

# Getting the Balance Right: Conceptual Considerations Concerning Legal Capacity and Supported Decision-Making

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**Abstract** The United Nations *Convention on the Rights of Persons with Disabilities* urges and requires changes to how signatories discharge their duties to people with intellectual disabilities, in the direction of their greater recognition as legal persons with expanded decision-making rights. Australian jurisdictions are currently undertaking inquiries and pilot projects that explore how these imperatives should be implemented. One of the important changes advocated is to move from guardianship models to supported or assisted models of decision-making. A driving force behind these developments is a strong allegiance to the social model of disability, in the formulation of the Convention, in inquiries and pilot projects, in implementation and in the related academic literature. Many of these instances suffer from confusing and misleading statements and conceptual misinterpretations of certain elements such as legal capacity, decision-making capacity, and support for decision-making. This paper analyses some of these confusions and their possible negative implications for supported decision-making instruments and those whose interests these instruments would serve, and advises a more incremental development of existing guardianship regimes. This provides a more realistic balance between neglecting the real limits of those with mental disabilities and thereby ignoring their identity and particularity, and continuing to bring them equally and fully into society.

**Keywords** Decision-making capacity · Disability · Guardianship · Legal capacity · Supported decision-making

## Introduction

The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) (United Nations 2006a) was entered into force in May 2008, and ratified by Australia two months later. The CRPD is based on significant, connected shifts in the conceptualization and implementation of the rights of those with disabilities, including (1) from a primary acknowledgment of negative rights (with positive rights as more or less derived from those negative rights) to a primary positive right to appropriate treatment, support and recognition before the law (Weller 2011); (2) from an emphasis on disabilities as deficiencies defined according to a medical model of health to a socially determined and socially constructed model, that sees disabilities as impairments that, through interaction with social barriers, impede full and equal participation in society (McSherry 2012; Morrissey 2012); and (3) from an emphasis on substitute decision-making as facilitated by established guardianship regimes that comport more with a best interests regime supported by the medical model of health, to a range of models of supported or assisted decision-making that are argued to better facilitate autonomy and self-determination (Forrester 2014; Smith and Sullivan 2012).

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In particular, Article 12 of the CRPD—Equal recognition before the law—requires, at 12.1, that “States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law,” at 12.2, that “States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life,” and at 12.3, that “States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.” These imperatives are clearly aimed at advancing the rights, equality, dignity, autonomy, and control enjoyed and exercised by people with disabilities, within what is perceived as the pervasive cultural and institutional contexts that have contributed to the social construction of the disabilities in the first place (Carney and Beaupert 2013). This is not surprising, given the strong involvement of disability organisations in drafting and negotiating the CRPD and the claim by many such organisations and spokespersons that disability is largely, if not totally, socially constructed (Shakespeare 2006).

While Australia has ratified the CRPD, it has been criticized for not moving sufficiently swiftly in the directions the CRPD requires of signatories, for example in contrast to a number of Canadian provinces. Nevertheless, a majority of jurisdictions have begun considering changes. Even at this relatively early stage of considering, comparing, and piloting the issues, structures, and processes, in order to better support self-determination for people with disabilities, the direction of change appears to be clear but largely unquestioned. Most of the reports, inquiries, and pilots are underpinned by a range of recurring conceptual and ethical assumptions, influenced to varying extents by a social constructionist model of health. Following a brief summary of these recent developments (no doubt incomplete), this paper challenges some of these assumptions. The analysis does not attempt to question specific assertions or recommendations in the Australian developments but to issue some general challenges to the ideas that inform them, that have already arisen elsewhere, and that have also appeared in the literature following the establishment of the CRPD. Firstly, it examines the frequently conflated concepts of legal capacity and decision-making capacity. It then examines some implications of this conflation for issues including competing models of decision-making capacity; the nature of and claims concerning supported decision-making in the context of current guardianship regimes’

substitute decision-making processes; and the prospects of the proposed shifts and new models achieving their aims, viz. to augment the autonomy of people with disabilities.

It is important to emphasise that the aim of the paper is not to decry the crucial moral progress that has been achieved by all those who have worked and continue to work in pursuit of greater independence, autonomy and rights for those people with all kinds of disabilities. They have been discriminated against for millennia, and the foot-soldiers of the global disability movement have made huge gains on their behalf in a very short time in relative terms (Charlton 2000). It may be precisely the gravity of the discrimination that this vital social movement has struggled to dismantle, that has resulted in some of the ideas and developments that are challenged here; it is not uncommon that responses to social problems may overshoot and/or encounter some initial glitches. But the broad thrust of the responses is more important than any flaws that show up along the way, and exposing these flaws and their inherent risks should be seen as an element of the main project.

### Recent and Current Australian Developments

The NSW Legislative Council undertook an inquiry into substitute decision-making for people lacking capacity in 2009. It acknowledged that the concept of assisted decision-making was strongly supported by a majority of inquiry participants, and that existing NSW legislation was limited in promoting assisted decision-making. It recommended that relevant legislation be amended to include an explicit statement of support for the principle of assisted decision-making and to provide for the relevant courts and tribunals to make orders for assisted decision-making arrangements (NSW Legislative Council 2010). The Office of the Public Advocate in South Australia conducted a trial of supported decision-making between 2010 and 2012 (Office of the Public Advocate SA 2011). This was an empirical project that was evaluated as having delivered specific benefits to most of the participants (Wallace 2012). The Victorian Law Reform Commission released a report in 2012 that recommended the adoption of a statutory scheme for

assisted (supported) decision-making (Victorian Law Reform Commission 2012).

A small trial was conducted in the ACT between 2012 and 2013 (ADACAS 2013), with a range of recommendations to facilitate supported decision-making. The executive summary of the report of the trial stated:

For Australia to fulfil its responsibilities under the UNCRPD, a spectrum of decision support responses need to become as mainstream as ramps, automatic doors and braille on ATM machines and be viewed as fundamental accessibility issues that are rights rather than additional extras in the life of a person with disability (ADACAS 2013, 6).

