2021

Adult Capacity and Decision Making Act Review

Sheila Wildeman

***Adult Capacity and Decision Making Act* Review**
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Summary
My submissions on the *Adult Capacity and Decision Making Act* [ACDMA][1] are rooted in and presume basic familiarity with the *Convention on the Rights of Persons with Disabilities* [CRPD] to which Canada is a party – not only Article 12's right to equality before the law (including the supports required to actualize legal capacity), but also Article 19's right to the supports required to live in community on equal terms with others. Together these provisions are at the core of the CRPD's interlinked entitlements through which Canada and other states have guaranteed people with disabilities equal access to civil, social, economic and cultural rights.[2]

Under the CRPD and domestic human rights law, Canada's federal, provincial and territorial governments must shift existing laws, policies and practices to reverse entrenched historical patterns whereby persons with intellectual and developmental, cognitive (including dementia) and mental health disabilities have been treated as objects to be managed rather than being recognized and supported as the directing forces in their lives. In Nova Scotia, this was acknowledged with invalidation of the *Incompetent Persons Act* and subsequent passage of ACDMA, in 2017. But, we now have an opportunity to go beyond tinkering at the edges of former guardianship laws. What is required is a coordinated, intersectoral approach, attentive to the expertise and experience of persons with disabilities who have been subject to exclusionary norms -- and attentive, also, to the range of regulatory tools available to help facilitate equal enjoyment of human rights and community membership.

I divide my submission into a primary procedural suggestion and a further set of substantive considerations and recommendations. The process point is: hold off ACDMA reform until we can convene a more comprehensive consultative assessment of ***supported decision making*** – the only topic singled out in ACDMA as requiring dedicated review. The suggestions that follow first distinguish a few different models of supported decision making to inform further public deliberation on that topic, and then identify residual elements of ACDMA that, even absent further public deliberation, are in clear need of reform.

In sum, my recommendations are:

> 1. Use this process to inform a further, comprehensive review of ACDMA and other NS laws that displace decision-making capacity, the objective being to enhance the coherence of these fragmented laws and their compliance with human rights.
>
> 2. Ground the above comprehensive (deferred) review in supported decision making: ie, promoting the ability of people with disabilities to direct their own lives through *measures to be explored per recommendation #1, potentially including*:
>
> > i. Recognition of the state's duty to provide persons with disabilities with the supports necessary to activate legal capacity in and beyond ACDMA;

[1] SNS 2017, c 4.
[2] See S Wildeman, "Protecting Rights and Building Capacities: Challenges to Global Mental Health Policy in Light of the Convention on the Rights of Persons with Disabilities" (2013) 41:1 JLME 48 (https://digitalcommons.schulichlaw.dal.ca/scholarly_works/365/)

ii. Creation of a formal Supported Decision-Making regime (options for which I discuss);
iii. Creation of a Decision Support Hub (responsible for research and dissemination of best practices for supporting decision making, and coordinating access to these supports with access to other disability supports and services as well as advocacy services);
iv. Creation of a Decision Support/Representation Tribunal (responsible for oversight of support and representation agreements and the application of other laws relating to legal capacity).

3. Short of the above comprehensive measures, I suggest a few priorities for more immediate and targeted reform (which overlap in part with, but may be detached from the above) to redress specific deficiencies of ACDMA:

1. Clarify government's responsibility to ***provide/fund the supports required*** to assist in demonstrating legal capacity in the context of capacity assessments and to enhance participation in representative decision-making;
2. Establish ***pro-active monitoring/visitation and advocacy services*** for persons represented;
3. ***Remove contemplation of court-ordered aversive stimulus interventions***.

Most of these recommendations involve resource commitments. However, those commitments must be examined in light of the prospect that consolidation and rationalization of existing services and supports may increase efficiencies. Moreover, government must include in its analysis of costs and benefits the significant prospect that extending supported decision-making across sectors / services, in a manner integrated with access to other resources, will strengthen disabled persons' agency and community participation in ways preventive of intensive crisis- and conflict-based interventions as well as long-term institutionalized control and thereby reduce the social, economic and personal costs of such interventions and systems over time.

Elaboration

1. Use this consultation process to create a discussion paper in anticipation of a more comprehensive review.

I expect my opinions will be shaped further through the advisory group process. However, my starting position is that this review should be approached as a preliminary scan of community experiences and opinions prior to a more extensive analysis of ACDMA, which in turn should be nested in a wider, **comprehensive review focused on laws relating to decision-making capacity in Nova Scotia and how these might be better harmonized with each other and with human rights, including the duty to accommodate (and not exacerbate disadvantage based in) disability.**[3]

[3] This is not the first time this recommendation has been advanced. See, eg, Law Reform Commission of Nova Scotia, *Final Report: The Powers of Attorney Act* (Nova Scotia, August 2015) at 11:

> "The Government of Nova Scotia should conduct a broad review of legislation and administrative programs and processes which regulate the right to legal capacity. The review should be dedicated to ensuring that Nova Scotia's laws and public programs respect, protect and promote the autonomy of all persons, in accordance with Canada's commitments under the United Nations Convention on the Rights of Persons with Disabilities.

COVID 19 delays, together with a will to report by year's end, led to a compression of public consultation (from June 1- June 18, 2021), with many potential informants unaware of the prospect until well after the 1st. As it turned out, the final week also coincided with the conference of states parties to the CRPD. This compressed time in addition to lack of a discussion paper to focus interlocutors (themselves challenged by ongoing urgencies during COVID-19) means that the base of material to inform next steps is likely to be thin, risking dissatisfaction from all sides.

I do not doubt that there were important insights shared in the consultation process. Indeed, I was present in two excellent focus group discussions. These were convened in an engaging and respectful manner and there were clearly many opinions worthy of attention. Moreover, I understand that significant work was done to engage persons with disabilities. However, elicitation of more precise feedback – particularly on the subject of supported decision making -- would require a public discussion paper. By this I mean a preparatory analysis raising targeted questions about how ACDMA has been functioning, identifying preliminary areas of concern and introducing alternative supported decision-making models.

As you are aware, the ACDMA review was mandated to specifically consider supported decision making (s71). Pragmatically, the review must also take account of how the regime is affecting a range of constituencies including older adults, people with intellectual and developmental disabilities, and people with mental health disabilities – along with how these effects may differ on lines of gender, race, sexual orientation, rural vs urban residency, income level, etc. I am not sure how much of that work was possible in the compressed period allotted despite the enormous efforts put in. My point is that without broad community engagement by way of a discussion paper and questions targeting a few key pressure points – again, centring on supported decision making -- we are unlikely to do more than make superficial changes reflecting the experience and interests of those who are already most closely familiar with the specifics of the legal regime (and the most powerful actors involved in it): lawyers.

A further reason for my recommendation to take this consultation as preliminary to a more comprehensive review is that such a review could potentially expand to the critically important work of placing ACDMA in the context of a wider set of laws and policies more commonly affecting the lives and decision-making authority of disabled people in Nova Scotia. If we are to take seriously the CRPD imperative to centre the agency of persons with intellectual / cognitive / mental health disabilities, we must attend to how this wider set of laws and services interact to affect the ability of persons with disabilities to direct their lives and attain equal community membership.

