# A New Paradigm for Protecting Autonomy and the Right to Legal Capacity

Prepared for the Law Commission of Ontario

Ву

Michael Bach and Lana Kerzner<sup>1</sup>

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#### **INTRODUCTION**

This paper addresses the question framed by the Law Commission of Ontario: "What principles and considerations should be applied when considering placing limitations on the ability of persons with disabilities to make their own choices?" The ability to make one's own decisions based on personal values and in the context of meaningful choices is a defining feature of what it means to be a person and a full citizen. A basic tenet of liberal-democratic philosophy is that the state has a primary role in protecting autonomy or the right of individuals to choose and pursue their own life path, and all the decisions that entails along the way – related to personal relationships, where to live, educate, work, what health care interventions to accept or reject, and a wide range of financial and property decisions.

Yet many people with more significant intellectual, cognitive and psychosocial disabilities<sup>2</sup> face substantial or total restrictions in making their own decisions. They often encounter others who presume they are unable to guide their own lives, are people who need to be 'fixed', or protected, and who limit or completely restrict the scope of their decision making.<sup>3</sup> Many people are physically isolated or socially and economically excluded and therefore without meaningful choices or the opportunity to develop a vision and direction for their own lives, and to make their own decisions.<sup>4</sup> Service provision in the disability and older adult sectors is often based on charity and protection models, and an assumption that because people need supports and care, others should make decisions on their behalf. Often service providers also require that they are provided decision making authority on behalf of those they are supporting so they can more efficiently manage the range of individual decisions related to care,

medications, activities, etc. As people age and their cognitive functioning declines, family, community members, and service providers often respond by restricting the scope of the person's decision making. Individual decision making is restricted in informal ways, and also through formally authorized substitute decision making and guardianship.

There is a growing critique of the substitute decision-making approach to managing individual decision making for people with intellectual, cognitive and/or psychosocial disabilities. Indeed, as early as 1982, Alan Borovoy directly challenged adult guardianship as

one of the most intrusive encroachments that a democracy can impose... a democratic society has no business rendering people susceptible to the loss of this most precious freedom on the basis of a question-begging definition and elastic terminology. Indeed, I see no reason why we have to go beyond . . . those kinds of emergency situations where an arguable cause (sic) might be made for some kind of encroachments on a person's liberty.<sup>5</sup>

How the state best protects and enhances autonomy is at the heart of the question this paper addresses. In this paper we explore negative and positive liberty approaches to protecting and enhancing autonomy. It is the relationship and tension between the two that informs and guides the analysis throughout.

Determining a person as incapable or incompetent to manage his or her affairs in some or all respects removes a person's authority over their own lives and vests this authority in another. While usually done in the name of protection, such removal of an individual's legal personhood is increasingly seen from a disability rights perspective as a violation that brings social and legal harm to individuals. The concern is that individuals are no longer addressed as persons in their own right when their legal

capacity to act is restricted, and thus their moral and legal status is more likely to be diminished in the eyes of those in close personal relationships, caregivers, community members, health and human services, and public institutions. This diminishment contributes to the risk of stereotyping, objectification, negative attitudes and other forms of exclusion which people with disabilities disproportionately face; and which increase powerlessness and vulnerability to abuse, neglect and exploitation.

Critical analysis of guardianship legislation from a human rights perspective has grown in recent years not only in Canada, but internationally. For example, the Mental Disability Advocacy Centre has undertaken a number of studies on guardianship law, policy and practice in Central and East European countries, and concludes in one of its reports, with respect to people under guardianship:

[They] are subject to significant, arbitrary and automatic deprivations of their human rights. These include a deprivation of their right to property, to work, to family life, to marry, to vote, to associate freely, and to access courts. Even if not specifically deprived of certain rights, a lack of procedural capacity ensures their inability to enforce them.<sup>8</sup>

In addition to challenges from the civil and disability rights movements, reliance on this substitute approach to decision making is increasingly challenged through developments in jurisprudence, legislation and international law. Most recently, the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD), ratified by Canada in March 2010, emphasizes in its guiding principles respect for individual autonomy, dignity and freedom to make one's own choices without discrimination on the basis of disability. Article 12 of the CRPD 'Equal Recognition Before the Law' recognizes the right to legal capacity on an equal basis with others without discrimination on the basis of disability and, in Article 12(3), the obligation of States

Parties to ensure access to supports individuals require to enjoy and exercise their legal capacity.

Jurisprudence and legislative reform in Canada and elsewhere are beginning to grapple with what full recognition of the right to legal capacity requires. There is little doubt that Article 12 has signaled and initiated a major transformation in the law of legal capacity – what many have referred to as a 'paradigm shift.' Oliver Lewis has suggested that the CRPD as a whole "has the potential to become a transformative international legal instrument which innovates domestic politics as much as policies" in its expressive, educational and proactive roles. With respect to Article 12, Gerard Quinn frames the shift as follows:

It is frequently said that Article 12 of the CRPD is emblematic of the paradigm shift of the convention... the deceptively simple proposition that persons with disabilities are 'subjects' and not 'objects' – sentient beings like all others deserving equal respect and equal enjoyment of their rights... I want to proceed by laying out what I believe lies at the bottom of the debate – namely conceptions – sometimes competing conceptions - of personhood. These conceptions are largely unstated but exert a powerful undertow. I want to work outwards from this notion (or notions) of personhood and onwards to the legal tool of capacity that help to secure notions of personhood in the lifeworld. I see legal capacity as instrumental to personhood. I want to use this vantage point as a rust solvent to clear away some easy or formulaic understandings of Article 12 and to arrive at a conceptual frame that helps us to truly grasp the profound paradigm shift of Article 12. <sup>10</sup>

In the second part of this paper we explore more inclusive conceptions of personhood than the traditional 'understand and appreciate' test of legal capacity provide, as a basis for a new legal paradigm of legal capacity. Quinn defines legal capacity this way:

legal capacity... provides the legal shell through which to advance personhood in the lifeworld. Primarily, it enables persons to sculpt their own legal universe – a web of mutual rights and obligations voluntarily entered into with others. So it allows for an expression of the will in the lifeworld. That is the primary positive role of legal capacity. Let me emphasise this. Legal capacity opens up zones of personal freedom. It facilitates uncoerced interactions.<sup>11</sup>

At the same time there is increasing emphasis on autonomy interests of people with disabilities, there is a growing focus on issues of protection from abuse and the need for treatment for older persons and people with psychosocial disabilities. Such concerns are valid and should not be minimized in any way given the growing incidence of elder abuse that is evident with a rapidly aging population, <sup>12</sup> the high rate of reported mental health conditions estimated to personally and directly affect 20% of the population, <sup>13</sup> the increasing incidence of mental health issues for older adults, <sup>14</sup> and the hugely disproportionately high rates of violence and abuse against people with disabilities. <sup>15</sup>

One of the most recent articulations of these concerns can be found in the Final Report (August 2010) of the Ontario Legislative Assembly's 'Select Committee on Mental Health and Addictions.' While the Committee did not make specific recommendations with respect to legal capacity, its report expresses a concern that the emphasis on autonomy rights interests and the right to refuse treatment "ties the hands" of professionals and families seeking to get care for clients and family members. The Committee advocates, therefore, that "the right to autonomy must be balanced with the right to be well" and recommends a number of measures that would effectively place greater constraints on autonomy than is currently the case in Ontario. 16

However, any re-balancing away from autonomy interests is notable and concerning in a few respects. First, there is no recognized 'right to be well' articulated in domestic or international law. Furthermore, conceptualizations of individual and social well-being tend to emphasize that integral to notions of wellness and well-being is the enjoyment of autonomy.<sup>17</sup> To set autonomy and wellness in conflict seems conceptually, ethically

and legally risky. Further, any direction to shift service delivery back towards more paternalistic models of care, at least with respect to those for whom involuntary treatment is considered to be a valid option, appear to run counter to the CRPD.

In light of these potentially contradictory developments in both domestic and international law and policy discourse, the challenge for law reform addressed by this paper can be characterized by five guiding questions:

- To what extent, if at all, can limitations on decision-making rights be imposed given Canada's commitments to international law on human rights and disability as reflected in the UN Convention on the Rights of Persons with Disabilities?
- How do we best ensure that people have access to the supports they require to maximize exercise of their legal capacity?
- What is the role of the state and other entities in ensuring individuals have access to the supports and accommodations required to maximize their legal capacity?
- How do we balance the right to autonomy with the duty to protect where
  people's decision-making abilities are limited, or where they are lacking
  needed supports, and/or where they are vulnerable to abuse and neglect?
- How do we manage this balance in a way that does not discriminate on the basis of disability?

With the aging of the population, advances in medical technology and other factors there is a growing proportion of people with intellectual, cognitive and/or psychosocial

disabilities. These trends make clear the urgent need to find a better balance between autonomy and protection, one consistent with international human rights law as reflected in the CRPD.

To address the guiding questions outlined above, this paper is organized into two major Parts, each with a number of sections:

Part One outlines the context and current framework of capacity law in Canada. In Section I we introduce and describe key terms on which the analysis rests. Section II provides an introduction to the UN Convention on the Rights of Persons with Disabilities and the main Articles that shape the examination of law in this paper. Perspectives from the disability and older adult communities on the issue of autonomy and substitute decision-making are outlined in Section III. In Section IV we review negative and positive liberty approaches to protecting autonomy, as the tension between the two is central to addressing how to best balance advancing autonomy and protect against abuse and neglect – common concerns that are used to justify substitute decision-making provisions. With these concepts and framework of international human rights law in mind, Section V outlines traditional and current legal capacity laws in Canada.

Part Two of this paper looks towards a new legal paradigm for maximizing autonomy guided by the CRPD. Section I critically examines usual assumptions about 'who' it is that exercises legal capacity, and proposes a minimum threshold for recognizing persons capable of directing decision making about their lives. Sections II and III elaborate a conceptual framework of decision-making supports and decision-making statuses by which legal capacity can be exercised in ways that account for the CRPD's

recognition of the obligation to provide people with supports needed for this purpose. A re-formulated 'duty to accommodate' is presented in Section IV, along with implications for governments and other entities in ensuring that people with disabilities are reasonably accommodated and supported in decision-making processes which are regulated in some way by human rights and other laws. Sections V and VI explore a range of safeguards to ensure decision-making processes respect the equal right to legal capacity, and look in particular at protecting autonomy in disputes about reasonable accommodation; where decisions fundamentally affect personal integrity; and in the face of serious adverse effects. These sections propose a range of institutional machinery to implement the recommended safeguards. Section VII provides a summary of the main concepts and proposals we recommend in this paper. A concluding section steps back to consider the original questions posed in this paper and the results of the analysis.

#### PART ONE

#### SETTING THE CONTEXT AND CURRENT FRAMEWORK OF CAPACITY LAW

#### I. TERMINOLOGY

#### A. Disability

We are guided in this paper by the description of disability articulated in Article 1 of the CRPD:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

As Michael Stein and Janet Lord note, the CRPD does not directly define the term 'disability': "[i]nstead, Article 1 of the Preamble affirms the social construction of disability in which limitations arise from a person's interaction with environmental barriers rather than as the consequence of an individualized impairment." This approach reflects a social and human rights model of disability. The model recognizes that it is society's failure to accommodate the needs of people with disabilities which give rise to the 'disabling disadvantage' that people with disabilities encounter in their daily lives, not some inherent mental, sensory or physical condition. <sup>20</sup>

We define the terms 'intellectual,' 'cognitive,' and 'psychosocial' disability as follows. An intellectual disability generally means having greater difficulty than most people with intellectual and adaptive functioning due to a long-term condition that is present at birth or before the age of eighteen. People with this label may have greater difficulty in carrying out everyday activities such as communicating and interacting with others, managing money, doing household activities and attending to personal care. While the

term 'intellectual disability' is technically distinct from other 'developmental disabilities' these terms are often used interchangeably. Cognitive disability refers to similar kinds of difficulties, usually with later onset than age eighteen but which may result from brain injury at an earlier age. People with cognitive disabilities include those who have experienced stroke, dementias or Alzheimer's disease, and older adults who experience other forms of cognitive decline as they age. People with psychosocial disabilities are those who experience mental health issues, and/or who identify as 'mental health consumers', 'psychiatric survivors,' or 'mad.' These are not mutually exclusive groups. Many people with intellectual or cognitive disabilities, as well as older adults also identify or are identified as having psychosocial disabilities.

### B. Legal Capacity and Incapacity

Throughout this paper we refer to the right to 'legal capacity.' We also refer to 'capacity' laws in Canada, which generally define the cognitive requisites considered necessary for individuals to be recognized as able to exercise legal capacity. In later sections of the paper, to avoid confusion, when we refer to 'capacity' as it is defined and used in Canadian law, we sometimes use the convention of placing the term 'mental' in front of it in square brackets in order to clarify that our reference to the term is with respect to its usage in law as a descriptor of individual mental/cognitive characteristics considered necessary to exercise legal capacity. Thus, we refer to the right to legal capacity and to criteria of [mental] capacity in Canadian law.

We also refer to 'legal capacity law' in Canada, rather than simply to 'capacity law' as is the usual case, to clarify that [mental] capacity laws in Canada effectively regulate and allocate the recognition of the right to legal capacity on the basis of certain mental criteria like the ability to understand information and appreciate consequences of a decision.

The term 'legal capacity' has a particular meaning in the context of international Conventions and is contained in the *Convention on the Elimination of All forms of Discrimination against Women*<sup>21</sup> (CEDAW) as well as in the CRPD.<sup>22</sup> It is generally understood in these Conventions as referring to people's capacity to have rights, and to have the capacity to act on those rights on an equal basis with others without discrimination on the basis of gender or disability. Legal capacity in this sense is a recognized status.

A legal opinion of the International Disability Alliance ("Legal Opinion") on the article of the CRPD that addresses legal capacity<sup>23</sup> describes legal capacity as consisting of two components: "the capacity to hold a right and the capacity to act and exercise the right…". <sup>24</sup> International human rights law constructs legal capacity to include both of these elements. <sup>25</sup> With respect to exercising the right to individual autonomy, which is the focus of this paper, the right to legal capacity means, for example, choosing where and with whom you wish to live, and most importantly, having those choices respected. The concept is relevant to all areas of an individual's life, including the exercise of legal capacity to enter a contact, to marry, to vote, to deal with property and to make personal life, personal care and health care decisions.

However, this term is not often found in Canadian law. The term 'capacity' is much more frequently used in Canadian legislation<sup>26</sup> and is commonly, but not always,

defined to refer to an ability to understand information relevant to making a decision and an ability to appreciate the reasonably foreseeable consequences of a decision or lack of decision. In this sense, 'capacity' refers to the cognitive requisites considered necessary for exercising one's right to legal capacity, and having it respected by others.

The term 'legal capacity' is not absent from Canadian legal discourse, and is used in the Law Society of Upper Canada's *Rules of Professional Conduct*<sup>27</sup> in relation to the concept of having legal capacity to instruct counsel, and also in Ontario's *Human Rights Code*, which guarantees to every person having legal capacity a right to contract on equal terms without discrimination.<sup>28</sup> However, the framing of the provision in the *Human Rights Code* appears to rest on the traditional assumptions of capacity law that some persons are without legal capacity. We challenge this assumption in this paper in light of the CRPD.

The concept of legal capacity is significant because it represents a shift in the understanding that many members of the legal community have attributed to it. A common understanding of legal capacity law in Canada views it in relation to a person's cognitive functioning. For example, in relation to Ontario's *Substitute Decisions Act* (SDA), the Office of the Public Guardian and Trustee's "Guidelines for Conducting Assessments of Capacity" states the following:

In its legislation, the Government of Ontario has codified the belief that mental capacity is, at its core, a cognitive function. The SDA operationally defines capacity as the ability to understand information relevant to making a decision and appreciate the reasonably foreseeable consequences of a decision or lack of decision. <sup>29</sup>

Thus, having the status of being considered legally capable is determined based on a person's own ability to understand information and assess consequences of making a

decision. Legal capacity, in this sense, is attached to the attributes of a person. In contrast, legal capacity as it is used in the *Convention on the Elimination of All forms of Discrimination against Women* and the CRPD is a social and legal status accorded independent of a person's particular capabilities.

The Legal Opinion illustrates this crucial aspect of legal capacity in its description of what legal capacity means for people who do not have disabilities, as follows:

A non-disabled citizen who owns real estate, or a car, a horse or a book is entitled to sell the house, to hire the car, gift the horse or lend the book. All these and similar dispositions as an owner are a part of his or her legal capacity. <sup>30</sup>

Defined in this way, legal capacity does not reflect an individual's ability to make decisions. Rather, it reflects an individual's right to make decisions and have those decisions respected, and signals a social model approach to defining and understanding disability. As such, a social model approach to defining legal capacity focuses not on the individual's attributes or relative limitations, but rather on the social, economic and legal barriers a person faces in formulating and executing individual decisions, and the supports and accommodations they may require given their particular decision-making abilities.

Across jurisdictions there are a wide variety of laws regulating legal capacity, and tests employed to determine requisite mental capacity. In fact, it has been stated that "[t]here are as many different operational definitions of mental (in)capacity as there are iurisdictions."<sup>31</sup> A review of these situates the current test employed in Canada.

Amita Dhanda describes three categories for the attribution of incapacity for people with disabilities as follows:<sup>32</sup>

- status attribution: presumes that a person with a specific type of disability lacks legal capacity. This results in formulations where a person with a specific type of disability is prohibited from performing a specific legal task.
- outcome test: capacity determinations are based on an evaluation of the decision made.
- functional test: legal capacity determinations are based on a person's ability to perform a specified function, such as understanding the nature of a contract.<sup>33</sup>

Increasingly, the first two approaches to regulating legal capacity have been brought into question internationally and successfully challenged in the courts. More recent statutory reform efforts (in the Republic of Ireland and elsewhere) have focused on the functional test of decision making capacity. A 'functional' approach to regulating legal capacity is increasingly recognized in both statutory law and jurisprudence and challenges the predominant status and outcome approaches. Canada's laws, too, are most consistent with the functional approach.

The importance of the functional approach for people with disabilities has been described as follows:

This approach is in the ascendant mainly because it is closer to human rights values and law, favouring a "tailor-made" approach to determining capacity. With this approach there is still a need to guard against paternalistic assumptions which may distort objective assessments of functional capacity.<sup>34</sup>

However, the International Disability Alliance (IDA) has recently challenged the functional test for legal capacity on the basis that its application constitutes discrimination in exercising the right to legal capacity on an equal basis with others.<sup>35</sup>

Instead, the IDA argues that disability should be recognized as "functional diversity" and that in the exercise of legal capacity the focus must be on providing supports and accommodations. The Alliance argues that the right to make decisions according to one's "will and preferences" can never be restricted on the basis of functional diversity or disability. We propose the concept of 'decision-making capability' below, as a way to conceptually integrate recognition of the functional diversity of individuals with an understanding of the array of supports and accommodations a person might need to enjoy and exercise their legal capacity.

In Part Two, Section III F. we propose a 'functional assessment' of decision-making capability where there are disputes about the ways in which a person can exercise their legal capacity. We believe that disputes will inevitably arise about whether a person can exercise their capacity legally independently – i.e. on the basis that they understand and appreciate the nature and consequences of a decision – or whether they can more appropriately exercise their legal capacity through supported decision making. We outline in Part Two, Section III why we think such distinctions are necessary, and how they can be made without discrimination in the exercise of legal capacity on the basis of disability. The challenge is to find a way for any person to claim their legal independence from others, who may counter that they *need* 'supports' to assist them in making decisions; while at the same time protecting from discrimination on the basis of disability those who do, in fact, need supports to make decisions and enter agreements with others.

#### C. Decision-making 'Ability,' 'Supports,' 'Capability' and 'Status'

We distinguish in this paper between 'decision-making ability,' 'decision-making supports', 'decision-making capability' and 'decision-making status.' We also use the term 'individual' decisions and decision-making to refer generally to the range of personal and property decisions that persons of majority age wish to make and control with respect to personal care/life decisions, health care decisions, and property decisions.

We refer to 'decision-making capability' in this paper rather than 'capacity' for conceptual reasons discussed below, but also because alternative terms like decision-making 'capacity' or 'mental capacity' seem so often confused with the concept of 'legal capacity' as discussed above. Decision-making capability is a core concept in the legal framework we propose. We use 'capability' in the very specific sense that Amartya Sen<sup>36</sup> has formulated the term as the basis for providing a more substantive approach to equality of recognition of the right to legal capacity than strictly formal theories of equality allow (i.e. treating likes [including those as defined by mental capacity] alike). We propose how Sen's 'capabilities approach' could be applied to ensuring equality of recognition in legal capacity in Part Two, Section I.D. below.

To introduce the notion here, 'capabilities' in Sen's formulation are not individual abilities or capacities *exclusively*. Capabilities are 'capabilities to function' where function refers to the getting of things done, or making things happen that are important to individuals and communities. Sen keeps the list of valued 'functionings' open to debate and dialogue. We suggest that 'individual decision making' or getting individual decisions made consistent with one's will and/or intention is a function that would clearly fall into

Sen's framework given the centrality of this function to basic human rights and goods. 'Capabilities' for the function of individual decision making are a combination of what we refer to as individual decision-making 'abilities' and of decision-making 'supports' and accommodations.

In this paper we argue for a very inclusive definitional framework of individual decision-making abilities considered requisite for recognizing decision-making capability and legal capacity. This includes the abilities to understand information and appreciate the nature and consequences of a decision, but can also include, at a minimum, the capacity to express one's intention or will in ways that at least one other person can reasonably describe as meaningful. That people have different decision-making abilities should not in and of itself be determinative of recognition of their legal capacity. Different decision-making abilities can be turned into decision-making *capabilities* with appropriate decision-making supports and accommodations sufficient to exercise legal capacity.

Drawing on Sen's framework, decision-making supports are the 'inputs' that help constitute capability – decision-making capability in this case. Needed decision-making supports can take a variety of forms including, for example, plain language and other communicational supports, life planning supports to assist a person in thinking about options for their living and other arrangements, and support individuals who assist in representing a person to others, etc. Together with a person's particular decision-making abilities, these kinds of supports help constitute their capability to make decisions in relation to others.

We discuss these decision-making supports in more detail in later sections. Other parties in decision-making processes must also reasonably accommodate people's particular decision-making abilities to enable them to act legally independently in making decisions and entering agreements with others, in part by enabling provision of decision-making supports in the decision-making process. As we also discuss below, such supports and accommodations are required under the CRPD. States Parties must take steps to ensure they are provided in order to be in compliance with the CRPD.

We believe this approach to defining decision-making capability moves beyond the ableist assumptions of capacity law as it now stands in Canada. It recognizes the centrality of disability-related supports and accommodations to exercising human rights – like the right to legal capacity – in a way that can ensure substantive equality of recognition as required under Article 12 of the CRPD.

Recognizing different constitutions of decision-making capability, depending on the particular mix of a person's abilities and supports needed, requires that we also recognize that people enjoy and exercise their legal capacity through different 'decision-making statuses.' For example, people who have the ability, on their own, to understand information and appreciate the nature and consequences of a decision, and can communicate that to third parties, are recognized as able to exercise their legal capacity in what we term a 'legally independent decision-making status.' Whereas traditional capacity law recognizes this ability as the exclusive, or only, criterion for exercising legal capacity, we suggest it is one set of abilities and associated status.

Where people do not have the requisite decision-making abilities on their own to understand information and appreciate the nature and consequences of a decision, even with accommodations and supports, we propose in this paper that they should retain their full legal capacity where decision-making can be managed through a 'supported decision making status.' This involves a trusted individual or network of individuals assisting the individual in decision making. Support can be provided in a variety of ways including interpretation and plain language support, as well as assistance in representing the person to others who may not understand his or her ways of communicating. Effectively, supported decision making distributes decision-making abilities required for competent decision-making processes across an individual and his/her supporters, as directed by the individual's will and/or intention, and thus results in individual's decision-making *capability* in the sense defined above.

Finally, we recognize that there will always be individuals who, for at least some period of time, will not be able to be sufficiently supported or accommodated by others to fully exercise their legal capacity. If their decision-making abilities are entirely non-evident to any others who could assist them in decision making, then supports and accommodations cannot be provided to enhance those abilities and constitute decision-making *capability*. We suggest in this paper that a temporary 'facilitated' decision-making legal status be established for individuals in this situation while personal relationships can be built that would enable the person's will and/or intention to become known by others as the basis for decision making.

We see no necessary discriminatory effect in recognizing that people have varying decision-making abilities – i.e. varying abilities to, on their own or with assistance,

understand information and appreciate the nature and consequences of a decision, or communicate their will and/or intention to others. What is essential is that fair and just arrangements are in place to determine the nature of a person's decision-making abilities and their particular needs for decision-making supports and accommodations. However, such determinations should not be undertaken as a matter of course simply because a person is presumed to have a disability. They are only required if a person's decision-making capability (their abilities plus any existing supports and accommodations) is reasonably questioned by other parties as sufficient to exercise their legal capacity with respect to a particular decision-making transaction. And, when required, the assessment of ability is undertaken only for the purpose of determining appropriate supports and accommodations.

Just as assessment of specific functional abilities are recognized as integral to the reasonable accommodation process to ensure non-discrimination on the basis of disability in employment practices, this too should be the case with respect to ensuring non-discrimination in the exercise of legal capacity. Assessment of individual decision-making *abilities* may be required in order to ensure that appropriate supports and accommodations are provided to maximize a person's decision-making *capability* and thus the enjoyment and exercise of their legal capacity. It is in this manner that we argue that a substantive 'equality of recognition' of legal capacity can be secured.

We are aware that in using the term decision-making 'ability' as only one element of decision-making 'capability' we are shifting the terms usually associated with the standard 'understand and appreciate' test which we discuss in more detail later in this

paper. For instance, the Supreme Court of Canada's decision in *Starson v. Swayze* in 2003, <sup>37</sup> interpreted the statutory test for mental capacity in Ontario's *Health Care Consent Act*<sup>38</sup> to have a relatively low threshold of decision-making ability. This decision was perceived by many in the disability rights community to significantly advance autonomy interests of people with psycho-social disabilities. Monique Dull has recently examined a number of lower court cases since the Supreme Court decision which interpret the threshold. <sup>39</sup> What is at stake in these interpretations of the threshold is the meaning of the term 'ability' or 'to be able' to understand and appreciate. Dull suggests that the statutory test's "focus on ability theoretically allows more patients to pass the test. Failure to understand or appreciate information the first time due to slower learning, poor teaching, or other barriers can be accommodated by different methods of explanation." Her analysis of the trend since 2003, however, points to a reversal of a broader interpretation to a higher and more restrictive threshold.

While the term 'ability' may allow for some plasticity in interpretation, our view is that it is helpful conceptually to make explicit that in addition to decision-making ability, the need and provision of supports and accommodation must be central to any analysis. It is for this reason that we take an 'additive' approach in conceptualization: ability + supports and accommodations = decision-making capability.

# II. RECOGNITION OF SUPPORTS AND ACCOMMODATION IN THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The CRPD is a guiding lens for the analysis and recommendations presented in this paper. The CRPD represents a decade of effort by governments and international agencies and institutions, and extensive investment by the disability rights community in

Canada and internationally. It is the first comprehensive international human rights instrument to consolidate legal recognition of human rights for persons with disabilities. It is understood to provide an authoritative interpretive lens to other international human rights instruments. In this section of the paper we explore how the CRPD provides a new foundation for legal capacity law in Canada.

The CRPD is a treaty which came into force on May 3, 2008. It was a historic event in that it is the first comprehensive international treaty to specifically protect the rights of the world's population of people with disabilities. <sup>41</sup> Its purpose is to "... promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity." <sup>42</sup> It prohibits all discrimination on the basis of disability and requires that all appropriate steps be taken to ensure reasonable accommodation. <sup>43</sup> It also provides several rights for people with disabilities, including rights relating to employment, education, health services, transportation, access to justice, accessibility to the physical environment, and abuse. <sup>44</sup> The CRPD calls on participating governments to change their country's laws, as necessary, to comply with its terms. <sup>45</sup>

Canada signed the CRPD on March 31, 2007 and ratified it on March 11, 2010. By ratifying the CRPD Canada undertook to adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the CRPD, and to take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against people with disabilities. This necessitates a critical review of legal capacity laws and legal provisions in Canada to ensure that they recognize and implement the rights set out in

the CRPD. A careful assessment of the applicability of international law in the context of legal capacity and decision-making must also be undertaken.

The framework we propose in this paper strives to give full effect and recognition of the purpose and terms of the CRPD with respect to the right to legal capacity, in particular to Articles 12, 3 and 5. Article 12 is particularly relevant to the topics of legal capacity and decision-making as it recognizes the following novel and progressive rights and obligations on the part of States Parties:

- the right to enjoy legal capacity on an equal basis with others;
- the obligation of governments to implement measures that provide access to support by those who need it to exercise their legal capacity; and
- the obligation of governments to ensure safeguards are in place to prevent abuse in relation to measures for the exercise of legal capacity.

The wording of Article 12 – 'Equal recognition before the law' - is reproduced in full, as follows:

- 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.

Canada's ratification of the CRPD included a declaration and reservation, which is of particular relevance to Article 12. The wording of the declaration and reservation is 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.

Canada interprets Article 33 (2) as accommodating the situation of federal states where the implementation of the CRPD will occur at more than one level of government and through a variety of mechanisms, including existing ones."<sup>47</sup>

It is clear from Canada's reservation, that there is an intention to maintain both substitute and supported decision-making in Canada's legal framework. However, what remains to be seen is how powerful the CRPD will be as a stimulus for reform.

