocks or uncertainties exist which frustrate the process?*

People do not really know what skills they should employ to be a supportive or co-decision-makers. It is a real gap. People are trying to sort out the responsibilities, the methodology, and the steps to supporting a good decision—but people are really on their own. Without good models, there can be slippage back to a de facto substituted system. It would be helpful to have some models or education around best practices that could be shared.

Additionally, some people who have been institutionally or historically in the field of working with adults with intellectual disabilities have a set way of doing things. Use of supported or co-decision-making may be adopted easily in language and

philosophy, but in practice there are calcified ways of doing things that are difficult to dislodge or change.

*iii. What issue(s) need clarifying in the process*

Some people cannot be persuaded that they will not be held liable. While this does not seem to be an issue in fact, there is fear around it, and it shapes some people's refusal to act as supported or co-decision-makers.

The rights, roles and responsibilities should be made more clear, in order to encourage people to step into these supportive or co-decision-making roles. Careful and detail-oriented people often make the best supported or co-decision-makers because they take the matter seriously. Without enough clarity, a cohort of good people is being missed in this process.

Some lawyers have great difficulty in taking instructions from people with capacity challenges or intellectual disabilities. Other lawyers feel very uncomfortable balancing their professional obligations of confidentiality with the reality of supported or co-decision-making. It is unclear to many lawyers if and where there is a breach to solicitor-client privilege.

It is unclear if there are enough people to be supportive or co-decision-makers. For those people relying on families, when their parents age-out, they will be dependent on social services, where the staff turn over rates are very high. There are significant numbers of marginalized individuals who are without someone to provide free help and support. For these people the chances of them ending up under guardianship is high; while for others of the same abilities, they may end up being their own decision-makers. There is a sense of inequity to this.

*iv. What works really well?*

There are some excellent support organizations and advocacy organizations. Some of these community organizations are contracted by the Public Guardian to help people with paperwork, which can include paperwork associated with supported or co-decision-making. This assistance is seen as especially useful in helping people overcome their fear about using supported and co-decision-making, particularly around seniors' issues. Community and Public Guardian presentations are also very helpful in transferring knowledge and allaying fears.

The community living organizations do excellent work in providing coaching and family supports. This work has extended to issues relating to supported or co-decision-making.

Some third parties really understand the new system or are more comfortable with the idea of supported decision-making. For instance, pharmacists have

been leaders in this, likely because the idea of taking medications has always been one which has a family or group support system.

The supported decision-making document is easy to use, free, and simple to understand. The co-decision-making system is more complex, but it still allows those who wish to have the court's blessing to receive it without going under a fully guardianship system.

Having a system which fundamentally allows the control to remain in the hands of the autonomous adult is important and successful.

*v. What thoughts / recommendations do you have?*

Continuing to move to a single point of entry for information and services is highly recommended. Often people are forced to chase down information and become distressed trying to use the internet to click on various forms. Having material, including forms and guidebooks, exclusively available online is a barrier. It is much better to maintain an in person service delivery model. Increasing connection between the Public Guardian and the Public Trustee is needed and ongoing; however, this also needs to be augmented by good information about social services. Having this fuller understanding of the services and options can help to reduce the reflex of moving to guardianship.

*d. Saskatchewan*

*i. Functionally, how is it all working in your jurisdiction? What is the “on the ground” experience in your expert opinion?*

In theory, the decision-making legislation in Saskatchewan, like most other modern generations of decision-making statutes, is supposed to be infused with a co- or supported decision-making approach wherever possible. There are excellent statements of principles which clearly indicate that the vulnerable or capacity-challenged adult should be in charge of, or involved in, as much of the decision-making as possible. That does not mean, however, that this happens “on the ground”.

Supported decision-making and guardianship are addressed in the same statute. It is unclear if this is a blessing or a curse. If each had their own statutes, then these regimes might be seen as more equal, and people might have to make a more conscious decision as to their route. In fact, co / supported decision-making is ghettoized.

The legislative models on paper are in a vastly different place than the reality. Plenary guardianships are very much still the norm. The legislative changes were not useless, and they are important, but overwhelmingly the orders granted are plenary. Where a co-decision-making model is used in formality, the reality is still that it is plenary substitute decision-making in practice. Since the

legislative option has been made available, only approximately 7% of cases involved any co-decision-making.

The harsh reality is that with the exception of the adult in question, the other actors want as much control, in the broadest version, as possible. Family, supporters, social service workers and third parties all prefer that plenary-type powers are sought; then people are allowed in practice to consult and support as they see fit.

Very often, no one in authority actually meets with the adult in question. Save and except a medical doctor, the adult may not actually have an opportunity to be seen, or connected with, social supports and services. The basis for the affidavit regarding capacity is generally provided by the medical doctor.

Lawyers are not fond of the co-decision-making legislation, and do not have a good understanding of what it means. Lawyers are also usually retained by the family members, who want to ensure that they can “get it all taken care of” in one fell swoop. The costs associated with formalizing supported decision-making can be significant. As such, it is often seen as being more practical and effective to reach for the broadest possible set of rights, to avoid having to redo the process later and spend more money (when capacity becomes further reduced).

The principles governing decision-making require that a court not grant an order for a form of substituted decision-making unless less intrusive options have been considered. However, in reality, this is often not done and the legal community does not prioritize this. This reality may be skewed by the fact that most people who are spending money on a lawyer to formalize decision-making processes are fairly far down the road in terms of needing substitute decision-making. Informal supported decision-making is likely happening on an ongoing basis within families of persons with capacity challenges, but these arrangements are not formalized in any way. These are considered ‘de facto’ orders.

There are two very different communities that are affected by decision-making legislation in Saskatchewan. The communities of seniors are by far the largest number of people under guardianship. The communities of people who have or who support people with intellectual disabilities are numerically smaller, but have a much stronger advocacy system around them. Overall, these two communities have opposite views. Seniors have often come from a life where they used to make their decisions and now cannot do so easily because of later life impairment. They can use some private planning like enduring powers of attorney ahead of time. Persons with intellectual disabilities and their supporters come from a place of less social power, in that the adults in question may have never been able to make their own decisions or craft their lives. They may have needed various supports their whole lives.



If there were greater education of all parties, including the third parties, then decision-making could move more towards the social work realm, and away from the legal realm. This would be a great leap forward in terms of culture and “on the ground” respect for persons with cognitive impairment and need of supports.

There was consensus that the Saskatchewan model leaned more towards the “assisted” rather than the “supported” decision-making model. It still has a high functional bent towards thinking of it as substituted or “highly advised” decision-making rather than the decisions being more in the hands of the adult with capacity challenges.

There was also consensus that the system of co-decision-making was designed in response to advocacy on the part of families of people with Down Syndrome and other intellectual disabilities. It was never really designed with the aging population in mind, nor to support people with psycho-social or brain injury impairment.

Regardless, having co-decision-making was considered a good idea, although the culture and supports to make it work in truth are not in place.

It was also agreed that the Public Guardian and Trustee was not in a good position to act as a co- or supported decision-maker due to practical considerations. Provincial auditor requirements and other rules and regulations do not lend themselves well to the co-decision-making processes. The ideal co-decision-making arrangement is typified by the caring and involved sibling who lives close by to the adult with an intellectual disability, and can help on a day-to-day basis, rather than an institutional representative.

