Recognition of people’s right to consent to health care is linked to legal capacity and to respect for physical and mental integrity. Traditionally, children and persons with mental illness have been denied this right and substitute decision-making systems have been used for their protection. Today, respect for rights and freedoms forces courts and legislators to find a balance between autonomy and protection. However, domestic law lacks vision and objectives, often ending up breaching both protection and autonomy rights, or prioritizing one to the detriment of the other. One should turn to the supported decision-making model, which addresses protection concerns while respecting people’s integrity and autonomy.

La reconnaissance du droit à consentir ou non à des soins de santé est liée à la question de la capacité juridique ainsi qu’à celle du respect de l’intégrité physique et mentale de la personne. Traditionnellement, les enfants et les personnes atteintes de maladie mentale se sont vu nier ce droit, et des systèmes de prise de décision au nom d’autrui ont été utilisés pour les protéger. Aujourd’hui, le respect des droits et des libertés oblige les tribunaux et les législateurs à trouver un équilibre entre autonomie et protection. Cela dit, la vision et les objectifs inscrits dans le droit interne présentent des carences; et il arrive souvent que l’on porte atteinte à la fois au droit à la protection et au droit à l’autonomie, ou que l’on accorde priorité à l’un de ces droits au détriment de l’autre. Nous devrions nous tourner vers le modèle de l’aide à la prise de décision, qui satisfait aux nécessités reliées à la protection de la personne tout en respectant l’intégrité et l’autonomie de celle-ci.

I. INTRODUCTION

Minors and people with mental illness have always been subject to restrictions on their capacity to be holders of rights and obligations and to exercise those rights. Society has traditionally sought to protect these two groups from making their own decisions, ostensibly for their own good and the good of others. Such protective...
attitudes have led to the adoption of paternalistic legislation which is still considered acceptable for children but is largely seen as violating the rights of persons with psychological disabilities. Increasingly, however, both international and domestic law have emphasized the equal dignity and freedom of all individuals, and autonomy has emerged as a new value that casts into doubt the value of protectionist regimes. While protectionism favours solutions that allow for substitute decision-making or decisions made by others, autonomy calls for the full involvement of affected persons in decision-making. Although autonomy may increasingly appear as the modern motto in the consent and capacity context, Canadian courts and policy-makers apply it with much hesitation. Indeed, decision-makers often return to a protectionist paradigm, stripping individuals of their autonomy rights if their choices are deemed to lead to a socially unacceptable outcome. Tension between protection and autonomy has caused conceptual confusion and negatively influenced the lives of those who remain affected by the protection-autonomy dichotomy. New ways must thus be sought to approach health care related decision-making in a way that is respectful of both protection and autonomy rights of children and persons with mental illness.

This paper problematizes the current Canadian approach to consent and capacity by pointing to the conceptual ambiguity and contradictory decision-making that marks Canadian law both in relation to those with mental illness and children. It argues that the confusion and contradictions can be traced to the inability to move beyond the categorical approach to consent and capacity, which cannot reconcile the need for protection with the modern impulse towards autonomy. The paper first sets out to delineate the importance of consent and capacity to the human condition, before reviewing historic approaches to the capacity claims of children and those with mental illness. This helps to situate the modern approach and to emphasize that, while movements towards the autonomy model have been made, the protectionist approach remains integral to decision-making. The second part of the paper suggests supported decision-making as an alternative model for conceptualizing and deciding matters of consent and capacity. Focusing on consent and capacity in the health care context, it briefly reviews the extent to which Canadian jurisdictions have begun to experiment with delivery models that approach, but do not fully embrace, supported decision-making. The discussion is intended to encourage rethinking of existing models of decision-making in addition to encouraging greater consideration of international legal norms and frameworks that have more fully espoused the supported decision-making regime.

II. CONSENT TO HEALTH CARE

A. Significance of Capacity and Consent

Legal capacity is intimately connected to one’s legal existence and equal recognition as a person. The Convention on the Rights of Persons with Disabilities [CRPD] clearly links legal capacity with legal personality; legal capacity is

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included in the article concerning equal recognition of the person before the law. As persons have a legal existence, they have legal capacity, which means, at a minimum, that they can be bearers of rights and obligations. However, as an examination of definitions, international instruments and comparative law demonstrates, legal capacity usually signifies not only the capacity to be a holder of rights, but also the capacity to exercise these rights. Legal capacity thus includes also the capacity to act and signifies being able to exercise one’s rights. It implies for example the right to make decisions in areas such as administering one’s own financial matters, accessing financial credit, inheriting and administering property, making a will, marrying and being involved in legal procedures. According to disability rights advocates, the finding of incapacity therefore undermines full personhood.

Consent and capacity constitutes not only an important right in its own sake but also implicates other rights. In case of mental illness, depending on legislation, individuals can be involuntarily committed to a psychiatric facility. Provincial mental health laws allow involuntary commitment where concerns over dangerousness arise, as the person who is involuntarily committed into a psychiatric institution is considered a threat to him/herself or to others. The decision to impose commitment or psychiatric evaluation can be made (depending on legislation), by a court, a physician, a psychiatrist practicing in a mental health institution, or even a police officer. Too often, the dangerousness determination is rooted in the very fact of the mental illness.