Canada is not unique in its concerns regarding Article 12. For most states, Article 12 is said to cause the most problems in their internal process of ratification.<sup>48</sup> Article 12 was a contentious issue in the entire drafting process of the CRPD,<sup>49</sup> and its interpretation remains subject to debate.<sup>50</sup> Canada interprets Article 12 as securing supported decision-making as a right while ensuring that availing oneself of supports does not undermine his/her full legal capacity. They have taken the position that, while not

prohibiting substitute decision-making regimes,<sup>51</sup> Article 12 places particular emphasis on the importance of supported decision-making.<sup>52</sup> In contrast, others are of the opinion that substitute decision-making is in conflict with the human rights principles enshrined in the CRPD, making it an obsolete approach.<sup>53</sup>

The language of Article 12 represents a shift from the traditional dualistic model of [mental] capacity versus [mental] incapacity and is viewed as an equality-based approach to legal capacity.<sup>54</sup> It is recognized as a major breakthrough in view of the continuing predominance in many legal systems which are based on determinations of mental incapacity and guardianship/substitute decision-making regimes.<sup>55</sup> Inclusion Europe<sup>56</sup> has stated that one of the most important aspects of the CRPD for people with intellectual disabilities are its principles regarding legal capacity<sup>57</sup> and Quinn has opined that Article 12 "...is the absolute core of the CRPD!"<sup>58</sup>

Article 3 of the CRPD also gives important direction in relation to legal capacity, as it sets out general principles which include the following:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- Full and effective participation and inclusion in society; and,
- Accessibility.

In addition, we argue in this paper that Article 5 of the CRPD, on "Equality and Non-Discrimination," has a direct bearing on how States Parties and public and private entities must support and interact with individuals with respect to enjoying and

exercising their right to legal capacity. The following paragraphs of article 5 are particularly relevant:

- 2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.
- 3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.

#### Article 2 of the CRPD defines reasonable accommodation as follows:

necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms;

This means that States Parties, including Canada, must ensure that reasonable accommodation is provided to people with disabilities in the decision-making process. This demands two things of the Canadian government. It must ensure that all parties to the decision-making processes accommodate the range of supports that a person requires to exercise his/her legal capacity, and must undertake its own activities to provide supports to people with disabilities and facilitate their access to supports.

Regardless of the debate over the continuing existence of substitute decision-making, the CRPD embodies a right to enjoy legal capacity on an equal basis (Article 12, para. 2), this right being fundamental to basic equality and full participation. This reading of Article 12 is consistent with Article 3's requirement to respect autonomy, as well as its emphasis on inclusion and accessibility. As well, without recognition of legal capacity, other guarantees in the CRPD become meaningless<sup>59</sup>, such as the guarantee of free and informed consent, <sup>60</sup> the right to marry, <sup>61</sup> and the right to political participation. <sup>62</sup> Further, Article 12 must be read and interpreted broadly to ensure consistency with the

purpose of the CRPD, being "...to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."

In this paper we examine the trend in many jurisdictions in Canada of moving towards legal recognition of supported decision-making and the promotion of autonomy as far as possible, finally extricating themselves from the archaic and paternalistic language of the need for care and charity. This is in accord with strong statements of the Supreme Court of Canada, where in *Starson* v. *Swayze*, <sup>64</sup> the Court stated that "[u]nwarranted findings of [mental] incapacity [sufficient to exercise legal capacity] severely infringe upon a person's right to self-determination." Nonetheless, as we also suggest in this paper, this trend is far from complete in Canada if we take Article 12 of the CRPD as the benchmark.

## III. DISABILITY AND OLDER ADULT PERSPECTIVES ON AUTONOMY AND DECISION-MAKING

Laws relating to legal capacity and decision-making are important to all Canadians. No one can ever be sure that they will not be considered under our current laws to be [mentally] incapable of acting legally independently – i.e. without the support of others, or substitute decision-making arrangements. However, there are some groups of people whose lives are more often, sometimes routinely and substantially, altered by determinations that they are 'mentally' and therefore 'legally' incapable, with the consequent imposition of substitute decision-makers. These include people with intellectual disabilities, psychosocial disabilities and older adults. The principles and considerations to be applied to maximize people's autonomy, which are set out in this

paper, aim to address the perspectives and concerns of both people with disabilities and older adults, and their advocacy organizations.

A common refrain of these groups of stakeholders that must be addressed is the quest for autonomy, in the face of their reality of isolation, systematic discrimination and fear of losing independence. Against this, concerns have been expressed relating to the potential cost to personal safety, well-being and life itself in the name of autonomy. This is especially so for people who are vulnerable and lack social and other supports. As cited above, the recent Final Report of the Ontario Legislative Assembly's 'Select Committee on Mental Health and Addictions' is a recent example of how these concerns are being expressed in policy discourse today.

People with intellectual disabilities are particularly at risk of falling under one of the various forms of substitute decision-making because their disability is equated with limitations in mental functioning and associated adaptive behaviors and activities of daily living. As a result, the national self-advocacy association of people with intellectual disabilities in Canada, People First of Canada, and the national family-based advocacy association, the Canadian Association for Community Living (CACL), have been actively advocating over the past 20 years for reform of Canada's legal capacity and decision-making regimes, demanding laws which are more consistent with the manner in which many members of the community make and communicate their decisions. At the founding conference of People First Canada, in 1991, the first resolution adopted by the membership was a call to end guardianship because of its violation of the right to make one's own decisions. The CACL launched a Task Force

on Alternatives to Guardianship at around the same time to propose directions for law reform consistent with the call by People First of Canada. A few years later a 'Coalition on Alternatives to Guardianship' was formed for which Orville Endicott and Kenneth Pike prepared a comprehensive background paper on alternatives. The report laid out a systematic legal and philosophical critique of guardianship law and outlined elements of a legal framework for supported decision making, some of which we draw upon in this paper.

The community living movement in Canada, led by CACL and People First of Canada and their affiliates, has promoted legal regimes which give recognition to supported decision making. In their vision, supported decision-making enables people to maintain full legal capacity while availing themselves of legally recognized access to supports. Community living organizations in Canada have actively participated in legislative reform as well as litigation, and some success has been achieved. For example, British Columbia's *Representation Agreement Act*<sup>69</sup> recognizes supported decision making and Ontario's Divisional Court, too, has recognized the importance of the role of supports.<sup>70</sup> The community living movement, both in Canada and internationally, actively promoted inclusion of Article 12 in the CRPD and recognition of the need for supports in exercising legal capacity. Inclusion International, the international federation of national organizations advocating for people with intellectual disabilities, has issued a position paper calling for an end to guardianship and advancement of supported decision-making.<sup>71</sup>

Views about decision-making models held by people with psychosocial disabilities and the psychiatric consumer/survivor advocacy organizations tend to emphasize features other than those of concern to other stakeholder groups. The consumer/survivor movement in the recent past has not been openly critical of Ontario's current legal capacity laws. In fact, to the contrary, many have welcomed the Supreme Court's influential decision in *Starson* v. *Swayze*. The decision was an important affirmation of the right of a person with a psychosocial disability to make his or her own treatment decisions, even when they were believed by psychiatric professionals to be unwise. In general, it sets a low standard for interpreting the *Health Care Consent Act* statutory test of capacity. The decision is the statutory test of capacity.

At the international level, people with psychosocial disabilities and their organizations have been advocating for a reform to mental health and legal capacity laws to better protect and promote autonomy in the face of involuntary committal and treatment, and systematic restrictions imposed on legal capacity on the basis of 'mental disorder' provisions in law. The World Network of Users and Survivors of Psychiatry advocates for much stronger protections for autonomy and for placing emphasis on access to supports for decision-making rather than the current focus in much mental health law on restricting liberty and choice based on assessment of a mental health 'disorder' and presumed 'risk' to oneself or others.<sup>74</sup>

The experience of the consumer/survivor community leads to some cautionary notes regarding any proposed framework which will impact on decision-making rights. Firstly, in the Ontario context, a commonly-held negative perception about community

treatment orders may shape ideas about appropriate decision-making models.

Community treatment orders are orders by a physician for a person to receive treatment or care and supervision in the community. They are legal alternatives to hospitalization, allowing people with psychosocial disabilities to live in the community with the requirement that they avail themselves of community supports. Some see them as manipulative in that people only agree to them under a threat of hospitalization. That is, either they agree to a community treatment order or their physician will admit them to a psychiatric facility involuntarily. Therefore, from the perspective of the consumer/survivor community, any reform to legal capacity laws involving mechanisms for provision of community-based support and acute treatment will likely need to be completely voluntary, leaving all control to the person with the disability as to whether they access supports/treatment.

Secondly, an important reality for some people with psychosocial disabilities is that the people who support them both in personal care and in decision making, too, have psychosocial disabilities. Any decision-making model that recognizes the role of supporters in decision making needs to ensure that there is no discrimination, intended or not, against some classes of decision-making supporters over others. People with disabilities who support others must be given equal respect in their roles.

Lastly, some people with psychosocial disabilities, as well as people with intellectual and cognitive disabilities, find that third parties often have a preference to communicate with and accept decisions from people who accompany the person, rather than the person him/herself. This usually results from presumptions about limited decision-

making abilities of people with disabilities. Such a presumption must be guarded against in reforming law, policy and practice for health care and other decision-making. That is, third parties must only accept decisions communicated by others if the person with the disability so chooses or legal authority exists to that effect.

Older adults, too, want their voices heard, and to be able to make decisions for themselves. However, their fundamentally different lived experience, differing as it does from people with disabilities, results in a different vision of how the law would best achieve their goals. Unfortunately, this difference in vision can have destructive results. In relation to British Columbia's guardianship reform efforts in the 1990s it was posited that failure to implement legislation resulted, at least in part, from a clash between disability rights theory and seniors' rights theory.

Supported decision-making, so important to people with intellectual disabilities and their advocacy organizations, is not on the radar of older adults. Older Adults' experiences of isolation significantly influence their views on legal capacity laws. With isolation comes a lack of people with whom they interact, including people who could potentially support them. At the same time, often with isolation also comes abuse. Thus, the significant issue for older adults is abuse and neglect. An important component of any decision-making regime would be the inclusion of a high level of review and oversight to address their concerns about abuse and undue influence. That said, a recent United Nations report examining issues of older persons from a global perspective calls for addressing elder abuse and other issues within a proactive human rights approach, and recommends a new international human rights mechanism for this purpose.

## IV. NEGATIVE AND POSITIVE LIBERTY APPROACHES TO PROTECTING AUTONOMY

An underlying question of this paper is: How does society and the state best protect and enhance autonomy and independence? In this section we turn for guidance to the philosophical distinction between negative and positive approaches to defining liberty. To draw upon Isaiah Berlin's distinction between negative and positive liberty, <sup>79</sup> the traditional approach to protecting autonomy has been one of negative liberty. That is, the state does not intervene to determine what life paths are 'best' for individuals to pursue. The state does not define the 'good life' for individuals; rather, it protects their rights to define and pursue this for themselves. The role of the state in this view is to set the broad constraints for individual choice and decision making through criminal, contract, corporate, civil, and health law, etc.

A primary mode of protecting autonomy in this negative liberty approach is to define who *cannot* exercise autonomy. In this view, drawing a boundary between the competent and incompetent has been seen as a 'necessary evil.'<sup>80</sup> It ensures freedom from restraint, and the right to privacy and autonomy for those who can meet the standards of competence to exercise autonomy. This boundary draws a zone that limits state intervention in order to protect the exercise of autonomy. The state defines a minimum threshold in order to protect the integrity of the various transactions, contracts and agreements individuals make with others, thus protecting the autonomy of all the parties. Acting in a manner that demonstrates independent capacities to understand information and appreciate the consequences of one's actions and decisions is the hallmark of this approach. Those unable to do so are defined as mentally 'incompetent' or incapable of exercising autonomy. Removing from persons their legal capacity to

transact with others is justified not only in the name of protecting the integrity of the transaction, but also of protecting the person. A standard statement of the principle is as follows: "The obligation to restrict the liberty of even clearly incompetent people only as far as it is necessary to do so for protecting them from harm."

The ethical and legal question in this classic approach to autonomy in bio-medical ethics and the theory of informed consent is on what basis, by what criteria, should autonomy be restricted? For centuries, moral and political philosophy and the law have established criteria of reason and rationality as the basis on which autonomy would be respected and restricted. When individuals have not met the legal tests, with the first dating back to Roman law, their autonomy has been restricted.

While autonomy and negative liberty are often equated as one and the same thing, they can be distinguished. Liberty is the principle which founds and grounds the right to autonomy. We can achieve and exercise our autonomy in many ways. We can say no to touch and intervention and constraint by others. We can choose to speak up, provided we have the space and protection to do so, or we can choose to remain silent. We can choose to withdraw from relations with others. We can also exercise our autonomy through the exercise of the associated right to legal capacity – our legal right to enter relationships and agreements with others that give effect to our individual decisions.

Negative liberty is the principle used to claim protection against unnecessary state intrusion into citizens' private and personal life and agreements and contracts they make with others. It is a particular view about what is required to protect against

constraints on freedom. What we need is the absence of coercion, regulation and intervention by the state and other entities. In this view, what Martha Albertson Fineman calls the 'myth' of autonomy, it is individual separation and freedom from others and from the state that is valued:

Autonomy... connotes on an ideological level that an individual who conforms to the dominant notions of independence and self-sufficiency is both freed from the prospect of regulatory government action and freed *through* governmental structures from interference by other private actors. The freedom through the government is the nonintervention point stated in positive terms – the right to be let alone is also the guarantee of privacy. In establishing and adhering to a norm of nonintervention and regulation for those individuals deemed self-sufficient, the state grants them autonomy.<sup>83</sup>

In a positive liberty view of autonomy we do not exercise our self-determination as isolated, individual selves, but rather 'relationally,' interdependently and intersubjectively with others. We evolve and realize capabilities for autonomy in relation to others and through social, economic and political conditions that make this possible. Catriona MacKenzie and Natalie Stoljar define this approach to autonomy as follows:

The term 'relational autonomy'... does not refer to a single unified conception of autonomy but is rather an umbrella term, designating a range of related perspectives. These perspectives are premised on a shared conviction, the conviction that persons are socially embedded and that agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender and ethnicity. Thus the focus of relational approaches is to analyze the implications of intersubjective and social dimensions of selfhood and identity for conceptions of individual autonomy and moral and political agency.<sup>84</sup>

A relational understanding of autonomy is particularly important for those who require the support and assistance of others in communication, understanding and representing themselves to others; the case for many people with intellectual, cognitive and/or psychosocial disabilities. In these formulations of what we could call the positive liberty view of autonomy, the state has a positive obligation to maximize the exercise and enjoyment of autonomy by providing individuals with the goods and services they

require for this purpose, and for developing their own decision-making capabilities to exercise their autonomy.

Over the 20<sup>th</sup> century a positive role of the state in enhancing and protecting individual autonomy evolved - to prevent against coercion in contracting and to protect the interests of vulnerable parties, and to ensure access to economic, social, and cultural goods that enabled people to maximize their pursuit of a good life. There are ongoing debates about the appropriate extent of the welfare state – whether about public education, publicly-funded health services, the role of labour unions and collective agreements in employment contracts, the social safety net, and provision of statefunded individual supports. Essentially, these have been debates about the positive duties and obligations of the state and other parties to enable citizens to achieve social and economic well-being; including where this involves regulating contractual arrangements like labour agreements, and other forms of agreement between parties like informed consent for health care. Despite a growing recognition of the positive duty of the state with respect to protecting and enhancing autonomy, its institutionalization has continued to run up against the same limit point: the assumption that there will always be some for whom autonomy, and thus legal capacity, cannot be realized.

How do we best formulate the role of the state in ensuring people have access to the basic goods and services that will enable them to identify, plan for and pursue choices that enable a good life? How do we formulate this duty to maximize autonomy, informed now by the CRPD, and its recognition of an equal right to legal capacity without discrimination on the basis of disability?

In recognizing this positive duty, we expand the question posed at the outset of this paper as follows: What principles and considerations should be applied in ensuring individuals have the supports and accommodations needed to maximize their autonomy without discrimination on the basis of disability, and what, if any, limitations are reasonable to apply in such determinations?

We grapple with this question in light of Berlin's discussion of the relationship between negative and positive liberty, and his concern that the value and principle of positive liberty could be used to justify an authoritarian and intrusive state that undermines negative liberty – to be free from state intrusion and protection. This is a particularly valid concern when it comes to the question of how to protect autonomy for those who may require supports, which are often provided or delivered in ways that restrict a person's autonomy. People may gain services, funded and delivered on the basis of positive obligations of the state to provide care and support, but lose their right to say 'no' or to choose an alternative method of receiving supports. The challenge these arrangements pose is how to shape positive obligations of the state to ensure the meeting of needs with its positive duties to ensure people have the supports and capabilities to exercise and enjoy their autonomy and legal capacity.

Our aim in this paper is not to advance a positive liberty approach to autonomy over a negative liberty approach. They are not mutually exclusive. Indeed, we suggest they are entirely interdependent. A negative liberty view is crucial to ground citizens' rights to refuse interventions by others; just as crucial as the positive obligations of the state to ensure people have access to supports and capabilities to actively exercise their

autonomy. Indeed, both views are essential to a full and robust theory of autonomy. Our aim is to consider how to achieve a more balanced integration of these two views of liberty and autonomy than current institutional arrangements in adult protection, mental health and disability-related services and supports often allow. In other words, we seek a better balance between negative liberty approaches to protecting autonomy and positive obligations of the state to meet support needs so people can make decisions they want to make. Quinn provides an apt metaphor for the positive and negative freedoms that legal capacity is meant to protect. For Quinn, legal capacity is both a 'sword' to advance positive freedom and make one's way through the world in 'uncoerced' relations with others; and a 'shield' protecting against others who would impose decisions upon you.<sup>86</sup>

In the next section we explore how Canada's traditional legal capacity laws have been designed and managed largely on the basis of an underlying negative liberty approach to protecting autonomy. While positive duties of the state to protect autonomy expanded over the 20<sup>th</sup> century, there has remained a predominant assumption that there is a group for whom decision-making rights must be limited in the name of their protection. The result has been that the negative liberty interest of individuals – to be free from undue state intervention in individual decision making – has been won and resolved at the cost of restricting the autonomy of a group of individuals considered to be without the requisite mental capacity or decision-making ability to manage individual decision making. In other words, negative liberty interests have been protected in part by the state not intruding in any substantive way on the responsibilities of parties to

support and accommodate one another in decision-making processes with respect to disability-related conditions.

In subsequent sections we chart an alternative path to balancing negative and positive liberty interests in managing decision-making and related contracting and consent procedures. Informed by provisions in the CRPD we suggest that the State has a positive duty to maximize legal capacity in individual decision making. Further, this duty requires parties in the decision-making process to provide supports and accommodation, with the assistance of government, to ensure non-discrimination on the basis of disability. The CRPD directs a clear departure from a paternalistic regime for managing decision-making to one based on autonomy and non-discrimination on the basis of disability.

## V. CANADA'S TRADITIONAL AND CURRENT LEGAL CAPACITY LAWS

There has been a long-standing dichotomy of opinions in relation to legal capacity laws which pit paternalism against autonomy. The debate continues and was reflected in the recent international deliberations relating to the article on legal capacity in the CRPD.<sup>87</sup>

The tradition of legal capacity-related laws that restricts people's right to autonomy was founded on the attitude that there is a need to act for the protection of those who are believed not to be able to care for themselves. It was to be exercised in a manner said to promote the "best interest" of the protected person. The underlying assumption being that the individual's personal and economic affairs could be better managed by others. However, Canadian laws have progressed substantially in the direction of promoting autonomy. There has been increasing recognition by the Supreme Court of

Canada and legal writers that respect should be given to the human rights and autonomy interests of people with disabilities.

In this section we outline the trajectory from traditional capacity laws in Canada which define an 'all or nothing' legally capable/incapable boundary, to more recent legislation and jurisprudence which articulates an expanded range of decision-making statuses through which people can exercise their legal capacity.

While our laws encourage autonomous decision-making, for the most part they create a wall around a group of people whose rights to decide for themselves are removed. This is so because Canadian laws have generally required, as a precondition of engaging in most activities, that an individual possess a requisite level of mental capacity or decision-making ability. When the required level of decision-making ability is absent, the law requires that a substitute decision-maker make decisions in his/her stead.

### A. Substitute Decision-making Laws

Legislation in Canada which addresses legal capacity most directly covers guardianship, <sup>90</sup> planning documents such as powers of attorney, consent to health care and admission to care facilities, and adult protection. These laws require that people be [mentally] 'capable' to make decisions about their property and personal care, including health care and long-term care residency. Overlaying these are more specific laws: for example, entering into a contract, <sup>91</sup> making a will, <sup>92</sup> acting as a director of a corporation <sup>93</sup> and giving evidence in court <sup>94</sup> each require a person to have a requisite level of mental capacity to do so. There are several additional laws in which legal capacity is addressed but is not the primary subject-matter of the legislation. Rather,

provisions are included in laws to cover off situations in which a person's assessed [mental] incapacity would expose a gap in the legal framework or otherwise affect its functioning. For example, the Canada Pension Plan (CPP) contains a provision allowing for payments to be made to another person or agency when the Minister is satisfied that the CPP recipient is "[mentally] incapable of managing his own affairs". <sup>95</sup>

Substitute decision-making laws most directly govern situations where people are found [mentally] incapable. These laws are common to all jurisdictions in Canada. For example, Ontario's *Substitute Decisions* <sup>96</sup> *Act* focuses on substitute decision-making, which involves decisions being made by one person on behalf of another, who is usually determined to be [mentally] incapable of making his/her own decisions. It usually takes one of two forms: guardianship, in which an order (usually by a court) is made appointing a substitute decision-maker, and planning documents, in which a person chooses, in advance of [mental] incapacity, who he/she wishes to make decisions on his/her behalf.

Taken together, it is hard to envision any significant area of life that one can engage in freely without potential interference on the basis of so-called [mental] 'incapacity'.

Some of these restrictions may seem reasonable, while others raise questions. But that civil, political and equality rights can be sweepingly restricted in so many fundamental aspects of people's lives speaks volumes about the status and recognition of people with intellectual, cognitive and psychosocial disabilities in Canadian society.

# B. Test of Mental Capacity as a Basis for Legal Capacity: The 'Understand and Appreciate' Test

The way in which the law defines mental capacity shapes the nature and extent of its interference with people's lives, as it is the ascription of mental (in)capacity that determines one's right to make decisions. It is thus essential to explore the meaning our laws attribute to legal capacity.

There is no single, uniform test or definition for legal capacity in Canadian law. <sup>97</sup> Yet, laws recognize some fundamental realities. The test for legal capacity is described as a cognitive one; <sup>98</sup> hence the focus on *mental* capacity as a condition for exercising *legal* capacity. [Mental] capacity is not considered from a global standpoint in that it is recognized that people may have abilities to make some types of decisions on their own and not others. For example, an individual may be able to understand medical information enough to decide to take a medicine for his/her cold, but not be able to understand information to decide whether to have a transplant. Additionally, an individual's level of decision-making ability may fluctuate over time. Someone who has dementia may have days when he/she is thinking particularly clearly and other days when he/she has a difficult time understanding even basic concepts.

As the test for [mental] capacity or decision-making ability differs depending on the relevant transaction, so too does the required level of [mental] capacity or ability: "[a] person can be [mentally] capable of making a basic decision and not [mentally] capable of making a complex decision." In *Calvert (Litigation Guardian of)* v. *Calvert*, <sup>100</sup> Mr. Justice Benotto concluded that while Mrs. Calvert "...may have lacked the ability to instruct counsel, that did not mean that she could not make the basic personal decision

to separate and divorce." Thus, a person with an intellectual disability may be able to know that she is unhappy where she lives and know that she wants to move to the residence where her friends live and which is near her family. She likely has the decision-making ability to make this decision independently. At the same time, she may not understand information in relation to a decision to purchase a house and may need support and certain accommodations to do so.

Despite the different tests for [mental] capacity, there are similarities between many of them in that they incorporate two basic requirements: the ability to understand relevant information and the ability to appreciate reasonably foreseeable consequences. <sup>101</sup>

This test is incorporated in several pieces of legislation in Canada, including Ontario's Substitute Decisions Act <sup>102</sup> and Health Care Consent Act, <sup>103</sup> Saskatchewan's Adult Guardianship and Co-decision-making Act <sup>104</sup> and Manitoba's The Vulnerable Persons Living with a Mental Disability Act. <sup>105</sup> Nonetheless, while this definition is common, it is not the only one that exists in Canada. <sup>106</sup>

Courts emphasize that an assessment of [mental] capacity is based not on the content of the decision ultimately made, but rather on the process for arriving at that decision. The fact that an individual makes a decision that others perceive as foolish, socially deviant or risky does not indicate that the decision was incompetently made. As Mr. Justice Quinn stated: "The right to be foolish is an incident of living in a free and democratic society." He added that "[t]he right knowingly to be foolish is not unimportant; the right to voluntarily assume risks is to be respected. The State has no business meddling with either. The dignity of the individual is at stake." 108

Assessing an individual's understanding is not an assessment of that person's prior knowledge. The question is the extent to which the person can retain, interpret and manipulate information once it is provided to him or her. For example, in Ontario, in order to make a power of attorney, there is a requirement that the person understand what a power of attorney is. 109 Many people, including but certainly not limited to people with intellectual disabilities, at the outset do not know what a power of attorney is. In order to assess a person's [mental] capacity to make a power of attorney, he/she must first be given all relevant information about the nature and effect of such powers. There is an important role to play for supports at this stage of the assessment. For example, people in an individual's support network likely are much more effective at communicating with that person than anyone else. Not only are they able to understand that person's method of communication, but they know how to communicate with that person in words and style that he/she understands. It is likely that involving support people will enhance a person's ability to exercise their legal capacity by giving them the best chance possible to learn the information they need to know to satisfy the legal test of [mental] capacity.

# C. Legal Recognition of Autonomy Interests, Interdependence and a Range of Decision-making Statuses

Presuming all people to be mentally or 'decisionally' capable is a crucial feature in the promotion of autonomy. Over 15 years ago Ontario's Court of Appeal articulated a common law presumption of [mental] capacity requisite to exercise legal capacity. Additionally, there are presumptions of requisite [mental] capacity in Ontario legislation which relate to specific interactions, such as legal capacity to enter a contract, 111 legal capacity to give or refuse consent in relation to personal care 112 and legal capacity with

respect to treatment.<sup>113</sup> Laws in other Canadian provinces also contain presumptions of [mental] capacity.<sup>114</sup> These provisions are consistent with trends in modern legislation around the world "... to enshrine a powerful presumption of [mental] capacity."<sup>115</sup>

While capacity-related law has focused on protecting autonomy by defining and managing criteria of *in*capacity and *in*competency, the political and legal discourse of women's and disability rights increasingly focuses on defining how to *maximize* autonomy, often through what we characterize as an approach that recognizes and foregrounds relationships and interdependence with others. Increasingly, the question is: how are the principles of autonomy and legal independence to be realized in legal and institutional terms in order to enable and support people to guide their own lives, make their own decisions, and challenge others who would diminish or remove their autonomy?

There has also been a growing recognition by the Supreme Court of Canada and legal writers shifting the focus from diminishing decision-making rights to maximizing autonomy. The emergence of the human rights movement following World War II and the enactment of the *Canadian Charter of Rights and Freedoms* ("*Charter*") in 1982 raised the importance of the values of liberty, autonomy and freedom from unnecessary intervention.

Weisstub's 1990 report on mental competency urges that priority be given to *Charter* rights. The Fram report, which was delivered over 20 years ago by the Advisory Committee on Substitute Decision-Making for Mentally Incapable Persons, too

emphasized this by stating that "[t]he *Canadian Charter of Rights and Freedoms*, as a constitutional document, is part of the fundamental law of Canada. As a result, consideration of the values given expression in the *Charter* must inform any review of the law relating to substitute decision making."<sup>117</sup>

Personal autonomy to make inherently private choices goes to the very core of the liberty interest protected under section 7 of the *Charter*. Further, section 15, the equality provision, mandates the promotion of a society in which all persons enjoy equal recognition at law. In this context, the Supreme Court of Canada has stated that "[h]uman dignity ... is enhanced when laws recognize the full place of all individuals and groups within Canadian society." The Court stated that the *Charter's* guarantee of equality "... is concerned with the realization of personal autonomy and self-determination. Human dignity means that an individual or group feels self-respect and self-worth."

In relation to legal capacity, the Supreme Court of Canada has clearly and explicitly recognized the autonomy interest of people with disabilities in its statement that "[u]nwarranted findings of incapacity severely infringe upon a person's right to self-determination". The Court also recently advanced the value to be placed in autonomous decision-making in relation to incapable people in *Nova Scotia (Minister of Health)* v. *J.J.* 121

Early legal recognition of interdependent decision-making and supports is apparent in the following two significant cases:

- In the 1983 decision of Clark v. Clark<sup>122</sup> Mr. Justice Matheson concluded that
   Justin Clark was "mentally competent" and that, notwithstanding his inability to
   speak and his intellectual disability, he was effectively able to communicate his
   wishes through the use of Blissymbols.<sup>123</sup>
- Mr. Justice Quinn in Re Koch<sup>124</sup> also recognized the role of supports when he said that "[i]t is to be remembered that mental capacity exists if the appellant is able to carry out her decisions with the help of others."<sup>125</sup>

A recent decision of the Human Rights Tribunal of Ontario 126 also acknowledged the role of supports. The case dealt with a labour strike in a group home which provides support services for people with intellectual disabilities. Employees who worked at the group home engaged in a legal strike and picketed the home. Ms. Kacan alleged that the picketing discriminated against her on the basis of disability. The issue in this interim decision focused solely on issues surrounding the [mental] capacity of Ms. Kacan in relation to bringing the human rights application. The decision confirmed that a friend could assist a person with a disability to launch a human rights complaint. The Tribunal's decision affirmed the significance of promoting the autonomy and dignity of people with disabilities, even where supports were required to exercise such autonomy. 127

According needed support to make decisions is at the heart of exercising one's right to autonomy, and the right to be recognized by law as citizens with rights to fully participate in society.<sup>128</sup> Recent legislative developments have incorporated such

approaches which are more consistent with maximizing autonomy interests. These can be classified into two forms: supported decision-making and co-decision-making.