Indeed, the suite of laws touching on decision-making capacity in NS have long required a comprehensive (rather than piecemeal) review and harmonization. These laws are so fragmented and at times opaque that professionals, families and directly affected individuals are often unable to navigate them. I refer (beyond the ACDMA) to the regimes for displacing decision-making authority under the *Hospitals Act, Personal Directives Act, Powers of Attorney Act, Adult Protection Act, Involuntary Psychiatric Treatment Act*, and personal information laws. Also touching on legal capacity are, e.g. the *Child and Family Services Act*

There is new impetus to move on the suggestion, however, as funding and service models across Health/Continuing Care as well as DCS / Disability Supports shift from institution-centred to person-directed models.

(which includes terms on capacity/fitness to parent), Civil Procedure Rules on litigation guardianship, and various mechanisms under the *Social Assistance Act* and Disability Support Program. Taken together, these laws (and related policies) fail to reflect a coherent rights-grounded understanding of legal capacity. Indeed, beyond a few sections of ACDMA, they fail to reflect the basic duty to accommodate disability central to anti-discrimination law, here translated as the duty to support adults with disabilities to make decisions about matters (including accessing services such as health care, housing, and income supports) affecting their important interests.

A comprehensive review, centred in ensuring equal access to the supports required to facilitate self-direction across social, professional and public service contexts and encompassing a suite of laws directly or indirectly limiting legal capacity, could explore what it would mean to imbue these laws with a system-wide commitment to supported decision-making. I recommend therefore that government treat the current exercise in consultation on ACDMA as a prelude to a thorough assessment of how this law fits with a wider suite of laws affecting legal capacity and how coordinated law reform may enhance the ability of persons with disabilities – indeed all Nova Scotians (all of whom rely over time on myriad regulatory supports) -- to direct their lives.

In what follows I build on this recommendation by distinguishing different ways of conceptualizing and operationalizing supported decision making and linking these to potential areas of law reform, before returning to some residual points on reform of ACDMA.

2. Ground a more comprehensive review in exploration of *supported decision making*, ie, promoting the ability of people with disabilities to be authors of their own lives.

A – What is supported decision making?

I turn to the subject this review was mandated to centre, yet which, in the absence of a discussion paper, has been positioned at the margins: supported decision making. My overarching understanding of supported decision making is that it is **"about providing the structures that will enable people with disabilities to determine their own lives."**[4] Law is able to provide or facilitate some, but not all, of these structures. The question is how law may assist in facilitating a culture shift in tandem with other initiatives from government as well as civil society.

We have a significant base of expertise in Nova Scotia and, more broadly, Canada, on supporting the decisions of persons with intellectual or developmental disabilities, other cognitive disabilities (such as dementia) or mental health disabilities – for instance, in the

[4] Michelle Browning, Christine Bigby & Jacinta Douglas, "Supported Decision Making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice" (2014) 1:1 Research and Practice in Intellectual and Developmental Disabilities 34-45 at 42.

context of medical treatment,[5] in the design and delivery of person-directed planning,[6] and through law and policy reform.[7] This experience and expertise builds on and contributes to wider global developments exploring supported decision making and, in an increasing number of jurisdictions in Canada and beyond, adopting supported decision making regimes.[8]

I will be interested to learn whether, as was the case in the lawyers' consultation I was part of, participants in this consultation have tended to hold the view that supported decision making is at best an aspirational ideal with no clear place in law. In the absence of information about the roots of the concept, or examples from other jurisdictions (BC, Yukon, Alberta, Victoria Australia, Austria, etc), there has been no ability for respondents to reflect in an informed way on this central aspect of the review.

Again, this is despite the mandated imperative to address supported decision making. In the lawyers' focus group, for instance, attendees gravitated toward how to correct aspects of ACDMA that they or their clients (most often seeking applications) have experienced as roadblocks. These observations informed recommendations such as: reduce time between application and court appearance, remove the invariability of a bond, reduce other costs and assessment requirements -- recommendations in turn framed by assertions that court-ordered representation is only sought in "the clearest cases," and often, in emergencies. Such claims raise questions: what constitutes the clearest of cases? Why are the expedited processes available under ACDMA too onerous? What concerns (eg, anticipated depletion of an individual's estate) underlie the expressed urgency? All this signals the importance of exploring a range of issues that this process appears to have been afforded insufficient time to take up in any detail.

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[5] William F Sullivan et al. "Primary care of adults with intellectual and developmental disabilities. 2018 Canadian consensus guidelines" (2018) 64 Can Fam Physician 254-79; Karen McNeil, "Managing "behaviours that challenge" - a paradigm shift?" Canadian Family Physician Newsletter (Apr 25, 2019); William F Sullivan & John Heng, "Supporting adults with intellectual and developmental disabilities to participate in health care decision making" (2018) 64 (Suppl 2) Can F Physician S32-S36. See also Surrey Place, "Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities" at https://ddprimarycare.surreyplace.ca/wp-content/uploads/2020/11/Decision-Making-Approaches.pdf.

[6] For background, see eg Anne-Marie Martin & Eileen Carey, "Person Centred Plans: Empowering or Controlling?" (2009) 12(1) Learning Disability Practice 32-37; Ontario Ministry of Children, Community and Social Services, "Creating Good Life in Community: A Guide on Person-Directed Planning": https://www.mcss.gov.on.ca/en/mcss/publications/developmentalServices/personDirectedPlanning/moreInfo.aspx. On local resources see, eg, Halifax Association for Community Living (Programs) at https://www.halifaxacl.com/programs; Autism Nova Scotia "Person Directed Planning Program" at http://www.autismnovascotia.ca/person-directed-planning-program#:~:text=The%20Person%2DDirected%20Planning%20P,goals%20that%20reflect%20their%20values.

[7] Supported decision-making laws exist (in markedly different forms) in BC, Yukon, Alberta, Manitoba, and Saskatchewan. Recent extensive law reform consultations have been undertaken in Ontario and Newfoundland. See the discussion papers prepared by Michael Bach and Lara Kerzner for both processes: Michael Bach & Lana Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity: Advancing Substantive Equality for Persons with Disabilities through Law, Policy and Practice* (Commissioned by the Law Commission of Ontario, October 2010); Bach, M. & Kerzner, L, *Supported Decision Making – A Roadmap for Reform in Newfoundland and Labrador: Final Report* (Toronto: Institute for Research and Development on Inclusion and Society (IRIS), 2020). In Nova Scotia, some attention was given to supported decision-making in the Law Commission study of Enduring Powers of Attorney under the Powers of Attorney Act, supra note 3. Bach and Kerzner (for IRIS) are currently conducting a national inventory of laws affecting legal capacity and Nova Scotia's Claire McNeil and Sheila Wildeman are advisors on that project.

[8] See the sources in note 7, supra, and see UN Human Rights Council, *Report of the Special Rapporteur on the rights of persons with disabilities* (12 Dec 2017) A/HRC/37/56.

As it stands, it may be impossible to reconcile the positions of those seeking to facilitate more direct access to representative status with the positions of people with disabilities like the My Home My Rights team, who united around the idea that they would never want someone else appointed to make their decisions. In the latter conversations there was little appetite for 'support' either, perceived as soft-selling control. Is it possible for mechanisms of supported decision making to bridge this divide? Until we have a clear foundation of concepts and models to guide conversation, we cannot know.

I believe that a careful probing of supported decision making -- not only as it exists "naturally" in people's lives but as it has been tried in various jurisdictions including through legal mechanisms -- will help strengthen public understanding, enhance the equality- and autonomy-promoting aspects of ACDMA, and provide a starting point to reconciling ACDMA and other NS regimes affecting legal capacity with human rights norms in and beyond the CRPD.

