

Article

## Supported Decision-Making for People with Cognitive Impairments: An Australian Perspective?

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**Abstract:** Honouring the requirement of the Convention on the Rights of Persons with Disabilities to introduce supported decision-making poses many challenges. Not least of those challenges is in writing laws and devising policies which facilitate access to formal and informal supports for large numbers of citizens requiring assistance with day-to-day issues such as dealing with welfare agencies, managing income security payments, or making health care decisions. Old measures such as representative payee schemes or “nominee” arrangements are not compatible with the CRPD. However, as comparatively routine social security or other government services become increasingly complex to navigate, and as self-managed or personalised budgets better recognise self-agency, any “off the shelf” measures become more difficult to craft and difficult to resource. This paper focuses on recent endeavours of the Australian Law Reform Commission and other local and overseas law reform and policy initiatives to tackle challenges posed both for ordinary citizens and those covered by special programs (such as Australia’s National Disability Insurance Scheme and “disability trusts” in Australia and Canada).

**Keywords:** supported decision-making; representative payees; disability trusts; law in action; evaluation

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### 1. Introduction

In its concluding observations on States parties’ initial reports, in relation to article 12, the Committee on the Rights of Persons with Disabilities has repeatedly stated that States

parties must “review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person’s autonomy, will and preferences.” ([1], para. 26).

In supported decision-making, the individual is always the primary decision maker, but it is acknowledged that autonomy can be communicated in a number of ways, thus provision of support in different forms and intervals can assist in the expression of autonomous decisions. Supported decision-making enables the individual to retain legal capacity regardless of the level of support needed. Forms of supported decision-making can therefore include advance directives, enduring powers of attorney, health care proxies, arrangements for financial decisions (e.g., payee regimes, banking systems), nominated representatives, and/or personal ombudsmen. These forms of support are more formal and offer less autonomy [...] on the support spectrum than less formal forms of support. Less formal but equally important forms of support can consist of support networks of family and friends and peer support ([2], p. 4).

Adoption of the *Convention on the Rights of Persons with Disabilities 2006* (“CRPD”) piqued renewed interest in neglected issues of decision-making by people with what may generically be described as having cognitive impairments, including the place of “supported decision-making” and the scope and form of any required legal backing or recognition. This has given rise to a plethora of law reform enquiries around the world, including most recently by the Victorian and the Australian Law Reform Commissions [3,4] and the Law Commission of Ontario [5,6].

Access to assistance with decision-making is taken for granted by most people as being an integral feature of living and working in a community. As is the case with substitute decision-making, access to assistance in making decisions engages four main groups of people who experience cognitive impairment: people with intellectual disability [7,8]; people with a mental illness [2]; people with an acquired brain injury [9,10]; and people living with dementia [11]. Where cognitive capacity is impaired for one reason or another, accessing such assistance may become more pressing; but demand for it will vary depending on many things, including family circumstances, stage of life-cycle, exigencies of life (such as where a person lives) and the source of the cognitive impairment. Thus for a person with an intellectual disability, the need may become most acute as a person moves into independent living or as parents age and are unable to continue providing care [12,13]. For someone with mental illness, needs for assistance commonly fluctuate [2]. For a person with an acquired brain injury, the need for support may more readily be supplied due to the existence of a stock of well-formed life preferences and values expressed prior to injury ([14], p. 198), even though injuries are most commonly sustained in late adolescence or early adulthood when life preferences are in transition. Someone with early stage dementia will initially be able to make most of their own decisions, and be able for quite some time to express their will and preferences as their condition advances, before reaching a stage where greater reliance is placed on any previously executed advance directive or enduring power, but otherwise will rely on heavily facilitated [11] or even substitute decision-making [15].

Assisted decision-making also takes many different forms [16–19], and there is limited agreement about basic concepts and principles [20]. For its part the UN Committee in its General Comment casts the net quite widely, writing in paragraph 29 that

A supported decision-making regime comprises various support options which give primacy to a person’s will and preferences and respect human rights norms. It should provide protection for all rights, including those related to autonomy (right to legal capacity, right to equal recognition before the law, right to choose where to live, *etc.*) and rights related to freedom from abuse and ill-treatment (right to life, right to physical integrity, *etc.*).

Many of these supports have their existence *outside* and quite independently of the law<sup>1</sup>, being reliant on natural familial or friendship relationships and civil society networks, including those constructed or facilitated by other individuals, services or agencies—whether lying inside or outside government (for non-legislative schemes see [22], pp. 171–74 (Canada), pp. 255, 281–82 (Sweden), pp. 320–22 (France)). Others draw on the law in some way—again mainly constituted within civil society or as informal support schemes, but assembled, facilitated by, or simply “recognized” under the law—as with the Canadian “support networks” or the potential strands of mentors, contacts, escorts and others under Sweden’s “PO Skåne” scheme as outlined by Piers Gooding ([23], pp. 12, 14). There is also arguably a very important distinction between support *for* decision-making (whether in “reading” another person’s preferences or “will” or by way of say following an advance directive) and supported decision-making which engages to some extent with legal capacity [24]. Support *for* decision-making is more easily grounded in the “best available” reading of the “will, preferences and rights” of the person being assisted, in order to realise what the Australian Law Reform Commission expresses as its first principle, namely that “[a]ll adults have an equal right to make decisions that affect their lives and to have those decisions respected” ([4], pp. 24, 64–67).

Towards one end of the spectrum of support options within the purview of the law lie those engaging with what we have previously termed “peripheral” laws (for example overcoming third party privacy barriers to accessing information needed to assist a person to form or realise their will or preferences) or similar assisted decision-making models, such as where a “correspondence nominee” receives official communications which are then explained more simply to the person ([14], p. 185). At the other end of the spectrum are higher stakes situations, such as large financial or property transactions, or the significant resources potentially at stake when negotiating Australia’s National Disability Insurance Scheme (“NDIS”) plans [25]. These may better lend themselves to a more actively “supported” form of decision-making, or overseas “co-decision-making” models (where both the person and their supporter must act in concert), such as that recommended by the Victorian Law Reform Commission (“VLRC” [3], chap. 9) but not proceeded with by Government [25].