As we referenced in the introduction and discuss in more detail below, 'supported' decision-making' enables a person to make his/her own decisions with the help of others. British Columbia's Representation Agreement Act has been hailed by the disability community as highly successful legislative recognition of supported decision-making. It allows for the creation of personal planning tools which enable adults to appoint someone "to help the adult make decisions or to make decisions on behalf of the adult." These planning tools, known as representation agreements, are progressive in that, unlike most personal planning tools, they allow for the appointment of individual(s) to help an adult make decisions. The British Columbia model is also notable for its more flexible approach to defining incapability. It recognizes shades of grey and establishes four factors to be taken into account, one of which recognizes the defining feature of support relationships, being one of trust.

Other Canadian jurisdictions, too, specifically recognize supported decision-making in their legislation. Manitoba, the Yukon Territories and Alberta legislation, with differences, recognize supported decision-making. 132

Ontario's *Substitute Decisions Act* does not specifically recognize supported decision-making *per se*, but does provide for consideration of the role of supports. One provision of the *Substitute Decisions Act*<sup>133</sup> relating to court-ordered guardianship is designed to promote autonomy. The language (in ss. 22(3) and 55(2)) is as follows:

The court shall not appoint a guardian if it is satisfied that the need for decisions to be made will be met by an alternative course of action that,

- (a) does not require the court to find the person to be incapableAnd
- (b) is less restrictive of the person's decision-making rights than the appointment of a guardian. 134

In *Gray v. Ontario*, <sup>135</sup> a case that addressed closures of institutions for people with "developmental disabilities" in Ontario, 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 of the Ontario Divisional Court concluded what appeared to be obvious: the consent of the person with the disability or his/her substitute decision-maker is required to any choice of community residential placement. <sup>136</sup> In addressing this issue, he highlighted the above provision as being particularly significant in that the section contemplates that where alternatives to appointing a guardian (which requires a finding of incapacity) will allow for decisions to be made, this is preferred to a guardianship order. <sup>137</sup> He went on to interpret the above provision in relation to supported decision-making as follows:

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. <sup>138</sup>

There are additional provisions in the *Substitute Decisions Act* that recognize a role for "supportive family members and friends." Guardians and attorneys (named in a power of attorney) are required to foster regular personal contact and consult with supportive family members and friends. However, decisions are still made by the guardian or

attorney, as the case may be. Thus, while these provisions encourage involvement of family members and friends, the involvement specified by the legislation does not promote the individual's ability to make his/her own decisions. This is so despite s. 66(8) which requires guardians and attorneys of the person to foster the person's independence as far as possible.

Co-decision-making is similar to supported decision-making in that an individual is legally recognized to assist someone with capacity issues to make his/her own decisions. The fundamental difference between these two approaches in current legislation is the manner in which the supporter is created. With co-decision-making the supporter is not chosen by the person whose capacity is in issue. Rather, the supporter is appointed by a court, and it is the court that decides that a supporter is necessary to assist with decision-making. While it is a less intrusive alternative to substitute decision-making, full choice is not respected: supports are not chosen, but imposed by courts. It is less desirable than supported decision-making because it does not as fully respect autonomy.

Saskatchewan's *Adult Guardianship and Co-decision-making Act*<sup>140</sup> incorporates the co-decision-making mechanism. It sets out procedures for the court appointment of either guardians for people who are incapable, or co-decision-makers for adults who need assistance in making decisions, but who do not require guardians. It is the court's determination as to whether a guardian or co-decision-maker is appointed. The court, too, decides who will be appointed to play these roles. A form of co-decision-making is also recognized in Quebec and Alberta.<sup>141</sup>

While supported decision-making and co-decision-making are each given some status in Canadian laws, substitute decision-making regimes, both in the form of guardianship and planning documents, have been most widely used and developed across all jurisdictions in Canada. Supported and co-decision-making have been introduced only relatively recently and are limited in their application. For example, Manitoba's recognition of supported decision-making in the *Vulnerable Persons Living with a Mental Disability Act* applies only to people with intellectual disabilities, British Columbia's *Representation Agreement Act* only allows for supported decision-making arrangements with respect to some aspects of property management, and Alberta's *Adult Guardianship and Trusteeship Act*'s provisions for supported and co decision-making apply only to personal and not property decisions.

These legislative developments are welcome in that they mark the beginning of a shift in the conceptualization of the state's legitimate role and positive obligation in decision-making interventions. Rather than understanding the primary role of state intervention as managing the boundary between those deemed legally capable and incapable and providing procedures for removing an individual's right to make decisions for themselves, the state's primary role should be viewed as supporting an individual's capacity to make his/her own decisions. This approach is consistent with a more inclusive understanding of autonomy and dignity than an exclusively negative approach to liberty would allow. Even in jurisdictions which do not provide a legislative mandate for supports in decision making, the clear direction from Canadian courts provides a substantial foundation for the recognition of supports to exercise legal

capacity. In what follows in Part Two of this paper, we lay out framework for fully recognizing the place of supports and accommodations in this regard.

#### **PART TWO**

## TOWARDS A NEW LEGAL PARADIGM FOR MAXIMIZING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY

The CRPD provides the foundation for a new legal paradigm for maximizing autonomy and the enjoyment and exercise of legal capacity. It makes clear that the enjoyment of legal capacity cannot be restricted on the basis of disability, and that people with disabilities are owed duties and obligations by the state to ensure they have supports to exercise their legal capacity; and to ensure reasonable accommodation by third parties in transactions. This distinction between the *right* to legal capacity without discrimination on the basis of disability, and the support to exercise legal capacity (in Article 12(1), 12(2) and 12(3) of the CRPD) opens up the legal space to fashion decision-making statuses for exercising the right to legal capacity beyond the status of legal independence exclusively – i.e. beyond the status of a person recognized as able to meet the understand and appreciate test entirely on his or her own. It opens up the legal space beyond the usual parameters of capacity-related law to be more inclusive of the diversity of people and the ways they reason and communicate. The question can no longer be: Does a person have the mental capacity to exercise their legal capacity? In other words, mental capacity can no longer serve as a proxy for legal capacity. Rather, the question is: What types of supports are required for the person to exercise his or her legal capacity? This is a profound shift in the law of legal capacity. It suggests that the testing and institutional machinery for determining mental capacity needs to be significantly re-focused. From questions about how to determine mental capacity, the CRPD directs a shift to asking about how people can best exercise their legal capacity. It directs that we ask about who gets what supports and

accommodations to enjoy, exercise and maximize their legal capacity, when, where and how.

In Part II of this paper, we explore key elements of this new legal paradigm, beginning with a critical philosophical examination of the usual criteria for recognizing a person as legally capable. A reformulation of what it means to be a person who exercises legal capacity is needed in order to ensure a fully inclusive account of 'who' gets what kinds of decision-making abilities supported and accommodated and in what kinds of ways.

## I. DEFINING 'WHO' EXERCISES AND ENJOYS THE RIGHT TO LEGAL CAPACITY

How wide is the net cast by the emerging shift and challenge to the traditional approach to legal capacity law, in terms of who is seen as a person capable of exercising and enjoying the right to legal capacity, and who is not? If jurisprudence cautions against "[u]nwarranted findings of [mental] incapacity," how far has the law re-drawn the boundary between those considered capable and those considered incapable? And, in light of Article 12 of the CRPD, if a finding of legal incapacity on the basis of disability constitutes discrimination, how do we conceptualize full autonomy and exercise of legal capacity for those with significant and profound disabilities whose forms of communication may be discernible, at best, to only a very few individuals?

Many people with significant intellectual, cognitive and/or psychosocial disabilities are not able to meet the usual test of mental or cognitive capacity to retain their right to autonomy and legal capacity – i.e. the understand and appreciate test. Indeed, it can be argued that many people *without* disabilities do not meet this test, if one considers the complex health procedures which a patient may need to decide on, or the complex

legal and financial transactions which people authorize everyday with their signatures.

Nonetheless, this is the test that gets triggered when others question the mental capacity of a person with an intellectual disability to make a health care decision or sign a lease agreement for an apartment, or even open a bank account.

But is this the only test of what it means to be a person who exercises legal capacity? In this section, we elaborate a more inclusive definition of decision-making abilities that can provide a foundation for recognizing and respecting persons who exercise and enjoy legal capacity. Quinn suggests that a more inclusive concept of personhood than that defined by the criteria of rationality so pervasive in legal incapacity law is

foundational to the debate about the paradigm shift of Article 12. I leave to one side the debate about when a person becomes a person and when a person ceases to be a person. The real debate concerns what are the essential *indicia* of personhood – the criteria by which we can ascribe personhood. Are there such criteria? What are they?<sup>144</sup>

We suggest how to define the basic criteria in this section.

### A. Expression of Will and/or Intention as Human Agency

Rather than focus on tests of mental capacity, we think it helpful to ask 'what are the actual tests of decision-making ability that most people have to demonstrate in their day-to-day affairs?' Most discussions of contract law, for example, in any number of case law books, or even the authoritative *Restatement (Second) of Contract Law* published by the American Law Institute, and also that of the 'Principles of European Contract Law' of the European Commission, define 'intention' as a necessary component of entering into a contract.

This idea that intention is the basis of human action and reflects human agency is consistent also with the theory of human action that analytic philosophy and the philosophy of law turn attention to, with the question: How are we to determine that a particular set of events in which a human being was involved represents intentional action on the part of a human agent to whom decisions and consequences can be attributed? While this area of analytic and legal philosophy has a long and rich tradition, there is substantial agreement around the set of ideas that what constitutes human agency is action which is informed by a person's will and/or intention, which are motivated by a person's beliefs and/or values about things they want or don't want. How we know whether action is intentional lies in how we describe the actions of others and their consequences, as intentional or willful or not.

In formulating a minimum threshold of decision-making ability and human agency below, we refer to both 'intention' and 'will' as their foundation. We distinguish these terms in the following way. Intention refers to an expressed desire, an articulated goal or objective, or a plan which has been communicated. Intention is about choosing 'ends' to pursue. As Jean-Paul Sartre has written "intention makes itself be by choosing the end which makes it known." From chosen ends, intentions can be discerned which give clear direction to others in guiding decision making. However, some people with significant intellectual and cognitive disabilities may not be able to formulate or communicate an intention in this sense, as a clear 'end' to which action or behavior is directed, or at least such behavior may not be evident to others. Nonetheless, what may be evident is the person's 'will' to live, to avoid pain, to seek pleasure, safety, or security. 'Will' in this sense refers to a faculty of the mind and is usually evidenced in

the range of choices by which a person is seen to operate. It's expression represents a decision – to live, seek safety, avoid pain, etc. The range of the will can be extremely limited, it can develop and grow over time with experience, but nonetheless it can be pointed to and described by others who know the person well; who know their history and particular way of being in the world and communicating with others.

A large body of research points to both the unexpected abilities of people with profound and multiple disabilities to make decisions when presented with choices in meaningful ways; and to the 'pre-intentional' and behavioural forms of communication which can be revealed as meaningful in the context of relationships with 'communication partners' who know them well. 146 Where some might describe a person's behavior, through a psychological assessment, as 'irrational' or 'meaningless,' others, who have personal knowledge about the person, may be able to re-describe his or her actions as intentional or willful. That is, the behavior communicates a person's will and/or intention to do or not to do something. In this account of will and/or intention, what is critical is that another person or group of people who know a person well can provide a description of his or her behavior that draws the connection between a person's intention or will and their behaviour. In their description are made the links between a person's intention or will, the actual things a person does, how they move, the sounds they make, the things they want to happen, and the interventions of others to assist a person in giving effect to those intentions; helping that person carry out, through consequential actions, the intentions they set. Through what Joel Feinberg calls the 'accordion effect,' the descriptions and re-descriptions of human action and their consequences can be told and written to reveal human agency, or to deny it. 147

For example, Audrey Cole, a parent of a man with a profound intellectual disability, and also a thinker, writer and activist on advancing alternatives to guardianship and a supported decision-making model reflects on the meaning of human will this way:

...human will - that instinctive and inherently human imperative, that sense of being, that thing that tells us we are here, that we can feel. I honestly don't think it has anything to do with intellect. Ian [her son] has it! It is what makes him stop, suddenly, and listen to the sounds of the birds or of the wind blowing through the trees. I am sure it is what makes him so sensitive to music. It is also what makes him instinctively draw back or resist things he doesn't understand (such as an unfamiliar medical procedure, for example). And it is certainly the thing that has prompted him on a couple of occasions when Fred [her husband] had been in intensive care to gently reach out and stroke Fred's arm - an intimacy that is not typical of Ian who usually would have to be prompted to make such personal contact. I don't know what it is but I do know we all have it! And if we take the trouble to get to know people who do not communicate in typical ways, we become very conscious of it. 148

The criterion of decision-making ability, that one is able to express their intention or will, and that it serves as a basis for agency through time, in at least some description by a community of knowing and valuing others, has strong foundations in philosophy. It is much more disability-neutral and inclusive than the criterion of demonstrating understanding of information and appreciating consequences of a range of choices available, to which people with intellectual, cognitive and/or psychosocial disabilities are so often subject.

## B. Personal Identity: a 'Narrative' Approach to Human Agency

The expression of intent or will is philosophically sound as a basis for ascribing human agency. However, on its own, it may still not be enough for some parties to recognize the decision making ability of an individual with more significant disabilities. They may not be convinced that a person's intention or will expressed and described in one situation or at one point in time, can be trusted enough over time to constitute their intention or will as the basis of legal relations like a contract. This is the criterion of

'personal identity' first formulated by the Enlightenment philosopher John Locke in the 17<sup>th</sup> century. His related theory of the 'continuity of consciousness' through time as the basis of self-consciousness influenced major political philosophers including Jean-Jacques Rousseau and Immanuel Kant, and their use of 'reason' and rationality as the tests of moral and legal personhood and capacity to act.

When the usual criterion of capacity states a person must understand information and appreciate the nature and 'consequences' of a range of choices and decide among them, the test is requiring a measurement of 'personal identity.' That is, the test is requiring that an individual have a capacity for memory so that the person who acts to enter a contract at one point in time can be trusted by the other party to understand its 'consequences' for their obligations into the future. Thus, testing for memory is often one of the main ingredients of capacity testing. It is why people with significant intellectual, cognitive or psychosocial disabilities — for whom remembering and generalizing learning from one situation to another may be difficult without supports; or who, like anyone else, may demonstrate different states of consciousness and memory on an episodic basis — are so often found legally incapable or in need of protection and thus substitute decision-making.

This idea of personal identity has been roundly critiqued in moral philosophy of personhood; and jurisprudence in some competency cases can be read similarly. Moral philosopher Paul Ricoeur, feminist philosopher Seyla Benhabib, Alisdair MacIntyre and a growing number of other philosophers present an alternative account of personal identity in the idea of the 'narrative self.' In *Oneself as Another*, Ricoeur challenges

directly the philosophical and legal notion that we can only demonstrate that we are the same person through time by showing that we have the same mental state through time. 150 Rather, he suggests, we all experience discontinuities in ourselves, we all become 'other' to ourselves through changes in character and mental state over time, conflicting desires and wishes, changes of mind. What ascribes personhood to us, as a person who is to be trusted through time, is that we can answer the question – 'Who are you?' 'Who is she?' – with a coherent narrative, a life story that makes sense of all the changes, and losses, and new directions and discontinuity, of illness and of healing, that make up any person's life. We become a person to the extent that we can, or that others who have personal knowledge about us can, tell a coherent story about who we are. Our actions and intentions can be made sense of in the context of the narrative coherence. It is this narrative coherence of my particular and unique life that renders reasonable the decisions that give effect to my intentions, not some abstracted 'reasonable person' standard; even if I need substantial assistance from others to make and carry out the decisions, my intentions or will inspire and motivate in those who know me well.

# C. A Minimum Threshold of Human Agency and 'Decision-making Ability' We can build a more robust and inclusive recognition of what it means to have decisionmaking ability on the basis of these criteria, as outlined above: 1) my capacity to express my will and/or intentions, at least to others who know me well, and who can then 'confer' or ascribe agency to my actions in their descriptions of me to others; and 2) being able to tell 'who' I am, my life story of values, aims, needs and challenges, or having my community of knowing and valuing others do that for me, and using that

narrative coherence of my life to help direct the decisions that give effect to my intentions. In effect, these establish a minimum threshold for characterizing what it means to be a person with practical reason and thought, someone with human agency in the present, whose legal capacity is recognized and maximized. This minimum threshold of human agency we might characterize as: to act in a way that at least one other person who has personal knowledge of an individual can reasonably ascribe to one's actions, personal will and/or intentions, memory, coherence through time, and communicative abilities to that effect. If to my actions can be ascribed intentions or my will which themselves can be woven into a coherent narrative, either by myself or others, even if the intentions or willful behavior represent some discontinuity with the past, then this should be sufficient ground for exercising my legal capacity. And, this ascription by others of my will and/or intentions should be the basis of my legal capacity, even if its exercise requires others to make transactions on my behalf.

But this is a dramatic departure from the usual standards of mental capacity on which the law of legal capacity has traditionally rested – the ability to understand information and appreciate the nature and consequences of a decision. The traditional criteria are based on individual skills and abilities of cognitive functioning, as though one had to demonstrate one could answer, in language others understood, certain skill-testing, 'decision-making capacity-proving' questions. This approach to defining criteria of capacity is rooted in an individualistic, bio-medical model of disability that the CRPD rejects. To make recognition of legal capacity dependent on a particular set of decision-making skills, as most current capacity assessment tools do, is to import ableist assumptions about what the demonstration of decision-making ability entails. This

approach to definition reproduces disability 'status' as the basis for restricting legal capacity, a clear violation of the CRPD, and systematically discriminates against people with intellectual, cognitive, psychosocial and communication disabilities; people whose disabilities may entail challenges with managing decision making.

## D. Shifting the Focus of Criteria for Legal Capacity from 'Mental Capacity' to 'Decision-making Capability'

The CRPD breaks the link between mental capacity and legal capacity, by prohibiting discrimination on the basis of disability in the enjoyment and exercise of legal capacity. On their face, mental capacity statutory provisions which articulate cognitive tests for having one's legal capacity recognized and protected appear to be in violation of the CRPD. While the CRPD establishes a definitive break between mental capacity and legal capacity, it provides only the most general of solutions – that is, that people are owed supports in order to exercise their legal capacity.

How do we actually go about attaching to the minimum threshold for what it means to have agency as a person, recognition of and respect for legal capacity? We need a concept that maintains the integrity of decision-making relationships and agreements for both parties, but one that recognizes the essentially social nature of human agency and individual decision making for all of us, and certainly when we are at the minimum threshold as characterized above. The concept must be able to encompass the supports and reasonable accommodations to which a person is due in the decision-making process.

We propose the concept of 'decision-making capability' as the conceptual foundation for putting into law, policy and practice the new paradigm of the right to legal capacity

recognized by the CRPD. In making this proposal, we are informed by Amartya Sen's 'capabilities approach', in which the notion of 'functioning' plays a central role, as a potentially productive way to move beyond the limitations of a 'mental capacity' test. It could also help build a more robust framework of the 'functional' test in a manner consistent with the promise of the CRPD and Article 12. Sen developed his 'capabilities approach' to grapple with the question of how development can expand "real freedom" which consists for him in individuals' capability to achieve 'functionings' they value. <sup>151</sup> Sen is interested in the actual social, economic and political, material requirements people have for fulfilling their rights, including a right like legal capacity we would argue. We do not exercise our rights outside of the social, economic and political contexts which afford us certain capabilities or deny them to us.

As such, Sen's framework provides insight for rethinking the ableist assumptions of the usual criteria for decision-making ability. In his framework, Sen links "commodities" (or goods and services that one actually gains access to), to "capability to function," (the ability to do something once one has the commodities/inputs) to actual "functionings" (like getting decisions made) which result in particular utilities (like 'happiness,' or in the case of the utility that Article 12 speaks to, 'self-determination'). Sen distinguishes functions and capabilities as follows:

A functioning is an achievement, whereas a capability is the ability to achieve. Functionings are, in a sense, more directly related to living conditions, since they *are* different aspects of living conditions. Capabilities, in contrast, are notions of freedom, in the positive sense: what real opportunities you have regarding the life you may lead. 152

Sen defines a "functioning" as "an achievement of a person: what she or he manages to do or be." While a systematic application of the capabilities approach to the area of

decision-making and legal capacity is beyond the scope of this paper, its core concepts provide a case for redefining the usual capacity tests in a manner that would be consistent with the principles and provisions of the CRPD – e.g. autonomy, freedom to make one's own choices and recognition of the responsibility of States Parties to ensure reasonable accommodation and supports to exercise legal capacity.

Martha Nussbaum has adapted Sen's capabilities approach and applied it to the case of significant intellectual disability. However, her application runs into the same difficulty that an individually-based functional testing approach to mental or decision-making capacity would encounter. She identifies the basic capabilities a person should be entitled to in order to live a life of dignity, and the kinds of social and economic conditions necessary to achieve these capabilities and pursue and live a good life of one's choosing. She does this in order to consider questions of social justice – i.e. how to allocate resources in ways that maximize the capabilities of all, recognizing that some may require more supports than others to achieve an equality in capability.

However, when she tests her theory with the case of people with significant intellectual disabilities she maintains a highly individualistic notion of disability in her analysis rather than a social model approach. Her definition of 'humanly central capabilities' like 'senses, imagination and thought' and 'practical reason' display this analytic bent. She defines practical reason as "[b]eing able to form a conception of the good and to engage in critical reflection about the planning of one's life." 'Senses, imagination and thought' are defined as "[b]eing able to use the senses to imagine, think, and reason – and to do these things in a 'truly human' way, a way informed and cultivated by an adequate

education, including, but by no means limited to, literacy and basic mathematical and scientific training." <sup>155</sup>

Not surprisingly Nussbaum arrives at a conclusion that since some individuals with more significant disabilities will never be able to achieve these capabilities, which she deems 'central,' other arrangements are needed. In reference to a woman she knows of with significant intellectual disabilities she writes,

So what we clearly ought to say, it seems to me, is that some of the capabilities on the list will not be attainable for her, but that this is extremely unfortunate, not a sign that she is flourishing in a different form of life [Nussbaum is looking to advance a more inclusive definition of human flourishing to challenge systematic segregation based on disability]. Society should strive to give her as many of the capabilities as possible directly; and where direct empowerment is not possible, society ought to give her the capabilities through a suitable arrangement of guardianship. But guardianship, however well designed... is not as good for Sesha [the woman she is writing about] as it would be to have the capabilities on her own... if we could cure her condition and bring her up to the capabilities threshold, that is what we would do, because it is good, indeed important, for a human being to function in these ways. 156

Nussbaum challenges the enlightenment notion of personhood as articulated by Kant – who establishes powers of reason and rationality as the defining features of personhood and of individuals deserving of equal moral worth. These features of moral personhood are imported, she suggests, into Rawls' account of persons and the primary goods deemed essential for an individual to pursue and realize their life plan. Her list of 'capabilities' includes measures that would address the need for care that persons with intellectual disabilities have, and that we all have in moments of dependency that come with illness and decline through aging. But 'care' is not a solution to the right to legal capacity. Even in Nussbaum's account, informed by a feminist reading and critique of the Kantian and enlightenment ideal of the sovereign self, freely choosing one's destiny by the powers of one's reason, care for the disabled seems to trump equal rights to

legal capacity and recognition. It's as though the standards of personhood that are set up for critique, return by the back door. Nussbaum, and others, have created room in theories of justice for selves that come with needs and interdependencies, but if the solution is care managed via guardianship, we are still lacking a moral argument for equal personhood consistent with the aspirations of the Convention, and certainly the equal right to recognition of legal capacity recognized in Article 12.

A closer application of Sen's capabilities approach that remains consistent with a social model approach to disability might go something like the following: people with disabilities have a right to enjoy legal capacity on an equal basis with others in all aspects of life. Like anyone else, legal capacity can only be restricted where a person is lacking the requisite decision-making capability to make a particular decision. Decision-making capability cannot be based on disability status. And, legal responsibility can only be diminished where a person lacked the requisite decisionmaking capability when carrying out actions which are now the focus of civil or criminal proceedings. Decision-making capability would then have three main components: a) decision-making abilities that meet the minimum threshold as defined above; b) needed decision-making supports (described in more detail below); and c) reasonable accommodation on the part of others in the decision-making process (i.e. the goods and services). This notion of decision-making capability combines an individual's particular decision-making abilities with the supports and accommodations needed to exercise legal capacity in relation to others including entering agreements and making contracts.

The broader account of 'legally capable' human agency and decision-making capability described in this section accords with the paradigm shift in human rights protections reflected in the CRPD. It establishes a philosophical foundation on which to ground the positive duty of the state to maximize autonomy for people with significant intellectual, cognitive and psychosocial disabilities that is beginning to be articulated in Canadian jurisprudence. It does so by challenging the idea that the only way to exercise legal capacity is through what could be termed a 'legally independent' status; the idea that one enters a contract, gives informed consent, and manages property transactions *independently*. This decision-making status has come to be equated with the right itself. If one cannot manage decision making independently, it is assumed that one does not have legal capacity. It is on this basis that many people with disabilities have the right to legal capacity restricted or denied altogether.

A broader account of human agency and personhood, or of persons who exercise legal capacity, and of the ways in which they exercise it, expands our understanding of how the right to legal capacity can be exercised. The notion of 'decision-making capability' – as a combination of unique decision-making abilities combined with supports and accommodations – provides a key conceptual tool with which to fashion a legal paradigm for recognizing the right to legal capacity that is consistent with the provisions of the CRPD and its social model approach to disability.

#### II. DECISION-MAKING SUPPORTS

The concept of the minimum threshold of what it means to be a person who exercises and enjoys legal capacity, and the concept of decision-making capability, provide a

much more inclusive framework for recognizing the right to legal capacity without discrimination on the basis of disability. Nonetheless, how people actually exercise their legal capacity will vary depending on the nature of their decision-making abilities and on the combinations of supports and accommodations they require to turn their decision-making *ability* into actual decision-making *capability*. A person who easily meets the 'understand and appreciate test' in the eyes of others will be respected as someone who goes into financial institutions or a doctor's office and can make decisions for themselves *by* themselves. Someone who can only meet the minimum threshold as defined above will require others to assist them in representing themselves to others in the decision-making process.

How do we define the scope of decision-making supports encompassed by Article 12(3) that are integral to constituting a person's decision-making capability? We suggest three main types of supports:

- Supports to assist in formulating one's purposes, to explore the range of choices and to make a decision;
- Supports to engage in the decision-making process with other parties to make agreements that give effect to one's decision, where one's decisions requires this; and
- Supports to act on the decisions that one has made, and to meet one's obligations under any agreements made for that purpose.

These criteria for defining decision-making supports are not fully inclusive of all the potential supports that could affect the exercise of a person's legal capacity. For

example, financial resources, housing and disability-related supports, etc. all affect the exercise of legal capacity in that the extent to which one has such resources expands or diminishes the range of one's choices. However, this broad range of supports — including income, disability-related supports, housing accessibility, etc. — we anticipate would likely be interpreted to be outside of the scope of "supports" envisioned by Article 12(3). State obligations to ensure these broader financial and community supports are accessed by people with disabilities are covered under other Articles of the CRPD including: Article 9 'Accessibility;' Article 19 'Living independently and being included in the community;' Article 20 'Personal mobility;' Article 24 'Education;' Article 28 'Adequate standard of living and social protection;' and others.

We expect that the scope of Article 12 is more likely to be interpreted as encompassing those goods and services that directly affect the exercise of one's legal capacity in the context of the decision-making processes one engages in to make individual decisions, understanding that the context for doing so is constrained in unequal ways for individuals depending on historic disadvantage and a range of other factors.

If we start with an account of legally capable human agency that is broader than the one usually assumed in capacity law, and keep the 'minimum threshold' in mind of the person whose will and/or intentions directs those supports, then at least six substantially different (although not mutually exclusive) kinds of supports to exercise legal capacity as provided for in Article 12(3) of the CRPD come into view:

- Life planning
- Independent advocacy

- Communicational and Interpretive
- Representational
- Relationship-building
- Administrative

#### A. Life Planning Supports

We choose our priorities and make individual decisions in the context of some understanding of our values, purpose and plans for our life. For most of us, most of the time, life may not feel very planful – so many contingencies disrupt our best laid plans. Nonetheless, even while we are constantly adjusting our plans, and priorities are shifting, we operate from an assumption that it is a good thing to have some direction in our lives. It is on this basis that we make day-to-day decisions, and the larger, defining decisions for our life paths.

Many people who have more significant intellectual, cognitive and psychosocial disabilities and who have been institutionalized and/or isolated through poverty and exclusion in their communities are often lacking these directions in their lives. It can be extremely challenging to make decisions about where to live, or how to be supported, or whether or not to accept certain medications or health care interventions over others. One of the key supports people require is assistance in person-centred life planning – a process of identifying values and purpose, making key decisions congruent with those interests, and making and executing the necessary agreements. Without such supports, individuals may be confused, uncertain and unclear in decision-making processes with others, and appear unable to make decisions.

A variety of community-based services and models are in place to provide such planning assistance. However, it is not universally accessible to those who require and would benefit from these services. As well, those who provide the service are often attached to funding agencies or service providers and the planning process is used to funnel individuals into certain funding levels or service models. The independence of such planning supports from funding agencies and residential care or home care providers has been identified as a critical component in the effectiveness of such services.<sup>157</sup>

#### B. Independent Advocacy

People with more significant intellectual, cognitive and psychosocial disabilities can often guide their own decision making. However, other parties to agreements, educated and operating within the assumptions of traditional capacity law, often assume otherwise. Challenging these assumptions, and those who would question a person's capacity, may be beyond the skills and personal resources of the individual with a disability. Access to independent advocacy may be a needed support in these situations to assist the individual in expressing their wishes and informing other parties of the individual's rights, and of the other parties' duties to respect those rights and accommodate accordingly.