B –Four manifestations of supported decision making and law's role in each

The CRPD's aspiration of shifting policy and practice from substitute decision making (whereby persons with disabilities are treated as objects of others' plans and decisions) to supported decision making (whereby persons with disabilities are supported to realize their own goals and express equal social membership) cannot be entirely downloaded to families or civil society, nor accomplished solely through statutes or public programming. Moreover, it cannot be limited to interventions focused on decision-making processes in the absence of attention to the availability of resources and options for choice. Rather, this 'paradigm shift' requires coordinated inter-sectoral efforts to ensure that people with intellectual, cognitive and/or mental health disabilities have equal access to human rights and to the basic goods of social membership. **I suggest that this requires coordination of laws and policies on decision-making capacity/authority with laws and policies enabling access to person-directed disability services and supports.**

Here are four ways I understand there to be space for supported decision making in NS law, some of which the province has made tentative inroads on and others not. All are relevant to the current task of reviewing ACDMA.

i – Supporting the ability <u>to demonstrate decision-making capacity at the point of assessment</u> under the ACDMA or other legal mechanisms for displacing decision-making authority.

Does the ACDMA provide this form of supported decision making? *Yes, on the surface and in a limited way – but this needs strengthening and to be nested in a broader set of laws, policies and services reflective of supported decision-making.*

ACDMA is an advance beyond other statutes in NS which limit legal capacity in that it stipulates (in s.3(d)) that decision-making capacity may manifest "with or without supports".[9] This recognizes that decision-making capabilities are integrally bound up with environmental or relational components. Supports are defined in ACDMA through a non-exhaustive list

[9] See also Guardianship and Trusteeship Act, SNWT 1994, c 29, s 12(1).

including communication and interpretive support, peer support, and coordination and referral for services.[10]

However, provision of supports at the point of assessment cannot be the sole mechanism for instituting supported decision making if we aspire to facilitate equal access to the power to direct one's life. These assessments artificially isolate legal capacity to a point-in-time "test" and thus invisibilize the many structural and slow-building factors that may be involved in facilitating or disabling the capability to understand and weigh information and assume a position of agency in one's life. That is, recognition at the point of capacity assessment that decision-making capacity may be exercised with or without supports presents a narrow picture of what supported decision making signifies.

I elaborate on limitations of ACDMA capacity assessment and the potential for provision of supports in those assessments in an appendix on the Capacity Assessment Form. For instance, provision of "support" at the point of assessment is, at least on the form, limited to communication or emotional supports to facilitate the assessment encounter. There is no place on the form for the assessor to take account of a wider range of factors[11] -- extending, potentially, to structural disadvantage and the need for enhanced access to resources or services facilitating autonomy and agency across the individual's life. Factors of relevance to such assessment might include access to income, food, shelter and other services as well as persisting relationships of trust and support reaching beyond intermittent communication assistance or emotional regulation to assistance reflecting on one's goals and preferences and advocating (including, potentially, politically) for their realization. Without such supports across one's life, decision-making capacity is more likely to become suspect – particularly at times when one comes into conflict with persons in authority or power -- and one is more likely to have difficulty demonstrating decision-making capacity at discrete points of assessment.[12]

In other words, the singular moment of capacity assessment through which law enters the lives of persons with disabilities with a view to removing decision-making authority is artificially circumscribed in its restriction of supports to those most immediately relevant to the declaration of capacity / incapacity (and even there, the set of prompts on the form is overly narrow). A more far-reaching approach to supporting legal capacity is required to meet the expectations of the CRPD, recognizing that Article 12 interacts with a set of other rights relating to social, cultural and economic equality.[13] On this view, supported decision making should involve, as a baseline, carefully taking an inventory of aspects of a person's life circumstances that enable versus disable agency. Such a broad-based assessment, aimed at identifying the supports a person may need to express agency over time – as opposed to a point-in-time assessment of capacity to make a discrete decision or set of decisions, aimed at determining whether to radically disrupt decision-making authority -- is among what is required to effect the shift toward supported decision making called for by the CRPD. Just

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[10] ACDMA, s. 3(s): "'support' means, in relation to an adult's capacity, such forms of support as may be reasonably and practically available to assist the adult in making a decision, including peer support, communication and interpretive assistance, individual planning, coordination and referral for services and administrative assistance." Notably, the Capacity Assessment Form only contemplates communication and emotional support, and fails to repeat or turn the assessor's mind to the wider (non-exhaustive) statutory list.
[11] For a wider set of immediate environmental factors as well as the potential to offer decision-making coaching or skills-building, see ACDMA, s.3(s); and the Surrey Place guide to capacity assessment at note 5, supra.
[12] I discuss this in "Insight Revisited: Relationality and Psychiatric Treatment Decision-Making Capacity" in *Being Relational: Reflections on Relational Theory and Health Law* (Vancouver: UBC Press, 2012).
[13] See "Protecting Rights and Building Capacities" supra note 2.

how this broader work may be facilitated by coordinating supported decision making with other regulatory mechanisms (existing or emerging) to enable person-directed services and supports is a question a comprehensive review could address.

For more detailed commentary on limitations of the capacity assessment form, see Appendix.

ii – Supporting decision making of people represented under the ACDMA

Does the ACDMA provide this form of supported decision making? *Yes, the duties of representatives are elaborated in ways that build in certain informational, communication, and other facilitative supports. One problem however is ensuring compliance of representatives. Moreover, absence of a formal supported decision making regime may mean that some who would avoid legal incapacitation / "representation" through an arrangement based in supports are instead subject to displacement of their legal authority.*

Once a person is deemed incapable of making a given type of decision, even with support, the ACDMA judge places them under a representation order. In turn, an appointed representative must adhere to an extensive set of duties, including to inform and explore the wishes of persons represented, to guard against undue influence or conflicts of interest, and to comply with the represented person's prior capable wishes or (absent those) contemporaneous wishes unless it would be "unreasonable" to do so. (*It would be optimal to hear from representatives: how do they interpret and apply this caveat? Is this applied consistent with the spirit of the legislation / human rights norms?*). Where neither wishes nor values are known, the representative is to make a decision that promotes the person's well-being, which includes their interest in autonomy and social inclusion. The representative must also work to foster autonomy and so seek to facilitate a lifting of the order where possible.

These duties make the representative much like a decision-making supporter under other regimes (eg, BC's *Representation Agreement Act* [RAA])[14]. However, one concern reflected in the lawyers' focus group was that, absent dedicated education and oversight, those with representative power under the Act do not understand or even attempt to comply with these requirements. While it is possible that they may be challenged in court for failure to properly carry out their duties (see s.59(3) ACDMA), the likelihood is low given the barriers persons under representation face in accessing courts and lack of understanding of these duties across affected constituencies. These barriers to contesting a representative's appointment or a representative's decision make the new Act less radically different from the old than it may appear. The question of access to advocacy and oversight is addressed below in connection with discrete reforms to ACDMA separable from the need for a more comprehensive review centred on supported decision making – but these matters are related.

