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Assumptions of Decision-Making Capacity: The Role Supporter Attitudes Play in the Realisation of Article 12 for People with Severe or Profound Intellectual Disability

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Abstract: The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was the first legally binding instrument explicitly focused on how human rights apply to people with disability. Amongst their obligations, consistent with the social model of disability, the Convention requires signatory nations to recognise that “... persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” and mandates signatory nations to develop “... appropriate measures to provide access by persons with disability to the support they may require in exercising their legal capacity”. The Convention promotes supported decision-making as one such measure. Although Australia ratified the UNCRPD in 2008, it retains an interpretative declaration in relation to Article 12 (2, 3, 4), allowing for the use of substituted decision-making in situations where a person is assessed as having no or limited decision-making capacity. Such an outcome is common for people with severe or profound intellectual disability because the assessments they are subjected to are focused on their cognition and generally fail to take into account the interdependent nature of human decision-making. This paper argues that Australia’s interpretative declaration is not in the spirit of the Convention nor the social model of disability on which it is based. It starts from the premise that the intention of Article 12 is to be inclusive of all signatory nations’ citizens, including those with severe or profound cognitive disability. From this premise, arises a practical need to understand how supported decision-making can be used with this group. Drawing from evidence from an empirical study with five people with severe or profound intellectual disability, this paper provides a rare glimpse on what supported decision-making can look like for people with severe or profound intellectual disability. Additionally, it describes the importance of supporters having positive assumptions of decision-making capacity as a factor affecting supported decision-making. This commentary aims to give a focus for practice and policy efforts for ensuring people with severe or profound cognitive disability receive appropriate support in decision-making, a clear obligation of signatory nations of the UNCRPD. A focus on changing supporter attitudes rather than placing the onus of change on people with disability is consistent with the social model of disability, a key driver of the UNCRPD.

Keywords: UNCRPD; supported decision-making; severe or profound cognitive disability; human rights; decision-making capacity

1. Introduction

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is not only the first human rights treaty of the twenty-first century, it is the first legally binding instrument that

explicitly provides an explanation of how human rights can be applied to people with disability [1]. Although Australia ratified the Convention in 2008, it included an Interpretative Declaration specifically relating to Article 12. An interpretative declaration is, "... a unilateral statement, however phrased or named, made by a State or an international organization, whereby that State or that organization purports to specify or clarify the meaning or scope of a treaty or of certain of its provisions" ([2], p. 21). Australia's Interpretative declaration relating to Article 12 states: "Australia declares its understanding that the Convention allows for fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards" [3]. Substituted decision-making occurs where "guardians and administrators [are] appointed to make decisions in the 'best interests' of the person concerned" ([4], p. 26). Australia's interpretative declaration has the effect of enabling Australia to retain laws that use substituted decision-making in situations where a person is believed to have no or limited decision-making capacity, denying them their right to legal capacity. Because such an assessment outcome is common for people with severe or profound intellectual disability, Australia's declaration has the effect of excluding them from the protections promised under Article 12. It is important to note that at the time at which Australia created the Interpretative Declaration, the theory around supported decision-making and understanding of Article 12 was in its infancy. There is a clear need to incorporate contemporary understandings of supported decision-making, the social model of disability, and Article 12, into practice and legal reform particularly in relation to those with more severe cognitive disability.

The UNCRPD promotes supported decision making as the vehicle by which people with disabilities can exercise their legal capacity to the greatest extent possible [1]. Considering its clear relationship with supported decision-making it is important to operationally define legal capacity, as it is conceptualised in this paper. Legal capacity is a universal human attribute enshrined in law. It allows a person to be recognised as a person before the law [1]. Accepting the right to legal capacity as a given, this paper's focus is on the more practical construct of decision-making capacity. Decision-making capacity is conceptualised within the context of this paper as a person's ability to lead a self-directed life with support. It is acknowledged that while the term "decision-making capacity" is not considered synonymous with the notion of legal capacity, where a person is perceived to have decision-making capacity, they are more likely to have their right to legal capacity, under Article 12 realised.