*ii. What, if any, roadblocks or uncertainties exist which frustrate the process?*

For older adults, or family members supporting them, the requirement to “air their dirty laundry” in public is inhibiting. For many families, admitting that their family member has dementia is a matter of losing face and public status. This is particularly true for older adults who have been leading members of the community. Families would rather cover it up and keep it quiet. The co-decision-making process requires a certain level of divulgence to the public, which is inhibiting. Further, people who are interested in being substitute or co-decision-makers do not like having to put their own finances into the public sphere. As a result, many appropriate supporters are inhibited from stepping forward. However, there is a sense that if people understand why they need to divulge the financial information and that it can be kept private, then this might go a ways towards helping increase acceptance.

There is a significant lack of public legal education on co-decision-making. Co-

decision-making applications do not need to be expensive or difficult, although this is not well-understood. In fact, much of the process is really just filling in forms and should not require a lawyer to be involved, but for the fact that the process is in the Court of Queen's Bench. The fact that the process resides in the court system actually blocks access to justice.

Judicial education is also needed. Judges are not given the education needed to appropriately support co-decision-making and least intrusive approaches.

With respect to liability, co-decision-making in Saskatchewan can't go against the decision of the adult unless property or person will be harmed (and this is not defined in terms of level). So the person is responsible for helping manage the process of the decision-making to give the adult the tools to come to the decision. Outside of fraud or theft it is hard to imagine someone concocting a process.

There is some concern about liability by third parties but not as much worry about the liability of co-decision-makers. The lawyers, however, are in fact quite concerned about the liability and the duties of the co-decision-maker and the liability of the third parties.

### *iii. What issue(s) need clarifying in the process*

Lawyers find the process clear in the legislation and the forms are also quite clear. However, in practice, the process is very complex, and people need a lawyer to get through the system. Words like "service" or "style of cause" are utterly intimidating and confusing to people who are not in the legal field. However, there are in fact very few lawyers who practice in this area.

When the legislation was developed it tried to balance a simple and understandable process with protection against unreasonable family and health care professionals. Overwhelmingly, the culture swung to the side of protection, and thus the system became more complex and less clear.

Additionally, there is a lack of clarity around what types of decisions a co-decision-maker can block or have to allow, even if they do not agree with. The legislation requires that the co-decision-maker cannot stand in the way of the decision that the adult wants to make which is reasonable "on its face". However, if the concern is deeper than "on its face" what role does the co-decision-maker have and how should they proceed?

### *iv. What works really well?*

In Saskatchewan what works well is the property management aspect of the decision-making. There are good provisions for accountings to be rendered, provisions for reporting and overall supervision of the property. This is not

actually always done in practice but the system is there. Courts feel comfortable working in the area of property, but not in the area of personal care decisions.

*v. What thoughts / recommendations do you have?*

Getting co-decision-making out of the Court of Queen's Bench would be very helpful. Movement towards a more informal tribunal system, or a system such as Manitoba's Vulnerable Person's Commissioner should be considered. Requiring a co-decision-making plan including a budget would be helpful. Having NGOs actively engaged in supporting people to use less intrusive approaches would be very useful. Having at least a full-time staff member at the Public Guardian and Trustee office dedicated to co-decision-making would very useful.

There should be dedicated education to judges, lawyers, social workers, advocacy groups and the community about how to do co-decision-making and why it is important. Training for co-decision-makers might even be mandatory and plans and metrics should be established so that it can be measured against.

Co-decision-making should be closer to the model of sentencing circles than guardianship. Ideally, there should be a panel of individuals with a lawyer as one of the supporters helping a person with intellectual disabilities make decisions, or in the case of an older adult, then a geriatric specialist as well. This is unlikely to ever work in practice, however, as resources are not available.

There should be a continuing outreach component on this subject. People need to understand what is being asked of them so that they do not inappropriately agree to be a co-decision-maker without understanding the time, effort and requirements.

A new legislative model should allow for a range of options, with different levels of support, and report to an informal tribunal.

*e. Manitoba*

*ii. Functionally, how is it all working in your jurisdiction? What is the "on the ground" experience in your expert opinion?*

In Manitoba, the Vulnerable Person's Commission derives authority from the *Vulnerable Persons Living with a Mental Disability Act*.<sup>122</sup> The Commission appoints substitute decision-makers for people with mental disabilities who require assistance. Typically these "deficiencies" must manifest before the age of 18. Clients of the Commissioner's office include people with such conditions as Down Syndrome, traumatic brain injury, and cerebral palsy. When any person turns 18 in Manitoba they are presumed to have the rights of a capable adult. If they are not able to make their own decisions, then an application can

be made to the Commissioner for a substitute decision-maker for personal or financial issues.

If the adult is captured by the vulnerable person's legislation, then the Commissioner will make an assessment as to what areas of support or substituted decision-making are needed. If there is no appropriate friend or family member then the adult will be placed with the Public Guardian and Trustee. Accountings are required and cases are reviewed minimum every 5 years. The Commissioner accepts complaints as well, as appropriate.

Supported decision-making in Manitoba is only legislatively referred to in a very limited fashion. In s.6(1) of the Act supported decision-making is defined. However, if it is read closely, one sees that it is defined and referred to only in that section and then it is not referred as a term again anywhere else in the Act. Section 6 (2) notes that people providing support should be recognized and respected, but not really how that is to be accomplished. The term supported decision-making is alluded to again in the guiding principles to the *Act*, including references to "providing support" and "support network" of a vulnerable person.

On the ground, supported decision-making is really about trying to get a network of people around a person with cognitive impairment to help in everyday decisions, and less about formal financial or life decisions. The existence of a solid support network, even informally, can avoid a person being put under a substitute decision-making regime. Often, the support network is deemed enough to support the capacity of the vulnerable person.

The principles of respecting supporters combined with the obligation to use least intrusive measures infuses supported decision-making throughout the broader regime. As such, even if one is appointed to be a substitute, this does not obviate responsibility to be engaged in supported decision-making as well. Rather, it is included in the substituted decision-maker's responsibilities. The adult in question must be aided in their capacity to understand the decisions in their lives, and any substitute must continually involve the adult in decisions to the greatest extent possible. It is, however, not pure supported decision-making in that the ultimate decision does not belong to the adult, but rather to a proxy.

Functionally, the community living associations are predominately against substituted decision-making. A few requests are made to terminate substituted decision-making arrangements in favour of supported decision-making; but they are rare. More often, people work within informal networks of support until there is significant need and then application to the courts for a guardianship order is the next step.

The Commission has approximately 5000 "vulnerable persons" under their aegis, but only 1600 of them have formal substitute decision-makers. As such, supported decision-making is clearly happening in this void, as only 35% of

clients have a substitute. De facto supported decision-making often works fine, until a third party such as financial institutions, health care service workers or government agencies become involved. When these types of third parties become involved there usually is a movement towards changing the relationship to a substituted decision-making model. Third parties are often not comfortable with supported decision-making.

*ii. What, if any, roadblocks or uncertainties exist which frustrate the process?*

The process has been taken out of the court system in Manitoba, but the appeal system is to the Court of Queen's Bench. Not everyone understands this multi-tiered system. Overall, people do not understand how supported decision-making is supposed to work in Manitoba and the legislative interpretation is unclear.

Social workers are also quite overprotective in Manitoba. This can be true of community service workers as well. Guardianships are supposed to be the last resort, but they are often looked to as a first option instead.