In short, the requirement of an ACDMA representative to inform the represented person and comply with their ("reasonable") wishes indicates an effort to build into the Act mechanisms to facilitate self-direction which reflect, in some measure, the ethos of the CRPD. Reform of ACDMA to institute a regime of supported decision making (discussed below) might enable graduated forms of support short of displacing legal authority. However, even putting aside questions about how reasonableness is currently being operationalized as a limitation on compliance with wishes, it is unclear that representatives even minimally understand or

[14] RSBC 1996, c 405.

attempt to comply with their duties under ACDMA. This informs another recommendation below – to institute education mechanisms, including mechanisms targeting representatives and those they represent for orientation and refresher courses on the representative's duties and other aspects of the Act. I link this to a proposed Decision Support Hub.

iii - Formal supported decision-making arrangements

The third kind of supported decision-making arrangement potentially facilitated through law involves formal designation of a decision-making supporter. *This is not a feature of the current Act*.

Different models of supported decision making have been recommended and/or adopted in other jurisdictions. There are many questions a review should explore before concluding which if any of these is desirable. The overarching analysis should be grounded in affirmation of equal personhood and human rights, and in overcoming longstanding systemic and structural oppression.

Questions that would assist in grounding those aspirations and orienting the commission include: Are Nova Scotians with disabilities experiencing barriers in accessing financial or other resources because of difficulties informal supporters have accessing information or assisting in communications or other aspects of decision making? Are families turning to substitute decision-making regimes for this reason? Alternatively, are Nova Scotians with disabilities being subjected to *de facto* substitute decision making, without exploration of their interest in and ability to decide for themselves? How might a formal model of supported decision making contribute to redressing these or other challenges? More ambitiously, how might such a model contribute to a broader effort to promote the interest of persons with intellectual or developmental disabilities, dementia or mental health disabilities in goal-setting as well as navigating and accessing public services -- ***consistent with the emerging ethos of person-directed planning and funding across disability supports and continuing care*****?**

Cost effectiveness must of course also be explored – but this should be done mindful of opportunities to create new system-wide efficiencies; the often hidden costs of denying basic human rights and agency (including costs of removing people with disabilities and their family members from the NS workforce); and the justice-based priority of extending opportunities to cultivate and express decision-making capabilities beyond those already enjoying "natural" supports.

In light of the above we may begin to consider the strengths and weaknesses of various alternative formal supported decision-making regimes.[15] I do not purport to cover them all here – in particular, I am holding off on an analysis of Bach and Kerzner's carefully-constructed model recently proposed for Newfoundland,[16] but it would be an excellent exercise to compare that model to those noted here (and others to be explored in a more comprehensive review).

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[15] For a circumspect review of recent law reform processes and recommendations, see Shih-Ning Then, Terry Carney et al, "Supporting decision-making of adults with cognitive disabilities: The role of Law Reform Agencies – Recommendations, rationales and influence" (2018) International Journal of Law and Psychiatry https://doi.org/10.1016/j.ijlp.2018.09.001. See also Samantha Backman, "The Right to Legal Capacity for Canadians with Disabilities: A Quest for Dignity, Equality, and Autonomy" (2020) 8:1 McGill Centre for Legal Pluralism and Human Rights Internship Program Working Paper Series esp at 27-32 and 34.

[16] See note 7, supra.

The 2019 *Guardianship and Administration Act* [GAA] adopted in Victoria, Australia[17] instituted a supported decision-making regime premised on a set of general benefits imputed to such regimes –i.e., that they:

- provide greater clarity for third parties about the nature and extent of a supported decision making arrangement, allowing them to deal with a supportive guardian or administrator more confidently than if the relationship were informal;

- provide guidance to a supportive administrator or guardian about their role and obligations;

- allow for greater monitoring and safeguards than informal arrangements.[18]

Victoria's GAA requires tribunal appointment of supporters and approval of support arrangements, and sets a threshold for entering into such arrangements guided in part by whether the supporter and supported person are in a relationship of trust, as well as whether the person supported is likely to meet functional capacity standards *where supports are in place*. A parallel supported decision-making arrangement, which by contrast does not permit certain high-stakes financial decisions, is created under Victoria's *Powers of Attorney Act, 2014* – it allows persons who meet a straightforward functional decision-making capacity test (ability to understand and appreciate the nature and consequences of the agreement) to appoint someone to support certain decisions in the absence of tribunal-based appointment.

As to the kinds of decisions that may be included in a formal supported decision-making regime, the terms of standard form supported decision-making agreements under BC's *Representation Agreement Act* [RAA] give a sense of the possibilities, contemplating an array of health, personal care and routine financial decisions and giving further content / limits to the latter in the regulations.[19]

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[17] *Guardianship and Administration Act* 2019 (Vic).

[18] *Guardianship and Administration Act* 2019 "Supported Decision Making" (Justice webpage): https://www.justice.vic.gov.au/justice-system/laws-and-regulation/guardianship-and-administration-act-2019

[19] "Routine management of an adult's financial affairs," one of the areas of decision-making included in RAA Standard Form Agreements, is defined in the regulations as follows:

2 (1)For the purposes of section 7 (1) (b) of the Act, the following activities constitute "routine management of the adult's financial affairs":

(a)paying the adult's bills;

(b)receiving the adult's pension, income and other money;

(c)depositing the adult's pension, income and other money in the adult's accounts;

(d)opening accounts in the adult's name at financial institutions;

(e)withdrawing money from, transferring money between or closing the adult's accounts;

(f)receiving and confirming statements of account, passbooks or notices from a financial institution for the purpose of reconciling the adult's accounts;

(g)signing, endorsing, stopping payment on, negotiating, cashing or otherwise dealing with cheques, bank drafts and other negotiable instruments on the adult's behalf;

(h)renewing or refinancing, on the adult's behalf, with the same or another lender, a loan, including a mortgage, if

(i)the principal does not exceed the amount outstanding on the loan at the time of the renewal or refinancing, and

(ii)in the case of a mortgage, no new registration is made in the land title office respecting the renewal or refinancing;

(i)making payment on the adult's behalf on a loan, including a mortgage, that

As already conveyed with regard to Victoria's alternative regimes, one basis for distinguishing among formal supported decision-making models is their *triggering mechanisms*. Some require court-based or tribunal appointment (as noted, Victoria's regime for supportive guardians/administrators, which contemplates a range of decisions including significant financial decisions like sale of real estate).[20] Others are instituted through an inter-party agreement, the terms of which are governed by statutory criteria but need not be