This paper considers the issues raised at both ends of that spectrum and the two rather different social contexts engaged, examines recent law reform recommendations designed to address such

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<sup>1</sup> Of course general principles of law pervade and lie in the background of civil society interactions, and some of these principles might be invoked on occasion to buttress some of these arrangements or even provide redress in some situations: see for instance [21].

issues, and touches on Victoria's 2014 reforms (dealt with in more detail elsewhere: [25]). Part 2 reviews the General Comment [1] and the equality principle of Article 12 of the CRPD [26] which it is designed to elaborate. The following Part analyses various recent law reform or legislative initiatives in Australia and cognate jurisdictions in light of precepts enunciated in the General Comment, to assess how well the measures achieve goals of citizen accessibility and protection of vulnerable groups such as people who are isolated from family, friendship of other informal support networks.

The paper argues that the challenges of balancing the competing values and goals of the CRPD are wider than just the pace and degree of transformation from substitute to supported decision-making, but include deciding on the mix between informal and formal arrangements, finding adequate safeguards against abuse of more routine instruments such as durable powers or legislative hierarchies of proxy decision-makers, and establishing a better evidence base for policy making and law reform.

## **2. Supported Decision-Making, the Convention on Rights of Persons with Disabilities and the Equality Principle**

Australia pioneered a least restrictive, presumptively limited guardianship reform model in the 1980s, entrusting adjudication of the need for orders to multi-disciplinary tribunals rather than follow overseas preferences for courts or specialised courts [27–29]. That tribunal model has been preserved as the preferred model in Australia, and although the guardianship list of the Victorian Civil and Administrative Tribunal (“VCAT”) moved to mainly single member hearings, the guardianship division of the NSW Civil and Administrative Tribunal (“NSWCAT”) has retained mainly multi-member panels, which the VLRC encouraged VCAT to emulate at least for more complex matters ([3], paras. 21.50, 21.53, 21.78–82, 21.147–151).

The Australian guardianship model embodies a number of progressive features, including: easy and cost free accessibility; flexible, inquisitorial hearings before representative and expert decision-making panels; introduction of conciliation and case-management procedures to screen out unnecessary applications; adherence to principles of intervention as a last resort and in the least restrictive manner; requirements to ascertain and respect the wishes of the person subject to an order; and periodic review of orders [27,30,31]. However even reformed guardianship intrinsically and unavoidably entails taking away the autonomy and choice of the person subject to an order. Guardianship, whether of the person, the property and finances of a person, or over health decision-making, inevitably involves appointment of a proxy decision-maker. The person affected may be consulted by a guardian about the exercise of such powers, but the power itself has been transferred to the guardian, contrary to the CRPD preference (or obligation) to instead support people to make their own decisions.

Despite a number of enquiries and academic commentary, Australia has been slow to legislate supported decision-making by comparison with Canada or Sweden [6,32,33]<sup>2</sup>.

### *2.1. Supported Decision-Making in Australia*

In NSW a Parliamentary Committee recommended in 2010 recognition of supported decision-making in parallel with substitute decision-making ([35], p. 63), but it was not until 2014 that Victoria became

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<sup>2</sup> For an extended review of the then Canadian law in the various provinces, and the implications of the CRPD, see [34].

the first to legislate, though only the reform allowing for personal nomination of a supporter was actually enacted before Parliament was dissolved for the 2014 State Election, and its rather ill-drafted provisions for tribunal appointment of a “supportive guardian” lapsed when Parliament rose [25]. Aside from giving credit for Victoria’s introduction of at least some form of alternative to existing substitute decision-making (guardianship and enduring powers of attorney), the main advance contained in the lapsed Bill, it will be suggested below, was the injection of greater recognition of CRPD principles within what would remain principally a renovated, but still quite traditional, adult guardianship model.

In part this caution about wholesale adoption of supported decision-making is warranted, in that international evidence of what types of assisted decision-making regime “work” is lacking [6,7,14,36], along with information about its possible differential appeal based on personal characteristics of people involved (e.g., a cultural preference for collaboration: [6], p. 124) or between disability categories (see [6], pp. 135–36, suggesting its greatest appeal is for people with intellectual disabilities). Australian pilot studies of different models of assistance are few in number, small in scale and unable to afford a rigorous evaluative design [20]. They also arguably concentrate on the more extensive forms of assistance required by people with more profound levels of cognitive impairment, to the neglect of the more routine day-to-day situations where assistance may be needed.

## 2.2. *The CRPD General Comment*

The May 2014 General Comment #1 on Article 12 of the CRPD [1], issued by the UN Committee on the Rights of Persons with Disabilities which is charged with monitoring the Convention, added urgency to debates about supported decision-making within legal, policy and practice circles, despite its somewhat idealistic insistence on complete “abolition of substitute decision-making regimes”<sup>3</sup> and the immediate (as distinct from parallel) development of supported decision-making alternatives (see [1], para. 28). While the status within international law of a General Comment is that of an authoritative rather than binding instrument, such statements are influential when interpreting the relevant Convention, and are a powerful influence on domestic policy debates.

While there is always a risk of complications through bringing the law to bear on arrangements better left for informal resolution in civil society, there is little disagreement with the UN Committee in its General Comment that law has *some* role to play, at least in the sense that “[l]egal recognition of the support person[s] formally chosen by a person must be available and accessible” ([1], para. 29(d)). However in policy terms there is vigorous debate both about whether law should be too heavily involved (for fear of net-widening due to say the public mistakenly presuming or accepting de facto paternalism or substitute decision-making by supporters [14,37]), and about whether the CRPD requirement can be met by say strongly favouring supported over substitute decision-making, or whether it instead requires more immediate abandonment and replacement of substitute decision-making regimes by supported decision-making as General Comment #1 insists ([1], para. 26).