Health care reveals most starkly the link between consent and capacity and other fundamental rights. A determination of incapacity can lead to interventions such as surgery (including sterilization and psychosurgery), prescription of medication (including psychotropic drugs), forms of psychiatric treatment (including electroshock) and admittance into a health care facility, such as a hospital (including psychiatric institutions). It has even been argued that involuntary psychiatric treatment can constitute torture or inhuman and degrading treatment. There may also be subsequent consequences. For example, some

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6 The right of involuntary patients to refuse treatment is recognized in Fleming v Reid (1991), 4 O.R. (3d) 74 (C.A.) [Fleming].
7 See e.g. Saskatchewan Mental Health Services Act, S.S. 1984-85-86 C. M-13.1, s. 19.
8 See e.g. Manitoba Mental Health Act, C.C.S.M. c. M110, s.8(1).
9 See e.g. Quebec Act Respecting the protection of persons whose mental state presents a danger to themselves or to others, R.S.Q., c. P-38.001, art.8.
10 See e.g. Ontario Mental Health Act, R.S.O. 1990, s. 17.
11 Fleming supra note 6.
psychotropic drugs can adversely affect cognitive abilities, thus putting individuals on a slippery slope towards greater dependence. It is therefore not surprising that the negotiations of articles 12 (equal recognition before the law) and article 17 (protecting the integrity of the person) of the CRPD were often intertwined, and the Chair of the drafting committee noted that these two articles overlap and go to the heart of the Convention.

Most societies accept that the exercise of capacity can be subject to requirements, such as age, or the capacity to understand one’s actions and their consequences. Therefore, some groups do not automatically exercise their legal capacity, and are often prevented from making personal choices. Children and those with mental illness are most often affected. Persons with psychosocial disabilities tend to be doubly affected by determinations about their decision-making capacity because of specific laws concerning mental illness and institutionalisation, in addition to laws focused on consent. They, more than any other group, are likely to be involuntarily admitted to health care facilities, especially psychiatric hospitals, and to receive medication and other treatments involuntarily. States’ interventions during the CRPD negotiations made plain that they wanted specifically to protect their ability to make decisions about the treatment of this group of people. Questions concerning children’s capacity tend to arise when a child, with or without the approval of his or her guardian, refuses potentially life-saving treatment, often because of religious conviction. Several cases involve Jehovah’s Witnesses, who, usually supported by their parents, refuse blood transfusions. Other cases may concern children who prefer that their parents not be told that they have sought treatment or advice related to pregnancy, sexually transmitted diseases or drug addiction.

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13 Fleming, supra note 6.
14 Ad Hoc Committee Daily Summaries of Discussions, 8th session, 15 August 2006, notes on file with the author.
15 Such as Ontario’s Mental Health Act supra note 10 at c. M.7.
16 One might also note that people with intellectual disabilities are also routinely deemed to be incapable of making personal decisions. However, they have not been included in this study, as the negotiations on the CRPD and the lobbying by disability organizations revealed that this group does not contest the role of supportive family as decision-makers as strongly as persons with mental illness. This is a generalization but the statement is reflective of claims made by organisations representing each group of persons with disabilities. Based on interventions by representatives of both groups during the Ad Hoc Committee negotiations for the CRPD, persons with psychological disabilities were mostly represented by the World Network of Users and Survivors of Psychiatry [WNUSP], and persons with intellectual disabilities were represented by Inclusion International. See negotiations archives online: UN Enable <http://www.un.org/esa/socdev/enable/rights/adhoc-com.htm>.
Whether decisions involve children or persons with psychological disabilities, the patient’s integrity is always in question: Will the person be able to have a say in the type of treatment he or she will receive? Will the person have to live with the consequences of treatments that have been chosen against his or her will? The consequences for the affected individual are profound and may include rejection by one’s community, strain in family relations, breach of one’s deepest moral and religious convictions, or serious physical and mental side effects that will have consequences on one’s quality of life.

**B. From the Protection Perspective to Liberation Movements**

Historically, both minors and the mentally ill have been subject to restrictions on their capacity to be holders of rights and obligations alongside numerous restrictions on their capacity to act and exercise these rights. The emergence of the rights of the child is directly linked to the emergence of the notion of childhood as a time of vulnerability that demands societal protection. This realization sparked off an era of state intervention, contrasting with earlier consideration of children as property of their fathers, who held life and death rights over them. The phenomenon of abusive child work in urban centres in the 19th century produced destitute children roaming the streets and coincided with an increase in juvenile crime. Philanthropic, often church-led protective initiatives and legislative responses followed. The need to contain children in irregular situations was sometimes expressed with a mixture of pity and alarm. An 1886 British pamphlet titled “Children’s Rights” typically described the number of “neglected and famished children... this vast army of unkept, ragged, almost naked starvelings as they quickly march, with bare feet past your door”, and then declared that if these children continued to be “left alone by the Church and the State, they [would] inevitably grow up to propagate their vile class and to inflict a terrible retribution upon the society that neglects them.” Protection became the focus and the best interests of the child principle was applied without any procedural guarantees or legal guidance.