Similar pilot projects are being or have been undertaken by the NSW Office of Ageing, Disability and Home Care, together with the Public Guardian and NSW Trustee and Guardian (NSW Family and Community Services 2013), due for completion in 2014, and by the Office of the Public Advocate Victoria (Office of the Public Advocate Victoria 2014).

As one of its current research and advocacy projects—Decision-making support in Queensland’s guardianship system (Office of the Public Advocate Qld n.d.)—the Office of the Public Advocate in Queensland has published a literature review that recognises growing momentum for the reform of guardianship law and practice, in the context of the CRPD and the introduction of the National Disability Insurance Scheme in Australia, which aims to place people with disabilities at the centre of decision-making that affects them. The literature review is part of a wider research project that will identify the systemic barriers and enablers in relation to protecting and supporting the right of a person to make their own decisions. Like other inquiries and reports, the project recognises that “the focus must shift from what a person cannot do to the supports that should be provided to enable people to make decisions and exercise their legal capacity” (Office of the Public Advocate Qld 2014a). An Issues Paper was published in November 2014, canvassing advance care planning, capacity, support for decision-making, and related matters pertinent to the current Queensland guardianship system (Office of the Public Advocate Qld 2014b).

Finally, the Australian Law Reform Commission (ALRC) has undertaken an inquiry into Equality, Capacity and Disability in Commonwealth Laws, which aimed to:

examine laws and legal frameworks within the Commonwealth jurisdiction that deny or diminish the equal recognition of people with disability as persons before the law and their ability to exercise legal capacity, and consider what, if any, changes could be made to Commonwealth laws and legal frameworks to address these matters (Australian Law Reform Commission. 2013).

The ALRC inquiry commenced in 2013 and submitted its final report in November 2014 (Australian Law Reform Commission 2014)

### Legal Capacity and Decision-Making Capacity

Article 12 of the CRPD—equal recognition before the law—requires that signatory states accord people with disabilities legal capacity on an equal basis with others in all aspects of life and that they provide access to people with disabilities to the support required in exercising their legal capacity. Much has been made of the idea of legal capacity in subsequent academic commentary, inquiries, reports, pilots, and legislation, but the failure of the CRPD to explicitly define what is meant by legal capacity in Article 2 to explicitly define what is meant by legal capacity (United Nations 2006a) has led to its being used in different and inconsistent ways, which may affect the interests of those whose legal capacity is being promoted, albeit largely unwittingly.

Although the CRPD provides no explicit, succinct definition, there is reason to believe that the idea of legal capacity contained in the CRPD and its associated documentation is distinct from that of decision-making capacity. To *accord* people with disabilities legal capacity on an equal basis with others, cannot be the same as *attributing* to them equal decision-making capacity; the former sounds like rights talk, whereas decision-making capacity is just that: a capacity *on the basis of which* certain rights may be accorded. This distinction is supported by subsequent recommendations for implementing the CRPD:

Imagine having your capacity to make decisions, sign contracts, vote, defend your rights in court or choose medical treatments taken away simply

because you have a disability. For many persons with disabilities, this is a fact of life, and the consequences can be grave. When individuals lack the legal capacity to act, they are not only robbed of their right to equal recognition before the law, they are also robbed of their ability to defend and enjoy other human rights. Guardians and tutors acting on behalf of persons with disabilities sometimes fail to act in the interests of the individual they are representing; worse, they sometimes abuse their positions of authority, violating the rights of others. (United Nations 2007, 89)

Article 12 of the Convention recognizes that persons with disabilities have legal capacity on an equal basis with others. In other words, an individual cannot lose his/her legal capacity to act simply because of a disability. (However, legal capacity can still be lost in situations that apply to everyone, such as if someone is convicted of a crime.)

The Convention recognizes that some persons with disabilities require assistance to exercise this capacity, so States must do what they can to support those individuals and introduce safeguards against abuse of that support (United Nations 2007).

The use of “*capacity to make decisions ...*” is somewhat misleading. You cannot have your decision-making capacity taken away, but you can have your capacity to make decisions taken away, if we understand “*capacity to make decisions*” here to mean the right to make them. This interpretation is supported by the subsequent statement that someone cannot lose their legal capacity to act simply because of a disability, although they can lose it in situations that apply to everyone, such as being convicted of a crime. The legal capacity to act (to exercise legal capacity, in the words of Article 12) must be different from decision-making capacity, if anyone can lose it as a result of a criminal conviction, since the vast majority of people convicted of crimes clearly do not thereby lose decision-making capacity. There are therefore good reasons to interpret the CRPD, when it talks about legal capacity, to be talking about something different from decision-making capacity. At times, however, its language is imprecise and misleading, and it is possible that this imprecision in drafting and the lack of an explicit definition of legal capacity in the CRPD has sown the seeds of conflation and a consequent flowering of confusion and mis-statement. Some examples follow.

If legal capacity is better conceived as a right to act than as a contingent capacity, then statements like these

from the International Disability Caucus (n.d.) might have had less chance of appearing:

Legal capacity is fundamental to a person’s self-determination.

If a person does not have legal capacity—including the right to exercise this legal capacity—then a “*presumption of incapacity*” flows all over an individual’s life ...

Everyone needs their legal capacity and their right to exercise their legal capacity acknowledged and respected.

The first statement reads as if legal capacity simply means decision-making capacity. If not, it approaches tautology. The second statement seems to *distinguish* legal capacity from the right to exercise it, although legal capacity is said to *include* the right to exercise it. This is inconsistent with the interpretation of the CRPD’s distinction between decision-making capacity and legal capacity, as explained above. But without legal capacity and the right to exercise it, a presumption of incapacity is said to flow over a person’s life. What things are being referred to here is quite opaque, given that linguistic convention in this area takes *presumptions* of capacity and incapacity to refer to decision-making capacity or its absence. The third statement could be rendered with the same meaning by saying “Everyone needs their right to exercise their legal capacity acknowledged and respected,” unless, again, legal capacity means decision-making capacity.

