



SUPPORTED DECISION MAKING A ROADMAP FOR REFORM IN NEWFOUNDLAND & LABRADOR

FINAL REPORT

by **Michael Bach** and **Lana Kerzner**



A LEGAL CAPACITY RESEARCH REPORT

from IRIS – Institute for Research and Development on Inclusion and Society

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DISCLAIMER

This report, and the legal research and analysis contained in it, is not intended to be legal advice. The legal content is intended solely to provide background and context for the policy analysis and options presented.

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EXECUTIVE SUMMARY

Background

Legal capacity is the legally-recognized capacity and power to make personal life, health care and financial decisions. The right to equality in exercising legal capacity without discrimination based on disability has been recognized under the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD).

Community stakeholders have expressed concern that several laws and policies in Newfoundland and Labrador operate in ways that restrict or deny the exercise of legal capacity by imposing guardianship and substitute decision making based on disability.

The provincial government has acknowledged these concerns and mandated the exploration of “supported decision making” alternatives to guardianship and substitute decision making.

Scope of Research

IRIS – Institute for Research and Development on Inclusion and Society was engaged by the Newfoundland and Labrador Association for Community Living, on behalf of the ‘Steering Committee on Citizenship and Legal Capacity for All’ to: identify key issues and barriers to legal capacity; recommend directions for reform; and outline a ‘roadmap’ to implement them. The review involved focus groups and key informant interviews with community stakeholders and senior government officials, as well as extensive legal research.

The ‘Decision-Making Capability’ Approach to Legal Capacity

Laws regulating legal capacity in Newfoundland and Labrador, and the rest of Canada, evidence three main approaches to defining criteria for who can make legally valid decisions:

- The ‘status’ approach restricts capacity based on a ‘mental disability’ or ‘disorder.’
- The ‘outcome’ approach adds to the status approach behavioural criteria – like not being a harm to oneself or others.
- The ‘cognitive/functional’ approach establishes cognitive criteria like being able to understand information and appreciate consequences relevant to a decision for determining who can exercise legal capacity.

The UN Committee on the Rights of Persons with Disabilities has found all these approaches to be discriminatory because they restrict access based on disability.

The alternative “decision-making capability approach” is non-discriminatory because it recognizes that the capacity to understand information and appreciate consequences in making decisions can be provided by the person themselves (independent decision-making capability), or by others supporting a person (interdependent decision-making capability).

Several features of Canada’s current laws that reflect this approach were examined.

Legal Regime Regulating Legal Capacity in Newfoundland and Labrador

The research examined international law, the *Canadian Charter of Rights and Freedoms*, and several pieces of provincial legislation and jurisprudence regulating legal capacity, including: the *Mentally Disabled Persons' Estates Act*, *Enduring Powers of Attorney Act*, *Adult Protection Act*, *Advance Health Care Directives Act*, *Mental Health Care and Treatment Act*, *Judicature Act*, and *Human Rights Act*.

Research Findings: Key Issues and Barriers in Exercising Legal Capacity

A. Personal and Inter-personal barriers:

1. People often “relinquish their voice”, after sustained loss of autonomy;
2. Some are “not ready” to make choices on their own, and lack the opportunities and supports to do so;
3. Some individuals are making choices that result in severe risk or harm;
4. Families are feeling pressured by health and social services systems and financial institutions to apply for guardianship to protect a person’s future; and
5. Some have seen families, support providers and appointed representatives who, in their perception, are exercising undue control over adults with disabilities.

B. Program issues and barriers:

1. Limited resources and clear direction means programs fit “people into boxes;”
2. Province-wide capacity to deliver responsive and individualized supports in health care, home support and community services is lacking;
3. Lack of affordable housing options providing choice, support, safety and inclusion;
4. Inadequate future planning services are “short-changing” future financial security;
5. Concern that some Regional Health Authority staff appear ineffective in supporting a person’s right to decide;
6. “Institutional mistrust” among some health and community support providers and government departments; and
7. Community-based health and social service providers not providing needed supports for decision making.

C. Policy issues and barriers:

1. No mandated approach to create alternatives to guardianship and substitute decision making;
2. A patchwork system of decision-making support and community capacity leaves people without needed:
 - a) Independent person-centred planning facilitation;
 - b) Assistance to arrange and access decision-making supports;
 - c) Flexible and responsive individualized funding for disability supports;
 - d) Community navigation support; and
 - e) Assistance in working with other parties to arrange accommodations;

3. Gaps for youth in care transitioning to adulthood who need decision-making support; and
4. Decision-making supporters are denied access to a person's information because of privacy concerns and so cannot effectively assist.

D. Legal issues and barriers:

1. Legislation evidences a fragmented approach and gaps in regulating legal capacity to make different types of decisions, i.e., property, personal and health care;
2. Legislation evidences inconsistent requirements for exercising, and approaches to, legal capacity;
3. Supports and accommodations are only minimally recognized in law;
4. Legislation primarily reflects a bio-medical approach to disability; and
5. Some, but inconsistent, recognition of less/least restrictive alternatives to guardianship exists.

Examined against the *Canadian Charter of Rights and Freedoms*, the legal research finds three main issues with Newfoundland and Labrador's legal capacity laws:

1. Legislation based on the mainstream approaches to legal capacity results in discrimination, contrary to s.15 of the *Charter*;
2. Legislation which restricts legal capacity results in deprivations of liberty and security of the person, and are suspect for violations of people's s. 7 *Charter* Rights;
3. The manner in which the legislation balances values of autonomy and equality against protection from harm must be re-examined to ensure *Charter* compliance.

Assessment of Options for Meeting Constitutional Imperatives for Reform

The *Canadian Charter of Rights and Freedoms*, along with evolving domestic and international human rights obligations, establish an imperative to reform the current legal capacity regime in Newfoundland and Labrador. Three main options for community stakeholders, the provincial government, and legislators to consider are:

- ***Option A – Phased in fully inclusive decision-making capability approach to legal capacity, enabled by full recognition of supports and accommodations in law and policy:*** Would adopt a comprehensive approach to legally recognizing *both* independent and interdependent decision-making capability with supports and accommodations as required, and develop policy, guidelines, training, and community-based capacity to support implementation.
- ***Option B – Supported cognitive/functional approach to legal capacity, where law and policy recognize the role of supports and accommodations in enabling a person to meet cognitive tests of legal capacity in all circumstances:*** Would establish consistent cognitive/functional tests for legal capacity across main statutes in the legal capacity regime and recognize supports and accommodations to enable people to exercise legal

capacity on that basis. Provincial policy and guidelines would be developed to support implementation.

- ***Option C – Status quo legal regime but with an enhanced focus on decision-making supports and accommodations:*** Would not change the legal capacity regime, but would introduce policy and practice guidelines, information resources and training to maximize provision of supports and accommodations for decision making to meet legal requirements to exercise legal capacity within the current framework of the law.

Nine criteria were selected to assess the three main options, as follows:

1. Meets Canada’s obligations consistent with the CRPD;
2. Is *Charter* compliant, according to *Charter* informed principles ensuring a right to equality in the exercise of legal capacity;
3. Recognizes and enables access to supports and accommodations for decision making;
4. Addresses fragmentation and inconsistency in the regime for regulating legal capacity;
5. Safeguards integrity of the decision-making process to maximize legal capacity;
6. Maximizes beneficiaries;
7. Provides a cost-effective approach to meeting support needs;
8. Meets disability, mental health and seniors’ communities’ concerns; and
9. Is a feasible option to implement.

The assessment concluded that option A best meets these criteria and addresses the concerns motivating this consultation and research, because it:

- is the only option that addresses the current exclusion of people with more significant intellectual, developmental, and cognitive disabilities and people living with mental health issues from exercising and enjoying legal capacity;
- best fulfills *Charter* informed principles for an inclusive legal capacity regime;
- is best able to meet community concerns and calls to ensure people with more significant disabilities are supported to exercise legal capacity; and
- would introduce more consistency to the legal regime.

In comparison, options B and C would not meet the criteria, or motivating concerns, to the same extent:

- Options B and C would exclude a large and growing group from the benefits of exercising legal capacity.
 - While they would recognize supports and accommodations for decision making to some extent, they would exclude people who are unable to meet a cognitive test of legal capacity even with supports and accommodations.
- Thus, these options would not be *Charter* compliant.
- The options would not address community concerns identified in a “community response” (in Appendix I) to a draft of this report, which rejects such options because

they exclude those with more significant disabilities, “those for whom legal reform is most necessary” their report states.

Recommendations and Roadmap for Reform

Based on the analysis we identify eleven main recommendations for an initial 5-year reform strategy to implement option A, and to deal with the complex and intersecting issues identified:

1. Establish a Joint Government-Community Legal Capacity Reform Steering Committee and inter-departmental leadership to steer the initiative;
2. Provide coordination through the Disability Policy Office;
3. Initiate a proactive approach to ensure Charter-compliance and consistency and clarity in the province’s legal capacity regime;
4. Adopt the decision-making capability approach to guide law reform;
5. Begin the legislative reform process by reforming the Mentally Disabled Persons’ Estates Act to provide a platform from which to build consistency and clarity in the province’s legal capacity regime;
6. Establish a policy and guidelines for reasonable accommodation as it applies to the exercise of legal capacity;
7. Mandate a proactive process for exploring least restrictive alternatives;
8. Review capacity of the community-based health and social services sector to deliver independent planning and community navigation supports;
9. Pilot initiatives for implementing supports for decision making at all decision-making points in health care and other settings where a need for guardianship or substitute decision making is considered;
10. Deliver information resources and training on the meaning of liberty and equality in the exercise of legal capacity; and,
11. Develop a data collection strategy to track and document the use of guardianship and substitute decision making in all sectors.

Conclusion

The reforms recommended in this report would better align the province’s legal, policy and program framework with Constitutional and human rights obligations, and government priorities to enable people to live independently and contribute to inclusive and supportive communities in Newfoundland and Labrador.

Taking these steps would respond to calls from the disability community to address longstanding barriers to liberty and equality in the exercise of legal capacity, especially for people with intellectual, developmental or cognitive disabilities, and mental health issues.

List of Acronyms/Short Forms

Charter	<i>Canadian Charter of Rights and Freedoms</i>
CRPD	<i>Convention on the Rights of Persons with Disabilities</i>
UN	United Nations
UN Committee	United Nations Committee on the Rights of Persons with Disabilities

Note to Readers on:

‘Decision making’ and ‘decision-making’

- This term is used in two ways: as a noun to describe the process of making a health care, financial or personal decision that a person goes through; and as an adjective to describe types of arrangements or processes for decision making. Consistent with editing guidelines, when used as a noun, the term is not hyphenated. When used as an adjective it is hyphenated, for example ‘supported decision-making arrangements’ or ‘decision-making processes.’

‘Cognitive tests’ of legal capacity

- This report uses the phrase ‘cognitive tests’ to refer to those tests of legal capacity which establish that a person must be able to demonstrate certain cognitive abilities as a requirement for exercising legal capacity. A common cognitive test is the ‘understand and appreciate’ test which is often stated more fully as follows:

An adult is capable to make a decision where that adult

- a. is able to understand the information that is relevant to making the decision; and
- b. is able to appreciate the reasonably foreseeable consequences of that decision.

See, for example, Newfoundland and Labrador’s *Advance Health Care Directives Act*, s. 14, and Newfoundland and Labrador’s *Adult Protection Act*, s. 6(2).

The ‘understand and appreciate’ requirement for legally valid decisions

- The ‘understand and appreciate’ test is often used in legislation for two purposes simultaneously. One is to describe a set of cognitive criteria that must be met for the law to consider an individual capable. In doing so, it also defines requirements for a legally valid decision. These are usually conflated and seen as one in the same. However, they are, in fact, two distinct, but interconnected, requirements. One relates to an individual’s own cognitive abilities and the other relates to what is required to validate a decision, which may or may not depend exclusively on the cognitive abilities of the individual. In current law these are the same.

- However, in section II of the report we discuss the ‘decision-making capability approach’ to defining the requirements of legal capacity. In this approach the two requirements are separated: ‘understanding and appreciation’ are required to create a legally valid decision, but the cognitive abilities required for understanding and appreciation can be provided by a person on their own or directed by the person who is provided with the assistance of decision-making supporters who are guided by the person’s will and preferences in making a decision in the circumstances.

INTRODUCTION

For the past decade, the disability community in Newfoundland and Labrador has called on the provincial government to address the systematic restrictions people with disabilities experience in exercising their legal capacity. Legal restrictions on making personal life, health care and financial decisions about their lives have a disproportionate and discriminatory impact on people with intellectual, developmental, and cognitive disabilities, and people living with mental health issues.

IRIS – Institute for Research and Development on Inclusion and Society – was engaged by the Newfoundland and Labrador Association for Community Living, on behalf of the provincial ‘Securing Citizenship and Legal Capacity for All’ Steering Committee, to study why these restrictions happen and to point to needed reforms.

This report documents the results of the study and recommends directions for reform.

B. Background to the Study

The Newfoundland and Labrador disability community began calling for an end to disability-based restrictions on decision-making after Canada ratified the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD)¹ in 2010. Article 12 of the CRPD recognizes that people with disabilities have a right to enjoy legal capacity on an equal basis. It also recognizes a government obligation to ensure people have access to decision-making supports they may require for exercising legal capacity.

In 2011, the disability community convened a landmark international conference in St. John’s titled “Securing Citizenship and Legal Capacity for All” to celebrate the ratification, examine restrictions on legal capacity, and look at options for supporting people in their decision making. Participants called for law reform so that people were not left legally powerless in their lives through guardianship or substitute decision making.²

¹ United Nations, *Convention on the Rights of Persons with Disabilities*, G.A. Res. 61/106 [adopted by consensus at the UN on Dec. 13, 2006] [CRPD], Article 12, online:

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>.

² See Newfoundland and Labrador Association for Community Living, Children and Adolescents with Neurological Disability Organization (CANDO) and Consumers Health Awareness Newfoundland and Labrador (CHANNAL), “Securing Citizenship and Legal Capacity for All International Symposium June 20-22, 2011: Summary Report and Key Learnings” (St. John’s, NL: Newfoundland and Labrador Association for Community Living, 2011).

In 2012, the provincial government released “*Access. Inclusion. Equality - A Provincial Strategy for the Inclusion of Persons with Disabilities.*” The strategy recognized “supported decision making” as one tool to address the gaps in enjoyment of legal capacity.³

Since 2011, provincial political parties and successive governments have committed to recognizing supports for decision making. The Newfoundland and Labrador Minister of Justice and Public Safety up to the May 2019 provincial election was mandated to work with stakeholders and colleagues “to develop measures to encourage supported decision making.”

Most recently, consultations for the anticipated provincial accessibility legislation identified “barriers to supported decision making” as one of seven main barriers to accessibility in the province. The “What We Heard” report from the consultations points to participants’ interest in seeing the government adopt a “shared responsibility” approach with the community to ensure that people have access to the decision-making supports they need.⁴

Along with growing public recognition of this issue, broader government commitments like those summarized in Appendix H increasingly emphasize associated principles of inclusion and personal choice and control for people who have disabilities and mental health issues, and seniors.

C. Terms of Reference for this Report

The terms of reference called for IRIS to consult with community representatives and government stakeholders to:

- Identify key issues in implementing law, policy, and community systems reform to enable legal capacity and supported decision making for people with disabilities and mental health issues in Newfoundland and Labrador consistent with and guided by:
 1. The Government of Newfoundland and Labrador’s commitments to supported decision-making, person-directed supports and planning and individualized funding;
 2. *The Canadian Charter of Rights and Freedoms (Charter)*, particularly sections 7, 15, and 1;
 3. The UN *Convention on the Rights of Persons with Disabilities (CRPD)*, Article 12;
 4. “Summary Report and Key Learnings” from the Securing Citizenship and Legal Capacity for All International Symposium, June 20-22, 2011;

³ Government of Newfoundland and Labrador, *Access. Inclusion. Equality - A Provincial Strategy for the Inclusion of Persons with Disabilities* (2012), pg. 33, online: <https://www.gov.nl.ca/cssd/files/disabilities-pdf-dpo-access-inclusion-equality.pdf>.

⁴ Government of Newfoundland and Labrador, “What We Heard Report: Accessibility Legislation Consultations” (December 3, 2019), online: <https://www.engagenl.ca/engagement-initiatives/accessibility-legislation>.

5. “Proposed Statutory Framework for the Right to Legal Capacity and Supported Decision Making in Newfoundland and Labrador,” developed based on June 2011 Symposium outputs;
 6. UN CRPD Committee, General Comment No. 1 (on Article 12); and
 7. “Concluding Observations” by CRPD Committee (issued May 2017 on Canada’s First Report on the CRPD), which calls on the federal and provincial/territorial governments “to create a consistent framework for recognizing legal capacity and to enable access to the support needed to exercise legal capacity.”⁵
- Determine a set of preferred options for reform to address these issues in the Newfoundland and Labrador context, given:
 1. government priorities;
 2. law and policy context; and
 3. community capacity.
 - Outline a ‘Roadmap for Reform’ – including a time frame and needed processes to guide and manage the reform process.

D. Organization of the report

The report is organized into ten main sections:

- I. Approach to the consultation and research
- II. Key terms and concepts
- III. Concerns about guardianship and substitute decision making
- IV. Newfoundland and Labrador’s current legal regime for regulating legal capacity
- V. Personal-interpersonal, program and policy barriers to exercising legal capacity
- VI. Barriers in law to exercising legal capacity
- VII. Guardianship and substitute decision making: do data limitations hide the problem?
- VIII. Options for meeting constitutional imperatives for reform
- IX. Recommended directions
- X. An initial five-year roadmap for reform

⁵ See Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report to Canada, May 8, 2017, para. 28, online: https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fCAN%2fCO%2f1&Lang=en.

There are ten appendices attached to this report:

- Appendix A: Key Issues in Designing and Implementing a Supported Decision Making Regime: Report on Initial Focus Groups
- Appendix B: Approaches to Defining Requirements for Legal Capacity in Newfoundland and Labrador Statutes
- Appendix C: Legal Basis for the ‘Decision-Making Capability Approach’ to Regulating Legal Capacity
- Appendix D: Implementing the Decision-Making Capability Approach: In Practice, Programs, Policy and Law
- Appendix E: The Legal Landscape for Regulating Legal Capacity in Newfoundland and Labrador
- Appendix F: What we Heard: Personal and Inter-Personal, Program and Policy Barriers to Exercising Legal Capacity and Decision Making
- Appendix G: Assessment of Options for Meeting Constitutional Imperatives for Reform
- Appendix H: Promising Initiatives: Context for Reforming the Legal Capacity Regime in Newfoundland and Labrador
- Appendix I: The Community Response to the Report: “Supported Decision-Making: A Roadmap for Reform in Newfoundland & Labrador”
- Appendix J: Towards an Inventory of Tools and Resources for Supported Decision Making

I. APPROACH TO THE CONSULTATION AND RESEARCH

There were four phases to consultation and research process:

- Initial consultation with government departmental officials and community stakeholders to identify the range of issues to be considered;
- Key informant interviews and analysis;
- Legal research; and
- Report preparation.

A. Initial Consultation to Identify Key Issues

- Researchers met with government officials and community stakeholders in March and April 2018 to identify their perspective on key issues to address in implementing supported decision-making:
 - Two focus groups (approximately 40 participants) were conducted with government officials from departments of:
 - Justice and Public Safety;
 - Health and Community Services;
 - Children, Seniors and Social Development; and
 - Advanced Education and Skills.
 - Researchers also met in focus group format with representatives of the ‘Steering Committee on Citizenship and Legal Capacity for All’, and some members of their respective community organizations, including:
 - Coalition of Persons with Disabilities, Newfoundland and Labrador;
 - Consumers Health Awareness Network Newfoundland and Labrador (CHANNAL);
 - Newfoundland and Labrador Association for Community Living; and
 - SeniorsNL.

The key issues identified through this focus group process are presented in Appendix A. They guided the key informant interviews, the analysis of interview data, and the legal research.

B. Key Informant Interviews

Researchers undertook interviews with key informants both in government and in community services. The interviews were designed to gather information about:

1. Opportunities, challenges and good examples in the province for enhancing personal choice and decision-making capability under the current laws, policies and programs related to supports for decision making, including:

- assessing support needs
 - determining eligibility for publicly funded supports;
 - facilitating person-directed planning;
 - allocating funding;
 - navigating and arranging community-based options; and
 - delivering, managing and monitoring supports.
2. Implications for both government and community sectors of moving towards a fully inclusive supported decision-making approach, taking account of:
- a. how roles and responsibilities for delivering decision-making supports are most effectively designed and delivered;
 - b. options for tapping and aligning the capacities and roles of informal supports, community agencies and government programs to support and carry out these roles;
 - c. how adult protection services are being delivered; and
 - d. scope for the Public Trustee to play an expanded role with supported decision-making approaches.
3. The duty to accommodate persons in decision-making processes in health care and other settings.

Interviews were conducted in April-May 2018 on a confidential basis, using an open-ended interview approach focused on the themes listed above. Participants included:

- Thirteen senior officials with the following government departments and public agencies were interviewed:
 - Department of Health and Community Services (including from the senior leadership team, and Mental Health and Addictions, and Adult Protection);
 - Department of Children, Seniors and Social Development (including from In Care, Adoptions, Poverty Reduction Strategy, and Disability Policy Office);
 - Office of the Public Trustee; and
 - Newfoundland and Labrador Human Rights Commission.
- Ten individuals with health and community service agencies, including:
 - Health care providers;
 - Youth services;
 - Disability-related home and community support services;
 - Residential and housing services;
 - Training and employment services; and
 - Seniors' home support services.

Both researchers conducted all the interviews, except one. Detailed interview notes were taken by both researchers. Data gathered from focus groups and key informant interviews were analyzed to identify themes about key issues and barriers in exercising legal capacity, and creating a policy, program and practice framework to implement supports for decision making.

C. Legal Research

Once the consultation and interviews were complete, extensive legal research was conducted over a period of many months, including review of provincial legislation regulating legal capacity. Two types of statutes were examined: 1) ‘core’ statutes, an objective of which is to regulate legal capacity in some manner; and 2) ‘secondary’ statutes which have a bearing on the exercise of legal capacity, although that is not their stated purpose. This review included analysis of the types of approaches to legal capacity reflected in the core statutes, including the status, outcome, cognitive/functional and decision-making capability approaches. This analysis is discussed in Sections IV and VI of the report and presented in Appendix B.

In addition, a review was undertaken of jurisprudence on legal capacity, complemented with a separate, extensive review of what Canadian jurisprudence tells us about how *Charter* equality rights apply to the exercise of legal capacity in light of the CRPD. Lana Kerzner undertook this research to develop guidance for a robust examination of the approaches to legal capacity as they are currently reflected in law in Newfoundland and Labrador and in other provinces/territories and the federal jurisdictions in Canada. That paper, titled “Canada's Legal Capacity Laws: An Equality Rights Analysis in Light of the Canadian Charter of Rights and Freedoms and the Convention on the Rights of Persons with Disabilities” will be published in December 2020.⁶

D. Report Preparation and Review

The first draft of this final report was presented to government officials from across departments in October 2019. It was also presented at that time to community representatives at a public meeting convened by the Newfoundland and Labrador Association for Community Living.

Feedback from government officials was compiled by officials from the Disability Policy Office and from the Department of Justice and Public Safety and communicated verbally to the consultants in February 2020. That feedback provided suggestions on form of the report, requested some clarifications and provided suggestions on the proposed ‘roadmap’ process.

⁶ Lana Kerzner, “Canada's Legal Capacity Laws: an Equality Rights Analysis in Light of the Canadian Charter of Rights and Freedoms and the Convention on the Rights of Persons with Disabilities” (Toronto: IRIS – Institute for Research and Development on Inclusion and Society, 2020).

Many of the comments were incorporated. As well, the Public Trustee reviewed the report and made a few editorial suggestions with respect to references in the report to that Office, which were incorporated.

Feedback from community representatives was compiled by the 'Steering Committee on Securing Legal Capacity and Citizenship for All' and was presented in written form to the researchers in December 2019. Their report highlights a number of personal examples demonstrating the harms of guardianship and substitute decision making. Some of these examples were incorporated into the final report. The community response report was highly supportive of option A for reform as presented in a section VIII below, because it is a fully inclusive approach. The community response report also recommended a proactive role for community representatives in the implementation of the roadmap. Their report is included as Appendix I to this report. The draft report was also sent to community service providers who were interviewed. We received no comments that questioned the presentation or analysis of findings.

With significant interruptions due to the COVID-19 pandemic this final report and related legal research was finalized in October 2020. It incorporates feedback from both government officials and community representatives.

II. KEY TERMS AND CONCEPTS

A. Defining Disability

Groups disproportionately affected by restrictions on legal capacity include people who have intellectual disabilities, developmental disabilities, cognitive disabilities and mental health issues. Definitions of these terms, for the purpose of this report, are as follows:⁷

- An **intellectual disability** generally means having greater difficulty than most people with intellectual or adaptive functioning due to a long-term condition that is present at birth or before the age of eighteen.
- **Developmental disability** is sometimes used interchangeably with ‘intellectual disability’ but may also include people with cerebral palsy, autism spectrum disorder, or fetal alcohol syndrome.
- **Cognitive disability** refers to similar kinds of difficulties, usually with onset after age eighteen. It refers to conditions such as brain injury, stroke, Alzheimer’s disease or other dementias, and cognitive decline associated with aging.
- People with **mental health issues** are those who identify as ‘mental health consumers’, ‘psychiatric survivors,’ or ‘mad.’

B. Legal Capacity – Mainstream Approaches

Legal capacity is the power to make and direct decisions with legal consequences – about one’s life, relationships, health care and property. We exercise legal capacity in creating, changing and terminating legal relationships, contracts and agreements with others. Article 12 of the CRPD recognizes that people with disabilities have a right to enjoy legal capacity on an equal basis.⁸

Despite the CRPD, not everyone in Newfoundland and Labrador (and the rest of Canada) is allowed to make their own decisions, and thus exercise their legal capacity. Exercising legal capacity rests on meeting certain legal requirements as established under law. Specific requirements vary depending on the type of decision, for example, marrying, consenting to

⁷ These characterizations are drawn largely from Michael Bach and Lana Kerzner, “A New Paradigm for Protecting Autonomy and the Right to Self-Determination” (Toronto: Law Commission of Ontario, 2010) [Michael Bach and Lana Kerzner], 14-15, online: <https://www.lco-cdo.org/wp-content/uploads/2010/11/disabilities-commissioned-paper-bach-kerzner.pdf>. However, that background research paper used ‘intellectual disability’ instead of ‘developmental disability.’ This report uses the term intellectual and developmental disability because it is more inclusive of those who face decision-making difficulties and is also used by Statistics Canada for data collection and reporting purposes. The definition is adapted accordingly.

⁸ CRPD, note 1, Article 12.

health care, creating a power of attorney, entering into a financial transaction with a bank or other business, or making a will.⁹

Laws in Newfoundland and Labrador, and the rest of Canada, evidence three main approaches to defining legal capacity. These are referred to as the ‘mainstream approaches’ in this report, and are as follows:

- Status approach – This approach uses a status (e.g. age or ‘mental disorder’) as a condition for restricting legal capacity and does so in the name of protecting a person. For example, the Newfoundland and Labrador *Mentally Disabled Persons’ Estates Act* defines a “mentally disabled” person as one “(i) in whom there is such a condition of arrested or incomplete development of mind, whether arising from inherent causes or induced by disease or injury, or (ii) who is suffering from a disorder of the mind, requiring care, supervision and control for the protection of his or her property.”¹⁰
- Outcome approach – This approach restricts legal capacity based on the harm that may result, or is resulting, from the person’s actions or behavior. However, the restriction is usually only imposed where the behavior is seen to be a consequence of a “mental disorder.” For example, under the Newfoundland and Labrador *Mental Health Care and Treatment Act* a person may be involuntarily committed to and treated in a psychiatric facility where, in part, an assessment has been made by an authorized health professional that the person “(i) has a mental disorder, and (ii) as a result of the mental disorder (A) is likely to cause harm to himself or herself or to others or to suffer substantial mental or physical deterioration or serious physical impairment if he or she is not admitted to and detained in a psychiatric unit as an involuntary patient” .¹¹
- Cognitive/Functional approach – In this approach, the basis for exercising legal capacity is that a person has certain requisite cognitive abilities. Laws which evidence this approach often require a person to have the ability to understand relevant information and appreciate reasonably foreseeable consequences necessary to meet the functional requirements for making a particular decision in the circumstances. This approach could be formulated to recognize the supports and accommodations a person may need for this purpose. Functional requirements for making legally valid decisions are often tailored to the particular decision to which they apply. For example, the requirements for making a health care decision, making a power of attorney and making a Will are not

⁹ For a review of common law tests of capacity in Canada, see British Columbia Law Institute, “Report on Common-Law Tests of Capacity”, BCLI Report no. 73, September 2013, online: http://www.bcli.org/wordpress/wp-content/uploads/2013/09/2013-09-24_BCLI_Report_on_Common-Law_Tests_of_Capacity_FINAL.pdf.

¹⁰ *Mentally Disabled Persons’ Estates Act*, R.S.N.L. 1990, c. M-10, s. 2.

¹¹ *Mental Health Care and Treatment Act*, S.N.L. 2006, c. M-9.1, s. 19.

precisely the same. The exercise of legal capacity is denied to those who cannot demonstrate the requisite cognitive/functional abilities. For example, under Newfoundland and Labrador's *Adult Protection Act* an adult is defined as lacking capacity where the adult is "unable to understand information relevant to the decision" or "is unable to appreciate the reasonably foreseeable consequences of a decision or the lack of a decision."¹²

The UN Committee on the Rights of Persons with Disabilities finds all of these approaches to regulating legal capacity discriminatory because they restrict enjoyment and exercise of legal capacity based on disability-related factors.¹³

C. Decision-making Capability Approach to Legal Capacity

The decision-making capability approach is an alternative approach to defining the legal requirements for exercising legal capacity. It addresses the limitations and discriminatory aspects of the mainstream approaches and recognizes two main ways to meet the understand and appreciate requirements for exercising legal capacity, as follows:

- **Independent** decision-making capability
 - The person demonstrates that with the appropriate supports and accommodations they have the capacity to understand information and appreciate consequences of a particular decision, and thus decide on their own; and,
- **Interdependent** decision-making capability
 - Together, the person and recognized decision-making supporters have the capacity to understand information and appreciate consequences of a particular decision, guided by the principle of the 'best interpretation of the person's will and preferences in the circumstances.'

Those who exercise legal capacity *interdependently* because they have a significant disability and, as a result, cannot exercise legal capacity *independently*, will rely on the interpretive support of decision-making supporters. These supporters bring "the best interpretation of [the person's] will and preferences"¹⁴ to guide decision making in the circumstances.

This approach recognizes that the understanding and appreciation required for a legally valid decision can be provided by a person themselves or, if a person does not have the needed cognitive abilities on their own, decision-making supporters can bring their own understanding and appreciation to the making of a decision. In this 'interdependent' approach the exercise of

¹² *Adult Protection Act*, S.N.L. 2011, c. A-4.01, s. 6.

¹³ UN Committee on the Rights of Persons with Disabilities, "General Comment No. 1 – Article 12: Equal Recognition Before the Law," UN Doc. No. CRPD/C/GC/1 (April 2014) [General Comment No. 1], para. 15, online: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en.

¹⁴ General Comment No. 1, note 13, para. 21.

legal capacity and the legally valid decisions made still attach to the person, provided that their supporters are acting based on the person’s will and preferences.

The decision-making capability approach also responds to situations ***where a person cannot act independently or interdependently*** because no decision-making supporters are available, willing or able to act for them.¹⁵ In these situations, a ‘facilitator’ is appointed, who may have no prior knowledge of the person. Their role is to facilitate the decision to be made and thus this is referred to as “facilitated decision making.” They also have a duty to assist the person to develop relationships with others who can come to know them well and provide interpretive and other decision-making supports.

The decision-making capability approach is consistent with Article 12 of the CRPD and its interpretation in “General Comment No. 1” by the UN Committee on the Rights of Persons with Disabilities. The General Comment references the obligation of decision-making supporters to be guided by a person’s will and preferences as the basis for making legally valid decisions. It presents this as the alternative to legal provisions based on the status, outcome, and cognitive/functional approaches to legal capacity.

Law has evolved in Canada over the past 20 years consistent with this approach. It is beginning to recognize the role of supports, including interpretive supports, and accommodations, in enabling people to meet the requirements for understanding and appreciation. The legal basis in Canadian law is discussed in Appendix C. Appendix D provides examples of the types of measures governments and service providers use to implement this approach in practice, programs, policy and law.

There are three main features of the decision-making capability approach, namely, “‘supports’ for decision making”, “supported decision making” and “‘reasonable accommodation’ in decision making”.

1. “Supports” for Decision Making

For many people, a main condition for exercising legal capacity is the “support” needed for this purpose. The UN Committee on the Rights of Persons with Disabilities defines supports for legal capacity as: “a broad term that encompasses both informal and formal support arrangements, of varying types and intensity.”¹⁶

Supports for decision making include any measure to assist a person to have power over their decisions, whether about personal matters, health care or property. The General Comment No. 1 references many examples, including: trusted persons who assist a person to express their

¹⁵ See Michael Bach and Lana Kerzner, note 7, 14-15.

¹⁶ General Comment No. 1, note 13, para. 17.

will and preferences, make and communicate a decision; information to assist in making decisions; communication technologies; and also, accessibility to buildings, places and services where a person wants to legally transact with third parties. It recognizes that persons have a right to support to exercise legal capacity.¹⁷

2. “Supported Decision Making”

“Supported decision making” is one type of arrangement for providing supports for decision-making, with certain defining features. It involves decision-making support people who assist a person to understand, make and communicate a decision, or interpret their will and preferences and help make and execute plans needed to give them effect. Supporters are appointed and legally recognized in this role based on a relationship of personal knowledge, trust and commitment to the person, and may act under an informal or more formal arrangement, depending on the context.¹⁸

3. “Reasonable Accommodation” in Decision Making

The UN Committee defines “reasonable accommodation” for the purposes of exercising legal capacity, as “any necessary modifications or adjustments to allow persons with disabilities to exercise their legal capacity, unless it is a disproportionate or undue burden” and references the wide range of supports for decision making as examples.¹⁹ The duty to accommodate in this context refers to the duty of other parties in a decision-making process to ensure non-discrimination in the exercise of legal capacity, including through the provision of needed supports and adjustments to the decision-making process.

D. Guardianship and Substitute Decision Making (Formal and Informal)

- **Guardianship** refers to an appointment, usually by a court, of a substitute decision maker who is given authority to make property and/or personal care decisions for a person who is determined to be incapable, at law, to make those decisions. For example, under s. 3.(1) of the *Mentally Disabled Persons’ Estates Act*:

The court or a judge may, on the application of a person having an interest in, having a claim against or wishing to make a payment to the estate of a mentally disabled person or of a person who has the custody of or who has responsibility for the care or treatment of a mentally disabled person, make an order appointing a guardian for the custody and management of the estate of that mentally disabled person and committing to the guardian the custody and management of that estate.

¹⁷ General Comment No. 1, note 13, para. 35.

¹⁸ General Comment No. 1, note 13, para. 29.

¹⁹ See General Comment No. 1, note 13, para. 34.

- **Substitute decision making** refers to the process whereby a person or entity makes decisions on behalf of a person who is believed to be incapable. Substitute decision making may arise as a result of a formal legal process or appointment (e.g., guardianship or power of attorney) or may occur informally without a legal process, and possibly in a manner that is inconsistent with the law. Substitute decision making arrangements which exist formally through a legal vehicle can take various forms. For example, a court may appoint a substitute decision maker through a guardianship proceeding as described above. Additionally, an individual can engage in advance planning and make their own appointment of a substitute decision-maker. For example, s. 3.(2) of the *Advance Health Care Directives Act* provides for a person to appoint their own substitute decision maker to make health care decisions for them at a point in the future where they are not competent to do so.²⁰

It is important to underscore that a person who has a disability and is, or is perceived to be, incapable, is at risk of having decision-making taken away from them in two kinds of ways – formally and informally.

- **Formally** – when a legally-regulated procedure determines that a person cannot meet the requirements or ‘test’ (status, outcome or cognitive test) considered necessary to make decisions in the circumstances. For example, under s. 17 of the *Mentally Disabled Persons’ Estates Act*, the court may make a “declaration of incapacity,” meaning that the person is found incapable of managing their affairs, and a guardian is appointed as a substitute to manage their affairs for them. A less known example is found in, s. 20 of the *Income and Employment Support Act*²¹ which provides that an officer of the provincial government is empowered to decide that an income supports applicant or beneficiary is incapable of managing their affairs. On that basis the officer is authorized to make the benefit payment to a trustee, i.e., another person who is to use the income support for the benefit of the person.
- **Informally** – when a family member or an entity like a community service agency restricts a person from making decisions or acting upon them. This could be for any number of reasons, for example, assuming the person cannot make decisions or fear for their safety. These are not legal determinations that a person is incapable, but they have the effect of restricting or denying a person’s right to decide.

The above three concepts, namely, ‘legal capacity,’ and the different approaches to defining the requirements for exercising it, ‘guardianship,’ and ‘substitute decision making’ set the

²⁰ *Advance Health Care Directives Act*, S.N.L. 1995, c. A-4.1, s. 3(2).

²¹ S.N.L. 2002, c. I-0.1, s. 20.

parameters for this report. Related legal provisions in Newfoundland and Labrador are presented in Section IV and discussed in more detail in Appendix E.

E. Legal Capacity Regime

This report uses the term ‘legal capacity regime’ or ‘legal regime regulating the exercise of legal capacity’ to mean the set of provisions established under statute, regulation, or through jurisprudence which together constitute the requirements for exercising legal capacity and making legally valid decisions. The regime includes the measures and procedures for making findings of legal incapacity and for imposing guardianship or substitute decision making.

The concept of ‘regime’ is used to convey that while there is a complex set of intersecting domestic and international sources of law regulating the exercise of legal capacity, they can be viewed, described, and analyzed as a whole. Together, they define the rules and requirements through which persons and other entities transact in legal relationships.

Legal regimes have been defined as “patterns of structuring multiple legal authorities”²² that operate in different areas of criminal, civil, public, and private law. This is an apt description of a legal capacity regime. Legal scholarship and analyses examine the phenomenon at different scales, including sub-national, national, and global legal regimes in a particular area of law, with some studies taking a historical perspective to examine changes in legal regimes over time.²³

While the term ‘regime’ may have negative connotations in some contexts, it is used in legal research and in this report in a purely descriptive sense. Ultimately, legal regimes regulating the exercise of legal capacity can be characterized as more or less inclusive, or more or less discriminatory, based on disability.

²² Lauren Benton, *Law and Colonial Cultures: Legal Regimes in World History, 1400–1900* (Cambridge, UK: Cambridge University Press), 3.

²³ For example, William Hurst, *Ruling before the Law: The Politics of Legal Regimes in China and Indonesia* (Cambridge, UK: Cambridge University Press, 2017).

III. CONCERNS ABOUT GUARDIANSHIP AND SUBSTITUTE DECISION MAKING

This report was commissioned because of concerns about the impact and the harms that can come when others assume power and control over a person's decision making. This usually happens with the best of intentions: to protect people and safeguard their interests. However, doing so restricts their autonomy and self-determination and, at worst, can be a means by which people become victim to financial and other forms of abuse and neglect.

These concerns have motivated disability community representatives in Newfoundland and Labrador,²⁴ across Canada,²⁵ and internationally²⁶ to call for an end to findings of legal incapacity and to the imposition of guardianship and substitute decision making. They call instead for alternatives that do not strip their right to legal capacity as the cost of getting needed decisions made.

We were advised by key informants of situations where family members were appointed guardians by the Supreme Court. The application for guardianship was made, not because they wanted it, but because they believed they had no other option in order to get needed health care and financial decisions made for their loved one. For disability community representatives and advocates the primary problem was not that the person was at immediate risk of harm or isolation in these circumstances. Families were doing the best they could. They felt the problem is the lack of alternatives to guardianship and substitute decision making in situations where people otherwise could have retained their rights to decide and been assisted by family members and others to make decisions. Some informants saw this lack of recognition and availability of support alternatives as a profound violation of the person's rights and status in the community.

A 2016 decision of the Nova Scotia Supreme Court makes clear the personal costs and harms that can come with the imposition of guardianship and loss of legal capacity. Referring to the applicant in the case, Landon Webb, the decision states:

He essentially lost control over his own personhood. He could not make decisions for himself about where he should live, what he should do, who he could visit with, what medical treatment

²⁴ See Newfoundland and Labrador Association for Community Living, Children and Adolescents with Neurological Disability Organization (CANDO) and Consumers Health Awareness Newfoundland and Labrador (CHANNAL), "Securing Citizenship and Legal Capacity for All International Symposium June 20-22, 2011: Summary Report and Key Learnings" (St. John's, NL: Newfoundland and Labrador Association for Community Living, 2011).

²⁵ See Coalition on Alternatives to Guardianship, "The Right to Legal Capacity and Supported Decision Making for All – A Preliminary Brief to The Law Commission of Ontario in Response to: Legal Capacity, Decision-Making and Guardianship, Interim Report, October 2015 (Toronto: Canadian Association for Community Living, 2015).

²⁶ See Inclusion International, *Independent But Not Alone: A Global Report on the Right to Decide* (London: Inclusion International, 2014), online: <https://inclusion-international.org/independent-alone/>.

he should receive, what he did with his own money, or who he should have relationships with. The most basic freedoms that people take for granted were denied to him...

Landon Webb's story is a terrifying one. At a time in his life when most young adults are anticipating independence, in whatever form that takes for them, he could not even access the internet. The more he struggled against the restraints on his liberties the tighter they got... Once he was declared incompetent it seemed as though everything he said and did to assert that he was competent was further proof of his incompetence.²⁷

While the research for this report did not uncover any comprehensive studies of guardianship in the Canadian context, a recent U.S. study²⁸ reports many associated harms, including:

- negative impact on functional ability, health status and well-being;
- social isolation;
- loss of self-esteem, feelings of hopelessness, inadequacy and incompetency;
- feelings of being demeaned and socially stigmatized; and
- significant concerns with guardians financially abusing those under their authority, overbroad application of guardianship orders, physical abuse and neglect, restriction on voting rights, and restricting people in developing and enjoying their sexuality and sexual identity.