The 2014 General Comment seeks to identify what it terms “key provisions” to be incorporated in supported decision-making arrangements to avoid “over-regulat[ing] the lives of persons with

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<sup>3</sup> Both Australia and Canada made interpretive reservations, stating that retention of substitute decision-making was acceptable as a last resort ([4], p. 48; [6], p. 119).

disabilities” and in order to comply with the equality principle of Article 12 of the Convention [26], including principles of:

- *Universal access*: Neither high care needs, nor unconventional/rare modes of communication, nor cost are to be a barrier to access to support (paras. 29(a), (c), (e));
- *Facilitation of support for vulnerable groups*: Recognition of “an obligation to facilitate the creation of support, particularly for people who are isolated and may not have access to naturally occurring support in the community” (para. 29(d));
- *Respect for will and preferences, not best interests*: Provision of “[a]ll forms of support in the exercise of legal capacity, including more intensive forms of support, must be based on the will and preference of the person, not on what is perceived as being in his or her objective best interests” (para. 29(b));
- *Individual choice*: The right to refuse or change support (para. 29(g));
- *Avoidance of mental capacity assessments*: “The provision of support to exercise legal capacity should not hinge on mental capacity assessments; new, non-discriminatory indicators of support needs are required in the provision of support to exercise legal capacity” (para. 29 (i)); and
- *Provision of safeguards*: Protections around “all processes relating to legal capacity and support in exercising legal capacity” to ensure respect for the will and preferences of the person (para. 29(h)) and mechanisms to verify the identity, or challenge actions of, a support person believed not to be acting on the will and preference of the person (para. 29 (d)).

These principles form a basis for any assessment of legislation, proposals for legislative reform, or non-legislative schemes of support.

But what is the essence of the equality of recognition before the law which is sought to be realised by Article 12? So far as relevant for present purposes, Article 12 reads:

Article 12—Equal recognition before the law

- (1) States Parties reaffirm that persons with disabilities have the right to recognition everywhere *as persons before the law*;
- (2) States Parties shall recognize that persons with disabilities *enjoy legal capacity on an equal basis* with others in all aspects of life;
- (3) [provide access to support required “in exercising their legal capacity”];
- (4) [provision of safeguards];
- (5) ...take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

By one reading, it might be said that the overarching philosophy of Article 12 is simply that of “equality before the law”. But as Nandini Devi perceptively observes ([38], p. 794), “it is important to distinguish between mental capacity (decision-making ability) and legal capacity” and to appreciate that Article 12 is designed to support the exercise of the mental or other capacity everyone is presumed to possess for engagement in their own decision-making.

### 2.3. Equality before the Law: Human Agency

Keying instead to the long-standing legal jurisprudence around “legal capacity” would come at the heavy price of impliedly endorsing a binary divide between capacity and incapacity (however wide or smoothly graded may be the points in between). This is why this traditional bifurcated way of thinking about the issue is now disfavoured. Such thinking underpinned the ALRC’s rejection as one of its framing principles of a presumption of capacity (because it endorses a binary divide), instead expressing its first principle as “all adults have an equal right to make decisions that affect their lives and to have those decisions respected” ([4], pp. 24, 64–67).

Of course Article 12(1) actually opens with such a universal proposition, endorsing the precept that “persons with disabilities have the right to recognition everywhere as persons before the law”. So Article 12(2) can be read as elaborating this principle as that the *law* must respect the decisional rights (or choices) of people with disabilities. Or doing so as far as *legal* enjoyment of TH Marshall’s notion of social citizenship or social participation is concerned (see for example [39,40]). Read this way, Article 12(3) spells out a commensurate right to the necessary supports to realise such decisional choices. While much of the focus in what follows is on realisation of individual choice and autonomy (a “negative” or “civil” right), paragraph 3 of Article 12 enunciates the rather neglected corollary of the “socio-economic” (or “positive”) right, when it speaks of the obligation for States Parties to “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity”.

Thought of in these terms, the core concept of paragraph 3 of Article 12 might be reconceptualised as that of the endorsement of human *agency*; as an expression of the “self” within its social context. So expressed, agency is properly conceived as not as a “rationalist” exercise (of appreciating, retaining and weighing relevant information and then conveying a decision) but an exercise grounded in adequate expression of “will, preferences or rights” (thus validating “circle of support” and other ways of realising such expressions of will or preferences). So far so good; and an interpretation fully embraced by Australia’s ALRC Report in 2014.

However with some disabilities, including severe intellectual disability, the breadth or range of decisions ultimately amenable to agency may be heavily circumscribed by a history of over-protective upbringing, or a lack of willingness of parental or other carers to accept (or correctly interpret) the wishes and agency of the person cared for. Or the severity of the cognitive impairment may mean that the range of areas where decisions can meaningfully be facilitated and any “will, preferences and rights” conveyed may be very restricted, at least without unrealistically high levels of investment in training and resourcing to build the capacity of others to accurately read will and preferences. While the General Comment includes in paragraph 18b the important clarification that “[w]here, after significant efforts have been made, it is not practicable to determine the will and preference of an individual, ‘best interpretation of will and preference’ must replace ‘best interests’ determinations” [1], even that process can be quite resource- and time-intensive.

Accurately reading expressions of agency can be problematic in other ways too. There are the complications posed by shifting or fluctuating agency, whether over the life course or due to episodic illness [41], as with mental ill health or the decline (and fluctuating periods of lucidity) of a dementia. Of course in the case of late stage dementia, with its slow but ultimately complete “unbecoming of the

self”, there is at least a rich and dense life history of earlier expressions of will and preferences to draw on, leaving only the vexed question of whether the “current” person can be projected as a future reading from that past self (further [42]). For as Louise Harmon pointed out nearly a quarter of a century ago, the assumption of diachronic stability of values and preferences is imperfect, so that what in substance is a form of substituted decision-making is presented as a fictional expression of human agency [43].