The ALRC’s inquiry into Equality, Capacity and Disability in Commonwealth Laws illustrates how the imprecise and misleading language of the CRPD can be adopted. For example, it posed the question “Should there be a Commonwealth or nationally consistent approach to defining capacity and assessing a person’s ability to exercise their legal capacity? If so, what is the most appropriate mechanism and what are the key elements?” (Australian Law Reform Commission 2013, 7).

While including “defining capacity” and “a person’s ability to exercise their legal capacity” in the same question does not logically imply they are the same thing, running them together like this may well be based on, and further entrench the idea that, assessing someone’s legal capacity amounts to assessing their decision-making capacity. Forrester points out that in considering the question posed by the ALRC, “it is appropriate to examine

whether there is a consistent definition and application of the element of legal capacity across the different states and territories” (Forrester 2014, 790). She indicates that “the element of legal capacity in a health care context is variously referred to as decision-making ability, decision-making capacity, disability, mental incapacity and the inability to make reasonable judgements” (Forrester 2014, 794), and that while it is not clear whether these terms mean the same thing, they all serve in practice to remove or dilute from persons with disabilities the legal right to make health care decisions in the normal way.

While these examples suffer from internal linguistic confusions and lack of clarity, other commentators display a more overt slippage from one distinct thing (legal capacity understood in the sense of a right to act and be recognised as a legal actor) to another (capacity in the sense of decision-making capacity). For example, McSherry quotes the definition of legal capacity of the Council of Europe’s Commissioner for Human Rights as “a person’s power or possibility to act within the framework of the legal system” (McSherry 2012, 23; Commissioner for Human Rights 2012, 7); states that legal capacity is constituted by two elements, legal standing—being viewed as a person before the law—and legal agency—the ability to act within the framework of the legal system; and says that Article 12.2 and 12.3 of the CRPD taken together, ensure that legal agency is encompassed by the CRPD’s concept of legal capacity. Up to this point, legal capacity is being understood in the sense of legal agency and the recognition of this agency, and McSherry interprets Article 12 as attributing legal capacity to those with disabilities equally with others. The next step involves the slippage, because McSherry then describes two traditional approaches to determining “whether or not a person lacks legal capacity” as being the *status approach* and the *cognitive approach*, with the latter being divided into subsidiary *outcome-based* assessment and *functional* assessment (McSherry 2012, 23–24). But these various named approaches are the traditional, alternative and competing means by which *decision-making capacity* is defined (White, Willmott, Then 2014; Devereux and Parker 2006; Parker and Cartwright 2005), and by this stage McSherry has ceased talking about legal capacity and begun to employ terms like “decision-making abilities” as the subject of the different approaches.

Some sources and commentators recognize that decision-making capacity and legal capacity are not the same thing. We have seen, for example, that the Council of Europe’s Commissioner for Human Rights defines

legal capacity as “a person’s power or possibility to act within the framework of the legal system” (Commissioner for Human Rights 2012, 7). This includes the ability to hold rights and exercise them and to take actions that the law must recognize, whatever level of decision-making abilities a person may demonstrate (Devi 2013). Smith and Sullivan—having noted that dementia can strip away core features of personhood, remove recognition of others as well as interests, skills, character, and moral agency—discuss a model of supported decision-making “which allows people with impaired capacity to retain their full legal capacity where decision-making can be managed through a ‘supported decision-making status’” (Smith and Sullivan 2012, 32). This clearly articulates the conceptual and empirical truth that people who have lost decision-making capacity do not thereby lose their legal capacity, understood as legal standing and legal agency, albeit via a formalized process such as an advance health directive or an appointed substitute decision-maker.

What accounts for the conflation of and slippage between legal capacity and decision-making capacity? The bioethical Poirot might see his first clue, the sharing of the word “capacity” between both concepts as no mere coincidence but underpinned by a network of linked considerations. The enactment of the CRPD was the result of strong social forces acting in response to perceived discrimination against people with disabilities, particularly those with intellectual disabilities and mental disorders, within the wider historical and international context of continuing social action to achieve equality, enhanced rights, and maximum autonomy for members of many vulnerable minority groups. Different constraints, impositions, and restrictions of freedom were seen to emanate from traditional paternalistic structures, in particular the biomedical model of healthcare, that have maintained the marginalization of people with disabilities from mainstream society and its benefits. The disability movement was actively engaged in drafting the CRPD (Szmukler, Daw and Callard 2014), and it is not surprising that its themes are strongly informed by the social constructivist model of health and healthcare (Weller 2011).

While the CRPD does not define disability, it understands it as resulting “from the interaction between a person’s impairment and obstacles such as physical barriers and prevailing attitudes that prevent their participation in society. The more obstacles there are the more disabled a person becomes” (United Nations 2006b, ¶9). Hence, one of its primary requirements of signatories is to modify the hostile environments in which people with disabilities

find themselves, including by removing discriminatory attitudes and practices, increasing social inclusion, and emphasizing and supporting the positive abilities of people with disabilities (Weller 2011). Specific processes to effect these changes include removing, or at least reducing the incidence of, substitute decision-making in favour of supported decision-making. This is theorized by its adherents as accommodating disabilities and supporting people in ways that will enable them to exercise their legal capacity, in contrast to existing processes that are seen as denying this. Crucially, the model is seen as being *led* by the individual concerned, rather than by others, with the individual being supported in various ways to make their own decisions and choices (Devi 2013).

Now, if

- disability is seen as proportional to social obstacles, and
- greater equality for the disabled requires the removal of social obstacles, and
- an important social obstacle is a discriminatory biomedical model of healthcare that defines things like decision-making capacity,

then it should not come as a surprise that, in trying to enlarge the scope of freedom and autonomy for people with disabilities, a model that attributes *some form* of decision-making capacity to *all* people with disabilities would emerge, and that this would tend to conflate that particular capacity with that freedom and autonomy. This is consistent with a core concept of supported decision-making—that all or virtually all people can be supported to make their own decisions, that in doing so they lead the process, and that supported decision-making can replace substitute decision-making.