The best interests principle was also applied to persons with mental illness. Many of the provincial mental health acts have their roots in the 19th century British Lunatic Asylum Act. At their basis, these acts have the possibility of involuntary admission into these “asylums” for protection purposes. The need for treatment itself constituted the main reason for committal. Admitted persons were subject to involuntary treatment in the name of their best interest. Courts continue to affirm that protection should be exercised in the best interests of the person in

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22 See e.g. British Factories Act 1833 (3 & 4 Will. IV) c. 103.
25 See e.g. S.B.C. 1897, c.17.
26 Gray, Shone & Liddle, *supra* note 24 at 32-35.
need of protection.\textsuperscript{27} While the Supreme Court has placed high value on the “individuality of the mentally incompetent person”,\textsuperscript{28} it has, on a more paternalistic note, affirmed that it “undoubtedly has the right and duty to protect those who are unable to take care of themselves, and in doing so it has a wide discretion to do what it considers to be in their best interests.”\textsuperscript{29}

Critics and patient rights advocates have denounced reliance on the best interests principle as being overly paternalistic, not respectful of adults’ rights, vague, subjective and open to abuse.\textsuperscript{30} Yet, it remains anchored in domestic legislation.\textsuperscript{31} References by states to the best interests principle in proposals submitted during the CRPD negotiations as well as its presence in earlier versions of the convention text speak volumes about its centrality to approaches to persons with disabilities.\textsuperscript{32} By contrast, child rights advocates do not contest the use of the best interests principle, as children are a group that needs special protection due to their development needs and their dependence on adults. However, critics recognize the risk that the best interests principle may be, and has been used to contradict child rights.\textsuperscript{33} While there is no definition of best interests and no uniform criteria for its use, advocates emphasize that its application, as well as the outcomes of its application, need to respect children’s rights, including their autonomy rights. This is clearly required by the CRPD, and it has also been recognized in Quebec law.\textsuperscript{34}

While traditional protection approaches have not disappeared from law pertaining to children and persons with psychological disabilities, the discourse started shifting away from protection towards rights and autonomy in the late 1950’s. The civil rights movement emphasized empowerment, revealed the injustices of some state-led policies and legislation and also coincided with the development of international human rights instruments\textsuperscript{35} and led to human rights protection in national legislation.\textsuperscript{36} For persons with psychological disabilities, the

\textsuperscript{27} E. (Mrs.) v Eve, [1986] 2 S.C.R. 388 at para 63 [Eve].
\textsuperscript{28} Ibid at paras 89, 94.
\textsuperscript{29} Ibid at para 99.
\textsuperscript{31} See e.g. Nova Scotia Hospitals Act, R.S. 1989s. 54A, 54B, and the Adult Protection Act, R.S.N.S. 1989, c. 2, s.9.
\textsuperscript{32} See Daily Summaries supra note 30; Background documents, article 17, online: UN Enable <http://www.un.org/esa/socdev/enable/rights/ahcstata17bkgrnd.htm>. It is to be noted that due to the successful lobbying by disability organizations, it did not get included in the Convention text.
\textsuperscript{34} See art. 33 C.C.Q., and Commission des droits de la personne et des droits de la jeunesse c. Commission scolaire des Phares, 2009 QCTDP 19 (Canlii) at 323.
\textsuperscript{35} The International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights were adopted in 1966. This led to the development of many more human rights conventions, including the Convention on the Rights of the Child in 1989 and the Convention on the Rights of Persons with Disabilities in 2006.
\textsuperscript{36} Notably the Canadian Charter of Rights and Freedoms, Constitution Act, 1982, Part I, Schedule B Canada Act 1982 (U.K), 1982, c.11, which is considered to be the main piece of legislation in
1960s saw calls for ending involuntary committal, limiting committal to those deemed dangerous to society, and introducing the concept of consent to treatment, which implied the possibility to refuse treatment. Some, following the reasoning of Szasz, even posited mental illness as myth, and many argued that mental hospitals constructed the conditions that were equated with illness. At the same time, terms used for the mentally ill who received psychiatric treatment evolved from “lunatics”, to “patients”, and to “survivors”, inspired by movements led by persons with psychosocial disabilities.

Similar views were made about children’s rights in the 1970s. Authors, such as Farson and Holt, who followed the “child liberation movement”, drew attention to the fact that children are human beings of the same value as adults, and that consequently they should have similar rights and responsibilities as adults. Critics questioned laws’ role in artificially keeping children in a state of incapacity and immaturity and argued that many children are as capable as adults while others need experience to become capable through the exercise of rights. If presumed incapable, children will not be able to show that they are capable, or learn to be capable. While the influence of the liberationists has waned, some authors still argue for the autonomy of children, and there is some recognition that children’s autonomy and protection rights are interdependent.

C. Today’s Ambivalence: Between Protection and Autonomy

Modern legislation continues to exhibit remnants of paternalism but law has become more respectful of the rights of persons with disabilities. Autonomy Canada to give effect to internationally recognized human rights, and which gives constitutional protection to procedural rights, and to the protection of personal integrity.

