



# NDIS Support for Decision Making Consultation

Submission from  
Deakin University

Submission prepared by Dr Jo Watson and  
endorsed by Deakin's Disability and Inclusion  
Academic Team

# NDIS Support for Decision Making Consultation

**Lead Author: Jo Watson (B.A.Sc. Speech Pathology, PhD)**

**Contact person: Jo Watson**

**Contact email: [joanne.watson@deakin.edu.au](mailto:joanne.watson@deakin.edu.au)**

## **Note about authorship:**

Although this submission has been authored by [Dr Jo Watson](#), it has been endorsed by the Disability and Inclusion academic team at Deakin University, Victoria, Australia.

## **Acknowledgments:**

Deakin University's Disability and Inclusion team acknowledges the traditional owners of the land on which this publication was produced, the Wurundjeri people of the Kulin nations. We acknowledge the deep spiritual connection to this land of Aboriginal and Torres Strait Islander peoples. We extend our respects to community members and Elders past and present.

## **Who is this submission focused on?**

While Deakin's Disability and Inclusion team recognise that the Support for Decision Making Consultation paper and proposed capability framework are an important step forward for supporting NDIS participants to achieve genuine choice and control, we are concerned that not everyone's needs have been considered in the proposed policy and practice framework. The group we are concerned about are people with intellectual disability and complex communication support needs particularly those who communicate informally. It is estimated that people with intellectual disability who communicate informally make up 0.4 to 1.3% (Arvio & Sillanpää, 2003; Rousseau et al., 2015) of the general population, and a significantly greater proportion of NDIS participants. This submission draws on a body of empirical and practice research specifically focused on supported decision making for this group of people.

## **A word on terminology**

Throughout this submission the term Profound Intellectual and Multiple Disability (PIMD) will be used to describe people with intellectual disability with complex communication and support needs who communicate informally. This term is used globally to describe people who have more than one disability, the most significant of these being an intellectual disability. People typically referred to by this term communicate their will and preference informally, and sometimes unintentionally, using a range of communication systems such as eye gaze, facial expression, gesture, vocalisation, and behaviours that some people may find challenging. Many people with PIMD are passive communicators, and therefore the acknowledgment of their communication attempts by supporters can be

challenging, resulting in their expressions of will and preference being ignored (Finlay, Williams, de, Baum, & Scior, 2015; Lima et al., 2012; Vlaskamp, Hiemstra, Wiersma, & Zijlstra, 2007).

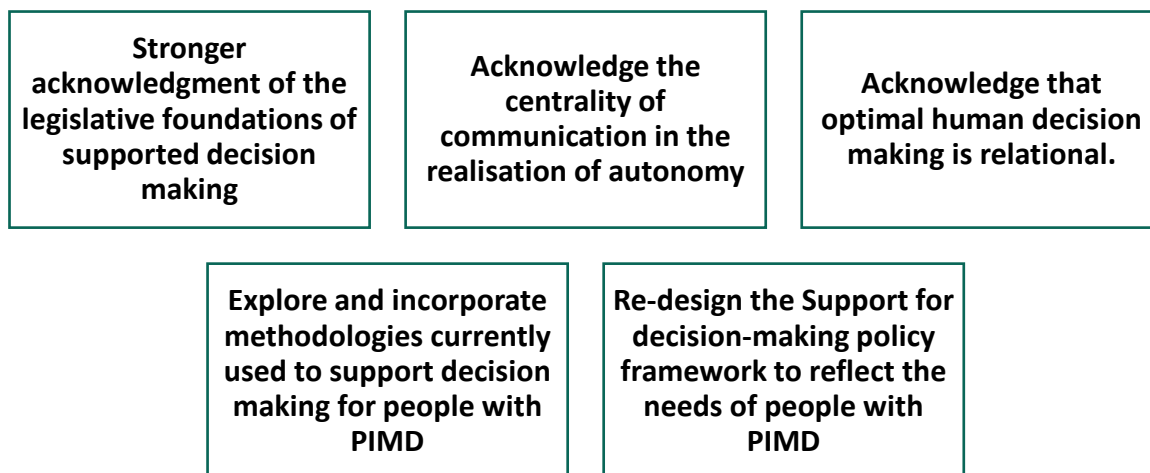
Although the consultation papers make a distinction between ‘supported decision making’ and ‘support for decision making’, throughout this submission we have chosen to use ‘supported decision making’. This term is used internationally in the legislative, practice and policy literature, and in our opinion the introduction of a ‘new’ term overly complicates this area of practice for people who have difficulties in the way they think, including people with intellectual disability.