The concept of agency of course lies at the heart of respect for personhood and civil rights [44], including such important protections as insisting on consent as the basis for health care or as the foundation of enforcement of civil bargains. However agency and consent are often mistakenly thought of as involving points in time, rather than in terms of ongoing life course transactions. The imposition of restrictions on liberty of people with a disability presents this in high relief, such as say the locking of doors within an aged care facility (or routinely in a dementia wing) to mitigate risks of “wandering” (further [4], chap. 8). The diminution of agency at the point of imposition of the restriction for the first time is of course important. But of arguably greater importance is the monitoring and oversight of the ongoing justification for the restriction [4]; something that arguably better engages the public law domain of *regulation*, rather than the private law domain of consent or agency [45].

So support or facilitation of agency is not straightforward, due to these differing social contexts. It is further complicated by the answer to the questions of whether expression of agency is to be thought of in individual or relational terms, and whether agency is assumed to be a live ongoing concern or as something that may be delegated to others (whether expressly or by default), as now discussed.

#### 2.4. Support as Autonomy-Enhancing or Support as Delegation of Choice?

Embedded in some of the formulations of what the CRPD requires by way of *support* under Article 12, is an assumption that citizens always want assistance in realising their autonomous decisional choices, rather than ever see the delegation of that choice to a *substituted* decision maker. But of course non-disabled decision-makers already *do* regularly opt for delegation to a substitute. This is the reason that the law has developed a variety of avenues to cater to that need, including agency, ordinary powers of attorney, enduring powers of attorney, medical powers of attorney, and enduring personal guardianship [46]. Advance directives, for their part, are generally a weaker form of instructional guidance to shape the way a substitute exercises that power, with one study showing that three-quarters of people with a psychiatric illness prefer such directives and only around a quarter prefer advance appointment of a proxy [47]; though on the other hand it seems that it is usually too late to consider making such appointments once dementia patients are in need of accommodation in residential care settings [48].

Despite the ready availability of comparatively cheap and convenient avenues for formal delegation of responsibility for decisions, by far the most common form of delegation is the *de facto* one. Such *de facto* delegation occurs whenever someone who is aware of ability to execute a formal instrument opts *not* to do so. Studies reveal that even terminally ill patients aware of the crucial decisions arising in relation to their future care, not uncommonly opt to leave such matters to be addressed *informally* by family or friends ([49], p. 4), whether due to their value preferences, cultural reasons (ethnic or racial background), or factors such as literacy levels [50].

It is therefore suggested here that a key unresolved question is that of how “pure” must the rejection of substitute decision-making be? For instance, presumably it is perfectly Convention compliant to permit a person with a cognitive impairment and who is *capable* of making a decision between the choice and the delegation avenues, to validly select either alternative. To do otherwise would contradict the equality principle, since a person without a cognitive impairment unquestionably has that choice. Yet by implication some commentators appear to conclude that *support* for a person with a disability must principally be directed at facilitating or expanding the personal choice or agency of the person, rather than entertain similar delegations to third parties. While it is accepted that the choice between possible supporters might properly be open to some additional oversight controls (for example some supported decision-making pilots have reported that paid or professional supporters with potential conflicts of interest in the role are sometimes preferred over unpaid family, friends or volunteers), there is also understandable reluctance to endorse arrangements which may perpetuate de facto substitute decision-making by others, with the obvious risk of paternalism that this entails, even if doing so comes at the price of narrowing the options for de facto delegation.

Given the endemic and overweening paternalism that has infected decision-making for people with cognitive impairments in the past, it is surely right to be very leery of anything that might contribute to a perpetuation of such derogation of Article 12 rights in the future. However support for people with very extensive cognitive impairment under the third of Michael Bach and Lana Kerzner’s [51] supported decision-making models (“facilitated decision-making”), while perfectly consistent with the notion of “best interpretation of will and preferences” contained in paragraph 18b of the General Comment [1], is a form of facilitated decision-making which necessarily shades towards proxy decision-making [25,42]. As Nandini Devi has argued, “the facilitated decision-making status is similar to substituted decision-making because decisions are made on behalf of adults lacking the standard decision-making ability, even though it seeks to promote individuality and freedom.” ([38], p. 802). As I have contended elsewhere, supported decision-making in this form may be almost identical to optimally operating guardianship, both functionally and in terms of public perception of the roles of the supporter/guardian ([8], p. 62; [37], p. 12).

That does not detract from the very significant benefits for people with cognitive impairments from the very important symbolic or “cultural” shift entailed by adopting facilitated decision-making in place of any ideal guardianship proxy relationship [8], but it surely provides an antidote to unrealistic expectations of how pure is the agency realised under supported decision-making. Against that backcloth, the next Part turns the spotlight on recent reforms and proposals for reform.

### **3. Recent Reforms and Reform Proposals**

Recent law reform activity throws into relief both the practical challenges of giving content to human agency through meaningful support, and of avoiding unintended consequences or other pitfalls, such as extension of paternal control (“net-widening”) or public misunderstanding (misreading support as entailing conferral of proxy decision-making powers).

### 3.1. Australian, Ontario and Victorian Law Reform Recommendations

Various concrete recommendations and models for possible reform of traditional adult guardianship laws have been advanced recently, though legislation has been lacking outside Canada.

In 2012 the Victorian Law Reform Commission recommended supplementing traditional guardianship and administration orders with two additional measures: supported decision-making and co-decision-making. Each was recommended to be available either at the initiative of the person themselves or as a tribunal order made on application to the guardianship list of VCAT ([3], paras. 8.13–31, 8.78–87). Co-decision-making was not proceeded with by Government, which in 2014 brought in legislation for personal nomination or tribunal appointment of supporters, only the first of which became law before Parliament was dissolved for the November 2014 State Election which saw a change of government. Both measures were cast in somewhat problematic form [25], as discussed further below.