Not having enough legal aid in this area is a problem. But even if legal aid was available, the lawyers may not want to take on the client out of fear of being able to take direction. Ironically some lawyers have indicated that they will take instruction from a substitute decision-maker only, and not the vulnerable adult, when the very issue at hand is about avoiding having a substitute decision-maker appointed. It can be a vicious circle.

In many cases, supported decision-making is not presented at all as an option to families. Some social service workers are quite afraid of having a support network involved. The process also requires the community worker to attend monthly meetings and be actively involved, which they may not feel that they have the time or knowledge base to do.

*iii. What issue(s) need clarifying in the process*

There was consensus that research and evaluation of what works and what does not work should be undertaken. There is no ongoing contact with monitors to see if supported decision-making is actually happening or not.

Information is generally lacking on supported decision-making. Community living organizations have done work on education regarding the *Vulnerable Persons Living with a Mental Disability Act* and other supported decision-making issues, but some members of the community are uncertain as to how supported decision-making affects them. Workers in the social service system feel comfortable with guardianship or substituted decision-making much more than supported decisions-making systems. There is a lack of clarity about who makes the decision and what the liabilities or implications of that decision are.

There is a lack of clarity between certain systems. For instance, if a vulnerable adult wants to leave high school and move out of the family house at 18, and not stay until age 21, then they can fall into a black hole of services relating to housing. Supporters will have a very difficult time trying to exert authority or get information on behalf of the adult. The supported decision-making platform does not seem strong or clear enough to provide real leverage in advocacy.

Some people think supported decision-making is a right in Manitoba. It is not actually a right, but the guiding principles are important and should infuse the entire area. Whether this is achieved, however, is highly doubtful.

#### *iv. What works really well?*

Informal supported decision-making systems work well. Supported decision-making has been defined, however obliquely, in Manitoba law since 1996, and is part of its guiding principles, which is good. The message is out there for people to embrace.

Funded NGOs working in this area around community living do a good job. They require stable funding in order to ensure that they can continue to do their work.

Community organizations are generally good at working in this area, providing workshops. One organization works directly with older people and gives educational seminars on supported decision-making. The government generally has not actively engaged in providing educational programs, but the non-profit sector can do a good job if it have appropriate funding.

#### *v. What thoughts / recommendations do you have?*

The whole concept of having a supported decision-maker for people with intellectual disabilities needs to start when the individual is a child. If it was understood and embraced by family, schools and third party systems along the lifecourse, then there would be fewer abrupt roadblocks later on. Support networks are not built easily or overnight, so years need to be invested in this process. There is significant interest in Manitoba for revising its system to make supported decision-making more front-and-centre and more clearly understood. However, having the informal Commissioner process was seen as a leading model in Canada.

## *2. Experiential Experts*

*Beverley is in the advanced stages of Multiple Sclerosis and doctors are recommending many different medical options. Her main caregiver, her daughter Samantha, is an excellent supporter and caregiver for her mother. She also understands her mother and knows how to*

*communicate with her, even when Beverly's speech and writing become limited by her condition.*

*Samantha does not feel comfortable with having the sole responsibility for helping Beverly to make health care decisions or end of life related decisions, and access appropriate care as her health conditions become more complex. Samantha is overwhelmed by the medical information about her mother's condition and feels a lot of pressure around making the best decisions when her mother loses the ability to communicate her wishes and make decisions.*

*Beverly does not want to overburden Samantha with the upcoming medical decisions so she has decided to create a representation agreement. She has appointed her nephew and a close family friend to act as representatives alongside Samantha. The understanding is that the group will act as joint supported decision-makers as long as possible, and become substitute decision-makers once Beverly is no longer able to participate in decision-making. This arrangement allows for a communal decision making process, and Samantha feels more comfortable and better able to continue to support her mother, knowing she will not have to make all the decisions regarding her mother's medical treatments.*

#### *a. Introduction to the Role of Representation Agreements*

In total, ten interviews were conducted with supported decision makers, representatives (supportive decision-makers) and caregivers of supported decision makers. The average participant in this sample had been a part of a representation agreement for five years, with a maximum of nine years and minimum of three months. None of the participants had altered their agreement at any time. Most were unaware that you were able to alter a representation agreement.

Although participants all described themselves as being part of a supported decision-making relationship, they generally characterized representation agreements as a legal means to make decisions on another person's behalf when they are no longer able to do so, suggesting a substitute, advance planning framework. Half of the representatives interviewed were also the designated power of attorney for their supported decision maker. There was a general agreement that representation agreements differ from powers of attorney and advanced directives. Powers of attorney were identified as a legal means for financial arrangements, whereas a representation agreement was seen to primarily concern healthcare decisions.

Day-to-day use of the agreement varied widely. Some participants described using their representation agreement to oversee small household matters, such as paying the telephone bill for the supported decision maker. Others utilized the agreement to monitor finances, arrange personal care and navigate the healthcare system. Several representatives had used the agreement to

successfully set up Registered Disability Saving Plans and Guaranteed Investment saving accounts for their supported decision maker.

Representatives also use representation agreements to advocate for their supported decision maker. This was most often detailed with respect to hospitals and care homes. Overall, representation agreements were described as a tool to ensure health, welfare and safety.

#### *b. Creating an Agreement*

Most participants went to a lawyer to help them draft their agreement. One participant relied exclusively on Internet documents to set up their arrangement. Others used the help of organizations such as the Planned Lifetime Advocacy Network, Family Caregiver's Network Society, NIDUS and the Law Society of British Columbia.

The process of setting up an agreement was described as confusing. Participants were grateful to have the support of organizations to help them draft the agreements and questioned why there were not more resources dedicated to supporting this process. Many participants were glad to have completed their agreement but were unsure of how to direct friends or family in setting up their own. Accessibility is a large barrier for people to set up a representation agreement.

Participants who researched representation agreements themselves were often confused by the vocabulary: supported decision maker, adult, representative, representee and monitor. Seeking legal help was expensive for many of the participants and cost was identified as a barrier in obtaining an agreement.

There were various rationales for selecting whom to include in an agreement. Often, more than one representative would be named, most often three in total. Participants described a mechanism to help representatives make decisions by using a two out of three consensus. This approach was seen as beneficial to protect both the interests of the supported decision maker as well as a mechanism to relieve stress from the representatives.

Young adults were most likely to have their parents as representatives. Extended family and friends also took on representative roles. In situations where there were no family or friends in place members from the represented religious community stepped in.

Selection of representative(s) was based on geographic location, family relation and knowledge of the agreement. Logically, lawyers who had experience in this field were noted as knowledgeable while those without experience were described as less helpful in deciding whom to include in the agreement. Overall monitors were not seen as very helpful and only one agreement had a monitor



in place; participants were more likely to use 2:3 representative decision-making process or entrust an alternative representative.

### *c. Forming a Supported Decision Making Network*

Participants described their decision-making process in detail. Spouses and siblings were noted as common sources to turn to for advice. Some participants had a core group of five or more decision makers with only one or two appointed as designated representatives. Others described receiving help indirectly from their family—not with making the decision itself but with living with the results of their decision. The most common experience of this was spouses helping care for their in-laws.

Representatives expressed that they consult with their supported decision maker before showing the agreement to others. For agreements that worked well, the supported decision-maker was at the centre of all decisions. Representatives, friends, family and healthcare professionals would all surround the supported decision maker.