There is an important role to be played by non-legal or social advocacy<sup>158</sup> whenever a legal regime removes the right of an individual to make decisions. This view has been held by the disability community for several years; the Ontario Association for the Mentally Retarded (now Community Living Ontario) called for the establishment of an

independent advocacy system in the early 1980s.<sup>159</sup> The role of an advocate can be seen as facilitating the implementation of decisions made by an individual who may wish support and assistance in doing so. This role emphasizes self-determination and independence.<sup>160</sup> In more general terms, advocacy is consistent with ensuring "...full participation in the daily life of our communities by all those who so desire."<sup>161</sup> However, the line between giving advice, information or support and actually making or being seen to be making decisions for another person without their guidance must be kept clear. This line is a fine one, which can easily be crossed in practice.<sup>162</sup>

An advocacy model could be community-based and advocacy services could be provided by volunteers or professionals. There is precedent for creating an advocacy framework in legislation. See, as an example, the *Provincial Advocate for Children and Youth Act, 2007*<sup>163</sup> as well as Ontario's *Advocacy Act, 1992*. Even though the Ontario legislation has been repealed, it is a useful model to look at as an example.

Reference should be made to "You've Got a Friend", the Report of the Review of Advocacy for Vulnerable Adults in Ontario, for a thorough examination of the nature of, and various options for, the delivery of advocacy. 166

#### C. Communicational and Interpretive Supports

One of the main challenges that persons with more significant intellectual, cognitive and psychosocial disabilities face in decision-making processes with other parties relates to their oftentimes unique forms of communication. Different oral and non-verbal signs of communication may not be understood by third parties, and individuals may require augmentative and alternative communication systems. These may include signing,

gestural and vocalization systems, computer-assisted and electronic devices as well as non-electronic communication output aids.

As well, individuals may require interpretive assistance for intake and processing of information from other parties, including plain language assistance, sign language interpreters and a range of computer-assisted voice activation and other devices. All of these supports assist a person in managing the communication and processing of information essential to making decisions and communicating them to others.

#### D. Representational Supports

For people with very significant intellectual, cognitive and/or psychosocial disabilities, planning supports, advocacy and communicational and interpretive supports may not be enough for other parties to understand them sufficiently to enter agreements with them. These are the individuals who are close to the 'minimum threshold' of human agency identified above. Others cannot encounter them as individuals because they do not have the understanding of their forms of communication, their life histories, their wishes and hopes for the future, or their basic intentions. In these situations, the individual often disappears in the eyes of others behind the clinical categories that so dominate their biographies.

What we refer to in this paper as 'representational' supports are required in these situations. Other individuals help communicate who a person is, and to share their biography with others. These are individuals who have a knowledge of the person born out of a relationship of trust and understanding of their unique ways of communicating,

and who, through shared life experience, have come to understand who the person is, what he or she values and wants and what he or she dislikes or rejects.

This personal knowledge of another is the foundation on which the individual can be represented to the world, and is the basis on which decision-making processes can be managed. Those providing representational support may assist the person by carrying out the intellectual processing required to translate intentions and wishes into actual decisions and agreements with others.

Representational support is distinguished here from Powers of Attorney or other agents appointed by an individual to act on his/her behalf. In these cases, an individual is still acting legally independently in the sense that the test for appointing such agents is that the individual appreciates the nature and consequences of the appointment. While the agent may 'represent' the person in making agreements, this is distinct from what we define as 'representational support' above. By that term, we mean representatives who assist the person directly in communicating their person to others – which may involve interpreting the individual's actions and behaviours, and narrating the person's identity – wishes, hopes, fears – to other parties.

As outlined above, this form of support is recognized in the B.C. *Representation*Agreement Act, which provides for an individual to appoint others to assist in making decisions or to make decisions for them.

#### E. Relationship-building Supports

Many individuals with significant intellectual, cognitive and psychosocial disabilities simply do not have others in their lives with whom they are in a trusting relationship based on shared life experience and personal knowledge. A life of discrimination and exclusion has left them without such relationships. This does not mean that such relationships cannot be developed. There is a large body of good practice and tools to assist people with more significant disabilities in developing personal relationships with others. However, this work takes time, intentional relationship building, and community-based supports to facilitate the process, identifying individuals who can play this role and provide the person with a support network.

For people with significant disabilities the outcome of relationship-building supports is the development of relationships and support networks which can provide representational supports at some point in the future. In their case, the access to representational supports maximizes exercise of their legal capacity.

#### F. Administrative Supports

Entering agreements with others that give effect to one's decisions can also require a range of administrative supports – for example, completing arrangements for a loan, or purchases. As well, there is growing use of individualized and direct funding to enable people with disabilities to purchase their disability-related supports and services. This method of funding provides for greater choice in deciding which supports to use, which attendants to hire, or which home-care agencies to contract. As policy consideration is given to individualized, direct funding, which can significantly enhance autonomy,

questions of legal capacity often come to the fore with respect to persons with intellectual, cognitive and/or psychosocial disabilities. Even if the person can choose the people he/she would like to deliver services, and can provide even limited direction, how can they manage funding which may run into the thousands of dollars per month? This concern can become a reason for restricting access to this form of funding, and thereby can lead to a restriction of a person's autonomy in decisions about their disability-related supports and services.

Administrative supports are a key element of the support system in assisting individuals to carry out the agreements into which they enter. A variety of arrangements have been established through agreements between individuals, funding agencies, financial institutions, and community agencies to provide an administrative structure for managing funds, paycheques and remittances for persons receiving individualized funding for their supports. When such supports are inaccessible or unavailable, the prospects for individuals to significantly enhance their autonomy are thereby limited.

In summary, different and unique combinations of types of supports will be accessed by people differently due to their own unique personality, characteristics and needs. The framework we propose in this paper envisions that the right to access supports includes a right to access the types of supports and combinations of supports that most enhances each person's autonomy. It cannot be assumed that a regime which legislatively recognizes 'supports' fully embodies this vision. For example, Manitoba's *The Vulnerable Persons Living with a Mental Disability Act* <sup>167</sup> appears at first blush to fully embrace 'supported decision-making'. However, 'supported decision making' is

defined in the Act as follows: "... 'supported decision making' refers to 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." This definition appears to limit itself to support networks and, in any event, may well not be interpreted to include the broader range of supports to which individuals should have access under Article 12(3) of the CRPD.

#### III. TYPES OF DECISION-MAKING STATUS

How do we decide who gets what decision-making supports? We do not want to establish regimes where supports are mis-allocated, or imposed on people who do not want or need them. Their particular way of exercising and enjoying their legal capacity could, otherwise, be at risk. In other words, there is a basic question of distributive justice to be grappled with in the allocation of decision-making supports and accommodations.

To assist in conceptualizing a fair allocation of supports for the exercise of legal capacity, it is helpful to draw on the distinction between types of decision-making status that is already emerging in Canadian law. In Part One, we outlined the emergence in both Canadian jurisprudence and legislation of new forms of decision-making status beyond the traditional binary distinction between acting legally independently with no support, and being placed under a substituted authority. Drawing on these developments, and the conceptual framework we introduced in the preceding section (of a minimum threshold and decision-making capability) we outline in this section a new

schema of types of status that is informed by the paradigm shift of the CRPD and a broader account of decision-making capability. Each of the statuses imply a particular combination of decision-making abilities and supports and accommodations. While the actual range of individual decision-making abilities and needed supports and accommodations could no doubt be drawn out on a continuum, our framework suggests that legal capacity is enjoyed and exercised in substantially different ways depending on two main factors:

- Whether or not a person's particular decision-making abilities means that they need another person to help communicate and represent their will or intention to others;
- Whether or not a person meets the minimum threshold as defined above –
  where at least one other person can reasonably understand the person's will
  and/or intention, and communicate that to others for the purposes of a
  decision-making process.

With these factors in mind, we propose three main decision-making statuses to be recognized in law.

# A. Legally independent Status: a Re-formulation of the Understand and Appreciate Test

This is the status usually articulated in moral philosophy and the law, essentially the 'freely contracting agent.' This is the status in which an individual is recognized as able to act alone – give consent on his or her own, enter a contract on his or her own, etc.

The defining feature of this status is that the person understands information and appreciates the consequences of his or her decision, is able to communicate that

understanding and intentionality to a third party in a way that party understands, and is free of coercion from other parties. That said, those acting in a legally independent manner may legitimately call on the support/assistance of others as needed in the various considerations that go into making a decision. What defines this status, however, is that the person makes the decision exclusive of any other formal representations by others acting in a support role to the person in the decision-making process.

The criterion for acting in a legally independent status is defined by what we propose as a re-formulated 'understand and appreciate' test; that is, in a legally independent status there is reasonable evidence that the person:

- has the ability, by him or herself or with assistance, to understand information that is relevant to making a decision; and
- has the ability, by him or herself or with assistance, to appreciate the reasonably foreseeable consequences of a decision <sup>169</sup>

This does not mean that people in a supported decision-making status do not necessarily meet such a test. It does mean that if a person does not meet the test, they are either in a supported or facilitated decision-making status.

#### B. Supported Decision-making Status

This status is based on what is articulated in moral and feminist philosophy as 'relational autonomy' and discussed in the earlier section on negative and positive approaches to liberty. It starts from the assumption that no self is isolated, but is rather essentially an intersubjective creation and accomplishment made possible by the 'ethics of care' of

others. While we all make decisions with the assistance of others, this intersubjectivity and interdependence is more visible for some older adults and adults with disabilities than others. This group needs support from others to communicate, express and represent themselves to third parties, and/or to process information. They cannot, or choose not, to manage these activities on their own.

What distinguishes this status from the other two is that individual support persons are appointed in some manner in order to assist the individual in making decisions and/or representing and communicating the person's will and/or intention to others. In a supported decision-making status, support persons or representatives could be appointed in four ways:

- an individual could appoint those he/she wishes to assist or represent him/her in decision-making (as under the *Representation Agreement Act* of British Columbia);
- 2) where a person cannot manage the appointment process, or adequately understand the process, an individual or group of individuals could be recognized/appointed by an administrative tribunal, upon an application by the individual or group. The requirement would be that the individual or group have a trusting relationship with the individual and be committed to the person's well-being and to assisting and representing them on the basis of their best understanding of the person's will and/or intention; 170
- 3) where an individual does not have anyone in a close personal relationship that they can appoint or who would apply for appointment, and where this type of decision-making status would best enable a person to exercise their legal

capacity, a tribunal or court could appoint a co- or supporting decision maker as provided under the legislative schemes in Alberta and Saskatchewan as outlined above. In these cases, the individual can communicate sufficiently that a co-decision maker can understand the person, but not sufficiently for third parties to be confident, in their absence, that the person understands information and appreciates the nature and consequences of a decision or agreement.

4) where an individual(s) has been acting in a *de facto* manner to support a person in making decisions, that person may be legally recognized as a supporter upon swearing an affidavit that states they have sufficient personal knowledge to understand the person's ways of communicating their will and/or intention and commit to taking any consequential actions to give effect to the person's will and/or intention and they agree to meet all the legal duties associated with the supported decision-making status and to acting as a fiduciary. <sup>171</sup> As we discuss below in Section VI, a *de facto* arrangement cannot be established in a situation of serious adverse effects.

The minimum threshold for exercising legal capacity through a supported decisionmaking status is:

An individual can act in a way that at least one other person who has personal knowledge of the individual:

- can reasonably ascribe to the individual's actions, personal will and/or intentions consistent with the person's identity; and
- can take reasonable consequential actions to give effect to the will and/or intentions of the individual, which respect the individual's dignity of risk.

Recognizing the role of support and representation in a supported decision-making process shifts the focus of competency from the individual, to the decision-making process. A competent decision-making process is one in which supporters and representatives are guided by the will and/or intentions of the individuals in ways that give the individual decision-making capability. Guidelines are needed to assist supporters and representatives in one or more of six tasks that are carried out in supporting a person who meets the minimum threshold to engage with others in decision-making processes, but who does not meet the test of legal independence. The following tasks would be carried out in supporting a person in this status:

- ascribing will and/or intention to a person's sometimes unique behavior and forms of communication;
- describing to or interpreting for others what that behavior means or is communicating in terms of a person's will and/or intention;
- narrating to others how this particular expression of will and/or intention is part of
  a person's identity and how it makes sense in their life story thus assisting
  others to understand the person's will and/or intention and the decisions that
  would flow from it as 'reasonable' in the circumstances;
- translating the person's will and/or intention into consequential transactions and decisions to give them effect in relation to a particular circumstance or decision that needs to be made;
- communicating to others decisions that will be made based on the person's will and/or intentions; and

 assisting the person in making decisions and transactions that give effect to their will and/or intentions – i.e. by assisting them in gaining some understanding and appreciating the nature and consequences of a decision or transaction.

In order to ensure competent decision-making processes for individuals in this status, supporters would have a duty to follow certain principles and guidelines for playing the roles identified above. We suggest adapting these principles and guidelines from those in the Ontario Substitute Decisions Act and Health Care Consent Act for guiding substitute decision makers, and in the B.C. Representation Agreement Act for guiding representatives in supporting or making decisions for others. It is our view that if we accept the minimum threshold of human agency as described above, that persons with such agency are not, in fact, [mentally] incapable as currently defined under Ontario legislation. Nonetheless, they may need assistance and support, which may take the form of representation, in order to complete the needed transactions to give effect to their will and/or intentions. Provisions exist in the Ontario Substitute Decisions Act and the Health Care Consent Act which require that substitute decision makers make decisions in accordance with wishes and/or instructions that the [mentally] incapable person made prior to their incapability, and that take into consideration any current wish which can be ascertained. 172 Along with the duties described in s.16 of the B.C. Representation Agreement Act, they provide a good starting point for articulating the duties of supporters and representatives for those in the supported decision making status. We adapt the duties for supporters and representatives from these three statutes in order to outline the kinds of guidelines for assisting a person in this status. In assisting and representing a person in a supported decision-making status to make

decisions, and in taking consequential actions to give effect to their will and/or intentions, supporters and representatives have the following duties:

- Consult, to the extent reasonable, with the adult to determine his or her current wishes.
- Be bound in decision-making by the person's wishes or instructions that are applicable to the current situation and that were expressed by the person in a prior planning document.
- Be guided by any wishes or instructions that the supporters and representatives have ascertained the person has expressed in the past and which they believe would apply in the current situation.
- Be guided by the person's wishes and instructions expressed in the current situation.
- Use reasonable diligence in ascertaining any such wishes and instructions.
- Comply with a person's wishes and instructions in ways that respects their dignity of risk.
- In translating a person's will and/or intention into needed decisions and transactions, supporters and representatives are likely to have a greater or lesser extent of discretion depending on how directive the person's expression of will and/or intention is. Where specific directions are lacking about the transactions required to give the overall intention effect, then the supporters and representatives must consider how the person would assess their own best interests in deciding among the range of options available.

On first blush, the duties of supporters and representatives to a person in a supported decision-making status appear to be largely the same as the duties of substitute decision makers. One might ask what difference, if this is the case, does it make whether or not a person is in a supported decision making or substitute status? However, in looking more closely at the legislation and the concept of supported decision-making as a status to exercise legal capacity, there are two important differences. First, the substitute decision maker is not, in all cases, bound to comply with the person's wishes. In the case of the Ontario Substitute Decisions Act, the substitute decision maker is bound to comply where the wish or instruction is a prior one - i.e. where it is assumed it was made while the person was legally capable. However, the substitute decision maker is not bound to comply with a current wish or instruction made by a person who is found legally incapable under the Act. 173 By contrast, in the case of supporters or representatives assisting a person who is in a supported decisionmaking status, they are always bound to be guided by the wishes and instructions of the individual. Second, by virtue of a requirement that the wishes of a person in a supported decision-making status must be followed, people become subjects of their own lives, rather than objects of interventions. This is consistent with what Quinn refers to as the "profound message" of the *Convention* – "that persons with disabilities are not 'objects' to be managed or cared for, but human 'subjects' enjoying human rights on an equal basis with others." <sup>174</sup> A supported decision-making status makes legal capacity and recognition of oneself as a subject much more widely available.

#### C. Facilitated Decision-making Status

By 'facilitated status' 175 we mean a status in which others facilitate the making of needed decisions. This status is envisioned for individuals in the following circumstances:

- People with significant disabilities who are not able to act legally independently,
  and who have no other people in their lives who have personal knowledge about
  them sufficient to understand their ways of communicating, their will and/or
  intentions as a basis for decision-making (as in a supported status).
- Individuals who have indicated wishes in a prior planning document, like that for a power of attorney, which is triggered when a person is not able to act legally independently or through a supported decision-making status.
- Individuals who did not establish prior planning documents, who do have others in their lives who know them well and are committed to acting for them, but where these supporting others are unable to discern the person's current will and/or intentions sufficient to guide decision making for example, people who have experienced traumatic injury, illness or a dementia which has left them in a coma, or with dramatically impaired cognitive and communication function.

There are two methods by which a facilitated status could be created, as follows:

- A facilitator could be appointed by an administrative tribunal;
- A facilitator could be created by a planning document (e.g. power of attorney, or a 'Ulysses Agreement' 176) in which a decision-maker is appointed at a time when the individual was acting legally independently or in a supported decision-making status in respect of that appointment.

A person could be in a facilitated status in respect to some or all areas of their lives, including health and other individual decisions, financial decisions and situations in which serious adverse effects are occurring.

Unlike the common parlance in relation to capacity laws, the fact that a person is in a facilitated status would not define them as being 'legally incapable' and would not represent a statement or judgment about their cognitive status or abilities.

As described above, some people may be in a facilitated status because they have no other persons in their lives who know them well enough to understand the particular ways they communicate their will and/or intention sufficient to direct consequential action by others (the criterion for supported decision making). The understanding that others can provide in these situations is a form of assistance some individuals need to exercise their legal capacity, if not in a legally independent status, then in a supported decision-making status. However, this form of support is not like a communication technology that can be purchased and applied. It develops only in the context of a personal relationship that takes time to develop. Thus, individuals who are in a facilitated status because of a lack of relationships in their lives, would be owed a duty by the state under Article 12(3) to take measures to develop such relationships in their lives, as the basis for the support they need to maximize their legal capacity.

Facilitators would be duty-bound to facilitate the making of needed decisions on the basis of any knowledge they may have, or could reasonably be expected to acquire, about the person's will and/or intentions previously expressed. If there is no such information available, or if the information is too limited to be usefully instructive with

respect to particular decisions, the principle of 'best interests' would apply. Again, the Ontario *Substitute Decisions Act* and the *Health Care Consent Act* provide some guidelines for substitute decision makers to act in the best interests of a person, which would be appropriate for facilitators as well.<sup>177</sup>

The criteria for best interests would be:

Based on the facilitator(s)' best understanding of the person's prior wishes, instructions and values, what decision would best to:

- o improve the quality of the person's life;
- o prevent the quality of the person's life from deteriorating,
- reduce the extent to which, or the rate at which, the quality of the person's
   life is likely to deteriorate; or
- benefit the person in ways that outweigh the risk of harm, in comparison to an alternative decision.

We propose that these three decision-making statuses define the basic boundaries by which legal capacity is exercised in distinctive ways. They are not fixed statuses. An individual may move from one to the other and back again, depending on the evolution of their decision-making abilities and needs for support, in relation to particular decisions or types of decisions. As well, these statuses would be consistent with the functional test of decision making capability as described above. That is, the status would be adopted or applied in respect of a particular decision, or if an individual so chose in respect of a range of decisions. Supporters and facilitators designated for either the supported or facilitated decision-making status would be duty-bound to not

impose the status if the individual wished to be supported in other ways to exercise their legal capacity and could be found able to do so.

## D. An Inclusive Principle for Recognizing Legal Capacity: Linking Types of Decision-making Supports and Decision-making Status

A person with a disability in any of three decision-making statuses may need one or more of the six types of supports to exercise their legal capacity. The cluster of supports needed will vary from person-to-person depending on their particular decision-making abilities and the nature of decisions to be made. However, which type of supports are used, and how, can substantially alter the decision-making relationship and process. If too few, or the wrong supports are accessed, autonomy may be unnecessarily restricted. The issue of securing justice in administration of legal capacity law shifts substantially in this analysis from an exclusive to an inclusive approach. Rather than an exclusive focus on determining who can exercise their legal capacity independently, the analysis shifts to how to fairly allocate supports and accommodations to ensure that each person exercises and enjoys their right to legal capacity in ways that maximize their autonomy. Our analysis suggests a foundational principle on which to guide law, policy and practice that recognizes an equal right to legal capacity as provided for in the CRPD:

People enjoy and exercise their right to legal capacity differently depending on a person's unique characteristics. A person's autonomy and legal capacity is maximized equally to the extent that they access the supports and accommodations they need to exercise their legal capacity; and to the extent that supports and accommodations adapt to each person's evolving decision-making abilities and capabilities.

'Fair' allocation in this formulation is allocation that ensures persons receive the type and extent of supports they require to exercise their legal capacity – not more, not less.

This principle for recognizing the right to legal capacity articulates both a positive and negative liberty approach to autonomy. Having one's autonomy respected, regardless of disability, expands the realm of negative liberty for a group of people for whom it has so long been denied. That is, it establishes that people have the legal capacity to say 'no' to others who would impose treatment or confinement, or a particular service upon them in the name of protection. At the same time, it recognizes that the space for exercising autonomy is not devoid of intervention by the State and other parties; that it is not defined as the negation of any intervention or regulation. Rather, autonomy is a social and inter-dependent accomplishment that rests on the positive duties of the State, and of other parties to the decision-making process in any particular circumstance regulated by law.

The principle also makes clear that as a person's abilities evolve, supports and accommodations should be adapted, and the decision-making status through which they exercise and enjoy their legal capacity may also change with respect to some or all decisions they make. No longer should legal capacity legislation identify a 'presumption of capacity,' for which procedures are outlined about how to remove legal capacity when a person is found without the requisite [mental] capacity. Rather, legal capacity legislation should incorporate an 'assumption' of legal capacity as articulated in the principle above.

**Figure 1** presents the dynamic nature of decision-making capability – as a relationship between decision-making abilities, decision-making supports and accommodations, and decision-making status. People move between statuses as abilities, supports and accommodations evolve.

Legally independent decision-**Maximizing Legal Capacity** making status Supports & Accommodation not yet feasible Supports & Accommodation sufficient Supported decisionmaking status Supports & Accommodation not yet feasible Supports & Accommodation sufficient **Facilitated** decision-making

Figure 1 - Maximizing Legal Capacity

### E. Proposed Legislated Right to Legal Capacity, and Newly-formulated Presumption of Legal Independence

Based on the framework of decision-making supports and statuses presented in this section, we propose a legislated recognition of the right to legal capacity without discrimination on the basis of disability. This means that while legal capacity cannot be removed, the decision-making status through which one exercises it can be changed. As well, to ensure that no individual is denied the opportunity to be considered able to exercise their legal capacity through a legally independent decision-making status, we recommend that legal capacity legislation incorporate a newly-formulated principle, based on the minimum threshold of legal independence defined above, to the effect that:

All persons of majority age are presumed to be capable of acting legally independently, where this means the person has the ability, by him or herself or with assistance, to understand information that is relevant to making a decision; and to appreciate the reasonably foreseeable consequences of a decision.

This statement of presumption is distinct from the current presumption of [mental] capacity in most current legal capacity law. The difficulty with the current formulation from the perspective of the CRPD is twofold. First, a 'presumption' is rebuttable; it assumes that, in this case, the legal recognition and associated right can be withdrawn and restricted. Second, positioning mental capacity as a criterion of legal capacity appears to us to violate the intent of Article 12. Alternatively, the proposed presumption stated above is a presumption only that a person exercises their legal capacity in a

legally independent manner. Stated this way, it provides that if this presumption is rebutted, i.e. that a person cannot exercise legal capacity through this status, he/she will exercise it through another status. In either case, he/she will not lose their legal capacity.

# F. Status Determinations and a 'Functional Assessment' of Decision-making Capability

In making status determinations, a 'functional assessment' of decision-making capability would be needed to deal with situations where there is reasonable question as to whether a person has the capability to understand and appreciate, even with assistance, the nature and consequences of a decision; or if a person meets the minimum threshold for supported decision making. The assessment should explore the following questions:

- 1) Does the person appear to have the decision-making abilities to understand information and appreciate the nature and reasonably forseeable consequences related to a particular decision?
- 2) If not, would additional supports and/or accommodations enable the person to satisfy (1) above? Have the supports been put in place to assist this person to understand and appreciate the nature and consequences of his or her intention and to engage and communicate in this decision-making process?
- 3) If not, can at least one other person who has personal knowledge of the individual reasonably ascribe to his or her actions: personal will and/or intention; memory; coherence of the person's identity through time; and communicative abilities to that effect?

- 4) Are other parties to this decision reasonably accommodating the person?
- 5) Has the State provided sufficient supports to maximize the person's decisionmaking capability?

It is important to distinguish this approach to functional assessment of decision-making capability, from the 'functional test' of legal capacity as discussed above, in relation to other measures of capacity like the 'outcome' and 'status' approach. Our proposed approach to assessment focuses on what accommodations and supports a person requires to manage the decision-making process in a way that maximizes their legal capacity, given their unique decision-making abilities. It is not used to determine whether or not a person has legal capacity, but rather the status through which they will exercise it, when disputes arise in this regard among parties in a decision-making process.

This section has outlined a framework of decision-making statuses to exercise legal capacity. In order to maximize legal capacity equally as the CRPD requires, we suggest that the crux of the issue will be to ensure that individuals are exercising their capacity through the most appropriate status. As we have suggested above, where there is some question about whether a person is acting through the most appropriate status, there will be need for a functional determination of decision-making capability. This will necessarily involve an inquiry into whether all needed supports and accommodations are being provided. A number of challenges may arise in such an inquiry, including determining whether or not a third party is providing reasonable accommodations; the extent to which an individual is able to access needed supports through state provision;

whether or not an individual can exercise their legal capacity in a legally independent status or requires some other status; and a person's intentions if they are supported by representatives with different views and interpretations.

The next section begins to address these challenges and issues by exploring the principles and nature of the duties to accommodate and provide supports as recognized in the CRPD. Subsequent sections look at safeguards that need to be in place to address disputes that may arise with respect to the nature and type of decision-making supports a person is able to access through accommodation from third parties or through state provision.

### IV. DUTY TO ACCOMMODATE: FOUNDATION FOR STATE AND THIRD PARTY SUPPORT OBLIGATIONS IN THE DECISION-MAKING PROCESS

How do we formulate the duties to ensure people have supports to maximize exercise and enjoyment of their autonomy and legal capacity? There are two broad classes of parties implicitly and explicitly identified in the language of the CRPD. First, States 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)). Second, States Parties have an obligation to "take all appropriate steps to ensure that reasonable accommodation is provided" (Article 5(3)). The latter obligation also implicates third parties to decision-making processes. How do these obligations of both States Parties and other third parties intersect in a particular decision-making process to maximize exercise of legal capacity? What is the positive duty of the state? What is the duty of third parties?

In this section we articulate the legal duties to accommodate of both the state and third parties in relation to supports. The accommodation and supports framework described in this section is somewhat novel but builds upon the firm foundation of Canada's human rights laws and the *Charter*. In order to implement this framework, relevant provisions would need to be incorporated into all legal capacity-specific legislation and apply to all interactions where capacity is in question.

#### A. What Does Accommodation in Decision Making Mean?

People plan their lives on the basis that they have a right to live as they choose. In contrast, an individual who has been found to be legally incapable does not have the freedom to make his/her personal choices; decisions are imposed by others.

Reasonable accommodation is required to avoid such differential treatment. It maximizes a person's right to prove his/her ability to make capable decisions, demonstrate his/her capacity to others and thus exercise legal capacity on an equal basis with others.

Accommodation can be relevant whenever an individual interacts with a third party. An individual with an intellectual disability may not, at the outset, understand the content of the information exchange between him/herself and the third party. For example, he/she may not understand the attendant risks of a medical procedure, the implications of opening a bank account or the meaning of a power of attorney. There are a broad range of accommodations that may be required to enable a person to understand information sufficiently to make these kinds of decisions, including:

- informal assistance from family and friends;
- plain language assistance, assisted/adaptive communication, visual aids, etc.;
- supported decision-making representatives/networks; and,
- interpreters (sign and spoken language) and intervenors (for people who are deaf-blind).

What follows are two illustrations of the manner in which supports accommodate a person to make her own decisions, without which she might be unable to do so. These scenarios relate to Jane, who has an intellectual disability.

Jane would like her mother to do her banking for her. For her mother to have the legal authority to do so in Ontario, Jane could make a power of attorney but would need to meet the legal test of capacity to do so. This would require her to understand what a power of attorney is and what the implications are of making one. If, at the outset, a lawyer asks Jane what a power of attorney is and what the effect of making one is, the lawyer may conclude that she does not meet the test of capacity to make one. This is because, when in the lawyer's office, Jane feels intimidated by a person of authority, is not able to explain a power of attorney in her own words, looks at the lawyer blankly and prefers to talk about her upcoming vacation. In general, Jane expresses herself using words and gestures that strangers do not know how to interpret, but which are meaningful and clear to people who know her well. It is likely that if her best friend explains the concept of a power of attorney in language that she understands, and does so at her pace in non-intimidating

surroundings, she will learn the meaning and implications of the document.

In this way, accessing supports provides her with the vehicle to exercise and demonstrate her capacity. The supports accommodate her to make decisions equally with others.

Jane's doctor believes she needs a medical procedure. Providing accommodation in the form of supports may require the doctor to give her some written material in plain language which explains the procedure and its risks and benefits. If Jane takes it home and spends some time reviewing it, she may come to a point where her understanding of the procedure is sufficient to make her own decision. Without material in plain language and the benefit of time, Jane might not understand the procedure. Without these accommodations, the doctor might well conclude that she is incapable, thus invoking a substitute decision-making alternative.

In summary, an ability to make a decision is not black and white.<sup>178</sup> It can be enhanced by accommodations in that they facilitate individuals with disabilities to be able to exercise their right to make decisions as do others. As we describe in the next section, where the *Charter* or human rights laws apply and accommodation is a legal requirement, providing accommodation for the decision-making process too, is a legal requirement.