A study on the guardianship system in Ontario also points to several concerns with safeguards and due process and points to barriers people under guardianship face in seeking revocation of guardianship orders and restoration of their rights.²⁹

In responding to the draft of this report, community representatives reported examples in Newfoundland and Labrador of similar kinds of outcomes and harms, including:

- *Some persons report difficulty with access to health-related information and treatment because of legal capacity issues. Others report they have avoided health care procedures out of fear that guardianship may be suggested.*
- *People fear not being able to reinstate their citizenship once a guardianship order is in place (i.e., in cases of brain injury and intellectual disability).*
- *Seniors are often over medicated to support ease of care or management. This is an issue being raised in the national dementia strategy. One person described her*

²⁷ *Webb v. Webb*, 2016 NSSC 180.

²⁸ National Council on Disability, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities* (Washington, 2018), 118-123, online: <https://ncd.gov/publications/2018/beyond-guardianship-toward-alternatives>.

²⁹ ARCH Disability Law Centre, *Decisions, Decisions: Promoting and Protecting the Rights of Persons with Disabilities Who Are Subject to Guardianship* (Toronto: Law Commission of Ontario, 2014), online: <https://www.lco-cdo.org/wp-content/uploads/2014/02/capacity-guardianship-commissioned-paper-arch.pdf>.

husband's cognitive deterioration, in light of over-medication, saying she knew him better than doctors after being married to him for half a century. She had to become extremely vocal to advocate on his behalf. She spoke of the importance of his life narrative which in her view validated his legal capacity.

- *Some people who are living with mental health issues who become incarcerated say they are denied their medications when they are detained.*

The community response report also recounted the experience of a woman who was restricted in exercising legal capacity through many years of institutionalization. After she moved to the community, she was denied choices by a community service agency:

Jane [not her real name] was going to Church but relegated to the crying room where parents took their children. [She] began to ask for Holy Communion and though it is not based in Church doctrine, the support agency decided Jane did not possess legal capacity and was not entitled to receive the sacrament.

Jane is permitted one cup of tea a day, though it is her favourite pastime. Tea is withheld in the event of a behavioral incident and advocates believe she is often set up to fail. She is not permitted without formal process to visit anyone in their homes, though it was normal for her to do so for years...

The lack of respect for her abilities to demonstrate choices and control and the failures to build upon this remarkable woman's spirit, wills and preferences are lived, in part, by many people in our province.

Concerns about the restriction of a person's legal capacity must be balanced against the public interest to ensure that needed decisions are made so that people who are unable to make those decisions are protected from risk of harm to themselves or others. How the current legal regime in Newfoundland and Labrador manages the balance between protecting a person's right to equality in their exercise legal capacity, and protecting people from harm, as well as options to better manage this balance, are examined in Sections VI and VIII.

IV. NEWFOUNDLAND AND LABRADOR’S CURRENT LEGAL REGIME FOR REGULATING LEGAL CAPACITY

This section provides an overview of laws which apply in Newfoundland and Labrador to decision-making including guardianship, substitute decision making, and recognition of support alternatives. We refer to this set of laws as the ‘legal capacity regime,’ as defined in Section II. The regime operating in the province has seven main sources of law that have an impact on or establish requirements for exercising legal capacity:

- International law
- Constitutional law, including the *Canadian Charter of Rights and Freedoms*
- Human Rights legislation
- Provincial legislation – ‘Core’ statutes regulating legal capacity (a main purpose is regulation of legal capacity) and ‘Secondary’ statutes (regulates legal capacity in some manner, although this is not a primary purpose of the statute)
- Provincial policy
- Federal legislation
- Jurisprudence

Key provisions from each of these sources are summarized in Table 1. This set of provisions, although not a full inventory, largely sets out the parameters of the legal regime regulating legal capacity in the province. Appendix E provides a fuller discussion of these sources.

Table 1: Overview of Regime Regulating Legal Capacity in Newfoundland and Labrador

Source of Law Regulating Legal Capacity	Key Provisions
International Law	<p>CRPD</p> <ul style="list-style-type: none"> ▪ Canada ratified the CRPD, which provides in Article 12 that States Parties: <ul style="list-style-type: none"> ○ “shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” (Article 12(2)). ○ “shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity” (Article 12(3)). ○ shall ensure that measures relating to legal capacity provide for safeguards to prevent abuse (Article 12(4)).³⁰ Article 12(4) elaborates on design and goal of the safeguards. <p>General Comment No. 1 on Article 12</p> <ul style="list-style-type: none"> ▪ In its General Comment on Article 12 the UN Committee on the Rights of Persons with Disabilities states that “[n]on-discrimination includes the right

³⁰ For full text of Article 12 and the CRPD see note 1.

Source of Law Regulating Legal Capacity	Key Provisions
	<p>to reasonable accommodation in the exercise of legal capacity (art. 5, para. 3)” and that “[t]he right to reasonable accommodation in the exercise of legal capacity is separate from, and complementary to, the right to support in the exercise of legal capacity.”³¹</p> <p>Canada’s ‘declaration and reservation’ on Article 12</p> <ul style="list-style-type: none"> ▪ Canada’s ‘declaration and reservation’ states its understanding that Article 12 permits both supported and substitute decision making.³²
Constitutional Law	<p>Constitution Act, 1867 – Distribution of Legislative Powers</p> <p>Under Canada’s <i>Constitution</i>, s.92(13) and 92(16), legal capacity has been considered a matter under legislative authority of the provinces.³³ Parliament, too, has enacted legislation which addresses legal capacity in various contexts.³⁴</p> <p>Canadian Charter of Rights and Freedoms</p> <p>Section 7 of the <i>Charter</i> recognizes rights to life, liberty and security of the person, and section 15 recognizes the right to equality without discrimination based on disability.</p>
Provincial Legislation – Core Statutes (primary role or purpose is to regulate exercise of legal capacity)	<p>Some Newfoundland and Labrador statutes have as a primary purpose or role the regulation of decision making, and as such are ‘core’ statutes of the regime regulating legal capacity. These include:</p> <ul style="list-style-type: none"> ▪ Mentally Disabled Persons’ Estates Act³⁵ (MDPEA) – provides for the court to appoint a guardian of the estate of a “mentally disabled person” or of a person who is declared to be a person “incapable of managing his or her affairs”. ▪ Enduring Powers of Attorney Act³⁶ (EPAA) – sets out the requirements relating to enduring powers of attorney for finances and designation agreements for the Registered Disability Savings Plan (RDSP). ▪ Adult Protection Act³⁷ (APA) – provides legislative authority for delivery of services to adults “in need of protective intervention” with a set of “Service Principles” in s. 8 which emphasize least restrictive and intrusive supports and support for decision making. This Act is currently under review.

³¹ General Comment No. 1, note 13, para. 34.

³² See United Nations, Reference: C.N.153.2010.TREATIES-7 (Depositary Notification) CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES NEW YORK, 13 DECEMBER 2006 CANADA: RATIFICATION, online: <https://treaties.un.org/doc/Publication/CN/2010/CN.153.2010-Eng.pdf>.

³³ *Constitution Act, 1867* (U.K.), 30 & 31 Vict, c. 3, reprinted in R.S.C. 1985, App II, No. 5, s. 92(13).

³⁴ See Faisal Bhabha and Brendon Pooran, “Equality in the National Interest: Implementing the CRPD Right to Supports in Legal Decision Making under Canadian Federalism” (Toronto: IRIS – Institute for Research and Development on Inclusion and Society, 2020) [Faisal Bhabha and Brendon Pooran].

³⁵ R.S.N.L. 1990, c. M-10.

³⁶ R.S.N.L. 1990, c. E-11.

³⁷ S.N.L. 2011, c. A-4.01.

Source of Law Regulating Legal Capacity	Key Provisions
	<ul style="list-style-type: none"> ▪ Advance Health Care Directives Act³⁸ (AHEDA) – sets out requirements for creating a legally valid advance health care directive and sets out legal rules for health care decision-making for “incompetent patients”. ▪ Mental Health Care and Treatment Act³⁹ (MHCTA) – provides for interventions for people with a “mental disorder”, including involuntary admission and treatment in a psychiatric unit, and community treatment orders. ▪ Judicature Act⁴⁰ (JA) – was not designed to regulate legal capacity but was recently interpreted to give authority to the Supreme Court of Newfoundland and Labrador to appoint guardians of the person as well as their estates.⁴¹
Provincial Human Rights Legislation	<ul style="list-style-type: none"> ▪ Human Rights Act⁴² – prohibits discrimination on various grounds including on the basis of disability⁴³ in areas such as employment, provision of goods and services, and contracts.⁴⁴ To the extent that interactions or legal transactions involving decision-making are covered by the <i>Human Rights Act</i>, people with disabilities have the right to exercise legal capacity on an equal basis, consistent with the Act. ▪ The right is limited by an exception in the Act relating to the exercise of legal capacity: the Act does allow discrimination on the basis of disability in the context of contracts offered to the public where a person “refuses to contract with another person who does not have the legal capacity to contract” and the person is a person with a disability, as set out in the Act.⁴⁵
Provincial Legislation – <i>Secondary Statutes</i> (affect regulation of legal	<p>These include, for example:</p> <ul style="list-style-type: none"> ▪ Income and Employment Support Act⁴⁶ ▪ Trustee Act;⁴⁷

³⁸ S.N.L. 1995, c. A-4.1

³⁹ S.N.L. 2006, c. M-9.1.

⁴⁰ R.S.N.L. 1990, c. J-4.

⁴¹ *A.A. (Re)*, 2019 NLCA 7, para. 46.

⁴² S.N.L. 2010, c. H-13.1.

⁴³ Section 9(1) of the Act includes ‘disability’ as one of the prohibited grounds. For the purpose of the Act ‘disability’ is defined in s. 2, and is defined to include “a degree of physical disability”, “a condition of mental impairment or a developmental disability”, “a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or language” and “a mental disorder”

⁴⁴ Section 11 (goods, services, accommodation and facilities), s. 14 (employment) and s. 21 (contracts that are offered to the public).

⁴⁵ Act s. 21(2). This exception applies to a person with a disability within the meaning of subparagraph 2(c)(ii) (i.e., a condition of mental impairment or a developmental disability) and 2(c)(iii) (i.e., a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or language). It does not apply to other types of disabilities set out in s. 2(c) including a “mental disorder”.

⁴⁶ S.N.L. 2002, c. I-0.1.

⁴⁷ R.S.N.L. 1990, c. T-10.

Source of Law Regulating Legal Capacity	Key Provisions
capacity, but not as a primary purpose or role)	<ul style="list-style-type: none"> ▪ Public Trustee Act, 2009;⁴⁸ ▪ Wills Act;⁴⁹ ▪ Residential Tenancies Act;⁵⁰ ▪ Elections Act;⁵¹ ▪ Personal Health Information Act;⁵² and, ▪ Access to Information and Protection of Privacy Act.⁵³
Federal Legislation	<p>Federal statutory provisions impacting the exercise of legal capacity for people in Canada, include, for example:⁵⁴</p> <ul style="list-style-type: none"> ▪ The <i>Income Tax Act</i>'s provisions relating to the Registered Disability Savings Plan (RDSP) require that a person have “contractual competence” in order to personally enter into an RDSP or regain control over an RDSP opened on one’s behalf.⁵⁵ ▪ The <i>Canada Pension Plan</i>,⁵⁶ and <i>Criminal Code</i> provisions relating to medical assistance in dying,⁵⁷ each contain provisions regulating legal capacity of people who have limitations in cognitive capacity.
Jurisprudence	<p>Case law in Canada defines legal rules governing the exercise of legal capacity in different areas of decision making, including capacity to make a will (testamentary capacity),⁵⁸ the nature of understanding and appreciation as it applies to the test of capacity in a particular context,⁵⁹ and capacity to enter a contract.⁶⁰ In Newfoundland and Labrador, a recent relevant case clarified the role of the Supreme Court in appointing a guardian of the person:</p> <ul style="list-style-type: none"> ▪ In <i>A.A. (Re)</i>⁶¹ the Court of Appeal set out principles applicable to the Supreme Court’s exercise of its jurisdiction to appoint guardians of the person

⁴⁸ S.N.L. 2009, c. P-46.1.

⁴⁹ R.S.N.L. 1990, c. W-10.

⁵⁰ S.N.L. 2018, c. R-14.2.

⁵¹ S.N.L. 1992, c. E-3.1.

⁵² S.N.L. 2008, c. P-7.01.

⁵³ S.N.L. 2015, c. A-1.2.

⁵⁴ See Faisal Bhabha and Brendon Pooran, note 39.

⁵⁵ *Income Tax Act*, R.S.C. 1985, c. 1 (5th Supp), s. 146.4.

⁵⁶ *Canada Pension Plan*, R.S.C. 1985, c. C-8 and *Canada Pension Plan Regulations*, C.R.C., c. 385, s. 55.

⁵⁷ *Criminal Code*, R.S.C. 1985, c. C-46, s. 241.2(1)(b).

⁵⁸ There is an abundance of jurisprudence dealing with this issue. See e.g., *Hall v. Bennett Estate* (2003), 64 O.R. (3d) 191, (277 D.L.R. (4th) 263 C.A.); *Leung v. Chang*, 2013 BCSC 976, para. 35.

⁵⁹ For example, in *Starson v. Swayze*, the Supreme Court of Canada determined that in comparison to what was generally understood as the legal requirement at the time, a relatively low threshold of ‘mental capacity’ was needed to meet the statutory test for giving informed consent, under Ontario’s *Health Care Consent Act*. See *Starson v. Swayze*, 2003 SCC 32, [2003] S.C.J. No. 33 [Starson SCC].

⁶⁰ S. M. Waddams, *The Law of Contracts*, 7th ed. (Toronto: Canada Law Book, 2017), 467-468.

⁶¹ *A.A. (Re)*, 2019 NLCA 7, paras. 70 to 107.

Source of Law Regulating Legal Capacity	Key Provisions
Provincial Policy	<p>For example:</p> <ul style="list-style-type: none"> ▪ The <i>Adult Protection Act</i> “Policy Manual” provides an “Adult Protection Decision Tree” which requires exploration of alternatives to declaring an adult “in need of protective intervention,”⁶² including supportive services, ▪ The Newfoundland and Labrador Human Rights Commission has issued statements and guidelines on the duty to accommodate, although these do not directly address the context of legal capacity.⁶³

⁶² See, Government of Newfoundland and Labrador, *Adult Protection Act: Provincial Policy Manual* (Effective June 30, 2014), online: https://www.cssd.gov.nl.ca/apa/pdf/ap_act_prov_policy_manual.pdf.

⁶³ Newfoundland and Labrador Human Rights Commission, “Frequently Asked Questions”, “What does the term ‘accommodation’ mean?”, online: <https://thinkhumanrights.ca/education-and-resources/frequently-asked-questions/>; “Guidelines for the Use of Service Animals” (2015), online: <https://thinkhumanrights.ca/education-and-resources/guidelines/guidelines-regarding-the-use-of-service-animals/>; “Guidelines for Accommodation of Environmental Sensitivities,” online: <https://thinkhumanrights.ca/education-and-resources/guidelines/guidelines-for-accommodation-of-environmental-sensitivities/>.

V. PERSONAL/INTER-PERSONAL, PROGRAM, AND POLICY BARRIERS TO EXERCISING LEGAL CAPACITY

A comprehensive review of all related programs, service delivery systems, and public policies identified in the focus group discussions and key informant interviews was beyond the scope of this consultation and research. Nonetheless, the information gathered reveals many barriers at all these levels. Together, they appear to systematically restrict equality in decision-making for a significant and growing group of people living with disabilities and mental health issues.

A. Overview of Barriers

Consultations and key informants reported many barriers people with disabilities experience to exercising choice and control in their lives within the social, health care and economic environments shaped by the province's legal regime for exercising legal capacity. Based on the research we identify four main types of barriers:

- at the personal level and in inter-personal relationships;
- in service delivery (e.g., health care, disability/home supports, social services and benefits, and public services);
- in public policies; and
- those within the legal regime itself.

These barriers appear to be connected and reinforcing, with barriers in law shaping the context for policy, programs and personal relationships. For example, the definition of a “mentally disabled person” in s. 2(f) of the *Mentally Disabled Persons' Estates Act* defines a status and expectation about people who live with ‘mental disabilities.’ The Act states:

- (f) "mentally disabled person" means a person
- (i) in whom there is such a condition of arrested or incomplete development of mind, whether arising from inherent causes or induced by disease or injury, or
 - (ii) who is suffering from a disorder of the mind,
- requiring care, supervision and control for the protection of his or her property [...]⁶⁴

The Act establishes a direct link between this legally defined status and provisions in s. 3.(1) for appointing a guardian of finances/estate for persons who are defined this way. As presented in Appendix B, many other provisions in Newfoundland and Labrador's regime make similar equations and requirements for exercising legal capacity and appointing guardians or substitute decision makers, if not always with the same terms.

⁶⁴ *Mentally Disabled Persons' Estates Act*, R.S.N.L. 1990, c. M-10, s. 2(f).

These provisions, directly and indirectly, create expectations for people with disabilities themselves, families, health care professionals, financial institutions and society more generally that people with mental disabilities are unable to make decisions for themselves and require “supervision and control” for their protection. They also set legal standards for doctors, banks and other businesses about what it requires for others to transact with them.

Key informants pointed to many ways in which people with disabilities are often unable to exercise choice and control in their lives because of diminished self-regard and devaluing and disempowering expectations of family members and others in their community. They also shared experiences of being denied access to public services, community programs, financial transactions and health care because they were considered incapable. They revealed numerous barriers in provincial policies for funding and delivery of community services and provision of disability supports that make them unresponsive to their aspirations, needs and choices. The expectations and requirements established in the legal regime can be seen to underlie many of these experiences.

B. Summary of Findings

Key informant interviews and consultations identified many substantial and intersecting barriers that restrict opportunities for decision making and the exercise of legal capacity. Many spoke of the multiple ways in which people end up “relinquishing” their voice, as one informant put it, in interactions with family, community members, service providers, and government agencies. For many people, their choices are constrained, or non-existent, because of poverty, lack of adequate and affordable housing, and social isolation.

This happens at all stages of adults’ life span – from youth, through working life, to senior years, and seems to be particularly acute at key transition stages, like youth ‘ageing out’ of care. There are excellent examples of supporting often very marginalized people to find their voices and exercise legal capacity within the limits of the law as it currently exists. However, these appear to happen primarily in situations covered by the *Adult Protection Act* policy manual. The kind of mandated process and supports that policy makes available is for a relatively small number of individuals. Providers are struggling to find the right balance between promoting autonomy and protecting people from harm. Other than those operating under the terms and resources of that policy, they are doing their best, in the absence of clear mandates in law, policy and programs to guide their efforts.

Lack of concerted and collaborative efforts across community and public sectors on supporting people in decision making is leading to “institutional mistrust”. This appears to be resulting, at least in part, from health and social service providers lacking the mandate, tools and resources they need to deliver effective supports for decision making and to accommodate people in the decision-making process. Uneven and limited community capacity across the province for this

purpose was raised numerous times. These gaps point to the need for a systematic review of the needs for, and best ways of delivering, community-based supports for decision making for people who are marginalized in exercising legal capacity.

A policy framework to enable such outcomes also appears to be lacking; one that provides clarity and distinction between the functions of person-centred planning, clinical assessment, and allocation of home support and other services. In particular, consensus is lacking about the place of ‘independent’ planning facilitation, proven to be a critical resource in enabling people to exercise choice and control in their lives and to navigate community and government systems for this purpose.

The following tables summarize information gathered in the research about barriers at the personal, program and policy levels. A full ‘What we Heard’ report about these barriers is presented in Appendix F. Following this section is an analysis of underlying legal barriers experienced by people with disabilities in decision-making.

Table 2: Personal and Inter-personal Barriers to Exercising Legal Capacity

Personal and inter-personal barriers	What we heard and why these barriers happen
1. People “relinquish their voice”	<ul style="list-style-type: none"> ▪ A lifetime of not being valued, abuse, traumatic experience, low self-esteem, and mistrust of formal systems like police and the courts leads people to “relinquish their voice” as one informant stated.
2. Some “not ready” to make choices on their own	<ul style="list-style-type: none"> ▪ Intensive supports are lacking to assist people with complex needs and social and economic marginalization. Capacity to exercise choice can be severely limited by factors such as social rejection, mental health issues, addictions, violence-induced brain injury, being drawn into the sex trade since age 12, for example, chronic homelessness, incarceration and the ongoing effects of trauma.
3. Some individuals make choices that result in severe risk or harm	<ul style="list-style-type: none"> ▪ There is a lack of guidance about when and how to intervene in situations where a person’s actions are causing harm to themselves or others, and they refuse support. Informants indicated that lack of clear policy direction and program support make it difficult for providers to navigate these complex situations.
4. Families feeling pressured to apply for guardianship to protect a person’s future	<ul style="list-style-type: none"> ▪ Some families experience pressure from financial institutions, health care, education and community and government services to place family members under guardianship in order to manage wealth transfer, future planning and to protect their family member
5. Some perceive that families, support providers and appointed representatives are exercising undue control	<ul style="list-style-type: none"> ▪ Lack of awareness about a supported approach to decision making leads some family members to seek legal guardianship to protect the person. In other cases, family members exercise control informally. ▪ Some support providers and some appointed under enduring powers of attorney do not always act at the direction of the person/principal who appointed them. Without safeguards many people are being subjected to control and abuse.

Table 3: Program Barriers to Exercising Legal Capacity

Program barriers	What we heard and why these barriers happen
1. Limited resources and clear direction means programs are “fitting people into boxes”	<ul style="list-style-type: none"> ▪ Some people with disabilities and families report that community providers or Regional Health Authorities (RHAs) are unable or unwilling to fully deliver programs in a person-centered way that enables the exercise of legal capacity. Instead, they fit “people into boxes.”
2. Province-wide capacity to deliver responsive and individualized supports in health care, home support and community services is lacking	<ul style="list-style-type: none"> ▪ Some people with disabilities, families and service providers report: <ul style="list-style-type: none"> • Lack of program resources/funding mean unmet need; • Uneven capacity across the province to deliver needed support; • Inflexible/non-portable home supports; • Lacking capacity to respond to diverse, individual needs; • Over-reliance on informal support of families.
3. Lack of affordable housing options that provide choice, support, safety and inclusion	<ul style="list-style-type: none"> ▪ Without adequate, affordable, and secure housing people are unable to gain control over their lives. “Emergency response [is] the only response” for many individuals in a system that is “addicted to crisis.”
4. Inadequate future planning services are “short-changing” individuals in ensuring a financially secure future;	<ul style="list-style-type: none"> ▪ Many individuals are not accessing income benefits they are eligible for (e.g., insurance benefits, Registered Disability Savings Plans) because they and their families lack financial planning support or fear a substitute decision maker will be appointed as the cost of access.
5. Concern that some Regional Health Authority staff are ineffective in supporting a person to decide	<ul style="list-style-type: none"> ▪ Some people with disabilities, families and service providers report: <ul style="list-style-type: none"> • Lack of awareness about the rights relating to decision making and how to support it; • RHA funding driven by clinical assessment, instead of a person-centred plan of personal goals, needs, and opportunities; • Independence is lacking between assessment and planning functions, which limits the scope for self-direction; • More expertise is needed to develop person-centred approaches; • When a person’s supports come to a “crashing halt,” there seems little capacity to navigate the community and create new options; • Limited in providing effective planning, navigation and community coordination because they are primary gatekeepers to funding.
6. “Institutional mistrust” among some health and community support providers and government departments	<ul style="list-style-type: none"> ▪ Some government, RHA and community stakeholders are not effectively collaborating to address a growing number of complex situations where a person has multiple needs related to housing, health, income, support, and developmental and safety concerns.
7. Community-based health and social service providers not providing needed supports for decision making	<ul style="list-style-type: none"> ▪ People with disabilities, families and service providers report: <ul style="list-style-type: none"> • Supporters are not listened to in the long-term care system; • Being told guardianship is needed to access health care services; • Imposed treatment and lack of options in mental health care; • Providers lack capacity for a person-centred, supported decision-making approach, and the individualized funding to do so.

Table 4: Policy Barriers to Exercising Legal Capacity

Policy Barriers	What we heard and why these barriers happen
1. No mandated approach to create alternatives to guardianship and substitute decision making	<ul style="list-style-type: none"> Substitute decision making and guardianship often result because there is no mandated process for creating less restrictive, decision-making support alternatives. The exception is the Policy Manual for the Adult Protection Act which does mandate a process.
2. Patchwork system of decision-making support and community capacity leave people without needed:	<ul style="list-style-type: none"> There is a recognized need for health care and community services systems to proactively help create alternatives to substitute decision making, but informants pointed to lack of policy direction and community capacity to create alternatives.
a) Independent person-centred planning facilitation;	<ul style="list-style-type: none"> No provincial strategy exists for delivering person-centred planning facilitation, which assists a person to develop and execute personal plans. Some identified community-based “independent” planning support as an important resource.
b) Assistance to arrange and access decision-making supports;	<ul style="list-style-type: none"> The facilitation approach used under the Adult Protection policy has created effective alternatives to guardianship but is not broadly available. Some doubted whether RHAs were best positioned to deliver this support more broadly.
c) Flexible and responsive individualized funding for disability supports;	<ul style="list-style-type: none"> While individualized funding results in greater choice and control for individuals, the existing patchwork of home care and other agencies are not currently mandated, designed or assisted to provide individualized funding and support options.
d) Community navigation support; and	<ul style="list-style-type: none"> Community navigation supports are needed to complement person-centred planning support, to assist the person and their network activate their plans with community support agencies and health care, etc. However, informants advised that no clear policy is in place.
e) Assistance in working with other parties to arrange accommodations.	<ul style="list-style-type: none"> Informants reported that people experience discrimination because others assume they are not capable of making their own decisions (e.g., in health care, banking). There is no clear Human Rights Commission policy or guideline as it applies to decision making in these contexts.
3. There are gaps for youth in care and those with significant support needs;	<ul style="list-style-type: none"> Many youths transitioning from children’s services to the adult disability supports system are in “legal limbo” because they cannot act legally independently or get needed support. The current “age-based” and “IQ-based” eligibility criteria is not responsive to their needs.
Decision-making supporters are denied access to a person’s information and so cannot effectively assist.	<ul style="list-style-type: none"> Informants raised concerns that rules of RHAs and other provincially and federally regulated organizations (like the Canada Revenue Agency) deny a person’s informal decision-making supporters from providing basic assistance like changing a person’s address or filing taxes. This triggers formal guardianship or substitute decision making.

VI. BARRIERS IN LAW TO EXERCISING LEGAL CAPACITY

The barriers people experience in their personal relationships, in health and community services and in existing policy mandates appear to be structured and enabled in many ways by the legal regime regulating legal capacity. This section reviews these barriers.

Approach to Legal Analysis

Main statutes and jurisprudence that comprise the regime for legal capacity in Newfoundland and Labrador were compiled (as presented in Table 1 and discussed in Appendix E), studied, and analyzed. We looked for themes, coherence within the regime, and areas where regulation is lacking, outdated or inconsistent with Canada's Constitutional requirements. The four different approaches to legal capacity discussed in Section II – namely, the status, outcome, cognitive/functional and decision-making capability approach – provided a framework for the analysis.

Our findings are described below in two sections. Section A describes the main themes that emerged from the legal research and analysis; and Section B examines the legal capacity laws against the *Canadian Charter of Rights and Freedoms*.

A. Main Themes

1. *Legislation evidences a fragmented approach and gaps in regulating legal capacity to make different types of decisions, i.e., property, personal and health care*

The statutory scheme results in gaps whereby some statutes cover only some kinds of decisions, and some kinds of decisions are inadequately addressed. In particular, there is greater emphasis on property decisions than personal care (non-health care) decisions. There are limited options for addressing situations of incapacity (as defined in legislation) in relation to personal (non-health care) decisions.

For example:

- The *Mentally Disabled Persons' Estates Act* and *Enduring Powers of Attorney Act* cover property only.
- The *Advance Health Care Directives Act* covers health care decisions but no other personal care or other types of decisions.
- The *Adult Protection Act* only covers situations where a person meets the criteria of being "in need of protective intervention". For people who come within the scope of this statute (in conjunction with s. 22.1 of the *Mentally Disabled Persons' Estates Act*) intervention may cover both personal care and property.

- Up until February 2019, the status of guardianship appointments of the person (as opposed to property i.e., the estate) was unclear. This has been addressed through a recent decision of the Newfoundland and Labrador Court of Appeal in *A.A. (Re)*⁶⁵ which concluded that the Supreme Court of Newfoundland and Labrador has jurisdiction to appoint a guardian of the person. The decision lays out a number of principles applicable to the exercise of the jurisdiction.⁶⁶ However, as the court pointed out, these are not statutorily mandated. Also, the substantive and procedural implications of these principles have yet to be determined.

2. Legislation evidences inconsistent requirements and approaches to legal capacity

For example:

- Provisions in the *Mentally Disabled Persons' Estates Act* address legal capacity in a manner which relies heavily upon a status as a person with a particular condition, and also references a level of inability to conduct one's affairs. There are two different triggers of guardianship which rely on this mix in different ways. (s. 2(f) and s. 17).
- The *Enduring Powers of Attorney Act* contains one provision which interprets "legal incapacity" based on a mix of cognitive function and status as a person with a 'mental disability' (s. 2(1)(c)) and another which interprets "capacity" based on a mix of cognitive and non-cognitive factors (s. 15(2)). The latter provision for appointing designates for designation agreements, although not fully consistent with the interdependent decision-making capability approach, partially evidences how interdependent decision-making capability can be implemented in law. By virtue of that provision an adult may make a designation agreement to designate representatives to be holders of their Registered Disability Savings Plan (RDSP). In deciding whether a person has the 'capacity' to do so the person does not need to meet the usual cognitive test of 'understanding' and 'appreciation'. In particular, s. 15(2) requires that relevant factors be considered, which include those that are non-cognitive in nature. For example, these factors include the person's demonstration of preferences and expressions of feelings of approval or disapproval; and whether there is a relationship characterized by trust between the person and their designate.
- Both the *Adult Protection Act* (s. 6(2)) and the *Advance Health Care Directives Act* (s. 14) employ the formulation of capacity that is often seen in other Canadian jurisdictions and is sometimes referred to as the 'understand and appreciate' test. This is a pure cognitive test.

⁶⁵ 2019 NLCA 7.

⁶⁶ *A.A. (Re)*, 2019 NLCA 7, paras. 70 to 107.

- The *Mental Health Care and Treatment Act* removes a person’s control over decisions on the basis that the person has a ‘mental disorder’ (status approach) and meets additional criteria related to harm (outcome approach), cognition (functional approach), and need for treatment or care and supervision (s. 17(1)(b)).
- The *Judicature Act* gives the Supreme Court of Newfoundland and Labrador authority to appoint guardians of the person and estate. The Newfoundland and Labrador Court of Appeal applied a contextual interpretation to that Act, and thereby articulated a cognitive test to be employed for assessing whether or not to appoint a guardian of the person.⁶⁷

3. Supports and accommodations are only minimally recognized in law

To the extent that there is any recognition in law in Newfoundland and Labrador that people may access supports and accommodations to exercise legal capacity, it does not go so far as to ensure that people have a legal right to do so.

There is some law that tacitly recognizes the role that supports and accommodations play. For example:

- The *Adult Protection Act*’s articulation of service principles for the delivery of programs and services recognizes a role for “... support, assistance and advice from family and friends to help ... understand choices and to make and communicate decisions” (s. 8). Also, the *Adult Protection Act* contains a provision for arrangement of support services for a person who is believed to be ‘an adult in need of protective intervention’ (s.20(1)(a)(iv)).
- The recent Court of Appeal decision in *A.A.(Re)* gives tacit recognition to supports and accommodations in considering the principles that should guide the Supreme Court’s consideration of whether to make a guardianship order. In particular, the decision specifies that the court should consider “... whether guardianship is the best way in the circumstances to provide the protection and assistance the person concerned needs” (para. 82).

We did find one legal provision where the opposite is the case: discrimination against some people with disabilities in the context of contracts is justified under the *Human Rights Act* where a person "does not have the legal capacity to contract" (s. 21(2)). This provision could be interpreted to remove any duty to accommodate and to foreclose claims of discrimination for some people with disabilities who do not meet the common law test of capacity to contract.

⁶⁷ *A.A. (Re)*, 2019 NLCA 7, para. 76.

4. Legislation reflects a bio-medical approach to disability

Terms used in legislation include: “mental infirmity arising from disease, age, habitual drunkenness, the use of drugs or other cause...” (*Mentally Disabled Persons’ Estates Act* s. 17 and 18); “mental disorder” (*Mental Health Care and Treatment Act*, s.2(1)(k)) and “mentally disabled person” (*Mentally Disabled Persons’ Estates Act*, s. 2(f)).

Terms such as these are inconsistent with the social model and human rights approach to disability which has been affirmed by the Supreme Court of Canada⁶⁸ and articulated in the CRPD.⁶⁹

5. Some, but inconsistent, recognition of less/least restrictive alternatives to guardianship/substitute decision making exists

Provisions which recognize less/least restrictive alternatives to guardianship/substitute decision-making are important mechanisms for preserving a person’s legal capacity. These types of provisions, and related processes, are evident to a very limited extent in some legislation. Examples include the *Adult Protection Act* and, to a much lesser extent, the *Mentally Disabled Persons’ Estates Act*, and the recent Newfoundland and Labrador Court of Appeal decision in *A.A. (Re)*.⁷⁰

For example:

- The *Adult Protection Act* and its related policies and practices place great emphasis on finding individualized solutions in the community to avoid determining that an adult is in ‘need of protective intervention’. Legislative and policy provisions include, for example:
 - Service principle – “an adult who is or may be in need of protective intervention should receive the most effective but the least restrictive and intrusive form of support or protection” (s. 8(d));
 - Consideration of “less intrusive course of action” in context of emergency intervention (s. 23(1)(b) and 23(2)(b)); and,
 - Where professional/supportive services are offered and accepted at the evaluation and investigation stages, the process for declaring an adult in need of protective intervention does not proceed further.⁷¹

⁶⁸ *Québec (Commission des droits de la personne et des droits de la jeunesse) v. Montréal (City); Québec (Commission des droits de la personne et des droits de la jeunesse) v. Boisbriand (City)*, [2000] 1 S.C.R. 665, 2000 SCC 27, paras. 79 to 81.

⁶⁹ CRPD, note 1, Preamble and Article 1.

⁷⁰ *A.A. (Re)*, 2019 NLCA 7.

⁷¹ See, Government of Newfoundland and Labrador, *Adult Protection Act: Provincial Policy Manual*, note 69.

- Provisions exist in the *Mentally Disabled Persons' Estates Act* that allow for alternatives to guardianship in limited circumstances: those for temporary maintenance (s. 16) and in very limited circumstances regarding disposal of estates (s. 18). These are less restrictive alternatives to full guardianship but do not apply to all guardianship applications. For the most part, based on statutory language, guardianship applications are considered without a required process for determining whether a less restrictive alternative exists that might avoid the need for appointing a guardian. Thus, the *Mentally Disabled Persons' Estates Act* does not recognize options, such as supports and accommodations, that might be complete alternatives to any guardianship appointment.

Despite the very limited recognition of 'alternative course of action' provisions in Newfoundland and Labrador, the path has been laid with clear direction from the Newfoundland and Labrador Court of Appeal articulating their importance. In its decision in *A.A. (Re)*⁷², in which it clarified that the Supreme Court has jurisdiction to appoint a guardian of the person, it named 'alternative course of action' considerations as a principle for the Court to apply when dealing with applications of guardianship of the person and did so even in the absence of specific statutory language. As noted in Table 1, the Court of Appeal stated that the Court should consider "whether guardianship is the best way in the circumstances to provide the protection and assistance the person concerned needs."⁷³

Other than the provisions and principles outlined above, there does not appear to be explicit recognition of alternative courses of action to avoid guardianship and related substitute decision-making processes. In contrast, alternative course of action provisions exist in many other statutes across Canada.⁷⁴

The automatic appointment of the Public Trustee as guardian for involuntary patients (*Mentally Disabled Persons' Estates Act* s. 20(4)) and for adults 'in need of protective intervention' (*Mentally Disabled Persons' Estates Act* s. 22.1(3)) are situations that are particularly restrictive of legal capacity. The appointments occur in the absence of a process for determining whether guardianship by the Public Trustee is truly necessary, and whether other options might be possible, including involvement of supports in the person's life. In these circumstances alternative course of action provisions and processes would be a critical aspect of protecting the person's exercise of legal capacity.

⁷² 2019 NLCA 7.

⁷³ *A.A. (Re)*, 2019 NLCA 7, para. 82.

⁷⁴ See, for example, Manitoba's *Vulnerable Persons Living with a Mental Disability Act*, C.C.S.M. c. V90, ss. 49 and 84; Ontario's *Substitute Decisions Act, 1992*, S.O. 1992, c. 30, ss. 22(3) and 55(2); Yukon's *Adult Protection and Decision-Making Act*, which is Schedule A to *Decision Making, Support and Protection to Adults Act*, S.Y. 2003, c. 21, ss. 2(c) and (d), 32(1), 37(1).

B. Considerations for Assessing Compliance with the Canadian Charter of Rights and Freedoms

This section of the report lays out considerations for assessing Newfoundland and Labrador's legal capacity laws for their compliance with the *Canadian Charter of Rights and Freedoms*. It is not intended to be a comprehensive and fulsome analysis of *Charter*-compliance of the entire legal regime for regulating legal capacity in the province; but, rather, to lay out a path to conduct that analysis going forward.

Relevance of the CRPD

Analyzing compliance of Newfoundland and Labrador's legal capacity laws against the *Charter* must consider the relevance of international human rights treaties ratified by Canada, including the CRPD. That Canada's legal capacity laws, including those of Newfoundland and Labrador, are inconsistent with the CRPD, most notably Article 12, has been well documented.⁷⁵ Thus, the purpose of this legal research was not to re-examine existing research findings, but rather, to explore what would be required to achieve compliance with Article 12 in jurisdictions in Canada and in Newfoundland and Labrador.

Article 4 of the CRPD clarifies that meeting obligations under the *Convention* involves a broad and flexible approach to take account of the particularities of each State Party. In Canada, this means taking account of Canada's Constitution, including the *Charter*. Therefore, whatever approach to legal capacity law reform is arrived at in Newfoundland and Labrador, it must be compliant with over-riding constitutional requirements.⁷⁶ In this regard, the *Charter* takes precedence over laws (both federal and provincial/territorial) which are inconsistent with it.⁷⁷ It applies to all legislation, including regulations, and to government entities.⁷⁸ Thus, any reforms to the legal regime for exercising legal capacity must not be inconsistent with the *Charter*.

In interpreting the *Charter* for this purpose, the United Nations treaties to which Canada is a party, including the CRPD, must be taken into account. The Supreme Court of Canada has been clear in its opinion that the obligations found in international human rights treaties to which Canada is a party are "... a relevant and persuasive factor in *Charter* interpretation."⁷⁹

⁷⁵ See Committee on the Rights of Persons with Disabilities, "Concluding observations on the initial report to Canada," note 5, para. 28; Lana Kerzner, "Supported Decision-Making Innovations: The Canadian Experience" in Charles O'Mahony and Gerard Quinn, eds., *Disability Law and Policy: An Analysis of the UN Convention*, (Dublin: Clarus Press Ltd, 2017), 111-113.

⁷⁶ Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11.

⁷⁷ P.J. Monahan, B. Shaw, & P. Ryan, *Constitutional Law* (5th ed.) (Toronto, ON: Irwin Law, 2017), 427.

⁷⁸ Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11, s. 32. P.J. Monahan, B. Shaw, & P. Ryan, P. *Constitutional Law* (5th ed.) (Toronto, ON: Irwin Law, 2017), 427 and 429.

⁷⁹ *Reference re Public Service Employee Relations Act (Alberta)*, [1987] S.C.J. No. 10, [1987] 1 S.C.R. 313, paras. 59 - 60, Dickson, C.J.C. dissenting. With respect to the applicability of this passage, Corbett and Sadoway state the

Regardless of whether Newfoundland and Labrador’s legal capacity laws are examined against the *Charter* or the CRPD, the analysis points to the same directions for addressing these shortcomings. The following statement of the Supreme Court of Canada is instructive in this regard:

“... the Charter, as a living document, grows with society and speaks to the current situations and needs of Canadians. Thus, Canada’s current international law commitments and the current state of international thought on human rights provide a persuasive source for interpreting the scope of the Charter.”⁸⁰

Guided by the interpretive guidance of the CRPD, our research and analysis of Newfoundland and Labrador’s legal capacity laws against the *Charter* results in findings as follows:

1. Legislation based on the mainstream approaches to legal capacity results in discrimination, contrary to s.15 of the Charter

If the law denies legal capacity on the same basis for everyone regardless of disability it does not amount to discrimination.⁸¹ However, restrictions based on disability, as currently exist in the Newfoundland and Labrador regime, can be characterized as discriminatory, contrary to the equality provision, s.15, of the *Charter*.⁸² How that conclusion is arrived at is presented in summary fashion as follows:⁸³

- Legal capacity tests which apply only to people who have mental disabilities⁸⁴ are discriminatory on their face. This amounts to direct discrimination.
- Even legal capacity tests which, on their face, apply equally to all, can in practice, impose unequal burdens on people with disabilities, thus amounting to adverse effect discrimination.⁸⁵
- The cognitive test of capacity found in Newfoundland and Labrador statutes,⁸⁶ creates a distinction between people who meet the test and people who do not meet it. Most

following: “Although originally written in a dissenting judgment, the following passage by Brian Dickson C.J.C. has been cited often enough to permit its being regarded as a statement of the Supreme Court’s approach to the relation between international human rights agreements and the Charter.” Stanley M. Corbett and Geraldine Sadoway, *Canadian Human Rights Law & Commentary*, 3rd ed. (Toronto: LexisNexis, 2016), 75.