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(i)exists at the time the representation agreement comes into effect, or
(ii)is a renewal or refinancing under paragraph (h) of a loan referred to in that paragraph;
(j)taking steps under the *Land Tax Deferral Act* for deferral of property taxes on the adult's home;
(k)taking steps to obtain benefits or entitlements for the adult, including financial benefits or entitlements;
(l)purchasing, renewing or cancelling household, motor vehicle or other insurance on the adult's behalf, other than purchasing a new life insurance policy on the adult's life;
(m)purchasing goods and services for the adult that are consistent with the adult's means and lifestyle;
(n)obtaining accommodation for the adult other than by the purchase of real property;
(o)selling any of the adult's personal or household effects, including a motor vehicle;
(p)establishing an RRSP for the adult;
(q)making contributions to the adult's RRSP and RPP;
(r)converting the adult's RRSP to a RRIF or annuity and creating a beneficiary designation in respect of the RRIF or annuity that is consistent with the beneficiary designation made by the adult in respect of that RRSP;
(s)making, in the manner provided in the *Trustee Act*, any investments that a trustee is authorized to make under that Act;
(t)disposing of the adult's investments;
(u)exercising any voting rights, share options or other rights or options relating to shares held by the adult;
(v)making donations on the adult's behalf to registered charities, but only if
(i)this is consistent with the adult's financial means at the time of the donation and with the adult's past practices, and
(ii)the total amount donated in any year does not exceed 3% of the adult's taxable income for that year;
(w)in relation to income tax,
(i)completing and submitting the adult's returns,
(ii)dealing, on the adult's behalf, with assessments, reassessments, additional assessments and all related matters, and
(iii)subject to the *Income Tax Act* and the *Income Tax Act* (Canada), signing, on the adult's behalf, all documents, including consents, concerning anything referred to in subparagraphs (i) and (ii);
(x)safekeeping the adult's documents and property;
(y)leasing a safety deposit box for the adult, entering the adult's safety deposit box, removing its contents and surrendering the box;
(z)redirecting the adult's mail;
(aa)doing anything that is
(i)consequential or incidental to performing an activity described in paragraphs (a) to (aa), and
(ii)necessary or advisable to protect the interests and enforce the rights of the adult in relation to any matter arising out of the performance of that activity.
(2)For greater certainty, the activities that under subsection (1) constitute "routine management of the adult's financial affairs" do not include any of the following:
(a)using or renewing the adult's credit card or line of credit or obtaining a credit card or line of credit for the adult;
(b)subject to subsection (1) (h), instituting on the adult's behalf a new loan, including a mortgage;
(c)purchasing or disposing of real property on the adult's behalf;
(d)on the adult's behalf, guaranteeing a loan, posting security or indemnifying a third party;
(e)lending the adult's personal property or, subject to subsection (1) (v), disposing of it by gift;
(f)on the adult's behalf, revoking or amending a beneficiary designation or, subject to subsection (1) (r), creating a new beneficiary designation;
(g)acting, on the adult's behalf, as director or officer of a company.

[20] See note 17, supra.

reviewed or approved by a court or tribunal (eg, BC's RAA, and Victoria's regime of supportive attorneys under its Powers of Attorney Act (which encompasses health, personal care and financial decisions but not major financial transactions).[21] In some models inter-parties agreements must be deposited in a registry whereby third parties may confirm and examine them. Further, some regimes require that the person supported satisfy the functional understand/appreciate test widely adopted for confirming decision-making capacity to enter into an agreement/arrangement, while others are more flexible on threshold criteria.

BC's RAA falls on the side of utmost flexibility when it comes to triggering mechanisms. Representation Agreements under the RAA provide that adults may appoint someone to "help [them] make decisions, or to make decisions on behalf of [them]".[22] It is not clear whether or how agreements distinguish the conditions upon which a representative may shift from supporter to maker, if the person's role is not strictly delimited to one or the other. The regime is also flexible in the sense that it bases eligibility for standard form agreements (which exclude certain high-stakes decisions) on a set of considerations including being in a relationship of trust with the proposed representative, being able to express wishes and/or approval or disapproval of others, and/or awareness that making the agreement means the representative "may make . . . decisions or choices that affect" one.[23] The RAA expressly states that a person need not meet criteria of capacity to make a contract or decisions about health or personal care or finances, to make a valid Representation Agreement.[24]

As noted, Representation Agreements under BC's RAA are initiated by the parties without involvement of the court. While the adult's signature must be witnessed, it appears that the appointed supporter may make or at least participate in the determination of whether the threshold criteria for entering into an agreement are met – ie, there is no requirement of third party oversight on this point. In terms of protections (discussed further below), the RAA requires appointment of a monitor where certain types of decisions including those involving finances are contemplated;[25] moreover, it sets internal limits on the kinds of decisions that can be made and hives off certain high-stakes decisions (including withholding and withdrawal of life-sustaining treatment)[26] for a more conventional threshold of capacity: the ability to understand the nature and consequences of the agreement.[27] It does not permit representatives to refuse consent to involuntary detention or treatment under the BC Mental Health Act.[28]

Another way supported decision-making regimes differ relates to the duties of supporters. For example, similar to the role of representatives under ACDMA, a representative under BC's RAA (whether helping with or "making" decisions) must consult with the person and comply with their ascertainable wishes unless it is "unreasonable" to do so.[29] Unlike ACDMA, the

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[21] *Powers of Attorney Act 2014.* For a description of the suite of laws relating to supported decision-making in Victoria (including the Mental Health Act 2014 and National Disability Insurance Scheme Act 2013) see Office of the Public Advocate (State of Victoria) Supported Decision-Making in Victoria (October 2020, first published in November 2017) [pdf accessed online June 23, 2021].
[22] RAA, s.7(1).
[23] RAA, supra at s.8.
[24] RAA, supra at s.8(1).
[25] RAA, supra at s.12(1).
[26] RAA, supra at 7(2.1) and 9(3).
[27] RAA, supra at s.10.
[28] RAA, supra at s.11.
[29] RAA, supra at s.16, esp s.16(2).

RAA privileges current wishes over "prior capable" ones[30] -- except where a non-standard agreement (premised on a conventional functional capacity standard, but potentially enduring past loss of that capacity) expressly stipulates that prior capable wishes trump; such stipulation on privileging prior capable over contemporaneous wishes may specifically be made in relation to high-stakes matters like withholding or withdrawing life-sustaining treatment, or subjection to restraints to facilitate necessary health or personal care.[31] It would be important to learn from BC informants, including NIDUS, a non-profit that has played an integral role in the passing, implementation and study of BC's law, how these arrangements tend to be implemented and what concerns have arisen.

It would seem from the purposes section of the RAA and NIDUS commentary on it that the point of BC's RAA is to provide flexibility for people with pre-existing relationships of support (some of whom may not meet the conventional functional / cognitive test for making a power of attorney or other personal directive) to co-design decision-making support arrangements within facilitative as well as protective (eg, the 'reasonableness' caveat) statutory parameters, and in particular to save those without clear functional capacity and their families the expense and trouble -- and potentially, indignity -- of having a court or other remote third party appoint a substitute or supporter and otherwise settle the arrangement.[32] In practical terms, such agreements authorize the representative to get relevant information and to insert themselves into key conversations and/or documentation in order to assist with (or make) decisions where they might otherwise meet roadblocks.

However flexibility also brings uncertainty. As noted, the BC RAA contemplates that sometimes a representative will support the person to make decisions and sometimes they will make decisions on the person's behalf. Both roles require consultation and compliance with wishes – yet both allow non-compliance with consultation and wish-following where this would be unreasonable (or where wishes are not ascertainable). In those cases, prior capable wishes, or (failing that) deciding in light of the person's beliefs and values, or (failing that) deciding in accordance with their best interests, governs. Determination of whether the reasonableness caveat applies is left significantly to the representative's discretion –with the potential backstop of a monitor in some circumstances, plus the possibility that the adult or another might "object" to the Public Guardian and Trustee – who may in turn investigate and take one of a range of actions (appoint a monitor, recommend another person apply to a court to displace the representative, recommend that the court alter the agreement, or other action).[33] In addition, the person represented can withdraw from the agreement at any time – so long as they are capable of doing so, defined according to the type of agreement made (a relaxed, non-cognitive test for standard agreements; a more conventional functional test for the more challenging and high-stakes – potentially Ulysses-type – non-standard agreements per s.9). And yet: how will they know (in order to decide whether to withdraw or object) when decisions are made without them? There is no clear duty in the RAA to inform the adult that a representative has deemed consultation or wishes 'unreasonable'. And: even if they know, will they have the knowledge or assistance needed to object or terminate the agreement? To be clear, guardianship / substitute decision making laws are no better on keeping subjects of decisions informed or empowering them to contest decisions; the issues

[30] RAA, supra at s.16(3): "If . . . the adult's current wishes cannot be determined or it is not reasonable to comply with them, the representative must comply with any instructions or wishes the adult expressed while capable." See also Yukon, Adult Protection and Decision Making Act, SY 2003, c 21, Sch A, s.23(1).
[31] RAA, supra at s.16(2.1), s.9(1)(b)(vii) & (viii), s.9(3)
[32] RAA, supra at s.2 (purposes).
[33] RAA, supra at s.30.

are raised here simply as gaps in the RAA that might be filled in another supported decision making regime.