#### B. Legal Basis for Accommodation

There is a strong legal basis mandating a duty to accommodate in maximizing legal capacity. This emanates from the duty to accommodate found both in Canada's human

rights laws and jurisprudential interpretation in the context of discrimination in s.15 of the *Charter*. The promotion and protection of human rights and fundamental freedoms, along with the prohibition against discrimination and the duty to accommodate, which feature so prominently in Canadian law, are central tenets of the CRPD as well. As we have noted above, the right to equality and non-discrimination is recognized in Article 5 of the CRPD, which establishes that States Parties have an obligation to ensure the provision of reasonable accommodation.

The concept of accommodation describes a legal duty to take positive action to accommodate the unique needs of people with disabilities. More specifically, "'Accommodation' refers to what is required in the circumstances to avoid discrimination." Its goal is to avoid exclusion by ensuring the fullest possible participation in society. This duty to accommodate, however, is not unlimited in that accommodations are only required to the point of *undue hardship*. The Supreme Court of Canada in *Council of Canadians with Disabilities v. VIA Rail Canada Inc.*, 181 in relation to people with disabilities, elaborated on the duty to accommodate to the point of undue hardship, as follows:

The concept of reasonable accommodation recognizes the right of persons with disabilities to the same access as those without disabilities, and imposes a duty on others to do whatever is reasonably possible to accommodate this right. The discriminatory barrier must be removed unless there is a bona fide justification for its retention, which is proven by establishing that accommodation imposes undue hardship on the service provider. 182

The duty to accommodate requires that accommodations be individualized. This principle has been articulated by the Supreme Court of Canada in *Nova Scotia* (Workers' Compensation Board) v. Martin; Nova Scotia (Workers' Compensation Board) v. Laseur. 183 The Supreme Court has recognized that accommodation is a highly

individualized process that must be responsive to individual needs and must be implemented on an individualized basis. For example, accommodating a person with an intellectual disability may involve support people while accommodating an individual with an acquired brain injury may simply involve allowing more time to process information.

The process of accommodation has been recognized to be one that is a joint obligation. The person asking for accommodations, as well as those responsible for providing them, must co-operate in the accommodation process. Thus, a person with a disability, or his/her supporters, have a duty to advise third parties of the intention to rely on support persons for assistance in the decision-making process, and to advise on how they wish this to be done.

# C. Accommodation, the *Canadian Charter of Rights and Freedoms* and Human Rights Laws

Both the *Charter* and human rights legislation protect equality rights. And, in fact, "... there is considerable cross-fertilization between statutory human rights cases and equality cases decided under the *Charter*." However, while human rights legislation applies to both private and public actors, <sup>187</sup> the *Charter* only applies in the public sphere. <sup>188</sup>

The federal government and each Canadian province and territory have their own human rights laws which exist to protect individuals from discrimination and promote equality. These have pre-eminent importance in Canada's legal framework, and are described as fundamental laws which are "quasi-constitutional" in nature. These

human rights statutes apply to several areas of activity, including the provision of services, such as those of lawyers, banks and health professionals.

The duty to accommodate in relation to the provision of services is explicitly recognized in most human rights statutes in Canada. Importantly, Supreme Court of Canada commentary on the duty to accommodate is relevant across jurisdictions. Therefore, while the duty to accommodate may not have the same precise meaning in each Canadian jurisdiction, the provision of services throughout Canada should be undertaken giving full effect to supports as an accommodation, in accordance with the applicable human rights legislation and jurisprudence.

Additionally, the *Charter* applies specifically to government activity and to legislation. The Supreme Court of Canada has interpreted the *Charter* to include a duty to make reasonable accommodation up to the point of undue hardship. <sup>190</sup> This positive duty on the state to provide accommodation to address differences, <sup>191</sup> has been affirmed by the Supreme Court in relation to disability. <sup>192</sup> In Justice McIntyre's words, "the accommodation of differences ... is the essence of true equality." <sup>193</sup> More specifically, "recent *Charter* jurisprudence has affirmed the proposition that the government may owe a positive duty to ameliorate pre-existing disadvantage." <sup>194</sup> In relation to s.15(1), the Supreme Court has stated:

Section 15(1) ensures that governments may not, intentionally or **through a failure of appropriate accommodation**, stigmatize the underlying physical or mental impairment, or attribute functional limitations to the individual that the underlying physical or mental impairment does not entail ...<sup>195</sup> [emphasis added]

The concepts of discrimination and the duty to accommodate in the provision of services goes to the heart of one's ability to exercise legal capacity on an equal basis

with others; many important, and often life-altering decisions are made in the context of service provision. This includes decisions about health care where health professional services are provided, financial decisions, where banking services are provided and decisions about legal matters, where legal services are provided. Supreme Court of Canada jurisprudence has delved into the circumstances under which services must be provided in a non-discriminatory fashion in the context of s.15 of the *Charter*. These decisions are of particular relevance, therefore, in the context of legal duties to accommodate decision-making processes.

In *Eldridge* v. *British Columbia (Attorney General)*, <sup>196</sup> the Supreme Court of Canada compelled the equal provision of medical benefits. In this case the Court found that medical benefits were provided in a discriminatory fashion in that there was a failure to provide sign language interpreters for Deaf patients. The Court held that this failure violated s.15(1) of the *Charter* and that the appellants, who are Deaf, were not accommodated to the point of undue hardship. <sup>197</sup> Mr. Justice La Forest stated that the Supreme Court "…has repeatedly held that once the state does provide a benefit, it is obliged to do so in a non-discriminatory manner;" <sup>198</sup> and that "[i]n many circumstances, this will require governments to take positive action, for example by extending the scope of a benefit to a previously excluded class of persons". <sup>199</sup>

However, it is important to note that in the Canadian context access to a benefit that the law has not conferred has been treated differently by the Supreme Court with respect to the extent of the state's obligation to provide supports and reasonable accommodation. The parents of autistic children, in *Auton (Guardian ad litem of)* v. *British Columbia* 

(Attorney General), <sup>200</sup> alleged that the Province's failure to provide an emerging form of therapy constituted discrimination under s.15 of the *Charter*. Madam Chief Justice McLachlin distinguished this factual situation from that in *Eldridge*. She held that s.15 did not compel the government to provide such therapy because s.15's application was limited to ensuring that benefits already provided be conferred in a non-discriminatory manner. Madam Chief Justice McLachlin stated that while the goal of s.15(1) is to combat discrimination and ameliorate the position of disadvantaged groups, "[i]t's specific promise, however, is confined to benefits and burdens 'of the law'."<sup>201</sup> Because British Columbia's law did not provide the benefit that was being sought, s.15(1) was not violated.<sup>202</sup>

The duty to accommodate embodied in the *Charter* and human rights legislation provides a solid foundation for the proposition that there is a duty to accommodate and provide supports so that each person may exercise his/her legal capacity on an equal basis with others. However, the limits of the duty to accommodate such as articulated in *Auton*, along with the limitation imposed by the undue hardship standard, illustrate the ways in which the legal right to accommodations in Canadian law is limited. It may be that our current laws, thus, do not extend far enough to meet the full obligation to provide access to support in exercising legal capacity that is required of Article 12(3) of the CRPD. Our proposed contextualized duty to accommodate in relation to decision making, set out in the next two sections, is intended as a legislative and procedural approach to expand the duty in compliance with Article 12(3) and 5(3).

# D. Proposed Contextualized Duty to Accommodate in Relation to Decision Making

People whose capacity is in question are a historically disadvantaged group, justifying a comprehensive and easily enforced duty to accommodate. The duty to accommodate proposed in this paper is tailored and specific to the decision-making context. We argue that for people whose decision-making capability is in issue accommodations must always be a legal requirement. Embedding the duties of both the state and third parties directly in legislation is the only approach which will give full effect to the words and intention of Article 12(3) and Article 5(3) of the CRPD. The duties of both non-governmental third parties and the state to ensure accommodations must be engaged regardless of whether the activity is covered by specific human rights legislation or the *Charter*. While the duty must be a stand-alone one contained in legal capacity-specific legislation, the nature and extent of the duty would draw heavily upon human rights legislation, the *Charter* and the wealth of jurisprudence which articulates and interprets the duty.

Consistent with the values of non-discrimination and inclusion that our courts have upheld and guarded, the legal capacity-specific duty to accommodate must apply to all domains covered both by human rights laws and the *Charter*. This includes government and private actors in relation to areas of interaction such as goods, services, facilities, housing, contracts and employment. The nature and extent of the duty must be the same in all these situations. To do otherwise could result in arbitrarily differential treatment of people with disabilities, dependent on factors unrelated to the issues of decision-making ability and supports.

Positive steps must be taken at the outset of a transaction between parties, one of whom has a disability and is therefore owed a duty of accommodation, to ensure that people whose decision-making abilities are in question are given the opportunity to access the supports they need to demonstrate their decision-making capability. In this regard, according to the Supreme Court,

The principle that discrimination can accrue from a failure to take positive steps to ensure that disadvantaged groups benefit equally from services offered to the general public is widely accepted in the human rights field.<sup>203</sup>

This positive duty applies regardless of whether the individual is in a legally independent, supported or facilitated status. It may be impractical, and in fact discriminatory, not to provide/allow for the provision of supports at the beginning of a transaction, given the impact on the subsequent decision-making process for failing to do so.

For example, it is important to consider the very likely situation where a person with a disability is not given the opportunity of supports and accommodations at the *beginning* of a decision-making transaction. For example, a person with an intellectual disability may go to a physician with a medical issue and not actually understand and appreciate the nature and consequences of choosing a surgical intervention over a non-surgical one to deal with the issue. If the physician does not take the pro-active responsibility to inquire whether the person requires decision-making supports at the outset, the person may not avail him or herself of such supports and choose an option that the physician seems to recommend, without full understanding of the consequences. If the surgery option is decided upon, it may have life-long consequences that the individual did not wish and that could have been avoided had the decision been more in keeping with the

individual's actual wishes. Nonetheless, at this point, there is no monetary or other remedy that could reverse the non-pecuniary damage caused by the surgical intervention which was inconsistent with the decision the individual would have made with supports.

A duty to proactively inquire into the need for decision-making supports helps to avoid such outcomes. In addition, given that it may not always be apparent that decision-making ability is an issue, and that decision-making ability changes over time, there must be an ongoing duty to take positive steps to provide supports at any time where there are reasonable grounds to believe that supports may be necessary.

#### E. Duties of Third Parties and the State

The duty to accommodate is always a multi-party process and in relation to decision-making involves the person with the disability, third parties and the government. The third party with whom the interaction takes place owes the person with the disability a duty to reasonably accommodate them in the decision-making process. This may involve the simple act of respecting the supports as provided by the person. Or, it may require positive action on the part of the third party to provide those supports requested by the person. However, as the law has articulated, this duty is not unlimited. That is, it extends until the point of undue hardship.

But does access to needed supports stop at the point that non-governmental third parties experience undue hardship in accommodating a person in the decision-making process? The CRPD requires governments to take positive action to provide supports

for people with disabilities in the decision-making process. In this regard, Article 12 (3) of the CRPD states:

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

This paper proposes that all levels of government have a shared responsibility to assume duties in relation to the provision of such supports. The extent and nature of these supports may well extend beyond the duty to provide reasonable accommodation, as articulated in Canadian human rights laws and *Charter* jurisprudence. Conceptually, while the duty to accommodate and governments' duty to provide support overlap somewhat, they do differ in that governments' duty to provide support may extend beyond the limits of undue hardship where a government's role is relevant.

While it is our interpretation that governments' duty to provide supports extends beyond that of non-governmental third parties, we also note that it is not an unlimited duty in view of the modifying words, "appropriate measures", in Article 12(3) of the CRPD. Further, we note that Article 12(3) should be interpreted within the context of the CRPD as a whole, including Article 5(3) which requires states to take only "appropriate steps" to ensure reasonable accommodation. Thus, individuals' right to supports to exercise legal capacity does not impose an unlimited duty on the state.

Based on the analysis of the duty to accommodate as discussed above, and the obligations of governments under Article 12(3) and Article 5(3) we suggest the following set of principles and guidelines for managing the intersection of duties between the State and third parties in ensuring reasonable accommodation and supports for people with disabilities in decision-making processes.

- 1) People with a disability have a right to supports to assist in development, participation in community life, to enable access and to exercise legal capacity. The CRPD makes clear the obligation of the State to provide supports for people with disabilities, and these must be available to the person to enable them to enter transactions for the purpose of exercising their legal capacity.
- 2) Third parties have a duty to accommodate people with disabilities in transactions and decision-making processes. This means that third parties must:
  - accommodate whatever supports a person brings into the decisionmaking process; and
  - must provide additional supports, to the point of undue hardship, to enable the person to exercise legal capacity in a manner that maximizes their autonomy.
- 3) Individuals wishing to make decisions, their representatives, and third parties may require assistance in determining appropriate supports and accommodations, and in making needed arrangements to access them. A community-based resource centre is required to provide individuals, their representatives and/or third parties a place to go for information and assistance in determining support and accommodation needs, and in making needed arrangements. Assessment of needed supports and accommodations should be decision-specific, and cannot be based on disability status. The focus of the assessment is to determine what supports

- the individual requires to make their own decisions either independently or with the support of others.
- 4) Where additional supports are required in order to maximize the exercise and enjoyment of legal capacity beyond what the person brings to the decisionmaking process, and beyond what a third party can reasonably provide as an accommodation, governments have an obligation in accordance with the CRPD to provide such measures. These should include the following activities:
  - maintain an office dedicated solely to assisting people to access supports;
  - provide information and resources to people with disabilities and third parties outlining the types of supports that may be of benefit along with practical mechanisms for putting the supports into practice;
  - provide funding for supports to people whose decision-making capability is in question and who are in need of supports; and,
  - maintain a registry of planning documents (e.g. representation agreements) which name supporters.

In the next section we explore how disputes with respect to managing the duty to accommodate can be addressed as part of a system for safeguarding the integrity of the decision-making process.

## V. SAFEGUARDING DECISION-MAKING PROCESSES AND THE RIGHT TO LEGAL CAPACITY

In this and the next two sections we highlight a number of risks that a legal, policy and practice framework to support the exercise of legal capacity must account for. We suggest that an institutional framework for safeguarding decision-making processes that enhances, protects and promotes an equal right to legal capacity should be based on three guiding principles:

- Respect for autonomy in decision-making
- Respect for personal dignity
- Safety and the duty to protect

The CRPD recognition of the right to legal capacity without discrimination on the basis of disability requires a re-balancing of these principles in the direction of maximizing autonomy, and preventing the traditionally paternalistic approaches towards people with disabilities and older adults in the name of safety and protection. Safeguards are necessary to promote the integrity and utility of each of the decision-making statuses to ensure that people are not unnecessarily denied a decision-making status that would more effectively enable them to enjoy and exercise their legal capacity. Moreover, there may be a particularly high risk of abuse when the person has a disability or is an older adult as isolation and/or limited financial and other resources often come into play with these groups.

Safeguards must be designed to protect and respect the integrity of all aspects of decision-making. They must also take into account the overarching principles which guide our framework, being respect for autonomy, respect for personal dignity and

protection against abuse and neglect. In order to promote and protect legal capacity without discrimination on the basis of disability, there are four main areas to be safeguarded:

- Safeguarding the integrity of the decision-making process
- Safeguards to ensure appropriate decision-making status is recognized, accommodated and supported
- Safeguards where decisions fundamentally affect personal integrity
- Safeguarding against serious adverse effects, including neglect and abuse

In this section we address the first three areas of safeguards. Given the particular complexity of safeguarding against serious adverse effects and at the same time respecting the right to legal capacity without discrimination, we devote the next section to this area on its own.

### A. Proposed Institutional Framework for Safeguarding Integrity of Decisionmaking Processes

We propose eight main features of a system to safeguard the integrity of decisionmaking processes that maximize exercise and enjoyment of the right to legal capacity without discrimination on the basis of disability:

1. Legislated Framework for Legal Capacity and Decision-making Supports

The CRPD recognizes a right to legal capacity, and the obligation of States Parties to
ensure supports are available to exercise legal capacity. Indeed many other Articles in
the CRPD reference State Parties obligations to provide for needed supports to realize
recognized rights. A legislative framework outlining supports and services benefits

would give full effect to these obligations. Ideally, a legislative framework would mandate provision of supports needed for people to exercise legal capacity, and would provide for the institutional framework outlined in this section. A legislative mandate for these supports would also give effect to the interdependence we outline in the previous section between third party duties to accommodate in decision-making processes, and the role of governments to make reasonable efforts in providing supports beyond the point of undue hardship to these parties. In the Canadian context, such legislation would likely fall primarily within the powers of provincial and territorial governments.

- Legislated Duties and Liability of Representatives and Facilitators
   Representatives and facilitators are in a fiduciary relationship with the person. Essential duties of representatives and facilitators include:
  - · Act diligently, honestly and in good faith;
  - Act in accordance with all applicable legislation and any Administrative Tribunal orders;
  - Act in accordance with any relevant agreements;
  - Keep information about the adult, and his/her affairs, confidential;
  - Keep records in relation to all aspects of their role; and,
  - Involve supportive family members and friends.

In the British Columbia *Representation Agreement Act* representatives who comply with the legislated duties would not be liable "for injury to or death of the adult or for loss or damage to the adult's financial affairs, business or assets.<sup>204</sup> We recommend comparable but more expansive protections and recommend the following language:

Representatives and facilitators who comply with all legislated duties would not be liable for any injury death, loss or damage that results from actions they have taken in their role as representatives or facilitators.

#### 3. Monitors

A monitor is a person whose role would be to protect the decision-making rights of the adult and oversee the work of the representative or facilitator. More specifically, monitors must ensure that the representative or facilitator complies with all legal duties expected of them. They can be appointed by the one who creates the role of representative/facilitator. This will usually be either the person whose decision-making status is affected or the Administrative Tribunal (outlined below).

Monitors should be required to make reasonable efforts to determine whether the representative or facilitator is complying with their legal duties. Monitors may require the representative or facilitator to produce accounts and records. If the monitor finds wrongdoing, either intentional or not, he/she should make all attempts to resolve it with the representative/facilitator and the person. However, if these efforts fail, resort should be had to the Administrative Tribunal, whose job it will be to adjudicate such disputes.

The monitor role could be modeled after that created in British Columbia's Representation Agreement Act, <sup>205</sup> with necessary modifications, taking into account the successes and limitations of that system.

#### 4. Community-based Resource Centre

People whose decision-making status is in issue, as well as third parties with whom they interact, require a resource to provide information and assistance with the practicalities of the accommodation process and accessing of supports. To this end, a community based resource centre must be established in legislation. It should be government funded but at arm's length, and run by a board of directors, the majority of whom are people with disabilities. The Nidus Personal Planning Resource Centre and Registry<sup>206</sup> in British Columbia is an example of such a resource centre. However, its role and impact are limited by the absence of legislative authority for its existence.

An important role for the Resource Centre would be to create and maintain a registration system. The system would keep track of every supported and facilitated decision-making arrangement in existence, including names of representatives, facilitators and monitors. This allows third parties to satisfy themselves that people who are acting as representatives or facilitators, *prima facie*, have legitimate authority to do so.

#### Examples of registration systems are:

- Nidus Personal Planning Resource Centre and Registry in British Columbia operates a centralized registry for representation agreements and enduring powers of attorney (<u>www.nidus.ca</u>); and
- Registration systems in Quebec. There are two types of Quebec mandates
   (planning documents). "Notarized mandates" are registered with the
   Chambre des notaries (<a href="http://www.cdnq.org">http://www.cdnq.org</a>) and registration of "mandates

before witnesses" is done with the Barreau du Quebec's Registre des mandats.

### 5. Legal Capacity and Support Office

It is not an uncommon experience for people with disabilities and older adults to experience isolation and abuse. A Legal Capacity and Support Office must exist to address these concerns. It would have a dual role, not dissimilar to some roles of Ontario's Public Guardian and Trustee. It would be required to investigate allegations of serious adverse effects as defined in Section VI.A below as well as act as a facilitator or monitor of last resort. Each of these roles would be undertaken in conjunction with appropriate input and direction from the Administrative Tribunal. One role of the Legal Capacity and Support Office will be to arrange for supports as needed to address situations where serious adverse effects are occurring or may occur and there is reason to believe that a person's ability to make and/or act on their decisions will be enhanced by such supports.

- 6. Administrative Tribunal with a Focus exclusively on Decision-Making

  The role of the Administrative Tribunal would be to have exclusive jurisdiction over decision-making cases. The Tribunal could give direction on any question related to a person's decision-making status, or role of other persons in relation to that status, including where questions or issues were raised related to:
  - Duty to accommodate;
  - State provision of supports;
  - Decision-making status;

- The appointment of supporters and facilitators the Administrative Tribunal
  would have authority to appoint supporters and facilitators, adjudicate any
  conflicts about whether one or more persons should be appointed in this
  capacity instead of others, and hear any matter to informal appointment of
  supporters;
- The appointment of monitors where the Administrative Tribunal determines
  that supporters or facilitators are not meeting their legal obligations, it should
  have the power to appoint monitors;
- Applications to approve and recognize people wishing to act as supporters;
- Decisions fundamentally affecting people's personal integrity (for people in the supported status).

In summary, the Administrative Tribunal would adjudicate in disputes over what type of support is required; whether reasonable accommodations have in fact been made; and the status through which a person should be empowered to exercise their legal capacity. As well, it would be empowered to make judgments in cases where representational support is required to exercise legal capacity, and there is dispute over who will provide that representational support if the person is not able to indicate a choice in ways that others understand. The extent to which an Administrative Tribunal, in the context of administrative law in Canada, could compel private entities as well as the government to provide accommodations and/or supports requires further analysis. The scope of its mandate would likely need to be laid out in a related statute. 207

While some of the concerns the Tribunal would be mandated to address may be pursued by launching human rights complaints/applications or pursuing remedies for *Charter* violations in court, the Tribunal would provide for a more comprehensive remedial scheme specifically tailored to the decision-making context. Human rights and *Charter* remedies can be time consuming and expensive to pursue. Decisions about the most fundamental aspects of people's lives cannot be held up waiting for processes and decisions by slow moving court and tribunal processes. This is particularly so because litigation involving people whose capacity is in question has its own unique complexities.

Any remedial process, like that provided by an Administrative Tribunal, must take into account the inevitable barriers that people with intellectual, cognitive and/or psychosocial disabilities experience in pursuing legal avenues. A host of barriers have been documented in relation to both courts and administrative tribunals. These include difficulty understanding court/tribunal processes, lack of accommodation during the hearing and having the very right of their participation challenged on the basis of alleged incapacity. <sup>209</sup>

For example, access to remedies for a breach of the duty to accommodate in the decision-making process must not pose a further barrier for people with disabilities to make their own decisions. A remedial process must be established which does not require the person with the disability to expend an inordinate amount of time or money to prove his/her right to make his/her own decisions. There must be an expeditious, fair and accessible method of adjudicating and resolving disputes about supports. This

must require that a dispute resolution mechanism (e.g. adjudicative hearing or mediation) be activated almost immediately. Ontario's Consent and Capacity Board adjudicates consent and capacity issues and should be explored to determine the applicability of its model.

The Administrative Tribunal would be legislatively created. Because the cases in the Administrative Tribunal's mandate impact upon the core values of liberty and autonomy, its decisions must be reviewable. The Tribunal should approach cases in a manner that maximizes an individual's legal capacity. For example, if there is concern about supporters or facilitators breaching their fiduciary duties, an initial approach might be to require relationship-building supports to strengthen the supported decision-making relationship. However, if there is an intentional breach of fiduciary duties, an alternative support arrangement is required. Thus, the Administrative Tribunal would have to have a wide degree of latitude to deal with each case on its own facts with a goal to promoting autonomy as much as possible. This relies on highly skilled and knowledgeable tribunal members, who have training in capacity issues and experience with people with disabilities and older adults.

Mediation is often an effective dispute resolution mechanism. It is more informal and expeditious than a tribunal process. It has the potential to more effectively preserve existing relationships between the person and representatives/facilitators. These relationships are often built on trust and close personal relationships, and every effort should be made to encourage and support them. Thus, mandatory mediation should be part of the Administrative Tribunal process.

#### 7. Access to Legal Counsel

Any decision-making status other than that of being legally independent necessitates the involvement of other people in an individual's life, people whose actions can have a significant impact on their lives. While the Administrative Tribunal described above is a necessary safeguard, the safeguard is only of significance to the extent that it is used. As the Administrative Tribunal is a legal forum, people whose decision-making status is in issue should have access to that forum; access must not be impeded by their inability to access and/or pay for a lawyer. Thus, state funding must be available to hire a lawyer, should an individual be unable to pay.

#### 8. Formal Advocate

Independent advocacy is an important aspect of an individual's right to make their own decisions. In general, advocates can assist the individual in expressing their wishes and inform other parties of the individual's rights, and of their corresponding duties. The roles played by the advocate could include the following:

- Provide advice in relation to decision-making statuses that may be of relevance to the person;
- Provide information to an individual in relation to legal processes and options where there is a capacity issue;
- Explain to an individual who is the subject of a capacity proceeding the nature and implications of the proceeding, including explaining the significance of any possible orders or consequences;

Support individuals who are in the supported or facilitated status, including assisting the person to address neglect and abuse by the representative or facilitator.

## B. Safeguards to Ensure Appropriate Decision-making Status is Recognized, Accommodated and Supported

There may be times when parties in a decision-making process disagree about the decision-making status through which a person should exercise their legal capacity. For example, a person with an intellectual disability may wish to make a health care decision on his or her own – i.e. to act legally independently in this decision. The physician may believe the person is unable to do so and that he/she requires representational support and a supported decision-making status. However, the person and his/her advocate may believe the person requires only interpretive assistance and plainer language about the procedure in question.

A person should have access to necessary appeal processes for this determination, because what is at stake is their right to act legally independently – without support from others in a representational role. The defense of other parties in such appeal processes may be that they have provided reasonable accommodations and are still not satisfied that the person, on his or her own, is able to understand and appreciate the consequences of the decision; and that representational supports are required. This may raise questions of whether the government has fulfilled its responsibility to provide supports for decision-making beyond the point of undue hardship on the part of the third party.

There are likely to be other challenging situations which call for a determination of a person's decision-making status, for example, where a person's actions and communication indicate intentional behaviour which places the individual and/or others at substantial risk of harm. If others are seeking to have a person designated in a facilitated status because they believe the person's behavior is in conflict with his or her own will, intentions or other expressed desires, the safeguards outlined below will be particularly important to follow. The challenge here is whether it can be reasonably claimed that a person's actions and intentions are in conflict with what others know about their will as it has been demonstrated in the past.

Where there are disputes about the decision-making status through which a person will exercise their legal capacity, the Legal Capacity and Support Office must provide timely and accessible information, mediation and dispute resolution mechanisms. Where these are not satisfactory to resolve the dispute, parties may take their disputes to the Administrative Tribunal. The Tribunal should be mandated to make determinations about decision-making status, and related reasonable accommodations and supports required. Individuals must be provided legal counsel and any other needed supports in order to access and participate in these processes.

In making status determinations, especially about whether someone should be in a facilitated status, the Administrative Tribunal must adhere to strict safeguards to protect against erroneous or discriminatory allocation of this status. Safeguards should include the following:

- 1) Any status determination must begin with a presumption of legal independence as defined above. Where a party seeks to rebut this presumption, inquiry must be made into whether third parties and governments have met their obligations to provide reasonable accommodations and supports to assist a person in exercising their legal capacity.
- 2) If the Tribunal is not satisfied that reasonable accommodations and efforts have been made by third parties and governments, then it would order remedies to that effect; and require implementation and assessment of those remedies prior to making a determination that the person cannot act legally independently.
- 3) If there is reasonable evidence to rebut the presumption of legal independence, and the Tribunal is satisfied that reasonable accommodation and effort has been made by third parties and governments to provide supports for decision making in a legally independent status, a presumption exists that the person meets the criterion for supported decision-making status as defined above.
- 4) If the Tribunal makes a finding that a person cannot act in a legally independent status, it shall not determine that the person is in a facilitated status unless it is satisfied that:
  - o no reasonable accommodations and support arrangements could currently be established that would enable a person to meet the minimum threshold for supported decision making; and

- that the person would benefit from having decisions made through a facilitated status.<sup>210</sup>
- 5) If the Tribunal is not satisfied that reasonable accommodations and supports have been provided, then it would order remedies to that effect, as above, and not make a determination that a person can only act through a facilitated status until their efficacy was assessed.
- 6) Status determinations must afford the person being assessed the opportunity to involve their supports in any manner and to any extent necessary to accommodate his/her ability to participate in the assessment. The right to access supports in this manner was articulated in *Koch (Re)*.<sup>211</sup>
- 7) Status determinations must afford a person the right to have a lawyer present at the assessment, and be advised of that right.
- 8) Prior to undertaking a status determination, the person must be advised of the purpose of the assessment, the significance and effect of a status finding, and depending on the circumstances, the person's right to refuse to be assessed (see, for example, Ontario's *Substitute Decisions Act*, s. 78(2)<sup>212</sup>).
- 9) Objective and disability-sensitive guidelines must be created and legislatively entrenched with which all status assessments must comply.<sup>213</sup>
- 10) Upon the determination that a person should be placed in a facilitated status, the State has an obligation to invest in supports that assist the person to develop personal support relationships sufficient to act in a supported decision-making or legally independent status at some point in the future.
  Periodic reviews must be established to determine whether adequate

investment is being made in developing such relationships, and whether a person should remain in a facilitated status.

#### C. Safeguards Where Decisions Fundamentally Affect Personal Integrity

Some decisions are considered by people with disabilities, their families and/or advocates to raise particular risk of abuse and exploitation because they so fundamentally affect personal integrity. Such decisions may include non-therapeutic sterilization, non-therapeutic abortion, cochlear implant surgery, non-therapeutic plastic surgery, sex re-assignment surgery, assisted suicide (in jurisdictions that provide for this), etc. The list of these types of decisions is not fixed, and certainly evolves over time.