⁸⁰ *Health Services and Support-Facilities Subsector Bargaining Assn. v. British Columbia*, 2007 SCC 27, [2007] 2 S.C.R. 391, para. 78.

⁸¹ General Comment No. 1, note 13, para. 32.

⁸² The s. 15 *Charter* analysis is based on current s. 15 Supreme Court of Canada jurisprudence, including the following cases: *Quebec (Attorney General) v. Alliance du personnel professionnel et technique de la sante dt des services sociaux*, 2018 SCC 17; *Kahkewistahaw First Nations v. Taypotat* 2015 SCC 30; and *Quebec (Attorney General) v. A*, 2013 SCC 5.

⁸³ For a fuller analysis of how cognitive tests in legal capacity laws in Canada are not *Charter*-compliant, see Lana Kerzner, note 6.

⁸⁴ See e.g., *Mentally Disabled Persons’ Estates Act*, R.S.N.L. 1990, c. M-10, s. 20(4).

⁸⁵ *Eldridge v. British Columbia (Attorney General)*, [1997] 3 S.C.R. 624. para. 77.

people who do not meet the test are members of an enumerated class of Canadians that the equality provision in the *Charter* protects: people with ‘mental disabilities.’ The test results in a distinction based on disability.

- The distinction found in the test draws a discriminatory distinction that has the effect of perpetuating arbitrary disadvantage based on a person’s mental disability. The cognitive test of capacity does not respond to the needs and actual capacities of people with mental disabilities. The basic formulation does not allow for an evaluation of each person’s decision-making capability, which may well be constituted through non-cognitive means. People with mental disabilities are adversely impacted by the cognitive test of capacity in such a way as to entrench their historic disadvantage and, by excluding them from being able to make decisions and engage in transactions, widens the gap between them and the rest of society.
- Measures for restricting legal capacity based on mental disability undermine the development and exercise of personal autonomy of a group already burdened by stereotypes that configure mental disability as a sign of less equal worth. Rather than recognize mental disability as an indicator of needs for support and accommodation, these measures deepen the historic disadvantage of this group. In so doing they systematically undermine the fundamental value of personal choice and control, which is integral to achieving not only self-determination but also full membership and participation in society. It is in compounding the stereotyping and disadvantage this group already faces that the legal measures restricting autonomy constitute discrimination.
- In summary, the cognitive test embedded in the statutory regime for legal capacity amounts to adverse effect discrimination against people with mental disabilities.
- This conclusion is reinforced by the interpretation by the Committee on the Rights of Persons with Disabilities about the approaches to capacity, all of which are found in Newfoundland and Labrador legislation. In particular, the Committee stated that: “Discrimination through denial of legal capacity may be present in different ways, including status-based, functional and outcome-based systems. Denial of decision-making on the basis of disability through any of these systems is discriminatory.”⁸⁷ It concluded that all of these approaches are contrary to Article 12 of the CRPD.⁸⁸

⁸⁶ See e.g., *Adult Protection Act*, S.N.L. 2011, c. A-4.01, s. 6(2), and *Advance Health Care Directives Act*, S.N.L. 1995, c. A-4.1, s. 14.

⁸⁷ UN Committee on the Rights of Persons with Disabilities, “General comment No. 6 (2018) on equality and non-discrimination”, UN Doc CRPD/C/GC/6 (April 2018), para. 47.

⁸⁸ General comment No. 1, note 13, para. 15.

2. Legislation which restricts legal capacity results in deprivations of liberty and security of the person, and are suspect for violations of people's s. 7 Charter Rights

- Section 7 of the *Charter* enshrines the right to “life, liberty and security of the person.” To establish a s. 7 violation, it must be established that the right to life, liberty or security of the person was denied in a manner which is contrary to the principles of fundamental justice.⁸⁹
- The Supreme Court of Canada has named protection of individual autonomy and dignity interests as underlying both liberty and security of the person.⁹⁰
- Newfoundland and Labrador’s substitute decision-making provisions found in the *Mentally Disabled Persons’ Estates Act, Advance Health Care Directives Act, Mental Health Care and Treatment Act, Adult Protection Act* and *Judicature Act* remove the right to make decisions in certain circumstances as set out in the legislation and described above in section VI.A. and Appendix B. As such, they interfere with both autonomy and dignity.
- The Supreme Court of Canada has described the ‘liberty’ and ‘security of the person’ interests as follows:
 - “Liberty protects ‘the right to make fundamental personal choices free from state interference’”
 - “Security of the person encompasses ‘a notion of personal autonomy involving . . . control over one’s bodily integrity free from state interference’ ... and it is engaged by state interference with an individual’s physical or psychological integrity, including any state action that causes physical or serious psychological suffering”⁹¹
- Some principles of fundamental justice are prohibitions against:
 - Unduly vague laws
 - Laws that are arbitrary or bear no rational relation to their legislative objective
 - Laws that are overbroad to their legislative objective
 - Laws that have a gross disproportionality between their objective and the harms that they impose.⁹²
- Legal capacity laws in Newfoundland and Labrador are diverse. Examined against the principles set out above, they are suspect for s. 7 violations. However, some more clearly engage liberty and security of the person interests, and/or are more inconsistent with the principles of fundamental justice than others.

⁸⁹ Section 7 of the *Charter* provides as follows: “Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.”

⁹⁰ *Carter v. Canada (Attorney General)*, 2015 SCC 5, para. 64.

⁹¹ *Carter v. Canada (Attorney General)*, 2015 SCC 5, para. 64.

⁹² Robert J. Sharp and Kent Roach, *The Charter of Rights and Freedoms*, 6th ed. (Toronto: Irwin Law, 2017), 260.

- Therefore, each of the laws which regulate legal capacity in Newfoundland and Labrador must be analyzed rigorously to assess their compliance with s. 7. This analysis must be undertaken alongside considerations of how the CRPD and international human rights laws address these same matters. In particular, Article 14 of the CRPD states that “States Parties shall ensure that persons with disabilities, on an equal basis with others: (a) Enjoy the right to liberty and security of the person”.
- The analysis undertaken in Newfoundland and Labrador must take place against the backdrop of the Supreme Court of Nova Scotia’s decision in *Webb (Litigation guardian of) v. Webb*.⁹³ In that decision guardianship provisions in the *Incompetent Persons Act*,⁹⁴ were found to be unconstitutional: they violated the liberty and security of the person interests of s. 7 of the *Charter* in a manner not in accordance with the principles of fundamental justice, and could not be justified as a reasonable limit in a free and democratic society pursuant to s. 1 of the *Charter*.

3. *The manner in which the legislation balances values of autonomy and equality against protection from harm must be re-examined to ensure Charter compliance*

- The balancing underlying legal capacity laws involves consideration of two factors:
 - society’s role in ensuring that people who are vulnerable are protected from harm (societal interests);
 - The principle that everyone should enjoy the right to autonomy, able to live their lives without state interference, and to do so on an equal basis with others (individual rights).
- The balancing of rights and interests is evidenced in the *Charter* in two key provisions, namely s.1, and the principles of fundamental justice component of s. 7 (described above).
- Section 1 allows for limitation of *Charter* rights, including the s. 15 equality right, and the s. 7 right to life, liberty and security of the person. In particular, it provides that the rights and freedoms guaranteed in the *Charter* are “subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.” Thus, *Charter* rights are not unlimited.
- The Supreme Court of Canada has provided the framework for a s. 1 analysis which requires an assessment of whether a particular limit is justified.⁹⁵ This analysis directly engages the balancing of societal interests as against individual rights. The factors are as follows:

⁹³ 2016 NSSC 180, 1182 A.P.R. 284.

⁹⁴ R.S.N.S. 1989, c. 218, as amended, was repealed and replaced by the *Adult Capacity and Decision-making Act*, S.N.S. 2017, c. 4, on December 28, 2017.

⁹⁵ *R. v. Oakes*, [1986] 1 S.C.R. 103.

- The objective of the measure must be important enough to warrant overriding a *Charter* right;
 - There must be a rational connection between the limit on the *Charter* right and the legislative objective;
 - The limit should impair the *Charter* right as little as possible; and,
 - There should be an overall balance or proportionality between the benefits of the limit and its deleterious effects.⁹⁶
- It appears that legislative approaches in Newfoundland and Labrador place disproportionate weight on protection against harm in a manner that sacrifices equality and autonomy interests more than is necessary. Alternative approaches to regulating legal capacity, including supports and accommodations, would provide protection from harm in a manner which gives greater respect for equality and autonomy. Measures to safeguard the integrity of the decision-making process in this manner are features of the decision-making capability approach to legal capacity as outlined above in section II. The measures aim to ensure the decision-making process accords with a person's true intentions while protecting against undue influence, coercion and involuntariness.

C. Summary of Legal Analysis

The legal framework regulating the exercise of legal capacity in Newfoundland and Labrador appears inconsistent, fragmented, incomplete and substantially reliant on outmoded and negative stereotypes of disability. While elements of a decision-making capability approach have been minimally adopted, largely the regime is based on the status, outcome and cognitive/functional approaches to defining requirements for exercising legal capacity.

As such, significant aspects of the regime appear to be inconsistent with the Charter. This conclusion is neither surprising nor sufficiently concrete to guide reform. How could a regime for exercising legal capacity be designed that *is* Charter compliant? A critical component of a re-design is the need to ensure that statutes evidence balancing of rights to autonomy and equality against harm prevention and response, in a manner that places greater emphasis than currently exists on respect for autonomy and equality, while sufficiently safeguarding against harm. The decision-making capability approach described above, we suggest, can successfully achieve the re-balancing required for *Charter* compliance.

⁹⁶ Robert J. Sharp and Kent Roach, *The Charter of Rights and Freedoms*, 6th ed. (Toronto: Irwin Law, 2017), 70.

VII. GUARDIANSHIP AND SUBSTITUTE DECISION MAKING: DO DATA LIMITATIONS HIDE THE PROBLEM?

How many people are affected by the legal, policy, program and personal and inter-personal barriers to exercising legal capacity in their lives, which the research and consultation identified? While there are some indications, the limitations of available data prevent us from drawing a clear picture of the scale of this issue.

While estimating the number of people who experience restrictions on their decision-making power was beyond the scope of our research, we did obtain the following information:

- As of November 2, 2020, the Public Trustee was acting as guardian of finances/estate for 269 persons. Forty of these cases were for persons identified as involuntarily psychiatric patients committed to hospital. Of these 269 “open files,” 63 had passed.⁹⁷
- Since January 2015, the Supreme Court of Newfoundland and Labrador has issued just over 500 guardianship orders (“letters of guardianship”) appointing private individuals as guardians of property or the person.⁹⁸

However, there are many other situations where data is not available, collected or publicly reported, including for situations where:

- a health care professional finds that a person lacks competency to make a health care decision and a substitute decision maker acts on behalf of that person under the *Advance Health Care Directives Act*;
- a provincial government officer directs that income support payments be made to a Trustee because the applicant/recipient is determined to be incapable of managing their financial affairs under the *Income and Employment Support Act*;
- a person is subject to substitute decision-making provisions under other provincial and federal legislation (see Table 1 for examples); or
- informal substitute decision making is imposed.

With respect to informal substitute decision making, the examples from the community response report (in Appendix I) and those gathered through the consultation and key informant interviews for this report indicate widespread concern about this practice.

One indicator of the scale of informal substitute decision making is the number of people who rely on others for decision-making assistance. While the national survey on disability has not collected this information since 2006, the Participation and Activity Limitation Survey from that

⁹⁷ Data provided by John Goodland, Public Trustee of Newfoundland and Labrador, in personal communication with Michael Bach and Lana Kerzner, November 2, 2020.

⁹⁸ Data provided by “Inquiries,” Supreme Court of Newfoundland and Labrador, via email communication with Michael Bach, November 12, 2020.

year indicates that 880,000 to 1,000,000 Canadians with disabilities has someone who helped them make daily decisions.⁹⁹ People with developmental or cognitive disabilities are over-represented in this group.

Along with demographic trends signaling an increasing prevalence of disability and dementia,¹⁰⁰ the magnitude of this need for decision-making assistance is growing. How that assistance is provided – the extent to which it is support for decision making or informal substitute decision making – is not known. Nor is the extent to which those providing decision-making support apply for guardianship over the person so that needed legal decisions can get made. What these numbers do indicate is that there is a growing proportion of Canadians at risk of losing legal capacity formally or informally due to their reliance on others for assistance with decision making.

Without a clearer picture of the numbers of people being restricted or denied in exercising legal capacity, the full scale of this growing problem remains hidden. In light of the community’s calls for action on this issue, and government commitment to respond, future policy development will need to address this critical data gap.

⁹⁹ Adele Furie, “Legal Capacity: Scale of the Issue in Canada” (Toronto: IRIS – Institute for Research and Development on Inclusion and Society, December, 2017).

¹⁰⁰ P. Smetanin, P. Kobak, C. Briante, D. Stiff, G. Sherman, G. and S. Ahmad, *Rising Tide: The Impact of Dementia in Canada 2008 to 2038* (Toronto: Alzheimer Society of Canada).

VIII. OPTIONS FOR MEETING CONSTITUTIONAL IMPERATIVES FOR REFORM

Findings from the research make clear that numerous legal, policy, program and personal and inter-personal barriers operate in ways that deny decision-making power in the lives of a growing group of people with disabilities or those with mental health issues.

As discussed in the previous section, the scale of this problem is not fully known because the data is simply not available. Nonetheless, and regardless of the actual numbers of people affected, the research indicates significant portions of the legal capacity regime in Newfoundland and Labrador are not compliant with a CRPD-informed interpretation of *Charter* requirements for equality in the exercise of legal capacity. This is not surprising. Many of the provisions in statutes constituting the regime are inherited from a pre-*Charter* and pre-CRPD era, with some still importing language and concepts from almost 200 years ago (for example, the reference to “natural fools” who are “deprived of their reason and understanding” as the basis for appointing guardians, under the 1824 *Judicature Act*).¹⁰¹

Current and evolving international human rights obligations have Constitutional implications and establish an imperative to reform the current legal capacity regime in Newfoundland and Labrador. Moreover, the research points to practices, programs and policies that could create stronger foundations for enabling people to exercise legal capacity on an equal basis.

A. Overview of Options for Reform

The findings from the research and consultation point to three main options to consider in ensuring the enjoyment of legal capacity on an equal basis:

- **Option A:** Phased-in fully inclusive ‘decision-making capability’ approach to legal capacity, enabled by full recognition of supports and accommodations in law and policy;
- **Option B:** Supported cognitive/functional approach to legal capacity, where law and policy recognize the role of supports and accommodations in enabling a person to meet cognitive tests of legal capacity in all circumstances; and
- **Option C:** Status quo legal regime but with an enhanced focus on supported decision-making practice.

We outline each option below, and then assess them against a set of criteria.

¹⁰¹ This language is from section 6 of the 1824 *Act for the better administration of justice in Newfoundland, and for other purposes*, 5 George IV, c. 67. It is imported into the revised *Judicature Act*, R.S.N.L. 1990, c. J-4, s. 3(1)(a).

Option A: Phased-in fully inclusive ‘decision-making capability’ approach to legal capacity, enabled by full recognition of supports and accommodations in law and policy

Main Features:

- Comprehensively adopt the decision-making capability approach in the legal regime, expanding legal recognition of both independent and interdependent decision-making capability, with supports and accommodations as required.
- Adopt enabling policies and guidelines to promote a decision-making capability approach, supports for decision making, and the duty to accommodate.
- Invest in needed service delivery reform to maximize development and delivery of supports for decision making.
- Develop policy, guidelines, information and training for health care, justice, social service and financial sectors to implement this approach in practice.

This option is effectively a universal design approach to exercising legal capacity. It would entail comprehensive and proactive steps to expand implementation of what has been referred to in this report as the ‘decision-making capability’ approach. It would apply to each of the laws which make up the legal capacity regime. It would begin with reform of the *Mentally Disabled Persons’ Estates Act*.

While the steps to implementation would be taken incrementally, they would be strategically directed by the fundamental requirement of the decision-making capability approach – that is, a recognition that persons may exercise their legal capacity independently or interdependently as those have been defined in section II of this report, as follows:

- Independent decision-making capability
 - The person demonstrates that with the appropriate supports and accommodations they have the capacity to understand information and appreciate consequences required for a particular decision, and thus decide on their own; and,
- Interdependent decision-making capability
 - Together the person and recognized decision-making supporters have the capacity to understand information and appreciate consequences of a particular decision, guided by the best interpretation of the person’s will and preferences in the circumstances.

Option B: Supported cognitive/functional approach to legal capacity, where law and policy recognize the role of supports and accommodations enabling a person to meet cognitive tests of legal capacity in all circumstances.

Main Features:

- Adopt the ‘understand and appreciate’ test for legal capacity across core and secondary statutes of the regime.
- Ensure consistency across tests of capacity so that they each recognize the role of supports and accommodations for demonstrating that a person meets the test of capacity.
- Ensure that laws recognize the role of supports and accommodations in all decision-making contexts and circumstances, in addition to the role they would play for meeting the cognitive test.
- Develop guidelines for the duty to accommodate in decision making..
- Develop policy, guidelines, information and training for health care, justice, social service and financial sectors to implement this approach in practice.

This option would not be as comprehensive as option A, but it would require the laws to recognize supports and accommodations more fully and consistently than they do now. By doing away with disability-related ‘status’ and ‘outcome’ approaches currently in law, it would bring a more consistent approach to the legal regime and provide for greater recognition of supports for decision making. Resulting reforms would mean that more people with disabilities will be able to make their own decisions, but still some would be excluded. It would leave substitute decision making and guardianship in place for those who cannot meet the cognitive test, even with supports and accommodations.

Current examples to illustrate the kinds of reforms necessitated by this option include:

- legal recognition of supports to meet a cognitive capacity test. For example, in the Northwest Territories *Guardianship and Trusteeship Act*, "capable" is defined in s.12(1) as having "the ability, by himself or herself, or with assistance" to understand information and appreciate reasonably foreseeable consequences.
- legal provision for those who meet a cognitive capacity test to enter supported decision-making arrangements as, for example, in Alberta's *Adult Guardianship and Trusteeship Act*, which provides in s. 4(1) that an adult may make a supported decision-making authorization if they understand its "nature and effect."

Option C: Status quo legal regime but with an enhanced focus on decision-making supports and accommodations

Main Features:

- Maintain the legal regime as it currently exists with a mix of status, outcome, cognitive/functional and emergent decision-making capability approaches to legal capacity.
- Develop guidelines for the duty to accommodate in decision making, within the current legal capacity regime.
- Develop policy, guidelines, information and training for health care, justice, social service and financial sectors to maximize decision-making supports and accommodations in practice within current legal parameters.

This option would not alter the legal framework regulating legal capacity but would achieve some progress over the current situation with a focus on policy, program and practice reforms. While these types of reforms would not achieve the goals of being comprehensive, consistent, inclusive or mandatory, they would likely promote more widespread accessibility by promoting and enabling use of supports and accommodations for making decisions. The aim would be to encourage more people with disabilities to take control over their own decisions, where the law doesn't impose a barrier to doing so, and to encourage their supporters and other parties in decision making to assist in achieving this outcome.

In summary, while there are fundamental differences between each of these options there is a commonality across all of them: they each offer an enhanced focus on, and recognition of, the role that supports and accommodations play in exercising legal capacity. It is important to note that none of the options necessarily requires implementation of an entirely new supports system. Any of the chosen options could be designed to leverage, train and adapt existing informal and formal supports. Some additional community capacity is likely required for this purpose.

B. Criteria for Assessing Options

Assessing and choosing among these options, or adapting and considering others, should be undertaken against a set of criteria that would address practice, program, policy and legal barriers to people exercising greater choice and control in their lives. The following nine criteria are recommended to assess the three options and were selected based on: the mandate which motivated this research and consultation, the objectives established at the outset, the findings as presented, and the dimensions of reforms as outlined in the options above.

The assessment criteria are:

1. Meets Canada’s obligations under the CRPD

The options should be consistent with Canada’s obligations under international law. While Article 12 of the CRPD has been interpreted by the UN Committee on the Rights of Persons with Disabilities to mean that guardianship and substitute decision making provisions constitute violations and should be replaced by measures for supported decision making, Canada has taken a different view. It has registered with the UN a ‘declaration and reservation’ stating its understanding that Article 12 permits both supported and substitute decision making.¹⁰²

2. Is Charter-compliant: Charter-informed principles for legal capacity regimes in Canada

The options should maximize compliance of the regime with the *Charter*. The research and legal analysis found various ways the current legal regime results in discrimination, deprives people of their liberty, security of the person and equality rights and often fails to adequately balance respect for autonomy and protection from harm.

In order to achieve *Charter* compliance, a set of specifically crafted guiding principles is proposed for this purpose, based on the legal research for this study, and a recent study on legal capacity regimes in the broader Canadian context.¹⁰³ The principles derived, are based on examining:

- the *Charter* provisions most relevant to the exercise of legal capacity, being sections 7, 15 and 1;
- related jurisprudence and legal scholarship; and,
- the obligations to interpret the *Charter* consistent with Canada’s international human rights obligations, including those under the CRPD.

We refer to these principles as “*Charter*-informed principles for legal capacity regimes in Canada.” They are not presented as “*Charter*-proof” guidance to protect from scrutiny any particular provision or reform designed in accordance with the principles. As is well recognized, the requirements of *Charter* compliance evolve through jurisprudence. That said, these principles are intended to be concrete guideposts to maximize compliance, based on comprehensive inquiry about application of the *Charter* to regimes for legal capacity, in light of human rights obligations under international law. As such, the principles are one guide for assessing legal capacity regimes in Newfoundland and Labrador and, indeed, in all jurisdictions

¹⁰² See United Nations, “Reference: C.N.153.2010.TREATIES-7,” note 37.

¹⁰³ These principles are also discussed in IRIS – Institute for Research and Development on Inclusion and Society, *Implementing Equal Access to Legal Capacity in Canada: Experience, Evidence and Legal Imperative. Final Report* (Toronto: IRIS – Institute for Research and Development on Inclusion and Society, 2020).

in Canada, should policy decisions be made to take a proactive approach to reform. The principles are as follows:

Provisions for legal capacity must:

1. Respect the right to equality, which requires that they:
 - a. are based on universal access;
 - b. recognize that decision-making capability can be exercised:
 - i. independently, and/or
 - ii. interdependently; and,
 - c. recognize that supports for decision making, regardless of severity or type of disability, is integral to the right to equality in the exercise of legal capacity.
2. Protect the right to liberty and security of the person.
3. Balance the rights to equality and to liberty and security of the person, with societal interests to protect persons from harm, and thus:
 - a. promote personal autonomy;
 - b. protect equal enjoyment and exercise of legal capacity without discrimination based on disability; and,
 - c. protect persons who may be vulnerable to harm when they are unable to exercise legal capacity either independently or interdependently.
4. Recognize that disability cannot be used to justify restriction of legal capacity to address or prevent serious harm.
5. Recognize that restriction of legal capacity is itself a harm, undermines legal and social personhood and risks social devaluation based on disability. Thus, any such restriction must:
 - a. Be disability neutral in application; and,
 - b. Be proportional to the degree to which such measures affect the person's rights and interests, and;
 - c. Meet criteria in their design and application which recognize the gravity of the restriction and the harm that can result. For example, the restrictions must be:
 - i. applied as a last resort, only after all steps have been taken to ensure the person has access to supports required to exercise legal capacity independently or interdependently;
 - ii. provided in the least restrictive manner;
 - iii. tailored to the person's circumstances;
 - iv. applied for only as long as is necessary to address or prevent the harm;

- v. imposed only after a full and fair process to assess the need for restrictions and reasonable alternatives under the circumstances;
- vi. subject to a right to appeal; and, subject to regular review by a competent, independent and impartial authority or judicial body to assess whether the benefits outweigh the harms in the circumstances, and that the need for such restrictions continues to be justified; and,
- vii. combined with measures to put in place supports to enable a person to exercise legal capacity as soon as practically possible.

3. Recognizes and enables access to supports and accommodations for decision making

The consultations, key informant interviews and legal analysis found only partial and tacit recognition of supports and accommodations in the current regime. As well, a biomedical rather than social and human rights approach to disability still predominates. This results in discriminatory restriction of people’s exercise of legal capacity. Therefore, options should entail provisions for full and consistent recognition of supports and accommodations, which is fundamental in a social and human rights approach to disability. Legislation should provide concrete measures to facilitate and enable access to supports and accommodations, as one measure that this criterion is met.

4. Addresses fragmentation and inconsistency in the regime for regulating legal capacity

The legal analysis indicated that current provisions result in a fragmentary and inconsistent approach to recognizing and regulating legal capacity. The options for reform should evidence a comprehensive and consistent approach to defining legal capacity and provide clarity and transparency about the conditions on which legal capacity is to be exercised, and the ways a person and supporters can put those conditions in place to the greatest extent possible (e.g., information about accommodations, and ways to arrange less restrictive means for exercising legal capacity, to appoint supporters, or resolve disputes. With inconsistent approaches in the current regime to recognizing and exploring less restrictive alternatives to substitute decision making, the options should ensure that any form of substitute decision making is a very last resort, and provisions should lay out mandatory requirements to ensure this outcome.

5. Safeguards integrity of the decision-making process in a manner that maximizes legal capacity

Safeguarding the integrity of the decision-making process in a manner that protects vulnerable persons from harm, and also maximizes their exercise of legal capacity is an important criterion – both from the perspective of the “*Charter*-informed principles” outlined above, and also as raised by participants and key informants for this research.

6. *Maximizes beneficiaries*

The options should maximize the number of Newfoundlanders and Labradorians who will benefit under the regime. By ‘benefit’ we mean being able to exercise legal capacity in health care, financial and personal life decisions, and receiving the supports and accommodations necessary for that purpose.

7. *Provides a cost-effective approach to meeting support needs*

We include this criterion given concerns expressed by participants in the consultation and research about whether reforms would entail a large-scale investment in supports for decision making and a delivery system for that purpose. In the context of tight fiscal realities in the province, as referenced in Appendix H, the ‘Context for Reform’, these are legitimate concerns and should be included in criteria for assessment of options.

8. *Meets disability, mental health and seniors’ communities’ concerns*

The options should address the concerns raised by the communities of interest which have advocated for reforms of restrictive laws and policies regulating legal capacity. These concerns were well articulated in the 2011 conference on ‘Securing Citizenship and Legal Capacity for All’ and underlie the government’s mandate to explore supported decision making.

9. *Is a feasible option to implement*

Implementing reforms of the nature presented in the options would engage a large number of stakeholders, would affect transactions across many sectors including health care, justice, financial institutions, community services, and contracting for goods and services more generally. It would entail addressing privacy concerns and create new obligations for many actors in these sectors. As such, the option must be feasible to implement and include practicable and concrete measures for adapting a wide range of practices as required under the option.

C. Assessment of Options

Appendix G provides a chart assessing these options according to the criteria above. The assessment concluded that option A best meets these criteria and addresses the concerns motivating this consultation and research, for the following reasons:

- Only option A addresses the current exclusion of many people with more significant intellectual, developmental, and cognitive disabilities and people living with mental health issues from exercising and enjoying legal capacity. It does so by recognizing supported decision-making arrangements for people to act ‘legally interdependently’

when unable to meet the cognitive requirements for exercising legal capacity by themselves, even when they have supports and accommodations.

- Option A appears to best fulfill *Charter* informed principles for an inclusive legal capacity regime. Neither option B nor C would be *Charter* compliant, as defined in this report.
- Option A is best able to meet community concerns and calls to ensure people with more significant disabilities are supported to exercise legal capacity.
- Option A would introduce more consistency to the legal regime.

In comparison, options B and C would not meet the criteria, or motivating concerns, to the same extent:

- Options B and C would exclude a large and growing group from the benefits of exercising legal capacity.
 - While they would recognize supports and accommodations for decision making to some extent, they would exclude people who are unable to meet a cognitive test of legal capacity even with supports and accommodations.
- Thus, these options would not be *Charter* compliant.
- The options would not address community concerns identified in a “community response” (in Appendix I) to a draft of this report. The report rejects such options because they exclude those with more significant disabilities, “those for whom legal reform is most necessary” their report states.

IX. RECOMMENDED DIRECTIONS: A PHASED-IN FULLY INCLUSIVE APPROACH TO LEGAL CAPACITY

Having considered the three options it appears that option A most fully addresses the barriers identified, responds to the conclusions of the legal analysis of the current regime and the constitutional imperatives for reform, and on balance scores highest on the assessment criteria.

Full-scale implementation of option A would require a multi-year effort. A detailed strategy for that purpose is impossible to design at the beginning, given the range of contingencies and variables that will likely affect implementation. To begin the process and lay out a clear path going forward, we have defined an initial 5-year plan for implementation. The aim would be to create a platform for a sustainable process going forward. We point to some ‘early wins’ and some needed building blocks for ensuring effective implementation of a strategy over the longer-term.

Based on the analysis, we identify eleven main recommendations for an initial 5-year reform strategy that is comprehensive and robust enough to effectively deal with the complex and intersecting barriers identified in this report:

1. *A Joint Government-Community Legal Capacity Reform Steering Committee and inter-departmental leadership*

- Implementing option A will require a multi-dimensional and multi-year reform process. It will require both cross-government coordination and active engagement with disability community representatives and the community service delivery sector as implementing decision-making supports will require community leadership and services transformation. A joint table where cross-government and community representatives can bring multiple perspectives would best facilitate the needed collaboration. Community representatives would be appointed as individuals and sign confidentiality agreements to ensure options could be explored and government information could be shared in an environment of mutual trust.
- Recent experience with this joint government-community approach to policy development at both federal and provincial levels, which goes beyond a community consultation process, provide helpful examples.¹⁰⁴

¹⁰⁴ The COVID-19 Disability Advisory Group was co-chaired by federal Minister Carla Qualtrough and a disability community representative. The committee worked on a confidential basis and developed recommendations that were adopted as part of the government’s pandemic response, including ethics guidelines for health care providers and the Covid-19 disability benefit. See <https://www.canada.ca/en/employment-social-development/news/2020/04/background-2020-04-covid-19-disability-advisory-group.html>. A provincial-level example is the “Nova Scotia Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities Program” created by the provincial government to design recommendations for transforming the

- An inter-departmental leadership team at the ADM level would assist in effective cross-government leadership and coordination. Different departments would have distinct roles in the process. For example, the Department of Justice and Public Safety would lead the needed law reform process, in particular addressing *Charter* non-compliance of the current regime. Lead roles for other departments in addressing specific policy and program issues will also need to be mandated.

2. Provide coordination through the Disability Policy Office

- As the report indicates, measures will be needed to address practice, program, policy and legal barriers to the exercise of legal capacity on an equal basis. The Disability Policy Office of the Department of Children, Seniors and Social Development is well-positioned to provide sustained coordination within government, and in collaborating with community sectors, on the various aspects of a strategy.

3. Initiate a proactive approach to ensure Charter-compliance, and consistency and clarity in the province's legal capacity regime, based on Charter-informed principles

- In order to achieve *Charter* compliance, and consistency and clarity within the legal capacity regime as whole, a shift is needed from the 'reactive' approach of the current regime, with the resulting patchwork of provisions, to a 'proactive' approach reflected in option A. This effort should begin with a systematic review of the core legislation of the legal capacity regime in the province, against the lens of the decision-making capability approach to legal capacity. The aim would be to identify key gaps and barriers in the current legal regime. The statutes for primary consideration include:
 - *Mentally Disabled Persons' Estates Act*;
 - *Enduring Powers of Attorney Act*;
 - *Adult Protection Act*;
 - *Advance Health Care Directives Act*;
 - *Mental Health Care and Treatment Act*; and,
 - *Judicature Act*
- Legal counsel and other officials from across departments suggested a secondary set of laws be considered for their impact on regulating the exercise of legal capacity.

program. The Committee was co-chaired by an assistant deputy minister and a community representative. See https://novascotia.ca/coms/transformation/docs/Choice_Equality_and_Good_Lives_in_Inclusive_Communities.pdf.

While these statutes may not be foundational to the exercise of legal capacity in the province, they should also be examined for inconsistency and gaps. They include:

- *Trustee Act*;
 - *Public Trustee Act, 2009*;
 - *Wills Act*;
 - *Residential Tenancies Act*;
 - *Elections Act*;
 - *Personal Health Information Act*; and
 - *Access to Information and Protection of Privacy Act*.
- The ‘*Charter*-informed Principles for Legal Capacity’ presented in Section VIII.B.2 above, are proposed to assist in this exercise.
 - Based on this review, priorities for reform should be identified.

4. Adopt the decision-making capability approach to guide law reform

- A number of features should be introduced into law and policy so that the core statutes of the legal regime incorporate the decision-making capability approach, thus promoting *Charter* compliance, as described in Section II and Appendices C and D. These include recognition in law and policy of:
 - a) Decision-making capability, both independent and inter-dependent;
 - b) Decision-making supports to enable a person to constitute their decision-making capability;
 - c) Supported decision-making arrangements, along with parameters for and processes to govern them;
 - d) Mandatory exploration of support alternatives where needed for demonstrating decision-making capability to exercise legal capacity independently or interdependently;
 - e) Safeguards to protect integrity of the decision-making process and to address situations of harm, abuse and neglect, and;
 - f) Mechanisms for disputes resolution.
- Fully incorporating these measures across the legal regime in Newfoundland and Labrador will address the main legal barriers people now face to exercising choice and control in their lives.
- It should be noted that proposed legal measures emphasize *recognizing* supports for decision making, rather than mandating *provision* of such supports. Nonetheless, proactive steps to improve and maximize access to supports must be taken within existing fiscal constraints and could build on promising initiatives in the province and highlighted in Appendix H. Recommendations 6 through 10 below outline proposed steps for this purpose.

5. Reform the *Mentally Disabled Persons' Estates Act* to provide a platform from which to build consistency and clarity in the province's legal capacity regime

- It will likely be necessary to take a phased approach to adopting in law the decision-making capability approach, as the implications for the whole legal regime will need ongoing examination and amendment. A first step is needed, however, and it is proposed that initial adoption take place through reform of the *Mentally Disabled Persons' Estates Act*.
- This statute is pivotal, and at the core of the regime for legal capacity in the province. The archaic language and provisions are well-recognized by government and community stakeholders alike. Reviewing and reforming this statute with the *Charter*-informed guidance principles is an essential first step in the overall reform strategy. Introducing legal provisions that adopt a decision-making capability approach to legal capacity would provide a platform and a model for reform to achieve consistency and clarity in other statutes which are also central to the legal capacity regime, as well as for those secondary statutes that have an important impact on its enjoyment and exercise.
- Provision for appointing representatives for supported decision-making arrangements, for both independent and interdependent decision-making capability, is a key element of a decision-making capability approach to legal capacity. Reforms for this purpose could build upon the provisions for designating representatives under the *Enduring Powers of Attorney Act*.¹⁰⁵

6. Establish a policy and associated guidelines for reasonable accommodation in the exercise of legal capacity

- The Newfoundland and Labrador Human Rights Commission should develop a policy which articulates how the duty to accommodate applies to exercising legal capacity and should provide practical guidelines for doing so. Third parties require clear understanding of their obligations in this regard. Some human rights commissions in Canada have developed accommodation guidelines for ensuring non-discrimination in access to services, education and employment practices. However, fulsome guidelines for ensuring non-discrimination in the exercise of legal capacity require further development. The Newfoundland and Labrador Human Rights Commission could build on the policy that the Ontario Human Rights Commission has developed relating to the applicability of Ontario's *Human Rights Code*, and the duty to

¹⁰⁵ *Enduring Powers of Attorney Act*, R.S.N.L. 1990, c. E-11, s. 15(2).

accommodate, in the area of consent and capacity, in the context of persons with mental health issues.¹⁰⁶

7. Mandate a proactive process for exploring least restrictive alternatives

- This should be a legislatively-mandated process, guided by the principle of least restrictive alternative and should apply to any person who is the subject of an application for substitute decision making in the mental health, health care decision making, personal or property/financial decision-making context. The process could be modelled on the policy under the *Adult Protection Act*.
- Accountability, guidance and direction are needed with respect to how the exploration of alternatives is to take place, methods by which opportunities for accessing alternatives and supports can be maximized, along with relevant evidentiary requirements and an administrative structure to support the process.

8. Review capacity of the community-based health and social services sector to deliver independent planning and community navigation supports

- There is a need to develop community-based infrastructure to enable people to access and develop the supports they require to exercise their legal capacity in transactions in their daily lives. Navigation support, as discussed in this report and for which there appears to be government commitment and certainly community support, is a cornerstone of this infrastructure. Nonetheless, the policy and program framework for delivering community navigators requires consideration. A review of the capacity of the sector to deliver independent planning and navigation support, including assistance with arranging needed supports to exercise legal capacity, is needed for this purpose.
- This review should cover home care and other health and social support providers directly serving people with disabilities, including the Regional Health Authorities. The purpose would be to identify policy and program measures to ensure community capacity to deliver needed independent planning, navigation and decision-making facilitation supports to individuals who need assistance in exercising legal capacity in a range of health care, financial, and other community contexts.

¹⁰⁶ See Ontario Human Rights Commission, “Policy on preventing discrimination based on mental health disabilities and addictions” (2014), Chapter 16, online; <http://www.ohrc.on.ca/en/book/export/html/11238>.

9. *Pilot initiatives for implementing supports for decision making at all decision-making points in health care and other settings where a need for guardianship or substitute decision making is considered*

- In order to address barriers at the practice level, and to consider implications for community-based programs and policy, pilot initiatives for supports in decision making are an essential input. They would help to create a code of practice for supports in decision making, involve design of supported decision-making arrangements that could be tested and revised, and help to build a community of practice and expertise in the province that will be needed for ongoing training and learning across several sectors. Pilots would engage existing community agencies, and individuals with disabilities, their families and representative organizations and community-based leaders in developing and testing approaches to meet the diverse community contexts in the province.
- Initiatives should be designed to model effective practices for fostering decision-making support networks and be designed to pilot delivery of a range of decision-making supports at all decision-making points in health care and other settings where legal capacity is questioned. Primary focus should be on people with intellectual, developmental, or cognitive disabilities or mental health issues.
- There is a growing body of experience, both in Canada and internationally, with designing and implementing local, community-based demonstration initiatives, within both provincial and/or national contexts.¹⁰⁷ A range of tools and resources developed through these initiatives could be adapted for the Newfoundland and Labrador context. See examples of tools and resources in Appendix J.

10. *Deliver information resources and training on the right to liberty and equality in exercising legal capacity*

- The resource and training strategy should be targeted to the health care and social services sector, policing, justice system, and financial services industry. The resources should provide information about the right to equality in legal capacity, the barriers people with disabilities experience at all levels and steps that can be taken in the current regime, and as the regime changes, to address these barriers.
- A learning and training advisory group, with representatives from across these sectors should be established to guide identification of information and training needs and to design appropriate strategies. A scan of needs should be undertaken to ensure design and delivery of a responsive strategy for each sector.

¹⁰⁷ See for example, K. Shogren, M. Wehmeyer, J. Martinis, J. & P. Blanck, *Supported Decision-Making. In Supported Decision-Making: Theory, Research, and Practice to Enhance Self-Determination and Quality of Life* (Cambridge: Cambridge University Press, 2018).

11. *Develop a data collection strategy to track and document the use of guardianship and substitute decision making in all sectors*

- The research points to significant data gaps about the numbers of people affected by guardianship and substitute decision making. An audit of existing data sources should be undertaken in light of the different ways in which guardianship and formal and informal substitute decision making is imposed – including in health care, provision of income assistance, and other settings. Collecting data about informal substitute decision making will prove a challenge. Consideration might be given to incorporating questions about those requiring decision-making assistance into existing provincial surveys, and/or working with the federal government to re-introduce related questions into Statistics Canada population surveys.

X. IMPLEMENTING RECOMMENDATIONS: AN INITIAL FIVE-YEAR ROADMAP

Implementing the proposed recommendations will require strong leadership by government and multiple stakeholders in the disability community, health, social services, and justice sectors. Success will depend on various government departments examining the issues and together developing comprehensive, coordinated, and practical approaches to change. It will require significant collaboration across government and community sectors, and a sustained reform effort.

Many provincial government-community initiatives already underway align well with the recommend directions. A strategic, comprehensive, and multi-dimensional reform effort should build upon these strategic directions. Related government policy reports and commitments all emphasize that the province listened to and heard the disability and broader community's concerns and is committed to a shared responsibility approach to addressing them. Government commitments and initiatives outlined in Appendix H are strongly aligned with the proposed directions. They provide a framework of shared principles to guide implementation, and complementary initiatives to build upon.

Terms of reference for the consultation and research called for outlining a 'roadmap' for implementing recommended directions. A detailed roadmap would require further consideration and input by government and community stakeholders. To assist this process, we plot the eleven recommendations within a strategic framework of key tasks over an initial five-year period.