The above-noted fluidity of the representative's role under the RAA has been criticized both as compromising autonomy unduly, and as producing uncertainty for third parties on questions of consent, responsibility and liability -- especially of concern where significant financial or health/personal care decisions are in issue.[34] On the other side, again, those who advocated for the RAA in the 1990s affirm that this flexibility allows responsiveness to individual circumstances without the stress, complexity, and potential insult to people's dignity of going to a capacity assessor, tribunal or court. The idea is affirm decision-making capability (or as representatives of NIDUS state it, to celebrate agency) on the part of represented persons[35] while allowing leeway on the part of representatives (or, in theory, interactive representative-represented units) to interpret contemporaneous wishes as well as set reasonable limits thereon – with the idea this will be informed by an ethos of respect for personhood and agency.

Supported decision making powers – risks and protections

Ontario's recent law commission process inquiring into legal capacity, decision-making and guardianship (issuing in a final report in 2017)[36] recommended a circumscribed supported decision-making regime. The limitations placed on that regime included a threshold requirement of understanding and appreciating the nature and consequences of the agreement,[37] duties of support clearly distinguished from representation ("making" decisions),[38] restriction of the kinds of decisions contemplated to "routine" property and personal care decisions, required appointment of monitors, and itemized duties of the supporter including keeping records on their actions. The Law Commission of Ontario (LCO) also recommended ongoing research on how supported decision-making regimes are being implemented in Ontario and elsewhere to inform further protections and innovations.

This cautious approach reflected a will to provide alternatives to guardianship and substitute decision making while being responsive to concerns of the Advocacy Centre for the Elderly, Mental Health Legal Committee and estate lawyers[39] that because supported decision-making regimes entail that the resultant decisions remain in the name of the supported adult, coercion and other abuses may be more difficult to forensically reconstruct and achieve accountability for than in substitute decision-making regimes. Beyond potential problems protecting the

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[34] For an effort to respond to these concerns, see Yukon's Act, Adult Protection and Decision Making Act, SY 2003, c 21, Sch A, at ss.13, 25-26 (separately addressing liability of supporters and (a clearly distinct role) "representatives").

[35] See Christine Gordon, Nidus, *The British Columbia Representation Agreement Act: The Right to Supported Decision Making in Canada* (International Conference on Good Policies for Persons with Disabilities 22-23 January 2012; Vienna, Austria).

[36] See Law Commission of Ontario, *Legal Capacity, Decision-making and Guardianship (Final Report)* (Toronto: March 2017).

[37] Also present in Alberta's and Yukon's supported decision arrangements. See Adult Guardianship and Trusteeship Act, SA 2008, c A-4.2, s.4(1); Yukon Adult Protection and Decision Making Act, SY 2003, c 21, Sch A, s.6.

[38] Also present in Alberta's and Yukon's supported decision arrangements. Adult Guardianship and Trusteeship Act, SA 2008, c A-4.2; Yukon Adult Protection and Decision Making Act, SY 2003, c 21, Sch A, s.5(2).

[39] Ibid, Chapter IV "Concepts of Legal Capacity and Approaches to Decision-making: Promoting Autonomy and Allocating Legal Accountability" Part F (Public Comments). https://www.lco-cdo.org/en/our-current-projects/legal-capacity-decision-making-and-guardianship/final-report/4-concepts-of-legal-capacity-and-approaches-to-decision-making-promoting-autonomy-and-allocating-legal-accountability/

interests of persons vulnerable to being taken advantage of, they raised the uncertainty third parties may have concerning responsibility or liability.[40] It is important to note, however, that guardianship and Powers of Attorney are also not free of the risk or fact of abuse – and (as the LCO determined) supported decision-making regimes may admit of various protective mechanisms.

Stated generally, those protective mechanisms may include:

- criteria imposed at the appointment stage (including conventional functional capacity criteria (Alberta, Yukon, LCO),[41] potentially combined with tribunal or court-based appointment);

- required appointment of a monitor or multiple supporters who must act unanimously in some or all decisions (eg, BC's RAA, LCO);

- limiting matters a supporter can assist with and/or the kinds of information they can access (eg, BC's RAA; Alberta,[42] LCO)

- a requirement that notes be kept on decisions supported (LCO)

- a registry allowing for public examination of support agreements (Ireland)

- periodic mandatory judicial or tribunal oversight or streamlined mechanisms for accessing such oversight and/or access to an expert advocacy service (Ireland).

To briefly address the first issue -- protections at the stage of appointment (a full exploration of each term is not possible here), these include tribunal evaluation of the supporter against criteria including conflict of interest. In Victoria, the tribunal must take into account:

- the proposed supported person's preferences (so far as they can be ascertained);
- the desirability of preserving existing family relationships and other relationships important to the proposed supported person;
- the nature of the relationship between the appointee and the proposed supported person, in particular whether it is characterised by trust;
- whether the appointee will be available to the proposed supported person, and able to meet and communicate with them;
- the capacity of the appointee to recognise and give due regard to the importance of the relationship the proposed supported person has with their companion animal.[43]

Moreover, the Victorian model provides that the tribunal (the VCAT) appointing supporters may only do so in the following circumstances:

- the proposed supported person consents to VCAT making the order;

[40] Ibid.
[41] See Yukon Adult Protection and Decision Making Act, SY 2003, c 21, Sch A; Alberta Adult Guardianship and Trusteeship Act, SA 2008, c A-4.2.
[42] Adult Guardianship and Trusteeship Act, SA 2008, c A-4.2, s 9(1).
[43] Judicial College of Victoria, Guide to the Guardianship and Administration Act 2019 (Vic) (Feb 2020) at 51.

- if the proposed supported person is given practicable and appropriate support, they will have decision-making capacity in relation to the relevant personal or financial matter; and
- the supportive order will promote the person's personal and social wellbeing.[44]

Here the first criterion (consent) appears to insert a background functional capacity assessment into the arrangement (as understanding and appreciation are typically baked into consent); in any case it suggests attentiveness to potential coercion. The second criterion indicates that supported decision-making arrangements are to be limited to situations where the individual is likely to have functional capacity to make the contemplated decisions, with support. Questions arise around how these assessments are to be made, which could be explored through more attention to Victoria's regime as it has been operationalized.

Summary – Distinguishing Formal Supported Decision-Making Regimes

In sum, different kinds of formal supported decision-making arrangements have been recommended or recognized in different jurisdictions. We may differentiate these based in

> 1) whether they require a functional test of capacity (the ability to understand and appreciate the consequences of entering into the supported decision making arrangement) or alternatively institute an alternative, more flexible test;
>
> 2) whether validation of the arrangement requires formal approval by a court or tribunal or simply an agreement of the parties;
>
> 3) what safeguards are inscribed (eg, conditions of appointment, required appointment of monitors, limitation on the decisions included in support arrangements, requirements to keep records, judicial or tribunal oversight, access to advocacy services).