### Legal Capacity, Decision-making Capacity, and Supported Decision-making

These linked ideas—that all people can make their own decisions with appropriate support, that those needing support should initiate and lead the process of supported decision-making, and that this model of decision-making can replace substitute decision-making—have been strongly argued in recent literature. Such a quasi-absolute approach does not appear in the CRPD,

although again, the CRPD is less than clear about this. This section of the paper demonstrates that this linked set of ideas is also conceptually confused and confusing. Together with the conflation of legal capacity and decision-making capacity, this confusion may pose risks to some people who are thought to be benefited by moving to supported decision-making.

Some commentators interpret the CRPD as acknowledging that some people are not able to achieve decision-making capacity, even with support, and that they will benefit from appropriately crafted substitute decision-making arrangements (Weller 2011). However, the CRPD gives mixed messages. Having accepted that anyone can lose legal capacity as a result of committing a crime, and thus distinguishing legal capacity from decision-making capacity (as explained above), the Handbook for Parliamentarians on the CRPD proceeds to issue ambiguous statements such as:

With supported decision-making, the presumption is always in favour of the person with a disability who will be affected by the decision. The individual is the decision-maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual. Even when an individual with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to the wishes of the individual (United Nations 2007, Ch 6).

And (citing with approval British Columbia’s statutory supported decision-making arrangements):

One of the main innovations in the legislation is that persons with more significant disabilities can enter into representation agreements with a support network simply by demonstrating “trust” in the designated supporters. A person does not need to prove legal competency under the usual criteria, such as having a demonstrated capacity to understand relevant information, appreciate consequences, act voluntarily and communicate a decision independently, in order to enter this agreement (United Nations 2007, Ch 6).

However, in addition to the conflation of “legal competency” with decision-making capacity that we have discussed, the Handbook is saying:

- that (without any qualification) the individual with the disability is the decision-maker;
- that some individuals with disabilities require total support; and
- that individuals with significant disabilities can be represented by support networks if they demonstrate “trust” in the network, without proving that they can understand relevant information or appreciate the consequences of decisions.

Several questions naturally arise in response to these assertions. Firstly, if individuals are *always* the decision-makers, how does “total support” enter the picture? Does not the idea of “total support” imply that at least some individuals *cannot* be decision-makers and hence need a process of substitute decision-making or decision-making in their best interests (where best interests here includes reference to whatever the person can be understood to have wanted)? If not, what does “total support” mean? Second, how can all individuals be decision-makers *themselves*, if some individuals cannot understand relevant information and appreciate the consequences of their decisions? And third, if individuals who cannot understand relevant information and appreciate the consequences of their decisions are simply to “trust” their networks, how does this differ from substitute decision-making, and hence how is it superior to that model in terms of the benefits and augmented rights that are supposed to accrue under the model of supported decision-making? The abundance of inconsistencies like these illustrates a poorly conceptualized schema that militates against coherent policy deliberation in the context of justified but realistic enlargement of the rights of those with disabilities.

This sort of conceptual confusion has led to interpretations of Article 12 of the CRPD as calling for the replacement of guardianship laws and practices with the supported decision-making model, rather than a more measured introduction of supported decision-making in appropriate contexts, for example with people

... with acquired brain injuries, intellectual impairments, or psychiatric disabilities who have the ability to communicate (either verbally, with assisted communication, through an interpreter or non-verbally) and who have some choice-making abilities (including the ability to evaluate options and recall having made a choice (Smith and Sullivan 2012, 33).

This basis of “some choice-making abilities” is at issue in descriptions of the nature and processes of supported decision-making. For example, Devi describes support networks or circles involving key people in the individual’s life who support, interpret, and facilitate in relation to decisions. They are said to understand the individual’s life history, communication forms, and her desires. Support can include gathering information, explaining it and assisting the individual to understand the consequences of a decision (Devi 2013). Now, gathering and explaining information to people with unquestioned decision-making capacity, to facilitate their decision-making, is a commonplace. We all depend on information that we do not literally gather ourselves. We also often need different aspects of that information explained to us, including technical medical information, and some of this explanation will involve describing the consequences of a decision. If these things apply to both those with unquestioned decision-making capacity and those with a requirement for support in decision-making, it would seem that in the latter case there must be at least some fundamental “choice-making abilities.” If so, what exactly does a requirement for support in decision-making amount to, particularly in relation to people who cannot understand relevant information, appreciate consequences, act voluntarily, or communicate decisions?

Devi adverts to Bach and Kerzner’s framework for supported decision-making that proposes a three-tiered categorization of legally independent, supported, and facilitated decision-making status (Bach and Kerzner 2010). This model allows for support or assistance in the first, “independent” category, such as easy-to-read language, even though members of the category can independently understand the information and appreciate the consequences of a decision, consistent with the analysis above. The second, “supported” category includes individuals who need support to express their will in decision-making. Support includes consulting the individual to determine his wishes and translating his intentions. Devi indicates that these things may be achieved by, *inter alia*, a tribunal appointing a trusted support person on application by the individual. The third, “facilitated” category includes those with significant intellectual disabilities who have no friends or family who know them well enough to know how to communicate their will and preferences but where a facilitator can still facilitate decision-making on the basis of developing knowledge of the person within a relationship. This

category has also been described as including individuals who have stated their wishes in an advance health directive or power of attorney document when acting “legally independently” (Morrissey 2012, 432).