The November 2014 Final Report the Australian Law Reform Commission, proposed a model for introducing supported decision-making across various areas of direct Commonwealth responsibility, such as aged care, social security and e-health. The model provides for and strongly preferences supporters (appointees without substitute decision-making powers) but also includes provision for “representatives” (last resort appointees carrying proxy decision-making powers) ([4], pp. 99–119). The model includes detailed specification of statutory objects and fundamental principles, reinforced by finely crafted formulations of guidelines ([4], para. 3.4 and chap. 3 generally), forming a package designed not only for Commonwealth consumption but also to serve as a “template” to inspire and inform State and Territory governments in reviewing their own laws and policies, since this is the level of government with major constitutional responsibility for such matters. Developed from its “framing” principles of dignity, equality, autonomy, inclusion and participation, and accountability ([4], para. 1.34), four decision-making principles are delineated: the right of all persons to make and have decisions respected; to be supported to make decisions; for supported decisions to be directed by the “will, preferences and rights” of the person; and for provision of appropriate safeguards.

For its part, the Law Commission of Ontario’s Discussion Paper on *Capacity, Decision-Making and Guardianship* [6], elaborates issues raised earlier in its (still on-going) more limited project dealing with capacity to take advantage of Canada’s tax and social security advantaged equivalent of Australia’s disability trusts (further: [52,53]; *Social Security Act 1991* [54], Part 3.18A ss 1209L-1209ZE). That earlier Commission Discussion Paper—*Capacity of Adults with Mental Disabilities and the Federal RDSP* [5]—had hinted at some of the possibilities (and conundrums) posed. The Commission in its earlier paper canvassed several possible options in a search for alternatives to guardianship as the way of supplying the necessary advice needed about what it characterised as the “demanding” and “complex” ([5], p. 18) decisions and investment choices associated with setting up, or handling the subsequent distribution of funds from Registered Disability Savings Plans (“RDSP”), while also striving to meet expectations of doing so at negligible cost to government ([5], p. 40).

One such option being considered by the Ontario Law Commission is to move away from “capacity” tests (as also urged by the UNCRPD Committee’s Comment) and concentrate instead on operationalising Michael Bach and Lana Kerzner’s [51] focus on the ability to express (or for others to

“read” from conduct or other signs) a person’s will and intentions, along lines partially captured by the legal tests of capacity found in the law in the province of Newfoundland and Labrador, and that in British Columbia ([5], p. 24). As later explained, this entails a desirable shift from a cognitive to a non-cognitive (or expressive) enquiry, but it poses practical problems of implementation for someone isolated from a circle of trusting relatives or friends able to read their will and intent ([6], pp. 77–78, 136, 143–45). Community volunteers, though difficult to recruit, would be one possible answer to this ([6], pp. 152–54), but there are also wider issues about the accountability of supporters for their work ([6], pp. 133–34). These and other difficulties in operationalising supported agency for people with severe cognitive impairments or social isolation are sought to be catered for by what Bach and Kerzner term the option of “facilitated decision-making” for those not able to enjoy either autonomous or supported decision-making, but for whom facilitation guided by will and preferences is required ([6], p. 125).

A less radical approach canvassed by the LCO would involve retaining but transforming capacity through lowering the bar, by removing any common law or (as in Victoria) statutory gloss that capacity must be viewed as entailing the ability to “understand and appreciate” issues (see [6], p. 76). For example in Victoria the *Guardianship and Administration Bill 2014* defined decision-making capacity in high threshold terms as:

- Cl 4(1) For the purpose of this Act, a person has capacity to make a decision in relation to a matter (*decision making capacity*) if the person is able—
- (a) to *understand* the information relevant to the decision and the *effect* of the decision; and
  - (b) to *retain* that information to the extent necessary to make the decision; and
  - (c) to *use or weigh* that information as part of the process of making the decision; and
  - (d) to *communicate* the decision and the person’s views and needs as to the decision in some way, including by speech, gestures or other means [italics added].

Such tests arguably place undue emphasis on rational cognitive capacity—retaining, processing and comprehending information—at the expense of “lower threshold” or more functionally-oriented measures of capacity to express one’s will [55]. This reform approach of lowering the threshold is exemplified for supported decision-making by Yukon and British Columbia’s “representation agreements” ([5], pp. 58–59) and by the unproclaimed Newfoundland and Labrador “designation agreements” ([5], p. 53). Equally, execution of more routine private planning instruments such as the delegation of proxy power of decision under an enduring power of attorney might be permitted more readily under such a test, as in Saskatchewan ([5], p. 52), a test said to reflect the supposed “simplicity of the common law”.

A different reform tack altogether, also briefly considered by the LCO, contemplates replacing the criterion of capacity with a focus on “vulnerability”, as Margaret Hall proposes [56]. This is sought to be justified partially in recognition that guardianship already seeks out or aims to create stable, ongoing “relationships of responsibility” which counter any vulnerabilities, and that this search for any “vulnerability gap” between the ability of the person and the current challenges or demands likely to be encountered is already the essence of a “functional” interpretation of capacity. However whether such a more open-ended consideration of the subjective dimensions of relational or situated

vulnerability, the capacity to craft an intervention to relieve it, and the return of more judgmental evaluations entailed in this approach is yet a sufficiently refined model as to serve as an adequate replacement, must surely still be doubted (further [42]). Not only does the current formulation of a vulnerability test lack the fabled “bright line” capacity for delineating when to invoke or not invoke the intervention, but it is dubious whether there is a line at all.