Table 5: Roadmap to the Right to Equality in the Exercise Legal Capacity in Newfoundland and Labrador

Milestones	Key Tasks				
	Year 1	Year 2	Year 3	Year 4	Year 5
1. Joint Government-Community Legal Capacity Reform Steering Committee and inter-departmental leadership	Government commits to the process, mandates and appoints the Steering Committee with representation from across government and community sectors. Government establishes an interdepartmental committee to ensure cross-government coordination. In Year 1 committee develops terms of reference, action plan and launches implementation.	Leadership continues with Joint Government-Community Steering Committee and the interdepartmental committee			
2. Policy leadership and coordination from Disability Policy Office	Disability Policy Office appointed to provide policy development and process coordination				
3. Initiate proactive approach to achieve Charter compliance	Proposed principles adopted to guide legislative reform and policy development Principles applied to analyze existing regime and guide all law reform and policy				

Milestones	Key Tasks				
	Year 1	Year 2	Year 3	Year 4	Year 5
	proposals				
4. A decision-making capability approach adopted into the legal regime	Guidelines based on the proposed approach are developed to steer legislative proposals and ensure a fully inclusive, non-discriminatory statutory and policy framework	Review all elements of the statutory regime for legal capacity to consider how best to introduce this approach (review of the APA is currently underway). Needed law reforms consulted upon, proposed, introduced and adopted.			
5. Reforming the <i>Mentally Disabled Persons' Estates Act</i>	Consultation launched on reform of the <i>Mentally Disabled Persons' Estates Act</i> , including introduction of the decision-making capability approach. Law reform proposals introduced into legislature in Year 1	Law reforms adopted, and regulatory development completed, and regulations adopted			
6. Policy and guidelines for reasonable accommodation in legal capacity	Human Rights Commission launches consultation to develop guidelines	Proposed guidelines developed, reviewed and adopted by the Commission	The Commission produces and delivers information resources and training materials on the Guidelines		
7. A mandated	Disability Policy Office	Legislative proposals	Legislative	Needed	

Milestones	Key Tasks				
	Year 1	Year 2	Year 3	Year 4	Year 5
proactive process for exploring least restrictive alternatives that maximize decision-making capability	launches consultation with government and community stakeholders, in collaboration with Director of Adults in Need of Protective Intervention, to consider how to expand the current process to other situations where substitute decision making is being considered (e.g., health care decisions, mental health care admission and treatment, personal and property guardianship.	developed and introduced for mandating proactive processes for exploring least restrictive alternatives where restriction of legal capacity is at risk.	changes adopted	information and training materials developed	
	Legislative implications and options considered.		Regulatory framework and policy guidelines developed.	Ongoing Training and monitoring	
8. Review of capacity of community-based health and social services sector to deliver independent planning and community navigation supports	Review launched with consultations across province, through a joint government-community stakeholder advisory committee. Aim is to consider ways of enhancing community capacity to ensure persons with disabilities have access to the supports required to exercise power, choice and control in their lives	Recommendations produced and considered by government. Budget proposals for new investments considered	Policy and investment framework implemented	Capacity development underway	

Milestones	Key Tasks				
	Year 1	Year 2	Year 3	Year 4	Year 5
9. Pilot initiatives for implementing supports for decision making	Government commits to and invests in pilot project development. Design underway of an initial pilot project in each of the four Regional Health Authority areas.	Pilot projects launched	Interim evaluation. Community forums held on designing and implementing pilot initiatives	Training and learning tools developed. Sustainability and scaling plan developed and implemented to expand pilot sites	Pilot capacity significantly expanded across province.
10. Information resources and a training strategy	A Legal Capacity Learning and Training Advisory Group is established. A scan of information and training needs in key sectors is undertaken. Initial information resources developed to support internal and external consultative exercises.	Report of consultation of information and training needs produced and considered by Advisory Committee, which leads development of recommendations and strategy. Additional information resources developed as law and policy reforms introduced.	information materials for each sector developed, and training strategy implemented.	Ongoing information and training strategy	
11. Develop a data collection strategy	Develop and undertake an audit of information sources Consider options for data collection	Launch data collection strategy	Report Continue data collection		

CONCLUSION

People with intellectual, developmental and cognitive disabilities, or mental health issues who are living in Newfoundland and Labrador face discriminatory restrictions in the enjoyment and exercise of their legal capacity – the power to make personal, health care and financial decisions about their own lives. Whether viewed from the perspective of the *Canadian Charter of Rights and Freedoms* or the United Nations *Convention on the Rights of Persons with Disabilities*, these restrictions violate fundamental rights in Canada to equality and liberty.

Community stakeholders and the provincial government have taken significant leadership in identifying and examining these issues. This review results from their joint commitment to examine root causes and identify support alternatives that would mean disability is no longer a reason to deny people their basic rights. It points to structural issues that need to be addressed in community practices, programs, public policies, and the legal regime in the province.

Chief among the challenges to address are the barriers identified in the framework of laws that constitute the province's legal capacity regime, in particular: the *Mentally Disabled Persons' Estates Act*; *Advance Health Care Directives Act*; *Adult Protection Act*; *Enduring Powers of Attorney Act*; *Judicature Act*; and the *Mental Health Care and Treatment Act*.

The legal research demonstrates that outmoded approaches to legal capacity are found throughout the regime. No longer accepted references to a biomedical approach to disability remain intact and must be replaced by the current social and human rights model of disability, which has been adopted by the Supreme Court of Canada. The regime for regulating legal capacity is comprised of a set of statutes that are inconsistent with one another and leave some matters unaddressed, resulting in lack of clarity. There is limited recognition of supports for decision making and less/least restrictive alternatives to guardianship and substitute decision making. Accommodations are only minimally recognized in law. The analysis concludes that the manner in which this body of legislation balances values of autonomy and equality against protection from harm must be re-examined and reformed, guided by *Charter*-informed principles.

Despite the systemic issues and challenges to address, the report points to impressive accomplishments in provincial policy commitments and initiatives. Thus, if adopted, the recommended directions for law, policy, program, and practice reform would not begin in a vacuum. They would find fertile ground in progress already made. The initial 5-year Roadmap this report lays out suggests a pathway to help make this happen.

Launching a reform process along the lines recommended in this report will require proactive leadership and collaboration by both community stakeholders and the provincial government. Innovations already developed in Newfoundland and Labrador hold considerable promise for

designing such a collaboration. It will need to sustain robust efforts to address the longstanding barriers still preventing people with disabilities and mental health issues from taking their rightful place as full citizens of the province.

Appendix A

Key Issues in Designing and Implementing a Supported Decision-Making Regime in Newfoundland and Labrador: Report on Initial Focus Groups

INTRODUCTION

- The Newfoundland and Labrador Minister of Justice and Public Safety was mandated to work with stakeholders and colleagues “to develop measures to encourage supported decision making”. The purpose is to address barriers faced by people with disabilities and seniors to exercising legal capacity.
- IRIS – Institute for Research and Development on Inclusion and Society (www.irisinstitute.ca) was commissioned by the Newfoundland and Labrador Association for Community Living to assist government and community stakeholders to identify key issues for design and implementation, and to develop options.
- IRIS met with officials and community stakeholders on March 8 and April 25, 2018 to identify their perspective on key issues to address in implementing a supported decision-making approach:
 - Two focus groups were conducted with government officials from departments of:
 - Justice and Public Safety
 - Health and Community Services
 - Children, Seniors and Social Development
 - Advanced Education and Skills
 - IRIS also met with representatives of the “Steering Committee on Citizenship and Legal Capacity for All,” and some members of their respective community organizations.

The following issues were identified through these consultations.

Types of Issues Identified

- A. Legal recognition for different ways to exercise legal capacity
- B. Implications for contract and health care law
- C. Mechanisms for adjudication and disputes resolution
- D. Safeguarding people who may be vulnerable
- E. Implications for Delivery of Government Programs
- F. Determining Government oversight roles and responsibilities
- G. Developing sector and community capacity to enable supported decision making
- H. Designing an effective implementation process

Each of these issues is outlined in more detail below, with questions raised by officials and community stakeholders concerning implementation of a new approach.

Review of Issues – Questions to Explore

A. Legal recognition for different ways to exercise legal capacity – consistent with recognizing a right to legal capacity without discrimination based on disability

1. Need for a definition of legal capacity to act that is inclusive of people who do not meet the usual cognitive test
 - What happens to the usual cognitive test? Is it replaced by another test and, if so, what is that test?
2. Duties to accommodate in decision making are not currently specified in law or guidelines. What would the implications be for the human rights framework?
3. Provisions needed for:
 - a. specifying different ways to exercise legal capacity
 - b. appointing representatives and decision-making supporters
 - c. thresholds required for this purpose (what tests need to be met to make different kinds of appointments)
 - d. a last resort of substitute or facilitated decision making – when representative and supported arrangements aren't in place or are not working.
4. What statutes would be affected if these provisions were to be implemented
 - What form would the statutes take?
5. Would the revised regime adapt guardianship of persons pursuant to court orders under the *parens patriae* jurisdiction of the Supreme Court?
 - What would happen to current orders?
6. What rules should govern the making and the content of supported decision-making arrangements?
7. Potential liabilities of decision-making supporters, and proxies for income support
 - What are they?
 - How should they be addressed?
8. Are there situations where supported decision making is not appropriate? What about persons with varying levels of mental capacity?
9. Are there limitations that need to be in place regarding the qualifications of a person who can be appointed as a decision-making supporter? Who can act as a supporter? What are the criteria and are they strong enough? Ex: what about a person with a conviction for financial crimes?
10. What would the impact be on the current framework for Advance Health Care Directives?
 - Do we need to look at current definition of a spouse (check this reference)?
 - For children in care who may not want to go to biological parents for Health Care Directives or supported decision-making arrangements, what are their options as they approach the age at which they can make these arrangements?
11. Constitutional and *Charter* questions that arise for a regime that recognizes different ways of exercising legal capacity

- Are there constitutional issues at play depending on the scope of potential amendments required?
12. What would be the impact of legislative change on the following pieces of legislation? Examine implications for existing legislation and common law, including the following statutes:
- *Mentally Disabled Persons' Estates Act*
 - *Human Rights Act, 2010*
 - *Enduring Powers of Attorney Act*
 - *Advance Health Care Directives Act*
 - *Mental Health Care and Treatment Act*
 - *Adult Protection Act*
 - *Trustee Act*
 - *Public Trustee Act, 2009*
 - *Wills Act*
 - *Residential Tenancies Act, 2000*
 - *Elections Act, 1991*
 - *Judicature Act - Rules of Court*
 - *Personal Health Information Act, ATIPPA, 2015, and others.*
13. Explore intersections with federal law – e.g., in the context of legislation dealing with elections, banking, income tax, personal information protection.

B. Implications for contract and health care law

1. Examples of scenarios that must be addressed:
 - a. An elderly person with dementia wants a mobile phone; acquiring one requires choosing among an array of contracts which he struggles to understand. A salesman exploits his vulnerability to sell him a product he does not need and cannot afford.
 - b. A person with intellectual disability may in fact have legal capacity to contract on a particular matter with some accommodation or support, but potential contractual partners decline to enter the contractual relationship, fearing that the contract may later be found invalid because of doubts about the person's capacity.
 - c. A person in a supported decision-making arrangement needs a health care decision made.
 - d. Questions are being raised about whether actions, failure to act, by decision-making supporters are placing the person in a situation of harm
 - e. A person who has a RDSP in their name, is not able to withdraw from a bank because the bank operates by a strict standard of contractual capacity.
 - f. A person with a significant disability is in a position to hire support workers – what is their contractual power to do so?

2. Questions to address:
 - a. How can the law address the vulnerability without denying legal agency, when decision-making abilities are diminished?
 - b. What are the implications of supported decision making on the obligations of a contracting party who suspects that a person seeking to contract has a diminished understanding of the nature and consequences of a decision? What would be the obligation of a contracting party who suspects that a person should have a supported decision maker but has not had one appointed?
 - c. How can a person defend against an allegation that they need supports to transact?
 - d. How can financial institutions meet their legal obligations, including compliance with laws and regulatory requirements, while accommodating and supporting individuals?
 - e. How would we ensure that the financial sector continues to do business in NL given the significant difference in the law of capacity here as compared to other jurisdictions?
 - f. How would this affect employment contracts, where a person under disability could hire workers with the assistance of their supported decision maker?
 - g. How would medical practitioners fulfill their duty to obtain informed consent, given that this is fundamental to the health care system?
 - i. Consider how to protect health care providers who act on the basis of decisions conveyed by a supported decision maker.

C. Safeguarding people who may be vulnerable

1. Examples of scenarios which must be addressed:
 - a. In controlling access to their personal information – i.e., privacy concerns, especially if a public registry is required for supported decision-making arrangements
 - b. Addressing situations of harm and potential harm – where people have a decision-making support arrangement in place, or where there is apparent need for one
 - c. Holding their agents – whether under powers of attorney or decision-making supporters accountable
 - d. Managing financial and other administrative in needs in executing decisions
2. Questions to address:
 - a. How best to safeguard people with supported decision-making arrangements, or who may need supports, and who are in situations of harm or significant risk of harm? Consider cost to the individual(s) involved; costs to the public purse; expediency; effectiveness; and other factors.

- b. How to integrate potential legislative reform with the existing adult protection regime?
- c. What would be the safeguards to ensure that a person entering into a contract is not being taken advantage of by the other contracting party?
- d. What about supported decision makers who are clearly acting in ways that are not in the best interests of the person they support?
- e. Would there be a duty to report in the event that a contracting or other interested third-party suspect that a supported decision-making transaction is not being conducted in the interests/respecting the wishes of the supported party?
- f. Is some form for registering supported decision-making arrangements an effective and practical safeguard?

D. Mechanisms for adjudication and disputes resolution

1. Anticipated need for adjudicating disputes, for example:
 - a. Whether a person can make decisions on their own or requires supports;
 - b. Whether third parties have met the duty to accommodate;
 - c. Whether third parties can rely upon an assumption that all persons have legal capacity when contracting
 - d. Where there is dispute as to the legitimacy or appropriateness of the appointment of an attorney or decision-making supporter
 - e. Appointment of last resort arrangement
 - f. Whether supporters are acting according to the best interpretation of a person's desires and preferences
 - g. Whether supporters' actions, or failure to act, will place a person in a supported decision-making arrangement at unjustifiable risk of harm
2. What mechanisms should be designated to play this role
 - a. Is there an existing body in Newfoundland and Labrador that could assume this role?
 - b. Adapted?
 - c. New?
 - d. Implications – costs (both initial and ongoing), authority, training requirements, etc.

E. Implications for Delivery of Government Programs

1. What implications for delivery of income support, HCS programs, individualized funding and health care if there will be new requirements to consider supports in decision making?
2. How does assessment of need for supported decision-making arrangements, fit into other needs assessment, e.g., need for supportive housing?

3. Shifting to person-centred and client-centred approaches
 - a. What implications for current plans and delivery, of introducing supported decision making?
4. What implications for Regional Health Authorities?
 - a. How does provision of supported decision making figure in decision-making, allocating resources?
 - b. What role for RHAs in facilitating these arrangements?
 - c. How to facilitate any needed culture shift in RHAs to make this work?
5. How to build capacity within government structures for program delivery – knowledge, training, guidelines, assessment tools, etc.?

F. Determining Government oversight roles and responsibilities

1. Recognizing supported decision-making arrangements will require new roles for government relating to, for example:
 - a. Information and public awareness
 - i. For persons who may wish to avail of supported decision making
 - ii. For persons who wish to provide support to those who need it to make decisions
 - iii. For the general public to understand the nature and consequences of any changes and how that may affect their rights in contracting
 - b. Considering how supported decision-making arrangements get authorized – is approval by gov't required in any cases?
 - c. Contracting for and arranging community supports as may be needed
 - d. Responding to complaints and concerns
2. Could some of these roles be added to existing offices and agencies? e.g., Public Trustee, Adult Protection, or other(s)
 - a. How best to define these new roles?
 - b. Implications for adding these roles to existing offices? Authorities? Costs and other resources required?
3. What are the options for oversight mechanisms that could be implemented – including options that have no financial impact? If the model proposed cannot be funded, what alternatives exist that can still provide the level of protection that is needed?

G. Developing sector and community capacity to enable supported decision making

1. Training of various sectors – Legal recognition of supported decision-making will affect many sectors (lawyers, financial institutions, health care providers, etc.), and will require training and information to develop understanding and awareness
 - a. However, there is no law school in NL and all lawyers here are trained in other jurisdictions. It is not likely that this be taught in law schools in other

- jurisdictions. Special training would be needed for both new lawyers as well as existing lawyers and judges. How would this be accomplished?
- b. How would training be developed and delivered for the financial sector, health sector, others in the general public regarding a new supported decision-making regime?
2. Community-based supports – to assist in setting up arrangements, person-centred planning, conflict mediation, public promotion and awareness, independent advocacy
 - a. Who delivers?
 - b. How are agencies designated?
 - c. Additional costs?
 - d. Reach – who gets covered, who isn't?
 - e. Is there an estimate regarding the numbers of supported decision-making arrangements that may be in place if this regime is implemented?
 - f. Would any of these roles fall to Government in the absence of community-based supports? What are the resources implications of this?

H. Designing an effective implementation process

1. How to implement in a way that does not interfere with informal processes of support and representation that are currently working well?
2. If it is not possible to implement this regime at all once:
 - a. What would a phased approach look like?
 - b. What would be the critical path?
 - c. What would be the implications of implementing this regime?
 - d. What are the most critical areas to address first if full implementation is not possible at the present?
3. If the Provincial Government were to begin with a review of the *Mentally Disabled Persons' Estates Act*, what key features would be desirable to include?
 - a. What aspects of the recent Nova Scotia revised legislation are seen as positive? What aspects of that recent legislation are seen as negative and what changes would be proposed?
4. How to transition existing substitute orders and arrangements?

11Appendix B

Approaches to Defining Requirements for Legal Capacity in Newfoundland and Labrador Statutes

Approaches to Defining Requirements for Legal Capacity in Newfoundland and Labrador Statutes

Statute	Provisions Recognizing Legal Capacity	Approach to Legal Capacity	Types of Decisions Regulated	Consequence of the Finding under the Provision
<p>Judicature Act</p>	<p>s. 3.(1)(a)</p> <p>Interpreted by the Court of Appeal of Newfoundland and Labrador, in <i>A.A. (Re)</i>, 2019 NLCA 7, to grant jurisdiction to the Supreme Court of Newfoundland and Labrador to appoint guardians of the person and Estate. The criteria for appointment are elaborated upon by the Court of Appeal as follows:</p> <p>Para. 25:</p> <p>“...this statutory provision [section 6 of the <i>Judicature Act, 1824</i>], which is homologated into the current <i>Judicature Act</i> by virtue of section 3(a), confers on the Court the jurisdiction to appoint guardians of the person (as well as their estates) of individuals who by reason of mental disability are ‘unable to govern themselves and their affairs’.</p> <p>Para 76:</p> <p>“the applicants must establish on a balance of probabilities that the person in question:</p> <p style="padding-left: 40px;">(i) is unable to understand the information that is relevant or</p>	<p>Status and cognitive/functional</p>	<p>Personal decisions and decisions relating to a person’s estate</p>	<p>Based on a finding of incapacity, a guardian of the person or Estate can be appointed by the Supreme Court under s. 3(1)(a), referencing s. 6 of the <i>Judicature Act</i> of 1824.</p>

Statute	Provisions Recognizing Legal Capacity	Approach to Legal Capacity	Types of Decisions Regulated	Consequence of the Finding under the Provision
	<p>necessary to make a decision about his or her personal care; or (ii) is unable to appreciate, or reason in respect of, the reasonably foreseeable consequences of those decisions or of failure to make those decisions.”</p>			
<p>Mentally Disabled Persons’ Estates Act</p>	<p>s. 2(f): (f) "mentally disabled person" means a person (i) in whom there is such a condition of arrested or incomplete development of mind, whether arising from inherent causes or induced by disease or injury, or (ii) who is suffering from a disorder of the mind, requiring care, supervision and control for the protection of his or</p>	<p>Cognitive/ Functional</p>	<p>Estate</p>	<p>Based on this approach, a guardian of property can be appointed by a court or judge under s. 3.</p>

Statute	Provisions Recognizing Legal Capacity	Approach to Legal Capacity	Types of Decisions Regulated	Consequence of the Finding under the Provision
	<p>her property, whether or not he or she has been committed to the hospital under the <i>Mental Health Care and Treatment Act</i>;</p>			
	<p>16. (1) Where it appears to the court or a judge</p> <ul style="list-style-type: none"> (a) that the mental disability of a person is in its nature temporary; (b) that it is expedient to make temporary provision for his or her maintenance and that of persons dependent upon him or her; and (c) that money is readily available, 	Status	Property	<p>A guardian is not appointed. The court or judge may order that available money be used for defined purposes related to the maintenance of the person and their dependents and, if so, shall appoint a person to use the available money for the specified purposes.</p>
	<p>s. 17</p> <p>(1) Where it is proved to the satisfaction of the court or a judge that a person through mental infirmity arising from disease, age, habitual drunkenness, the use of drugs or other cause is incapable of managing his or her affairs, the court or judge may declare that without making a declaration of mental disability.</p>	Status and Cognitive/ Functional	Estate	<p>Appointment of guardian of the estate</p>
	<p>s. 18. (1) Where it appears to the court or a judge</p> <ul style="list-style-type: none"> (a) that a person is through mental infirmity arising from disease, age, habitual drunkenness, the use of drugs or other cause incapable of 	Status and Cognitive/ Functional	Estate, only as specified in s. 18	<p>A guardian is not appointed. The court or judge may authorize a person to dispose of the money in a manner the court or judge considers appropriate.</p>

Statute	Provisions Recognizing Legal Capacity	Approach to Legal Capacity	Types of Decisions Regulated	Consequence of the Finding under the Provision
	<p>managing his or her affairs; and (b) that the value of his or her personal estate or money payable to him or her under a contract of insurance does not exceed the sum of \$2,000,</p>			
	<p>s. 20. (4) The public trustee is the guardian of the estate of a person referred to in subsection (1) [“every person who has been admitted to the hospital as an involuntary patient under the <i>Mental Health Care and Treatment Act</i>”] Note: The criteria of ‘involuntary admission’ and ‘involuntary patient’ is set out in s. 17 of the <i>Mental Health Care and Treatment Act</i>; see section on this <i>Act</i> below.</p>	Status and Outcome	Estate	Public Trustee becomes guardian of the estate, regardless of whether the person meets the tests in s. 2 or 17
	<p>22.1 (1) A director appointed under the <i>Adult Protection Act</i> shall, in accordance with subsection 22(9) of that Act, notify the public trustee where a person has been declared to be an adult in need of protective intervention under that Act [...] [Note: definition of ‘adult in need of protection’ is set out in s.5 of the <i>Adult Protection Act</i>: s. 5 An adult in need of protective intervention means an adult who lacks capacity and who (a) is incapable of caring for himself or herself, or who</p>	Cognitive/ Functional and Outcome	Estate	Public Trustee becomes guardian of the estate

Statute	Provisions Recognizing Legal Capacity	Approach to Legal Capacity	Types of Decisions Regulated	Consequence of the Finding under the Provision
	<p>refuses, delays or is unable to make provision for adequate care and attention for himself or herself; or</p> <p>(b) is abused or neglected.</p>			
Enduring Powers of Attorney Act	<p>s.2(1)(j) "legal incapacity" means mental disability of a nature</p> <p>(i) such that were a person to engage in an action he or she would be unable to understand its nature and effect, and</p> <p>(ii) that would, but for this Act, invalidate or terminate a power of attorney, RDSP or another legal agreement;</p>	Cognitive/ Functional	Powers of Attorney and Designation Agreements for RDSPs	<p>The authority under the power of attorney or designation agreement are triggered or continued, as specified under the agreement.</p> <p>Person cannot revoke or terminate an enduring power of attorney, or change the named attorney, if not legally capable s. 11</p>
	<p>s.15(2) In deciding whether an adult who may lack legal capacity to enter into an RDSP has the capacity to enter into a designation agreement, all relevant factors shall be considered, including</p> <p>(a) whether the adult communicates, orally or otherwise, a desire to enter into the RDSP and the designation agreement;</p> <p>(b) whether the adult demonstrates preferences and can express feelings of approval or disapproval;</p>	Cognitive/ Functional and elements of Decision-making Capability	Making a designation agreement with 2 adults who are thereby legally authorized representatives to act as holders of an RDSP when the adult lacks 'legal capacity' to establish the RDSP themselves. See s. 2(f) and 15(1).	Where a person is not able to satisfy the test, the adult is not entitled to appoint designates under a designation agreement (s. 15(3)). In this case an application to court can be made for an order appointing the Public Trustee as the designate of the adult under a designation agreement s. 15(3)

Statute	Provisions Recognizing Legal Capacity	Approach to Legal Capacity	Types of Decisions Regulated	Consequence of the Finding under the Provision
	<p>(c) whether the adult is aware that entering into a designation agreement or changing or revoking it means that the designates may make, or stop making, decisions or choices that affect the adult as they relate to the RDSP; and</p> <p>(d) whether the adult has a relationship with the persons who are intended to be designates that is characterized by trust.</p>			
<p>Adult Protection Act</p>	<p>5. An adult in need of protective intervention means an adult who lacks capacity and who</p> <p>(a) is incapable of caring for himself or herself, or who refuses, delays or is unable to make provision for adequate care and attention for himself or herself; or</p> <p>(b) is abused or neglected.</p> <p>6. (2) An adult shall be considered to lack the capacity to make a decision where that adult</p> <p>(a) is unable to understand information relevant to the decision where that decision concerns his or her health care, physical, emotional, psychological, financial, legal, residential or social needs; or</p> <p>(b) is unable to appreciate the reasonably foreseeable consequences of a decision or the lack of a decision.</p>	<p>Cognitive/Functional and Outcome</p>	<p>As set out in the <i>Adult Protection Act</i>, and with the purpose of reducing the risk to, and meeting the care needs of the adult, decisions about: where the person will live; the care and custody of the person; payment for supports; finances and benefits; personal contact and relationships; and, service planning.</p>	<p>One criterion of being classified as ‘an adult in need of protective intervention’ is that the adult ‘lacks capacity to make a decision’ related to health care, physical, emotional, psychological, financial, legal, residential or social needs (s. 6(2)(a)). By definition, an adult who does not lack capacity to make such decisions will not be classified as such and is not at risk of being caught under the provisions of the Adult Protection Act. Conversely, an adult who lacks capacity to make decisions and meets the other criteria in s. 5 is subject to the Act’s provisions, including delivery of services mandated under the authority of the</p>

Statute	Provisions Recognizing Legal Capacity	Approach to Legal Capacity	Types of Decisions Regulated	Consequence of the Finding under the Provision
	<p>(3) Where an adult is determined to lack the capacity for decision-making referred to in subsection (2) in one particular context, he or she shall not be presumed to lack the capacity for decision-making in those other contexts or all of them unless the contrary is proven.</p> <p>(4) An adult's method of communicating with others is not grounds for deciding that he or she is incapable of making decisions.</p> <p>(5) For the purpose of this section, capacity for decision-making may be assessed by those persons approved by the minister in the regulations</p>			Director.
	<p>s. 8 'Service Principles'</p> <p>(g) an adult who is or may be in need of protective intervention should, if desired, be encouraged to obtain support, assistance and advice from family and friends to help that adult understand choices, and to make and communicate decisions.</p>	Elements of Decision-making Capability	As set out in the <i>Adult Protection Act</i> , and with the purpose of reducing the risk to, and meeting the care needs of the adult, decisions about: where the person will live; the care and custody of the person; payment for supports; finances and benefits; personal contact and relationships; and service planning.	N/A
Advance Health Care Directives Act	<p>s. 7(b)</p> <p>For the purpose of this section, there shall, in the absence of evidence to the contrary, be a presumption</p>	Status	Health care decisions	A substitute decision maker may make health care decisions as per ss. 9 and 10 of the <i>Act</i> ; and in the case of an emergency health care a health care

Statute	Provisions Recognizing Legal Capacity	Approach to Legal Capacity	Types of Decisions Regulated	Consequence of the Finding under the Provision
	<p>(b) that a person who is 16 years of age or older is competent to make health care decisions; and</p> <p>(c) that a person who is younger than 16 years of age is not competent to make health care decisions.</p>			<p>professional is not required to obtain a substitute decision maker's consent, as per s. 9(2).</p>
	<p>s. 14 A maker shall be considered competent to make an advance health care directive where he or she is able to understand the information that is relevant to making a health care decision and able to appreciate the reasonably foreseeable consequences of that decision.</p>	<p>Cognitive/ Functional</p>	<p>Making an advance health care directive, defined as "a document in which a maker sets out that maker's instructions or the maker's general principles regarding his or her health care treatment or in which a maker appoints a substitute decision maker or both" (s. 2(a))</p>	<p>Person is not able to make an advance health care directive (s. 3)</p>
<p>Mental Health Care and Treatment Act</p>	<p>s.17(1)(b) – Involuntary Admission (i) has a mental disorder, (ii) as a result of the mental disorder (A) is likely to cause harm to himself or herself or to others or to suffer substantial mental or physical deterioration or serious physical impairment if he or she is not admitted to and detained in a psychiatric unit as an involuntary patient, (B) is unable to fully appreciate the nature and consequences of the mental disorder or to make an informed decision</p>	<p>Status and Outcome and Cognitive/ Functional</p>	<p>Psychiatric assessment, treatment, and liberty of movement</p>	<p>Powers to, without consent, apprehend, convey, observe, detain, restrain, assess, control and treat</p>

Statute	Provisions Recognizing Legal Capacity	Approach to Legal Capacity	Types of Decisions Regulated	Consequence of the Finding under the Provision
	<p>regarding his or her need for treatment or care and supervision, and (C) is in need of treatment or care and supervision that can be provided only in a psychiatric unit and is not suitable for admission as a voluntary patient;</p>			
	<p>s.40(2)(a) – Community Treatment Orders</p> <ul style="list-style-type: none"> (i) the person is suffering from a mental disorder for which he or she is in need of continuing treatment or care and supervision in the community, (ii) if the person does not receive continuing treatment or care and supervision while residing in the community, he or she is likely to cause harm to himself or herself or another, or to suffer substantial mental or physical deterioration or serious physical impairment, (iii) as a result of the mental disorder, the person is unable to fully appreciate the nature and consequences of the mental disorder and is therefore unlikely to voluntarily participate in a comprehensive community treatment plan, (iv) the services that the person 	<p>Status, Outcome and Cognitive/ Functional</p>	<p>Psychiatric assessment, treatment, and liberty of movement</p>	<p>Powers, without consent, to Impose medical and other supports, including income and housing; treatment, care and supervision</p>

Statute	Provisions Recognizing Legal Capacity	Approach to Legal Capacity	Types of Decisions Regulated	Consequence of the Finding under the Provision
	<p>requires in order to reside in the community so that he or she will not be likely to cause harm to himself or herself or to others, or to suffer substantial mental or physical deterioration or serious physical impairment,</p> <ul style="list-style-type: none"> (A) exist in the community, (B) are available to the person, and (C) will be provided to the person, and <p>(v) the person is capable of complying with the requirements for treatment or care and supervision set out in the community treatment order;</p>			

Appendix C

Legal Basis for the Decision-Making Capability Approach

INTRODUCTION

We look below at how the law has evolved in Canada over the past 20 years to recognize the role of supports, including interpretive supports, and accommodations, in enabling people to meet the requirements for understanding and appreciation consistent with the decision-making capability approach. The main features of Canada's laws that reflect aspects of the decision-making capability approach are:

1. Mandatory process for exploring alternatives to guardianship/substitute decision making;
2. Duty to accommodate in the decision-making process;
3. Supports for decision making and 'supported decision making';
4. Inclusive, non-cognitive, test of capacity to appoint a decision-making supporter;
5. Role a person's 'true intentions' and 'free will' play in demonstrating legal capacity;
6. Provision for validly interpreting 'true intentions' and 'free will' as the basis of decisions; and,
7. Safeguards

These features are described below, drawing on examples from Canadian law.

1. *Mandatory process for exploring alternatives to guardianship/substitute decision making*

The importance of mandatory process for exploring alternatives to guardianship has been underscored by the Newfoundland and Labrador Court of Appeal in its recent decision in *A.A. (Re)*.¹ Statutory provisions for 'alternative courses of action' to guardianship were perhaps the earliest building block of an approach to legal capacity which gives scope for recognizing the role of accommodations and supports to enable some people to exercise legal capacity, who would otherwise be restricted from doing so. These types of provisions now exist in many Canadian jurisdictions.² Some specify that guardianship cannot be ordered unless alternatives, including support or assistance "have been tried or carefully considered".³

¹ 2019 NLCA 7.

² *Adult Protection and Decision Making Act* being Schedule A to the *Decision-Making Support and Protection to Adults Act*, S.Y. 2003, c. 21, ss. 2(d) and 32(1)(c); *Substitute Decisions Act*, 1992, S.O. 1992, c. 30, s. 22(3) and s. 55(2); *Adult Guardianship and Trusteeship Act*, S.A. 2008, c. A-4.2, ss. 13, 26 and 46; *Adult Guardianship and Co-decision-making Act*, S.S. 2000, c. A-5.3, ss. 14(2) and 40(2); *Guardianship and Trusteeship Act*, S.N.W.T. 1994, c. 29, ss. 7(1.1) and 31(1.1).

³ *Adult Guardianship and Co-decision-making Act*, S.S. 2000, c. A-5.3, s. 14(2)(a) and s. 40(2)(a); *Adult Protection and Decision Making Act* being Schedule A to the *Decision-Making Support and Protection to Adults Act*, S.Y. 2003, c. 21, s. 32.

For example, Yukon's *Adult Protection and Decision-Making Act*⁴ contains 'guiding principles' which leaves no ambiguity about the significance of considerations of supports as an alternative course of action.⁵ Additionally, the 'alternative course of action' provision in that statute also recognizes supports as being relevant to avoiding a guardianship order. The court may make an order appointing a guardian if "forms of available support and assistance less intrusive than guardianship have been tried or carefully considered."⁶

Ontario's *Substitute Decisions Act* provides an example of a different formulation of an 'alternative course of action' provision. Pursuant to that Act the court is prohibited from appointing a guardian "if it is satisfied that the need for decisions to be made will be met by an alternative course of action that ... is less restrictive of the person's decision-making rights than the appointment of a guardian".⁷ This provision does not provide examples of alternative courses, such as supports or assistance. Despite its less precise language, in *Gray v. Ontario*,⁸ the Ontario Divisional Court interpreted the 'alternative course of action' provision to include supported decision making. This case addressed closures of institutions for people with 'developmental disabilities' in Ontario. In it an issue arose as to whether there was a requirement to obtain consent of the resident or "his or her next of kin or substitute decision maker" to the community placement selected for him/her. Mr. Justice Hackland concluded that consent of the person with the disability or his/her substitute decision-maker is required to any choice of community residential placement. In addressing this issue, he highlighted the 'alternative course of action' provision in the *Substitute Decisions Act* and interpreted that provision to recognize supported decision-making as an alternative to guardianship:

The Ministry's current process has not required the appointment of a guardian in support of the "supported decision making" process, which in many cases will be consistent with the words and the intention of section 55(2) of the Act. As argued by counsel for the Intervenor, Community Living Ontario, a process short of full or partial guardianship is preferable in many cases, as it best recognizes the autonomy and dignity of the individual and the inclusiveness of the decision-making process.⁹

As illustrated in the Gray decision, 'alternative course of action' provisions have potential to create significant space for extensive support arrangements to be recognized, which would allow people who would otherwise fall under guardianship to nonetheless exercise legal capacity.

⁴ *Adult Protection and Decision Making Act* being Schedule A to the *Decision-Making Support and Protection to Adults Act*, S.Y. 2003, c. 21.

⁵ *Adult Protection and Decision Making Act* being Schedule A to the *Decision-Making Support and Protection to Adults Act*, S.Y. 2003, c. 21, s. 2.

⁶ *Adult Protection and Decision Making Act* being Schedule A to the *Decision-Making Support and Protection to Adults Act*, S.Y. 2003, c. 21, s. 32(1)(c).

⁷ *Substitute Decisions Act*, 1992, S.O. 1992, c. 30, s. 22(3) and s. 55(2).

⁸ *Gray v. Ontario*, [2006] O.J. No. 266, 2006 CanLII 1764 (S.C. (Div. Ct.)).

⁹ *Gray v. Ontario*, [2006] O.J. No. 266, 2006 CanLII 1764 (S.C. (Div. Ct.)), para. 47.

2. Duty to accommodate in the decision-making process

The duty to accommodate is a core feature of domestic and international human rights law. It exists pursuant to both the *Canadian Charter of Rights and Freedoms* and federal, provincial/territorial human rights laws, and its application to decision-making is beginning to be fleshed out. In the same way that accommodations are needed in employment practices to prevent disability-based discrimination, there is a need to accommodate some persons with disabilities in decision making, whether they exercise it independently or interdependently. In the context of decision-making the duty to accommodate is defined in the CRPD General Comment on Article 12 as “any necessary modifications or adjustments to allow persons with disabilities to exercise their legal capacity, unless it is a disproportionate or undue burden.”¹⁰ It references accommodations for decision making as including “accessible information regarding decisions which have legal effect” and “personal assistance.”¹¹ Accommodations could include, for example, a physician taking more time with a person in a medical appointment, or a financial institution providing communication assistance including communication intermediaries. Some specific guidelines for accommodation in the context of decision making have been developed by the Ontario Human Rights Commission.¹²

3. Supports for decision making and ‘supported decision making’

Decision-making supports are essential in enabling the exercise of decision-making capability, both independently and interdependently. Canada was one of the first countries to grant legal recognition to supports for decision making. Now many countries, inspired by innovations in Canada, have laws which also recognize such supports.¹³ While Canada’s developments began before the coming into force of the CRPD, the CRPD, and Article 12, in particular, prompted much law and policy reform world-wide.

Article 12(3) recognizes the obligation for State Parties to provide access to the support a person may require in exercising their legal capacity. And the UN Committee on the Rights of Persons with Disabilities provides extensive elaboration of what ‘supports’ mean and require in this context. The General Comment on Article 12 defines “supports” for decision making as “a broad term that encompasses both informal and formal support arrangements, of varying types and intensity.”¹⁴ Legal commentary commonly identify a range of supports for this purpose, including:

¹⁰ UN Committee on the Rights of Persons with Disabilities, “General Comment No.1 – Article 12: Equal Recognition Before the Law,” UN Doc. No. CRPD/C/GC/1 (April 2014) [General Comment No. 1], para. 34, online: <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>.

¹¹ General Comment No. 1, note 10, para. 34.

¹² See Ontario Human Rights Commission, “Policy on preventing discrimination based on mental health disabilities and addictions” (2014), Chapter 16, online: <http://www.ohrc.on.ca/en/book/export/html/11238>.

¹³ Antonio Martinez-Pujalte, “Legal Capacity and Supported Decision-Making: Lessons from Some Recent Legal Reforms” (2019) 8(1) *Laws* 4.

¹⁴ General Comment No. 1, note 10, para. 17.

- independent advocacy;
- representatives appointed by or on behalf of the person;
- person-centered planning assistance;
- communication assistance;
- interpretive support;
- opportunity and relationship-building support; and,
- administrative support.¹⁵

Canada’s laws have begun to evidence ways in which supports can enhance a person’s exercise of legal capacity. For example, Nova Scotia’s *Adult Capacity and Decision-making Act*¹⁶ defines ‘capacity’ to mean the ability “with or without support” to understand information and appreciate consequences.¹⁷ Similarly, in the *Guardianship and Trusteeship Act*¹⁸ of the Northwest Territories, the ability to ‘understand’ and ‘appreciate’ may be met “by himself or herself or with assistance”.¹⁹ These statutes have taken the first step at departing from the strict formulation of the ‘understand and appreciate’ test. They are more inclusive of some people with disabilities as they recognize that people may rely upon supports and assistance to meet the “understand and appreciate test”. Despite this, they still exclude people who are not able to meet the cognitive standard even with supports and assistance.

“Supported decision making”, the term referenced in the 2017 mandate for the Newfoundland and Labrador’s Minister of Justice and Public Safety, is a term frequently used in the context of legal capacity law and policy reform for implementation of Article 12. Rather than being viewed as a goal, it is better characterized as a vehicle for achieving the goal of liberty and equality in the exercise of legal capacity or, in the words of Article 12, “equal recognition before the law”. Nonetheless, it is indeed a critical vehicle. It is a particular kind of support arrangement with certain defining features, as follows: It involves decision-making support people assisting a person to understand, make and communicate a decision, or interpret their will and preferences and help make and execute plans needed to give them effect. Supporters are appointed based on a relationship of personal knowledge, trust and commitment to the person, and may act under an informal or more formal arrangement, depending on the context.²⁰

¹⁵ See, for example, R. Dinerstein, "Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road From Guardianship to Supported Decision-Making." Human Rights Brief 19, no. 2 (2012): 8-12; and, Bach and Kerzner referring to Michael Bach and Lana Kerzner, “A New Paradigm for Protecting Autonomy and the Right to Self-Determination” (Toronto: Law Commission of Ontario, 2010) [Michael Bach and Lana Kerzner], 72, online: <https://www.lco-cdo.org/wp-content/uploads/2010/11/disabilities-commissioned-paper-bach-kerzner.pdf>.

¹⁶ *Adult Capacity and Decision-making Act*, S.N.S. 2017, c. 4.

¹⁷ *Adult Capacity and Decision-making Act*, S.N.S. 2017, c. 4, s. 3(d).

¹⁸ *Guardianship and Trusteeship Act*, S.N.W.T. 1994, c. 29.

¹⁹ *Guardianship and Trusteeship Act*, S.N.W.T. 1994, c. 29, s. 7(1)(b) and s. 31(1)(b).
General Comment No. 1, note 10, para. 29.

Canada's laws which recognize supports for decision making are sometimes described as recognizing 'supported decision making'. More accurately, though, they evidence aspects of supported decision making but not all of the features that comprise "supported decision making" as understood by the UN Committee on the Rights of Persons with Disabilities. The terms and scope of the arrangements recognized in Canada's laws vary widely.²¹

For example, British Columbia's *Representation Agreement Act* allows supporters, referred to in the Act as "representatives", to be appointed to "help the adult make decisions".²² Alberta's *Adult Guardianship and Trusteeship Act* provides that an adult may create a "supported decision-making authorization", and in it, may authorize a supporter to "assist the adult in making the decision" and "communicate or assist the adult in communicating the decision to other persons".²³

In contrast, Manitoba's *Vulnerable Persons' Living with a Mental Disability Act* does not grant legal status to supporters. Nonetheless, the existence of a "support network" is a consideration relevant to the process and determination for appointing a substitute decision-maker.²⁴ The statute is unique in Canada because of the richness with which it articulates what is meant by "supported decision making". The term is defined as "the process whereby a vulnerable person is enabled to make and communicate decisions with respect to personal care or his or her property and in which advice, support or assistance is provided to the vulnerable person by members of his or her support network,"²⁵ and defines "support network" to mean "one or more persons who provide advice, support or assistance to a vulnerable person...".²⁶ It describes the role of supported decision making as follows: "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."²⁷ And the preamble, which sets the tone for the Act, recognizes "...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".²⁸

In Newfoundland and Labrador, modest legal recognition has so far been given to support arrangements to assist a person to exercise their capacity. Under the *Adult Protection Act's* legislated "Service Principles", "an adult who is or may be in need of protective intervention

²¹ For a more comprehensive review of Canada's laws that recognize supports see Lana Kerzner, "Supported Decision-Making Innovations: The Canadian Experience" in Charles O'Mahony and Gerard Quinn, eds., *Disability Law and Policy: An Analysis of the UN Convention*, (Dublin: Clarus Press Ltd., 2017).