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37 Gray, Shone and Liddle, supra note 24 at 30.
38 Ibid at 37-38.
44 See e.g David Archard, Children: rights and childhood, 2nd ed, (London: Routledge, 2004).
rights are recognized and the best interests standard is no longer central to a determination of capacity. But, an examination of case law relating to children and to persons with psychiatric disabilities clearly shows some hesitation to move away from the initial protection paradigm. It appears, for example, that recognition of a person’s capacity poses a problem when the person refuses treatment that is lifesaving or deemed to be in the person’s interests more generally. Conclusions about capacity and the right to make certain decisions are too often really backdoor assessments about the reasonableness of the decision rather than the capacity of the person to make it in the first place. Refusal of treatment can be equated with incapacity by some psychiatrists and this approach may be approved in courts. While assessors of capacity should only be interested in the process the individual went through to arrive at a decision, their conclusions may inappropriately reflect their subjective views about the substantive decision made by the patient. Courts’ bias for psychiatric assessments that favour decisions which seem rational or in the best interests of the patient, indicate that paternalistic attitudes have not completely given way to a guarantee of rights. Similarly, case law shows that when children make decisions that are deemed unreasonable by the decision-maker, they are more likely to be defined as immature minors than when their decisions seem to be in their best interests.

In Starson v. Swayze, the Supreme Court enlarged the scope of capacity by admitting that it is enough if the patient merely recognizes some of the manifestations of his or her illness, instead of having to recognize the particular diagnosis by the physician (bipolar disorder in the case of Starson). Moreover, deterioration of the person’s condition is irrelevant to the determination of capacity. However, general resistance to disconnecting illness and finding of capacity remains. Courts from other jurisdictions have not necessarily felt bound

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47 See e.g. Starson, supra note 30 at para 75
48 Ibid at para 91.
49 Ibid at paras 76, 91. The dissenting judges agreed with this (see paras 19, 36). Also, according to Sklar, this principle should bind all Canadian jurisdictions: Ronald Sklar, “Starson v Swayze: The Supreme Court Speaks Out (Not all That Clearly) on the Question of ‘Capacity’” (2007) 52:6 The Canadian Journal of Psychiatry at 390.
50 See Katherine Brown & Erin Murphy, “Falling through the Cracks: The Quebec Mental Health System” (2000) 45 McGill LJ 1037 at 1068.
51 Kerzner, supra note 46.
53 Starson, supra note 30 at para 79.
54 Ibid at para 119.
by a decision that applies to Ontario legislation. Other provinces may use other tests to determine capacity. A hesitant move away from paternalism can also be seen in the conditions for involuntary commitment which can no longer be justified as in the person’s best interests. The criterion is generally that of the dangerousness of the person to him/herself or to others. As it is recognized that involuntary commitment infringes on a person’s autonomy rights, conditions for commitment may be quite stringent even giving rise to the criticism that the dangerousness regime does not sufficiently protect the patient. However, while the law is focused on the protection of the value of autonomy through the guarantee of rights, one can find some elements of the protection regime. In particular, courts have sometimes interpreted the notion of dangerousness more in conformity with the best interests principle, and legislative changes towards the danger standard have been treated as “a reformulation of the welfare test”. Even in a jurisdiction like Ontario, where conditions for involuntary treatment and admission of patients with mental illness are extremely stringent, courts have managed to introduce a welfare understanding of the notion of dangerousness.

Similar hesitation in the move away from protectionism and the consequent confusion also arises with respect to children. Legislation that deals with children’s capacity to consent to health care varies greatly across provinces. Even where legislation recognizes the possibility for minors to make health care related decisions, there are generally provisions that limit this right to consent, especially in the case of life threatening situations or other emergencies. In addition to legislation, case law gives some clarity to the question of minors’ right to consent to health care which is increasingly respectful of mature minors’ autonomy, but ultimately favouring life-saving approaches. The supremacy of the paternalistic and protectionist best interests principle in questions concerning a child’s health care decisions was recognized by the Supreme Court of Canada in the recent case of A.C. v. Manitoba, which concerned medical treatment given against a child’s wishes. While the Supreme Court made some advances in assuring mature children’s participation rights, it clearly endorsed the judge’s power to determine in each case what is in the child’s best interests.

58 It should be noted that generally appeals of decisions of involuntary commitment are allowed in provincial legislation. See e.g. the Ontario Consent and Capacity Board, created under the Health Care Consent Act, S.O. 1996.,
59 Institute of Law Research and Reform, supra note 19 at s. 20 (1.1).
62 Subotic v Roopchand, 14 July 1989, Elgin 701/89 (Ont. Dist. Ct), recounted in Brown & Murphy, supra note 50, 1054.
63 See art.16-17 C.C.Q.
64 A.C, supra note 18.
D. Canadian Ambiguity on the International Scene

In the development of the CRPD, Canada played a leading role as facilitator to article 12, which deals with persons with disabilities’ equal recognition before the law, including recognition of their legal capacity. This article was one of the most difficult ones to negotiate because of divergence in the definition of legal capacity: whether it implied only the capacity to a holder of rights or whether it includes the capacity to exercise rights. If legal capacity is understood as implying the capacity to act, it means that all persons should be able to make decisions concerning their personal affairs, including decisions affecting their physical and mental integrity. Survivors of psychiatry present at the negotiations likened the loss of legal capacity to “civil death”, because in many countries, the finding of incapacity may lead to full guardianship.