This is in accordance with most supported decision-makers wishing for their representatives to check in with them prior to using the agreement to enforce a decision. People that receive and interact with the agreement include: doctors, specialists, lawyers, social workers, financial institutions, social services and organizations that support peoples with disabilities.

### *d. What Participants Like Best About Being in an Agreement*

Representatives explained that one of the best things about being a part of a representation agreement is a rewarding feeling from knowing you are helping the supported decision-maker. Other themes identified include: reducing uncertainty regarding end of life decisions, trying to prevent undue family stress, and a sense of security knowing that things are in place to care for the supported decision-maker.

From the perspective of the supported decision-maker, entrusting their rights to another individual can be both scary and empowering. Participants expressed that knowing they are not leaving any loose ends for their family is comforting. Creating a representation agreement was viewed as a proactive step in controlling future care decisions.

By and large representatives understood the weight of this obligation and also felt honored to be a part of the process. It was noted many times that the process of creating an agreement was difficult, expensive and confusing. Many participants were proud and relieved to have completed a representation agreement.

### *e. Representation Agreements and Authority*

*Valerie is a supported decision-maker for her daughter, Hazel, who has Down's Syndrome. When Valerie heard about using representation agreements for supported decision-making in British Columbia, she thought this kind of document would be a great vehicle for supporting Hazel's significant independence, while still allowing her to jump in to help Hazel communicate her wishes when people in authority failed to listen to her views. She had learned from personal experience that service providers often did not respect Hazel's insights into her own experience and needs, and doubted her judgement. Hazel's aunt Joan was also named as supported decision-maker. Hazel and Joan were very close, and sometimes lately Valerie had to be out of town for work, and was not available to respond to issues right away.*

*The representation agreement worked very well with people who knew the family well, such as teachers and social workers. However, when problems arose with Hazel's welfare cheque, Valerie and Joan found that due to frequent staff changes, few front line staff knew Hazel's situation. Few of them understood what a representation agreement was, and they were all reluctant to talk to Joan or Valerie until they came to the office in person to sign new Ministry forms. This meant that in practice helping Hazel out proved challenging and frustrating.*

*One day, Hazel was injured in a car accident. She was taken to emergency. The accident happened when her mother was out of town. The health care staff on duty did not know what a representation agreement was. Joan and Hazel had to spend a lot of time explaining supported decision-making to hospital staff, which delayed Hazel's care. When staff finally agreed to talk to Joan, instead of Hazel's estranged father, they still had a hard time accommodating Joan and Hazel's slow and interactive decision-making process. The busy staff tried to rush Hazel, which made her anxious and less able to problem-solve.*

Many participants expressed frustration regarding dealing with social services, care home, hospital and healthcare staff. Several common experiences emerged in this vein.

Participants who were in interaction with the BC Ministry of Social Development felt that representation agreements were not dependable. It was noted that the Ministry requires that designated decision-makers have separate authorization under a form specific to the department. Participants did not understand why this one Ministry in particular does not honour representation agreements, and were frustrated at not being able to help their supported decision-maker within this area.

The second theme that emerged was disrespect by hospital, healthcare and care home staff. Representatives described many situations where the supported decision-maker was ill or required extra care, and they would try their

best to support them by learning about their often complex medical condition. Hospital and healthcare staff were often too busy to explain treatment options or medications to both the supported decision-maker and their representative. As a result, participants felt overwhelmed and uneasy about the care provided for their loved ones.

Recognition of the document within health and social service sectors varied widely. Participants described that some organizations would take the word of the representative and would not require actually seeing a signed agreement. Others reported they are consistently required to show their agreement, and in some situations describe and provide education about what a representation agreement meant in terms of rights and responsibilities. In the health care field, reception of representation agreements seemed to vary depending on health authority, hospital and staff member.

Participants also described situations where medical and care staff were uninformed of representation agreements. When this situation occurred representatives would go to great lengths to describe to staff the legal weight, their rights as a representative and implications that the document entailed—often to varying results. Participants were frustrated that they had put in considerable effort to create a legal document that some hospital and healthcare staff were not knowledgeable. They felt that often staff did not listen to them when they tried to explain that they were legally appointed to help the supported decision-maker.

Representatives also described situations where they would act on behalf of the supported decision-maker without using or showing the representation agreement. Overall representation agreements are used in hospital and healthcare settings inconsistently.

#### *f. Levers to Better Support the Decision-making Process*

Participants were asked what would better support their decision making process. Common themes identified were accessibility, affordability and respect. Participants noted that finding information about representation agreements was a challenging task and agreed that the process of setting up an agreement should be made easier. This was particularly noted by older participants who may not be comfortable using the Internet to access online supports to create a representation agreement.

The expenses involved in setting up an agreement were identified as a barrier. Some participants wanted to set up an agreement by themselves but were overwhelmed with the process and so sought legal help. This legal assistance was a financial expense that not all participants could afford. It was also noted that people with a disability may not be able to work and so have less disposable income to seek help creating an agreement with a lawyer.

### *g. Education and Support of Representatives*

Representatives described the pressure that is put on them to make decisions on behalf of another person. Participants noted that when creating an agreement, it would be helpful to have specific case scenarios outlined with how the supported decision-maker would like the representative to act.

In our sample, supported decision-makers said they were aware of their rights and stated that they understood their agreement very well. Representatives were said they were aware of their rights. However, descriptions and definitions of supported decision-making provided by participants— notions of making decisions on behalf of another adult— suggest a substitute decision-making approach.

### *h. Participant Attentions and Concerns*

Although participants were generally pleased with their own agreement, there was also a concern for the potential that representation agreements can be used inappropriately. It was questioned how the supported decision-maker is deemed to be legally capable to create an agreement. The notion of informed consent, and the ability for a supported decision-maker to entrust another person when they may not be able to understand the ramifications is central. There were also concerns that a representative may bully a supported decision-maker into signing an agreement so they may take advantage of them financially. Participants wanted to know what checks were in place to prevent abuse, financial or otherwise.

Participants stated that their agreement was important to them because it helped provide clarity and support to their decision-making process. It was comforting for both representatives and extended family to know the wishes of the supported decision-maker would be followed when the adult was no longer able to make decisions for him or herself. Supported decision-makers were also pleased that their wishes are being looked after and their family will not be left to make decisions unadvised.

Participants noted that it is important for people to know representation agreements can be a powerful tool. Difficulties arise when health and social service workers do not respect the agreement. It is not easy to be a representative and there will be difficult decisions to make, and yet, it is also a huge honour to be entrusted to act on the behalf of another person. Representation agreements are seen as legally binding, yet fragile, documents, that are helpful only in as much as they are respected.

## IV. CONCLUSION

### A. Summary

*Li is a 70-year old man with fluctuating capacity due to brain injury caused by a fall 15 years ago. It is important to him that he have the dignity to make most of his own decisions but he is aware that sometimes he can't think as well as other times. He is interested in a supported decision-making arrangement, but knows that pragmatically it needs to have a provision to let his supported decision-maker make substitute decisions as well. He's not sure how he will know the difference or even if this matters. The bank manager, Mr. Tong, also knows Li's son Alexander. Mr. Tong wants to help but he's uncertain who he is supposed to take instructions from and when. How will he know when he is to take instructions from Li, and when to take instructions from Alexander? In the end, a supported decision-making agreement is made up by a lawyer, appointing Alexander as the supported decision-maker. However, significant time is taken with Mr. Tong working out, on a pragmatic basis, what banking limits and controls can be put in place to make it work. Everyone agrees to try it out, as they all want to help Li; however, some practical worries remain. Alexander's sister seems sure to be annoyed, and is worried about protecting her future expected inheritance.*

Overall, supported decision-making was found to be a welcome option in the five jurisdictions. However, in each of these jurisdictions, the same types of comments emerged: “we like having it but we do not really know how to use it well”. All informants referenced a lack of available information on supported decision-making. Even individuals engaged in supported decision-making relationships shared some confusion about what it was and how it was different from substitute decision-making.