²² *Representation Agreement Act*, R.S.B.C. 1996, c. 405, s. 7(1).

²³ *Adult Guardianship and Trusteeship Act*, S.A. 2008, c. A-4.2, s. 4.

²⁴ *Vulnerable Persons Living with a Mental Disability Act*, C.C.S.M., c. V90, ss. 49, 50, 53, 84, 85, and 88.

²⁵ *Vulnerable Persons Living with a Mental Disability Act*, C.C.S.M., c. V90, s. 6(1).

²⁶ *Vulnerable Persons Living with a Mental Disability Act*, C.C.S.M., c. V90, s. 1(1).

²⁷ *Vulnerable Persons Living with a Mental Disability Act*, C.C.S.M., c. V90, s. 6(2).

²⁸ *Vulnerable Persons Living with a Mental Disability Act*, C.C.S.M., c. V90, preamble.

should, if desired, be encouraged to obtain support, assistance and advice from family and friends to help that adult understand choices, and to make and communicate decisions.”²⁹

In summary, “supported decision making” references one type of “support” arrangement recognized in law. Legislative developments recognize an increasing range of supports and arrangements. Moreover, supports are explicitly recognized as an alternative course of action to guardianship in some Canadian jurisdictions.

4. Inclusive, non-cognitive test of capacity to appoint a decision-making supporter

Integral to the interdependent approach to meeting the “understand and appreciate test” is the legal recognition of those decision-making supporters who interpret a person’s intentions and willful action and translate them into legal transactions. The ‘understanding and appreciation’ is thus achieved ‘interdependently’ with the person and their supporter(s). A conundrum of this approach is how the person appoints such supporters when they do not, on their own, meet the understanding and appreciation usually required to make appointments.³⁰ Legal capacity regimes which recognize supports are at risk of leaving some people in a ‘catch-22’ situation: a person requires supporter(s) to help make decisions but does not meet the ‘understand and appreciate test’ required to appoint those supporters. For example, in Alberta and Yukon, “supported decision making” arrangements *per se* are legally recognized, but only those who are considered capable on the traditional ‘understand and appreciate’ test can appoint support persons for this purpose.³¹

British Columbia’s approach in the *Representation Agreement Act* is notable for the way in which it addresses this conundrum; it departs from a requirement that a person must meet a strict ‘understand and appreciate test’ to appoint supporters. It allows an adult to make a representation agreement appointing a person to help make decisions without requiring that the person possess the degree of cognitive ability required to meet the usual parameters of the ‘understand and appreciate test’. In particular, s. 8(2) of the Act requires that, when considering whether a person is incapable of making a representation agreement, relevant

²⁹ *Adult Protection Act*, S.N.L. 2011, c. A-4.01, s. 8(g).

³⁰ Commonly one is required to meet a cognitive test of capacity to create a power of attorney, appointing an attorney as a substitute decision maker. See e.g., the test of ‘capacity to give power of attorney for personal care’ under Ontario’s *Substitute Decisions Act, 1992*, S.O. 1992, c. 30, as follows:

“A person is capable of giving a power of attorney for personal care if the person,

(a) has the ability to understand whether the proposed attorney has a genuine concern for the person’s welfare; and

(b) appreciates that the person may need to have the proposed attorney make decisions for the person. (s. 47(1)).

³¹ *Adult Guardianship and Trusteeship Act*, S.A. 2008, c. A-4.2. Section 4(1) of the Act states: “An adult who understands the nature and effect of a supported decision-making authorization may make a supported decision-making authorization appointing one to 3 persons who have attained the age of 18 years and who meet the prescribed eligibility requirements as supporters.”; *Adult Protection and Decision Making Act* being Schedule A to the *Decision-Making Support and Protection to Adults Act*, S.Y. 2003, c. 21. Section 6 states: “An adult may enter into a supported decision-making agreement if they understand the nature and effect of the agreement.”

factors to be considered incorporate those which are non-cognitive in nature. These include the adult's demonstration of choices and preferences and expression of feelings of approval or disapproval of others; and whether there is a relationship between the person and representative characterized by trust. Similarly, Newfoundland and Labrador's *Enduring Powers of Attorney Act*'s provision for appointing designates for designation agreements contains comparable requirements.³² However, it applies only to designating representatives for the purpose of acting as a holder of the person's RDSP, those representatives acting in the nature of substitutes rather than supporters. Thus, the formulations in the *Representation Agreement Act* and *Enduring Powers of Attorney Act* exclude fewer people with disabilities than the formulations in Alberta and Yukon, because they recognize non-cognitive factors as legitimate and relevant.

5. Role a person's 'true intentions' and 'free will' play in demonstrating legal capacity

If a person is not able to 'understand and appreciate' the nature and consequences of a particular decision, in what meaningful sense can the person be said to exercise legal agency? This is a fundamental question for interdependent decision making and is at the heart of the tension in the CRPD referenced above. An interdependent approach recognizes that a particular decision, and the understanding and appreciation associated with it, are a means to an end. In a decision-making context the 'end' is, in the terms of the CRPD, the realization of a person's "will and preferences". Particular decisions, and the activities of understanding and appreciation undertaken to arrive at them, are the 'means to achieve a person's will and preferences as it applies in a particular context.

This work of interpreting a person's true intentions and free will in order to determine the legal validity of a decision, is beginning to be recognized in Canada's laws regulating legal capacity, proper. For example, Yukon's *Adult Protection and Decision Making Act* allows an adult to create a supported decision-making agreement and appoint an 'associate decision maker' to do the following:

- Assist the adult to make and express a decision
- Assist the adult to obtain relevant information
- Advise the adult by explaining relevant information and considerations
- Ascertain the wishes and decisions of the adult and assist the adult to communicate them
- Endeavor to ensure that the adult's decision is implemented³³

Alberta's *Adult Guardianship and Trusteeship Act* allows an adult to make a "supported decision-making authorization" in which the adult may authorize the supporter to do the following:

³² R.S.N.L. 1990, c. E-11, s. 15(2).

³³ *Adult Protection and Decision Making Act* being Schedule A to the *Decision-Making Support and Protection to Adults Act*, S.Y. 2003, c. 21, s. 5(1).

- to access, collect or obtain or assist the adult in accessing, collecting or obtaining from any person any information that is relevant to the decision and to assist the adult in understanding the information
- to assist the adult in making the decision
- to communicate or assist the adult in communicating the decision to other persons.³⁴

These planning document vehicles are progressive in that they acknowledge that decisions can legitimately be made in a manner which shares the tasks involved in the decision-making process, precisely because they are means to the end of achieving a person's aims. That is, all tasks do not have to be accomplished independently by one person. This recognition means that legally valid decision-making options are available to a broader number of people with cognitive disabilities as they can access supports from others who can take steps to translate their wishes into needed steps and agreements to fulfil them and communicate the decisions to others.

This relationship between a person's will and preferences and the decisions that give them effect are perhaps most evident and developed in testamentary law. Here, the law must settle disputes about whether a person's recorded Will³⁵ reflects their 'true intentions' and 'free will,' or whether suspicious circumstances and undue influence operated in the making of the Will. Jurisprudence and doctrines of undue influence and suspicious circumstances grapple with questions about whether the Will is a valid means to give effect to the person's intentions (i.e., the 'ends' they sought to achieve in making out their Will).

While these legal doctrines are not strictly a component of legal capacity laws traditionally understood, they inter-relate with, and are often considered alongside, capacity issues in determinations of legal validity. For example, the British Columbia Law Institute Report on Common-Law Tests of Capacity states as follows, concerning the capacity to make a Will: "The typical pattern in estate litigation sees testamentary capacity being considered along with a number of other issues. Concepts such as knowledge and approval, suspicious circumstances, and undue influence are often considered alongside testamentary capacity."³⁶

These related, but distinct, legal doctrines each play a significant role in impacting one's exercise of legal capacity. They address factors which are external to the person but at the same time interfere with the person's ability to express autonomous choices. These contextual factors point to a condition for exercising legal capacity that is not highlighted in the mainstream approaches – that is, that a person's expressed true intentions and free will are essential to legally valid decisions. In recognition of this, these concepts can be described as

³⁴ *Adult Guardianship and Trusteeship Act*, S.A. 2008, c. A-4.2, s. 4(2).

³⁵ In this report we use the term 'Will' to refer to an instrument by which a person makes a disposition of their property to take effect after their death.

³⁶ British Columbia Law Institute, "Report on Common-Law Tests of Capacity", BCLI Report no. 73, September 2013, 33, online: http://www.bcli.org/wordpress/wp-content/uploads/2013/09/2013-09-24_BCLI_Report_on_Common-Law_Tests_of_Capacity_FINAL.pdf.

legal tools which seek to uncover and give recognition to a person's true intentions and free will. A full review and analysis of these legal doctrines is beyond the scope of this research; however, a selection of pertinent sources is described below for the purpose of elucidating their connection to the exercise of legal capacity.

The concept of undue influence applies in a number of areas of law including testamentary law, contract law, the law relating to inter vivos gifts and to health care decision-making.³⁷ It has been described in general terms as follows:

The doctrine of undue influence is used by courts to set aside certain inter vivos gifts/wealth transfers, transactions, and planning and testamentary documents, where, through exertion of the influence of the mind of the donor, the mind falls short of being wholly independent. Where one person has the ability to dominate the will of another, whether through manipulation, coercion, or outright but subtle abuse of power, undue influence may be found."³⁸

Applying the concept of undue influence, courts intervene when it appears that the person's action is not actually a reflection of their true intention and free will. In the words of the British Columbia Supreme Court:

[i]n order to invalidate a will on the grounds of undue influence, the asserting party must prove that the influence exerted against the will-maker amounted to coercion, such that the will did not reflect the true intentions of a free will-maker and was not the product of the will-maker's own act. The undue influence must constitute coercion which could not be resisted by the will-maker and which destroyed his or her free agency.³⁹

In testamentary law, the related concept of suspicious circumstances links external factors to the capacity of the individual.⁴⁰ Suspicious circumstances have been described to include "circumstances tending to show that the free will of the testator was overborne by acts of coercion or fraud."⁴¹ Thus, this concept assumes that the true intentions and free will of the individual or, as cited in a recent decision of the Supreme Court of Newfoundland and Labrador

³⁷ See John E. S. Poyser, *Capacity and Undue Influence* (Toronto: Carswell, 2014), 301 to 303 for a description and comparison of testamentary undue influence and inter vivos undue influence. See S. M. Waddams, *The Law of Contracts*, 7th ed (Toronto: Thomson Reuters, 2017), 362 – 365 for a description of undue influence in contract law. See Trudo Lemmens, "Informed Consent" in Yann Joly and Bartha Maria Knoppers, eds., *Routledge Handbook of Medical Law and Ethics* (New York: Routledge, 2015) for a definition of undue influence in the health care consent context.

³⁸ WEL Partners, Undue Influence Checklist, September 2018, 1, online: http://welpartners.com/resources/WEL_Undue_Influence_Checklist.pdf.

³⁹ *Leung v. Chang*, 2013 BCSC 976, para. 35.

⁴⁰ *Vout v. Hay*, [1995] 2 S.C.R. 876, para. 27.

⁴¹ *Vout v. Hay*, [1995] 2 S.C.R. 876, para. 25.

the “offspring” of a person’s “own volition, and not the record of another person’s”,⁴² actually exist; and, that they can be uncovered.

The foundations upon which these legal doctrines rest provide the basis for a more inclusive alternative to the mainstream approaches to defining the conditions of legal capacity. Critically important for the purposes of the present research, is the assumption in these doctrines that a person’s true intentions and free will or volition are essential to ground a legally valid act.

Similar to this body of jurisprudence, in its General Comment on Article 12, the UN Committee on the Rights of Persons with Disabilities emphasizes that respect for a person’s “will and preferences” are the ground of a non-discriminatory approach to legal capacity. The Committee states that “it is imperative that persons with disabilities have opportunities to develop and express their will and preferences, in order to exercise their legal capacity on an equal basis with others.”⁴³ The Committee’s qualification that the person’s expressed “will and preferences” must be free of undue influence in health care and other decision-making contexts suggests a characterization of this notion similar to that of the ‘free will’ referenced in jurisprudence on undue influence and suspicious circumstances.

In summary, this body of law indicates that two related moments ground the exercise of legal capacity: 1) that a person ‘truly’ intends an act they carry out; and 2) that in carrying out that act they are doing so ‘freely’, or voluntarily.

6. Provision for validly interpreting ‘true intentions’ and ‘free will’ as the basis of decisions

As noted, some people with disabilities do not have the abilities to satisfy the mainstream cognitive conditions for exercising legal capacity. Yet, they do possess a will and they do have true intentions sufficient to ground decisions. Along the decision-making path in these circumstances, an interpretive role will be critical in translating a person’s ‘true intentions’ and ‘will’ into actual decisions. There are two stages in this interpretation process. First, interpretation may be needed to ascertain what a person’s true intentions and free will are in the circumstances, based on the record of their expressions and prior plans; and second, interpretation may be required about what specific actions should be taken to realize the person’s true intentions and free will in the circumstances. These interpretive actions, while ultimately resulting in legal consequences, may involve taking legal and non-legal steps.

Interpreting a person’s will and true intentions may come with uncertainty or indeterminacy. However, this is not an insurmountable difficulty if a person has around them decision-making supporters who have personal knowledge about them and their history (e.g., likes and dislikes, their forms of expression, their mental states and how their environment affects their

⁴² *Martin Estate*, 2011 NLSCTD 155, para. 33, citing *Lidstone v. McWilliams et al.*, [1931] 3 D.L.R. 455 (S.C.C.), 457.

⁴³ General Comment No. 1, note 10, para. 44.

behaviour); a trusting relationship in which the person feels free to express; and a personal commitment to play these roles. This is a task not unfamiliar to our legal system. As a practical and procedural matter in cases concerning undue influence and suspicious circumstances, courts must adjudicate among interpretations of a person's true intentions to arrive at the most valid interpretation that should apply. There are obvious interpretive challenges, including after a person has died so the person themselves is not able to attest to their true intentions. Nonetheless, courts are regularly called upon to make these determinations.

Legal provisions that enable supporters or representatives to validly interpret a person's will and preferences as the basis for making decisions in a particular circumstance are found in statutes which authorize the creation of planning documents to guide decision making in this manner. These statutes recognize that legally valid decisions do not have to be accomplished entirely by the person themselves. For example, in British Columbia, Yukon and Alberta a person can create a planning document which recognizes supporters to help with making decisions when a person is either episodically (as a result of a mental health issue) or permanently unable to act legally independently.

As discussed above, the principle articulated by the UN Committee on the Rights of Persons with Disabilities, in its General Comment No. 1, of "best interpretation of will and preferences" provides a basis on which to adjudicate competing interpretations of a person's will and preferences in situations of uncertainty and indeterminacy. As in testamentary law, the principle assumes that there are better and worse interpretations of what a person intends in the circumstances. Those interpretations can be arrived at by drawing on the record of a person's expressions and behavior, and on any evidence of undue influence in the situation.

7. Safeguards

There are evidence-based concerns (in Newfoundland and Labrador, and elsewhere) about the potential for abuse, neglect or exploitation under decision-making arrangements, including powers of attorney, for people who are not able to act legally independently.⁴⁴ Thus, safeguards are, and will always be, an integral component of legal regulation of such arrangements. This is the case for existing laws that recognize both substitute decision-making and decision-making supports and will be an important consideration for reform of any legal capacity regime (including one based on decision-making capability). Regardless of the

⁴⁴ For example, see Law Commission of Ontario, *Legal Capacity, Decision-making and Guardianship: Final Report* (Toronto: March 2017), 171-175, online <http://www.lco-cdo.org/wp-content/uploads/2017/03/CG-Final-Report-EN-online.pdf>; Law Reform Commission of Nova Scotia, *The Powers of Attorney Act: Final Report* (Halifax: Author, 2015), 41, online: <https://www.canlii.org/en/commentary/doc/2015CanLIIDocs2699#lfragment/zoupio-Toc3Page2/BQCwhgziBcwMYgK4DsDWszlQewE4BUBTADwBdoAvbRABwEtsBaAfX2zgGYAFMAc0IBMASgA0ybKUIQAiokK4AntADkykREJhcCWfKWr1m7SADKeUgCEIAJQCAGVsA1AIIA5AMK2RpMACNoUnYhISA>; The Seniors Resource Centre of Newfoundland and Labrador has also raised the issue of abuse under powers of attorney and made recommendations to address it, in their "Discussion Paper: Enduring Powers of Attorney" (2014), online: <https://www.citizensrep.nl.ca/pdfs/SeniorsResourceCentreEnduringPowersofAttorney.pdf>.

approach to legal capacity any legal regime takes, safeguards appear to address three broad purposes. These are:

- Promote and protect the exercise of legal capacity and right to autonomy;
- Protect from potential harm as a result of,
 - Inappropriate influence or abuse by supporters;
 - abuse by third parties; and,
- Ensure reliability and validity of transactions

The safeguards that exist in law in Canada serve these purposes either individually or in combination. Examples include:

- **Legislated duties of substitute decision makers and supporters**
 - e.g. Ontario's *Substitute Decisions Act*, s. 32 and s.66 (duties of guardians and attorneys under powers of attorney); British Columbia's *Representation Agreement Act* s. 16 (duties of representatives – covers both substitute decision makers and supporters);
- **Safeguarding integrity of the decision-making process**, for example, by providing for monitoring of appointed representatives to fulfill their obligations
 - e.g. British Columbia's *Representation Agreement Act*, s. 20; and, Newfoundland and Labrador's *Enduring Powers of Attorney Act*, s. 20.
- **Offices of Public Guardians and Trustees or Adult Protection with a mandate to address abuse and neglect**
 - e.g., Newfoundland and Labrador's *Adult Protection Act* provides legislative authority for delivery of services for adults who, inter alia, are abused or neglected (s. 20). The Act and its associated "Policy Manual" provide guiding service principles and authorize interventions for arranging supports in a way to best balance the protection of autonomy of persons who may be vulnerable to abuse, neglect or self-neglect, and their protection from harm;⁴⁵
- **Limiting decisions made with supports to certain categories or types of decisions**
 - e.g. Alberta's *Adult Guardianship and Trusteeship Act*, where supported decision-making applies only in respect of personal matters (s. 3); British Columbia's *Representation Agreement Act* limits representation agreements allowing for assistance to certain kinds of decisions (s. 7);
- **Providing for 'last resort' decision making on an emergency basis**

⁴⁵ In its prioritizing provision of supports and services for individuals in situations of harm, abuse and neglect, the Newfoundland and Labrador *Adult Protection Act*, S.N.L. 2011, c. A-4.01, with its related "Policy Manual" appears to achieve a good balance in safeguarding individuals in these situations while protecting their equal right to exercise legal capacity. See Government of Newfoundland and Labrador, *Adult Protection Act: Provincial Policy Manual* (Effective June 30, 2014), online: https://www.cssd.gov.nl.ca/apa/pdf/ap_act_prov_policy_manual.pdf.

- e.g., Newfoundland and Labrador’s *Advance Health Care Directives Act* (s. 9(2)); and,
- ***Providing avenues for dispute resolution, complaints and appeals***
 - e.g., Ontario’s *Substitute Decisions Act*, where the court may give directions on any question arising in a guardianship or under a power of attorney (s. 39 and 68) and provisions exist for passing of accounts (s.42); and, Newfoundland and Labrador’s *Enduring Powers of Attorney Act*, s. 21.

While the above safeguards apply to existing legal capacity regimes in Canada, they are equally relevant to a regime which is based on the decision-making capability approach.

We are not aware of evidence indicating that people are any more at risk under supported decision-making arrangements, than under substitute decision-making arrangements. Nonetheless, the UN Committee on the Rights of Persons with Disabilities stresses that while all persons are at risk of undue influence, for those who require support to make decisions the risk may be exacerbated. Indeed, in the Canadian context, the Yukon *Adult Protection and Decision Making Act* addresses the concerns regarding the potential for undue influence and for supporters to slip into the role of substitute.⁴⁶ This potential risk, however, does not justify imposition of substitute decision making. Rather, it requires safeguards and vigilance that respect the “rights, will and preferences” of the person.⁴⁷

Safeguards for people who exercise legal capacity interdependently are critically important. This is a vulnerable group, as the law has recognized. Indeed, substitute decision making is justified on the basis that it may be required to protect persons who are not able to meet the ‘understand and appreciate test’ needed to make a decision, from deteriorating health and abuse, exploitation or neglect by others. If persons in this situation are to have their legal capacity recognized, by enabling them to act interdependently with representatives, there is just as urgent a need for safeguards. Moreover, safeguard measures specified in Article 12(4) of the CRPD specify that any legal measures regulating legal capacity must respect “the rights, will and preferences” of the person.⁴⁸

The CRPD recognizes the need for safeguards tailored to the individual, primarily in Article 12(4), but also in Articles 15 - “Freedom from torture or cruel, inhuman or degrading treatment of punishment” and 16 - “Freedom from exploitation, violence and abuse”. Article 12(4) requires that safeguards:

- respect the rights, will and preferences of the person;

⁴⁶ *Adult Protection and Decision Making Act* being Schedule A to the *Decision-Making Support and Protection to Adults Act*, S.Y. 2003, c. 21, s. 5(2).

⁴⁷ General Comment No. 1, note 10, paras. 22 and 41.

⁴⁸ United Nations, *Convention on the Rights of Persons with Disabilities*, G.A. Res. 61/106 [adopted by consensus at the UN on Dec. 13, 2006] [CRPD], Article 12, online: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>.

- 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.

In summary, given the additional potential risks attendant to decision-making with supports, additional safeguards are warranted, and should be tailored to the decision-making capability approach, especially in light of the equivocal nature of interpretation by supporters. In concrete terms, and based on existing provisions in law, these additional safeguard provisions might include:

- ***Heightened safeguards for certain types of decisions or situations***, such as
 - decisions which fundamentally affect personal integrity or human dignity (such as sterilization that is not medically necessary to protect the person’s health, and ‘medical assistance in dying’), including requiring that legal capacity be exercised independently in these circumstances;
 - major decisions made through interdependent decision-making, including more onerous evidentiary requirements proving how the decision was arrived at, and the relationship between the adult and supporter(s);
 - provide for last resort decision making on an emergency basis;
- ***Legislated duties of decision-making supporters***, in addition to those commonly associated with regulation of substitute decision makers, for example, they should have a duty to:
 - be guided by the will and preferences of the person;
 - invest in and maintain a personal relationship of trust and connection with the person;
 - involve supportive family members and friends, as indicated by the person’s will and preferences;
- ***Oversight of decision-making supporters***, for example,
 - reporting requirements of decision-making supporters, for example, passing of accounts and management plans;
 - providing for appointment of monitors;
- ***Additional authority for offices that are mandated to address abuse and harm***, such as
 - Requiring exploration and facilitation of all possible less restrictive alternatives, including supports and assistance; and,
- ***Avenues for dispute resolution, complaints and appeals.***

Appendix D

Implementing the Decision-Making Capability Approach in Practice, Programs, Policy, and Law

INTRODUCTION

There is a well-recognized need for a new approach to legal capacity to address the discriminatory, disability-based restrictions and unjustified interference in a person's autonomy, which are found in legal regimes based on the 'status', 'outcome' and 'cognitive/functional' approaches to establishing conditions for exercising legal capacity. An approach that addresses these limitations has been described as the 'decision-making capability' approach to legal capacity.

Evidence gathered from research and demonstration initiatives, and evaluation of programs to implement supports for decision making, indicates that measures to implement the decision-making capability approach are needed at four main levels: practice, programs, policies and law. The following summary of measures are drawn from that evidence.¹

1. Practice measures to assist in constituting and exercising independent or interdependent decision-making capability

'Practices' refer to the actual ways that a person's family members or others involved in their lives, including health and social service providers, interact, communicate with, respond to, and assist a person. Some of these ways, like denying a person choice because of disability-based stereotypes or lack of accommodation in decision making, pose barriers to a person gaining power over their lives, while others enable a person to exercise greater choice and control.

In a legal capacity regime based on the decision-making capability approach, types of practice measures include:

- assessing the need for supports and accommodations in decision making – which involves determining if a person requires additional supports or accommodations for their decision-making capability and what those might be. Some assessment guidelines are available for this purpose in health care or other settings, for example determining capability for providing informed consent or instructing legal counsel;²

¹ The outline of measures presented here is drawn from Michael Bach and Lana Kerzner, "The Right to Equality in Legal Capacity: A Framework for Implementation" (Toronto: IRIS – Institute for Research and Development on Inclusion and Society, 2020).

² Practicing supported decision making in the health care context is one area where third parties – i.e., health care practitioners in this case – may need assistance to obtain informed consent through a supported approach. For an example of a practice tool informed by a decision-making capability approach and for the purposes of enabling supported approaches to informed consent, see Sullivan, WF., Bach, M., Heng, J., Henze, M., Kerzner, L., McNeil, K., Perry, A., Vogt, J., "Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities" (Toronto: Developmental

- providing access to needed supports – to the extent that supports are required, the third party may need to arrange access (to communication intermediaries or technologies), or seek assistance in identifying and arranging support options;³
- providing a decision-making supporter or representative who assists a person to make their decisions independently, and such an arrangement if it is formalized over time can be referred to as a supported decision-making arrangement;⁴ and,
- accommodating the decision-making process as may be needed – which may involve the third party arranging supports as above, and can include adapting their own practice (e.g., communicating in plain language or taking additional time), and agreeing to include others in the decision-making process, like a person’s family member, friend or advocate.⁵

Additional practice measures to assist a person to constitute interdependent decision-making capability refer to the ways and processes through which a person’s decision-making supporters assist a person to exercise control and legal capacity over decisions in their lives. Effective practice measures for this purpose⁶ include:

- developing and maintaining personal relationships of trust, personal knowledge and personal commitment among decision-making supporters and the person, as the basis for assisting the person to exercise control and legal capacity in their life, including in the following ways;
- expressing and developing personal will and preferences about things that matter to the person;

Disabilities Primary Care Program of Surrey Place, 2020), online:

<https://ddprimarycare.surreyplace.ca/wp-content/uploads/2020/11/Decision-Making-Approaches.pdf>.

³ A growing number of actors are developing resources to assist third parties in accommodating and supporting people to direct decision making in their lives. In the area of communication support see, for example, Communication Disabilities Access Canada which links up third parties with communication intermediaries through its “Communications Assistance Database,” online:

<http://www.cdacanada.com/communication-assistance-database/>.

⁴ Many examples of ‘supported decision-making agreements’ have been designed to recognize these more formal arrangements. For example, see the American Civil Liberties Union, “ACLU Supported Disability Rights Program Supported Decision-Making Agreement” (n.d.), online:

<https://www.aclu.org/other/aclu-supported-decision-making-agreement>.

⁵ For example, ARCH Disability Law Centre has developed guidance for legal professionals in accommodating the process of clients with disabilities instructing legal counsel. See “Tips for Lawyers and Paralegals on Providing Accessible Legal Services to Persons with Disabilities in Ontario,” online:

<https://archdisabilitylaw.ca/resource/guide-tips-for-lawyers-and-paralegals-on-providing-accessible-legal-services-to-persons-with-disabilities-in-ontario/>. In the health care context, Sullivan, et.al, note 2.

⁶ The practices listed in this section are referenced in several resources to assist individuals and their decision-making supporters carry out supports for, and supported, decision making planning and implementation process. For examples of such resources, see Able South Carolina, “The South Carolina Supported Decision Making Project,” online: <http://scsupporteddecisionmaking.org/resources/>.

- visioning and planning for the future, based on an understanding of the person’s evolving will and preferences;
- making and carrying out needed action plans or, in other words, the decisions needed to put the person’s vision, will and preferences into practice; and,
- reviewing and revising action plans as the person’s will, preferences and needs change.

2. Program measures

‘Programs’ refer to the structured delivery of goods and services by non-profit, public or private sector providers. They may be for residential support, health care, employment assistance, community participation or to meet other personal needs, like personal planning or navigating systems. Program design, quality and availability can all affect a person’s exercise of choice and control in their lives. Programmatic interventions for implementing the decision-making capability approach include:

- Information resources on types of supports and accommodations for independent and interdependent decision-making capability – which could be delivered online or through community services and offices of third parties (health services, financial institutions, etc.);⁷
- Training for third parties – on what it means to assess and support independent and interdependent decision-making capability, arrange and provide supports, and to ensure the duty to accommodate in decision making is fulfilled (for decision-making supporters, health care professionals, capacity assessors, social service providers, financial institutions, legal professionals, the justice system including police, corrections, crown attorneys and judges, and other parties as may be required);⁸
- Provision of decision-making supporters and independent advocates – which enable a person to access someone to assist them in decision making.⁹

⁷ The U.S. “National Resource Centre for Supported Decision-Making” is one example of a growing number of online information resource centres for individuals, families, and professionals. See <http://www.supporteddecisionmaking.org/about>.

⁸ See, for example, the U.S. Department of Justice, Elder Law Justice Initiative, “Finding the Right Fit: Decision-Making Supports and Guardianship- Online Course,” online:

<http://www.supporteddecisionmaking.org/sites/default/files/SDM-online-training-Finding-the-Right-Fit.pdf>. While the training does reference guardianship, the principles and approaches are suited for a supported decision-making context.

⁹ Sweden, for example, provides ‘personal ombuds’ which are available to assist a person with mental health and other disabilities to navigate decision making with health care providers and other third parties. Ireland, for example, has recently adopted decision-making support legislation and there is currently consultation underway on enhancing independent advocacy services as an essential support. See Dr. Michael Browne (2018), *Independent Advocacy in Ireland: Current Context and Future Challenge A Scoping Document*, online: <https://www.safeguardingireland.org/wp-content/uploads/2018/10/Advocacy-Scoping-Document-Final-310818.pdf>.

- Demonstration initiatives – which could include a variety of pilot projects to generate and mobilize knowledge and good practice in implementing supports for decision-making capability.¹⁰
- Technical resource and intermediary services – assisting individuals and decision-making supporters establish and maintain support arrangements, negotiate legal agreements with third parties as needed, and advise and assist third parties in reasonably accommodating a person in the exercise of legal capacity.¹¹

3. Policy measures

‘Policies’ are the decisions by governments or other public sector or private sector authorities about who gets what, where, when and how. They are also ‘non-decisions’ – decisions not to allocate resources to meet particular objectives. Policies directly affect the extent to which people can exercise choice and control over their lives, through the range of support options they authorize and the resources they mobilize for that purpose.

Policy measures to implement a decision-making capability approach include:

- Guidelines for assessing and delivering supports for independent decision-making capability – which establish common principles, procedures and guidelines for assessment and delivery of supports in a wide range of contexts;¹²
- Guidelines for the duty to accommodate in decision making – which specify the obligations of third parties under human rights law to ensure non-discrimination

¹⁰ There are a growing number of initiatives in Canada and internationally to pilot, demonstrate, document and evaluate the practice of supported decision making, and which provide lessons for other initiatives. See, for example, Elizabeth and Virginia Mulkern, *SUPPORTED DECISION MAKING PILOT: Pilot Program Evaluation Year 2 Report*, Prepared for the Center for Public Representation and Nonotuck Resource Associates, Inc. (n.d.), online: https://www.hsri.org/files/uploads/publications/SDM_Pilot_Evaluation_Year_2_Report_HSRI_2016_FINAL.pdf. Provincial-scale initiatives are currently being designed in Ontario and Manitoba, with the assistance of IRIS – Institute for Research and Development on Inclusion and Society.

¹¹ A good example of a such a resource is the ‘Nidus Personal Planning Resource Centre and Registry’ which supports people to develop and manage supported decision-making arrangements. See <http://www.nidus.ca/>.

¹² A variety of tools for assessing independent decision-making capability have been developed. However, they vary in the extent to which they incorporate guidelines for assessing need for accommodations and supports to enable a person to act legally independently. For an overview of tools used, see Deborah O’Connor, *Incapacity Assessments: A Review of Assessment and Screening Tools: Final Report*, Prepared for the Public Guardian and Trustee of British Columbia (April 20, 2009), 6, online: http://www.trustee.bc.ca/documents/STA/Incapacity_Assessments_Review_Assessment_Screening_Tools.pdf. The Government of Ontario has issued a set of guidelines for capacity assessment that is based on the cognitive/functional approach to legal capacity but does provide guidance for identifying and considering supports that may assist a person to meet the cognitive tests. See Ontario Ministry of the Attorney General, Capacity Assessment Office, “Guidelines for Conducting Assessments of Capacity” (May 2005), online: <http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/capacity/2005-05/guide-0505.pdf>.

in recognizing, supporting and accommodating decision-making capability to exercise legal capacity;¹³

- Provisions mandating exploration of support options – which establish the procedures and protocols by which publicly-regulated sectors (for example, financial institutions, transportation, communications, health care, government and community services) respond in situations where supports for decision-making capability may be required for a person to transact with the regulated entity, and to ensure that the entity provides reasonable access to processes to explore needed support arrangements.¹⁴
- Provisions for designating, financing, contracting and monitoring support program delivery – to the extent that public funding is allocated for financing and delivery support programs as identified above (provision of information, training, decision-making supporters and demonstration initiatives);¹⁵ and,
- Safeguard measures – which outline the criteria and procedures for public authorities to intervene and address situations where a lack of supports for independent or interdependent decision-making capability may be placing the person or others in situations of harm.¹⁶

¹³ For example, Ontario’s Human Rights Commission “Policy on preventing discrimination based on mental health disabilities and addictions” contains a section which elaborates on accommodation relating to decision-making capacity in Ontario’s human rights context. See Ontario Human Rights Commission, “Policy on preventing discrimination based on mental health disabilities and addictions”, 2014, Chapter 16, Consent and Capacity, online: <http://www.ohrc.on.ca/en/policy-preventing-discrimination-based-mental-health-disabilities-and-addictions/16-consent-and-capacity>.

¹⁴ Tools for this purpose are beginning to be developed in different sectors and different authorities. Not all of these tools will be developed by government authorities; many will need to be developed by respective regulatory bodies. For example, the Canadian College of Family Physicians has recently revised its “Primary care of adults with intellectual and developmental disabilities [IDD]. 2018 Canadian consensus guidelines” to guide physicians in implementing a supported decision-making approach in health care decision making. See William Sullivan and John Heng, “Supporting adults with intellectual and developmental disabilities to participate in health care decision making,” *Canadian Family Physician* (April 2018), 64 (Suppl 2) S32-S36.

¹⁵ There is significant scope for incorporating policy guidelines for supports for, and supported, decision making into delivery of supports and services. This is beginning to be reflected in provincial government policy guidelines. See, for example, a brief reference to “Participant Rights – Supported Decision Making” in the Nova Scotia Department of Community Services’ policy and program guidelines for its “Disability Support Program” (effective March 2016), online: https://novascotia.ca/coms/disabilities/documents/Disability_Support_Program_Policies.pdf.

¹⁶ The Newfoundland and Labrador “Policy Manual” for safeguarding measures is one example of provisions that balance the need to safeguard vulnerable adults who may lack independent decision-making capability with the provision of supports and services which enable them to maintain their legal capacity. See Government of Newfoundland and Labrador, *Adult Protection Act: Provincial Policy Manual* (Effective June 30, 2014), 69-72, online: <https://www.gov.nl.ca/cssd/files/apa-pdf-ap-act-prov-policy-manual.pdf>.

4. *Measures in Law*

These are statutory provisions for a legal capacity regime that implements the decision-making capability approach.¹⁷ The measures would include legal recognition of the following:

- a) the decision-making capability approach as the basis of the legal capacity regime, which would require that the understand and appreciate test may be met either independently or interdependently;
various types of decision-making supports to enable a person to constitute their decision-making capability in a manner most appropriate for them;
- b) supported decision-making arrangements, along with parameters for and processes to govern them, including:
 - duty to accommodate;
 - inclusive, non-cognitive test of capacity to appoint a decision-making supporter; and,
 - role that a person's true intentions and free, and their interpretation by decision-making supporters, play in demonstrating legal capacity;
- c) requirements to explore least restrictive support alternatives to ensure the exercise legal capacity on an equal basis, at all those points where substitute decision making may be triggered as a last resort;
- d) safeguards to protect integrity of the decision-making process (including rights to equality and liberty), and to address situations of harm, abuse and neglect, including mechanisms for disputes resolution.
 - heightened safeguards for certain types of decisions or situations
 - legislated duties of decision-making supporters, in addition to those commonly associated with regulation of substitute decision makers
 - oversight of decision-making supporters
 - additional authority for offices that are mandated to address abuse and harm
 - avenues for dispute resolution, complaints and appeals.

¹⁷ The provisions described in this section on measures in law emanate from the legal research findings in Appendix C of this report.

Appendix E

The Legal Landscape for Regulating Legal Capacity In Newfoundland and Labrador

INTRODUCTION

Describing the legal landscape, or what we refer to as the ‘legal regime’ for regulating legal capacity in Newfoundland and Labrador, itself required careful formulation in order to appropriately identify the issues that are germane to regulating legal capacity in the province. A three-step approach was undertaken to defining the legal regime:

1. Identify the sources of law regulating legal capacity in Canada;
2. Identify the sources of law regulating legal capacity in Newfoundland and Labrador; and,
3. Identify the range and type of legal rules or measures which together constitute legal and regulatory framework affecting the exercise of legal capacity in the province.

The results of this three-step legal research on defining the regime for legal capacity in Newfoundland and Labrador are presented below.

A. Sources of Law Regulating Legal Capacity in Canada

The exercise of legal capacity in Newfoundland and Labrador is governed by several legal sources, both domestic and international.

1. *Domestic Law*

Under Canada’s *Constitution*, provinces have primary jurisdiction over property and civil rights.¹ Thus, it is commonly believed that legal capacity is a matter under legislative authority of the provinces. Indeed, broad based legal capacity laws in Canada are provincial/territorial. Nevertheless, Parliament, too, has enacted legislation which addresses legal capacity in various contexts.² Additionally, the courts have developed a body of jurisprudence on matters of legal capacity. In summary, domestic sources of law for regulating legal capacity are:

- The *Canadian Charter of Rights and Freedoms* (“*Charter*”) recognizes constitutionally protected rights in Canada. Section 7 of the *Charter* recognizes rights to liberty and security of the person, and section 15 recognizes the right to equality without discrimination based on disability.
- Legislation – These are statutes passed by Parliament or the legislatures of provinces and territories, and include regulations adopted under them. Legislation affecting the exercise of legal capacity includes statutes governing guardianship, substitute decision making, powers of attorney, supported decision making, health care decision making, and mental health law. Additionally, the duty to accommodate people with disabilities grounded in human rights statutes requires accommodation in decision-making.

¹ *Constitution Act, 1867* (U.K.), 30 & 31 Vict., c 3, reprinted in R.S.C. 1985, App II, No 5, s. 92(13).

² See Faisal Bhabha and Brendon Pooran, “Equality in the National Interest: Implementing the CRPD Right to Supports in Legal Decision Making under Canadian Federalism” (Toronto: IRIS – Institute for Research and Development on Inclusion and Society, 2020, forthcoming).

- Case law/Common Law – This body of law comes from decisions issued by courts and tribunals in legal cases, often referred to as jurisprudence. These decisions may interpret certain provisions in existing statutes or establish rules not covered by legislation. Case law in Canada has defined many legal rules governing the exercise of legal capacity in different domains, including capacity to make a will (testamentary capacity),³ the nature of understanding and appreciation that may be required for a capable decision in a particular context,⁴ and capacity to enter a contract.⁵

2. *International Law*

Sources of international law regulating legal capacity include:

United Nations *Convention on the Rights of Persons with Disabilities (CRPD)*

This is an international human rights treaty.⁶ Canada became a State Party to the treaty upon ratifying it in 2010, with the support of all provinces and territories. Having ratified the CRPD, Canada is legally bound by it as a matter of international law. However, it is not binding in Canada as part of domestic law unless it is implemented.⁷ Based on Article 4(1) of the CRPD Canada is obligated to take defined steps towards its implementation.

With respect to legal capacity, Article 12 of the CRPD recognizes that:

- “persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” (Article 12(2)).
- State Parties have an obligation to “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity” (Article 12(3)).
- States Parties have an obligation to ensure that measures relating to legal capacity provide for safeguards, and that these must, inter alia, ensure respect for the “rights, will and preferences” of the person (Article 12(4)).

³ There is an abundance of jurisprudence dealing with this issue. See e.g., *Hall v. Bennett Estate* (2003) 64 O.R. (3d) 191, 277 D.L.R. (4th) 263 (C.A.); and *Leung v. Chang*, 2013 BCSC 976, para. 35.

⁴ For example, in *Starson v. Swayze*, the Supreme Court of Canada determined that in comparison to what was generally understood as the legal requirement at the time, a relatively low threshold of ‘mental capacity’ was needed to meet the statutory test for giving informed consent, under Ontario’s *Health Care Consent Act*. See *Starson v. Swayze*, 2003 SCC 32, [2003] S.C.J. No. 33 [Starson SCC].

⁵ S. M. Waddams, *The Law of Contracts*, 7th ed. (Toronto: Canada Law Book, 2017), 467-468

⁶ United Nations, *Convention on the Rights of Persons with Disabilities*, G.A. Res. 61/106 [adopted by consensus at the UN on Dec. 13, 2006] [CRPD], Article 12, online:

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>.