The article was also difficult to negotiate because disability groups asked that supported decision-making be recognized as the only possible way to deal with situations in which people with disabilities have difficulty in exercising their rights. With supported decision-making, those who have difficulty in making decisions, or are not capable of doing so, remain legally capable, but obtain assistance on a scale from 0-100%. The International Disability Caucus [IDC] explained: “as capacity increases, support decreases – a concept that is not allowed in guardianship”. Many states opposed completely eliminating substitute decision-making; Canada proposed a compromise text, based on the suggestion made by the IDC. The new text removed all reference to substitute decision-making, and included appropriate safeguards to protect rights of persons with disabilities. Canada explained that this way, the Convention would not formally prohibit substitute decision-making, but that it would encourage supported decision-making. Paragraphs three and four of article 12 thus read:

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

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65 See list of facilitators by article, Negotiation Archives, online: UN Enable <http://www.un.org/esa/socdev/enable/rights/ahc6listfacilitator.htm>.


67 Caucus of over 70 disability organizations that had decided to unite their voices to better lobby governments.


69 See Canada’s proposed text for article 12 at the 7th session of the Ad Hoc Committee, online: UN Enable <http://www.un.org/esa/socdev/enable/rights/ahc7canada.htm>. 
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.  

These gains proved very difficult to obtain, as many delegations expressed the need to be able to regulate the lives of persons who do not seem to be in control of their actions. Some wanted to distinguish between different types of disabilities, thus singling out psychological disabilities: “A distinction should be made between legal capacity of people with physical and mental disabilities”; “There is at least one category of disability (mental illness) for which a declaration of incompetence would not be discriminatory”. An unprecedented solution was suggested by China, and supported by the Russian and Arab delegations, involving the inclusion of a footnote to article 12, stating: “In Arabic, Chinese and Russian, the term ‘legal capacity’ refers to ‘legal capacity for rights’, rather than ‘legal capacity to act’”. After extensive consultations and informal meetings, the drafting committee finally decided to delete the footnote at its very last meeting, prior to the adoption of the convention in December 2006.

While playing a key role in advancing the rights of persons with psychosocial disabilities during the negotiations, Canada, surprisingly, is the only state party along with Egypt, to date, to have made reservations on the issue of legal capacity, indicating a regressive approach. Canada’s reservation and interpretation reads as follows:

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 that 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.

70 *CRPD, supra* note 2 at Art. 12, paras 3,4 (Author’s italics).
72 Intervention by Russian delegation, ibid.
73 Report of seventh session the Ad Hoc Committee, UN Doc. A/AC.265/2006/2, Annex II.
Such reservations have been deemed unacceptable by disability organizations and disability rights activists, since article 12, while not prohibiting substitute decision-making, should be understood as implying an obligation to move towards supported decision-making. Canada has thus sent mixed signals at the international level regarding its position on supported decision-making. It has simultaneously but irrationally moved from a champion of disability rights to the protection of status quo. The same tendency to cling to the protectionist paradigm is evident in Canada’s stance regarding children’s rights.

Unlike the CRPD, the Convention on the Rights of the Child [CRC] does not discuss legal capacity. However, it includes provisions that can be used to advance children’s right to make personal decisions. Article 12, particularly, which Canada supported during the negotiations of the Convention, deals with children’s right to be heard in all matters concerning them. Clearly this includes children’s right to express their opinion on questions concerning their health care, and the obligation of decision-makers to take their viewpoints into consideration. Indeed, article 12 gives children a procedural right and imposes a two-step legal obligation on states. First, children should be able to express their views in all matters concerning them, and second, their views should be given a certain degree of weight by decision-makers, depending on the child’s age and maturity. With reference specifically to judicial and administrative procedures affecting children, the article states that children should be heard either directly, or through a representative. This means that at every level, children should have the opportunity to be heard: in the doctor’s office, as well as in court if the refusal of health care becomes a child protection issue. It should also mean that parents, who usually have the power to consent on their child’s behalf, should use their power in a way that takes into account their child’s wishes. Indeed, article 5 of the CRC, also supported by Canada during negotiations, states that parental direction must be provided in a manner consistent with the evolving capacities of the child. The decrease in parental direction and the increase in the weight given to the views of the child should thus coincide.

The combined reading of articles 5 and 12 of the CRC clearly rules out total incapacity based solely on being a minor. Moreover, article 5 can be a basis for supported decision-making, as it asks States Parties to “respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the [CRC].” It therefore calls for those responsible for the child, including larger support networks, to support children as they exercise their rights.

While Canada was in favour of articles 5 and 12 on the child’s right to be heard during the negotiations on the CRC, it took special interest in article 3 dealing with

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78 Ibid at 50-51.
the best interests of the child.\textsuperscript{79} This truly reflects Canadian tradition and values related to the rights of the child, which are based on the concept of the best interests of the child. It goes along with the position that while being supportive of children’s right to express their views, children’s views are simply one of the many considerations when determining their best interests.

Given Canada’s position on provisions in the CRC, the case of A.C. v. Manitoba is particularly interesting, as the Supreme Court links the notions of the best interests of the child and the child’s right to be heard: \textsuperscript{80} two of the general principles of the rights of the child.\textsuperscript{81} Yet, it is notable that the interpretation of the CRC by its monitoring body, the Committee on the Rights of the Child, gives greater weight to children’s participation in decision-making, as it emphasizes \textit{all} children’s right to participate, not just the older ones. In its \textit{General Comment} on Article 12 on respect for the views of the child, the Committee states that there should be a presumption that every child has the capacity to express his or her views, and that it is up to states to evaluate children’s capacities.\textsuperscript{82} According to the Committee, all children should be given the opportunity to express their views in a way that is suitable to their age and individual needs, and no age limits should be placed on the child’s right to be heard.\textsuperscript{83} In the context of health care, the Committee welcomes legislation that determines a fixed age at which the right to consent transfers to the child but recommends that “where a younger child can demonstrate capacity to express an informed view on her or his treatment, this view is given due weight.”\textsuperscript{84} Needless to say that “due weight”\textsuperscript{85} indicates that the child’s wishes will never automatically take precedence, and that the best interests of the child will be an equally important consideration in the final decision. There is thus simply a difference of degree between the CRC and Canada’s approach to children’s consent. However, the current approach gives no consideration to supported decision-making, which could also be applied to children’s decision-making.