Certainly it would be unwise to dismiss such an approach out of hand, simply because it is so apparently open-ended and reliant on very subjective assessments. Thus in another context in the USA, where the most popular model of adult guardianship is the “social welfare” model first sketched nearly 30 years ago [57], it is at least arguable that for the elderly wishing to avoid unnecessary admission to residential aged care, a social welfare model is the “least worst”—in that, despite the conflict of interest entailed by being potential service providers, such guardians have both the expertise to help preserve home living for as long as possible, and the likelihood of actually doing so [58]. While this is likely to achieve little traction in an Australian context, despite introduction in Queensland of a private guardianship service [59] and North American examples of provision for and regulation of what are termed “professional fiduciaries” ([6], pp. 149–52), it is indicative of the need to retain an open mind about possible innovative new ways of tackling old problems.

As always in law reform, of course, there is a risk of misreading the needs of ordinary people in the rush to construct ideal models. At Commonwealth level in Australia, the workhorse provisions for meeting routine needs of people with some cognitive impairment have been what are termed “nominee” provisions.

### 3.2. Accessible Laws for Ordinary Situations? Nominee Provisions

Originally adopted to authorise making social security payments to an account of a third party nominee rather than the pensioner (what in the US are called “representative payee” schemes: [60]), nominee powers were later adapted to provide for the appointment of “correspondence nominees” (a less intrusive function) and, more recently, were taken as a template for National Disability Insurance Scheme (“NDIS”) arrangements for appointment of “plan nominees” engaged to assist people to settle the bundle of resources covered by their individualised budgets through personal plan entitlements under the NDIS [61].

It is evident that even these arrangements are not all the same, however. Representative payee provisions may create a de facto “money manager” but, for better or worse, they do not actually replicate the *powers* associated with financial guardianship orders or execution of enduring powers of financial management; though whether it would in practice be better if they did (by regulating what is now unregulated) is another question. Appointment of correspondence nominees to receive duplicate copies of social security letters (and bear responsibility for meeting procedural obligations to report things like changes of circumstances which may generate overpayment debts) plainly has important implications for the person’s privacy, but it is more “facilitative” in character than are the usual guardianship arrangements. On the other hand, a “plan nominee” under the NDIS arguably exercises much greater power than that of a representative payee, since the role is to negotiate the on-going level of resourcing a person requires to meet their disability needs (*National Disability Insurance Scheme Act 2013* (Cth) [62], sections 78, 84). It is thus more akin to the major life course shaping decisions

other people make about their education and training, choice of jobs or careers. These things, then, are not all the same at all.

In recognition of the importance of these different forms of nominee powers and their lack of congruence with CRDP principles, the ALRC Report has proposed standardising the model to bring it into line with the CRPD, including spelling out guiding principles and clarifying other elements. The Commission's new template adds provision for appointment of "supporters", whose role reprises (with a few alterations) the scope of responsibilities of existing correspondence nominees. While all existing nominee type provisions are recommended for replacement, the ALRC proposes leaving it to portfolio departments to decide whether the model should be extended to new fields.

The attraction of confining the scope of reforms to renovation of existing—but as found by numerous prior enquiries ([63], chap. 9; [64], para. 3.120; [65], chap. 7; [66], para. 9.40ff) plainly non-conforming nominee provisions<sup>4</sup>—is that it minimises the risk of overspill through extending the law into currently unoccupied areas where no new arrangements are needed, or where their well-meaning introduction may lead to unintended consequences such as third parties according to supporters powers of decision not actually conferred [37]. Or worse still, as the experience with informal schemes of support suggests [68], where extension of the model may result in supporters acting in ways which restrict the choices actually open to the person supported, or acting in ways which "shape" their choice to conform more closely with the views of the person acting as their supporter [69–71]. Either of these would run contrary to the spirit of Article 12 of the CRPD [26]. Of course the other side of the coin is that leaving the territory vacant may lead to even greater paternalism and restriction of choice, due to prevailing assumptions by carers or others that the person has no capacity for or right to agency. Well-designed empirical research then is sorely needed to answer questions such as whether the age-adjusted rates of appointment of representatives per head of population declines as the ALRC model anticipates will occur, or whether some supporters are appointed unnecessarily, or exercise unwarranted powers of decision [20].

### 3.3. *The National Disability Insurance Scheme*

The powers to appoint plan or correspondence nominees under Part 5 of the legislation governing Australia's National Disability Scheme are significant because the decisions made by plan nominees are potentially quite weighty, akin to those associated with Canada's Registered Disability Savings Plans [5].

Section 78 of the *National Disability Insurance Scheme Act 2013* [62] ("*NDISA 2013*") provides that unless the instrument of appointment of a plan nominee otherwise provides, a plan nominee can make any decision open to a participant regarding the "preparation, review or replacement" of a plan or "the management of the funding for supports" under that plan. The ALRC found the existing arrangements to be a mix of substitute, supported and informal decision-making, where "three key decision-making mechanisms include: autonomous decision-making by participants; informal supported decision-making; and substitute decision-making by nominees", though the low rate of appointment of Commonwealth nominees at NDIS trial sites, indeed none at all so far in NSW, meant that family

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<sup>4</sup> The existing protocols and protections are found in the Centrelink policy guide [67].

carers or other informal supporters were being relied on ([4], paras. 5.17, 5.30). Whether family members of people such as those with mild intellectual impairment will subsequently apply inappropriately for appointment simply to resolve disagreements about spending, as some have forecast [72], and if so whether such net-widening appointments are made, remains to be seen; though in a worrying sign, by late 2014, 85 applications had been made for guardians to be appointed under state legislation in the NSW Hunter region trial site ([4], para. 5.94).