⁷ Lana Kerzner, “Paving the way to Full Realization of the CRPD’s Rights to Legal Capacity and Supported Decision-Making: A Canadian Perspective”, Prepared for a Symposium at the University of British Columbia, In *From the Margins: New Foundations for Personhood and Legal Capacity in the 21st Century*, April, 2011, 17 to 28, online: [http://cic.arts.ubc.ca/files/2014/07/In From The Margins Paper-Lana Kerzner-FINAL-April 22 2011 2 .pdf](http://cic.arts.ubc.ca/files/2014/07/In%20From%20The%20Margins%20Paper-Lana%20Kerzner-FINAL-April%2022%202011%202.pdf).

Even though Canada has signed and ratified the CRPD, it also entered a ‘declaration and reservation’, which articulates Canada's position with respect to Article 12, as follows:

“Canada recognises that persons with disabilities are presumed to have legal capacity on an equal basis with others in all aspects of their lives. Canada declares its understanding that Article 12 permits supported and substitute decision-making arrangements in appropriate circumstances and in accordance with the law.

To the extent Article 12 may be interpreted as requiring the elimination of all substitute decision-making arrangements, Canada reserves the right to continue their use in appropriate circumstances and subject to appropriate and effective safeguards. With respect to Article 12 (4), Canada reserves the right not to subject all such measures to regular review by an independent authority, where such measures are already subject to review or appeal.”

United Nations Committee on the Rights of Persons with Disabilities (“Committee”)

The Committee monitors Canada’s, and other State Parties’, progress in implementing their obligations under the CRPD. The Committee has three main functions:

- Monitors progress in implementation, by reviewing a State Party’s report on progress, and issuing ‘Concluding Observations’ outlining positive steps taken by the State Party, the Committee’s concerns about implementation gaps, and its recommendations for steps the State Party should take to address these gaps. In its April 2017 ‘Concluding Observations’ to Canada’s first report on progress on implementing the CRPD the Committee recommended that Canada should take “leadership in collaborating with provinces and territories to create a consistent framework for recognizing legal capacity and to enable access to the supports needed to exercise legal capacity.”⁸
- Provides authoritative interpretations of what different articles in the CRPD require of State Parties to fulfill their obligations under the treaty. The Committee’s “General comment No. 1” interprets what steps State Parties must take to fulfil their obligations under Article 12 of the CRPD, on ‘equal recognition before the law’, and the exercise of legal capacity, in particular;⁹ and,
- Considers claims under the procedures of the “Optional Protocol to the Convention on the Rights of Persons with Disabilities”¹⁰ brought by individuals or groups that they are victims of a violation of the CRPD by the State Party. Canada acceded to the Optional Protocol in 2018 which means that Canadians can make such complaints.

⁸ United Nations Committee on the Rights of Persons with Disabilities, “Concluding observations on the initial report of Canada”, May 8, 2017, para. 28, online: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5.

⁹ UN Committee on the Rights of Persons with Disabilities, “General Comment No. 1 – Article 12: Equal Recognition Before the Law,” UN Doc. No. CRPD/C/GC/1 (April 2014) [General Comment No. 1], online: <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>.

¹⁰ UN General Assembly, “Optional Protocol to the Convention on the Rights of Persons with Disabilities”, 13 December 2006, A/RES/61/106, Annex II, online: <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/OptionalProtocolRightsPersonsWithDisabilities.aspx>.

B. Sources of Law Regulating Legal Capacity in Newfoundland and Labrador

In Canada, legal capacity is largely regulated under provincial and territorial jurisdiction.¹¹ Like all other Canadian jurisdictions,¹² Newfoundland and Labrador has several pieces of legislation that regulate legal capacity, and it is also regulated under case law. A summary of select key sources is outlined below.

1. Provincial Legislation

Some Newfoundland and Labrador statutes have traditionally been recognized to regulate decision making broadly and provide for guardianship, substitute decision-making in health care, planning documents (e.g., powers of attorney and advance health care directives) and authority to intervene in situations of abuse and neglect. Importantly, each of these statutes has a common element: they specify what it means to be ‘capable’ and have the legal right to make one’s own decisions. There is also some limited recognition of the role of supports and/or assistance for the exercise of legal capacity. These core statutes¹³ set out conditions for exercising legal capacity in different contexts, and are as follows:

- ***Mentally Disabled Persons’ Estates Act***¹⁴ (MDPEA) – provides for the court to appoint a guardian of the estate of a “mentally disabled person” or of a person who is declared to be a person “incapable of managing his or her affairs”.
- ***Enduring Powers of Attorney Act***¹⁵ (EPAA) – sets out the requirements relating to enduring powers of attorney for finances and designation agreements for the Registered Disability Savings Plan (RDSP).
- ***Adult Protection Act***¹⁶ (APA) – provides legislative authority for delivery of services to adults “in need of protective intervention”.
- ***Advance Health Care Directives Act***¹⁷ (AHCDA) – sets out requirements for creating a legally valid advance health care directive and sets out legal rules for health care decision-making for “incompetent patients”.

¹¹ In general, the power to legislate on matters of legal capacity lies with the provinces and territories as a result of the division of powers established under the *Constitution Act, 1867*. Section 92(13), describes provincial legislature’s authority over “property and civil rights in the Province”.

¹² See WEL Partners, “Assessing Capacity in Canada: Cross-Provincial Examination of Capacity Legislation”, online: <http://welpartners.com/resources/WEL-Capacity-Legislation-Cross-Provincially-chart.pdf> for a chart of legislation that deals with legal capacity in each jurisdiction in Canada.

¹³ In *A.A. (Re)*, 2019 NLCA 7, paras. 14 to 21, Green J.A., in the process of determining whether or not statutory authority exists in Newfoundland and Labrador authorizing the appointment of a general guardian of the person, chose the following statutory sources to examine on the matter: *Mentally Disabled Persons’ Estates Act*, *Mental Health Care and Treatment Act*, *Adult Protection Act* and *Advance Health Care Directives Act*. Thus, Green, J.A. viewed these as the sources in the province that address guardianship and related matters. Although the *Enduring Powers of Attorney Act* too addresses legal capacity, it was not reviewed as it was clearly not relevant, covering only powers of attorney and not guardianship.

¹⁴ R.S.N.L. 1990, c. M-10.

¹⁵ R.S.N.L. 1990, c. E-11.

¹⁶ S.N.L. 2011, c. A-4.01.

- ***Mental Health Care and Treatment Act*¹⁸** (MHCTA) – provides for interventions for people with a “mental disorder”, including involuntary admission and treatment in a psychiatric unit, and community treatment orders.

While the ***Judicature Act*¹⁹** (JA) is a statute which was not designed to regulate legal capacity, it can be considered a core statute relating to legal capacity regulation because of the authority it gives to the Supreme Court of Newfoundland and Labrador to appoint guardians of the person as well as their estates. The *Judicature Act*, which establishes the Supreme Court and its procedures, was recently interpreted by the Newfoundland and Labrador Court of Appeal *A.A. (Re)*²⁰ to provide the Court with the jurisdiction to appoint a guardian of the person.²¹ In particular, section 3 of the *Judicature Act* recognizes that jurisdiction can be conferred on the Court by the original 1824 judicature act.²² And section 6 of this original statute allows for such appointments as follows:

The said Supreme Court shall have power and authority ... to appoint guardians and keepers of the persons and estates of natural fools, and of such as are or shall be deprived of their reason and understanding, so as to be unable to govern themselves and their affairs, which the said Supreme Court shall have the power and authority to inquire of and determine, by inspection of the person, or by such other ways and means as to such Supreme Court shall seem best for ascertaining the truth.²³

The Court of Appeal in *A.A. (Re)*²⁴ interpreted the combined effect of the provisions of the current and 1824 Judicature Acts as follows:

Despite its use of terminology (“natural fools”) of an earlier era that would be regarded as insensitive and unacceptable today, this statutory provision, which is homologated into the current *Judicature Act* by virtue of section 3(a), confers on the Court the jurisdiction to appoint guardians of the person (as well as their estates) of individuals who by reason of mental disability are “unable to govern themselves and their affairs”. Traditionally in English law, there was a distinction between “fools”, representing those who had never had and never would have the mental ability to manage their own affairs, and “lunatics” representing those who during some stage in their life lost an ability to manage their affairs that they formerly had...

Both categories are covered by section 6 by the references to “natural fools” and those “as are or shall be deprived (emphasis added)” of their reason and understanding.²⁵

¹⁷ S.N.L. 1995, c. A-4.1.

¹⁸ S.N.L. 2006, c. M-9.1.

¹⁹ R.S.N.L. 1990, c. J-4.

²⁰ 2019 NLCA 7.

²¹ *A.A. (Re)*, 2019 NLCA 7, para. 46.

²² *An Act for the better administration of justice in Newfoundland, and for other purposes*, 5 George IV, c. 67.

R.S.N.L. 1990, c. J-4, s. 3(1)(a) references this Judicature Act.

²³ *An Act for the better administration of justice in Newfoundland, and for other purposes*, 5 George IV, c. 67, s. 6.

²⁴ 2019 NLCA 7.

²⁵ *A.A. (Re)*, 2019 NLCA 7, paras. 25 and 26.

The ***Human Rights Act***²⁶ of Newfoundland and Labrador also bears directly on the legal capacity. It has as its broad purpose the prohibition of discrimination. The Act prohibits discrimination on various grounds and in certain protected areas, including on the basis of disability²⁷ in areas such as employment, provision of goods and services, and contracts.²⁸ Thus, to the extent that interactions or legal transactions involving decision-making are covered by the *Human Rights Act*, people with disabilities have the right to exercise legal capacity on an equal basis, consistent with the Act. However, there is a significant exception relating to the exercise of legal capacity: the Act does allow discrimination on the basis of disability in the context of contracts offered to the public where a person “refuses to contract with another person who does not have the legal capacity to contract” and the person is a person with a disability, as set out in the Act.²⁹

Accommodations are integral to achieving non-discrimination. The ‘duty to accommodate’ grounded in human rights law has been defined as follows: “...the responsibility of one party to adapt or adjust facilities, services or employment requirements to meet the needs of an individual or group having a characteristic that is protected under human rights legislation.”³⁰ This duty is what is required to avoid discrimination, and the Newfoundland and Labrador Human Rights Commission states that the goal of accommodation “... is to ensure that the person can fully and equally participate in society.”³¹ The duty is not unlimited, as accommodation extends only to the point of undue hardship.³² The duty to accommodate is well known to apply in contexts such as access to buildings, print material, the workplace and schools.

²⁶ S.N.L. 2010, c. H-13.1.

²⁷ Section 9(1) of the Act includes ‘disability’ as one of the prohibited grounds. For the purpose of the Act ‘disability’ is defined in s. 2, and is defined to include “a degree of physical disability”, “a condition of mental impairment or a developmental disability”, “a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or language” and “a mental disorder”.

²⁸ Section 11 (goods, services, accommodation and facilities), s. 14 (employment) and s. 21 (contracts that are offered to the public).

²⁹ Act s. 21(2). This exception applies to a person with a disability within the meaning of subparagraph 2(c)(ii) (i.e., a condition of mental impairment or a developmental disability) and 2(c)(iii) (i.e., a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or language). It does not apply to other types of disabilities set out in s. 2(c) including a “mental disorder”.

³⁰ Russel W. Zinn, *Law of Human Rights in Canada*, Release No. 38 (Toronto: Thompson Reuters, March 2019), at 14-2.

³¹ Newfoundland and Labrador Human Rights Commission, “Frequently Asked Questions”, “What does the term ‘accommodation’ mean?”, online: <https://thinkhumanrights.ca/education-and-resources/frequently-asked-questions/>.

³² While the duty to accommodate is not expressly provided for in the Newfoundland and Labrador *Human Rights Act*, a review of case law and Newfoundland and Labrador Human Rights Commission Guidelines documents the applicability of the duty to accommodate to the point of undue hardship. See Newfoundland and Labrador Human Rights Commission “Guidelines Regarding The Use Of Service Animals”; Newfoundland and Labrador Human Rights Commission “Guidelines For Accommodation Of Environmental Sensitivities”; *Anne Malone v. City Wide Taxi*, Newfoundland and Labrador Board of Inquiry, File # 13-7707, February 8, 2016.

Human rights legislation is rarely intuitively understood to have a bearing upon the exercise of legal capacity. Other than the exception relating to contracts highlighted above, neither the Newfoundland and Labrador *Human Rights Act* nor the Commission's guidelines set out the way in which the *Act* applies to decision-making. Nonetheless an understanding of the relevance of human rights, the duty to accommodate and discrimination, to legal capacity is burgeoning. For example, the Ontario Human Rights Commission "Policy on preventing discrimination based on mental health disabilities and addictions" describes ways in which Ontario's *Human Rights Code* applies to legal capacity and decision-making.³³ Importantly, the Policy states that human rights principles to keep in mind in the context of capacity are "... inclusive design, individualized assessment, respect for dignity, autonomy, confidentiality, opting for the least intrusive and restrictive options wherever possible, and integration and full participation wherever possible."

These principles are equally applicable to the Newfoundland and Labrador *Human Rights Act* and coincide with the purpose of the *Act*. Its Preamble makes clear that the *Act* has as its purposes the promotion of equality and dignity, including "...having as its aim the creation of a climate of understanding and mutual respect for the dignity and worth of each person so that each person feels part of the community and able to contribute fully to the development and well-being of the community and the province."³⁴ Ensuring that everyone can exercise legal capacity on an equal basis is consistent with promoting a sense of dignity and inclusion in the community for people with disabilities. Conversely, denying power to control's one's decisions results in isolation and feelings of diminished self-worth.

The Ontario Human Rights Commission policy also suggests examples of ways in which environments can be designed to facilitate participation in decision-making. These are equally applicable in the Newfoundland and Labrador context, and are as follows:

- Offer plain-language self-help resources to help people with disabilities make their own decisions about taking part
- Establish an accessibility office, or trained staff that act as a resource for people with capacity issues to seek information or assistance
- Make sure that everyone can provide informed consent – that is, make sure everyone has the information they need to make a decision, including possible outcomes flowing from that decision
- Involve a support network or circle of support (such as family or friends) to help the person make decisions or interpret what a person wants when they need to make a decision.³⁵

³³ Ontario Human Rights Commission, "Policy on preventing discrimination based on mental health disabilities and addictions," Chapter 16, Consent and Capacity (2014), online: <http://www.ohrc.on.ca/en/policy-preventing-discrimination-based-mental-health-disabilities-and-addictions/16-consent-and-capacity>.

³⁴ S.N.L. 2010, c. H-13.1, preamble.

³⁵ Ontario Human Rights Commission, "Policy on preventing discrimination based on mental health disabilities and addictions," note 33, 68.

Both the Ontario Human Rights Commission and the Law Commission of Ontario stress the importance of providing accommodations for the processes for making determinations about a person's capacity and for meeting the test of capacity.³⁶

Newfoundland and Labrador's *Human Rights Act* cites the United Nations *Universal Declaration of Human Rights* in its preamble³⁷ thus signaling the significance of United Nations human rights instruments, the CRPD being one of them, to ground its interpretation. Thus, guidance on the relevance and applicability of the duty to accommodate to legal capacity can be appropriately gleaned from the Committee on the Rights of Persons with Disabilities, in its General Comments on the CRPD.³⁸ In its General Comment on Article 12 the Committee states that "[n]on-discrimination includes the right to reasonable accommodation in the exercise of legal capacity (art. 5, para. 3)." and that "[t]he right to reasonable accommodation in the exercise of legal capacity is separate from, and complementary to, the right to support in the exercise of legal capacity."³⁹

In summary, there is a wide latitude and scope for a broad interpretation of the *Human Rights Act* in relation to the exercise of legal capacity. There is opportunity to proactively detail and concretize the ways in which human rights law can be used to promote exercise of legal capacity on an equal basis for people with disabilities.

While the scope of the legal research was primarily on the statutes that have traditionally been associated with regulation of legal capacity, this does not mean that those laws are the only ones that have an impact on decision-making in the lives of people who live in Newfoundland and Labrador. Indeed, in most jurisdictions a multitude of laws have an impact on the exercise of legal capacity, and provisions which can be activated to restrict a person's power over some aspect of their lives, sometimes with a wide scope of discretion by the authority applying it, are often almost invisible in legislation ostensibly designed for unrelated purposes. This relative obscurity, in relation to more prominent core statutes, may contribute to a lack of public awareness and concern about how pervasive the state's power to regulate legal capacity actually is, whether through the executive, legislative or judicial branches of government.

For example, for some people, provisions in a core statute like the MHCTA may be applied to profoundly restrict their exercise of legal capacity if they are involuntarily detained and treatment. Or, if a person is under personal or property guardianship appointed either by the

³⁶ Ontario Human Rights Commission, "Policy on preventing discrimination based on mental health disabilities and addictions," note 33 68; Law Commission of Ontario, *Legal Capacity, Decision-making and Guardianship: Final Report* (Toronto: March 2017), 94, online <http://www.lco-cdo.org/wp-content/uploads/2017/03/CG-Final-Report-EN-online.pdf>.

³⁷ S.N.L. 2010, c. H-13.1, preamble.

³⁸ UN Committee on the Rights of Persons with Disabilities, "General Comment No.1," note 9; UN Committee on the Rights of Persons with Disabilities, "General Comment No. 6 on equality and non-discrimination," UN Doc. No. CRPD/C/GC/6 (April 2018), online: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en.

³⁹ General Comment No.1, note 9, para. 34.

Supreme Court or under the MDPEA, their power to make decisions in some or all areas of their life is removed for varying degrees of time.

However, for other people, restrictions on their legal capacity are authorized under statutes not commonly associated with regulating legal capacity. For example, the Newfoundland and Labrador *Income and Employment Support Act*,⁴⁰ along with its regulations, governs income support benefits. It provides for payment to a “trustee” where a person is determined to be unable to manage their affairs. Specifically, income support benefits may be paid to a third party on behalf of that person where “...an applicant or a recipient is temporarily or permanently incapable of managing his or her financial affairs.”⁴¹

Indeed, focus groups with senior government officials, conducted as part of the consultation and research, pointed to a range of provincial legislation beyond the core statutes that requires careful examination for their potential impact on people’s exercise of legal capacity. These include, for example:

- Trustee Act;⁴²
- Public Trustee Act;⁴³
- Wills Act;⁴⁴
- Residential Tenancies Act;⁴⁵
- Elections Act;⁴⁶
- Personal Health Information Act;⁴⁷ and,
- Access to Information and Protection of Privacy Act.⁴⁸

2. Federal Legislation

Additionally, some federal statutory provisions impact the exercise of legal capacity for people with disabilities in Newfoundland and Labrador.⁴⁹ For example, the *Income Tax Act*’s provisions relating to the Registered Disability Savings Plan (RDSP) require that a person have “contractual competence” in order to personally enter into an RDSP or regain control over an RDSP opened

⁴⁰ S.N.L. 2002, c. I-0.1.

⁴¹ *Income and Employment Support Act*, S.N.L. 2002, c. I-0.1, s. 20; *Income and Employment Support Regulations*, N.L.R. Reg. 144/04, s. 47. Also see *Income and Employment Support Policy Manual*, Chapter 14, “Administration of Income Support”, Advanced Education, Skills and Labour, online: <https://www.aesl.gov.nl.ca/policymanual/index.htm>.

⁴² R.S.N.L. 1990, c. T-10.

⁴³ S.N.L. 2009, c. P-46.1.

⁴⁴ R.S.N.L. 1990, c. W-10.

⁴⁵ S.N.L. 2018, c. R-14.2.

⁴⁶ S.N.L. 1992, c. E-3.1.

⁴⁷ S.N.L. 2008, c. P-7.01.

⁴⁸ S.N.L. 2015, c. A-1.2.

⁴⁹ See Faisal Bhabha and Brendon Pooran, “Equality in the National Interest: Implementing the CRPD Right to Supports in Legal Decision Making under Canadian Federalism” (Toronto: IRIS – Institute for Research and Development on Inclusion and Society, 2020) for a detailed review of federal laws that regulate legal capacity.

on one's behalf.⁵⁰ Provisions of the *Enduring Powers of Attorney Act* allow adults who may lack legal capacity and want to establish an RDSP to create a designation agreement to name a person as their legally authorized representative for that purpose.⁵¹ Similarly, the *Canada Pension Plan*⁵² and *Criminal Code* provisions relating to medical assistance in dying⁵³ each contain provisions relating to people who have limitations in cognitive capacity. These apply to all Canadians, including people in Newfoundland and Labrador.

3. Jurisprudence

As discussed in section VI below, the legal research identified gaps in the statutory framework that regulates legal capacity in Newfoundland and Labrador. These gaps are currently addressed through legal principles and rules from case law. Most notably, despite the provisions of the *Judicature Act*, there is no statute that comprehensively regulates legal capacity in the context of personal care decisions.⁵⁴ Pending law reform to address the gaps, the *parens patriae* jurisdiction continues to be relevant to situations where there is concern about the need to protect a person who is perceived to be mentally incompetent. The Supreme Court of Canada stated in *Re Eve*⁵⁵ that the exercise of this jurisdiction is "... founded on necessity, namely the need to act for the protection of those who cannot care for themselves. The courts have frequently stated that it is to be exercised in the "best interests" of the protected person ... for his or her "benefit" or "welfare"."⁵⁶ It is a broad jurisdiction without a finite list of the kinds of situations in which it can be invoked.⁵⁷ The Newfoundland and Labrador Court of Appeal, in *A.A. (Re)* concluded that the *parens patriae* jurisdiction of the Supreme Court of Newfoundland and Labrador, in addition to the *Judicature Act*, provides authority for it to appoint guardians of the person.⁵⁸

In *A.A. (Re)* the Court of Appeal set out a number of principles applicable to the Supreme Court's exercise of its jurisdiction to appoint guardians of the person.⁵⁹ The Court set out a test which would justify an order appointing a guardian of the person, as follows:

"... in order to justify an order appointing a guardian of the person related to general care, the applicants must establish on a balance of probabilities that the person in question:

⁵⁰ *Income Tax Act*, R.S.C. 1985, c. 1 (5th Supp), s. 146.4.

⁵¹ *Enduring Powers of Attorney Act*, R.S.N.L. 1990, c. E-11, s. 15 – 22.

⁵² *Canada Pension Plan*, R.S.C., 1985, c. C-8 and *Canada Pension Plan Regulations*, C.R.C., c. 385, s. 55.

⁵³ *Criminal Code*, R.S.C. 1985, c. C-46, s. 241.2(1)(b).

⁵⁴ *A.A. (Re)*, 2019 NLCA 7, para. 21. Note that there is legislation in the province that covers specific personal care decisions in limited circumstances. For example, health care decisions are regulated by the *Advance Health Care Directives Act* and the *Adult Protection Act*, S.N.L. 2011, c. A-4.01 provides for intervention when an adult is determined to be "in need of protective intervention".

⁵⁵ [1986] 2 S.C.R. 388.

⁵⁶ *Re Eve*, [1986] 2 S.C.R. 388, para. 73.

⁵⁷ *Re Eve*, [1986] 2 S.C.R. 388, para. 74.

⁵⁸ *A.A. (Re)*, 2019 NLCA 7, paras. 48 and 65.

⁵⁹ *A.A. (Re)*, 2019 NLCA 7, paras. 70 to 107.

- (i) is unable to understand the information that is relevant or necessary to make a decision about his or her personal care; or
- (ii) is unable to appreciate, or reason in respect of, the reasonably foreseeable consequences of those decisions or of failure to make those decisions.”⁶⁰

Other common law sources also play a significant role in the day to day lives of people with disabilities and seniors. For example, the test for testamentary capacity, which is the requirement that the testator meet a test of mental capacity to make a valid will, has been articulated by the Supreme Court of Canada and applies in Newfoundland and Labrador by virtue of common law, alongside the province’s *Wills Act*.⁶¹

In summary, it was beyond the scope of this research and report to undertake a detailed examination of each of the above-noted statutes and a systematic review of case law regulating legal capacity in the province. The statutes itemized above are a starting point for analysis of statutory law but likely form only a partial list of relevant laws. To ensure that the regulation of legal capacity in Newfoundland and Labrador complies with the *Charter* and CRPD, each piece of legislation and the array of legal principles and rules from case law that impact on decision-making should be scrutinized. The analysis and recommendations in this study provide a research-based framework to work towards compliance and consistency of legal approach in all domains of decision making regulated by the provincial regime for legal capacity.

⁶⁰ *A.A. (Re)*, 2019 NLCA 7, para. 76.

⁶¹ See e.g., the following examples of cases in Newfoundland and Labrador that articulate the test of testamentary capacity: *Melendy v. Drodge*, 2015 NLTD(G) 96, June 30, 2015 and *Martin Estate*, 2011 NLTD(G) 155, 2011/11/09.

Appendix F

What We Heard: Personal and Inter-personal, Program and Policy Barriers to Exercising Legal Capacity and Decision Making

INTRODUCTION

This ‘What We Heard’ report draws on the initial focus groups for the consultation and key informant interviews with both government officials and community stakeholders.

Researchers met with government officials and community stakeholders in March and April 2018 to identify their perspective on key issues to address in implementing a supported decision-making approach:

- Two focus groups (approximately 40 participants) were conducted with government officials from departments of:
 - Justice and Public Safety;
 - Health and Community Services;
 - Children, Seniors and Social Development; and
 - Advanced Education and Skills.
- Researchers also met in focus group format with representatives of the “Steering Committee on Citizenship and Legal Capacity for All,” and some members of their respective community organizations, including:
 - Coalition of Persons with Disabilities, Newfoundland and Labrador;
 - Consumers Health Awareness Newfoundland and Labrador (CHANAL);
 - Newfoundland and Labrador Association for Community Living; and
 - Seniors Resource Centre, Newfoundland and Labrador.

Researchers also undertook interviews with key informants both in government and in community services to gather information about:

- opportunities, challenges and good examples in the province for enhancing personal choice and decision-making capability under the current laws, policies and programs related to supports for decision making;
- implications for both government and community sectors of moving towards a fully inclusive supported decision-making approach; and
- the duty to accommodate persons in decision-making processes in health care and other settings.

Key informants included:

- Thirteen senior officials with the following government departments and public agencies were interviewed:
 - Department of Health and Community Services (including from the senior leadership team, and Mental Health and Addictions, and Adult Protection);
 - Department of Children, Seniors and Social Development (including from In Care, Adoptions, Poverty Reduction Strategy, and Disability Policy Office);
 - Office of the Public Trustee; and
 - Newfoundland and Labrador Human Rights Commission.

- Ten individuals with health and community service agencies, including:
 - Health care providers;
 - Youth services;
 - Disability-related home and community support services;
 - Residential and housing services;
 - Training and employment services; and
 - Seniors' home support services.

Both researchers conducted the focus groups and all the interviews, except one. Data gathered was analyzed to identify themes about key issues and barriers in exercising legal capacity, and creating a policy, program and practice framework to implement supports for decision making.

The analysis did not include a comprehensive review of all support arrangements and related policies and service delivery in the province. Nonetheless, the issues and consequences identified are indicative of arrangements that appear, in a systematic way, to impair enjoyment of the equal right to legal capacity.

Focus group participants and key informants identified barriers:

- at the personal level and in inter-personal relationships;
- in service delivery (e.g., health care, disability/home supports, social services and benefits, and public services); and
- in public policies.

It should be noted that a comprehensive review of all related programs, service delivery systems, and public policies identified in the focus group discussions and key informant interviews was beyond the scope of this consultation and research. Thus, definitive conclusions about them cannot be drawn based on this research. That said, the respondents pointed to wide-ranging barriers experienced.

A. Personal and Inter-personal Barriers to Exercising Personal Choice and Control

Key informants pointed to many ways in which both young people and adults with disabilities are not able to exercise choice and control in their daily lives because of self-perception, devaluation, and the nature of interactions and relationships with family members, health and community service providers:

1. People “relinquish their voice”

- Informants referenced situations where a person appeared to give up power over their lives after a lifetime of not being valued, being abused, traumatic experience, low self-esteem, mistrust of formal systems and anxiety about the justice system, including not having positive ‘run-ins’ with police and the courts. One provider said, “the system is frightening” for some people they support and

that as a result of these many factors some people “relinquish their voice” all together.

2. ***Some “not ready” to make choices on their own***

- Complex disability-related conditions and social and economic marginalization can mean that some people, as one provider put it, “are not ready for choices” without intensive support. Many of the providers interviewed indicated that when you layer on the effects of social rejection, mental health issues, addictions, violence-induced brain injury, being drawn into the sex trade since age 12, chronic homelessness, incarceration and the ongoing effects of trauma, the capacity to exercise choice can be significantly limited.
- Providers indicate these are complex challenges, not easily overcome. An individualized approach is needed, focused on: building personal relationships; obtaining secure housing; facilitating social participation, peer support and counselling; arranging community access; and enabling employment opportunities. They suggest that these steps are essential for a person gaining the confidence needed to start making personal goals and acting on them.

3. ***Over-control exercised by families, support providers and appointed representatives***

- Informants indicated that lack of options and awareness about the equal right to exercise legal capacity leads some family members of people with intellectual, developmental or cognitive disabilities or mental health issues to seek guardianship because of their concern to protect the person and their financial interests. Informants also suggested that some people are not able to finance the legal costs or wait for the legal process to conclude, given that it can take a couple of years (with the time it takes to obtain capacity assessments and for related court proceedings). Consequently, they try and manage informally. Some service providers who were interviewed indicated parents can effectively exercise decision-making control over their family member in practice, even if not legally.
- Concerns were also expressed that representatives appointed under enduring powers of attorney do not always act at the direction of the person/principal who appointed them, and without safeguards many people are being subjected to control and abuse.
- Despite the government policy commitment to individualized and person-centered approaches, some informants felt that home support agencies are not sufficiently designed, funded or required to enable people to have control and choice in their lives, and that too often the opposite results.
- Some informants expressed serious concern about the involuntary hospitalization and treatment of people with mental health issues, and the

automatic appointment of the public trustee as substitute decision maker for finances/estate in many of these circumstances. They felt that adequate consideration of community-based alternatives both for care and for decision making, is sorely lacking.

4. *At the “tipping point” with limited options: youth, adults with complex needs and aging parents*

- People with disabilities, family members, community providers and government officials all pointed to the challenges of assisting the growing number of people at key transition points where the pathway to needed supports is not clear. These individuals and families are at “tipping points” as one provider referred to it, where the options are limited and enabling personal choice and control are often foregone in a system that fails to adapt to changing needs and circumstances.
- Three types of situations were referenced: youth transitioning and ‘ageing out’ of children’s services, with no clear support arrangement or resourcing package on reaching adulthood; aging parents no longer able to care for sons and daughters with significant disabilities; and adults with complex needs who do not fit funding or community support program criteria. Community providers who were interviewed pointed to many examples where, driven by their commitment to delivering individualized supports, they adapt their resources to respond to complex situations. However, they also indicated that their capacity to do so is severely restricted without additional resources.

5. *Families encouraged to apply for guardianship to protect a person’s future*

- Some key informants indicated that families felt pressured into placing family members under guardianship in order to manage wealth transfer and future planning. Parents are being encouraged to place youth/adult sons and daughters under guardianship when they turn eighteen, as a matter of course.
- It was reported that for many parents it was a “catch-22”: if you refuse guardianship to protect a family member’s rights, you may be undermining their future financial security. No other legal options seem available.

6. *Making choices that result in severe risk or harm*

- Most key informants raised the challenge of how to effectively respond in situations where people are making choices that that are leading to harm. One provider indicated that “we meet them [clients] where they are at” because “we

have no power, we don't make the choices... you can't support someone who doesn't want to be supported, it's about the journey of change." While committed to the principle of individual direction and choice, and respect for the 'dignity of risk', informants indicated there was lack of clarity about when and how to intervene in situations of significant risk of harm to personal interests – for example, where a person with significant brain injury refuses assistance, and others are concerned about him "drinking away" his inheritance or insurance settlement. This person may meet the legal test of capacity but is making choices that undermine longer-term personal interests. As one respondent asked, reflecting the concerns of many others, "whose responsibility is it to step in?" in such situations; and "where is the line between dignity of risk and harm that justifies intervention?"

7. *Encountering systemic barriers to exercising choice and control*

Drawing from their personal, professional and service provider experience, many key informants pointed to ways that service and benefits systems restricted or denied personal choice and control – either to themselves, people they advocated for, or clients of agencies where they worked. Key informants made the following reports about barriers in these systems:

- Health care system:
 - Some individuals and families being told the person cannot access health care without their parents or family member first getting a guardianship order in place;
 - Family members not getting health issues addressed because of fear that physicians would trigger guardianship proceedings;
 - Health care providers refusing access to a patient's health information by the person's informal representatives (family member, friend, support providers); and,
 - Many physicians not having the time, confidence, and knowledge to provide effective health care to people with intellectual or developmental disabilities.
- Mental health care:
 - Patients not having control in health care decision making – either themselves or through advance directives or their WRAP plan (Wellness Recovery Action Plan) when involuntarily committed to a psychiatric facility;
 - Physicians having the authority to over-ride patient decisions, including through forced treatment and medications against a person's expressed

- will, which according to one informant's report increased a patient's paranoid delusions;
- Only being able to access a hospital-designated patient representative (advisor), when a patient would rather choose a person they know as their advisor/supporter in the health care system.
- Long-term care:
 - Spouses of patients in long-term care feeling not listened to by health care providers who refuse their requests to use or not use certain medications.
 - Justice system:
 - People being denied medications they need when detained in the criminal justice system.
 - Community supports system (i.e., alternate family care and home support):
 - People with disabilities being placed in an alternative family arrangement they do not choose, without the power to decide who will provide them support, and without tenure security – i.e., they can be moved out of their home if the alternative family chooses to end the support relationship, or move away;
 - Lacking access to needed individualized disability-related and home supports based on person-directed principles; despite widespread recognition that this is needed; and,
 - Families/informal care providers who help administer self-managed home care options, lacking the back-up support to deal with the care and management burden, the personal pressure that comes with this arrangement, and a variety of concerns including dealing with liability for employees.
 - Income security:
 - Similar to barriers representatives face in accessing health care information, a person's informal representatives not being able to transact with Canada Revenue Agency and other government services on their behalf, because they are not a legally appointed guardian or power of attorney;
 - Income support workers, who have significant discretion to arrange proxies for managing a person's income benefits if they believe the person is not capable, not effectively coordinating with community support providers to look at alternatives to assist the person to maintain control over their property; and,
 - Community service providers needing more legally recognized options to assist people with episodic difficulties to manage their income benefits, in ways that enable the person to direct and maintain authority while

drawing on the assistance of the provider to ‘hold’ and manage their income, through voluntary trusts or other mechanisms.

B. Program-level Barriers to Exercising Personal Choice and Control

Programs are the structured delivery of goods and services – whether through non-profit, community-based, public or private sector service providers. In the area of supports and benefits for people with disabilities there are a range of programs, including, for example, clinical or supports assessment, individual planning services, programs that deliver income benefits, and delivery of services like health care, home care, residential support and employment supports. Key informants pointed to ways in which current design and delivery of some programs often result in lack of choice and control, including:

1. *“Fitting people into boxes”*

- Some informants felt that both community providers and Regional Health Authorities are failing to deliver their programs in a person-centered and directed way and are not ensuring that their clients maintain authority over their decisions. One informant suggested, the predominant approach still is “fitting people into boxes,” based on an assessed ‘level of support’, or a program or placement that is available.

2. *“Culture barriers” in management and service delivery*

- For people with disabilities to gain authority over their lives a “culture shift” is needed as one informant put it, in programs and services which deliver disability supports, income benefits, health care and other supports. The shift “has to come from the management down” and is needed across the Regional Health Authorities, it was suggested, as well as community service providers. Key informants pointed to over-riding principles and priorities to guide this culture shift, including:
 - respect for a person’s autonomy and dignity;
 - building trusting relationships with the person which they can rely upon;
 - being guided in needs assessment by “starting where people are” – their concerns, life goals and interests, and nurturing expression of these where needed;
 - individualizing supports to deliver on those goals; and,
 - providing personal planning and community navigation support.

3. *Lack of program resources, individualized design, and province-wide capacity to deliver responsive and individualized supports*

Key informants identified many barriers in programs that prevented delivery of supports in the individualized and person-directed manner, which they universally indicated were required. They pointed to restrictions on choice and control for both individuals with disabilities and families:

- Lack of program resources/funding:
 - Some providers suggested that intensive case management and individualized support teams are required to address the complex of issues underlying powerlessness and lack of choice and control in a person's life. These issues vary among individuals, though common needs appear to be assisting with life skills; addressing economic insecurity; finding affordable housing; arranging personal disability-related supports; accessing transportation and learning about bus routes; dealing with 'hoarding' behaviour to prevent eviction; and addressing the daily violence in people's lives. However, providers suggested the resources and capacity to deliver these individualized responses at the scale required is lacking.
- Uneven capacity across the province:
 - There is obviously more program capacity in larger centres to provide these intensive, individualized supports. However, needed community-based capacity to provide individualized supports is limited overall, and varies dramatically across the province. Informants indicated that it is especially limited, or non-existent, in small centres, rural and remote areas. As some service providers indicated, this also poses a challenge where governments rely on community agencies to meet individualized support needs, with one provider noting that "child welfare often calls and says we need help with a complex case." However, as the provider noted, the needed capacity to effectively respond to those requests is often not available.
 - While effective approaches to delivering individualized supports in a person-directed manner are being created and delivered, there is lack of resources and capacity to effectively 'scale out' these approaches to address the inequities in capacity across the province.
- Inflexible/non-portable home supports:
 - Self-management of home supports was seen as an essential factor in enabling greater choice and control. However, some informants indicated that inflexibility in how those supports can be used prevented individuals from achieving personal goals. For example, it was reported that not being able to have a support provider assist a person to get to their place of work and on the job as needed, posed a major barrier to employment. Continuity of the support person throughout the day is essential for some

individuals. Some informants indicated that the provincial individualized funding project should help address this lack of flexibility.

- Need for community-based capacity to respond to diverse needs:
 - Key informants identified individualized, flexible and portable supports as essential features of an effective community supports system. Many also indicated that program capacity to deliver specialized options was needed, in addition to providing individualized home support including, for example: creating social enterprises where individuals could be part of ‘start-up’ business opportunities; exploring and arranging access to educational and training opportunities; needle exchange programs; supportive housing options; setting up voluntary trusts; and mechanisms to assist people to manage their income and benefits.
- Lack of sustainable funding for individualized and responsive community-based supports:
 - Key informants indicated that a sustainable funding model for these supports was lacking. Providers indicated that they were experiencing growing demand, and that that this was the case across the province.¹ One provider expressed the concern that the government funder was concerned about community agencies becoming too “dependent” on funding. The community view appeared to be that there was urgent need for a sustainable public funding model, responsive to growing demand for mental health and other community-based supports. They saw this as essential to achieve the objectives for community well-being the government had laid out in recent reports.
- Over-reliance on informal support of families:
 - Limited resources, growing demand, lack of individualized options, and inadequate community programming are all putting more stress on families to fill the supports gap for their family member(s) with a disability, and many are simply not equipped to meet this need.
 - One provider suggested this is a policy choice – downloading what was recognized as a public responsibility to informal care of families. Some adults with disabilities are forced to live at home with families or are forced out or leave as things break down in the family home. It was suggested by some key informants that disproportionate homelessness, hospitalization and incarceration of people with disabilities is resulting from an inadequately funded community supports system that over-

¹ This perception is confirmed by the findings of the ‘Provincial Home Support Program Review’, undertaken by Deloitte in 2016, which estimated an increase in demand of approximately 14% over the succeeding five years. See, Deloitte, *Provincial Home Support Program Review, Department of Health & Community Services: Final Report* (2016), 3, online: https://www.health.gov.nl.ca/health/personsdisabilities/pdf/executive_report_phsp_review.pdf.

relies on informal care without providing the back-up and financial supports required.

- It was acknowledged that policies and programs are beginning to recognize the role of families, with some provision for a ‘paid family caregiving option’ under the provincial home supports program, and that this option was both welcome and needed to be expanded and complemented with additional community and back-up supports. Nonetheless, as one the provider informant put it, “the overall the vision for a community-based support system isn’t there; it relies on the informal support system of families.”

4. ***Lack of affordable housing options leaving “emergency response as the only response” and “addiction to crisis”***

- Many informants spoke of the need for much more affordable, safe and inclusive housing options with effective linkages to community services. They indicated that more and more people are vulnerable to homelessness, abuse and neglect – and therefore powerlessness in their lives. This results from a combination of factors, including what were referred to by one informant as “unscrupulous landlords”, inadequate response by government to unmet housing needs, and an absence of tools (like adequately financed rent supplements as one informant suggested) to access available housing in the private market and then layer on the individualized supports that are needed. The consequence of inadequate funding to respond to housing and supports need, according to another provider, is “emergency response as the only response” for many individuals, and a system that is “addicted to crisis.”

5. ***Inadequate future planning “short-changing” individuals***

- Some key informants indicated that there are many income benefits – from federal, provincial and private sources (i.e., insurance benefits) – that individuals with disabilities are not accessing but could be if they and their families had access to support for future planning. One informant suggested that with “benefits being left on the table” individuals with disabilities are being “short-changed.” One example pointed to is the federally financed ‘Registered Disability Savings Plan.’ Many eligible individuals are not accessing this program because of lack of information and support in opening a plan. As well, it was suggested that because some adults are considered legally incapable of opening a plan on their own, their families fear that opening one on the person’s behalf could trigger third parties to require the person to be placed under guardianship. All of

these factors it was suggested unnecessarily restrict future choices and opportunities for people with disabilities.