From here on the term severe or profound intellectual/cognitive disability is used to describe those who are the focus of this paper. Over the last two decades, philosophies that have emerged within disability culture generally have discouraged the use of labels to describe people with intellectual disability for fear of their individuality being buried within stereotypes. Despite these views, there is a compelling argument for using specific language to signal the unique, and poorly understood, support needs of people with severe or profound cognitive disability. Although the use of a label does not take precedence over seeing the person first, an explicit acknowledgment of their needs is necessary if they are to receive the significant support they require to lead a self-determined life.

People with severe or profound intellectual disability require support in most aspects of their lives. They generally communicate informally using nonverbal behaviours such as facial expression, gesticulation, vocalisations, eye gaze and touch. They have difficulty understanding formal communication such as speech, sign, written text, pictures, or photos. In addition to communicating informally, many people with severe or profound intellectual disability communicate unintentionally. This means, they appear unaware that their actions can have an impact on their environment. This means that for effective information transfer communication partners infer meaning from the person's behaviours, an activity acknowledged in the intellectual disability related literature as an ambiguous and subjective task [5–7].

While research and practice guidance focused on Article 12 and supported decision-making for people with mild to moderate cognitive disability and mental illness is emerging [8–11], such guidance is clearly lacking for people with severe or profound cognitive disability. There are likely

to be numerous reasons for this lack of empirical attention. Firstly, within an Australian context, while an interpretative declaration allowing for substitute decision-making for people with severe or profound cognitive disability is in place, there is no legislative incentive for researchers to work toward enhancing this group's capacity to lead self-directed lives. Moreover, there is less ambiguity around the intention of Article 12 for people with milder as opposed to more profound cognitive disability, making research with this group less attractive. Flynn and Arstein-Kerslake, examining the granting of personhood through the permitting or denying of legal capacity, have articulated this, describing people with severe/profound cognitive disability as the "hard cases" ([12], p. 98). Additionally, a lack of empirical attention maybe due to widely-held prejudices regarding people with severe or profound cognitive disability's ability and right to be supported to lead self-directed lives [13,14].

These beliefs regarding people with severe or profound cognitive disability's ability and right to be supported to lead self-directed lives maybe rooted in the premise that a person's ability to make and communicate decisions is characterised solely by a set of cognitive based pre-requisites, such as an ability to understand abstract notions of causality. These cognitive skills are seen as independent of environmental factors such as support from family and friends [15]. These beliefs are emphatically rejected within the social model of disability [16–18]. Clough ([18], p. 31) argues that this focus on individualised cognitive skills "fails to accord with the reality of human interdependence" Moreover, Kittay argues that although the phenomenon of human interdependence is considered acceptable within the non-disabled community, for people with the most profound disabilities different rules apply. Rather than being embraced, their dependency on others is exceptionalised as problematic and in order to be recognised as having a human right to lead a self-directed life, they are expected to measure up to standards of cognitive capacity not applied to the rest of the population [17].

Such a focus on cognitive as opposed to ecological barriers to self-determination is exemplified in the medical model of disability and is in direct conflict with the social model, firmly embedded within the UNCRPD. The social model of disability promotes that the barriers and enablers to self-determination exist well beyond an individual, and are constructed by the society in which a person lives. Such an ecological view of self-determination is consistent with a supported decision-making approach, and places the onus of change on supporters, rather than those being supported. Brayley reflects Kittay's views calling for a system of law that moves away from this focus on cognition, to one that universally recognises that a person's legal capacity (and consequently their recognition as a person) does not rest on their individual cognitive capability but on the quality of support available to help them to make decisions [19]. Beamer and Brooks articulated this view half a decade before the drafting of the UNCRPD stating that:

The starting point is not a test of capacity, but the presumption that every human being is communicating all the time and that this communication will include preferences. Preferences can be built up into expressions of choice and these into formal decisions. From this perspective, where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices. ([20], p. 4)