Should people with disabilities who exercise their legal capacity through other types of decision-making status than legally independent status, be denied the opportunity to make these decisions? Is the risk of exploitation too high? The opportunity to make these decisions should not, by definition, be excluded from people with disabilities who make them by a supported status. However, where people exercising their capacity through this status wish to consider these types of decisions, the decisions should be reviewed by the Administrative Tribunal given the risks for exploitation and abuse. The Tribunal must be confident that persons making what are considered high risk decisions that significantly affect personal integrity are making them with free and informed consent even if with the assistance of a supported decision-making representative. For these types of decisions, in a supported status, monitors, too, play an important safeguarding role. Monitors appointed as part of the creation of a support mechanism

could review such decisions in an effort to determine whether the individual's intention is accurately being interpreted and expressed by the representative.

Because of the risks of misinterpretation of a person's will and/or intention for those who exercise their legal capacity through facilitated decision-making, decisions that substantially affect personal integrity like those listed above, should never be legally permitted to be facilitated for persons in this decision-making status.

## VI. PROTECTING AUTONOMY AND THE EQUAL RIGHT TO LEGAL CAPACITY IN THE FACE OF SERIOUS ADVERSE EFFECTS

People with disabilities and older adults face disproportionately high rates of abuse and neglect. The traditional approach to safeguarding against abuse and neglect for this group is to define them as 'vulnerable' or in need of protection, based on their demographic characteristics. This has led in many instances to an overly-paternalistic approach which has undermined individual autonomy. Our assessment is that current adult protection and mental health laws do not effectively meet the needs of people with disabilities and older adults in preventing and protecting against abuse and neglect, while at the same time promoting their full right to legal capacity.

H. Archibald Kaiser argues that, consistent with the social model of disability, the focus of mental health statutes must shift from coercion to the provision of supports and services. More specifically, we identify three main failures of legal frameworks and service delivery systems in relation to mental health services and in cases involving abuse and neglect. These cases pose particular risks to the equal exercise and enjoyment of autonomy and legal capacity for people with disabilities who may be at risk of or cause harm to themselves or others:

- There are significant gaps in access to and availability of appropriate community-based supports for people with intellectual, cognitive and/or psychosocial disabilities. Unfortunately, solely because of a lack of such supports, many people end up in institutional care and/or, under current mental health laws, involuntarily placed in a psychiatric facility. Both of these options, in our assessment, unduly restrict autonomy in the name of protection of individuals and the public.
- There is a lack of appropriate safeguards to ensure that in situations of abuse, neglect, or harm to oneself or others, appropriate supports are provided and that procedures are in place to ensure responses that more effectively balance autonomy and protection interests.
- Mental health law and service delivery are largely discriminatory in light of the CRPD. That is, assessment of a 'mental disorder' is systematically used in legislative frameworks and service delivery to make determinations that restrict legal capacity. These provisions and practices violate the CRPD requirements to recognize and protect the right to legal capacity without discrimination on the basis of disability. Under the CRPD, disability cannot be used as a justification for restricting liberty and autonomy.

This section outlines a definitional and institutional framework to address these issues, grounded in a re-evaluation of current adult protection and mental health laws.

#### A. Definition of Serious Adverse Effects and Who is Affected

While the terms 'abuse' and 'neglect' are used to describe the experience of people with disabilities and older adults, the terms are not concrete nor specific enough to guide interventions related to decision-making supports and exercise of legal capacity. Thus we have decided to use the term found in Ontario's *Substitute Decisions Act* for the purposes of describing when and how interventions should be triggered. The term used in the *Act* is "serious adverse effects." This term has the advantage of not confusing presumed intent with outcome; that is, the focus is on what the person actually experiences. As well, it does not trigger interventions on the basis of presumed risk in a situation, as mental health law usually does, without evidence that actual effects are occurring or may occur as a result. In these ways, the term "serious adverse effects" constrains the discretion for intervention that many other terms allow, and thus more effectively protects autonomy. The challenge is to develop a scheme of safeguards guided by this trigger that at the same time protect against what are unacceptably high rates of abuse and neglect of older adults and people with disabilities.

'Serious adverse effects' is defined in Ontario's *Substitute Decisions Act* in relation to both property and personal care. The definitions address two situations as follows:

- Loss of a significant part of a person's property, or a person's failure to provide necessities of life for himself or herself or for dependants<sup>216</sup>
- Serious illness or injury, or deprivation of liberty or personal security<sup>217</sup>
  We would enhance the definition of serious adverse effects to include the criteria currently in Ontario's *Mental Health Act* for involuntary committal to a facility for the purposes of psychiatric assessment. Subection 15(1) of the *Act* states:

Where a physician examines a person and has reasonable cause to believe that the person,

- (a) has threatened or attempted or is threatening or attempting to cause bodily harm to himself or herself;
- (b) has behaved or is behaving violently towards another person or has caused or is causing another person to fear bodily harm from him or her; or
- (c) has shown or is showing a lack of competence to care for himself or herself,

and if in addition the physician is of the opinion that the person is apparently suffering from mental disorder of a nature or quality that likely will result in,

- (d) serious bodily harm to the person;
- (e) serious bodily harm to another person; or
- (f) serious physical impairment of the person,

the physician may make application in the prescribed form for a psychiatric assessment of the person. <sup>218</sup>

Drawing on the criteria in these two statutes<sup>219</sup>, and with some revisions, we suggest a definition of serious adverse effects as follows:

A situation of serious adverse effects occurs when a person, as a result of his/her actions or those of others:

- a) Experiences loss of a significant part of a person's property, or a person's failure to provide necessities of life for himself or herself or for dependants; or
- Experiences serious illness or injury, and deprivation of liberty or personal security; or
- c) Has threatened or attempted or is threatening or attempting to cause physical and/or psychological harm to himself or herself; or
- d) Has behaved or is behaving violently towards another person or has caused or is causing another person to fear physical and/or psychological harm from him or her.

According to this definition serious adverse effects can attach to the individual in question as well as to others who are directly involved in the situation: people who experience harm as a result of an individual's actions; people who are attempting to support the individual; and/or people who are otherwise directly affected by the situation. Responses and interventions to situations of serious adverse effects should take all of these individuals into account, while at the same time assuring the legal capacity of the individual in question.

# B. Adult Protection and Mental Health Laws: A Re-Evaluation of Current Responses to Serious Adverse Effects

In determining the appropriate framework for addressing situations of serious adverse effects, the principles of respect for choice and personal dignity, including rights to privacy and dignity of risk, always need to be balanced with the duty to ensure safety. However, the balancing of these principles in both adult protection and mental health laws often tilts much too far in the direction of paternalism. The framework we present here is meant to redress this imbalance.

The historical approach to safeguarding against abuse and neglect for people with disabilities and older adults has been to define these groups as in need of protection.

Abuse and neglect legislation was designed to allow the state to intervene to take care of people. In general, it allows for state intervention in an adult's life to provide a range of health, social and other services. This has led in many instances to an overly-paternalistic approach which has undermined individual autonomy. In the words of the Supreme Court of Canada, "[t]he corollary of a judicial determination that an adult

is in need of protection is a corresponding limitation on that adult's autonomous decision making and liberty.<sup>222</sup>

Nonetheless, abuse and neglect legislation has evolved in Canada over time, since its introduction in the 1970s.<sup>223</sup> While a 'protectionist model' still exists,<sup>224</sup> models in some jurisdictions focus more on an adult's right to live at risk.<sup>225</sup> While some laws address abuse and neglect in comprehensive, discrete legislation, others are more limited in scope.<sup>226</sup>

An example of overly paternalistic adult protection legislation is Nova Scotia's *Adult Protection Act*, which is based on a best interests model.<sup>227</sup> Subsection 9(3) is illustrative and states as follows:

Where the court finds, upon the hearing of the application, that a person is an adult in need of protection and either

- (a) is not mentally competent to decide whether or not to accept the assistance of the Minister: or
- (b) is refusing the assistance by reason of duress,

the court shall so declare and may, where it appears to the court to be in the best interest of that person,

(c) make an order authorizing the Minister to provide the adult with services, including placement in a facility approved by the Minister, which will enhance the ability of the adult to care and fend adequately for himself or which will protect the adult from abuse or neglect.

The concern about the above provision is that there is no definition of 'mentally competent' and nor is there any indication of how 'mentally competent' is to be assessed or what the test is. There is no mention of the role of supports in enhancing the person's ability to address the situation without the intrusion of the Minister. On its face, such legislation does not appear to be consistent with Article 12 of the CRPD.

Ontario's approach to abuse and neglect tips the scale more in the direction of safeguarding autonomy. However, its shortfall is the absence of legally mandated supports. Thus, it too is not consistent with Article 12 of the CRPD. Ontario has no specific abuse and neglect legislation. Instead, Ontario's 'adult protection' scheme is contained in its substitute decision-making laws (the *Substitute Decisions Act*). The Public Guardian and Trustee has the responsibility to investigate situations where an individual is alleged to be incapable and serious adverse effects are occurring or may occur. The Public Guardian and Trustee may apply to the court for temporary guardianship. However, the role of the Public Guardian and Trustee, in contrast to comprehensive adult protection legislation, does not involve the provision of health and social services.

In general, as Robert Gordon has observed, "Canadian adult protection legislation and adult protection systems, particularly those found in the Atlantic provinces, have been subjected to critical analysis and commentary." Our assessment is that there is much room for reform and improvement of our laws that address abuse and neglect so as to give prominence to the role of the panoply of supports and to promote the full right to legal capacity to the maximum extent possible.

Mental health and capacity laws have long been associated with one another. With respect to Ontario's *Mental Health Act*, <sup>230</sup> and many other mental health laws in Canada and in jurisdictions around the world, similar concerns about the undermining of autonomy have been raised by ethicists, practitioners, legal experts, and consumer advocates. The primary concern and critique relates to the provisions for involuntary

admission. Pursuant to Ontario's *Mental Health Act* a person with a 'mental disorder' can be involuntarily admitted to a psychiatric facility if several conditions are met. The conditions relate to the person causing harm to him/herself or others or a lack of competence to care for him/herself in terms of both past behavior and future risk.

Various rationales have been articulated justifying involuntary hospitalization of people with psychosocial disabilities. These include the protection of society from harm and the state's power to help those who cannot help themselves. As each of these justifications result in removing a person's right to make their own decisions regarding psychiatric intervention, they must be balanced against the right to autonomy and self-determination. The evolution of mental health laws in Ontario has illustrated many attempts to strike an appropriate balance, with some skepticism voiced as to whether this will ever be possible. As these laws have evolved over time, there has been an increasing recognition of the need to tailor them in the direction of promoting personal rights.

With the ratification of the CRPD, we are forced to re-think the philosophical underpinnings of our mental health laws, and whether their purposes are justifiable. More concretely, we must assess whether they conform with the CRPD. There is renewed interest in reformulating mental health laws as there have been sweeping accusations that they are not in conformity with the CRPD. These accusations have perhaps been expressed most strongly by the World Network of Users and Survivors of Psychiatry ("Network") and are set out in detail in an Implementation Manual the Network prepared in relation to the CRPD. While the analysis set out in the

Implementation Manual is of relevance, it must be interpreted in the context of the laws of each province/territory in Canada.

Several articles of the CRPD have been cited for calling into question mental health laws. These include articles relating to non-discrimination (Article 5), legal capacity (Article 12), liberty (Article 14), physical and mental integrity (Article 17) and torture or cruel, inhuman or degrading treatment (Article 15).

Article 14 in relation to liberty and security of the person is of particular significance.

Most importantly, paragraph 1(b) states as follows:

States Parties shall ensure that persons with disabilities, on an equal basis with others:

(b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty. [emphasis added]

Mental health commitment laws rely on disability (i.e. mental disorder) as an essential determining factor for involuntary hospitalization. As such, disability is used to justify deprivation of liberty and is therefore in violation of Article 14. Peter Bartlett has expressed the view that by virtue of Article 14(1)(b) "... much of the existing Ontario *Mental Health Act* is in violation" of the CRPD. <sup>239</sup> For a similar reason, Ontario's involuntary hospitalization provisions violate the non-discrimination article (Article 5), which prohibits all discrimination on the basis of disability. In relation to Article 5, Bartlett goes on to say the following: "We do not lock up other people on the basis of prospective dangerousness, even when there is cogent statistical evidence of their dangerousness: why would we do so with people with mental disorder?" <sup>240</sup>

Enjoying legal capacity on an equal basis with others consistent with Article 12 recognizes a person's right to make decisions and have those decisions respected. It is difficult to see how imposed psychiatric intervention on people with psychosocial disabilities respects their right to make their own decisions. Involuntary hospitalization, thus appears to violate Article 12. Consistent with Article 12, decisions about whether to go to hospital should only be made by people themselves (with or without the assistance of supporters) or by facilitators, not by physicians. If these decisions are made by physicians instead, people are deprived of their right to exercise legal capacity on an equal basis with others.<sup>241</sup> This raises the question: how should mental health laws be designed so that people's right to exercise legal capacity on an equal basis with others is respected?

Commentary has raised the possibility of fusing mental health and capacity laws in an attempt to address discriminatory mental health laws. Thus, incapacity would be a criterion for involuntary psychiatric intervention. However, to say that it is acceptable to force psychiatric interventions on the basis of incapacity, rather than mental disorder, in our view, does nothing to lessen the loss of autonomy associated with our mental health laws. People with disabilities have a right to exercise legal capacity on an equal basis with others.

The recommendations for reform of adult protection, mental health law, policy and practice which follow are consistent with the approach to legal capacity we set out in this paper, and more effectively, we believe, respect autonomy of people with disabilities. The scheme of decision-making we propose in this paper allows for

decisions for admittance to a medical facility for psychiatric assessment and/or treatment to be made either by individuals themselves in a legally independent status, or by individuals with their support representatives for those in a supported decision-making status, but only where the individual indicates in usual ways their acceptance of this decision. Individuals in a facilitated status can be admitted for psychiatric assessment and/or treatment at the request of facilitators with certain safeguards. Such safeguards are required to protect autonomy interests of individuals. Our scheme removes the authority of physicians to involuntarily commit individuals to psychiatric facilities.

#### C. An Institutional Framework for Addressing Serious Adverse Effects

Informed by the above analysis of adult protection and mental health law, we recommend that developing safeguards to address serious adverse effects should be guided by three foundational principles. Firstly, respect for choice, personal dignity and integrity must be appropriately balanced against safety. In doing so, it must be clear that measures to prevent and protect against serious adverse effects do not undermine respect for personal choice and personal dignity and integrity. Secondly, individuals must have access to the supports they require to exercise their legal capacity in situations of serious adverse effects. Thirdly, the assessment of serious adverse effects must not be applied in a discriminatory manner. When a person with a disability finds him/herself in the same situation as a person without a disability, the law should treat each of them in the same manner. We must guard against the impulse to intervene when a person with a disability's lifestyle does not accord with 'social norms'. When a

person has a disability, there is often a tendency to view him/her as in need of protection and to cite behavior with which one does not agree as evidence of incapacity.

The approach to serious adverse effects should apply to everyone equally, and not establish a set of obligations that apply only to those who meet some disability-related criterion. It must recognize every adult's right to live at risk and make individual choices.

Based on these principles, a framework of law, policy and service delivery for mental health services and adult protection must be established to address serious adverse effects that promotes and appropriately balances both autonomy and safety. At the same time it must protect against discrimination on the basis of disability. We propose that such a framework would involve roles for our proposed Legal Capacity and Support Office and Administrative Tribunal, as well as legal counsel for those whose cases are brought to the Administrative Tribunal, independent advocates, and monitors for those in a supported or facilitated decision-making status.

1. Legal Capacity And Support Office: Investigations, Assessment of Support Needs, and Arranging Supports

The Legal Capacity and Support office would have the authority to investigate concerns, complaints, and allegations of serious adverse effects in situations where individuals are in a supported or facilitated decision-making status, or where there are reasonable grounds to indicate that a person is unable to act legally independently. In conducting these investigations, the Office may find that a person is unable to maximize their legal capacity through their current decision-making status, and may seek direction from the Administrative Tribunal relating to the appropriateness of the person's status.

The Legal Capacity and Support Office would also have a duty to intervene first to offer an assessment of support needs to the individual in question and to others involved; and second where such assessments are conducted, to offer and arrange needed supports as agreed to by the individuals involved. The assessment and provision would address two forms of supports: community resources and decision-making supports.

1) Community Resources – All too often, people with disabilities find themselves in unsafe situations, not because of incapacity, but because of the inadequacy of community supports. For example, a person with a disability who lives in specialized housing where government funded personal support assistance is provided may be experiencing abuse by a personal support worker. Her preferred solution may be to move to another housing complex to remove herself from the abusive situation, rather than taking direct action against the abuser. However, this would not be possible if there is no other support option available to her. Continuing to live in abuse may be the result, not of an incapably made decision, but rather because of a lack of community support alternatives in the form of personal support assistance.

Thus, maximizing a person's autonomy while minimizing serious adverse effects, requires that a sufficient supply and range of community resources be made available, especially to populations who have been historically subject to abuse and neglect. Community resources would assist individuals in coping with or removing themselves from their situation. This may involve supports in the provision of basic needs, such as assisting them to find a safe

place to stay, to find protection from potential abusers, and to obtain necessaries of life (such as food and clothing). Interviews conducted and literature reviewed for this paper on mental health systems, suggest it is the failure of adequate community supports and services that usually results in involuntary commitment to psychiatric facilities for assessment and/or treatment, depending on the jurisdiction.<sup>243</sup>

2) Decision-making Supports – Decision-making support must be available to enable a person to make his/her own decision about what to do in the face of serious adverse effects. For example, the person may benefit from life planning assistance, independent advocacy or relationship building support. The nature and types of decision-making supports is the same as those discussed more fully above. For example, consider an adult with an intellectual disability who lives with her brother. Her brother allows her only to be in the basement, which is rat-infested and has no access to hot water. He gives her small amounts of food, but she is always hungry and weak. She knows she is unhappy, and with the assistance of her support circle, understands the risks that she is taking by living with her brother. Her support circle assists her to decide to move out to a safer place, and helps her take the necessary action to do so.

The following is an example of where both types of supports come into view. Consider a couple's young adult son who develops a psychosocial disability. As he becomes more and more isolated, he displays behavior his parents do not understand, and

begins to become more aggressive and even threatening to the parents. The parents find themselves unable to cope. Their son refuses to see a doctor, is increasingly paranoid and the parents worry for his and their safety. Nonetheless, the son is clear about what he will do and not do. Both the son and the parents are experiencing serious adverse effects. While the son may refuse any support, the parents require intensive planning support to develop options, which may include arranging for a 'safe home' in the community that the son agrees to move to; or an advocate he trusts. While the parents may wish to have him receive psychiatric treatment, his refusal to do so should be respected. However, it should not mean the end of searching for alternative, effective support options. In this example, the necessary types of supports include: decision-making supports (planning supports for the parents, and independent advocate for the son) and community resources in the form of a safe house or other option.

The Legal Capacity and Support Office and the Community Based Resource Centre should be mandated to act collaboratively to intervene to offer and help arrange both types of support to those who are experiencing serious adverse effects.

At some point, however, the parents may perceive the son's condition as deteriorating to the extent that he can no longer express his will and/or intentions in ways that would direct reasonable consequential action. At that point, the parents may apply to the Tribunal for a determination about whether he is, in fact, in a facilitated status. If the Tribunal makes such a determination, and further that the parents should be appointed as facilitators, the parents could seek to admit their son to a psychiatric facility for assessment and/or treatment. Alternatively, the Tribunal could consider appointing

other facilitators if it was determined the parents were not suitable to play this role given familial history, or because the adult son had indicated wishes for others to provide that facilitation. In any event, if the son refuses admission, he would have the opportunity to appear before the Tribunal with an independent advocate and counsel to challenge the determination that he was in a facilitated status.

#### 2. Role of the Administrative Tribunal

The Administrative Tribunal, upon recommendations from the Legal Capacity and Support Office, would make determinations about an individual's decision-making status and authorize, within its mandate, accommodations and/or state provision of needed supports. Legal counsel and independent advocates would be made available to those whose cases are investigated by the Legal Capacity and Support Office and/or brought before the Tribunal.

#### 3. Role of a Monitor

The monitor's role in situations of serious adverse effects is crucial since the monitor oversees the actions and decisions of supporters and facilitators. Because of the gravity of the situation, it is essential that safeguards, such as monitors, exist to ensure supporters and facilitators meet their legal obligations. The monitor would be legally required to make inquiries into whether or not, and the extent to which, representatives and facilitators are acting appropriately in the face of serious adverse effects.

This approach to serious adverse effects should apply equally to everyone in either a supported or facilitated decision-making status, and to those who, on reasonable grounds, have their capacity to act legally independently questioned. The approach

outlined here does not establish a set of obligations that apply only to those who meet some disability-related criterion. It recognizes every adult's right to live at risk and make individual choices.

- D. State Intervention, Decision-making Status and Serious Adverse Effects
  In cases of suspected serious adverse effects, a framework for state intervention by the
  Legal Capacity and Support Office must follow a twofold inquiry:
  - 1) Determine whether:
    - a. serious adverse effects are actually occurring, and if so which types (i.e. a,b, c and/or d as described above); and
    - b. whether or not the person is able to act legally independently, with supports as needed, or whether they can act only through either a supported or facilitated decision-making status in relation to a particular decision or set of decisions;<sup>244</sup> and
  - 2) Determine what interventions (i.e. supports and safeguards) are required to address the situation.

The inquiry would be conducted by the Legal Capacity and Support Office where they receive a complaint or allegation that suggests serious adverse effects are occurring and where there are reasonable grounds to believe the person is not currently able to act legally independently in relation to the situation creating serious adverse effects.

Responding to allegations of serious adverse effects, the Legal Capacity and Support Office would investigate first to determine if serious adverse effects are occurring, and which type(s).<sup>245</sup> In the course of the inquiry the Office may find the situation is either a

medical emergency or may involve criminal behavior. In either of these cases, the Office would respond as follows:

- Medical emergency If it is determined that the situation requires emergency medical attention, the Office would make the appropriate referrals to emergency services. If the situation is found to be neither an emergency, nor a situation of serious adverse effects, the investigation is terminated and no inquiry into capacity for acting legally independently is made.
- 2) Possible criminal behavior Where the Legal Capacity and Support Office, in the course of investigating situations of serious adverse effects, obtains evidence of possible criminal conduct related to the situation, it may consider referring the matter to the police for criminal investigation. Where the Office is of the opinion that the possible criminal conduct (e.g. making threats to others, violent behavior, financial mismanagement) is a result of lack of needed supports, it may take advantage of other options before referring the matter on to the police.<sup>246</sup>

Where a finding of serious adverse effects is made, findings and recommendations would be presented to the Administrative Tribunal where there is a dispute about a person's decision-making status. In addition, matters could be referred to the Administrative Tribunal where the Legal Capacity and Support Office believes that action is required but does not have the necessary resources or jurisdiction.

In cases of alleged or actually occurring serious adverse effects, the duties of, and procedures to be followed by, the Legal Capacity and Support Office and the Tribunal

would vary depending on the individual's decision-making status; except in cases of medical emergency or possible criminal behavior. In either of these cases, the Office would respond as indicated above, regardless of the person's decision-making status. Below, we consider implications for each of the three decision-making statuses.

#### 1. Legally Independent Status

Based on our proposed framework, the following protocol would apply:

- 1) If the situation is not a medical emergency, and it is determined that it should not be referred for criminal investigation, but it is found to be a situation of serious adverse effects, the Legal Capacity and Support Office determines if the person is able to act legally independently, with or without additional decision-making supports and community based supports for basic needs. One of the factors to take into account in making this determination is if the person poses a danger to him/herself or others. Where this is the case, the Office would be under strict obligation to determine if the individual understands information and appreciates the nature and consequences of his/her behavior. If not, the Office may recommend the individual requires either a supported or a facilitated decision-making status with respect to some or all decisions.
- 2) If it is determined that the person is able to act legally independently with or without any additional decision-making supports, the Legal Capacity and Support Office would have a few options:

- a. Offer to the individual and any others directly involved in the situation (e.g. family, caregivers) an opportunity to conduct an assessment of possible decision-making supports and community based supports for basic needs.
- b. If the offer is accepted, the assessment is undertaken and the Office may recommend that the Community-Based Resource Centre be engaged to arrange needed supports and/or may make recommendations to the Tribunal about accommodations and/or supports that may require additional orders or funding. If the individual refuses the offer, but others directly involved accept an assessment of their own support needs then the assessment can proceed. This is to address situations, in particular, where serious adverse effects may be of type (d) where others are at risk of harm by the individual's actions or behavior. Depending on the outcome of the assessment, the Community-Based Resource Centre can be engaged to assist in arranging needed supports.
- 3) If such an assessment is refused by both the individual and others involved, the Office may, based on its own assessment of risk, initiate periodic contact with those involved to offer support and assistance. If it is determined that the person is not able to act legally independently, then the Office makes recommendations to the Administrative Tribunal about the appropriate decision-making status and associated arrangements. See below for protocols to be followed for those in supported or facilitated decision-making status.

4) A person acting through a legally independent status cannot be involuntarily committed to a psychiatric facility for psychiatric assessment or treatment.

#### 2. Supported Decision-Making Status

With supported decision-making arrangements, the person is still able to make decisions themselves if they meet the newly formulated 'understand and appreciate test' with the support of his/her representatives. Such understanding and appreciating may be undertaken almost entirely by support representatives in situations where people with significant disabilities have very limited communication. Because the stakes are so high in situations of serious adverse effects, it is essential to be sure that the supporters are meeting their fiduciary duties and all other legal obligations imposed on them.

Further, given that supported decision making created in a *de facto* manner does not have the usual safeguards associated with other forms of appointment of supporters (e.g. monitors), *de facto* supporters cannot act in situations of serious adverse effects. However, in situations of serious adverse effects they can become supporters through appointment directly by the individual, or through application to the Tribunal. It is essential to be sure that the person's decisions are made with the benefit of optimal support.

If there is a question as to the legitimacy of the actions/inactions of the representatives, resort must be made to the framework's safeguards set out above, including involving the monitor and raising the issue before the Administrative Tribunal. If there is no concern about the representatives, the decision made by the person must not be questioned. However, as with people who are in the legally independent status,

decision-making and other supports must be made available to the person to enhance his/her ability to make decisions.

Once the Legal Capacity and Support Office acts on an allegation of serious adverse effects and determines that such effects exist, that it is not a medical emergency, that it will not refer for criminal investigation, and that the person is in a supported decision-making status, the following protocol applies:

- In relation to a person's decision-making status, the Office may make one of several findings:
  - a. the individual already has formal or informal supported decision-making arrangements in place; or
  - the individual is not able to act legally independently without
     representational supports or a co-decision-maker, neither of which are yet
     in place; or
  - c. supported decision-making arrangements are not in place, and cannot be put into place because of the lack of availability of individuals who understand or know the person well enough to represent them in a supported decision-making status.

In situations of either (b) or (c), the Office would apply to the Tribunal for an order relating to establishing representational supports.

2) Once the Office establishes the nature of the supported decision-making arrangement, it could:

- a. Determine if the support representatives are meeting their fiduciary responsibility. If not, the Office can make a determination of why not, and either require supports be provided to the representatives to assist them in meeting their responsibilities; or recommend to the Tribunal that support representatives be replaced. The Office may request the Tribunal to appoint a representative. The priority would be on individuals whom the person wishes to appoint for this purpose, and/or who indicate they are in a personal relationship of trust and commitment to the person. If no other representatives are available, the Office can seek to be appointed by the Tribunal to act as support representative of last resort.
- Offer to the individual and any support representatives an opportunity to assess decision-making supports and community based supports for basic needs.
  - i. If the offer is accepted, the assessment is undertaken and the Office may recommend that the Community-Based Resource Centre be engaged to arrange needed supports and/or may make recommendations to the Tribunal about accommodations and/or supports that may require additional orders or funding.
  - ii. If the individual and/or some support representatives refuse the offer, but others directly involved accept, the assessment can proceed with those who agree to it. That is, where there is disagreement among the individual and/or some of the support

- representatives, and a situation of serious adverse effects exists, the assessment is justified.
- iii. If the assessment is refused by both the individual and support representatives, the Office may, based on its own assessment of risk, initiate periodic contact with those involved to offer support and assistance.
- c. Once a determination is made of serious adverse effects, and of the need for supported decision-making, the Office may involve any appointed monitor in the investigation, arrange for appointment of a monitor, and/or question whether the monitor is fulfilling his/her duties.
- d. A person acting through a supported decision-making status cannot be involuntarily committed to a psychiatric facility for psychiatric assessment or treatment.

#### 3. Facilitated Decision-Making Status

Because, by definition, a facilitator is not able to fully understand the person's will and/or intentions as the basis for reasonable consequential action that respects the person's dignity of risk, he/she should not be able to consent on a person's behalf to have them placed, or remain, in a situation of serious adverse effects. Their fiduciary responsibility would require them not to facilitate any decisions that place the person at substantial risk to themselves or others. However, some dignity of risk should be available to the person as the facilitator begins to discern their will and/or intention, or has prior knowledge of the person's wishes with respect to the risks they wish to assume.

Once the Legal Capacity and Support Office acts on an allegation of serious adverse effects, and determines that such effects exist, that it is not a medical emergency, and that the person is in a facilitated decision-making status, the following protocol applies:

- The Office determines if the facilitator is meeting his/her fiduciary responsibility. If not, the Office can make a determination of why not, and either require supports be provided to the facilitator to assist them in meeting their responsibilities, or recommend to the Tribunal that the facilitator be replaced. If no other facilitator is available, the Office may seek to be appointed by the Administrative Tribunal as facilitator of last resort.
- The Office may undertake an assessment related to needs for decision-making supports and other community resources. Unlike the other two statuses, the facilitator cannot refuse the assessment of needs, given the vulnerability of the individual in this status. The Office may recommend that the Community-Based Resource Centre be engaged to arrange needed supports and/or may make recommendations to the Tribunal about accommodations and/or supports that may require additional orders or funding.
- 3) The Office may, based on its own assessment of risk, initiate periodic contact with those involved to offer support and assistance.
- 4) The Office may involve any appointed monitor in the investigation, and/or question whether the monitor is fulfilling his/her duties.
- 5) The facilitator may determine that the individual being supported requires psychiatric or other medical assessment or treatment to deal with a situation

6) In all cases, the decision regarding medical or psychiatric intervention is made by the facilitator and not by medical professionals, although they may make a medical recommendation as requested by the Tribunal.