The second and third categories present difficulties. Firstly, the appointment of a trusted support person on application by the individual illustrates what can be called the “initiation problem.” Then has observed that legislation like British Columbia’s *Representation Agreement Act 1996* has adopted a more flexible approach than those utilizing a threshold concept of capacity, in order to determine whether an individual can enter into an agreement that authorizes supported decision-making and better respects autonomy (Then 2013). The Act states that an adult may make a representation agreement, even if they are incapable of managing their own health, personal, financial, and legal matters but that, in deciding whether they are incapable of *making the agreement*, or of changing or revoking its provisions,

... all relevant factors must be considered, for example:

- (a) whether the adult communicates a desire to have a representative make, help make, or stop making decisions;
- (b) whether the adult demonstrates choices and preferences and can express feelings of approval or disapproval of others;
- (c) whether the adult is aware that making the representation agreement or changing or revoking any of the provisions means that the representative may make, or stop making, decisions or choices that affect the adult;
- (d) whether the adult has a relationship with the representative that is characterized by trust (*Representation Agreement Act 1996 BC*, s8).

But how much more flexibility than the traditional threshold concept of capacity do these considerations represent? To demonstrate choices and preferences, indicate approval or disapproval of others (in relation to the supporting *role*, not just whether the other person was liked or not), be aware of what that role involves, and to trust the support person, together comprise something that closely aligns with what a threshold concept of capacity requires. The application for the appointment of a support person is a sophisticated process; it would require that the individual has sufficient decision-making

capacity for such a process in the first place, and if this is so, questions arise again concerning just what the nature of required decision-making support amounts to.

Second, if the facilitated category includes those who have written advance-care planning documents, and given that lack of decision-making capacity is a requirements for these to be activated, and if, in principle, these impose a legal requirement for the individual’s wishes to be carried out, we should wonder what extra expression of autonomy being included in this category provides.

Finally, it is not clear what the principled and practical differences are between the second and third categories, if in both categories an assistant (supporter or facilitator) communicates the individual’s will and preferences, although some commentators have interpreted Bach and Kerzner’s third category—including as it does those with significant intellectual disabilities—more realistically as one where “their will and preferences cannot be adequately ascertained, and who they describe as requiring ‘facilitated’ decision-making, that is, by other persons, until the person’s ‘will and preferences’, with the necessary supports, can be established” (Szmukler, Daw and Callard 2013, 248).

The initiation problem is an example of the wider issue of threshold versus alternative concepts of decision-making capacity. It is not surprising that the threshold concept is challenged by those who see Article 12 of the CRPD as allowing “an individual’s decision-making to be supported or assisted to preserve their autonomy to the maximum extent” (Then 2013, 146). But care is required here to avoid common pitfalls. To the extent that supported decision-making enlists a “sliding scale” model of decision-making capacity, it runs conceptual risks that also pose practical ones for those who are being supported. The sliding scale idea is thought to fill a conceptual and a legal gap between states of capacity and incapacity, i.e., a grey area where people need support for decision-making (Then 2013). But there are two different interpretations of the sliding scale concept, both of which are responses to what is perceived as the all-or-nothing, traditional approach to capacity. The first response points out that capacity should be regarded not as all or nothing in the sense that a person has capacity for everything or nothing but as all or nothing *within* decision-specific and time-specific contexts. The second response asserts that there are different *levels* of capacity and had its origin in debates between outcome-based and functional assessments of cognitive capacity (McSherry 2012).



In those debates, serious outcomes, such as death resulting from refusing treatment, were argued to demand higher levels of capacity, and this was based on the intuition that disregarding medical advice in serious situations was a likely *sign* of incapacity (Buchanan and Brock 1989). Functional definitions of capacity have eclipsed outcomes definitions, including in legislation, with the functional or procedural definition preventing the exercise of paternalistic medical interventions that *define* someone as lacking capacity just because they act contrary to medical advice. However, the core concept of different levels of capacity lingers and is arguably helping to motivate the push to supported decision-making that will fill out the perceived grey area between capacity and incapacity. For the same reasons as the outcomes model, in the context of treatment refusal was sidelined, and for underpinning logical reasons (Wicclair 1991; Checkland 2001; Parker 2004) the concept of different levels of capacity should not be entertained in the area of supported decision-making for people with disabilities. The first response to the all-or-nothing view should prevail, because people with intellectual disabilities will have capacity that varies according to the *decision at hand*, and/or according to the fluctuating nature of their disability over time. For example, a person with a relapsing and remitting psychotic illness will lose decision-making capacity when unwell and regain it once in remission. The crucial point here is that the capacity threshold is preserved on the decision-specific/time-specific version of the sliding scale idea, in relation to specific decisions and/or times.

The importance of preserving a threshold concept is consistent with the observations above about British Columbia's legislation. Far from moving to some more flexible arrangement, which purports to expand the range of individuals who can authorize their own healthcare and other matters, the legislation reimports what amounts to a threshold requirement under somewhat different language. This contradicts what the Handbook for Parliamentarians asserted in relation to this legislation, as discussed above, to the effect that an individual does not need to conform to traditional functional/procedural capacity criteria in order to enter a representation agreement. The legislation in this case has retained a realistic approach to decision-making capacity and the initiation of representation agreements, in contrast to the Handbook for Parliamentarians' contradictory and unworkable recommendations.

A number of risks to individuals with disabilities, who are the subjects of the proposed new models of supported decision-making and others, flow from the conceptual considerations canvassed so far. At one extreme of thinking about the rights of people with disabilities is the view that *all* people can be supported to make their own decisions. This is plainly false, but the ambit claim is presumably made in order to confer expanded legal rights on the greatest possible number of people. This is clearly abetted by the conflation of legal capacity and decision-making capacity. The problem here is to wrongly attribute to certain people capacities they do not have, rather than affording them the maximum legal capacity that is reasonable in the context of their particular problems, and that can be operationalized via existing or improved instruments, appointments and representations. This may result in unrealistic expectations of some people, who are then at risk of being inadequately supported. False beliefs that individuals are exercising newly conferred rights, for example by allegedly *initiating* a representation agreement with a trusted other, may delay interventions that would minimize the abuse and exploitation that people with disabilities can be subjected to and which the CRPD is keen to avoid. Such beliefs may also tend to camouflage the real seat of decision-making power in at least some cases, particularly in less formal and more loosely monitored arrangements that the supported decision-making models favour.