The law reform process will have to consider whether to prioritize the flexibility of an arrangement like BC's or the comparative protectiveness of the regime Ontario's LCO has recommended for Ontario – or a middle way as appears to have been the approach in Victoria, Australia.

A further word on formal regimes: I advise against adopting a *co-decision-making* regime like the one included in Alberta's Act.[45] Such regimes simulate guardianship by giving a veto to the co-decision maker. There is no purpose the model can serve that would not be covered by a formal supported decision-making regime and/or the type of consultative representation instituted in the ACDMA.

[44] Judicial College of Victoria, Guide to the Guardianship and Administration Act 2019 (Vic) (Feb 2020) at 50.
[45] Adult Guardianship and Trusteeship Act, SA 2008, c A-4.2, ss 17 & 21.

iv Institutional mechanisms for fostering research, public education and advocacy on supported decision making.

A broader conception of what may be included in a formal supported decision making regime is reflected in Ireland's *Assisted Decision Making (Capacity) Act 2015,* which creates a Decision Support Service to engage in investigation, service provision, and research and education to promote supported decision making. Aspects of this wider role are also present in the work of, eg, Ontario's specialized legal clinics (Advocacy Centre for the Elderly and ARCH Disability Law), and its Public Guardian and Trustee which pursues complaints about abuses of conferred decision-making powers.

Carrying forward the above exploration of formal regimes of supported decision-making, but building toward a more facilitative and educative model -- seeking not only to prevent abuses but to effect a deeper culture shift toward a culture of supports -- we may consider the Irish Decision Support Service. That Service has been given the following responsibilities under Ireland's 2015 reformed law relating to legal capacity and decision-making (the *Assisted Decision Making (Capacity) Act 2015*):

- regulate and register decision support arrangements
- supervise the actions of decision supporters
- maintain a panel of experts who will act as decision-making representatives, special and general visitors, and court friends
- investigate complaints
- promote awareness and provide information.[46]

The Service has yet to become fully functional in anticipation of resource commitments. I recommend that an entity in Nova Scotia be constituted on similar terms, mindful of ways we can draw on existing expertise and services and bring these into a more efficient and synergistic "hub". This would mean consolidating existing resources and supports, and fashioning new ones, to foster the development and exercise of decision-making autonomy as well as social and political participation in furtherance of disabled persons' human rights.

The NS Decision Support Hub would be responsible for research, public education, policy review, and service provision and/or referrals to advance the interests of people with disabilities in directing their own lives. It could partner with a range of government and civil society organizations, including the Accessibility Directorate, Human Rights Commission, People First NS, Inclusion NS, Autism NS, CMHA NS, the Alzheimer's Society, and others, to provide a range of services and partnered referrals, including:

- registering, overseeing and responding to complaints about supported decision making arrangements;
- establishing a roster of experts and/or directly provide services to assist with decision-making support, person directed planning and system navigation -- including where there is no family or other close connections;
- facilitating self-advocacy initiatives, including peer-led education and political participation expressive of personal and political agency;

[46] Summarized at https://www.mhcirl.ie/what-we-do/decision-support-service

- facilitating plain language education and communication and peer / self-advocate plain language editing opportunities;
- facilitating inclusive research about supported decision-making (in partnership with researchers located in universities and community organizations);
- hosting inclusive public seminars for people acting under the authority of supported decision-making laws, and others;
- providing or referring out to other resources or services that families, service providers, individuals with disabilities, and capacity assessors may need to activate supported decision-making, including on issues of housing, health, justice, education, relationships and recreation;
- providing or referring out to expertise (including peer-run services fostered through this hub) to assist with crisis prevention and intervention, again guided by an ethos of respect and support for agency; and
- providing referrals to and assistance in understanding and communicating with legal advocates (potentially working in partnership with Dalhousie Legal Aid Service, Nova Scotia Legal Aid and Legal Information Society NS).

Such a centre of knowledge co-creation and mobilization, service provision and advocacy would obviously not be restricted to dealing with court-ordered representation under the ACDMA. Rather, it would have the role of supporting decision-making and agency across the currently fragmented situations in which legal capacity and substitute decision making are engaged – spanning Health, Justice, and Community Services sectors. It would function as a catalyst for bringing a human rights-grounded approach to the suite of laws affecting legal capacity and integrating these with the laws and policies through which services for persons with disabilities, including older adults with dementia and persons with mental health disabilities, are constituted and distributed.

The initiative would establish Nova Scotia as a leader in meeting its obligations under statutory and constitutional non-discrimination law and the CRPD, while also advancing the province's accessibility priorities which require that government services and policies be modeled on universal design and attain full accessibility by 2030. In actualizing and coordinating key priorities across sectors, the Decision Support Hub would help to redirect resources from police, adult protection, institutionalization and mental health hospitalization to long term agency-respecting and -enhancing supportive practices.

C – Creation of a Decision Support/Representation Tribunal (for oversight of support and representation arrangements and other laws relating to legal capacity)

Here I return to the point about the need for a comprehensive, systems-wide review of laws affecting legal capacity -- mindful of the human rights-imbued imperative of supporting people with disabilities in exercising agency and choice. Taking a systems approach to legal capacity exposes the need for a more coordinated approach to these laws – whether taking the form of a single law or standardizing terms across these laws. It also exposes the need for an accessible tribunal to deal with disputes about capacity and the decisions of representatives and/or substitute decision makers.

The fact Nova Scotia has no tribunal comparable to Ontario's Consent and Capacity Board is a central reason why we have such a paucity of precedents contesting guardianship or the decisions of substitute decision makers under ACDMA, the prior Incompetent Persons Act, Personal Directives Act (which authorizes next of kin *not* appointed under a personal

directive to make substitute health care decisions, decisions to place another in long term care home, or decisions to engage home care) and Hospitals Act (which governs capacity to make health care or property-related decisions while in hospital). The IPTA tribunal, for its part, is a single, narrowly-configured body which leaves little scope for contesting the decisions of an SDM even under IPTA itself (the statutory term in question restricts the inquiry to whether the contested decision was a "capable informed consent").

Decisions on withholding or withdrawal of life-sustaining treatment, decisions about other issues of significance to health or personal care, decisions about where one resides, etc, are dealt with in NS laws on legal capacity / substitute decision making in ways that have enormous impact on persons with disabilities and yet are nearly impossible to challenge -- particularly in the circumstances people are likely to find themselves in when they are most likely to resist or contest these decisions. The same lack of empowerment affects family members who may wish to contest decisions of capacity assessors, appointed substitute decision makers or, conceivably (in future) decision supporters – often amidst heated disagreement at points of crisis (whether about withholding or withdrawal of care, whether a woman has capacity to decide to obtain an abortion, whether a substitute decision maker (or potentially, an individual and their supporter) should be able to sell the adult's house or their share in a commonly owned house in favour of moving to a group home, etc. Beyond access to advocacy services, a dedicated tribunal would likely be better able than the courts to ensure timely access to justice on matters reaching to people's most fundamental interests when they are most vulnerable to instrumentalization by others.

3 Further fixes to the ACDMA

The above suggestions centre on a comprehensive law and policy reform process aimed at fostering the ability of persons with intellectual disabilities, dementia, and mental health disabilities to direct their lives in a context of responsive supports. This includes contemplation of gradated decision-making supports encompassing existing ACDMA representatives, supported decision-making agreements (the particulars of which should be explored in a dedicated public engagement process) and a decision-making support hub as well as a dedicated tribunal, all intended to help overcome the current fragmentation of legal capacity assessment and displacement across institutions, professionals and transactions.