# E. Protocol for a Facilitator to Seek Admission of a Person to a Facility for Psychiatric Assessment and/or Treatment

There are likely to be situations where facilitators wish to admit to a psychiatric facility a person for whom they have been legally authorized to act as a facilitator, for the purposes of psychiatric assessment and/or treatment. Facilitators would be authorized to seek admission for this purpose, with certain safeguards, on the basis that the person is in a situation of serious adverse effects, or that others are as a result of the individual's actions. As noted above, only those in a facilitated status can be admitted for this purpose without their consent.

If the individual does not resist admission, the facilitator can go to an emergency department and seek to have the person admitted.

If the person does resist admission, the following protocol would apply for the facilitator, Legal Capacity and Support Office, and the Administrative Tribunal.

- 1) If the facilitator and the person are already at the admitting centre to a facility, and the person is refusing admission, the facilitator and/or the facility would contact the Administrative Tribunal which would provide adjudicators on a 24-basis to such facilities, on-site, via telehealth conferencing services or on some other emergency response basis. As in the protocol outlined above, the Tribunal adjudicator could seek input from the Legal Capacity and Support Office about the appropriateness of the status, the presence of serious adverse effects, and the availability of alternatives. The individual would also have access to an independent advocate and legal counsel for this purpose.
- 2) If the person and facilitator are not physically at the admissions centre to a facility, and the person is refusing to go to a facility for this purpose, the default process should be based on the principle of a duty to accommodate. The process should go to where the person is. Adjudicators with the Tribunal and representatives of the Legal Capacity and Support Office, as well as independent advocates and legal counsel, may go to a person's home or wherever else he or she may be to undertake the hearing and assessment. Realistically, and given the rural and remote nature of many communities, as well as inevitably scarce resources, this may require hearings by telephone.

3) If the Tribunal – after hearing evidence and arguments of the person and the facilitator, and the assessment of the Legal Capacity and Support Office and health professionals – determines that the facilitator is acting according to their legislated duties, that the person is in fact in a facilitated status, and that there is a situation of serious adverse effects, then they may order necessary steps be taken to have the person admitted. This may include the assistance of police or other emergency response services.

In summary, a commitment to maximizing autonomy requires that constraining choice and personal dignity only happen where serious adverse effects occur and the person is in a facilitated decision-making status. For those in a supported decision-making status, our framework allows for people to make their own decisions in relation to serious adverse effects, but suggests a number of checks and balances, including appointment of monitors, legislated duties of support representatives and recourse to an Administrative Tribunal. It also imagines a proactive role by both the Legal Capacity and Support Office and the Tribunal in ensuring needs assessment and a range of decision-making supports and community resources are provided as agreed to by individuals and others involved.

The procedures outlined above imply substantial investment of resources, and realignment of health professions' responsibilities, in order to ensure an independent and autonomous, but integrated role, for the Administrative Tribunal and the Legal Capacity and Support Office within the health care system, and to ensure legal counsel and independent advocacy as needed. That substantial investment would be required is no reason to suggest the proposals are not credible. The issue is what it will take to reasonably meet the requirements to maximize the equal right to legal capacity and autonomy without discrimination on the basis of disability. We believe the institutional framework, machinery and safeguards outlined in these sections provide a reasonable infrastructure to protect and enhance autonomy.

#### VII. SUMMARY OF PROPOSALS

This paper presents a number of proposals for a more robust framework than currently exists in Ontario and other jurisdictions for protecting and advancing the right to legal capacity and autonomy without discrimination on the basis of disability. The main proposals are summarized in this section.

#### A. Key Concepts and Principles

#### 1. Legal Capacity

Legal capacity reflects an individual's right to make decisions and have those decisions respected by others. It is not to be equated with mental capacity. The United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) breaks the link between the two; mental capacity can no longer be considered a criterion for recognizing the right to legal capacity as it is discriminatory on the basis of disability. We describe the principle of equal recognition of legal capacity this way:

People enjoy and exercise their right to legal capacity differently depending on a person's unique characteristics. A person's autonomy and legal capacity is maximized equally to the extent that they access the supports and accommodations they need to exercise their legal capacity; and to the extent that supports and accommodations adapt to each person's evolving decision-making abilities and capabilities.

The main concepts used in stating this principle are described below.

#### 2. Decision-making Capability

'Decision-making capability' is proposed as a core concept for a new paradigm for maximizing autonomy and the right to legal capacity. The concept recognizes that people have a range of decision-making abilities. Combined with supports and accommodations by others, a person's capability to make personal life/care, health care and financial decisions about their lives can be enhanced sufficient for making those decisions.

#### 3. Decision-making Ability

People have a range of decision-making abilities including, for some, the ability to understand information and appreciate the nature and consequences of a decision, and communicate that decision to others in ways they will understand. This ability has been defined in much legislation and case law as the deciding criterion for determining whether or not a person's right to legal capacity will be recognized and in what respects. Such provisions violate the right to equal recognition of legal capacity without discrimination on the basis of disability under the CRPD.

We define the minimum threshold of decision-making ability as follows:

to act in a way that at least one other person who has personal knowledge of an individual can reasonably ascribe to that individual's actions: personal intention or will; memory; coherence of the person's identity through time; and communicative abilities to that effect.

We suggest that competent decision-making processes can be designed guided by such abilities.

#### 4. Decision-making Supports

People require a range of decision-making supports to make decisions in their lives, and to turn their decision-making *abilities* into decision-making *capabilities*. Governments should ensure access to at least six main types of decision-making supports under Article 12(3) of the CRPD, including:

- Life planning
- Independent advocacy
- Communicational and Interpretive
- Representational
- Relationship-building
- Administrative

## 5. Decision-making Accommodations

Legal capacity laws have usually been designed on the basis that only those individuals who can meet the traditional 'understand and appreciate' test can legally engage in decision-making transactions. The duty to accommodate in Canadian law and in Article 5 of the CRPD provides a clear foundation for applying this duty to parties in decision-making processes.

#### 6. Decision-making Status

Three distinct decision-making statuses are proposed through which people are recognized to exercise their legal capacity. These statuses are based on distinctions already emerging in law in Canada, and their definition is also guided by the CRPD's

mandate to ensure supports that enable the exercise and enjoyment of legal capacity without discrimination on the basis of disability.

- a) Legally independent decision-making status –The minimum threshold for a person to act in this status is defined by the re-formulated 'understand and appreciate' test. That is, in a legally independent status there is reasonable evidence that the person:
  - has the ability, by him or herself or with assistance, to understand information that is relevant to making a decision; and
  - has the ability, by him or herself or with assistance, to appreciate the reasonably foreseeable consequences of a decision.
- b) Supported decision-making status People in this status access supports for the purpose of expressing and representing themselves to third parties, and/or processing information. People in this status do not meet the minimum threshold for acting legally independently. The minimum threshold for acting through the supported decision-making status is that there is reasonable evidence that:
  - An individual can act in a way that at least one other person who has personal knowledge of the individual:
    - can reasonably ascribe to the individual's actions, personal will and/or intentions consistent with the person's identity; and

- can take reasonable consequential actions to give effect to the will and/or intentions of the individual, which respect the individual's dignity of risk.
- c) Facilitated decision-making status This status is for those individuals with significant disabilities who do not meet either of the minimum threshold tests for legal independence or supported decision making with respect to a particular decision or set of decisions.

A person could be in a facilitated status in respect to some or all areas of their lives. The fact that a person is in a facilitated status is no judgment about their cognitive abilities. It simply reflects the fact that there are not, as of yet, any relationships in place for this person where others can reasonably discern their will and/or intention and describe it to others.

Facilitators could be appointed by an administrative tribunal or through a planning document in which a decision-maker is appointed at a time when the individual was acting legally independently or in a supported decision-making status in respect of that appointment.

While legal capacity cannot be removed, the decision-making status through which one exercises it can be changed.

#### 7. Presumption of Legal Independence

To ensure that no individual is denied the opportunity to be considered able to exercise their legal capacity through a legally independent status, a newly formulated principle of

'presumption of legal independence' is proposed based on the minimum threshold defined above:

All persons are presumed capable of:

- having the ability, by him or herself or with assistance, to
   understand information that is relevant to making a decision; and
- having the ability, by him or herself or with assistance, to appreciate the reasonably foreseeable consequences of a decision.
- 8. Functional Assessment of Decision-making Capability and Status
  In making status determinations a 'functional assessment' of decision-making capability
  would be needed to deal with situations where there is reasonable question as to
  whether a person meets the minimum thresholds of either legal independence and/or
  supported decision making. The assessment should address the following questions:
  - 1) Does the person appear to have the decision-making abilities to understand and appreciate the nature and consequences of a particular decision?
  - 2) If not, would additional supports and/or accommodations enable the person to satisfy (1) above? Have the supports been put in place to assist this person to understand and appreciate the nature and consequences of his or her intention and to engage and communicate in this decision-making process?
  - 3) If not, can at least one other person who has personal knowledge of the individual reasonably ascribe to his or her actions: personal intention or will; memory; coherence of the person's identity through time; and communicative abilities to that effect?
  - 4) Are other parties to this decision reasonably accommodating the person?

5) Has the State provided sufficient supports to maximize the person's decisionmaking capability?

#### 9. Duty to Accommodate

One of the main elements of the framework proposed in this paper is a legislated duty to accommodate. Without reasonable accommodations by other parties in the decision-making process, individuals will not be able to turn their unique decision-making abilities into real *capabilities* to make decisions and enter agreements with others.

Both the government and third parties have duties to ensure supports and reasonable accommodations to assist people with disabilities in maximizing exercise and enjoyment of their legal capacity. These duties should be exercised interdependently, according to the following principles:

- People with a disability have a right to supports to assist in development, participation in community life, to enable access and to exercise legal capacity.
- 2) Third parties have a duty to accommodate people with disabilities in transactions and decision-making processes. This means that third parties must:
  - a) accommodate whatever supports a person brings into the decisionmaking process; and
  - must provide additional supports, to the point of undue hardship, to enable the person to exercise legal capacity in a manner that maximizes their autonomy.

- 3) Assessment of needed supports and accommodations should be decision and individual specific, and cannot be based on disability status. The focus of the assessment is to determine what supports the individual requires to make their own decisions – either independently or with the support of others.
- 4) Where additional supports are required in order to maximize the exercise and enjoyment of legal capacity beyond what the person brings to the transaction or decision-making process, and beyond what a third party can reasonably provide as an accommodation, governments have an obligation in accordance with the CRPD to provide such measures. This obligation should include to:
  - maintain an office dedicated solely to assisting people to access supports;
  - provide information and resources to people with disabilities and third parties outlining the types of supports that may be of benefit along with practical mechanisms for putting the supports into practice;
  - provide funding for supports to people whose decision-making capability is in question and who are in need of supports; and,
  - maintain a registry of planning documents (e.g. representation agreements) which name supporters.

## B. Proposed Institutional Framework for Safeguarding Integrity of Decisionmaking Processes

Safeguards must be designed to protect and respect the integrity of all aspects of decision-making. An institutional framework for safeguarding decision-making processes that enhance, protect and promote an equal right to legal capacity should be based on three guiding principles:

- Respect for autonomy in decision-making;
- Respect for personal dignity;
- Safety and the duty to protect.

Eight main features are proposed to safeguard the integrity of decision-making processes:

1. Legislated Framework for Legal Capacity and Decision-making Supports

The CRPD recognizes a right to legal capacity, and the obligation of States Parties to
ensure supports are available to exercise legal capacity. Indeed many other Articles in
the CRPD reference State Parties' obligations to provide for needed supports to realize
recognized rights. A legislative framework outlining supports and services benefits
would give full effect to these obligations.

Ideally, a legislative framework would mandate provision of supports needed for people to exercise legal capacity, and would provide for the institutional framework outlined in this section. A legislative mandate for these supports would also give effect to the interdependence we outline in the previous section between third party duties to accommodate in decision-making processes, and the role of governments to make reasonable efforts in providing supports beyond the point of undue hardship to these

parties. In the Canadian context, such legislation would likely fall primarily within the powers of provincial and territorial governments.

#### 2. Legislated Duties of Representatives and Facilitators

Essential duties include to:

- Act diligently, honestly and in good faith;
- Act in accordance with all applicable legislation;
- Act in accordance with any relevant agreements or Administrative Tribunal orders;
- Keep information about the adult, and his/her affairs, confidential;
- Keep records in relation to all aspects of their role; and,
- Involve supportive family members and friends.

Representatives and facilitators who comply with the above duties would not be liable for any injury death, loss or damage that results from actions they have taken in their role as representatives or facilitators.

#### 3. Monitors

Monitors should be appointed to protect the decision-making rights of the adult where a supported decision-making representative or facilitator is involved. Monitors must ensure that the representative or facilitator complies with all legal duties expected of them. If the monitor finds wrongdoing, attempts to resolve it with the representative/facilitator and the person should be made. If these efforts fail, resort should be had to the Administrative Tribunal for adjudication.

#### 4. Community-Based Resource Centre

A community based resource centre must be established in legislation, with an armslength, independent status and a board of directors, a majority of whom are people with disabilities. It would provide information and assistance to individuals with disabilities, support representatives, facilitators and third parties in developing and accessing needed supports and accommodations for decision making processes. The centre would maintain a registration system of representation agreements, monitors and facilitators.

#### 5. Legal Capacity and Support Office

6.

This Office would be required to investigate allegations of serious adverse effects as well as act as a facilitator or monitor of last resort. It would arrange for needed supports to address situations where serious adverse effects are occurring or may occur.

## Administrative Tribunal with a Focus Exclusively on Decision-Making The role of the Administrative Tribunal would be to have exclusive jurisdiction over decision-making cases. The Tribunal could give direction on any question related to a person's decision-making status, or role of other persons in relation to that status,

including where questions or issues relate to:

- Duty to accommodate;
- State provision of supports;
- Decision-making status;
- Appointment of supporters and facilitators and the approval of people applying to act as supporters;

 Appointment of monitors – where the Administrative Tribunal determines that supporters or facilitators are not meeting their legal obligations, it would have authority to appoint monitors.

#### 7. Access to Legal Counsel

People who wish to take cases to the Tribunal related to decision-making supports, accommodations or status should have access to state funding for legal counsel, should an individual be unable to pay.

#### 8. Formal Advocate

Independent advocacy should be established to:

- Provide advice in relation to decision-making statuses that may be of relevance to the person;
- Provide information to people in relation to legal processes and options where there is a capacity issue;
- Explain to an individual who is the subject of a capacity proceeding the nature and implications of the proceeding, including explaining the significance of any possible orders or consequences;
- Support individuals who are in the supported or facilitated status, including assisting the person to address neglect and abuse by the representative or facilitator.

# C. Safeguards to Ensure Appropriate Decision-making Status is Recognized, Accommodated and Supported

There is substantial risk that a person could be inappropriately placed in a particular decision-making status because of lack of access to supports and reasonable accommodation. Given that this would unnecessarily restrict a person in exercising their legal capacity, the following safeguards are proposed:

- 1) Any status determination must begin with a presumption of legal independence as defined above. Where a party seeks to rebut this presumption, inquiry must be made into whether third parties and governments have met their obligations to provide reasonable accommodations and supports to assist a person in exercising their legal capacity.
  - 2) If the Tribunal is not satisfied that reasonable accommodations and efforts have been made by third parties and governments, then it would order remedies to that effect; and require implementation and assessment of those remedies prior to making a determination that the person cannot act legally independently.
  - 3) If there is reasonable evidence to rebut the presumption of legal independence, and the Tribunal is satisfied that reasonable accommodation and effort has been made by third parties and governments to provide supports for decision making in a legally independent status, a presumption exists that the person meets the criterion for supported decision-making status as defined above.

- 4) If the Tribunal makes a finding that a person cannot act in a legally independent status, it shall not determine that the person is in a facilitated status unless it is satisfied that:
  - no reasonable accommodations and support arrangements could currently be established that would enable a person to meet the minimum threshold for supported decision making; and
  - that the person would benefit from having decisions made through a facilitated status.<sup>247</sup>
- 5) If the Tribunal is not satisfied that reasonable accommodations and supports have been provided, then it would order remedies to that effect, as above, and not make a determination that a person can only act through a facilitated status until their efficacy was assessed.
- 6) Status determinations must afford the person being assessed the opportunity to involve their supports in any manner and to any extent necessary to accommodate his/her ability to participate in the assessment. The right to access supports in this manner was articulated in *Koch (Re)*.<sup>248</sup>
- 7) Status determinations must afford a person the right to have a lawyer present at the assessment, and be advised of that right.
- 8) Prior to undertaking a status determination, the person must be advised of the purpose of the assessment, the significance and effect of a status finding, and depending on the circumstances, the person's right to refuse to be assessed (see, for example, Ontario's *Substitute Decisions Act*, s. 78(2)<sup>249</sup>).

- 9) Objective and disability-sensitive guidelines must be created and legislatively entrenched with which all status assessments must comply.<sup>250</sup>
- 10) Upon the determination that a person should be placed in a facilitated status, the State has an obligation to invest in supports that assist the person to develop personal support relationships sufficient to act in a supported decision-making or legally independent status at some point in the future. Periodic reviews must be established to determine whether adequate investment is being made in developing such relationships, and whether a person should remain in a facilitated status.

# Some decisions raise particular risk of abuse and exploitation because they so fundamentally affect personal integrity, including: non-therapeutic sterilization, non-

Safeguards Where Decisions Fundamentally Affect Personal Integrity

therapeutic abortion, cochlear implant surgery, non-therapeutic plastic surgery, sex re-

We propose the following guidelines with respect to these types of decisions:

assignment surgery, assisted suicide (in jurisdictions that provide for this), etc.

D.

- People exercising their legal capacity through a legally independent decisionmaking status should not be restricted in any way from making decisions which are allowable under law, even if people require supports and accommodations to do so.
- 2) Where people who exercise their legal capacity through a supported decisionmaking status wish to consider these types of decisions, the decisions should be reviewed by the Administrative Tribunal, given the risks for exploitation and

abuse. The Tribunal must be confident that persons making high risk decisions that significantly affect personal integrity are making them with free and informed consent even if with the assistance of a supported decision-making representative. Monitors could review such decisions in an effort to determine whether the individual's intention is accurately being interpreted and expressed by the representative.

3) Because of the risks of misinterpretation of a person's will and/or intention for those who exercise their legal capacity through facilitated decision-making, decisions that substantially affect personal integrity like those listed above, should never be legally permitted to be facilitated for persons in this decisionmaking status.

#### E. Safeguarding Against Serious Adverse Effects

We propose a definition of serious adverse effects as follows:

A situation of serious adverse effects occurs when a person, as a result of his/her actions or those of others.:

- a) Experiences loss of a significant part of a person's property, or a person's failure to provide necessities of life for himself or herself or for dependants; or
- b) Experiences serious illness or injury, and deprivation of liberty or personal security; or
- c) Has threatened or attempted or is threatening or attempting to cause physical and/or psychological harm to himself or herself; or

d) Has behaved or is behaving violently towards another person or has caused or is causing another person to fear physical and/or psychological harm from him or her.

Serious adverse effects can attach to the individual in question as well as to others who are directly involved in the situation. In addressing serious adverse effects, the following roles would be required:

#### 1. Role of the Legal Capacity and Support Office

The Legal Capacity and Support office would be authorized to investigate allegations of serious adverse effects in situations where individuals are in a supported or facilitated decision-making status, or where there are reasonable grounds to indicate that a person is unable to act legally independently. The assessment and provision of supports would address two forms: community resources and decision-making supports.

#### 2. Role of the Administrative Tribunal

The Administrative Tribunal, upon recommendations from the Legal Capacity and Support Office, would make determinations about an individual's decision-making status and authorize accommodations and/or state provision of needed supports. Legal counsel and independent advocates would be made available to those whose cases are investigated by the Legal Capacity and Support Office and/or brought before the Tribunal.

#### 3. Role of a Monitor

The monitor would be legally required to make inquiries into whether or not, and the extent to which, representatives and facilitators are acting appropriately in the face of serious adverse effects.

#### F. Protocol for Responding to Allegations of Serious Adverse Effects

For cases of suspected serious adverse effects the following protocol is proposed for the Legal Capacity and Support Office to follow:

- Determine whether serious adverse effects are actually occurring, and if so which types; whether or not the person is able to act legally independently, with supports as needed, or whether they can act only through either a supported or facilitated decision-making status in relation to a particular decision or set of decisions; and what interventions (i.e. supports and safeguards) are required to address the situation.
- 2) Determine whether a medical emergency and/or criminal behavior is involved, and make referrals as needed, to emergency services or to the police. Where the Office is of the opinion that the possible criminal conduct is a result of lack of needed supports, it may take advantage of other options before referring the matter on to the police.
- 3) Where a finding of serious adverse effects is made, findings and recommendations would be presented to the Administrative Tribunal where: there is a dispute about a person's decision-making status; or the Office believes that action is required but does not have the necessary resources or jurisdiction.

- 4) For those in a *legally independent status*, if it is determined that the person is able to act legally independently with or without any additional decision-making supports, the Legal Capacity and Support Office would offer an assessment of needs and supports to the individual and others involved. The Community-based Resource Centre would be engaged as required. If the offer were refused, the Office may, based on its own assessment of risk, initiate periodic contact with those involved to offer support and assistance. A person acting through a legally independent status cannot be involuntarily committed to a psychiatric facility for psychiatric assessment or treatment.
- 5) For those in a *supported decision-making status*, once the Legal Capacity and Support Office determines that there are serious adverse effects, and that it is not a medical emergency, it may find that: a) the individual already has supported decision-making arrangements in place; or b) the individual is not able to act legally independently; and/or c) that the individual requires support representatives but no such persons are available to play this role. In situations related to either (b) or (c), the Office would apply to the Tribunal for an order relating to establishing representational supports.
  - The Office determines whether the support representatives are meeting their fiduciary responsibility. If not, the Office could require supports be provided to the representatives and arrange with the community resource centre for this purpose; recommend to the Tribunal that support representatives be replaced; and/or request the Tribunal to appoint a representative including, as a last resort, the

Office itself. Where the Office determines that supporters are meeting their fiduciary responsibilities, and an assessment of need for supports is refused by both the individual and support representatives, the Office may initiate periodic contact with those involved to offer support and assistance.

- Once a determination is made of serious adverse effects, the Office may involve any appointed monitor in the investigation, arrange for appointment of a monitor, and/or question whether the monitor is fulfilling his/her duties.
- A person acting through a supported decision-making status cannot be involuntarily committed to a psychiatric facility for psychiatric assessment or treatment.
- 6) For those in a *facilitated decision-making* status, a facilitator should not be able to consent on a person's behalf to have them placed, or remain, in a situation of serious adverse effects. Some dignity of risk should be available to the person as the facilitator begins to discern their will and/or intentions, or has prior knowledge of the person's wishes with respect to the risks they wish to assume.
  - Once the Legal Capacity and Support Office determines that there are serious adverse effects, and that it is not a medical emergency, and that the person is in a facilitated decision-making status, the Office determines if the facilitator is meeting his/her fiduciary responsibility. If not, the Office can require supports be provided to the facilitator to

assist them in meeting their responsibilities, or recommend to the Tribunal that the facilitator be replaced. If no other facilitator is available, the Office may seek to be appointed by the Administrative Tribunal as facilitator of last resort.

- At any time, the Office may undertake an assessment related to needs for decision-making supports and other community resources, and make arrangements for supports as needed. Unlike the other two statuses, the facilitator cannot refuse the assessment of needs, given the vulnerability of the individual in this status.
- The Office may involve any appointed monitor in the investigation, and/or question whether the monitor is fulfilling his/her duties.
- The facilitator may seek to admit a person to a medical or psychiatric facility for assessment and/or treatment. A physician cannot admit a person to a facility for this purpose, but the Office, Tribunal or facilitator can request a recommendation from a physician in this regard. If the individual resists the admission, they have a right to a Tribunal hearing to make a determination as to their status and/or the legitimacy of the facilitator's decision.

#### CONCLUSION

In this paper we have explored the question of the extent to which, if at all, limitations on decision-making rights can be imposed given Canada's commitments to international law on human rights and disability as reflected in the UN *Convention on the Rights of Persons with Disabilities* (CRPD). In so doing, we have examined how to ensure that people have access to the supports and accommodations they require to maximize exercise of their legal capacity, and the role of the state and other entities in assuring this outcome. In addressing the guiding question for this paper we have inquired into how the law can balance the right to autonomy while safeguarding people who may be vulnerable to abuse and neglect. Throughout, we have examined how to manage this balance in a manner that does not discriminate on the basis of disability.

People with intellectual, cognitive and/or psychosocial disabilities have faced a history of exclusion, denigration, victimization and denial of their rights. Sometimes, what has been considered the most progressive social policy has entrenched a paternalistic, self-justifying regime of total restriction on the autonomy of people with disabilities. The *Canadian Charter of Rights and Freedoms*, federal and provincial/territorial human rights *Codes*, and legal capacity legislation and jurisprudence have begun to crack the hold of paternalism in people's lives. However, far too often the very regimes instituted in the name of human rights and autonomy still draw back when it comes to equally recognizing the right to legal capacity.

The United Nations *Convention on the Rights of Persons with Disabilities* signals a new era in human rights as they apply to people with disabilities. Article 12 of the CRPD, providing for equal recognition of legal capacity without discrimination on the basis of

disability, requires an entirely new look at capacity law, adult protection laws, and mental health law. Existing provisions for the most part assume that a boundary between those considered legally 'capable' and those considered 'incapable' can be neatly discerned, and populations of people with intellectual, cognitive and psychosocial disabilities, as well as older adults, divided accordingly.

We have sought in this paper to undertake an examination of such law in light of the CRPD and its definitive challenge to the legally capable/incapable boundary when drawn on the basis of disability, and the border management across this divide. Our inquiry has led us to propose a legal framework for implementing the new paradigm for maximizing autonomy and the right to legal capacity instituted by the CRPD. Central to this framework is an approach that does not assume away the differences in people's decision-making abilities. We have proposed a minimum threshold and set of principles that make expression of a person's will and/or intention, even by others, the ground on which decision-making processes in health care, personal care and finance/property can justifiably rest. Consistent with a social model of disability, on which the CRPD rests, and which is increasingly recognized in legislation and case law, we have proposed 'decision-making capability' – as a combination of unique abilities plus supports and accommodations – as the focus of inquiry into what status is best suited for people to exercise their legal capacity.

We articulate distinctions between newly formulated statuses: legal independence, supported decision-making and facilitated decision-making. We recognize that these status distinctions are the determining feature in how a person exercises their legal capacity. Thus, we have suggested a set of guidelines for making these

determinations. In addition, we propose a shared responsibility between the state and other entities for ensuring access to a range of supports in the decision-making process and for managing the duty to accommodate in this regard. As well, we propose a number of guidelines to guard against inappropriate placement in a particular decisionmaking status. We recognize that for those in a facilitated status, by virtue of this status, their right to exercise legal capacity is necessarily limited. While some may suggest we are playing in semantics, and that this is in fact simply substitute decisionmaking by another name, we think the distinction essential. Those in a facilitated status retain their legal capacity. Its declaration is not that a person does not have decisionmaking ability. Rather, it is that others are not able to discern a person's will and/or intention sufficient to assist its translation into decisions and decision-making transactions. People in a facilitated status are owed obligations by the State and other entities to continue to provide supports and accommodations to enable greater understanding of a person's will and/or intention, and thereby provide a basis for supported decision making, if not legal independence.

The legal framework presented in this paper is consistent with the decisive shift the CRPD directs in disability-related policy and programming away from paternalism and toward autonomy. The emphasis on autonomy and freedom to make one's own decisions is infused in the CRPD's preambular statements and runs throughout the Articles of the *Convention*. That said, the *Convention* also recognizes the need for safeguards given the vulnerability to rights violations that so many people with disabilities face. We have sought in this paper to explore how to manage this shift in

the face of the abuse, neglect and harm to which people with disabilities and older adults are disproportionately victim; and also the risks and harms that others may face.

We have concluded that this re-balancing will not be accomplished without substantial legislative and institutional reform in legal capacity law, adult protection law and mental health law. To this end, we have proposed new institutional machinery to manage processes associated with ensuring adequate supports and accommodations, making determinations of decision-making status, and adjudicating disputes with respect to all of those decisions. In particular, we propose that involuntary commitment, in psychiatric or other facilities, in its current form, is in violation of the CRPD, and we recommend that physicians, simply by virtue of their health profession status, should no longer be empowered to make such decisions. We propose alternatives, including provision for those in a facilitated decision-making status to be admitted to acute care facilities at the request of their facilitators for assessment and treatment provided that certain safeguards are met.

Autonomy is a founding principle in a liberal-democratic society. As people with disabilities finally come to be recognized as full citizens, deserving of equal recognition in respect of all the human rights that attach to citizenship, new foundations for an inclusive society need to be built. In that effort, it is essential to confront the vestiges of an autonomy-denying paternalism still present in legal capacity and other laws. Some may suggest that the framework proposed in this paper tips the balance too much in the direction of autonomy in not ensuring that people who may be at risk to themselves or others are adequately protected and/or confined as some deem necessary.

However, we conclude that the CRPD advances autonomy and freedom to make one's own choices as priority principles and imposes substantial obligations on State Parties and entities they regulate. In this paper, we have suggested that the price of protecting and advancing autonomy in a liberal-democratic society is essentially threefold. First, we must protect the negative liberty that enables dignity of risk. Second, we require a proactive legislative, policy and delivery framework that realizes positive rights for needed supports and services in the community which are delivered in ways that nurture autonomy rather than organize its banishment. It is time to fully extend dignity of risk to people with disabilities, and constrain their choices only to the extent that we constrain the choices of others. In doing so, and in recognizing the historic disadvantage, vulnerability, isolation and abuse that people with disabilities face in hugely disproportionate numbers, we must also ensure that support systems are in place that enable and nurture capability. Third, new institutional machinery is needed to ensure a much better balance between protecting autonomy and safeguarding against risk. This may require new investments, or re-investing current resources in new functions. Constraining risk is not the answer; enabling a supported autonomy is. And the price is worth the outcome.