Although less than ideal, NDIS nominee provisions already outstrip their state and territory counterparts in terms of their decision-making guidelines. Section 80(1) *NDISA 2013* provides that it is the “duty of a nominee of a participant to ascertain the wishes of the participant and to act in a manner that promotes the personal and social wellbeing of the participant”. Subsection (4) authorises promulgation of rules prescribing “other duties” including a duty “to support decision-making by the participant personally” or “to have regard to, and give appropriate weight to”, the views of the participant: s80(4)(a), (b). The appointment of a nominee may not be made without the written consent of the participant after taking account of the participant’s wishes: *NDISA 2013* s 88(2)(a), (b). The appointment must also “have regard to” the existence of any person already empowered under guardianship order or other appointment conferring power to make decisions for the person: s 88(4)(a), (b) [This would include an existing Centrelink nominee]. The rules may prescribe persons “who must not be appointed” and lay down “criteria to which the CEO is to have regard” in making appointments: s 88(6)(a), (b). The ALRC found these principles to be lacking in some respects (such as their regard for “wishes” rather than on will, preferences and rights) but mainly focused on remedying the lack of provision to instead appoint a genuine supporter ([4], paras. 6.18, 6.23–27), and on renovating existing nominee provisions to fully conform to the template for a “representative”.

As the ALRC recognises, “one of the key difficulties in applying the Commonwealth decision-making model to the NDIS is determining how NDIS supporters and representatives interact with state and territory appointed decision makers” ([4], para. 5.88), a concern shared by the Victorian Office of the Public Advocate, not least because there are no equivalent federal agencies to undertake such gatekeeping and monitoring roles ([73], p. 26). The ALRC proposes possible solutions such as data sharing and consultation with State and Territory bodies as ways of overcoming very real concerns about possible unnecessary proliferation or overlapping of appointments, and dilution or lack of conformity to CRPD principles at State and Territory level. However there are also some other risks, including that of net-widening. The experience here is rather mixed so far. In the NSW case of *Re KCG* [74] the Guardianship Division of the Civil and Administrative Tribunal of NSW decided that, for a person lacking an individual as financial administrator or guardian, but whose finances were managed by NSW Trustee and Guardian, a guardian (in this case the Public Guardian) should be appointed, because:

The Tribunal’s view is that where important lifestyle and financial decisions are required to be made on behalf of a person who lacks the requisite decision making capacity (and cannot be supported to make decisions for themselves), such as Miss KCG, it is appropriate that an independent substitute decision maker such as guardian or financial manager (depending on the nature of the decision) is appointed to undertake that

responsibility. The NDIS nominee scheme is a substitute decision making scheme designed for people with disability like Miss KCG ([74], para. 67).

While *Re KCG* is an instance where a guardian was appropriately considered as being needed (the accommodation and other choices opened up by the NDIS generated a need for decisional support not previously arising), there can be an expansion of guardianship as a by-product of a person not involved with the NDIS happening to share accommodation with someone involved in the scheme, meaning that new arrangements might be made in ways impacting on the other person, as illustrated in *Re NZO* [75]. The Tribunal found it “ironic” that Ms NZO, who was 68 and thus outside eligibility to now become a participant in the NDIS, now needed a guardian when previously, despite her intellectual disability, she was able to manage perfectly well without one ([75], para. 27). By contrast a parent seeking guardianship of her 18 year old son in order to strengthen her hand in being accepted as an NDIS nominee rightly failed to obtain such an order, since it was inconsistent with least restrictive guardianship principles<sup>5</sup>.

Other cognate parts of the law may also contribute to or influence how well or poorly supported decision-making powers are exercised with respect to the NDIS, such as avenues for review of plans. Planning decisions about the provision of reasonable support are reviewable by the AAT<sup>6</sup> and that process is both supported and flexible [78]; though if an individual’s plan makes provision for conciliation, this is the first step [79]. To date four such reviews have been heard, all of which were unsuccessful (one due to lack of jurisdiction to review)<sup>7</sup>. If such review continues to prove to be a dry gully (despite it having some success in a cognate field in Victoria’s since abandoned review panel: [39,81–83]), pressure may build to turn to what might be termed “creative misuse” of supported decision making or proxy powers as a second best way of bringing leverage to bear.

### 3.4. Victoria’s 2014 Reforms and Reform Proposals

In mid-2014 Victoria introduced two pieces of legislation to give effect to the first half of the VLRC proposals to provide for both supported decision-making and for co-decision-making (as in some Canadian provinces: further [6], pp. 138–39). The *Powers of Attorney Act 2014* (“PA Act 2014”) [84] enabling a person to nominate a supporter had a speedy passage through the Parliament in August<sup>8</sup>,

<sup>5</sup> *Re KTT* [2014] NSWCATGD 6, at paras. 29–33.

<sup>6</sup> *National Disability Insurance Scheme Act 2013* Cth, sections 99–103. For an up-dated summary of decided cases see [76]. The Department of Social Services provides some level of support to people in bringing such applications [77].

<sup>7</sup> *Re TKCW and National Disability Insurance Agency* [2014] AATA 501 (Sen. Member Toohey; determining against inclusion of listening therapy and care of a sibling while therapy is provided for a person with autism); *Re Young and National Disability Insurance Agency* [2014] AATA 401 (Sen. Members Toohey & Handley; determining that a portable oxygen concentrator and insulin pump were more appropriately provided through the health system than under the NDIS); *Re Mulligan and National Disability Insurance Agency* [2014] AATA 374 (Sen. Member Toohey & Prof. McCallum, Member; determining that the substantially reduced functional capacity of s 24 eligibility was not satisfied); and *Re Burston and National Disability Insurance Agency* [2014] AATA 456 (Sen. Mem. Toohey; determining that no jurisdiction to review). The Mulligan decision is being challenged in the Federal Court: [80].

<sup>8</sup> The *Powers of Attorney Act 2014* (No. 57 of 2014) was introduced on 24 June 2014, completed its passage through the Parliament on 19 August and received the Royal Assent on 26 August 2014. Part 7 of the new Act makes provision for appointment of a “supportive attorney”.

but the *Guardianship and Administration Bill 2014* [85] (“*G&A Bill 2014*”) providing for tribunal appointment of a supporter on application to VCAT was not so fortunate, debate stalling in the Legislative Assembly and lapsing with the proroguing of Parliament for the November State Election where the government lost office.