Some jurisdictions have supported decision-making in statute but still most practitioners functionally prefer to use a plenary guardianship model. Other jurisdictions have openly embraced the concept of having a vulnerable adult keep decision-making autonomy, but despite this intention, are still somewhat challenged to integrate supported decision-making. Even where supported decision-making occurs it is challenging to monitor that slippage between supported and substitute decision-making, and ensure that practices honour the intentions of the supported adult, because even in jurisdictions such as British Columbia, which has a rich supported decision-making community, the term representative is used to denote both substitute and supported decision-makers.

Supported decision-making is seen by many as a way to get around the roadblock of privacy limitations. Generally, where the system is easy to access, cost was not a major barrier, and personal liability was also not an overwhelming worry for those engaged in supported decision-making.

Abuse and neglect will occur in all systems, legal or not. There was no expectation that supported decision-making would increase, or decrease, the risk of abuse or neglect. Rather, it is viewed as an option that allows individual autonomy to be protected to a greater degree, at least in theory. In practice, concerns still exist that the day-to-day decision-making is actually substituted.

There are no toolkits, educational standards or best practices for how to do supported decision-making specifically. Increased education for all parties is required, including, but not limited to: people with intellectual disabilities and their supporters, seniors and their supporters, caregivers, health care providers, social service workers, community case workers, non-profit organization staff, lawyers and judges.

## **B. Key Themes from the Research**

### *1. Supported Decision-making: An Inherently Informal Process Made Formal*

The act of supported decision-making is inherently an informal process. The laws governing supported decision-making are often making the flexible, trust-based relationships formal and binding in some way. It is not always an easy fit.

In essence, supported decision-making regimes are simply a legal framework formalizing what many community-based and grass-roots organizations, predominately in the field of intellectual disabilities, already do. In this sense, supported decision-making works very well on its own, outside the legal sphere. It happens on a daily, functional level. Where good relationships exist, the handling of funds and entering into arrangements is managed without much in the way of legal formality.

However, there are areas where increased formality is required. In particular, lawyers, health care professionals, government agencies and financial institutions often express the need for a more formalistic decision-making arrangement, with a clear sense of who is making what decision, and on whose proverbial shoulders liability sits.

### *2. Who is the Most Appropriate User of Supported Decision-making?*

Supported decision-making seems to work best when a person with an intellectual disability is assisted by one or more key people in their lives who they can consistently turn to and involve in discussions about making a decision. Supported decision-making appears less appropriate for people with mental health and psycho-social challenges in periods where they may be involved in a mental health break.

Older adults have not yet generally embraced supported decision-making as a formalistic concept of autonomy or personhood, but rather engage in it informally by including family members or friends in discussions. Use of

supported decision-making documents for older persons with dementia is generally viewed as an interim measure only, until the adult is able to put substitute decision-making regimes in place.

Supported decision-making is generally not well known or broadly accessed within any of the jurisdictions where it exists. People who care passionately about it as a way to preserve autonomy and rights are highly engaged around this topic, but the awareness has not yet filtered through into the everyday consciousness of ordinary citizens or legal professionals. There was a sense that substitute decision-making concepts were hard enough, and supported decision-making had not yet reached a tipping point of understanding in terms of use.

There is no clear evidence that supported decision-making is particularly affected by gender, race or ethnicity. Many cultures have a more communal sense of decision-making and supported decision-making may be a good option for those with these types of cultural norms.

There is not enough evidence at this point to determine whether literacy levels, indigenous culture, or regionality impact on the use or acceptance of supported decision-making in general.

### *3. Measures or Supports which Aid Supported Decision-making*

In each of the jurisdictions, experts strongly indicated that funded NGOs working in the field of aging, mental health and intellectual disabilities should play an important role in educating their constituencies about supported decision-making. Where they exist, programs which assist in form-filling, advocacy and brokering knowledge have a positive impact on the uptake of supported decision-making. Government systems (Public Guardian, Public Guardian and Trustee, Vulnerable Persons' Commissioner, etc) benefit by having designated staff who are engaged in community outreach, support and education, as well as to support in-house cases involving supported decision-making.

Increased education to the involved third parties, such as lawyers, health professionals and members of the financial sector, was consistently called for. With good understandings of supported decision-making, both formal and informal, these third parties can both have their concerns alleviated as well as help to support the autonomy of individuals. On the other side of the coin, increased understanding of the roles of substitute and supported decision-making, particularly in the financial sector, can help staff to be vigilant and act appropriately if abuse or neglect is suspected.

### *4. Use of Monitors*

The use of monitors was generally seen as a positive option for supported decision-making. While there was a lack of clarity around the specifics of the

role and day-to-day functions of the monitor, the idea that there is someone who can help support the overall review of the process and to aid the parties was considered a positive.

## C. Recommendations

This paper was produced to support the work of the Law Commission of Ontario with respect to a project focused on amending Ontario's legislation; however, significant themes emerged that point to current challenges experienced in all the jurisdictions we considered as part of this research. The recommendations below are provided for consideration of any jurisdiction exploring creating or enhancing supported decision-making regimes and practices. There is much for all of us to learn by considering what is working well, and not so well, in the various provinces and territories. Where helpful, we have constructed the language of the recommendations to reflect some of the unique features of the existing Ontario regime.

### 1. Forms

The Albertan “downloadable” Supported Decision-making form has been very positively received. It is free, easy to access and generally easy to understand. Informants considered this form a useful and practical formalization of an inherently informal process. For people who wish to reduce third party concerns about privacy and inclusion, this approach has been generally helpful. If a more layered approach is preferred, the Yukon legislation provides a “something for everyone” approach that allows people to pick and choose levels of support. The court-based Albertan co-decision-making approach is still too novel to accurately gauge effectiveness.

*An easy to use, downloadable form that allows an adult to appoint a supported decision-maker should be considered, if an open model is preferred in Ontario. If a more formal model is preferred, a still very flexible approach exists in the Yukon, which should be considered. If a court-based model is considered, the Albertan co-decision-making model should be further explored through deeper client-based research before being recommended.*

### 2. Terminology

Use of the term “representation agreement” in both British Columbia and the Yukon has been confusing and is not recommended. “Assisted decision-making” and “co-decision-making” are less confusing but still make it unclear who is the final decision-maker. Use of the term “Supported decision-making” is the best understood term, and the one that has gained the greatest understanding in terms of function and purpose.



*Use the term “supported decision-making” and “supported decision-maker” for greatest clarity and uptake.*

### 3. Tribunal and Court Involvement

The administrative tribunal system was overwhelmingly held to be the most promising approach for supported decision-making systems. Administrative tribunals were considered more accessible, less intimidating, and more expert in their deliberations around issues such as decision-making, least intrusive approaches and community linkages.