The lens provided by the CRPD makes it possible to identify, examine and systematically confront paternalism's hold in the lives of people with disabilities. It is incumbent on governments to do so as they take steps to meet the obligations the *Convention* sets out to ensure equal recognition of legal capacity without discrimination on the basis of disability. This paper is intended to assist in charting the many elements of that reform.

## **Endnotes**

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<sup>&</sup>lt;sup>1</sup> This paper was prepared by Michael Bach, Executive Vice-President of the Canadian Association for Community Living and Lana Kerzner, Barrister and Solicitor, who is a disability law lawyer in Ontario. The paper has been prepared for the Law Commission of Ontario, and we express our gratitude for their generous financial contribution for undertaking the research and preparation of this paper. We are also grateful for the financial contribution for student and background research made through the Community-University Research Alliance Project, titled 'Disabling Poverty/Enabling Citizenship: Examining Exclusions and Identifying Opportunities for the Full Participation of Canadians with Disabilities' and funded by the Social Sciences and Humanities Research Council. We express our sincerest appreciation to Justin Gould, law student, for his excellent research assistance. In writing this paper, we drew on two earlier papers we wrote: Lana Kerzner, "Embracing Supported Decision-Making: Foundations for a New Beginning" (March, 2009), written for the Canadian Association for Community Living and Michael Bach "The Right to Legal Capacity under the UN Convention on the Rights of Persons with Disabilities: Key Concepts and Directions for Law Reform" in Agustina Palacios and Francisco Bariffi, eds., Legal Capacity, Disability and Human Rights: a review in the light of the UN Convention on the Rights of Persons with Disabilities [published in Spanish] (Mexico: Liberia de Porrua, 2010). We also express our sincere appreciation to Jeremiah Bach who provided helpful suggestions on earlier drafts of this paper. <sup>2</sup> These terms are defined in Part One, Section I.

<sup>&</sup>lt;sup>3</sup> For example see Paul Longmore, "Medical Decision Making and People with Disabilities: A Clash of Cultures" (March 1995) 23:1 The Journal of Law, Medicine and Ethics at 82-87.

<sup>&</sup>lt;sup>4</sup> See, for example, Deborah Stienstra & Aileen Wight-Felske, eds., *Making Equality: History of Advocacy and* 

<sup>&</sup>lt;sup>5</sup> Alan Borovoy, "Guardianship and Civil Liberties" (1982) 3 Health L. Can. at 51-57, cited in Orville Endicott & Kenneth Pike, "Developing Legal Approaches That Reinforce Rather Than Disregard The Capacity Of Persons With Mental Disabilities To Make Choices" [(1995)unpublished, archived at Ontario Association for Community Living].

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- 2009) 17 at 25. <sup>19</sup> Daniel Mont, "Measuring Disability Prevalence," (March 2007) at 2-3, online: World Bank <a href="http://siteresources.worldbank.org/DISABILITY/Resources/Data/MontPrevalence.pdf">http://siteresources.worldbank.org/DISABILITY/Resources/Data/MontPrevalence.pdf</a> (last accessed: 7 October 2010). The social model of disability has been written about extensively. For an overview of its formulation, see C. Barnes and G. Mercer, eds., Exploring the Divide: Illness and Disability (Leeds, UK: The Disability Press, University of Leeds, 1996).
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<sup>30</sup>International Disability Alliance, "Legal Opinion on Article 12 of the CRPD" (21 June 2008) at 2, online: International Disability Alliance <a href="http://www.internationaldisabilityalliance.org/representation/legal-capacity-working-group/">http://www.internationaldisabilityalliance.org/representation/legal-capacity-working-group/</a> (last accessed: 7 October 2010).

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- <sup>63</sup> CRPD, Article 1. International Disability Alliance, "Legal Opinion on Article 12 of the CRPD" (21 June 2008) at 2.
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- Brydon v. Malamas, [2008] B.C.J. No. 1179, 2008 BCSC 749 at paras. 47-50.
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- <sup>94</sup> Evidence Act, R.S.O. 1990, c. E.23, s.18.
- <sup>95</sup> Canada Pension Plan Regulations, C.R.C., c. 385, s. 55.
- <sup>96</sup> Substitute Decisions Act, 1992, S.O. 1992, c. 30.
- <sup>97</sup> Banton v. Banton, (1998) 164 D.L.R. (4<sup>th</sup>) 176 (Ont. Gen. Div.) at 189.
- <sup>98</sup> Banton v. Banton, (1998) 164 D.L.R. (4<sup>th</sup>) 176 (Ont. Gen. Div.).
- <sup>99</sup> Calvert (Litigation Guardian of) v. Calvert, (1997) 32 O.R. (3d) 281 (Ont. Sup.Ct.) at 294.
- <sup>100</sup> Calvert (Litigation Guardian of) v. Calvert, (1997), 32 O.R. (3d) 281 (Ont. Sup.Ct.) at 294.
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- <sup>104</sup> The Adult Guardianship and Co-decision-making Act, S.S. 2000, c. A-5.3, s. 2(c).
- <sup>105</sup> The Vulnerable Persons Living with a Mental Disability Act, C.C.S.M. c. V90, ss. 46, 81.
- 106 See e.g. Representation Agreement Act, R.S.B.C. 1996, c. 405, s. 8(2).
- <sup>107</sup> Koch (Re) (1997), 33 O.R. (3d) 485 (Gen. Div.) at 512.
- <sup>108</sup> Koch (Re) (1997), 33 O.R. (3d) 485 (Gen. Div.) at 521.
- <sup>109</sup> Substitute Decisions Act, 1992, S.O. 1992, c. 30, ss. 8(1), 47(1).
- <sup>110</sup> Khan v. St. Thomas Psychiatric Hospital, [1992] 7 O.R. (3d) 303. The assertion of presumption of capacity was made in relation to competence to consent to psychiatric treatment.
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- <sup>121</sup> Nova Scotia (Minister of Health) v. J.J., 2005 SCC 12, [2005] 1 S.C.R. 177.
- 122 Clark v. Clark, (1983) 40 O.R. (2d) 383.

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<sup>123</sup> Clark v. Clark, (1983) 40 O.R. (2d) 383.
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- <sup>137</sup> *Grav v. Ontario*, [2006] O.J. No. 266 at para. 47.
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- These requirements exist in relation to guardians and attorneys for property as well as guardians and attorneys for personal care. See Substitute Decisions Act, 1992, S.O. 1992, c. 30 ss. 32(4), 32(5), 66(6), 66(7).
- <sup>140</sup> The Adult Guardianship and Co-decision-making Act, S.S. 2000, c. A-5.3.
- <sup>141</sup> Civil Code of Quebec (C.C.Q.), S.Q. 1991, c. 64, Art. 291. Article 291 of the states that the court appoints an adviser for a person of full age "...who, although generally and habitually capable of caring for himself and of administering his property, requires, for certain acts or for a certain time, to be assisted or advised in the administration of his property." See also Alberta's Adult Guardianship and Trusteeship *Act*, S.A. 2008, c. A-4.2.

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  163 Provincial Advocate for Children and Youth Act, 2007, S.O. 2007, c. 9.
- <sup>164</sup> Advocacy Act, S.O. 1992, c. 26, This Act was repealed on March 29,1996.
- One view is that the cause of the demise of the *Advocacy Act* was not related to the subject-matter in the Act per se. Rather it was the result of the government's approach to much of the health, education and social service systems in Ontario at the time. See Ernie S. Lightman & Uri Aviram, "Too Much, Too
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- <sup>167</sup> The Vulnerable Persons Living with a Mental Disability Act, C.C.S.M. c. V90.
- <sup>168</sup> The Vulnerable Persons Living with a Mental Disability Act, C.C.S.M. c. V90, s. 6(1).
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- See Canadian Association for Community Living, "Policy Statement on Legal Capacity," (Toronto: Canadian Association for Community Living, March 2010).

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  172 Health Care Consent Act, 1996, S.O. 1996, c. 2, Schedule A, ss. 21(1), (2); Substitute Decisions Act,
- 1992, S.O. 1992, c. 30., ss. 66(3), (4).
- <sup>173</sup> For example, compare Substitute Decisions Act, 1992, S.O. 1992, c. 30, s. 66(3)1 with s. 66(4b).
- <sup>174</sup> Gerard Quinn, "Resisting the "Temptation of Elegance": Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?" in Oddný Mjöll Arnardóttir & Gerard Quinn, eds.,

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Health Care Consent Act, 1996, S.O. 1996, c. 2, Schedule A, s. 21(2); Substitute Decisions Act, 1992,

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<a href="http://www.equalrightstrust.org/ertdocumentbank/err">http://www.equalrightstrust.org/ertdocumentbank/err</a> issue02%20reduced.pdf> (last accessed: 7 October 2010).

<sup>179</sup>British Columbia (Superintendent of Motor Vehicles) v. British Columbia (Council of Human Rights), [1999] 3 S.C.R. 868 at para 22.

180 New Brunswick Human Rights Commission, "Guidelines on Accommodating Students with a Disability"

(15 October 2007) at 9, online: New Brunswick Human Rights Commission <a href="http://www.gnb.ca/hrc-105">http://www.gnb.ca/hrc-105</a> cdp/e/g/Guideline-Accommodating-Students-Disability-New-Brunswick.pdf> (last accessed: 12 October

<sup>181</sup>Council of Canadians with Disabilities v. VIA Rail Canada Inc., 2007 SCC 15, [2007] 1 S.C.R. 650. <sup>182</sup> Council of Canadians with Disabilities v. VIA Rail Canada Inc., 2007 SCC 15 at para. 121, [2007] 1

S.C.R. 650.

183 Nova Scotia (Workers' Compensation Board) v. Martin; Nova Scotia (Workers' Compensation Board) v. Laseur, [2003] 2 S.C.R. 504, 2003 SCC 54.

Nova Scotia (Workers' Compensation Board) v. Martin; Nova Scotia (Workers' Compensation Board) v. Laseur, 2003 SCC 54 at para. 81, [2003] 2 S.C.R. 504.

<sup>185</sup> Ontario Human Rights Commission, "Policy and Guidelines on Disability and the Duty to Accommodate" (2000 as revised in 2009) at 18, online: Ontario Human Rights Commission <a href="http://www.ohrc.on.ca/en/resources/Policies/PolicyDisAccom2/pdf">http://www.ohrc.on.ca/en/resources/Policies/PolicyDisAccom2/pdf</a> (last accessed: 12 October 2010). 

\*\*British Columbia (Ministry of Education) v. Moore, 2010 BCCA 478 at para. 40, Rowles J.A.,

dissenting. Madam Justice Rowles' dissenting judgment engages in a careful analysis of the approaches to discrimination in human rights statutes as well as the *Charter* and how these intersect.

187 Raj Anand & Tiffany Tsun, "The Role of Human Rights Statutes in Advancing Equality" (2009) 25

N.J.C.L. 161.

<sup>188</sup> S. 32(1) of the Canadian Charter of Rights and Freedoms provides that the Charter applies to "the Parliament and government of Canada" and to "the legislature and government of each province."

<sup>189</sup> R. Sullivan, Sullivan on the Construction of Statutes, 5th ed. (Markham: LexisNexis, 2008) at 387. <sup>190</sup> Eldridge v. British Columbia (Attorney General), [1997] 3 S.C.R. 624 at para. 79; Robert J. Sharpe & Kent Roach, The Charter of Rights and Freedoms, 4th ed. (Toronto: Irwin Law, 2009) at 346.

<sup>191</sup> Ena Chadha & C. Tess Sheldon, "Promoting Equality: Economic and Social Rights for Persons with Disabilities under Section 15" (2004) 16 N.J.C.L. 27.

<sup>192</sup> Ena Chadha & C. Tess Sheldon, "Promoting Equality: Economic and Social Rights for Persons with Disabilities under Section 15" (2004) 16 N.J.C.L. 27; Robert J. Sharpe & Kent Roach, The Charter of Rights and Freedoms, 4th ed. (Toronto: Irwin Law, 2009) at 348.

Andrews v. Law Society of British Columbia, [1989] 1 S.C.R. 143 at 169.

<sup>194</sup> Ena Chadha & C. Tess Sheldon, "Promoting Equality: Economic and Social Rights for Persons with Disabilities under Section 15" (2004) 16 N.J.C.L. 27.

<sup>195</sup>Granovsky v. Canada (Minister of Employment and Immigration), 2000 SCC 28 at para. 39, [2000] 1 S.C.R. 703.

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

<sup>197</sup> Eldridge v. British Columbia (Attorney General), [1997] 3 S.C.R. 624 at paras. 80, 94.

<sup>198</sup> Eldridge v. British Columbia (Attorney General), [1997] 3 S.C.R. 624 at para. 73.

- <sup>199</sup> Eldridge v. British Columbia (Attorney General), [1997] 3 S.C.R. 624 at para. 73.
- <sup>200</sup> Auton (Guardian ad litem of) v. British Columbia (Attorney General), 2004 SCC 78, [2004] 3 S.C.R.
- <sup>201</sup> Auton (Guardian ad litem of) v. British Columbia (Attorney General), 2004 SCC 78 at para. 27, [2004] 3 S.C.R. 657.
- Auton (Guardian ad litem of) v. British Columbia (Attorney General), 2004 SCC 78 at para. 47, [2004] 3 S.C.R. 657.
- <sup>203</sup>Eldridge v. British Columbia (Attorney General), [1997] 3 S.C.R. 624 at para.78.
- Representation Agreement Act, R.S.B.C. 1996, c. 405, s. 23.
- Representation Agreement Act, R.S.B.C. 1996, c. 405, ss.12, 20 and 21.
- <sup>206</sup> Online: Nidus Personal Planning < <a href="http://www.nidus.ca/">http://www.nidus.ca/</a>> (last accessed: 13 October 2010).
- 207 It may be that a Tribunal may only do so in the context of a statutory framework that mandates provision of needed accommodations and supports, and eligibility criteria for this purpose. For example, the Ontario Social Benefits Tribunal/Social Assistance Review Board hears appeals and makes determinations for those for whom benefits under the provincial Ontario Disability Support Program or Ontario Works Program are refused, denied, canceled or reduced. In this case benefits and eligibility criteria and the role of the Tribunal are clearly laid out in related statutes.

  208 Tess Sheldon & Ivana Petricone, "Addressing the Capacity of Parties before Ontario's Administrative
- Tribunals: Promoting Autonomy and Preserving Fairness" (December, 2009) at 31-32, online: ARCH Disability Law Centre
- <a href="http://www.archdisabilitvlaw.ca/sites/all/files/FINAL%20REPORT%20Capacitv%20%20Admin%20-4">http://www.archdisabilitvlaw.ca/sites/all/files/FINAL%20REPORT%20Capacitv%20%20Admin%20-4">http://www.archdisabilitvlaw.ca/sites/all/files/FINAL%20REPORT%20Capacitv%20%20Admin%20-4">http://www.archdisabilitvlaw.ca/sites/all/files/FINAL%20REPORT%20Capacitv%20%20Admin%20-4">http://www.archdisabilitvlaw.ca/sites/all/files/FINAL%20REPORT%20Capacitv%20%20Admin%20-4">http://www.archdisabilitvlaw.ca/sites/all/files/FINAL%20REPORT%20Capacitv%20%20Admin%20-4">http://www.archdisabilitvlaw.ca/sites/all/files/FINAL%20REPORT%20Capacitv%20%20Admin%20-4">http://www.archdisabilitvlaw.ca/sites/all/files/FINAL%20REPORT%20Capacitv%20%20Admin%20-4">http://www.archdisabilitvlaw.ca/sites/all/files/FINAL%20REPORT%20Capacitv%20%20Admin%20-4">http://www.archdisabilitvlaw.ca/sites/all/files/FINAL%20REPORT%20Capacitv%20%20Admin%20-4">http://www.archdisabilitvlaw.ca/sites/all/files/FINAL%20REPORT%20Capacitv%20%20Admin%20-4">http://www.archdisabilitvlaw.ca/sites/all/files/FINAL%20REPORT%20Capacitvlaw.ca/sites/all/files/FINAL%20REPORT%20Capacitvlaw.ca/sites/all/files/FINAL%20REPORT%20Capacitvlaw.ca/sites/all/files/FINAL%20REPORT%20Capacitvlaw.ca/sites/all/files/FINAL%20REPORT%20Capacitvlaw.ca/sites/all/files/FINAL%20Capacitvlaw.ca/sites/all/files/FINAL%20REPORT%20Capacitvlaw.ca/sites/all/files/FINAL%20Capacitvlaw.ca/sites/all/files/FINAL%20Capacitvlaw.ca/sites/all/files/FINAL%20Capacitvlaw.ca/sites/all/files/FINAL%20Capacitvlaw.ca/sites/all/files/FINAL%20Capacitvlaw.ca/sites/all/files/FINAL%20Capacitvlaw.ca/sites/all/files/FINAL%20Capacitvlaw.ca/sites/all/files/file %20November%202009.pdf> (last accessed: 13 October 2010): "Making Ontario's Courts Fully Accessible to Persons with Disabilities [Report of Courts Disabilities Committee] (December 2006), online: Ontario Courts <a href="http://www.ontariocourts.on.ca/en/accessiblecourts.htm">http://www.ontariocourts.on.ca/en/accessiblecourts.htm</a> (last accessed: 13
- October 2010).

  209 See e.g. *Kacan v. Ontario Public Service Employees Union*, 2010 HRTO 795, File No. 2008-00381-I.
- We draw this formulation of the duty of the Tribunal to consider all possible support options prior to making a determination that the person should be placed in a facilitated status from the Substitute Decisions Act, 1992, S.O. 1992, c. 30, ss. 22(3), 55(2).
- Koch (Re), (1997) 33 O.R. (3d) 485 (Gen. Div.).
- In Koch (Re), (1997) 33 O.R. (3d) 485 (Gen. Div.) Mr. Justice Quinn said that this requirement is so important that even though a similar requirement does not appear in the Health Care Consent Act, a similar warning must be given under that act.
  <sup>213</sup>See e.g. Capacity Assessment Office, Guidelines for Conducting Assessments of Capacity (Toronto:
- Ministry of the Attorney General of Ontario, 2005) at I.1, online: Ministry of the Attorney General of Ontario <a href="http://www.attorneygeneral.jus.gov.on.ca/english/family/pqt/capacity/2005-05/guide-0505.pdf">http://www.attorneygeneral.jus.gov.on.ca/english/family/pqt/capacity/2005-05/guide-0505.pdf</a>
- (last accessed: 12 October 2010). <sup>214</sup> See Claudia Cooper, Amber Selwood & Gill Livingston, "The Prevalence of Elder Abuse and Neglect: A Systematic Review" (2008) 37:2 Age and Aging at 151-160. The Roeher Institute, Harm's Way: The Many Faces of Violence and Abuse against Persons with Disabilities (Toronto: Roeher Institute, 1995).
- <sup>215</sup> H. Archibald Kaiser, "Canadian Mental Health Law: The Slow Process of Redirecting the Ship of State" (2009) 17 Health L. J. 139 at para. 28. <sup>216</sup> Substitute Decisions Act, 1992, S.O. 1992, c. 30., s. 27(1).
- <sup>217</sup> Substitute Decisions Act, 1992, S.O. 1992, c. 30., s. 62(1).
- <sup>218</sup> Mental Health Act, R.S.O. 1990, c. M7, s.15(1).
- For the purposes of our proposed definition we do not include the provision in s. 15(1)(c) of Ontario's Mental Health Act, related to showing "lack of competence to care for himself or herself" as this seems covered by the definition in the Substitute Decisions Act regarding "failure to provide necessities of life". As well, we do not include the provisions of ss. 15(1)(c),(d), or (e) as these relate to presumed consequences of having a "mental disorder" and as such the formulation incorporates a starting point that appears discriminatory on the basis of mental disability.
- R. Gordon & S. Verdun-Jones, Adult Guardianship Law in Canada (Toronto: Carswell, 1995) at 2-1.
- <sup>221</sup> R. Gordon, "Adult protection legislation in Canada: Models, issues and problems" (2001) 24 Int'l J. L. & Psychiatry 117 at 118.

<sup>&</sup>lt;sup>222</sup> Nova Scotia (Minister of Health) v. J.J., 2005 SCC 12 at para. 23, [2005] 1 S.C.R. 177.

<sup>&</sup>lt;sup>223</sup> The first of this type of legislation was the Newfoundland Neglected Adults Welfare Act, R.S.N.L. 1990, c. N-3. British Columbia Law Institute, Canadian Centre for Elder Law Studies, "Law Reform Report on Abuse and Neglect and Capacity Issues in Canada: Canadian Legislation and Juristic Literature" (April 2007) at 1, online: British Columbia Law Institute, Canadian Centre for Elder Law Studies <a href="http://www.bcli.org/sites/default/files/Law\_Reform\_Report\_on\_Abuse\_and\_Neglect\_and\_Capacity\_Issue">http://www.bcli.org/sites/default/files/Law\_Reform\_Report\_on\_Abuse\_and\_Neglect\_and\_Capacity\_Issue</a> s in Canada.pdf> (last accessed: 13 October 2010).

Nova Scotia's Adult Protection Act, R.S., c. 2.

Yukon's Decision-Making Support and Protection to Adults Act has been described as "...abuse and neglect legislation which supports an adult's right to live at risk while capable," British Columbia Law Institute, Canadian Centre for Elder Law Studies, "Law Reform Report on Abuse and Neglect and Capacity Issues in Canada: Canadian Legislation and Juristic Literature" (April 2007) at 4, online: British Columbia Law Institute, Canadian Centre for Elder Law Studies

<sup>&</sup>lt;a href="http://www.bcli.org/sites/default/files/Law Reform Report on Abuse and Neglect and Capacity Issue">http://www.bcli.org/sites/default/files/Law Reform Report on Abuse and Neglect and Capacity Issue</a> s in Canada.pdf> (last accessed: 13 October 2010).

226 British Columbia Law Institute, Canadian Centre for Elder Law Studies, "Law Reform Report on Abuse

and Neglect and Capacity Issues in Canada: Canadian Legislation and Juristic Literature" (April 2007) at 7-13, online: British Columbia Law Institute, Canadian Centre for Elder Law Studies

<sup>&</sup>lt;a href="http://www.bcli.org/sites/default/files/Law Reform Report on Abuse and Neglect">http://www.bcli.org/sites/default/files/Law Reform Report on Abuse and Neglect and Capacity Issue</a> s in Canada.pdf> (last accessed: 13 October 2010).

British Columbia Law Institute, Canadian Centre for Elder Law Studies, "Law Reform Report on Abuse and Neglect and Capacity Issues in Canada: Canadian Legislation and Juristic Literature" (April 2007) at 11, online: British Columbia Law Institute, Canadian Centre for Elder Law Studies

<sup>&</sup>lt;a href="http://www.bcli.org/sites/default/files/Law Reform Report on Abuse and Neglect and Capacity Issue">http://www.bcli.org/sites/default/files/Law Reform Report on Abuse and Neglect and Capacity Issue</a> s in Canada.pdf> (last accessed: 13 October 2010).

Substitute Decisions Act, 1992, S.O. 1992, c. 30, ss. 27, 62.

R. Gordon, "Adult Protection Legislation in Canada: Models, Issues and Problems" (2001) 24 Int'l J. L. & Psychiatry 117 at 127.

230 Mental Health Act, R.S.O. 1990, c. M.7.

<sup>&</sup>lt;sup>231</sup> 'Mental disorder' is the term used in the *Mental Health Act*. It is defined in s. 1(1) as "any disease or disability of the mind" and is used in the involuntary hospitalization sections (ss.15, 20). <sup>232</sup> Mental Health Act, R.S.O. 1990, c. M.7, ss.15, 20.

These have been referred to as the 'danger standard' and the 'welfare standard' and have been described as the legal system's tools to involuntarily commit people who have psychosocial disabilities. See Katherine Brown & Erin Murphy, "Falling Through the Cracks: The Quebec Mental Health System"

<sup>(2000) 45</sup> McGill L.J. 1037 at 1037. <sup>234</sup> Michael Bay, "The Evolution of Mental Health Law in Ontario," in Mental Health and Patients' Rights in Ontario: Yesterday, Today and Tomorrow, 20th Anniversary Special Report, Psychiatric Patient Advocate Office (May 2003) 14 at 14. <sup>235</sup> Michael Bay, "The Evolution of Mental Health Law in Ontario," in Mental Health and Patients' Rights in

Ontario: Yesterday, Today and Tomorrow, 20th Anniversary Special Report, Psychiatric Patient Advocate

Office (May 2003) 14 at 15. <sup>236</sup> H. Archibald Kaiser, "Canadian Mental Health Law: The Slow Process of Redirecting the Ship of State" (2009) 17 Health L. J. 139 at paras. 34-35.

237 World Network of Users and Survivors of Psychiatry, "Implementation Manual for the United Nations

CRPD on the Rights of Persons with Disabilities" (February 2008), online: World Network of Users and Survivors of Psychiatry <a href="http://wnusp.rafus.dk/documents/WNUSP">http://wnusp.rafus.dk/documents/WNUSP</a> CRPD Manual.pdf> (last accessed:

<sup>13</sup> October 2010). <sup>238</sup> See H. Archibald Kaiser, "Canadian Mental Health Law: The Slow Process of Redirecting the Ship of State" (2009) 17 Health L. J. 139 at paras. 34-35; where he discusses mental health laws in the context of Articles 3, 8, 12, 14, 17, 19 and 28 of the CRPD.

<sup>&</sup>lt;sup>239</sup> Peter Bartlett, "Mental Health Law after the CRPD," in Honouring the Past, Shaping the Future: 25 Years of Progress in Mental Health Advocacy and Rights Protection, 25th Anniversary Report. Psychiatric Patient Advocate Office (May 2008) 217 at 220.

Patient Advocate Office (May 2008) 217 at 220.

241 World Network of Users and Survivors of Psychiatry, "Implementation Manual for the United Nations CRPD on the Rights of Persons with Disabilities" (February 2008) at 3, online: World Network of Users and Survivors of Psychiatry <a href="http://wnusp.rafus.dk/documents/WNUSP">http://wnusp.rafus.dk/documents/WNUSP</a> CRPD Manual.pdf> (last accessed: 13 October 2010).

242 John Dawson & George Szmukler, "Fusion of Mental Health and Incapacity Legislation" (2006) 188

British Journal of Psychiatry 504: Katherine Brown & Erin Murphy, "Falling Through the Cracks: The Quebec Mental Health System," 45 McGill L.J. 1037; Peter Bartlett, "Mental Health Law after the CRPD," in Honouring the Past, Shaping the Future: 25 Years of Progress in Mental Health Advocacy and Rights Protection, 25th Anniversary Report, Psychiatric Patient Advocate Office (May 2008) 217 at 220. <sup>243</sup> H. Archibald Kaiser, "Canadian Mental Health Law: The Slow Process of Redirecting the Ship of State" (2009) 17 Health L. J. 139; Peter Carver, "Mental Health Law in Canada" in Jocelyn Downie, Timothy Caulfield & Colleen Flood, eds., Canadian Health Law and Policy, 3d ed. (Markham, On: Lexis Nexis, 2007) 399.

Authority for this inquiry would be similar in some respects to the current powers of the Ontario Public Guardian and Trustee (OPGT) to investigate allegations of serious adverse effects where there are claims that a person is "mentally incapable." However, the current powers of the OPGT focus on making a determination of mental incapacity. While such powers may be based on a presumption of capacity, they do not provide for consideration of what decision-making supports a person may require in order to exercise legal capacity – either independently or via a supported decision-making status.

While there may be rationale to first determine whether or not the individual is acting legally independently, on the basis that the investigation into serious adverse effects may violate privacy and autonomy rights of legally independent persons, the two inquiries are fundamentally inter-related. The Office cannot inquire into whether a person is legally independent with respect to a particular situation – that is, he/she meets the understand and appreciate test - without some knowledge of what it is in the situation that is to be understood and appreciated.

246 The interface between independent authorities like the proposed Legal Capacity and Support Office

and the Administrative Tribunal, and criminal law, requires further investigation in the Canadian context. There do appear to be precedents in other jurisdictions. For example, an administrative body, the 'Settlement Agents Supervisory Board' of Western Australia, responsible for regulating the activities of licensed settlement agents or conveyancers has powers to consider referring matters to the police for investigation when it has evidence of criminal conduct of settlement agents. A fuller review would examine this and other examples in Canadian and international jurisdictions. See Government of Western Australia, A guide to investigations and disciplinary proceedings under the Settlement Agents Act 1981 (Perth: Settlement Agents Supervisory Board).

247 We draw this formulation of the duty of the Tribunal to consider all possible support options prior to

making a determination that the person should be placed in a facilitated status from the Substitute Decisions Act, 1992, S.O. 1992, c. 30, ss. 22(3), 55(2). 248 Koch (Re), (1997) 33 O.R. (3d) 485 (Gen. Div.).

In Koch (Re), (1997) 33 O.R. (3d) 485 (Gen. Div.) Mr. Justice Quinn said that this requirement is so important that even though a similar requirement does not appear in the Health Care Consent Act, a similar warning must be given under that act.

250 See e.g. Capacity Assessment Office, Guidelines for Conducting Assessments of Capacity (Toronto:

Ministry of the Attorney General of Ontario, 2005) at I.1, online: Ministry of the Attorney General of Ontario <a href="http://www.attornevgeneral.jus.gov.on.ca/english/family/pgt/capacity/2005-05/guide-0505.pdf">http://www.attornevgeneral.jus.gov.on.ca/english/family/pgt/capacity/2005-05/guide-0505.pdf</a> (last accessed: 12 October 2010).

<sup>&</sup>lt;sup>240</sup> Peter Bartlett, "Mental Health Law after the CRPD," in Honouring the Past, Shaping the Future: 25 Years of Progress in Mental Health Advocacy and Rights Protection, 25th Anniversary Report, Psychiatric