\textbf{III. MOVING BEYOND THE AMBIGUITY}

\textbf{A. Supported Decision-Making and Those with Mental Illnesses}

Persons with mental illness recognize that they may sometimes need help to make decisions. This is not surprising because, after all, doesn’t every person find

\textsuperscript{79} \textit{Ibid} at 126.
\textsuperscript{80} A.C., \textit{supra} note 18.
\textsuperscript{81} The Committee on the Rights of the Child has determined the principles of the CRC to be: Non-discrimination (art. 2), best interest of the child (art.3), right to life, survival and development (art.6), and respect for the view of the child (art.12).
\textsuperscript{82} Committee on the Rights of the Child, \textit{General Comment No.12: The right of the child to be heard}, 2009, UN Doc. CRC/C/GC/12, at para 20.
\textsuperscript{83} \textit{Ibid} at para 21.
\textsuperscript{84} \textit{Ibid} at para 102.
\textsuperscript{85} \textit{Convention on the Rights of the Child, 20 November 1989, 1577, U.N.T.S. 3} at art.12: “States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child”. (emphasis added)
\textsuperscript{86} \textit{Ibid} at art 3: “In all actions concerning children... the best interests of the child shall be a primary consideration”. (emphasis added)
him/herself sometimes in a vulnerable position, especially when serious medical decisions have to be made? Isn’t every person’s integrity worth preserving through attitudes and measures that value autonomy? Everybody, including the most able and capable adults sometimes make bad decisions, and might need some support in their decision-making process. One can even say that “[t]he right to be foolish is an incident of living in a free and democratic society. [T]he right to voluntarily assume risks is to be respected… The dignity of the individual is at stake.”

Autonomy in decision-making is both a normative and instrumental good. Having the freedom to make the decisions renders people less vulnerable the next time they are confronted with a similar situation. Amita Dhanda notes that “[a] label of incompetence can often play out as a self-fulfilling prophecy”. In short, consent and capacity decisions for both those with mental illnesses and for children can be made in a way that supports dignity and autonomy without sacrificing protection. Supported decision-making represents the way forward.

Supported decision-making recognizes that consent and capacity rarely requires zero-sum approaches. Supported decision-making respects autonomy while responding to protection concerns. People with mental illnesses want to be able to rely on their own networks for support, and it is important that these networks be legally recognized. The role of support circles is recognized in Re Koch, with the assertion by Quinn J that “mental capacity exists if the appellant is able to carry out her decisions with the help of others”. Health care related decisions can thus be made together with persons from this recognized support network, and such decisions should be legally validated. This would help move away from the capable/incapable dichotomy and focus on support instead. When persons do not have their own support network, which may be common among persons living with mental illness, it should be the state’s responsibility to offer support services. This is currently not a model that exists in Canada, and it is rare elsewhere as well. A good example, however, is provided by the Swedish personal ombudsman.

During the CRPD negotiations, the World Network of Users and Survivors of Psychiatry [WNUSP], which represented the interest of persons with psychosocial disabilities, advocated for the recognition of assistance and support for persons to be able to exercise their legal capacity instead of removing this capacity. WNUSP describes supported decision-making as:

the model [that] recognizes that interdependence in decision-making is a fact of life for all human beings and is based on the recognition and facilitation of relationships of trust between individuals. No competency tests would be imposed under this model and procedural safeguards only exist to ensure that the person providing support is meeting his or her obligations.

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89 Re Koch, supra note 87 at para 89.
90 PO-Skåne, online: <http://www.po-skane.org/ombudsman-for-psychiatric-patients-30.php>.
including the obligation to follow the wishes of the person receiving support. A new public office would be created to facilitate the development of trusting relationships for individuals who are currently isolated, and there is a residual judicial power of decision-making when the wishes of an individual cannot be ascertained or interpreted and an important decision must be made.\footnote{WNUSP comment at the Third session of the Ad Hoc Committee, online: UN Enable \<http://www.un.org/esa/socdev/enable/rights/ahc-stata12stcomments.htm#wnusp>.}

Such a model would allow for a sliding scale of support depending on the person’s need: from minimal to a high level of support. One could even argue that such assistance may be considered a reasonable accommodation, as much as sign language interpreters are for the deaf. Moving completely from substitute decision-making to supported decision-making would mean that assistance should be provided instead of holding the person incompetent.\footnote{Dhanda, supra note 88 at 429.} Consideration for a person’s capacity would therefore lose significance, because most people would become capable with assistance. This model would improve advance directives as the support person or network would help the person articulate his or her preference, and when not possible, they would attempt to get cues from the person to find out what his or her preference might be. This could include the use of advance directives, but it would not be limited to that. The model would be particularly well suited to persons with psychosocial disabilities, since many of them experience periodical episodes where they may be less in control of their decisions. It is therefore important that a trusted person, who knows the patient well, helps him or her to make a decision. The assistant could also make an informed guess of what the person’s preference would be if he or she was not going through such an episode.