The initiation problem and the threshold issue also apply to situations when decision-making capacity changes. If the individual, albeit in need of support, is the one who makes the decisions, supporters will have no conceptual place to stand when, on a threshold view of capacity, it falls below the threshold. Conversely, if a responsibility to take action when this occurs rests with the supporter, this presupposes a different model from that which is supposedly operating. It would involve moving to a substituted decision-making arrangement that many advocates of supported decision-making models argue should *replace* such arrangements.

### Social Model of Disability

We have seen that the drafting of the CRPD was strongly driven by the desire to continue to shift the understanding of disabilities as traditionally defined by the medical model of health, to a socially determined one,

where social barriers impede people with impairments from fully participating in society. This process is part of a broad picture of social action aimed at increasing autonomy and equality for all perceived vulnerable minority groups and thereby decreasing the discrimination experienced by these groups. One way of achieving these aims in the disability sector, particularly for those affected by intellectual and mental impairments, has been to broaden the attribution of decision-making capacity to most if not all people with such impairments, by introducing the concept—and, in some jurisdictions, the practice—of supported or assisted decision-making, that some adherents consider should significantly or even completely replace the current substitute decision-making regimes. In the previous sections the paper has demonstrated a number of conceptual issues that raise questions about these shifts.

The CRPD itself asserts that the more social obstacles there are to people with impairments, the more disabled that person becomes. Without further qualification—and there appears to be none in the CRPD—this is certainly a strong version of the social construction thesis concerning intellectual disabilities. Now, no one will dispute that most impairments can be rendered less difficult for people by changing the physical, social, and attitudinal environment in which they live. A person with paraplegia is enabled by modern wheelchair technology and modifications to the built environment and transportation to move, travel, access services, and so on, almost on a par with those who can walk. The community attempts, within its resource limitations and allocation policies, to normalize the capacities of those who are impaired in relation to those who are not. Biotechnology continues to research biophysical means to reduce inequalities even further. It is possible that, in the future, technology will even be able to cure paraplegia and tetraplegia. This would amount to removing all physical obstacles in these cases.

How analogous are the aspirations to remove all obstacles in the paralysis case and the intellectual disabilities cases? We might tend to think that, just as the capacity to move in the paralysis case is something we should attempt to optimize, so the capacity to do the thing that appears to be impaired in the latter case—to decide and manage things for oneself—should also be increased. But the social construction approach to this aspiration overemphasizes the role of social obstacles such as attitudes in restricting this capacity and romanticizes the extent to which it can be optimized.

Steele has outlined an “interactional” model of conceiving the interplay between impairments, disabilities, and social obstacles that steers a course between the essentialism of the biomedical model and the essentialism of the social construction model of health and disability. According to the social construction theorist, biomedical essentialism purports to *discover* impairment/disability within the individual, but Steele points out that the social construction model fails to acknowledge subjective discomfort, experience, and the fact that impairment will always be negatively evaluated despite good social supports. The interactional model acknowledges the essential, biological/experiential aspects of disability but also their interaction with external factors including social support, discriminatory attitudes, and cultural factors, and in some cases the role of social determinants in helping to bring about disabilities in the first place (Steele 2008).

The tendency to downplay the importance of the biological and experiential facts of impairment and disability results from the laudable aspiration to spread and maximize capacities that may be being denied. To this extent, various forms of supported decision-making will have a role to play in particular cases. These are consistent with the common principle that we can all do with some support in our decision-making, as sketched above. But the aspiration can drag us too far in its fulfilment and lead us to think that this has occurred even when we have no strong evidence that this is the case. For example, Morrissey describes approvingly Sweden’s personal ombudsman (PO) framework, whereby the disabled person authorizes a PO to discharge certain tasks, including helping to express and implement the principal’s decisions, which are expressly reserved to the principal (Morrissey 2012). To the extent that the PO framework is a means of extending to a person with decision-making capacity ways to carry out his wishes that were hitherto not available, this is surely a legitimate enlargement of freedom and legal capacity, correctly understood. But if it purports to extend to people who are currently not attributed decision-making capacity (again, correctly understood), the initiation problem again appears. Moreover, in the latter context, there will be no way of discerning the extent to which the PO may be projecting on to the principal her views concerning either the best interests of the principal or even his wishes, from outside the arrangement.

A related risk of overemphasizing the social model of disability is to pretend that we are doing something new and extending freedoms, when we are not. Morrissey (2012) suggests that advance health directives provide an opportunity to realize the social model of disability for people with psychosocial disabilities, by providing for the wishes of those who enact them ahead of mental health crises to be acted upon “when decision-making autonomy may be impacted” and that the social model requires a reconceptualization of advance health directives. But it is far from clear just how such instruments, first developed quite some time ago in at least some jurisdictions to cater for mental health eventualities in addition to the more usual end-of-life treatment abatement/refusal situations, provide an opportunity to realize the social model of disability. Providing for wishes to be operationalized “when decision-making autonomy may be impacted” implies that a judgement has been made concerning this autonomy; what could that judgement amount to apart from considering that the decision-making capacity of the person who has written the directive has now fallen below some threshold, upon which the instrument takes legal effect? The irony here is that while the advance health directive is uncontroversially a social instrument, and a social means of extending autonomy beyond existing decision-making capacity, it does not need rationalization in terms of a model that eschews a particular concept of decision-making capacity. These and related instruments were introduced as part of an incremental expansion of freedom/legal capacity, which is perfectly compatible with the correct understanding, as described here, of decision-making capacity and when it should be regarded as having been lost.