Yet specific elements of the Act require timely attention whether or not the above vision of a coordinated approach is adopted. The immediate problems that might be unharnessed from the above system-wide priorities and moved upon even without a comprehensive review or formal regime of supported decision making include:

- lack of clear assignment of responsibility to supply and fund the supports / accommodations required to be able to demonstrate decision-making capacity in the context of capacity assessments and to facilitate expression of wishes and foster autonomy in the context of representation;

- lack of access to advocacy supports for persons faced with capacity assessment and persons subject to representation;

- allowance for consent to aversive therapy by court order, per s34(2)(d).

I will deal with these in brief. First I reiterate an earlier point, now narrowed to capacity assessments and representation under the ACDMA: the Act should expressly acknowledge *the duty of government to fund supports* for facilitating demonstration of adequacy to the standard of capacity as well as informing wishes and fostering of autonomy in representation arrangements. This is an expression of the duty to accommodate disability to the point of undue hardship. Given the potential seriousness of the consequences of not accommodating disability in these contexts (ie, people losing access to the baseline respect for agency that is fundamental to human rights), the expectation on government is high.

On the second point, the problem with lack of advocacy supports for persons undergoing assessments and/or represented under the ACDMA is self-explanatory. Because persons are vulnerable to harm through abuse of legal arrangements suspending decision-making authority, government must provide accessible and robust advocacy services and proactive oversight mechanisms (such as periodic advocacy visits). This is particularly so because the individual's power to communicate with or employ others to contest a decision-making arrangement may be limited and the window in which serious harm may be suffered may be very small. I suggested above that advocacy resources be centred in a Decision Support Hub able to facilitate plain language and other supported access to legal and other advocacy – but in any case, clear entitlements to access legal aid should be written into the law and the forms used in capacity assessment, an agreement with legal aid should be in place and made public, and mechanisms for accessing legal oversight should be clarified and streamlined. (This relates to the proposal for a tribunal, above).

Third, in the first round of consultations, in 2017, concerns were raised by People First and others on s34(2)(d) of the ACDMA which, although framed as a limitation on a representative's independent authority, contemplates the possibility of court-ordered aversive stimulus interventions. This was identified by People First as a direct threat of violence. If the provision is to be retained, government should provide evidence of why and in what circumstances it could possibly be reconciled with human rights and with the ACDMA's ethos of advancing the wishes and otherwise promoting the well-being of persons with disabilities.

APPENDIX
ACDMA Form 1 – Capacity Assessment Report

The Capacity Assessment Report form[47] requires careful attention in light of the experiences of those who use it, those who have been subject to assessment and their families and friends, and legal counsel.

Reviewing the form brought to mind an experience I had consulting 6 or 7 years ago, with emergency room physicians asked to do assessments under the Personal Directives Act on the ability of older adults to decide whether to move into long term care. The doctors expressed exasperation given that the subjects of assessment were almost certainly in crisis (these tended to be requests from Adult Protection) and in some cases deprived of what they would need to have a fair shot at adequacy to the test – for example, deprived of nutrition and hygiene over a prolonged period, displaced from familiar home surroundings to the distracting and alarming setting of a hospital, and faced with perceived threats to security incentivizing denial of problems (which in turn increased the likelihood of failing the "appreciation" criterion). The doctors were mindful that these assessments were likely to seal the fate (in terms of living situation and possibly much more) of the people they were so briefly exposed to.

The question this raises is: How might it be possible to shift resources and expertise from such assessments oriented to depriving individuals of decision-making authority to processes of identifying what resources or supports could be put in place to help elicit their experiences, values, and preferences – and to help shape and select among a range of possible options?

The current assessment form limits contemplated supports to communication and emotional support from a trusted individual (or device) during the assessment conversation. This, while welcome in light of the alternative (no effort to facilitate communication and emotional readiness), is unlikely to reach to the underlying aspirations of supported decision making – ie, supporting people with disabilities in directing their lives.

The following itemizes my critiques and recommendations concerning the form:

1 – It is not clear when or how the assessor is to determine whether the assessment is "necessary" (per ACDMA s 12(2)). There should **be a threshold of reasonable grounds for assessment** contemplated and established before an assessment is undertaken. The possibility that discriminatory ascriptions of incapacity may be used against people with disabilities in ways that harm their self-respect and reputation should not be overlooked.

2 – Relatedly, at 1.3 and 1.4 the assessor is to set out how the assessment was precipitated. There is no place for specifically considering whether the person may have self-interested motives. The Ontario court decision *Re Koch*[48] provides an example of an intrusive assessment initiated by an ex-spouse concerned to limit his ex's spending (she had MS) – a process that then spiraled out of control to impinge on the assessed person's dignity and security in ways that reflected the assessors' own discriminatory bias. **Query how potential conflicts of interest might be identified, documented and explored such that later**

[47] Form 1 "Capacity Assessment Report", available on the website of the NS Public Trustee: https://novascotia.ca/just/pto/forms.asp
[48] Koch (Re), 1997 CanLII 12138 (ON SC), <https://canlii.ca/t/1vv7q

oversight bodies are apprised, and assessors might consider more carefully early on the propriety of proceeding with the assessment.

3 - The assessor may gather information from a variety of sources. Section 16(2) and (3) allow collection of personal information (and oblige persons approached for information to disclose it) while s.16(4) requires a court order for collection of financial information. Arguably the authority to collect personal information should be more specifically delimited. **How much latitude should be given assessors in order to gather personal information?** This is something to explore in connection with the issue of a legal threshold for proceeding with an assessment – again, given the damage that being assessed or having others aware one is being assessed could do to one's reputation and related interests.

4 - Part 5 of the form: The notice given to the adult does not advise them of **their right to contact legal counsel.** The "trusted person" noted may be someone who seeks to facilitate the order; and in any case, the right to consult counsel on whether, when or how to participate is critically important. The form should include **a contact number for legal aid.**

5 – Part 5 includes the statement "I provided the adult with a reasonable opportunity to undergo their capacity assessment under circumstances in which the adult is likely to be able to demonstrate their full capacity." Assessors should not be permitted to simply tick yes or no. There is room for elaboration at Part 8 ("I ensured the adult's comfort level by . . ." – the example given speaks to whether the location was comfortable and familiar). However**, more is required by way of prompts.** The following is informed by case law from the Consent and Capacity Board of Ontario. I suggest a series of prompts requiring attention to elements beyond comfort and familiarity of the location, such as:

- absence of sedation or other pharmacological interference?
- access to necessary medications?
- other environmental factors, eg
    - adequacy of nutrition / hydration?
    - Has the person had adequate sleep?
    - Has there been an effort to meet multiple times to reinforce understanding?
    - Particularly in cases of dementia, has there been an effort to establish whether mornings or evenings are best?

6 - The supports contemplated at Part 6 are restricted to provision of a trusted person (or a device) to facilitate communication or emotional regulation. The full set of (non-exhaustive) supports signaled in s.3(s) of the ACDMA should be listed. Further, as I argue in Part 2.B.i of my comments, a range of further social-structural supports should also be contemplated. We should explore the experiences of assessors and persons assessed on this point in order to reflect further on the fairness of the assessment process and how it might be enhanced. [49]

[49] See footnote 11, supra, and the Surrey Place form referenced at note 5.