There is little doubt that the cognitive approach to the granting of legal capacity underlies Australia's interpretative declaration in relation to Article 12. As described such an approach is reflective of the medical as opposed to the social model of disability. Considering the importance of the social model of disability within the drafting of the UNCRPD, it can be argued that while it continues to have an interpretative declaration with regard to Article 12 in place, Australia is contravening the Convention. McSherry further articulates this concern suggesting that while the universality of Article 12 is not recognised Australia is not acting within the spirit of the Convention [4]. Reinforcing these concerns, in 2014 the UN Committee on the Rights of Persons with Disabilities shared this view, articulating that it was "...concerned about the possibility of maintaining the regime of substitute decision-making, and that there is still no detailed and viable framework for supported decision-making in the exercise of legal capacity ... The Committee recommends that the State party [Australia] uses effectively the current inquiry process to take immediate steps to replace

substitute decision-making with supported decision-making and provides a wide range of measures which respect the person's autonomy, will and preferences and is in full conformity with article 12 of the Convention" [21]. In response to the UN Committee's report, the Australian Law Reform Commission (ALRC) mirrored the Committee's concerns in its 2014 Inquiry and Report, *Equality, Capacity and Disability in Commonwealth Laws* [22]. In its report the Commission emphasised the universality of the right to lead a self-directed life, suggesting that the understanding articulated in the Australian Declaration does not comprehend the true intention of Article 12, which extends beyond the provision of supported decision-making to include measures that respect a person's autonomy, will and preferences. The notion of 'will and preference', which is particularly relevant to people with severe or profound cognitive disability is explicitly mentioned in Article 12 (4) of the UNCRPD, indicating the Article's clear intention to be inclusive of this group. In its report the ALRC pays explicit attention to the exclusionary impact this lack of understanding of the intention of Article 12, has on people with severe or profound cognitive disability [22].

2. Empirical Study Methodology

This paper draws on research with five people with severe or profound intellectual disability and their support networks [23,24]. Each participant and their support network participated in a supported decision-making process [25]. This process provided a lens through which to observe and characterise the phenomena of supported decision-making and identify practical strategies for the realisation of Article 12 for this group. An interpretative, multiple case study design was used, and interview, focus group, questionnaire and observation data were collected and analysed.

The process of gaining ethics approval for this study was complex. There is ample discussion in the literature regarding the vulnerability of people with severe to profound cognitive disabilities when participating in research [26,27]. The HREC that evaluated the research proposal had particular concerns relating to obtaining consent from research participants with cognitive disability. The researcher spent considerable time with the HREC discussing these concerns, particularly the ethical question around whether to exclude this group from the study and its associated benefits or obtain proxy consent from people who know them well. A decision was made to obtain proxy consent from those who knew the participants well, using the principles of supported decision-making embedded in the study itself. It is important to note that there is concern in the literature around the validity of proxy reporting with regard to the expression of personal preferences [28,29]. McVilly *et al.* (2000) stated, "overall research findings to date indicate a need for caution when interpreting proxy-based data" ([29], p. 60). Heeding these concerns, those providing proxy consent were required to adhere to the principle of assent, an important characterisation of supported decision-making methodology used in the study. That meant any consents obtained by proxy were required to be accompanied by nonverbal indications that the person was comfortable participating in the study, and as mandated by the National Human Medical Research Committee (NHMRC) any indication at any time over the course of the study of refusal to participate had to be respected [30].

3. Empirical Study Findings and Implications

3.1. Characterising Supported Decision-Making for People with Severe or Profound Cognitive Disability

There is no doubt that supported decision-making for people with severe or profound cognitive disability is likely to look different than for other members of the population, but it is also undeniable that decision-making is a mandated right for all citizens living in jurisdictions that are signatory to the UNCRPD. This begs the question of "what is decision-making" for this group, or perhaps more usefully framed, "what is supported decision-making?"