In introducing the *G&A Bill 2014* the Minister’s Second Reading Speech described the proposals in these terms:

A supportive guardian appointed by VCAT will be able to assist a person in the same way as a supportive attorney appointed by a principal..., helping the person to gather and consider information, and to communicate and to implement their decisions. Once VCAT has appointed a supportive guardian, and specified the applicable powers in the appointment order, the same provisions of the Powers of Attorney Bill 2014 dealing with the powers of a supportive attorney will apply to the supportive guardian ([86], p. 2941).

However as explained in more detail elsewhere [25], while faithfully implementing VLRC proposals to enable appointees to access needed information, facilitate implementation of decisions and spell out duties owed to the person being supported, much of the good work in the package was undone by a very unfortunate choices of the terms “supportive *attorney*” and “supportive *guardian*” to identify the two appointees in the public arena. This flouted warnings of the considerable risk of the public mistakenly assuming that supporters are actually proxy decision-maker [8,37], even though no such power is actually conferred.

This misstep was a doubly unfortunate one because it contained at least two worthwhile measures. First, the *G&A Bill 2014* would have renovated guardianship principles of the principal Act to much more fully embrace the sentiments of the CRPD (abolition of guardianship aside), thus more closely reflecting the “personalised guardianship” model championed by some commentators as being at least a close relative of CRPD ideals of support ([17], p. 13; [87], pp. 1543–44 for the model and p. 1558 for ‘person-centred guardianship’). Secondly, because the Bill introduced a mediation principle which proved to be quite popular in NSW in screening out inappropriate applications ([88], p. 71) and which mirrored other overseas suggestions for bringing the law into closer conformity with Article 12 of the CRPD, such as the work of Jennifer Wright [89].

Even so, no false tears need be shed over the demise of the *G&A Bill 2014* since it also was fatally flawed in proposing an avenue of expedited making of guardianship orders on parental application once a person with an intellectual disability reached adulthood. This was despite such measures having been rejected by the architects of the pioneering 1986 legislation ([90], p. 19), and despite the availability of far more palatable options as recommended by the VLRC ([3], paras. 12.45, 12.130–12.132), including case management of more straightforward applications ([3], para. 21.120). As explained elsewhere, such defects seriously detracted from the commendable features of the Bill (see further [25]).

#### 4. Conclusions

As suggested in this paper, the challenges of balancing out the competing goals enunciated by the UN CRPD Committee in its 2014 General Comment [1] extend well beyond deciding on the pace and degree of transformation from substitute to supported decision-making.

Supported decision-making may or may not require engaging the law at all. Circles of support, micro-boards, or friendship networks, may better be cultivated purely within civil society, overseen simply by the advocacy, service protocols, health and welfare professional standards and other processes of the myriad of informal community, self-help, non-government and government human services agencies. However inadequate due to cost and other barriers, accountability of informal supporters may perhaps best be left to education and information strategies, the abuse mandate of Offices of the Public Advocate, or even the rightly pilloried avenues of redress in the courts [91,92], in order to avoid the more egregious social policy cost of formalisation having a chilling effect on willingness to offer support, or of rendering provision of support less visible to outside scrutiny. If law is thought necessary, existing principles (such as the law of associations) might even be a preferable way of building clarity and accountability into the work of informal networks ([6], p. 158, discussing a Victorian OPA proposal).

Certainly it is challenging enough to balance off, at the levels of theory or principle, say the interests of accessibility against maintenance of an adequate quality of supported decision-making, whether in informal or formalised settings. And the answer to where the balance lies will not necessarily be the same across national or over state and territory borders: it is likely to vary depending on the architecture of the legal system, the configuration of social services and relationships with civil society and informal sectors, as was demonstrated in the evaluation of the 1980s Victorian and NSW guardianship reforms, where the balance between values of autonomy and protection worked out differently in practice in the two jurisdictions due to differing institutional arrangements [27]. However it becomes much more difficult to find that balance when there is so little evidence about “what works”, or for whom, or to what degree. This is true not only of international experience with different forms of supported decision-making enshrined in or specifically recognised by law [7,36], but also in understanding the efficacy or otherwise of informal schemes [22]. As the former Chief Justice of the High Court of Australia Sir Anthony Mason warned regarding the perils of embarking on policy-making or legislative reform absent a sound evidence-based approach “[a]s things currently stand, [current] proposals seem to reflect little more than ideals that have not been carefully thought through, with the risk that they will result in experimental law-making” ([93], p. 173).

I currently don't have settled answers to the many design and implementation conundrums. Certainly there is a good case for “hastening slowly” [25], such as by prioritising development of a “genuine” prototype supported decision-making law, which can be modelled as a replacement for (e.g., renaming and re-working Centrelink (DSS) correspondence nominees) or as an addition to Commonwealth laws which already provide for some quasi (or actual) substitute decision-making provision (e.g., NDIS plan nominees); just as there is surely an irresistible argument for ensuring that reforms by way of CRPD compliant objects, principles, and guidelines are imposed on any such existing legal arrangements. The current open slather for Centrelink (DSS) nominee powers is palpably in breach of CRPD standards for instance. Perhaps the Victorian reforms which renovate some of the guiding principles for substitute decision-making and add an (appallingly named) supported decision-making option required to be considered after informal options but before guardianship, are also to be somewhat commended as cautious examples of “hastening slowly”. But the same surely cannot be said about the retrograde step of providing for expedited orders for parents when a

cognitively impaired person turns 18, or for not further boosting “will and preference” guiding values to the degree proposed by the ALRC.

But beyond that? Only time will tell.

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### Conflicts of Interest

The author declares no conflict of interest.

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