It follows that the alternative to the somewhat confused and confusing project of increasing autonomy and equality and decreasing discrimination for vulnerable minority groups, is to continue this incremental process. One way of achieving this is to focus on aspects of current guardianship regimes that might be modified in the same direction as that for which advance directives provide the best illustration. For example, in the context of withdrawing or withholding life-sustaining treatment from adults who lack decision-making capacity, it is argued that the traditional “best interests” test that must be exercised by substitute decision-makers and courts should be broadened. Willmott and colleagues have shown that the small number of Australian Supreme court cases where the court has exercised its *parens*

*patriae* jurisdiction to promote the welfare of vulnerable individuals in these situations, have demonstrated limited engagement with the wishes of patients (Willmott et al. 2014) and a lack of adherence to a coherent set of principles in deciding the cases (Willmott, White, and Smith 2014). They further argue that a coherent approach should give greater weight than is currently the case to the views and wishes of the patient, as far as they can be identified (Willmott, White, and Smith 2014).

The same argument can be applied in the case of individuals with intellectual and mental disabilities who are currently involved in guardianship processes. While the movement towards supported decision-making has been critical of the substitute decision-making model as depending too much on an objective, often medically based best interest standard for decision-making (Then 2013; Forrester 2014; Advocacy for Inclusion 2012), giving greater weight to the views and wishes of the patient *within* existing structures would be a more principled and transparent way of maximizing autonomy and legal capacity, in view of the opaqueness of many of the more informal arrangements favoured under the supported decision-making model.

## Conclusion

The CRPD has been in force for over seven years. Jurisdictions across the globe are at different stages of implementing what they take to be its guiding principles, which aim to enlarge the autonomy of people with intellectual disabilities. There exists a range of ways in which important elements of the Convention—particularly legal capacity, decision-making capacity, and supported decision-making—are being understood, interpreted, and conflated. Care is required to avoid enacting conceptual confusions that carry with them implementation risks that may not well serve those whose rights and freedoms these enactments would enlarge. Legal capacity and decision-making capacity must be clearly distinguished. The decision-making capacity of those with intellectual disabilities must be conceptualized and determined logically and realistically, and while it should be extended where there is evidence to do so, it should not be overstated. Supported decision-making and substitute decision-making require further conceptual work in delineating their differences and overlaps. The risks of less formal

arrangements of support and decision-making also require further conceptual and empirical inquiry. The social model of disability must be realistically interpreted and employed in extending greater freedoms and rights to those with intellectual disability. Current guardianship regimes should incorporate a greater emphasis on principals' known and/or previously expressed wishes.

## References

- ACT Disability, Aged and Carer Advocacy Service (ADACAS). 2013. Spectrums of support: A report on a project exploring supported decision-making for people with disability in the ACT. [http://www.adacas.org.au/decision-support/copy\\_of\\_SupportedDecisionMakingProjectFinalReport.pdf](http://www.adacas.org.au/decision-support/copy_of_SupportedDecisionMakingProjectFinalReport.pdf). Accessed July 3, 2014.
- Advocacy for Inclusion. 2012. Supported decision-making, legal capacity and guardianship. Implementing Article 12 of the Convention on the Rights of Persons with Disabilities in the Australian Capital Territory. [http://www.advocacyforinclusion.org/publications/supported\\_decision\\_making\\_legal\\_capacity\\_and\\_guardianship2012final.pdf](http://www.advocacyforinclusion.org/publications/supported_decision_making_legal_capacity_and_guardianship2012final.pdf). Accessed July 3, 2014.
- Australian Law Reform Commission. 2013. Equality, capacity and disability in commonwealth laws. Issues Paper 44. June 7, 2013 (modified November 24, 2014). <http://www.alrc.gov.au/inquiries/legal-barriers-people-disability>. Accessed July 3, 2014.
- . 2014. Equality, capacity and disability in commonwealth laws (ALRC Report 124). November 24, 2014. <https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>. Accessed December 16, 2014.
- Bach, M., and L. Kerzner. 2010. A new paradigm for protecting autonomy and the right to legal capacity. Ontario Law Commission. <http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner>. Accessed July 10, 2014.
- Buchanan, A.E., and D.W. Brock. 1989. *Deciding for others: The ethics of surrogate decision-making*. Cambridge: Cambridge University Press.
- Carney, T., and F. Beupert. 2013. Public and private bricolage—Challenges balancing law, services and civil society in advancing CRPD-supported decision-making. *UNSW Law Journal* 36(1): 175–201.
- Charlton, J. 2000. *Nothing about us without us: Disability oppression and empowerment*. Berkeley and Los Angeles: University of California Press.
- Checkland, D. 2001. On risk and decisional capacity. *The Journal of Medicine and Philosophy* 26(1): 35–59.
- Commissioner for Human Rights (Council of Europe). 2012. Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities. <https://wcd.coe.int/ViewDoc.jsp?id=1908555>. Accessed July 10, 2014.
- Devereux, J., and M. Parker. 2006. Competency issues for young persons and older persons. In *Disputes and dilemmas in health law*, ed. I. Freckelton and K. Petersen, 54–76. Sydney: Federation Press.
- Devi, N. 2013. Supported decision-making and personal autonomy for persons with intellectual disabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities. *The Journal of Law, Medicine and Ethics* 41(4): 792–806.
- Forrester, K. 2014. Legal capacity in a health care context: An opportunity to review. *Journal of Law and Medicine* 21(4): 789–796.
- International Disability Caucus. n.d. Legal capacity. <http://un.org/esa/socdev/enable/rights/ahc8docs/ahc8idclegcapfl.doc>. Accessed July 1, 2014.
- McSherry, B. 2012. Legal capacity under the Convention of the Rights of Persons with Disabilities. *Journal of Law and Medicine* 20: 22–27.
- Morrissey, F. 2012. The United Nations Convention on the Rights of Persons with Disabilities: A new approach to decision-making in mental health law. *European Journal of Health Law* 19: 423–440.
- NSW Family and Community Services (Ageing, Disability and Home Care). 2013. [http://www.adhc.nsw.gov.au/\\_\\_data/assets/file/0003/279039/SDMP\\_fact\\_sheet\\_Oct2013.pdf](http://www.adhc.nsw.gov.au/__data/assets/file/0003/279039/SDMP_fact_sheet_Oct2013.pdf). Accessed July 5, 2014.
- NSW Legislative Council (Standing Committee on Social Issues). 2010. Substitute decision-making for people lacking capacity. [http://www.parliament.nsw.gov.au/prod/parlment/committee.nsf/0/e00602d3c8f39ca5ca2576d500184231/\\$FILE/100225%20SDM%20Final%20Report.pdf](http://www.parliament.nsw.gov.au/prod/parlment/committee.nsf/0/e00602d3c8f39ca5ca2576d500184231/$FILE/100225%20SDM%20Final%20Report.pdf). Accessed July 5, 2014.
- Office of the Public Advocate (Qld). n.d. Current research and advocacy projects. <http://www.justice.qld.gov.au/justice-services/guardianship/public-advocate/current-projects>. Accessed July 5, 2014.
- . 2014a. Systems Advocacy. Decision-making support for Queenslanders with impaired capacity: A conceptual framework. [http://www.justice.qld.gov.au/\\_\\_data/assets/pdf\\_file/0004/249403/Decision-making-support-for-Queenslanders-with-impaired-capacity-A-conceptual-framework-March-2014.pdf](http://www.justice.qld.gov.au/__data/assets/pdf_file/0004/249403/Decision-making-support-for-Queenslanders-with-impaired-capacity-A-conceptual-framework-March-2014.pdf). Accessed July 5, 2014.
- . 2014b. Decision-making support in Queensland's guardianship system. An Issues Paper. [http://www.justice.qld.gov.au/\\_\\_data/assets/pdf\\_file/0018/314172/Issues-Paper-November-2014.pdf](http://www.justice.qld.gov.au/__data/assets/pdf_file/0018/314172/Issues-Paper-November-2014.pdf). Accessed November 20, 2014.
- Office of the Public Advocate (SA). 2011. Supported decision making. [http://www.opa.sa.gov.au/resources/supported\\_decision\\_making](http://www.opa.sa.gov.au/resources/supported_decision_making). Accessed July 5, 2014.
- Office of the Public Advocate (Vic). 2014. Supported decision-making pilot project. <http://www.publicadvocate.vic.gov.au/file/file/Research/Current%20projects/SDM%20project%20flyer%20FINAL.pdf>. Accessed July 5, 2014.
- Parker, M. 2004. Judging capacity: Paternalism and the risk-related standard. *Journal of Law and Medicine* 11(4): 482–491.
- Parker, M., and C. Cartwright. 2005. Mental capacity in medical practice and advance care planning: Clinical, ethical and legal issues. In *Mental capacity. Powers of attorney and advance health directives*, edited by B. Collier, C. Coyne, and K. Sullivan, 56–92. Sydney: Federation Press. *Representation Agreement Act 1996*, BC. [http://www.bclaws.ca/Recon/document/ID/freeside/00\\_96405\\_01](http://www.bclaws.ca/Recon/document/ID/freeside/00_96405_01). Accessed July 8, 2014.
- Shakespeare, T. 2006. *Disability rights and wrongs*. London: Routledge.