An analysis of the study's data provided a characterisation of supported decision-making for people with severe or profound intellectual disability, in terms of two distinct but interdependent roles. The data highlights the roles played by (a) the person with a disability (supported); and (b)

the supporters in the supported decision-making process. The role of the person with a disability in this dynamic was to express will and preference, either intentionally or unintentionally, using a range of communication modalities, including behaviour, vocalisation, vocal pitch, muscle tone, facial expression, eye movement, and physiological reactions (e.g., changes in breathing patterns). The role of supporters within this dynamic is to respond to the expression of will and preference of those they support. Within this decision-making dynamic, supporter responsiveness, as opposed to focus people's expression of preference, is the component that is amenable to change through structured practice guidance, making the enablement of responsiveness a crucial strategy for supported decision-making.

3.2. Supporter Responsiveness

The act of supporter responsiveness is not well examined in the research literature, and therefore, is poorly understood. The data collected evidenced that supporter responsiveness to the expression of will and preference of those they support is a multi-faceted activity, made up of a number of tasks. These tasks include acknowledging, interpreting and acting on the expression of will and preference of those they support. The study has highlighted, that although each of these tasks are important, none of them in isolation, characterise responsiveness. Rather, supporter responsiveness was observed to be reliant on the implementation of these tasks collectively. To respond, firstly supporters acknowledged/noticed, as opposed to ignored, expressions of preference, secondly, they interpreted these expressions of preference, assigning meaning to them, and thirdly they acted on this meaning.

In addition to the previous characterization, key factors underlying supporter responsiveness to the will and preference of people with severe or profound intellectual disability within a supported decision-making context were identified and examined. These factors were clustered into five overarching domains, (1) focus person's attributes; (2) supporter attitudes and perceptions; (3) relational closeness; (4) functioning and make up of circles of support; and (5) characteristics of the service system. A discussion of each of these factors is beyond the scope of this paper, and will be reported elsewhere. The remainder of this paper will focus on one identified theme, the association between supporter responsiveness to expressions of will and preference and the views they hold regarding the ability of those they support to lead self-directed lives. This emphasis on supporter responsiveness to the expression of preference of those they support is consistent with the social model of disability (embedded within the UNCRPD), where the onus of change is not on the person with a disability, but rather, the environment of which they are a part.

3.3. Supporters' Views Regarding the Ability of Those They Support to Lead Self-Directed Lives

The literature highlights a widely held belief that concepts relating to self-determination and autonomy are irrelevant to people with cognitive disability, because they have limited ability to lead self-directed lives [31–35]. “Historically, people with an intellectual disability have been assumed to be incapable of exercising the sort of control over their own lives which others take for granted” ([32], p. 362). Jenkinson and Nelms made the point: “since by definition intellectual disability is characterized by significant impairments in adaptive behaviour, discretion, social competence, and comprehension of own self-interest, the temptation has been to presume total incompetence in decision-making” ([36], p. 199). Ward and Stewart, referring to people with intellectual disability, stated “it is often assumed that they are eternal children, unable to speak on their own behalf and therefore not competent to make their own decisions” ([34], p. 305). This negative perception of the ability of those they support to lead self-directed lives is particularly apparent for people with severe or profound cognitive disability. Wehmeyer, Agran and Hughes surveyed over a thousand teachers regarding their understanding of self-determination of their students. They reported that the severity of a student's disability influenced these teachers' perceptions of the self-determination of their students. Specifically, teachers working with students with severe or profound intellectual disability

rated the capacity of their students to make decisions significantly lower than their colleagues working with students with milder intellectual disability [37].