*The Ontario Consent and Capacity Board seems well-placed to oversee supported decision-making challenges, with an appeal to Superior Court. Where court-based systems are in place, ensuring that public funding and advocacy is available is critical. Providing appropriate training to lawyers and judges about supported decision-making is essential. While the s.3 Counsel model exists in Ontario, possible expansion of this approach may be required.*

### 4. Privacy

Privacy concerns by third parties is one of the key drivers to formalize the often already informal supported decision-making systems in place for vulnerable adults. Some of those privacy concerns are real; others are a reaction to lack of confidence in privacy laws and obligations, including the law of consent.

*Third party actors such as lawyers, health care providers, risk managers, government service workers, community support workers and financial institution staff need significant support and training on issues of privacy, consent and working to support the capacities of socially vulnerable adults in order to avoid inappropriate substitute decision-making on their behalf.*

### 5. Education

While supported decision-making makes common sense to many people, and has generally been embraced as a concept that supports autonomy, few people feel confident that they know what it truly means, or how to effect it. Education in this area is required.

*Develop a series of educational and training materials in a variety of formats which provides practical “how to” training on best practices, micro-skills, obligations, risks and things to avoid. Ensure that companion materials are also available for the third party actors noted above, but in particular health care providers and financial institution staff. Roll-out this material effectively*

*across the province, preferably before the legislation comes into full effect, but certainly after any legislative implementation.*

## *6. Access to Justice*

Access to justice is a real and significant concern in the area of supported decision-making, particularly with adults who may have social vulnerability and/or cognitive impairment. Ensuring that NGOs who work directly with community are appropriately funded to provide their clients with practical as well as advocacy supports is critical.

*Community-based organizations should be funded to assist clients with form-filling, education delivery, outreach, and advocacy supports.*

## *7. Research*

Multiple barriers such as language, ethno-cultural heritage, disability, mobility challenges, newcomer status, gender and sexual orientation are likely to create increased difficulties for accessing justice in this field. However, research is lacking in drawing specific conclusions between the linkages of these barriers and supported decision-making.

*Increased sociological and legal research into multiple barriers and their impact on supported decision-making is required.*

## **V. APPENDICES**

### **A. Expert Interview Questions:**

1. Functionally, how is it all working in your jurisdiction? What is the "on the ground" experience of supported decision-making in your expert opinion?
2. What, if any, roadblocks or uncertainties exist which frustrate the process?
3. What issue(s) need clarifying in the process of supported decision-making
4. What works really well?
5. What thoughts / recommendations do you have?

### **Prompt Questions:**

1. What are some challenges that have emerged and how have people navigated these challenges effectively?
2. What kinds of community supports have empowered the person with capacity challenges to participate as much as possible in decision-making processes?
3. What supports are missing?
4. How have the decision-making processes been tailored to address and accommodate the unique abilities and communication styles of the adult decision-makers involved?
5. What kind of strategies or processes, if any, have been put in place or used to facilitate the supportive decision-making relationship?
6. How is the decision-making relationship best characterized in terms of the four categories of people interviewed?
7. 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?
8. 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?

9. What, if any, role does concern about liability play? This includes liability of the supported decision-maker, the adult, the liability of third parties (health care professionals, financial professionals, other)

10. What, if any, role does cost play in this regime?

## **B. Call for Participation in Research**

### *Research Project on Supported Decision-making in BC Opportunity to Participate*

Are you interested in sharing your story about supported decision-making? The Canadian Centre for Elder Law is conducting research into supported decision-making. We believe that people who use representation agreements in their day-to-day lives have wisdom to share about supported decision-making. We are currently talking to people across BC who use or are affected by representation agreements, including:

- People with disabilities and other challenges who are using supportive decision-making to help them make their own decisions
- Designated supported decision-makers
- Family and friends who help people with representation agreements and decision-making
- People acting as monitors

We are hoping to learn more about how agreements are best used and how supports could be enhanced to make supported decision-making more accessible for different people with disabilities.

If you would like to be interviewed, have questions or would like to otherwise participate in this project, please contact Raissa Dickinson at [rdickinson@bcli.org](mailto:rdickinson@bcli.org).

People with disabilities who use supported decision-making to make their own decisions will be offered a \$20 honorarium in appreciation of their time. You can find out more about this project, called Understanding the Lived Experience of Supported Decision-making in Canada, at: <http://www.bcli.org/ccel/projects/understanding-lived-experience-supported-decision-making>.

The Canadian Centre for Elder Law is a non-profit organization that conducts legal research, produces educational materials and proposes changes to the law to better serve people in Canada impacting by aging and mental capacity issues.

## ENDNOTES

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- <sup>2</sup> *Representation Agreement Act*, RSBC 1996, c 405 (RAA).
- <sup>3</sup> NA Kohn, JA Blumenthal, AT Campbell, “Supported Decision-making: A Viable Alternative to Guardianship?” (2013) 117:4, *Penn State Law Review* 1113.
- <sup>4</sup> *Vulnerable Persons Living with a Mental Disability Act*, CCSM c V90.
- <sup>5</sup> *Adult Guardianship and Trusteeship Act*, SA 2008, c A-4.2.
- <sup>6</sup> The legislation also cites other factors for the judge to consider.
- <sup>7</sup> RAA, note 2, S 7(1)(c) and (2.1).
- <sup>8</sup> *Adult Guardianship and Trusteeship Act*, note 5, s 17(2)(a).
- <sup>9</sup> *Health Care Consent Act*, 1996, SO 1996, c 2.
- <sup>10</sup> *Substitute Decisions Act*, 1992, SO 1992, c 30.
- <sup>11</sup> *Mental Health Act*, RSO 1990, c m.7.
- <sup>12</sup> Law Commission of Ontario, *Persons with Disabilities: Final Report - September 2012* (2012), online: Law Commission of Ontario <<http://www.lco-cdo.org/en/disabilities-final-report>>.
- <sup>13</sup> Law Commission of Ontario, *A Framework for the Law as It Affects Older Adults: Advancing Substantive Equality for Older Persons through Law, Policy and Practice* (2012), online: Law Commission of Ontario <<http://www.lco-cdo.org/older-adults-final-report.pdf>>.
- <sup>14</sup> Law Commission of Ontario, *Introducing the Framework: A Framework for the Law as It Affects Older Adults: Advancing Substantive Equality for Older Persons through Law, Policy and Practice* (2012), online: Law Commission of Ontario <<http://www.lco-cdo.org/en/older-adults-final-report-framework>>; Law Commission of Ontario, *Introducing the Framework, Persons with Disabilities: Final Report*” (2012), online: Law Commission of Ontario <<http://www.lco-cdo.org/en/disabilities-final-report>>.
- <sup>15</sup> Law Commission of Ontario, note 14.
- <sup>16</sup> Law Commission of Ontario, *Funded Research Papers: Legal Capacity, Decision-making and Guardianship* (2013), online: Law Commission of Ontario <<http://lco-cdo.org/en/capacity-guardianship-call-for-papers>>.
- <sup>17</sup> UN General Assembly, *Convention on the Rights of Persons with Disabilities* (CRPD), resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106.
- <sup>18</sup> UN General Assembly, note 17, Article 1.

<sup>19</sup> UN General Assembly, note 17, Article 19.

<sup>20</sup> UN General Assembly, note 17, Article 12. Emphasis added.

<sup>21</sup> RAA, note 2.

<sup>22</sup> Justice Marion Allan and Laura Watts, *Study Paper on A Comparative Analysis of Adult Guardianship Laws in BC, New Zealand and Ontario*, Canadian Centre for Elder Law, October 2006, 7 (Comparative Study Paper, Oct 2006) (Allan and Watts).