- Smith, A., and D. Sullivan. 2012. A new ball game: The United Nations Convention on the Rights of Persons with Disabilities and assumptions in care for people with dementia. *Journal of Law and Medicine* 20: 28–34.
- Steele, L. 2008. Making sense of the Family Court's decisions on the non-therapeutic sterilisation of girls with intellectual disability. *Australian Journal of Family Law* 22(1): 1–23.
- Szmukler, G., R. Daw, and F. Callard. 2014. Mental health law and the UN Convention on the Rights of Persons with Disabilities. *International Journal of Law and Psychiatry* 37(3): 245–252.
- Then, Shih-Ning. 2013. Evolution and innovation in guardianship laws: Assisted decision-making. *Sydney Law Review* 35: 133–166.
- United Nations. 2006a. Convention on the Rights of Persons with Disabilities. <http://www.un.org/disabilities/convention/conventionfull.shtml>. Accessed July 1, 2014
- . 2006b. Convention on the rights of persons with disabilities. Why a convention? <http://www.un.org/disabilities/convention/questions.shtml>. Accessed July 1, 2014
- . 2007. Handbook for parliamentarians on the Convention on the Rights of Persons with Disabilities. <http://www.ipu.org/PDF/publications/disabilities-e.pdf>. Accessed July 1, 2014.
- Victorian Law Reform Commission. 2012. Guardianship: Final report No 24. [http://www.lawreform.vic.gov.au/sites/default/files/Guardianship\\_FinalReport\\_Full%20text.pdf](http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20text.pdf). Accessed July 10, 2014.
- Wallace, M. 2012. Evaluation of the supported decision-making project. [http://www.opa.sa.gov.au/resources/supported\\_decision\\_making/may\\_2013\\_update](http://www.opa.sa.gov.au/resources/supported_decision_making/may_2013_update). Accessed July 10, 2014.
- Weller, P. 2011. The Convention on the Rights of Persons with Disabilities and the social model of health: New perspectives. *Journal of Mental Health Law (Special Edition)* 74–83.
- White, B., L. Willmott, and S.-N. Then. 2014. Adults who lack capacity: Substitute decision-making. In *Health law in Australia*, 2nd ed, ed. B. White, F. McDonald, and L. Willmott, 193–253. Sydney: Thomson Reuters.
- Wicclair, M.R. 1991. Patient decision-making capacity and risk. *Bioethics* 5(2): 91.
- Willmott, L., B. White, and M.K. Smith. 2014a. “Best interests” and withholding and withdrawing life-sustaining treatment from an adult who lacks capacity in the *parens patriae* jurisdiction. *Journal of Law and Medicine* 21(4): 920–941.
- Willmott, L., B. White, M.K. Smith, and D. Wilkinson. 2014b. Withholding and withdrawing life-sustaining treatment in a patient's best interests: Australian judicial deliberations. *Medical Journal of Australia* 201(9): 545–547.