Such a model would not only avoid violations of a person’s integrity and guarantee autonomy rights, but it would also be conducive to better protection of persons with disabilities. Indeed, it would allow the development, active use and recognition of support networks in the case of people who are often marginalized and disconnected from the community. It would give a strengthened role to their existing friendships and allow them to leave isolation with an appointed support person, when needed. This is clearly a way to move away from a conflict between protection and autonomy values.

Canadian law, however, remains largely embedded in the notion of substitution rather than support. Where a person is deemed to lack the capacity to consent, another person can consent on behalf of the patient. The substitute decision-maker can be a guardian, a family member, or a public trustee. Many provincial laws set up a hierarchy of individuals or agencies who may consent to treatment on behalf of an incapable person.\footnote{See e.g. Ontario Health Care Consent Act, supra note 58 at s. 20(1) or art.15 C.C.Q., art. 15.} Substitute decision-making is generally an all or nothing, zero-sum affair. Either a person has the capacity to consent in relation to a particular decision or they do not.
But, there has been some movement within Canadian jurisdictions towards supported decision-making. For example, there has been a move towards an alternative decision-making model which permits prior agreement so that a person, while capable, will be able to make arrangements for the time when he or she might be found to be incapable of making a decision. Examples include the Saskatchewan Health Care Directives and Substitute Health Care Decision Makers Act, the Manitoba Health Care Directives Act, or the British Columbia Representation Agreement Act. Generally, this means that the person in question will be able to choose his or her representative and to give directions in advance to that representative. While advance directives can be considered a form of support, and certainly preferable to traditional substitute decision-making, it does not move away from the capacity/incapacity distinction, since once the person in question is deemed incapable of making decisions, he or she will lose any say in the decision-making process. The appointed support person will make a decision on his or her behalf, following the advance directives given to him while the patient was mentally capable.

Other developments include adaptations to the role of substitute decision-makers to better respect the principles of dignity and autonomy. In Ontario, for example, it is understood that the substitute decision-maker, in advance agreement situations, must make a decision that complies with the most recent wish expressed by the patient, while he was capable. This is not expressly stated in the Health Care Consent Act itself, which includes the person’s wishes as simply one of the considerations when determining the person’s best interests. However, prioritizing the person’s wishes before even considering best interests has been developed as a guide for practitioners. The Act does state however, that “[t]he guardian shall encourage the person to participate, to the best of his or her abilities, in the guardian’s decisions on his or her behalf”.

A third development, co-decision-making, is closer to the supported decision making model of the CRPD. Saskatchewan and Manitoba have co-decision-making laws, which promote autonomy rights and the possibility for people, including those with mental disabilities, to make their own decisions and to get help for this decision-making, in a way that respects their dignity and independence. However, limitations exist to their application. Manitoba’s Vulnerable Persons Living with a Mental Disability Act explicitly excludes persons with “mental disorder”, and applies only to intellectual disabilities. As for Saskatchewan, arrangements made under the Health Care Directives and Substitute Health Care Decision Makers Act take precedence over the Adult Guardianship and Co-decision-making Act. Moreover, co-decision-making is not

96 College of Physicians and Surgeons of Ontario (CPSO), Policy Statement, Consent to Medical Treatment, September 2005, online: CPSO <http://www.c-p-s-o.on.ca/uploaded-Files/policies/policies/policy-items/Consent.pdf> at 6,
97 Supra note 58, s. 59(4).
98 C.C.S.M. c. V90, s.1(1).
exactly the same as supported decision-making, as the appointed co-decision maker must approve of the adult’s “reasonable” decision for this decision to be validated.

More informal assistance exists in British Columbia and Prince Edward Island, where legislation permits physicians to allow patients to be assisted by a person of his or her choice. However, nothing guarantees this assistance, as the physician in British Columbia simply “may allow the adult’s spouse, or any relatives or friends, who accompany the adult and offer their assistance, to help the adult to understand or to demonstrate an understanding…”  100 As for Prince Edward Island’s Consent to Treatment and Health Care Directives Act, it limits the right of assistance to patients, who already have been deemed capable.  101 A more interesting possibility exists in Québec, where the role of an advisor to an adult in need of protection has been formalized, but unfortunately the advisership is limited to the administration of property.  102

While some provinces have adopted legislation that allows for some degree of supported decision-making, all jurisdictions reserve the possibility of substitute decision-making. There is a deep-rooted belief that a person is or is not capable, and if the person is not, then decisions are better made by another person. Indeed, even the laws that emphasize autonomy are still within a framework which is based on the capable/incapable dichotomy.

B. Supportive Decision-Making and Children

Similarly, one can value children’s involvement in the decision-making processes from an early age as a way to reduce their vulnerability without going to the limits of child liberation doctrines. This would involve adopting a skeptical stance towards preconceived ideas related to capacity and rejecting strict age-based criteria for capacity. Currently, Canadian law does not contemplate the possibility of children exercising supported decision-making. This stands in contrast with the CRC which favours giving children increasing ability to make decisions that concern them, while direction from parents gradually moves to simple guidance as children gain maturity. Direction is important for young children but changes into less obstructive guidance as the child matures. It is certainly not necessary that a supported decision-making model be formalized in the case of children in the same way as it should be for adults. There is enough recognition in domestic law of parents’ duties and responsibilities towards their children. However, it is crucial that courts give the chance to children to express themselves every time a health care related decision has to be made for them. When giving weight to children’s preferences, it is also important that the role of parents in the child’s decision-making be assessed: What was the degree of guidance provided by parents in the child’s decision-making process? Was there appropriate support? Was the child’s choice independent enough considering the child’s age?