<sup>23</sup> *Patients Property Act*, RSBC 1996, c 349.

<sup>24</sup> Allan and Watts, note 22, 10-11.

<sup>25</sup> Allan and Watts, note 22, 10-11.

<sup>26</sup> Allan and Watts, note 22, 8.

<sup>27</sup> Allan and Watts, note 22, 7.

<sup>28</sup> RAA, note 2.

<sup>29</sup> UN General Assembly, note 17, Article 1.

<sup>30</sup> See for example, *Adult Guardianship Act*, RSBC 1996, c 6, s 3; RAA, note 2, s 3; *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181, s 3; *Decision-Making Support and Protection to Adults Act*, SY 2003, c 21, s 3; *Adult Guardianship and Trusteeship Act*, note 5, s 2; *Adult Guardianship and Co-decision-making Act*, SS 2000, c A-5.3, s 3; *Vulnerable Persons Living with a Mental Disability Act*, note 4, Preamble; *The Health Care Directives Act*, CCSM c H27, s 4; *Substitute Decisions Act*, note 10, s 2; *Code civil du Québec*, LRQ, c C-1991, s 154; *Health Care Consent Act*, note 9, Schedule A, s 4(2); *Consent to Treatment and Health Care Directives Act*, RSPEI 1998, c C-17.2, s 3; *Hospitals Act*, RSNS 1989, c 208, s 52; *Advance Health Care Directives Act*, SNL 1995, c A-4.1, s 7; *Guardianship and Trusteeship Act*, SNWT 1994, c 29, s 1.1; *Guardianship and Trusteeship Act*, SNWT (Nu.) 1994, c 29, s 1.1.

<sup>31</sup> Mental Disability Advocacy Center, *Legal Capacity in Europe: A call to action to the EU and governments*, 9, online: <[http://mdac.info/sites/mdac.info/files/legal\\_capacity\\_in\\_europe.pdf](http://mdac.info/sites/mdac.info/files/legal_capacity_in_europe.pdf)>.

<sup>32</sup> Mental Disability Advocacy Centre, *Supported decision-making: An alternative to guardianship* at 3, online: <<http://mdac.info/en/resources/supported-decision-making-alternative-guardianship>>.

<sup>33</sup> Mental Disability Advocacy Centre, note 32 (emphasis theirs).

<sup>34</sup> Mental Disability Advocacy Centre, note 32, 7.

<sup>35</sup> United Nations, *Backgrounder: Disability Treaty Closes a Gap in Protecting Human Rights* (2008), online: UN Enable <<http://www.un.org/disabilities/default.asp?id=476>>.

<sup>36</sup> CRPD, note 17.

<sup>37</sup> BC Adult Abuse and Neglect Prevention Collaborative, *Vulnerable Adults and Capability Issues in BC: Provincial Strategy Document* (2009), 17, online: Canadian Centre for Elder Law <[http://www.bcli.org/sites/default/files/Vanguard\\_%2816May09%29.pdf](http://www.bcli.org/sites/default/files/Vanguard_%2816May09%29.pdf)>.

- <sup>38</sup> BC Adult Abuse and Neglect Prevention Collaborative, note 37.
- <sup>39</sup> BC Adult Abuse and Neglect Prevention Collaborative, note 37.
- <sup>40</sup> RAA, note 2.
- <sup>41</sup> RAA, note 2.
- <sup>42</sup> RAA, note 2, s 7(1).
- <sup>43</sup> RAA, note 2, s 7(1).
- <sup>44</sup> RAA, note 2, s 7(2). Re the exclusions in subsection c, consent to abortion or electroconvulsive therapy is permitted only with a written recommendation by the treating physician and another doctor, and consent to psychosurgery and a number of other treatments may never be provided by a representative.
- <sup>45</sup> RAA, note 2, s 16(1).
- <sup>46</sup> RAA, note 2, s 20.
- <sup>47</sup> RAA, note 2, s 34(2).
- <sup>48</sup> RAA, note 2, s 30.
- <sup>49</sup> *Yukon Decision-Making Support and Protection to Adults Act*, note 30.
- <sup>50</sup> *Yukon Decision-Making Support and Protection to Adults Act*, note 30, Part 1, s 4.
- <sup>51</sup> *Yukon Decision-Making Support and Protection to Adults Act*, note 30, s 5(1).
- <sup>52</sup> *Yukon Decision-Making Support and Protection to Adults Act*, note 30, s 8.
- <sup>53</sup> *Yukon Decision-Making Support and Protection to Adults Act*, note 30, s 11.
- <sup>54</sup> *Yukon Decision-Making Support and Protection to Adults Act*, note 30, s 9(1).
- <sup>55</sup> *Yukon Decision-Making Support and Protection to Adults Act*, note 30, s 12.
- <sup>56</sup> *Yukon Decision-Making Support and Protection to Adults Act*, note 30, s 15.
- <sup>57</sup> *Adult Guardianship and Trusteeship Act*, note 5.
- <sup>58</sup> *Adult Guardianship and Trusteeship Act*, note 5, s 4.
- <sup>59</sup> *Adult Guardianship and Trusteeship Act*, note 5, s 4.
- <sup>60</sup> *Adult Guardianship and Trusteeship Act*, note 5, s 13(4)(a).
- <sup>61</sup> *Adult Guardianship and Trusteeship Act*, note 5, s 13(5).
- <sup>62</sup> *Adult Guardianship and Trusteeship Act*, note 5, s 13(4)(c).
- <sup>63</sup> *Adult Guardianship and Trusteeship Act*, note 5, s 17(1).

<sup>64</sup> *Adult Guardianship and Trusteeship Act*, note 5, s 10(1).

<sup>65</sup> *Adult Guardianship and Trusteeship Act*, note 5, s 86.

<sup>66</sup> *Adult Guardianship and Trusteeship Act*, note 5, ss 102-104.

<sup>67</sup> *The Adult Guardianship and Co-decision-making Act*, note 30.

<sup>68</sup> *The Adult Guardianship and Co-decision-making Act*, note 30, s 15.

<sup>69</sup> *The Adult Guardianship and Co-decision-making Act*, note 30, s 17(2).

<sup>70</sup> *The Adult Guardianship and Co-decision-making Act*, note 30, ss 6-7.

<sup>71</sup> *The Adult Guardianship and Co-decision-making Act*, note 30, s 12.

<sup>72</sup> A hearing is not required if the court orders that a hearing is not required – for example, where all parties consent.

<sup>73</sup> *The Adult Guardianship and Co-decision-making Act*, note 30, s 33.

<sup>74</sup> *The Adult Guardianship and Co-decision-making Act*, note 30, s 39.

<sup>75</sup> *The Vulnerable Persons Living with a Mental Disability Act*, note 4.

<sup>76</sup> *The Vulnerable Persons Living with a Mental Disability Act*, note 4, s 6(1).

<sup>77</sup> *The Vulnerable Persons Living with a Mental Disability Act*, note 4, preamble.

<sup>78</sup> *The Vulnerable Persons Living with a Mental Disability Act*, note 4, s 1.

<sup>79</sup> *The Vulnerable Persons Living with a Mental Disability Act*, note 4, s 6(2).