6. *Some concerns that Regional Health Authority staff lack needed awareness, have conflicting mandates and roles, and lack trusting relationships*

- The consultation did not include a systematic survey or interviews with government officials, social workers and community health nurses who are mandated to undertake needs assessment and allocate services through provincially funded programs, like the home supports program delivered through Regional Health Authorities (RHAs). However, some key informants – including community service providers, people with disabilities, families and representatives of their organizations – raised concerns about the ways in which the functions provided by RHA social workers and community health nurses were designed and delivered. These concerns include:
 - Individual support plans driven only or primarily by clinical assessment:
 - The gatekeeping role in RHAs is accomplished through the clinical assessment and home support planning functions led by social workers or community health nurses on behalf of the RHAs and the Department of Health and Community Services. Some key informants suggested the combining of these two functions under the RHA does not give the individual planning function the scope that it needs to be truly accountable to the person’s needs and choices. They believed that the clinical assessment is one important input, but that the planning process should be driven more by the person’s goals and aims. Clinical assessment should be about what the needs are to achieve those personal goals, and how those needs can best be met.
 - Lack of independence between assessment and planning functions:
 - Informants believed the lack of independence of the person-directed planning function, from clinical assessment and resource allocation, is resulting in planning which is ineffective and inefficient because: it is insufficiently person-directed and person-centered; and, because it fails to adequately tap and maximize existing community resources to meet a person’s needs as defined by the goals they wish to pursue.
 - Clinical assessment by RHAs is an essential and critically important input to the planning process, these key informants believed. However, based on their experience, they also believe that community-based providers are better positioned to deliver the planning and community navigation function. Because they are not the funder, they are not conflicted in their role to assist the person to develop a support network, nurture

expression of individual goals, identify the full range of their needs to achieve those goals, and then tap whatever community opportunities and resources they can find to present options to meet those needs, including with funding from the RHAs. Separated from the funding role, community-based providers indicated they can start from building a trusting relationship with the person, bring to the planning process their extensive knowledge about community resources and then can maximize community responsiveness to an individual's goal-directed needs through their networks for inter-agency communication, collaboration and coordination.

- Lack of needed expertise
 - Some key informants suggested that because social workers are largely generalists, they lack the needed specialist knowledge to deal with complex cases. One informant expressed serious frustration about the lack of effort, process and machinery to convene the range of clinical and other experts required to address complex issues. They said, “there is zero understanding of the multi-factorial approach needed” among the government RHA social workers and community health nurses they engage with. Community-based providers were having to educate RHA social workers, this informant suggested: “No one is prepared to take responsibility. Very frustrating to try and manage... We can't even get the basic level of support sorted out, let alone improving upon what is needed.” Informants suggested that part of the reason was that social workers were often unavailable to deal with complex situations because they had such heavy caseloads (80-90 clients according to some informants), and many were perceived as lacking the necessary expertise.
- Lack of community navigation supports when supports come to a “crashing halt”:
 - Many informants suggested that an essential component of a system to enable people to exercise choice and control in their lives is having ‘navigation support’. Lack of coordination and navigation support to assist individuals to make their way through what can be a maze of community programs, options and benefits, also means that the potential of both the informal and formal community support systems are not being maximized.
 - An important dimension of navigation support is having a clear point of response in the community to help individuals and families identify their needs, explore options, and make decisions about how to best get them addressed. Some providers indicated that this “is the biggest service we provide – we can connect people, using our common sense, to the resources they need.” In describing the value of providing this service,

one provider reported that a parent drove three-to-four hours to meet them, anticipating the end of children's services for their adult child, and said to the provider "you cannot believe the relief I feel, I need a number to call, someone who knows me, who can sort it out, the support through [a children's agency] comes to a crashing halt at age 18."

- Informants perceived that the need is large and growing for a more systematic provision of community navigators. Having access to this support would address, they believed, many barriers to the choice and control people need in their lives. One provider indicated that the primary need of approximately 25% of the people they were supporting was for navigation support. However, community providers reported that they are not being resourced or mandated to undertake this as part of their day-to-day functioning, despite the demonstrated need.
- A pilot initiative to develop navigational supports was referenced as a welcome and positive development.
- RHAs limited in effective planning, navigation and community coordination by gate-keeping role:
 - Some key informants believed that community organizations are much better poised to deliver individual planning and navigation support than government social workers, who are more strictly bound by program mandates and their gate-keeping role in government. Informants suggested that this results in individual planning, navigation and community coordination that is not responsive to individual goals and choices.
- Not trusted by some community members:
 - One provider suggested that "people don't trust government; you need community providers who can build that trust." This was due, it was suggested, to two main factors. First, the collapsing together of clinical assessment and individual planning, when the two functions are better delivered independently. Secondly, some informants perceived a cultural norm and expectation among RHA staff that government social workers shouldn't develop too close a relationship with individuals; that this would undermine fairness in the system. One person believed that this underlay what many experienced as "constant turnover" of social workers in their clients' lives and helped to breed lack of needed expertise along with mistrust in the system.
 - The exception to this assessment was for individuals who accessed adult protection services. That system appears to be much more effective in deploying government social workers to undertake planning, arrange needed resources and link needed community services to respond to individuals in crisis situations. The focus appears to be on building long-

term, sustainable solutions. We discuss in the next section the policy and legal basis for this different approach in the adult protection system.

7. Prevalence of “institutional mistrust”

- One key informant suggested that “institutional mistrust” was growing between some government and some community sectors because of a failure among some RHA social workers and community agencies to effectively resolve issues arising in difficult individual cases. This mistrust is undermining, in the informant’s perception, the needed collaboration and coordination to address a growing number of increasingly complex and multi-factorial situations where housing, health, income, support, developmental and safety needs of individuals must be dealt with simultaneously. The consequence of this mistrust, they believe, is a misalignment of resources and missed opportunities so that needs go unaddressed, and community capacity to effectively respond goes untapped and undeveloped. It was perceived that, as a result, people are not getting the arrangements in place in their lives that would give them greater voice, choice and control, and ultimately greater health and well-being.

8. Community-based health and social service providers lacking tools and information resources on supports for decision making

- Some key informants who were staff with community-based providers indicated that while they are committed to supporting people’s increased choice and control, they lack structured tools, training and back-up to fully incorporate this approach into their delivery. Some mentioned that there is scope for expanding this focus within professional development.
- Some providers indicated that they were lacking psychologists who could do updated assessments of capacity, including of the supports that people may require to exercise decision making in their lives.
- There was also awareness that people with disabilities faced barriers to accessing health care and other community services – whether because of built environment barriers, how services were delivered and lack of accessible communication. Some informants pointed to the need for assistance in barriers assessment/auditing and ways to make their services more accessible, as part of a broader strategy to enable people to access services they choose.

C. Policy Barriers in Exercising Personal Choice and Control

Policies are decisions by the legislature and governments about who will get what benefits and who will face what restrictions, and on what conditions. Policy decisions are reflected in legislation, regulations and policy statements and guidelines. Key informants pointed to a wide

range of policy decisions that affect exercise of legal capacity and access to disability-related supports needed for this purpose, including policy decisions about:

- *Criteria for legal capacity* – What eligibility criteria must be met to exercise capacity;
- *Safeguards* – What measures will be in place to safeguard individuals;
- *Range of supports* – What range of planning and other supports, which are needed to enable people to exercise choice and control in their lives, will be resourced through government investment;
- *Eligibility for supports* – What eligibility criteria for accessing what supports, and what balance between individual, family and community contributions;
- *Scope of funding* – How much public funding will be allocated to which needed supports, and what principles will guide the allocation;
- *Mechanisms for delivery* – What mechanisms will be employed for making supports available, and whether they will be delivered directly through public services or contracted out through community agencies, and how to maximize equitable delivery across the province; and,
- *Adjudicating disputes* – Which entities will be authorized to adjudicate and on what basis.

Key informants identified the following policy issues affecting the exercise of legal capacity in Newfoundland and Labrador, and the consequences they raise for individuals, families and community stakeholders.

1. *Lacking consensus about delivery of person-centered planning support: government-based or ‘independent’ planning facilitation*

- Informants had differing views about how best to deliver person-directed planning. The existing policy is for social workers or community health nurses attached to RHAs to deliver planning supports. However, as discussed above in the section on ‘program barriers’, community-based key informants provided a number of reasons why they believed this was not an effective approach. One key informant suggested, “HCS [Health and Community Services, under which RHAs are administered] is not doing person-centered planning, they are identifying needs.”
- Some suggested that the planning function should be delivered through community-based agencies and designated as “independent planning facilitation” to minimize any conflicts of interests between planners and funding or service delivery mandates. It is anticipated this would maximize community connections for the person and bring a holistic perspective to the planning process. Informants also see this independence as an important factor in assisting a person to develop a personal support network as the foundation for making a supported decision-making arrangement possible in their lives.

- Whether the planning function is based in government or community, most informants suggested that the current policy framework for delivery through RHAs has not resulted in:
 - as one informant put it, “getting our front-line workers to think person-directed, support planning”; or,
 - coordinating and positioning clinical assessment within a broader planning support framework that promotes person-centeredness, self-advocacy and self-determination.
- This appears to be an important area for further policy consideration aimed at ensuring the most effective framework for assisting people to develop supportive relationships and to guide a person-centered planning and community navigation process that gives them greater choice and control in their lives.

2. *Lacking a policy framework for community navigation supports*

- As discussed above, some informants indicated that there is need for community navigation supports to complement the planning function and that this too should be based in the community. These functions may be ‘two sides of the same coin’, with ongoing person-centered planning support complemented with a navigation function to assist the person and their network in activating and coordinating plans with funders, community support agencies, health care provision, employers, and educational opportunities, etc.
- However, no clear policy framework for this service has been established, despite the consensus among the disability community, service providers and government that this support is essential if people with disabilities who have more complex needs are to be able to live and participate in community. Some informants suggested that the individualized coordination of supports that community navigators provide could only be delivered through a designated and specifically mandated role. They indicated that home support providers are not able to provide this cross-community assistance. Nor, did they believe, were RHA social workers able to do so, given their large caseloads. The exception was in the case of the mandated process under adult protection as discussed below in sub-section 4.

3. *Gaps for youth in care and those with significant support needs*

- There was a consensus among both government and community-based key informants that the transition from children’s services to the adult system places some youth at significant risk and does not provide effective options for youth who are not able to act independently at age 19, including those who are above current IQ cut-offs for program support. Informants suggested that the policy

framework needs to shift, informants put it, from “an age-based” and “IQ-based” transition system to a needs-based transition system.” Policy issues identified include addressing needs for:

- **Resolving the “legal limbo”** as one informant put it for youth at age 19 who do not meet current tests of legal capacity, but who are “ageing out” of the custody of the provincial government through child protection services and who do not have family to return to;
- **Delivering individualized planning support** – to provide for an early start to future planning, to fully explore potential supports to enable the birth family to re-integrate the child or be involved in some manner, and to develop long-term strategies;
- **Facilitating long-term supportive relationships** of care, trust, and commitment for youth in care that give them that “permanent person in their life” as one informant put it, which will help a young person transition into exercising choice and control in their adult lives;
- **Addressing needs of youth with autism and behavioural challenges** whose IQ may measure above the supports eligibility ‘cut-off’ of around 70 and thus make them ineligible for some programs, but who nonetheless require support for independent living, attending college or university, or searching for and maintaining employment;
- **Proactive support to youth who are on community treatment orders**, and who are ending up ‘stuck in the shelter system’ because they are unable to get income assistance, and thereby have their choices severely restricted;
- **Investing in community infrastructure for effective youth services** through designated community agencies given the mandate to address the personal support, planning and legal capacity issues of youth with these needs, especially those with complex disability and health challenges (which some suggested could include a “hub-model” in communities to coordinate the range of agencies to meet youth support needs);
- **Creating a “joint approach” across Departments**, as one informant put it, especially across Departments of Children, Seniors and Social Development, Justice, and Health and Community Services – which, some key informants indicated, have operated with different policies on youth services and youth in care making a coordinated policy framework and delivery system as yet unattainable.

4. ***Lack of effective mechanisms for addressing decision-making support needs, other than through the adult protection system***

- One key informant suggested that when it comes to implementing a supported decision-making approach, “the nub of the issue, and it’s a thorny question, is where is the line between a supported decision-making approach and substitute decision making?” This question was raised by many informants who considered it applicable to a variety of contexts, including for:
 - youth in care who are transitioning to adulthood;
 - managing home support;
 - assisting adults with challenging and complex needs through community service agencies;
 - health care and mental health care decision making;
 - those in contact with the justice and corrections system;
 - those making decisions like ‘medical assistance in dying,’ which will have a fundamental impact on physical or mental integrity; and,
 - those in contact with the adult protection system.
- The adult protection system is the one context where there is a clear legislative, policy and service delivery framework to respond to the need for decision-making support. It is guided by “service principles” laid out in the *Adult Protection Act* including a principle (g) in the legislation which emphasizes support in decision making and states that: “an adult who is or may be in need of protective intervention should, if desired, be encouraged to obtain support, assistance and advice from family and friends to help that adult understand choices, and to make and communicate decisions.”
- The RHAs administer the adult protection system under the ‘Provincial Director,’ and designate social work staff to respond to concerns about an adult who may be in “need of protective intervention,” which the *Act* defines as an “adult who lacks capacity and who (a) is incapable of caring for himself or herself, or who refuses, delays or is unable to make provision for adequate care and attention for himself or herself; or (b) is abused or neglected.”
- Based on interviews with government officials, delivery of adult protection services under the *Act* appears to have been implemented with high regard for the principle of providing support in decision making. Of the over 900 cases in which RHAs have responded to concerns or complaints made under the *Act*, informants estimated that in only 5 of those cases as of April 2018, was ‘protective guardianship’ put into place. In the remainder of the over 99% of the cases, the designated RHA social worker (who receives specialized training for this purpose), convenes relevant government officials, community agencies and health professionals to arrive at a person-centered plan to address the concern.

- The procedures for interventions are laid out in the *Act's* detailed policy manual.² The process is designed to engage the person in the decision-making process. There is a focus on supported decision making, according to the key informant, which can include various accommodations in the decision-making process, including arranging for communication aides, a 'spokesperson' to assist in expressing the person's intentions where this is needed, or a translator if a person's mother tongue is not English. Diagnoses are not used to determine legal capacity, the informant emphasizing that "having dementia doesn't mean a person can't make decisions with supports." Using this process, based on the presumption that the adult is capable with supports as needed, the provincial government reports that less than 10% of the 1500 reported cases of adults at risk of abuse or neglect (since the Act came into force June 30, 2014) go to formal investigation.³
- In summary, the adult protection system results in less than one percent of cases, initially responded to on the basis that a person may lack legal capacity to independently make needed decisions, proceeding to a substituted decision-making arrangement. Success factors appear to be:
 - a clear legislative framework which includes a principle of support for decision making;
 - a detailed policy guideline for proactively responding to situations where supports may be needed to assist a person in decision making;
 - a designated delivery system across the province to manage response (i.e., through the RHAs);
 - commitment to and delivery of a person-centered planning process, with a designated planning support agent (the RHA social worker in this case);
 - a mandated process of engaging a range of actors who may be able to design an individualized response to the situation; and,
 - training of the planning facilitator/convener.
- It appears that much has been learned through implementation of the adult protection system about how to effectively support youth and adults with disabilities and complex needs, and who are in situations of serious abuse or neglect, to make and guide their own decisions, without resorting to substitute decision making. However, this framework and learning does not appear to have been effectively transferred to the other contexts where key informants indicated that a more comprehensive and coordinated approach to supports for decision making was also urgently needed.

² See, Government of Newfoundland and Labrador, *Adult Protection Act: Provincial Policy Manual* (Effective June 30, 2014), online: https://www.cssd.gov.nl.ca/apa/pdf/ap_act_prov_policy_manual.pdf.

³ See, Government of Newfoundland and Labrador, "Review of the Adult Protection Act," (no date), online: <https://www.engagenl.ca/engagement-initiatives/review-adult-protection-act>.

5. ***Lack of framework to effectively address both privacy concerns and supports for decision making***

- Some key informants pointed to two main privacy concerns preventing them from effectively assisting people in decision making. Concerns raised, include:
 - In seeking to provide treatment or support for a youth or adult, in fulfillment of what is understood as their wishes, community health and social service agencies face barriers to accessing needed personal information because disclosure is not authorized by an RHA or other authority; and,
 - Parents or other supporters are prevented by a provincial or federal government authority (like the Canada Revenue Agency) from obtaining or changing personal information of the youth or adult they are assisting and who is not able to communicate or direct on their own.

6. ***Need for a policy framework for individualized funding***

- Many informants believed that individualized funding should be available throughout the supports system. Informants suggested that evidence gathered through practice to date and anticipated from the provincial individualized funding pilot now underway, should provide the basis for fuller implementation of this funding option. In its agenda, *The Way Forward: Realizing Our Potential*, the provincial government has committed to developing an 'Individualized Funding Model'.⁴
- However, community-based informants suggested that a clear policy framework would be needed, including investment in capacity for planning and navigation supports, and for community capacity to respond to requests to put together individualized packages of supports. Some informants suggested that while individualized funding results in greater choice and control for individuals, the existing patchwork of home care and other agencies are not currently mandated or designed to respond to the anticipated demand for individualization.

7. ***Lacking a policy framework for building community capacity for person-centered and individualized approaches***

- Many community-based informants indicated that a more comprehensive policy framework is needed for effective investment in sustainable community capacity to deliver on the principles of person-centeredness, choice and control, and to respond to:

⁴ Government of Newfoundland and Labrador, *The Way Forward: Realizing our Potential* (2017), 43, online: <https://www.gov.nl.ca/thewayforward/files/Way-Forward-Part-2.pdf>.

- increasing demand for individualized supports, including for increasingly complex situations;
 - need for effective person-centered planning and navigation supports, including development of support networks and assistance for decision making to assist youth in transition and other high-needs groups (e.g., people in contact with the justice system, dealing with homelessness, with addictions issues, etc.);
 - anticipated demand for individualized support packages; and,
 - need for back-up support and administrative assistance to individuals and families in managing their support arrangements.
- Many informants felt that the growing demand for such supports could not be met by the existing community system, because the system’s current capacity is:
 - very fragmented, with uneven capacity depending on the community and sector;
 - undeveloped in more rural and remote areas, with a widening gap between growing demand for these services and available capacity;
 - not universally designed with shared principles of person-centeredness, choice and control, resulting in conflicting cultures between agencies; and,
 - based on a patchwork approach, with no overall vision for the community-based system.
 - One community-based informant suggested it is time to “rip the band-aid off of the current community system because in in 3-4 years, you will find that the providers can’t meet the needs.”
 - Community-based informants suggested that the capacity to deliver community supports should also be designed into the primary health care system, building on current good practice examples in Newfoundland and Labrador. As this is a first point of response for some individuals, effective health care delivery can significantly improve health and well-being outcomes for individuals. This perception aligns with recently reported research in Ontario which shows poor health outcomes and preventable deaths for people with developmental disabilities, for example, that result from barriers to effective and timely primary health care.⁵

8. *Need for clarity about the duty to accommodate in decision making processes in health care and services available to the public*

⁵ See, Elizabeth Lin, Robert Balogh, Yona Lunskey, et. al., *Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario* (Toronto: Institute for Clinical Evaluative Sciences, 2019), online: <https://www.ices.on.ca/Publications/Atlases-and-Reports/2019/Addressing-Gaps-in-the-Health-Care-Services-Used-by-Adults-with-Developmental-Disabilities>.

- Many key informants pointed to examples where people with intellectual, developmental or cognitive disabilities or mental health issues experience discrimination in accessing services because third parties assume they are not capable of making their own decisions. Even filing complaints of discrimination may pose a challenge for some individuals, if they are unable to demonstrate capacity to consent for this purpose.
- Informants pointed to what they perceived as discriminatory practices in consent and decision-making processes with health care providers, financial institutions, public services, and commercial entities. It was suggested that a clear guideline from the Human Rights Commission would help address this discrimination, including information about: 1) the duty to accommodate in decision making; 2) helpful strategies for supports and accommodation in decision making; and 3) supported approaches to providing informed consent in health care, advising legal counsel, filing a human rights complaint, and other decision-making contexts.
- It was also suggested by some informants that professional codes of conduct be developed outlining policies on accommodation in decision making, to be adopted by health professionals, government-funded and delivered services through RHAs and other programs.

Appendix G

Assessment of Options for Meeting Constitutional Imperatives for Reform

Assessment of Options for Legal Capacity Reforms

Option Criteria for Assessment:	A. Expand both independent and interdependent decision-making capability	B. Supported cognitive approach: expand independent decision-making capability only	C. Status quo – adopt decision-making support practice
1. Meets Canada’s obligations under the CRPD	Would be consistent with Article 12 of the CRPD and the General Comment No. 1 by the UN Committee once it was fully implemented.	Would not be consistent with the interpretation of Article 12 by the UN Committee. However, it would be consistent with Canada’s declaration that Article 12 permits both supported and substitute decision making.	Would not be consistent with the UN Committee’s interpretation given legal analysis of current provisions.
2. Is <i>Charter</i>-compliant	Fully meets the principles.	Meets the principles to some extent as it recognizes and enables access to supports and accommodations to exercise legal capacity, for those who would not meet the cognitive/functional test of capacity without those interventions.	Would not meet the principles, as the legal regime as it stands relies on discriminatory approaches.
3. Recognizes and enables access to supports and accommodations for decision making	Meets this criterion.	Meets this criterion for those who are able to act legally independently	Meets this criterion for those able to meet current criteria for legal capacity in the law
4. Addresses fragmentation and inconsistency in the regime for regulating legal capacity	Meets this criterion.	Meets this criterion.	Does not meet this criterion.
5. Safeguards integrity of the decision-making process in a manner that maximizes legal capacity	Does this both for people who exercise capacity independently and interdependently.	Safeguards integrity in a manner that maximizes legal capacity only for those who can act independently.	Does not meet this criterion.
6. Maximizes	Provides recognition of legal	More restrictive access criteria than	Most restrictive of the three

Option Criteria for Assessment:	A. Expand both independent and interdependent decision-making capability	B. Supported cognitive approach: expand independent decision-making capability only	C. Status quo – adopt decision-making support practice
beneficiaries	capacity the largest number possible, including those who require others to interpret their true intentions and free will and apply them in the circumstances.	option A, although it would expand access for those who need support and accommodation to exercise legal capacity independently.	options.
7. Provides a cost-effective approach to meeting support needs	Intended to maximize current informal and formal supports through training, information and promotion.	Meets this criterion for those who can exercise legal capacity independently. However, it would likely increase substitute decision making and guardianship authorizations for those who do not. Arranging for appointment of guardians through the courts as currently provided for, imposes costs on individuals and families.	As with option B, would be cost-effective for a smaller group at the outset, but increase costs related to substitute decision making.
8. Meets Disability, Mental Health and Seniors Communities' Concerns	Addresses the concerns by including provision for those whose legal capacity is currently denied or restricted as a result of intellectual, developmental or cognitive disability, or mental health issue.	Would not meet the community's concerns for a legal framework that is fully inclusive of those with disabilities, including those with more significant disabilities. Based on inputs for this consultation and research, it is anticipated that many in the disability community would register deep concern that the mandate of the government to consider supported decision making was not fulfilled, if this group were left out because interdependent decision-making capability was not recognized.	Would not meet the community's concerns for a fully inclusive framework. Similar to option B, groups who have led the advocacy for a transformed system would likely be concerned that their claims for an equal right to exercise legal capacity were being put off for another day.
9. Is a feasible option	While the option signals extensive	Same assessment as for option A.	Likely more feasible to

Option Criteria for Assessment:	A. Expand both independent and interdependent decision-making capability	B. Supported cognitive approach: expand independent decision-making capability only	C. Status quo – adopt decision-making support practice
	<p>reforms, it could be implemented in an incremental manner, with law reform of key statutes regulating legal capacity focused upon first. This could provide a platform for more comprehensive reforms in the future. In addition, a range of information resources, training tools, and community development initiatives could complement the introduction of law and policy reforms, consistent with this option. Moreover, no large investment in provision of supports or a new delivery system would be required, as outlined in the option, although significant reforms would be needed in key sectors. As noted, this could be accomplished through policy guidance, information resources, training, education and promotion.</p>		<p>implement than other options as it does not entail law reform.</p>

Appendix H

Promising Initiatives: Context for Reforming the Legal Capacity Regime In Newfoundland and Labrador

INTRODUCTION

Moving forward on substantive reforms to the legal regime in Newfoundland and Labrador would take place in the context of current constraints and challenging trends. There are also many promising initiatives already committed to by government that align closely with the directions for reform recommended in the report. These are outlined below.

A. Constraints and Challenging Trends

Several of the promising initiatives outlined below respond to three key trends in the province, which relate directly to persons with disabilities, seniors and people with mental health issues, namely:

- ***Ageing of the population and increasing prevalence of disability and mental health issues***

Newfoundland and Labrador has the fastest aging population in the country. Combined with out-migration from the province, a declining birth rate, and especially rapidly aging population in small rural and remote communities, the trend is also towards an increasingly disabled population, especially of people with cognitive disabilities associated with aging. There is also growing prevalence of mental health difficulties. These trends pose significant challenges for home supports and long-term care policy. Without intervention, it is predicted that the “unprecedented population challenge” of an aging population especially, will have a “drastic impact on the economy, governance and the overall quality of life for people in the province.”¹

While policy analysts often point to fiscal challenges for governments, some research suggests these may be over-stated and also points to societal benefits associated with aging populations. These include improvements in quality of life with increased leisure time, increased health status, wealth sharing, and reduced impact on the environment with declining energy consumption, among others.²

- ***Tight fiscal realities***

Addressing the population health challenges will pose significant difficulties in the context of the well-recognized tight fiscal reality currently in the province, anticipated to become even tighter in the coming decades with population trends.

- ***Growing demand for home support services***

¹ These are findings of “The Population Project” of the Harris Centre at Memorial University. See <https://www.mun.ca/harriscentre/PopulationProject/>.

² See, for example, Adriana Barton, “The upside to Canada’s aging population,” *Globe and Mail* (September 4, 2014), online: <https://www.theglobeandmail.com/life/health-and-fitness/health/the-upside-to-canadas-aging-population/article20769416/>.

The 2016 report by Deloitte, *Provincial Home Support Program Review*, prepared for the Department of Health and Community Services,³ indicates that in the context of these population shifts there will be increasing demand for home support services, adding pressure to an already stretched system. With the especially rapid population aging in small rural and remote communities, the capacity of the home support and other programs to effectively respond will become increasingly challenging.

B. Promising Initiatives

Despite these challenges, there are promising initiatives on which to build a sustained, multi-year effort to reform the laws, policies, programs and practices which restrict or deny to people with disabilities, seniors and mental health issues legal capacity and power over their lives. These initiatives include:

- ***Transforming government services and community capacity through sharing responsibility and improved partnerships***

The provincial government has acknowledged the complex set of economic, social and fiscal challenges facing the province, and identified core strategies to address them in *“The Way Forward: A vision for sustainability and growth in Newfoundland and Labrador”*⁴ and its associated roadmap titled *“The Way Forward: Realizing our Potential”*.⁵ This agenda aims to introduce significant efficiencies into government, share responsibility for improved outcomes with individuals, families and communities through more effective partnerships, and transform the capacity of the community supports sector. With respect to the latter, a more recent *“The Way Forward”* was released focused on *“A Sector Work Plan to Advance the Social and Economic Contribution of Community Organizations in Newfoundland and Labrador.”*⁶ The plan makes a number of commitments to strengthen the capacity of the community sector overall. While it does not reference disability-related support organizations specifically, it does reference employment and social support, housing, youth and seniors-serving organizations. If implemented, the measures would address some of the concerns about capacity of the sector identified through the consultation for this report.

³ *Provincial Home Support Program Review, Department of Health & Community Services: Final Report* (2016), 3, online: https://www.health.gov.nl.ca/health/personsdisabilities/pdf/executive_report_phsp_review.pdf.

⁴ Government of Newfoundland and Labrador, *The Way Forward: A vision for sustainability and growth in Newfoundland and Labrador* (2016), online: https://www.gov.nl.ca/thewayforward/files/the_way_forward.pdf

⁵ Government of Newfoundland and Labrador, *The Way Forward: Realizing our Potential* (2017), online: <https://www.gov.nl.ca/thewayforward/files/Way-Forward-Part-2.pdf>.

⁶ Government of Newfoundland and Labrador, *The Way Forward with community: A Sector Work Plan to Advance the Social and Economic Contribution of Community Organizations in Newfoundland and Labrador with community* (April 2019), online: <https://www.gov.nl.ca/thewayforward/files/The-Way-Forward-with-Community.pdf>.

- ***Improving opportunities to grow assets and wealth***

The government is also taking steps to ensure greater opportunities for individuals with disabilities and their families to grow their assets and manage inter-generational wealth transfer to improve prospects for future financial security. For example, the government has ended liquid asset testing for recipients of long-term care and the community support services system (as of October 2018).⁷ This is an important step in improving long-term financial security of persons with disabilities and in providing conditions for people to own their own homes while remaining eligible for income security. The need to address this disincentive to homeownership was stressed by community members in the consultation.

- ***Inclusion strategy and accessibility legislation***

The provincial government has committed to a bold set of principles to advance inclusion of persons with disabilities in Newfoundland and Labrador, and in 2012 introduced “*Access. Inclusion. Equality - A Provincial Strategy for the Inclusion of Persons with Disabilities*” prepared through the provincial ‘Disability Policy Office.’⁸ The follow up “*Action Plan 2015-2018*”⁹ recognizes the importance of supports for decision making, person-centred approaches, and individualized funding. As one means of shifting the funding and supports system in this direction, an ‘individualized funding’ pilot initiative has been launched to test an approach that gives individuals more direct control over how to spend their disability-related support dollars. In addition, the government has committed to introducing accessibility legislation and has completed consultations for this purpose.

- ***Transformation of the mental health system***

In 2015, the ‘All-Party Committee on Mental Health and Addictions’ was established as a result of a private members’ motion supported by all members of the provincial legislature. After a number of consultations, the committee delivered on its mandate with the release in 2017 of “*Towards Recovery: A Report by the All-Party Committee on Mental Health and Addictions: A Vision for a Renewed Mental Health and Addictions*”

⁷ See Newfoundland and Labrador, Executive Council, Children, Seniors and Social Development Health and Community Services, “Provincial Government Introduces New Financial Assessment Process for Long-Term Care and Community Support Services” (October 1, 2018), online: <https://www.gov.nl.ca/releases/2018/exec/1001n01/>.

⁸ Government of Newfoundland and Labrador, *Access. Inclusion. Equality - A Provincial Strategy for the Inclusion of Persons with Disabilities* (2012), online: <https://www.gov.nl.ca/cssd/disabilities/dpo-access-inclusion-equality-strategy/>.

⁹ Government of Newfoundland and Labrador, *Access. Inclusion. Equality - A Provincial Strategy for the Inclusion of Persons with Disabilities: Action Plan 2015-2018* (2015), online: https://www.cssd.gov.nl.ca/disabilities/pdf/dpo_isap.pdf.

System for Newfoundland and Labrador”¹⁰. The report outlined over 50 recommendations to address the lack of both acute and community-based mental health services in the province in the face of the opioid crisis in the province and across Canada and the fast-growing proportion of people with mental health issues. The government adopted all 54 recommendations in its 2017 “The Mental Health and Addictions Plan.”¹¹ In its 2017 and 2018 Budgets, the government signalled investments to expand community-based services to communities throughout the province, construct a new mental health and addictions facility in St. John’s and expand acute care services in Happy Valley-Goose Bay. The strategy is based on empowering mental health care patients and users by emphasizing principles which are recovery-focused, person-centred and inclusive, among others.

- **Poverty reduction strategy**

The current provincial ‘Poverty Reduction Strategy’ adopted in 2014,¹² has provided a framework for ongoing progress reporting and provincial government budgetary investments in each of the subsequent years. Several of the initiatives launched throughout this time frame under the goals for “improved access to and coordination of services for people with low income” and for a “stronger social safety net,” align with goals that key informants for this study stressed as priorities. Thus, the strategy includes investments ranging from supporting youth transitions, to investment in affordable housing for persons with disabilities, to supporting people with complex needs to live in the community. All of these initiatives, and more under the strategy, can be designed to help realize an agenda to ensure people with disabilities also have access to the supports they require to exercise legal capacity, making and fulfilling decisions to live more independently and be included in the community.

These various government commitments and initiatives align with principles of empowerment, person-centredness, community-based support and individualization, all of which underlay the recommendations presented above. Implementing the recommendations would enable people to gain greater control over their lives so they can live more independently and be more fully included and participate in their communities, both socially and economically. As formulated, the recommendations would deliver on the aims of “*The Way Forward*” in a manner that taps the resources of individuals, families and communities to make that happen.

¹⁰ Newfoundland and Labrador, All-Party Committee on Mental Health and Addictions “Towards Recovery: A Report by the All-Party Committee on Mental Health and Addictions: A Vision for a Renewed Mental Health and Addictions System for Newfoundland and Labrador”
https://www.health.gov.nl.ca/health/all_party_committee_report.pdf.

¹¹ Government of Newfoundland and Labrador, *Towards Recovery: The Mental Health and Addictions Action Plan for Newfoundland and Labrador* (2017), online: <https://www.gov.nl.ca/hcs/files/mentalhealth-committee-mentalhealth-pdf-mentalhealth-addictions-plan.pdf>.

¹² Government of Newfoundland and Labrador, *Poverty Reduction Strategy Progress Report* (June 2014), online: https://www.cssd.gov.nl.ca/poverty/pdf/prs_progress_report.pdf.

Appendix I

The Community Response to the Report “Supported Decision-Making: A Roadmap for Reform in Newfoundland & Labrador”

Identification of Gaps in the Report and Expanding on Critical Concerns of the Community

**Prepared by
Steering Community on Legal Capacity and Citizenship for All**

December 2, 2019

Background:

In June, 2011 an international symposium was held in St. John's, Newfoundland and Labrador, entitled “Securing Citizenship and Legal Capacity for All”.

The symposium featured strong representation from persons with mental health issues, intellectual, developmental and cognitive disabilities, seniors, youth in crisis and indigenous persons. Also participating were representatives from several Government departments and agencies impacted by the legal framework surrounding legal capacity.

Persons with lived experience came together with legal and social policy experts to examine the newly ratified United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). The specific focus was on "Article 12- Equal recognition before the Law".

Many persons bringing lived experience expressed deep concerns that, under the existing legal framework, the law can take away one's right to make decisions about their lives. This right can be passed to substitute decision-makers they do not know or trust.

In order for many persons to achieve inclusive lives in the community, support and accommodation in decision making may be required. This support is needed in order to manage various transactions and medical decisions necessary in everyday life. Unfortunately, trusting supporters, family and friends, who have knowledge of an adult's will and preferences, are not legally recognized to provide support in decision-making.

Current Status:

The Government of Newfoundland and Labrador has committed to law reform, thereby advancing supported decision-making options for people with cognitive, intellectual, developmental disabilities and mental health issues. Funding was made available through the Disability Policy Office of the Department of Children, Seniors and Social Development.

This created the opportunity to engage the Institute for Research and Development on Inclusion and Society (IRIS) to develop an issues paper, to conduct consultations and prepare associated reports to advance a legal reform agenda. Jurisdiction governing design-making largely rests within the provincial Government. The Department of Justice and Public Safety has the primary responsibility for law reform.

The consultants met with several community-based organizations, particularly the "Steering Committee on Securing Legal Capacity and Full Citizenship for All". IRIS also met with numerous Governmental departments leads and agencies. The Newfoundland and Labrador Association for Community Living managed the logistics of the contract.

This resulting report is called **Supported Decision-Making: The Next Step**.

Pending input from Government and community to the final draft, this report is now completed. This document is the formal community response.

Options for Meeting Constitutional Imperatives for Reform

There is a critical decision to be made regarding the scope of the legal reforms. The consultants presented these options and commentary.

"Evolving domestic and international human rights obligations establish an imperative to reform the current legal capacity regime in Newfoundland and Labrador. Two main options for community stakeholders, the provincial government and legislators to consider are:

- **Option A - Fully inclusive approach to legal capacity, with supports and accommodations:**
This comprehensive option would be guided by the decision-making capability approach and would expand recognition of *both* independent and interdependent decision-making capacity with supports and accommodations as required.
- **Option B - Cognitive approach to legal capacity, with supports and accommodations:** This option would recognize supports and accommodations to enable people to meet the cognitive/functional test of independent decision-making capability, and to exercise it on that basis."

The consultants pursued Option A as the critical path in arriving at a "Roadmap for Legal Reform". Justification for this approach is based on several important points.

- Inclusion is supported by the community and by government in many high-profile announcements, documents and strategies.
- Option A is compliant with Article 12 of the UN Convention on the Rights of Persons with Disabilities.
- Option A is also alert to the issue of legislative compliance with the Canadian Charter of Rights and Freedoms.
- Option B is not inclusive. Option B retains a cognitive test which discriminates against persons with disabilities.

The consultant's report is remarkably well reasoned and researched. In responding to gaps in the report, the community feels there is a need to provide a wider description of a number of issues beyond the scope of work outlined for the consultants. In particular, there is a need to describe individual and family impacts when supports and accommodations are not legally recognized in decision-making.

Many people, including professionals of all walks of life, have a sincere belief that guardianship is a legal and humane way to protect people who cannot manage on their own. The lived experience contradicts this view. Persons with disabilities regard guardianship, in all its forms, as stripping away the rights and freedoms of persons. Advocates have commented that guardianship has been used to enable ease of care and custody of persons who are apparently not seen as having full human rights.

Identification of Gaps in the Report and Expanding on Critical Concerns of the Community (which should be more strongly stated in the report).

1. The community supports the fully inclusive approach represented by Option A and rejects Option B. Option B leaves people out and while it achieves the removal of discrimination for some persons, it excludes those with more significant disabilities; those for whom legal reform is most necessary.
2. The case against guardianship and substitute decision-making needs to be more fully explained. Supporting testimonials to this effect are included throughout this document.

Examples:

-Some persons report difficulty with access to health-related information and treatment because of legal capacity issues. Others report they have avoided health care procedures out of fear that guardianship may be suggested.

-The vast majority of professionals are generalists. The lack of first-hand knowledge leads to an under-appreciation that guardianship does not have a history of protecting people. It is a deeply invasive measure that has been used to enable the institutionalization and sterilization of persons. It is also costly process and cannot be passed on.

3. Article 19 of the UN CRPD- The Right to Live in the Community

Article 19 is deeply relevant in discussions connected to supported decision-making. The UN CRPD and the General Comment on this article contains clear statements in support of the right of people to live in the community with appropriate supports and to have control over their lives. This Article should be front and centre in the establishment of key principles of legal reform and implementing a holistic approach to social policy.

4. The recent "Ash Decision" (2019) represents a new, but clear and present danger, given the court has laid out a detailed process for establishing guardianship. The impacts of the decision are feared to be broader, influencing not only formal guardianship, but other less visible forms of substitute decision-making that could lead to the same result.

5. The impact of (relatively new) privacy legislation is under-stated in the report. This legislation applies to all public bodies, including Government departments, agencies, health boards, school boards and municipalities. Privacy legislation has had the unintended, but massive, impact of removing the rights of some individuals from getting access to critical medical information or receiving medical attention. On the same basis, if a person cannot act fully independently, supporters do not have the standing to assist individuals with financial or contractual transactions.

Examples:

-People report difficulties dealing with CRA and other agencies to access due process because of privacy legislation. Individuals can only interact if they have an independent ability to communicate, or if a power of attorney is in place. One has an obligation to pay taxes but no provision is made to make personal inquiries or to avail of appeal mechanisms.

-Many people cannot change their address. Unless the person involved can speak for themselves, and demonstrate their intelligence, simple functions have emerged as significant barriers.

-One person, trying to act for her sister, could not get her a MCP card. She was told she would need guardianship.

6. Parents, relatives and spouses, who would have been able in the past to provide navigational supports and were accepted as speaking on behalf of individuals, are now being told they have no status to act.

7. Many people do not have the ability, or no longer have the ability, to put in place legal documents such as a power of attorney or enduring power of attorney to appoint others to represent them in substitute decision-making. This leaves costly, ineffective and invasive court proceedings, which is guardianship, as the remaining option to have medical or financial decisions made.

8. It should be clearly understood that supported decision-making is an additional alternative to traditional powers of attorney. It is not disruptive to those who wish to stay with or prefer to stay with the power of attorney.

9. Another recent significantly new development permits people with disabilities to have money/assets under certain conditions and still access supports and services. Seniors are no longer means tested for disability supports and notably receive pensions and other income from the Federal Government. Poverty reduction strategies have been constructive on pushing back on the welfare wall. The Registered Disability Savings Plan (RDSP) and Support Trusts can mobilize significant financial assets aimed at providing safe and secure lives in the community. Many people will need to be able to call upon supports to manage money in ways that are quite different than the past.

10. Demographics and outmigration are huge factors. There is some question as to whether there is a widely enough shared understanding of the scope of the issue of aging families. Over 50% of persons with a disability are living with family members, who at some point may no longer be able to offer the support they are providing. The human and financial costs are going to be enormous if nothing constructive is done.

11. Legal reforms should be undertaken in a broader social policy context. Newfoundland and Labrador requires a coordinated and focused strategy which creates "an option" to animate and coordinate the resources of individuals, families, Government and communities to support persons with disabilities to live in their own homes in the community. This opportunity represented through the acceptance of the

challenges as a shared responsibility is not fully appreciated. There are few competing creative ideas on the table considering the scope of the issues.

12. As the province has a significant Indigenous population, overcoming the barriers to full and equitable inclusion and the guarantee of self-determination requires a considered examination of the strengths and challenges facing disabled members of this often-marginalized group within Canadian society.

Understanding that Indigenous individuals and their families may hold worldviews, beliefs and customs that differ from individuals in mainstream society, there must be an effort to provide meaningful intervention and supports that respect these divergent identities.

Given the Indigenous experience in this country, there is a clear need to respect the issue of sovereignty by recognizing distinctions between the rights and privileges of tribal citizens and those of Canadian citizens. Any efforts to provide remedies related to supportive decision making should at a minimum acknowledge the potential role of community Elders, family connections, cultural norms and protocols as well as the lingering impacts of generational trauma, lateral violence, systemic racism and a historic pattern of insufficient consultation with Indigenous people.