Some elements of the model of supported decision-making for persons with disabilities would help to strike a balance between autonomy and protection rights for children. First, while the parents’ role cannot be denied, it would be essential,

100 Health Care (Consent) and Care Facility (Admission) Act, R.S.B.C. 1996, s.8 [Emphasis added].
101 S.P.E.I. 1996, s.4.
102 Art. 291 C.C.Q.
especially for adolescents, to be able to rely on a support network beyond parents, with whom children might have conflicting views, or who, on the contrary, might unduly influence children’s decision, for example, because of religious beliefs. As Day suggests, if a child’s choice is not an independent one because of the parents’ role in the decision-making, instead of simply considering the child incompetent and taking over the decision-making process, the court might offer the child other support for reaching an independent choice. This support can be from the child’s circles, such as someone from the extended family or another trusted person, or it could be someone suggested by the court, such as a doctor, a child psychologist, or another person who is knowledgeable of the issues surrounding the decision, has experience with communicating with children, and who can build a trusting relationship with the child. The purpose would not be to propose solutions to the child but to help the child think through the situation and the choices in a way that would lead to an independent choice. This choice could still be weighed against the child’s best interests. Such support is something that certainly already exists in the lives of many children whose parents or close friend play this supportive role. However, it should be ensured that each child faced with a health care decision can have the assistance of a support person to make an independent and informed choice.

The issue is thus about giving the child certain procedural guarantees (such as the right to be heard, the right to support in decision-making, the right to have one’s maturity evaluated), which will enable the child to exercise his or her autonomy rights without strict considerations of age and maturity. These rights will in turn help to respond to protection concerns about the child, as the child will be able to use trusted support to reach a well-considered and informed decision. It is thus less likely that the child will act impulsively or in conflict with persons in authority, such as parents or doctors. Involving younger children will also develop their decision-making capacity, and they will be more likely to make “reasonable” decisions as they mature. Moreover, this participation will not be contrary to the best interests of the child. From an international law viewpoint, the best interests of the child should still be determined even in the case of a mature minor. In fact, international law tends to reinforce both protection and participation rights by raising the limits of the protective minimum age and lowering the participatory age. For example, the Human Rights Committee has affirmed that protective ages must not be set unreasonably low and that in any case a State Party to the Covenant on Civil and Political Rights cannot absolve itself under the Covenant from the obligation to children under eighteen, even if they have reached the age of majority under domestic law. This is contrary to the domestic vision of childhood, which links protection only to children under a certain age, or grants participation rights only to children above a certain age. Canadian law has much to

103 The necessity to distance parents from decision-making related to their adolescent child is sometimes recognized. See e.g. P.H., supra note 52.
105 Kovell & Howe, supra note 45, at 9.
106 Human Rights Committee, General Comment 17, article 24, 1989.
107 See e.g. provincial child welfare legislation which only protects children under the age of 16 (Nova Scotia, Newfoundland and Labrador, Prince Edward Island, Ontario, Manitoba, Saskatchewan, and the Northwest Territories)
learn from international law in considering protection and autonomy values as complementary.

IV. CONCLUSION

Canadian law related to capacity and consent to health related treatment has moved from a protective model towards a greater appreciation for the importance of giving effect to a patient’s autonomy rights. However, the current approach lacks clear vision. Protection concerns are still present and seem to conflict with autonomy rights: when a person is deemed in need of protection, the person may be completely denied legal capacity to exercise his or her rights. This paper has argued for an increased attention to the supported decision-making model to consent and capacity for both individuals with mental illnesses and children. Supported decision-making acknowledges the autonomy rights of children and persons with psychological disabilities while recognizing that the most vulnerable cannot be left to their own fate. It promotes autonomy without jeopardizing protection concerns, thus helping to overcome the tensions between protection and autonomy that continues to befuddle Canadian approaches to consent and capacity. In addition to reducing conflict between the falsely incompatible values of autonomy and protection, supported decision-making moves away from indeterminate notions of maturity and mental capacity. It allows the person to remain legally competent, while receiving help in times of vulnerability.

Vulnerability is a social construct. “People don’t come ready-made as vulnerable. Their vulnerability is … brought about by social arrangements that are not sensitive to circumstances.” Perhaps no group in Canadian society is as vulnerable as groups that can be deemed incapable of consenting to what happens to them. Vulnerability exists, but it does not have to be a label that enhances marginalization, ignores rights or demands paternalistic measures. Vulnerability can and should be addressed while still respecting dignity and autonomy.

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108 See e.g. the Supreme Court of Canada in Granovsky clearly recognizes the social model of disability and the fact that the vulnerability of persons with disabilities comes more from societal attitudes than from actual impairments (Granovsky v Canada (Minister of Employment and Immigration), [2000] 1 S.C.R. 703.)

109 Quinn, supra note 5.