<sup>80</sup> We offered participants and host organizations the option of holding a focus group involving multiple experiential experts. Although the host organizations initially suggested a focus group approach, in the end all experiential experts preferred a one-on-one interview.

<sup>81</sup> P Gill, K Stewart, E Treasure & B Chadwick, “Methods of data collection in qualitative research: interviews and focus groups” (2008) 204:6 *British Dental Journal*.

<sup>82</sup> A Hardon, C Hodgkin & D Fresle, *How to Investigate the Use of Medicines by Consumers* (2004), 24, online: World Health Organization <<http://apps.who.int/medicinedocs/pdf/s6169e.pdf>> (Hardon, Hodgkin and Fresle).

<sup>83</sup> Hardon, Hodgkin and Fresle, note 82.

<sup>84</sup> For example, the researcher has conducted research and/or given research presentations in each of the jurisdictions.

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<sup>86</sup> As explored in Hardon, Hodgkin and Fresle, note 82.



<sup>87</sup> Hardon, Hodgkin and Fresle, note 82, 24.

<sup>88</sup> LS Whiting, "Semi-Structured Interviews: guidance for novice researchers" (2008) Nursing Standard 22.

<sup>89</sup> CA Moser & G Kalton, *Survey Methods in Social Investigation*, 2d ed (Franham, UK: Gower, 1985), 20-61.

<sup>90</sup> CA Moser & G Kalton, note 89.

<sup>91</sup> CA Moser & G Kalton, note 89, 79.

<sup>92</sup> National Disability Authority, *Report of the Commission on the Status of People with Disabilities* (1996), online: National Disability Authority <[http://www.nda.ie/website/nda/cntmgmtnew.nsf/0/9007E317368ADA638025718D00372224/\\$File/strategy\\_for\\_equality\\_01.htm](http://www.nda.ie/website/nda/cntmgmtnew.nsf/0/9007E317368ADA638025718D00372224/$File/strategy_for_equality_01.htm)>.

<sup>93</sup> CRPD, note 17.

<sup>94</sup> A Potok, *A Matter of Dignity: Changing the World of the Disabled*, (Toronto: Bantam, 2003).

<sup>95</sup> KA Heyer, "Disability Lens on Sociolegal Research: Reading *Rights of Inclusion* from a Disability Studies Perspective" in DM Engel & FW Munger, *Rights of Inclusion: Law and Identity in the Life Story of Americans with Disabilities* (Chicago: University of Chicago Press, 2003), 261.

<sup>96</sup> LA Chappell, "Emergence of participatory methodology in learning difficulty research: Understanding the context." (2000) 28 *British Journal of Learning Disabilities*, 38-43; J Porterm & P Lacey, "Researching Learning Difficulties" (London: SAGE Publications, 2005).

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<sup>98</sup> R Garbutt "Is there a place within academic journals for articles presented in an accessible format?" (2009) 24:3 *Disability & Society* 357-371; N Hodge, "Evaluating life world as an emancipatory methodology" (2008) 23:1 *Disability & Society* 29-40; M Priestley, P Waddington, & C Bessozi, "Towards an agenda for disability research in Europe: Learning from disabled people's organizations" (2010) 25:6 *Disability & Society* 731-746.

<sup>99</sup> N Watson, "Researching the lives of disabled children and young people, with a focus on their perspectives" (2012) 26:3 *Children & Society* 192-202.

<sup>100</sup> S Scambler, "Exposing the limitations of disability theory: The case of juvenile batten disease" (2005) 3 *Social Theory and Health* 144-164.

<sup>101</sup> M Nind, *Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges* (2009), online: University of Southampton <<http://eprints.soton.ac.uk/65065>>; A Young, "Obtaining views on health care from people with learning disabilities and severe mental health problems" (2006) 34 *British Journal of Learning Disabilities* 11-19; Economic & Social Research Council National Centre for Research Methods, *Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges* (2008) online: Economic & Social Research Council <<http://eprints.ncrm.ac.uk/491/1/MethodsReviewPaperNCRM-012.pdf>>.

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<sup>102</sup> L Townson, S Macauley, E Harkness, R Chapman, A Docherty, J Dias & N McBulty, “We are all in the same boat: Doing ‘people-led research’” (2004) 32 *British Journal of Learning Disabilities* 72-76; C Harrington, M Foster, S Rodger & J Ashburner, “Engaging young people with Autism Spectrum Disorder in research interviews” (2013) *British Journal of Learning Disabilities*, in press.

<sup>103</sup> Watson, note 99.

<sup>104</sup> G Ottmann & J Crosbie, “Mixed method approaches in open-ended, qualitative, exploratory research involving people with intellectual disabilities: A comparative methods study” (2013) *Journal of Intellectual Disabilities*, in press.

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<sup>106</sup> G Teachman & BE Gibson, “Children and Youth With Disabilities Innovative Methods for Single Qualitative Interviews” (2013) 23:2 *Qualitative Health Research* 264-274.

<sup>107</sup> R Fassinger & S Morrow, “Toward Best Practices in Quantitative, Qualitative, and Mixed-Method Research: A Social Justice Perspective” (2013) 5:2 *Journal for Social Action in Counseling and Psychology* 69-83.

<sup>108</sup> Ottmann & Crosbie, note 104.

<sup>109</sup> K Stalker, “Some ethical and methodological issues in research with people with learning difficulties” (1998) 13 *Disability & Society* 5-19.

<sup>110</sup> N Groove, J Porter, K Bunning & C Olsson, C “Interpreting the meaning of communication by people with severe and profound intellectual disabilities: Theoretical and methodological issues” (1999) 23 *Journal of Applied Research in Intellectual Disabilities* 190–203; KR McVilly, R Burton-Smith & J Davidson, “Concurrence between subject and proxy ratings of quality of life for people with and without intellectual disability” (2000) 25 *Journal of Intellectual and Developmental Disability* 19–39.

<sup>111</sup> O Barr, R McConkey & J McConaghie, “Views of people with learning difficulties about current and future accommodation: The use of focus groups to promote discussion” (2003) 18:5 *Disability & Society* 577-597.

<sup>112</sup> MD Fetters, LA Curry & JW Creswell, “Achieving Integration in Mixed Methods Designs—Principles and Practices” (2013) 48:6 *Health Services Research* 2134-2156.

<sup>113</sup> Ottmann & Crosbie, note 104.

<sup>114</sup> PhotoVoice participants take photographs which represent their views and stories, then come together as a group to develop narratives for their photos.

<sup>115</sup> C Wang & MA Burris, “Empowerment through Photo Novella: Portraits of Participation” (1994) 21:2 *Health Education & Behavior* 171-186.

<sup>116</sup> LS Lorenz & B Kolb, “Involving the public through participatory visual research methods” (2009) 12:3 *Health Expectations* 262-274.

<sup>117</sup> This was not true of all experts. Three of the experts also identified as being “supporters” of persons with intellectual disabilities or dementia.

<sup>118</sup> BC Expert #3, with a background in government and academics.

<sup>119</sup> RAA, note 2.

<sup>120</sup> Valerie Temple and M. Mary Konstantareas, “A comparison of the Behavioural and Emotional Characteristics of Alzheimer’s Dementia in Individuals with and without Down Syndrome” (Spring 2005), 24 (2) *Canadian Journal on Aging*, 179-189, 187.

<sup>121</sup> Allan and Watts, note 22, 10-11.

<sup>122</sup> *Vulnerable Persons Living with a Mental Disability Act*, CCSM c V90.