13. The Adult Protection Act's success in surrounding persons with supports and animating a team-based approach is a stunning alternative to more invasive measures. In the alternative, Government will face the responsibility for thousands of individuals left without community and family supports because of isolation and insufficient means.

14. The duty to accommodate to the point of undue hardship must apply to the decision-making process. This will be vital in protecting individual autonomy and the exercise of legal capacity. It is further recognized in a system that must be workable and the clarification of the specific responsibilities under the duty to accommodate would provide an expedient process for the discharge of 3rd party responsibilities and a smooth verification process.

15. The sanctity of contracts and the liability concerns of doctors and lawyers have to be respected and protected for supported decision-making to be safeguarded and accepted.

16. The safeguards and protections that are contained in the UN CRPD Article 12 (4) in a supported decision-making context provide a higher level of protection, particularly for those who may need supports but do not meet the current definition of an "adult in need of protective intervention". Supported decision-making is more nuanced and suited to layers of safeguards against improper conduct. The creation of the supported decision-making option re-enforces the best intentions of adult protection. This is a point that might get lost.

17. The legislative response (Nova Scotia) to the "Webb Decision" lacks perspective on the human face of lived experience or the social policy context on matters associated

with building inclusive communities. Community representatives have shared a view on Nova Scotia as a poor candidate from which to seek guidance, given its highly segregated history. Newfoundland and Labrador and British Columbia have progressive records on disability related issues and have consistently provided leadership to Canada.

18. Human Rights issues are at the center of the treatment of individuals.

Examples:

-Some persons report difficulty with access to health-related information and treatment because of legal capacity issues. Others report they have avoided health care procedures out of fear that guardianship may be suggested.

-Concerns raised by many groups involved having treatments that they do not agree to on moral or spiritual grounds without having an advocate or supporter present (i.e., electroconvulsive therapy, certain drug therapies).

-People fear not being able to reinstate their citizenship once a guardianship order is in place (i.e. in cases of brain injury and intellectual disability).

-Seniors are often over medicated to support ease of care or management. This is an issue being raised in the national dementia strategy. One person described her husband's cognitive deterioration, in light of over-medication, saying she knew him better than doctors after being married to him for half a century. She had to become extremely vocal to advocate on his behalf. She spoke of the importance of his life narrative which in her view validated his legal capacity.

-Some people who are living with mental health issues lose their rights to citizenship or personhood. They report being unable to legally put a supported decision maker into place in periods when they are not in crises. They have said they are only allowed to name a "substitute decision maker" when they are in hospital and in crisis. Many don't want to lose the right to make their own decisions, except in extreme cases, but recognize the need for support.

- Some people who are living with mental health issues who become incarcerated say they are denied their medications when they are detained.

19. In addition to the human rights lens, there are social policy and fiscal considerations. It is clear Government does not have the capabilities to provide all answers for solutions to supporting individuals. The legal system must support the broader and well articulated vision of Government in support of the aspirations of its citizens. This commitment is all people have a right to equality, the assurance of a safe and secure life in inclusive communities, in typical homes and communities, with friends and economic security.

What are the next steps?

The Department of Justice and Public Safety is the lead department in Government on law reform. The Minister, through the Premier's Mandate letter, has been committed to a leadership role.

However, legal reforms will impact and support the work of other departments and agencies. These departments and agencies have been a part of the process from 2011 onward, but staff changes impact significantly on process of achieving law reform.

The role of coordinating across Government departments has been managed by the Disability Policy Office to this point, which resides in the Department of Children, Seniors and Social Development.

This is the Department responsible for coordinating the implementation of the Provincial Strategy for the Inclusion of Persons with Disabilities. Ministerial leadership from within this department is seen by the Steering Committee as essential to managing Governments collaborative mission.

The mandate of the Department of Children, Seniors and Social Development is as follows.

"The Department supports individuals, families and communities in Newfoundland and Labrador in achieving improved health, social well-being, reduced poverty and ensures the protection of children, youth and adults from abuse or neglect.

The Department promotes the values of inclusion, diversity, and healthy active living and leads the development of policies, programs and partnerships to improve services and the overall social development of the Province."

High level ministerial and cabinet leadership is presumed to be necessary at various points.

Consistent with the Provincial Government's commitment to community engagement, community representatives have been diligent collaborators in pursuit of positive legal reforms. Moving forward, the community believes it is necessary to maintain an ongoing role and strong working relationship with Government.

This paper is the community contribution to the draft report and brings this phase to an end. Once these commentaries are finished, the report is to be finalized and work can begin on implementing the legal reform started with the initiative "Securing Legal Capacity and Citizenship for All".

The following represents community perspective, in greater detail on the Options provided and the question of "how to" enact legal reforms.

Examining Options A and B:

Community principal response to the report:

- The community continues to support a fully inclusive approach represented in the report in Option A and rejects Option B as discriminatory.
- The Steering Committee accepts the report as vigorous and balanced in responding to the "how to proceed", inclusive of the roadmap to advance legal reform.

The report establishes two basic paths to protect legal capacity and to recognize on a formal and informal basis the supports and accommodations needed by persons with disabilities.

The consultants identify Option A as the consistent and inclusive path forward. Option A is consistent with the UN Convention on the Rights of Persons with Disabilities and provides a UN CRPD informed analysis of the Canadian Charter of Rights and Freedoms.

Reflections on Option A: The Inclusive Approach

The Minister publicly announced in 2016, the Government's intention to repeal and replace the Mentally Disabled Person's Estates Act. He spoke to a clear understanding that inclusion is the issue at the center of Government policy. Guardianship and guardianship-like approaches were not at all consistent with Governments thinking or values system.

In 2018, the Minister again indicated that Government was fully supportive of an inclusive model and again recognized guardianship was not the direction this Government wanted to pursue.

These are the bed rock commitments from Government to the community which drives the community expectation. Option A responds to the Minister's commitments.

The Vision and Aspirations of the People are Supported by Option A:

- People are able to live in homes of their own with the support they may require, and in communities and neighborhoods that provide connections to family, friends and activities that are valued by the individual.
- People are able to make choices and decisions, with support if wanted and needed, about their own lives and futures as embraced in the current discussions around legal reform on supported decision-making.
- People will have access to sufficient financial resources that will adequately provide for their basic needs and support their involvement in their community.
- The need and value of greater investment in support to live in the community is widely acknowledged by government and community.

- Ultimately, billions of dollars, over a generational period, can be created to support supported living in the community through Registered Disability Savings Plans, insurances and estate planning. There is an opportunity to transform the quality of outcomes for individuals through active efforts to unlock this potential.
- Develop a coherent social policy that builds on shared responsibility and mobilizes individuals and families, particularly young families, to take action to protect for a time when primary caregivers are no longer able. Considering the thousands of families not yet alert to the threats of institutional placement, it is timely to consider supporting younger families to plan with the gift of time on their side.
- Provide recognition of the importance of informal networks of support and how these can be facilitated at a community level.
- Provide access to disability related supports and clear strategies to enable adults with a disability to remain or live in a home of their own. With independent planning and navigational supports emerging as a recommended support system, seniors can have much more credible plans to remain in their own homes.

Examples:

-The Way Forward lays out Government's plan to introduce individualized funding

-One example of a progressive measure is seniors are no longer subject to the testing of assets to qualify for supportive services. Seniors no longer need to give away their life savings to avoid Government claw backs.

How does legal reform proceed under Option A?

Minister Parsons admitted to being challenged on "how to" tackle legal reform. Given the scope of reform involving cross- departmental impacts while working with limited internal human resources, he reached out to community representatives and to the Disability Policy Office for help.

The community responds positively to the consultant's report with it's clear path to solutions:

- In responding to the "How To?" implement Option A question, the community understands legal reform and associated policy implications are challenging.

Failure to find a way to validate supports and accommodation will create a crisis amplifying the isolation and vulnerability of a significant part of the population to unnecessary restrictive living.

This report was structured to respond ultimately to the "how to" question. The main policy implications are identified. This was done by reaching out to a fairly wide constituency for direct input. The report was, in the community view, quite successful in lighting a path to go forward.

- The consultant's report identifies a patchwork of policies and laws throughout many jurisdictions, which can be cobbled together in a more coherent inclusive framework. Once inclusion is affirmed as the way forward, much of the work to be done is related to putting existing things together differently.
- The roadmap provides a significant response on "how to" move forward giving consideration and very detailed analysis of the provincial, federal and international legal framework, bringing coherency to the issues at hand and constructive on places to start.
- The Canadian Charter of Rights and Freedoms (Sections 15 and 7, et al) provides for rights that are *not yet realized*. The consultant's report identifies clear commentary growing in the courts acknowledging the extremely invasive nature of guardianship and similar mechanisms as the absolute last resort.
- The demonstration of the "how to" is evident in implementation of the Adult Protection Act. There is a good representation of supported decision-making principles and practise embedded in the approach taken under the Adult Protection Act.
- The community is anxious to hear the Government's response and to work collaboratively with Government to implement inclusive legal reform.

Rejecting Option B: The Cognitive/Functional Approach

Option B leaves many people out.

Is there a shared understanding of the impacts of guardianship?

There is no question that public attitudes and positive awareness has changed dramatically towards persons with disabilities, but the invasive, gut-wrenching realities

of powerlessness, isolation, exclusion and vulnerability associated with guardianship and similar instruments remain a threat to those who may be subject to its powers.

Many people with intellectual, cognitive, or mental health issues have legal capacity systematically removed, in Newfoundland and Labrador and throughout Canada, through guardianship/substitute decision- making, or involuntary commitment. These measures are usually justified in the name of protection and the best interest.

In 1991, People First of Canada passed a resolution at their Annual General Meeting calling for Alternatives to Guardianship. In the name of protection, guardianship had been the central instrument leading to the institutionalization, sterilization and abuse of tens of thousands of people.

The cost to liberty and the costs associated with court processes affecting guardianship, especially if there is a challenge to the order, is a deeply misguided approach.

Guardianship cannot pass from one person to another, so the process may have to be repeated. Even in the most altruistic circumstances, guardianship is a sad development.

It does appear the vast majority of people are disempowered and live outside the legal and medical universe altogether. It is hard to quantify the number of people who have no transactional or medical intersections in their lives.

It is important to note, Newfoundland and Labrador led Canada in the process of closing institutions and reconnecting persons to their communities. The province is very famous for the leadership provided. In the passing years, connecting people back to communities has been a stunning success.

There is a concern for the loss of corporate memory in Government and community about the institutional history and the devastation arising. Since the closure of institutions and the development of the community-based health care system, there is too much faith placed on the notion that we cannot and will not go back there.

However, the lack of options for persons needing supports, where there are financial ceilings on available supports, require urgent attention. As a result, very young persons (30's,40's) are finding themselves being placed in long-term care and end- of-life living arrangements through substitute decision-making measures.

There is a perception that Government will take care of individuals in the future. The question is "what will this care look like?".

People in the province generally know about under staffing and the poor quality of life afforded in most end-of-life facilities. In their helplessness, the main coping mechanism is not to think about the future. Others rely on the hope the person they are supporting dies before them. It is for many the key element in their planning.

This province needs to become proactive in planning for the issues resulting from demographics and disability support needs.

Lack of clarity on the issue of Government being able to provide well for the numbers that are coming will lead to devastating results for many individuals and families. The selection of Option A starts the collaborative journey. The concluding remarks are drawn from the Provincial Strategy.

he Provincial Strategy for the Inclusion of Persons with Disabilities Strategic Direction #2

Moving Forward Together: Nothing About Us Without Us

The motto of the international community of people with disabilities is "Nothing About Us Without Us". This means it is essential for people to be involved in the decisions which most intimately affect them.

Individuals know instinctively what is best for them. All individuals have the right to express their wishes and to have their wishes recognized. Often, persons with disabilities have had decisions made for them, including where to live, with whom and what happens during each day. Individuals often have not been a part of these decisions because of stereotypes, communication barriers or lack of decision-making supports.

When individuals are supported and/or enabled to identify their own needs and best ways to meet those needs, solutions tend to be more successful. Everyone has the right to make their own decisions and use support if they choose. Recognizing legal capacity is the principle by which a person with a disability may be supported by another person that they have chosen and who understands them well. This is also called supported decision-making.

Making sure that individuals have the opportunity to identify their own needs also enables self-reliance, self-determination and empowerment for the individual. Guesswork is eliminated, misunderstandings are reduced and decisions are less likely to be impacted by the stereotypes and myths that surround having a disability. When decision-making is supported in a dignified and respectful manner, outcomes are more appropriate and meaningful; one's quality of life increases.

Strong and effective public policy relies upon the experiences and knowledge of people who are most impacted. Engaging community organizations of persons with disabilities in the development of public policy is essential to ensure policies are well-informed and successful.

The concept of "Nothing About Us Without Us" was embedded throughout the consultation process and will continue to guide the Provincial Government. The expertise of people with personal experience will inform and strengthen public policy and program directions.

Introduction of Appendix's

Below you will find a true story illustrating the impacts on one individual who was denied legal capacity through most of her life. Things become more real when there is a human face attached. (Appendix A)

There is also an appendix providing specific examples of the impact of the denial of legal capacity. The point is to stress that the legal reform initiative does not take place in a vacuum from the lives of the people that live in our province. In addition to human rights issues, the responsibility for the plight of persons denied legal capacity will fall disproportionately to Government. The shared goal of persons to continue to live in their homes and communities is at stake and can only be achieved through the establishment of proper legal foundations, strong principles, values and shared responsibility. (Appendix B)

Also provided are the texts of Article 12 and Article 19 of the UN CRPD referenced in the document. (Appendix C and D)

Appendix A

The Human Face of Legal Capacity Denied

Below are many examples of challenges identified by people who have first-hand of the frustration, poverty, isolation and suffering of those denied legal capacity.

Systemic Issues:

- Legal capacity issues affect all people's rights to personhood and citizenship. As such, any person could find themselves in a situation where their legal capacity was denied. Strokes, dementia and brain injury are all examples of regular occurrences. Most adults have some lived personal experience or the experience of a family member. This is the time to draw on that collective knowledge.
- The main areas where the lack of recognition of legal capacity impacts individuals are in transactions, business, investments, taxation, freedom of information and privacy legislation, consent to treatment, health management and naming those you wish to support if you need such supports.
- In the current Newfoundland and Labrador context, young persons are falling into state custody as a result of aging families and caregivers passing or becoming unable.
- Option B discriminates. Those persons most needing supported decision-making would be excluded because they would not meet the cognitive test. This opens individuals at high risk for institutional placement, guardianship and guardianship

like instruments becoming the "go to" for ease of care on the same historically discriminating basis.

- Planning for a time when those who provide support or care to individuals are no longer able is complex to near impossible because of the difficulty of navigating systems when you are a person with no legal standing.
- The Ash (2019) decision in the Newfoundland and Labrador Courts details a process for the establishment of guardianship. This threatens a large number of individuals who fear losing their individual rights accorded to persons.
- It is unlikely all persons considering this report will appreciate the vast difference between expressive and receptive language. Many persons can understand things at an exponentially higher rate than their ability to express their will and preference in traditional ways.
- Individuals and families do not generally have the human or financial resources to go it alone. Governments have serious issues with health care spending as a growing percentage of GDP. There is a dangerous reliance on Government as the entity that will take care of people. Lost in this rationalization is the appreciation for what that might look like. Drawing on the present-day events and projecting in the future, there is a direct threat that persons will be segregated, restrained and otherwise abused because the system is not prepared for the crisis.

Financial Issues

- Some people said they are losing their rights to citizenship and/or personhood by those that promote guardianship simply to complete a financial transaction. When a person attempts to transact and the "understand and appreciate test" is applied, the alternative of guardianship is promoted in some quarters of the legal community.
- Many people report not being able to benefit from their rights to make financial decisions because they do not want to put in place a substitute decision maker. For example, they chose not to start a business or to open a registered disability savings plan due to the fear of having to put guardianship in place and thus lose many rights they currently enjoy, making decisions for themselves with supports they already naturally have in place.

Health Issues

- Some people living with mental health illness have reported they have lost their rights to citizenship and been involuntarily committed based on section 24 or detained in a psychiatric unit under subsection 81(4) of the *Mental Health Care and Treatment Act*, without their support teams being consulted even though they have developed a wellness recovery action plan (WRAP) in situations when they require support to make decisions. They expressed frustration that a psychiatrist alone has the right to do that without their supporters being consulted. They reported dissatisfaction at being offered a stranger as a patient representative rather than an individual of their choosing and with whom they have already developed trust. Thus, it seems that their WRAP has no legal authority. They also voiced they believe it is unfair that they lose some tangible items in these situations unnecessarily (phones, cigarettes, paper and writing materials)
- One man with a mental illness described being given medications without his consent when he was in crises. He said it contributed in his opinion to increasing his paranoid delusions that people in the hospital were out to get him.
- Some seniors have stated that they have experienced a slow decline in their cognitive abilities that comes and goes. Advanced health care directives have a limited range and it would be preferable to have options to allow them to make their own decisions with the support they need rather than having to use a substitute decision maker.
- One young woman voiced her desires to make her own decisions with support. Her aging mother explained how she currently helps her to make decisions. The young woman expressed her fears about what might happen when her mother is no longer living.
- Many people from many groups expressed a desire to choose, based on trust, who they want to support them rather than this being determined by courts, or medical personnel.
- Concerns are raised about the use of restraints, including chemical restraints.

Appendix B

Jane Ward (name altered)

This is a true story.

This is an illustration of the types of experiences people encounter when individual rights and freedoms are compromised under formal/informal guardianship instruments and substitute decision-making. Embedded in Jane's life story are many examples representing what happens to people that are excluded entirely from choice and control in their own lives. The alternate side of this story is the experience of the power of supports in the community and having one's communication, will and preferences respected.

Jane was born in 1963. Nobody knows her real name. She spent her early childhood at the Children's Home. The children in this home were kept in full cages and staff were admonished not to show any affection towards the children.

At a certain point, Jane was moved to the institution known as Exon House until the closure of institutions began. The creation of a community-based health care system ushered in the concept of building inclusive communities. Processes were put in place for people to come back to communities. Jane came out of the institution and joined her new community.

Jane developed many institutionally-taught behaviours, including a very high level of self-injurious behaviours. To this day she continues to be terrified of hospitals and anyone wearing a white coat. She has deep and obvious ligature marks on her wrists and ankles and has a need to wear her clothes very tight, as she spent the vast majority of her childhood in full restraints. Not unlike others, she had all of her teeth removed to prevent her ability to bite herself in frustration arising from her abusive treatment.

She is not, and has never been, under a formal guardianship order of the court but clearly, she has been a ward of the state and all that has implied in her life. She does not use traditional speech, but is quite capable of making her fundamental choices and preferences known to those who would care to listen.

In 1984, Jane was moved to the community where she now lives. She was first placed in a group home. Eventually, she was moved to a series of disastrous living arrangements where she was subjected to a total loss of dignity and respect in matters such as being undressed in front of others and required to go to bed at 6 o'clock each and every day.

In 1986, Jane went to work because employment agencies had been created to respond to the return of individuals from the institution to the community. The emerging change in values recognized people's lives would be richer if they were fully included in the community.

At one point, after the abuses which took place in some of her living arrangements, Jane ended up living in a hotel, where her friends rotated and provided support to her as nothing had been put in place for her. At this point she had no possessions, no clothes and everything she owned was in a single garbage bag.

In 1987, Jane was supported to bid on a contract to run the cafeteria at the community college. She was refused on the basis of not meeting the test of legal capacity. She was supported to start a smaller snack business, but eventually settled into working at various businesses and organizations until she retired a few years ago.

Employment provided a wonderful opportunity for Jane to broaden her social horizons. One of the great things that took place for Jane, at this time, was that an informal support group grew up around her. At one point in time a plan emerged to move her to another community where nobody knew her and she knew nobody. She would also lose her job. Her support group mobilized very quickly and successfully stopped her from being taken from her community.

Once she had the support of her network, she eventually found an apartment and this worked for about a year. This was happening at a time when the concerns for personal liability were peaking. Volunteers were being asked to take on legal responsibility for workplace-based injuries and no workers compensation was being provided.

In 2005, Jane and her support team were featured in a 1/2-day session at the Newfoundland and Labrador Supported Employment Conference. Thirteen people who were instrumental in her life (friends, social workers, fellow workers), formed a circle with Jane, while conference attendees listened as each member of the group spoke of the ways in which they understood, supported and valued Jane's friendship.

Jane, as stated, is well able to communicate her preferences, likes and dislikes and no person that knows her would ever consider otherwise. In effect, Jane had a personal support network that had grown organically, resembling supported decision-making.

Jane flew to a National conference in Halifax and loved the experience. There were absolutely no issues. Her personal support person had a large vision and understanding of Jane's potential. When the second opportunity came for Jane to go on vacation with her support person and friend, it was not considered due to liability considerations.

She was then moved to a community based cooperative living arrangement. This was a good experience at the outset, since the board and Government were very much in tune with the values of social inclusion. Jane was deeply involved in the community. Overall, things were pretty good. In addition to the offer to include Jane on her family vacation, Jane was enjoying going to Church with her supporter.

Things began to go wrong again.

In Jane's community the policies of her living support agency have become restrictive, custodial and questionable. While the operational approaches of supportive services agencies vary across the province, this agency in its current form takes a rather restrictive approach.

Jane was going to Church but relegated to the crying room where parents took their children. When it was discovered she was going to the crying room as a matter of

course, advocates succeeded in having her included with the population. Jane began to ask for Holy Communion and though it is not based in Church doctrine, the support agency decided Jane did not possess legal capacity and was not entitled to receive the sacrament.

The person who was most instrumental in Jane's life was transferred from her because of other staff complaints that these activities were rocking the boat. Since losing her lifeline support with whom she had such a deep connection, there has been a constant erosion of community inclusion and Jane is not seen out and about. Her friends have largely given up trying to include Jane.

Jane is permitted one cup of tea a day, though it is her favourite pastime. Tea is withheld in the event of a behavioural incident and advocates believe she is often set up to fail. She is not permitted without formal process to visit anyone in their homes, though it was normal for her to do so for years.

For the greater part of her life, the decision- making around Jane has for the most part of her life resembled guardianship. Yet, for about ten years, when given the opportunity Jane flourished and fit very well into the community. Almost all of the institutionally-taught behaviours faded into the background.

The lack of respect for her abilities to demonstrate choices and control and the failures to build upon this remarkable woman's spirit, wills and preferences are lived, in part, by many people in our province.

Appendix C

UN CRPD

Article 12 – Equal recognition before the law

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

4. 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.

5. 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.

Appendix D

UN CRPD

I. Article 19 – Living independently and being included in the community

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.

Appendix J

Towards an Inventory of Tools and Resources for Supported Decision Making

About the Inventory

For a shift to a decision-making capabilities approach to legal capacity, change is necessary at various levels. IRIS has conducted a preliminary scan of available tools and resources that aim to assist stakeholders with understanding and implementing decision-making supports and accommodations. To date, we have identified over 30 resources that reflect a range of tools to support individuals and communities.

Going forward, this inventory will be developed into a user-friendly database, including:

- Supplementary information and links to relevant legislative frameworks for resources produced in different jurisdictions
- Additional resources and tools, identified through an ongoing search process and through submissions from community stakeholders

Resources gathered to date have been classified according to several factors with stakeholders/users in mind, including:

- Format or type of resource
- Intended primary audience
- Relevance to decision-making area(s)
- Relevance to IRIS' eight core function(s)

Types of Resources:

The sample include a range of resource types: guides targeted to certain types of decisions or users; samples of decision-making support agreements; personal stories of self-advocates and families; training and learning tools for professionals; worksheets; general information guides; and info sheets. Additional resource types will be added as we identify them.

Primary Audiences:

Of the resources identified so far, sixteen are intended for primary users who are people with disabilities and their supporters/families; 10 are targeted towards supporters or potential supporters; 6 are intended for medical professionals; 5 are for general audiences; 1 is for legal professionals; and 2 are for disability staff and other front-line workers. Note that some resources are written with multiple audiences in mind

Decision Areas:

18 resources are relevant to health care decisions; 19 are relevant to personal and lifestyle choices; 18 are relevant to finances and property; and 12 are relevant to decision-making processes in general.

Supporting Core Functions in Community-based Delivery of Decision-making Support:

The resources were analyzed according to their 'fit' with one or more of the core functions identified for community-based initiatives, as described in "A Framework for Community-based Initiatives for Supporting Decision Making and the Equal Right to Decide" developed by IRIS.

The eight core functions are:

1. **Change community norms** – about the place and rights of people with intellectual/developmental, cognitive, psychosocial and communication disabilities – through community forums, awareness raising, the sharing of personal experience and community planning.
2. **Explore a person’s current situation and aspirations** – through the provision of planning facilitators who assist a person to begin planning for their future and identifying who they would like to assist them.
3. **Identify needed supports and accommodations** – with the assistance of a planning facilitator who helps the person identify what would be of most assistance.
4. **Arrange needed supports for decision making** – whether this be one-time supports, an individual advocate, or a supported decision-making arrangement where the person has designated decision-making supporters to assist them.
5. **Support real life opportunities to make decisions** – by a planning facilitator and support network assisting the person to take decisions, encountering others in their community, as they seek to put their plans into action.
6. **Arrange accommodations as needed** – as issues or difficulties may be raised with other parties as a person seeks to make decisions in health care or with a bank, for example, provide assistance to the person and the other party to adapt the decision-making process to be more inclusive and responsive to the person.
7. **Legally challenge obstacles as needed** – sometimes if accommodations and supports cannot be arranged, legal avenues may be available to challenge the lack of decision-making rights and supports.
8. **Safeguard a person’s autonomy** – recognizing that a person may be vulnerable to harm, neglect, abuse or undue influence, take steps to make sure the oversight is in place to protect the person and their interest, while continuing to support their right to decide.

The majority of resources identified to date are related to exploring, planning for and arranging decision-making supports and accommodations:

- Core Function 2: 18 resources
- Core Function 3: 12 resources
- Core Function 4: 9 resources.

There are also a significant number of resources related to making decisions and exercising legal capacity:

- Core Function 5: 5
- Core Function 6: 4
- Core Function 8: 3

However, only 1 resource in this category is related to legally challenging obstacles to decision-making (Core Function 7).

Other Trends and Observations:

Based on the sample of tools collected so far, a number of preliminary trends have emerged.

Tools we have identified range in their inclusivity and accessibility. For example, some assume that capacity assessments are necessary, while the majority are grounded in a decision-making capabilities perspective. Many tools targeted towards people with disabilities include visual cues, which may or may not improve the accessibility for readers. Some of the resources include complimentary content for people with disabilities and their supporters. There are also variations in terms of the length and scope of resources, with some taking an expansive approach of including numerous topics, appendices and supplementary tools, while others remain focused on a particular decision area or component of the decision-making process. Our preliminary assessment is that accessibility is often hindered by resources that try to tackle too much, and that resources need to be intentional in terms of their target audience(s) and their strategies for communicating information. *The Right to Make Choices: International Laws and Decision-Making by People with Disabilities* addresses these challenges by being available in a plain text longer version, as well as an “easy-read” version that is divided into shorter components and includes effective visual cues. The *Making Decisions* series by NUI Galway is published by stand-alone decision-making areas, but it offers broader contextual information for readers through an introductory section entitled *Making Decisions-Capacity*.

Tools that are situated within a clear legislative framework tend to be more effective in providing tangible/ useful information to readers. Many of the resources reviewed contain information that is not bound to a specific jurisdiction or legal framework (i.e. about processes, practical tips, broader contexts, etc.), but also reference local legislation or policies in particular sections or appendices. In many cases, resources can benefit from enhanced clarity about which of its components are tied to existing legal frameworks and which are universal. We found that resources that explicitly identify relevant legislative parameters are the easiest to navigate. For example, *Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities* immediately alerts readers to the various legal contexts for supported decision making in jurisdictions across Canada, ensuring that the application of the tool is appropriate to each user’s context. (Note: this part of our analysis will continue to evolve, and future versions of the inventory will include information about legislative and policy frameworks for users.)

This initial sample suggests there is a need for complimentary tools for working with professionals and service providers, particularly in contexts where decision-making supports and accommodations are not supported by an existing legal framework. Many resources targeted towards individuals and their supporters identify that there is a need to communicate clearly and persuasively with a range of professionals as supported decision-making processes take place; however, sector-specific tools to support individuals and supporters in the communication processes with these professionals are very limited. For example, ACLU’s *Brainstorming Guide: How are we already using supported decision-making?* invites users to begin preparing for conversations with doctors, bankers, lawyers and others who may have concerns or questions about supported decision-making processes. We see an unmet need for supplementary tools such as sector-specific one-pagers that explain supported decision-making and connect this information with the individual’s decision-making context.

Finally, the tools we have identified are limited in terms of the range of decision areas and core functions they address. For example, communities would benefit from additional resources that focus on shifting community norms about the capacity of all people to make decisions on an

equal basis, on strategies and opportunities to legally challenge barriers, and on safeguarding autonomy. Going forward, development of tools and resources should target these key areas that are currently under-addressed.

Sample: In-Progress Inventory of Tools related to Decision-Making Supports and Accommodations (DMS+A)

Title	Type of Resource	Author	Relevant to Which Core Function											Overview / General Description		
			Relevant to Which Types of Decisions				Gen	1	2	3	4	5	6		7	8
			General	Financial/Property	Health Care	Personal Life										
Supported decision-making	Web page	Government of Alberta		x	x	x		x								Topics include: general overview; who can be a supporter; ending support; videos Links to DMS+A authorization form and termination forms and Adult Guardianship and Trustee Act
Supported Decision Making - Adult Guardianship and Trusteeship Act	Info Sheet	Government of Alberta		x		x	x	x								Provides overview of: the AGTA; what is supported decision-making; how to enter a SDM arrangement; and guiding principles. Note: the resource makes the assumption that SDM is relevant to people with "mild disabilities."
PRACTICAL Tool for Lawyers: Steps in Supporting Decision-Making	Targeted Guide (to type of decision, step in the DM process, roles in decision making)	American Bar Association & National Resource Center for Supported Decision-Making		x	x	x		x	x	x	x			x		Purpose is to support lawyers to identify, consider and initiate decision-making options that are less restrictive than guardianship. Offers a nine step process for lawyers to identify DMS+A options for clients.
Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities	Targeted Guide (to type of decision, step in the DM process, roles in decision making)	Surrey Place			x				x	x	x	x				Tool to assess and promote decision-making capabilities of adults with IDD. Provides an overview of DMS+A in Canadian jurisdictions; common errors to avoid during assessment; provides a fillable form for assessing independent, inter-dependent, and dependent decision areas.
Supported decision-making agreements: could this help me?	General Information - What are DM supports and accommodations	Yukon Health and Social Services		x	x	x	x									Provides practical information about when and how supported decision making agreements are helpful; how to make an agreement; and how to work with an associate. Purpose is to raise awareness about DMS+A as a possible strategy and to normalize accessing support for making important decisions.
Supported decision-making: A User's Guide for People with Disabilities and Their Supporters	General Information - What are DM supports and accommodations	Disability Rights Maine		x	x	x			x	x	x	x				The goal of this Guide is to illustrate how decision making supports can be used to help people with disabilities in making their own decisions, and in reducing more restrictive means of support such as guardianship. Provides an overview of DMS+A; alternatives to guardianship; self-advocacy tips; identifying when support is needed/what kind of support; identifying supporters; supported decision-making agreements.

Inventory of Tools related to Decision-Making Supports and Accommodations (DMS+A)

Title	Type of Resource	Author	Relevant to Which Types of Decisions												Overview / General Description
			General	Finance/Property	Health Care	Personal Life	Relevant to Which Core Function								
			Gen	1	2	3	4	5	6	7	8				
Supported Decision Making Practice Framework	Info Sheet	NSW Government	x										x	The info sheet is a diagram that visually communicates the guiding framework for decision-making supports. It offers a simple best practice framework centred on upholding the person's right to make their own choices and build capacities.	
It's My Choice! Vol 2 A Guide for People with a Disability, their Family, Carers, Friends and Advocates	Targeted Guide (to type of decision, step in the DM process, roles in decision making)	Inclusion Melbourne		x	x			x					x	Goal is to support people with disabilities to express preferences/feelings, make choices, and shape their own lives. It addresses day-to-day choices and also bigger lifestyle choices and decisions about the future. It provides complimentary information and tools for family, friends and advocates. It includes sections on: Feelings and communication; identifying lifestyle preferences; tips for trying new things; life planning with supports; understanding choices; role of services and supports for the individual; prompts for reflection; addressing challenges/conflicts; human rights; glossary of terms	
Training Guide - Introduction to Supported Decision Making: A one day workshop for disability services staff	Training and Learning Tools	NSW Government	x			x								The introduction to Supported decision Making workshop has been designed as a one-day face-to-face program for disability services staff. This workshop has been developed to assist staff who have responsibilities within their agencies to support decision making. It includes sections on: Feelings and communication; identifying lifestyle preferences; tips for trying new things; life planning with supports; understanding choices; role of services and supports for the individual; prompts for reflection; addressing challenges/conflicts; human rights; glossary of terms	
Identifying Alternatives to Guardianship	Worksheet	DC Government		x	x	x					x			This tool was designed to help with identifying a person's ability to make decisions and manage key areas of life. It is intended to help with exploring alternatives and less restrictive options to guardianship. It includes questions in the areas of : daily life and employment; healthy living; personal safety and security; social and spirituality; community living; citizenship and advocacy.	

Inventory of Tools related to Decision-Making Supports and Accommodations (DMS+A)

Title	Type of Resource	Author	Relevant to Which Types of Decisions											Overview / General Description				
			General	Financial/Property	Health Care	Personal Life	Gen	1	2	3	4	5	6		7	8		
Policy on preventing discrimination based on mental health disabilities and addictions	other categories TBD	Ontario Human Rights Commission	x												x	x	x	S.13 outlines Ontario's policy on the Duty to Accommodate, including principles of accommodation, determining appropriate accommodations, forms of accommodation, duties and responsibilities of parties involved
Making Decisions - Capacity	Targeted Guide (to type of decision, step in the DM process, roles in decision making)	NUI Galway	x															An introduction to exercising capacity and finding support for decision-making process. This is the introductory section to a series of "Making Decision" tools, which are organized by key decision areas and covered in detail in the series.
Making Decisions - Your Health	Targeted Guide (to type of decision, step in the DM process, roles in decision making)	NUI Galway			x													
Making Decisions - Your Money	Targeted Guide (to type of decision, step in the DM process, roles in decision making)	NUI Galway		x														
Making Decisions - Your Place to Live	Targeted Guide (to type of decision, step in the DM process, roles in decision making)	NUI Galway				x												This series offers a consistent, plain language guide about how to begin exploring how to get supports and make decisions, with information and tips related to each decision area. Each includes a practical story that demonstrates that process someone took to get support making a decision in each area.
Making Decisions - Your Relationships	Targeted Guide (to type of decision, step in the DM process, roles in decision making)	NUI Galway				x												
Making Decisions - Your Will	Targeted Guide (to type of decision, step in the DM process, roles in decision making)	NUI Galway		x														

Inventory of Tools related to Decision-Making Supports and Accommodations (DMS+A)

Title	Type of Resource	Author	Relevant to Which Types of Decisions											Overview / General Description
			General	Finance/Property	Health Care	Personal Life	Relevant to Which Core Function							
			Gen	1	2	3	4	5	6	7	8			
ACLU Supported Decision-Making Agreement - ACLU DISABILITY RIGHTS PROGRAM SUPPORTED DECISION-MAKING AGREEMENT	Examples of Decision-making Support Agreements	ACLU		x	x	x								Example of supported decision making agreement.
ACLU Supported Decision-Making Agreement - Quality Trust Sample Supported Decision-Making Agreement	Examples of Decision-making Support Agreements	ACLU												Example of supported decision making agreement.
Nonotuck Resource Associates and Center for Public Representation Supported Decision-Making Agreement	Examples of Decision-making Support Agreements	Supported Decision-Making Project		x	x	x								Example of supported decision making agreement.
When Do I Want Support Tool	Worksheet	ACLU		x	x	x								A tool to guide users in making decisions about support and things to think about such as: Who you might want to support you? What kind of support do you need? You can use the information in this form to help you fill out a Supported Decision-Making Agreement.
Feeling Like a Member of Society with Rights	Personal Story - Video	Centre for Family Involvement	x											Marisa, a self-advocate, shares why she thinks guardianship is unnecessary.
Relationship Mapping	Personal Story - Video	Centre for Family Involvement	x											Presents an example of how a relationship map can be used at the outset of setting up supports for decision making to identify who are potential supporters.
Supported Decision-Making: Frequently Asked Questions	Info Sheet	ACLU	x											General information for general audiences about what is supported decision-making, how does it work, how does it relate to person-centred planning, and a detailed comparison to guardianship.

Inventory of Tools related to Decision-Making Supports and Accommodations (DMS+A)

Title	Type of Resource	Author	Relevant to Which Types of Decisions											Overview / General Description
			Gen	Finance/Property	Health Care	Personal Life	Relevant to Which Core Function							
			Gen	1	2	3	4	5	6	7	8			
Brainstorming Guide: How are we already using supported decision-making?	Worksheet Targeted Guide (to type of decision, step in the DM process, roles in decision making)	ACLU											This tool is designed for families and supporters to: help identify ways that decision-making supports are already in place, and areas where they could be used in future; help formalize supported decision-making arrangements to prevent the need for guardianship or conservatorship; to help think about ways to support learning and practicing decision-making; and to help explain to professionals the ways in which the decisions of a person with a disability are informed and safe.	
How to Make a Supported Decision-Making Agreement	Worksheet Targeted Guide (to type of decision, step in the DM process, roles in decision making)	ACLU											The resource provides a series of exercises and worksheets in preparation for setting up a supported decision-making agreement. It also includes a sample agreement, as well as some US-based forms for sharing personal information.	
Shared Decision Making: A Model for Clinical Practice	Targeted Guide (to type of decision, step in the DM process, roles in decision making)	Elwyn, G. et al. .											This article responds to a lack of guidance about how to accomplish a shared decision making approach in routine clinical practice. It offers a three-step model that is practical for clinicians. How to do SDM in routine settings, in short to integrate good communication skills with the use of patient decision support tools. The model also includes the use of decision support interventions, which summarize information in formats that are accessible to patients.	
Supported Decision Making Good Practice Guide	General Information - What are DM supports and accommodations	Mental Welfare Commission for Scotland											This guide discusses: 1. What supported decision-making is and why it is relevant and important. 2. The human rights framework that supports autonomy and supported decision making. 3. The role that supported decision-making can play in reinforcing principles that underpin Scottish legislation. 4. What must be taken into account when providing supported decision-making. 5. Examples of supported decision-making.	
The Right to Make Choices: International Laws and Decision-Making by People with Disabilities	Targeted Guide (to type of decision, step in the DM process, roles in decision making)	ASAN											This guide (the plain-text version) helps people with disabilities and their families understand decision-making laws. Readers will learn about different kinds of support to make choices. It provides information about how the CRPD intersects with national disability laws, and different laws around th world (USA, Canada, Sweden, UK, Bulgaria, . It also provides examples of how people in different countries have changed their laws to help people with disabilities make our own choices.	

Inventory of Tools related to Decision-Making Supports and Accommodations (DMS+A)

Title	Type of Resource	Author	Relevant to Which Types of Decisions				Relevant to Which Core Function								Overview / General Description			
			Gen	Finance/Property	Health Care	Personal Life	Gen	1	2	3	4	5	6	7		8		
Communication Supports in Exercising Legal Capacity, Control and Autonomy	Training and Learning Tools	Communications Disabilities Access Canada (CDAC)	x	x	x	x												This resource is about the communication supports people may need to control what happens in their lives and to express preferences, choices and decisions that matter to them. It includes 5 webinar sessions and supplementary resources on: 1) Communication and Capacity: Context and Guiding Principles. 2) Communication Disabilities: Barriers and Impact on Autonomy and Control. 3) Legal Context for Communication Supports. 4) Communication Supports for people who speak, or who use pictures, symbols, letter boards or devices. 5) Communication Supports for people who communicate primarily using body language, vocalizations and behaviours.
The Right to Make Choices: International Laws and Decision-Making by People with Disabilities -EASY READ EDITION	Targeted Guide (to type of decision, step in the DM process, roles in decision making)	ASAN	x			x												The Easy Read version is divided into five parts, each containing one subject discussed in the toolkit: Supported decision-making, guardianship, the Convention on the Rights of People with Disabilities, the state of the law on guardianship and supported decision-making in multiple countries, and the glossary explaining the terms we use in the toolkit.
People with Disability and Supported Decision-Making	Targeted Guide (to type of decision, step in the DM process, roles in decision making)	National Disability Service		x	x	x		x	x	x								Significant legislative changes are occurring across Australia that will increase the obligations on a wide range of organisations, including NDIS providers, to support people with a disability to make their own decisions. This guide outlines practical information about how to implement SDM in this context.
A Guide to Supported Decision-Making: protecting individual rights and reducing the risk of elder abuse	Targeted Guide (to type of decision, step in the DM process, roles in decision making)			x		x											x	This guide provides older adults, seniors, family members, caregivers and service providers with an overview of the current options available to inform decision-making about financial and personal matters. Information and knowledge about these tools and supports can contribute to protecting an individual's autonomy and rights and may reduce the risk of elder abuse.
Supported Decision-Making Authorization Form	Examples of Decision-making Support Agreements	Unknown	x															Form for establishing SDM agreements.

[TheSupportedDecisionM
akingModelManualforIn
dividualsandFamilies](#)

Targeted Guide (to type of
decision, step in the DM
process, roles in decision
making)

South Carolina
Supported Decision
Making Project

	x	x	x			x	x	x							
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This manual was written to provide information about Supported Decision Making to individuals with disabilities and their families. You will read how Supported Decision Making can be used in place of more restrictive means, such as guardianship, to preserve a person's autonomy and independence, while still providing the person with support from his or her family, friends, and community. It includes: a worksheet for individuals to explore what kinds of decisions/life areas they need support in; a sample SDM agreement; and lists of additional resources.