The value of supporters having a positive perception of the ability of those they support to lead self-directed lives is reflected within the research literature. This literature provides evidence that people are more likely to lead self-determined lives, when those who support them have a positive view of their ability to lead self-directed lives [38,39]. Reviewing over one hundred articles, Harchik *et al.* (1993) concluded that people who are expected to express choice and preference are more likely to behave autonomously, be happy, and exhibit positive as opposed to negative behaviour [38]. Rawlings *et al.* (1995) conducted a participant observation study of four women with intellectual disability. They concluded that supporters who presume those they support can guide the decisions that are made about them are likely to be willing and able to “encourage, recognise and respond to expressions of choice” ([39], p. 143). In contrast, Antaki *et al.*, drawing from their analysis of interactions between staff and fifteen people with intellectual disability, report that the negative perceptions of the capacity of a person to guide their own decisions, is one factor responsible for reducing the opportunities people with intellectual disability have for decision-making [40]. The impact of supporters’ assumptions regarding a person’s ability to lead a self-directed life is not only reflected in the research literature relating to people with intellectual disability, but also that related to acquired brain injury (ABI). Drawing from two case studies and the research literature, Knox *et al.* (2013) discuss the impact of clinicians holding negative assumptions regarding decision-making for people with ABI. They suggest that negative assumptions held by rehabilitation professionals that people with ABI cannot participate in decisions is a factor that influences the self-determination of their patients [41].

The importance of positive perceptions of a person’s ability to lead self-directed lives is not only reflected in the research literature, but in principles guiding contemporary law and policy. For example, the UNCRPD promotes an assumption of decision-making capacity [1], while the English and Welsh Mental Capacity Act 2005 (MCA), has as its first principle, a need for supporters to assume a person has decision-making capacity [42]. This focus on the need for a change in supporter attitudes, rather than a change in people with disability, is reflected in the social model of disability, solidly embedded within the UNCRPD.

Findings from my research further highlights the importance of supporters having positive perceptions of the ability of those they support to make decisions. Supporters who held such perceptions, predominantly demonstrated greater responsiveness to expressions of will and preference overall, than those who did not hold these beliefs. Considering the value of supporter responsiveness within a supported decision-making process, this finding is legally and practically important. It reinforces the value of inclusion of principles such as “a person must be assumed to have capacity”, in legal frameworks such as the UNCRPD [1] and the English and Welsh Mental Capacity Act [42]. In practice, it points to a need for supporters having a belief in the universality of decision-making capacity, inclusive of those with severe or profound cognitive disability.

4. Conclusions

Australia’s interpretative declaration regarding Article 12 of the UNCRPD, allowing for substituted decision-making, stems from a belief that some Australians, such as those with severe or profound cognitive disability, are not capable of having their will and preference reflected in the decisions made about them. This paper has challenged this view, providing a characterisation of supported decision-making for people with severe or profound cognitive disability.

Supported decision-making for people with severe to profound intellectual disability is an interdependent and complex process carried out between supporters and supported. Within this dynamic, both parties contribute differently. The person facing the decision contributes by expressing their will and preference, using a range of informal communication methods such as body language, facial expression, gesture, and physiological reactions (e.g., changed breathing patterns).

Supporters contribute to the process by responding to these expressions of will and preference, through acknowledging (as opposed to ignoring), interpreting and acting on this expression. Effective supporter responsiveness was found to be most likely when supporters had a positive view of the decision-making capacity of those they supported.

This paper calls for an emphasis on legislative, policy and practice guidance that aims to enhance supporters' understanding that a person's ability to lead a self-directed life is universal, as relevant to people with severe or profound cognitive disability as those with milder disability. The findings reported in this paper, point to the value of this emphasis in enhancing supporter responsiveness to a person's will and preference, an essential component of supported decision-making. Such a focus is consistent with the social model of disability, a construct that is core to the UNCRPD, where the onus of change is not on the person with a disability, but the environment of which they are a part. This environment includes the perceptions supporters hold regarding a person's ability to lead a self-directed life, and therefore have access to supported approaches to decision-making. Without this focus, the promises of Article 12, and the recommendations of the ALRC report, are likely to remain a pipe dream for people with severe or profound cognitive disability and their supporters.

Due to their complex lives decision-making is obviously challenging for people with more severe cognitive disability. However, if signatory nations to the UNCRPD are to live up to their obligations under Article 12, interpretative declarations, such as Australia's need to be abandoned, and significant attention needs to be paid to how best to support all citizens to have their preferences heard and reflected in the decisions that are made about their lives, both practically and within the context of law reform.

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Abbreviations

The following abbreviations are used in this manuscript:

UNCRPD United Nations Convention on the Rights of Disability
SDM Supported decision-making

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