## **Structure of submission**

Although we have considered the questions posed by the NDIA to guide our submission, we have focused on the consultation and proposed policy framework broadly, posing a range of suggestions and elaborating on each of these particularly as they relate to the background information, key principles, capability framework, and proposed next steps.

## Summary of recommendations:

In the submission we have proposed 5 recommendations. These are summarized in Figure 1 below.



*Figure 1: Summary of Deakin university recommendations*

## Suggestion 1:

### Stronger acknowledgment of the legislative foundations of supported decision making

In recent years there has been a paradigm shift around concepts of self-determination, autonomy, and choice for people with disability. Australia's ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), in 2008, signaled the Australian government's commitment to ensuring the right of all Australians to lead self-determined lives. Australia's subsequent adoption of the National Disability Strategy 2010-2020, designed to implement the Convention, across all jurisdictions, has acted as an additional driver of the self-determination agenda for Australians with disability and their supporters (Commonwealth of Australia., 2011). The NDIS Act (2013) was introduced to legislate for a new system of services and supports promising to give ALL Australians with disability choice and control and choice over the supports and services they receive (Commonwealth of Australia., 2013). At a state level, there has been significant progress in terms of guardianship reform with a view to aligning such reform with our obligations under the Convention. For example, Victoria's relatively new Guardianship and Administration Act (2019), emphasises the notion that a person's will and preference should drive the decisions made about them, rather than perceptions regarding their best interest. In fact, the Act makes no mention of 'best interest', a decision by the Victorian government that is in sync with our obligations under the Convention. This Act is welcomed by proponents of the CRPD as a positive step forward in much needed guardianship law reform (Watson et al., 2020). Each of these legislative drivers has instigated a shift in the way people with disability are viewed in terms of their right to lead lives of their choice. These drivers need to be acknowledged by the National Disability Insurance Agency (NDIA) as fundamental and reflected in their work in this space.

In Section 3.2 'Human Rights and Legislative considerations' of support for decision making consultation document, the importance of the CRPD in relation to individual autonomy has been acknowledged. However, the authors' reference to Article 4 of the CRPD requiring "nations to replace substitute decision making with supported decision making in a way that respects a person's will and preference" is incorrect. It is Article 12 that requires this, not Article 4.

## Summary of Suggestion 1:

### Stronger acknowledgment of the legislative foundations of supported decision making

We recommend that the background information to the proposed NDIS Support for Decision Making key principles, policy and capability framework have a stronger focus on the key international and national legislative drivers of supported decision making. We suggest this stronger focus better emphasise the clear obligations Australia, as a signatory to the CRPD, particularly under Article 12, has in terms of supporting universal legal capacity. In terms of the principles themselves we suggest a stronger alignment with the evidence-based principles developed by the Australian Law Reform Commission around supported decision making, which although now 7 years old reflect contemporary evidence and practice.

## Suggestion 2:

### Acknowledge the centrality of communication in the realisation of autonomy

There is limited focus within the NDIS supported for decision making documents on the needs of people with complex communication needs, particularly people who do not use symbols to communicate or people who communicate informally. Central to an inclusive view of communication and decision making is the acceptance that “all people, no matter how severe their disability, can and do attempt to communicate” (Mirenda et al., 1990, p.3). This is important, as a person’s communication is fundamental to any decision-making process. This notion of communication being a universal construct was reflected in early discussions and practice relating to supported decision for people with intellectual disability. Beamer and Brookes’ (2001) characterization of supported decision-making suggests that the process of decision-making support should not be defined in terms of capacity but rather in terms of the quality and quantity of support available to the person to communicate.

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.

(Beamer & Brookes, 2001 p.4).

Despite this sentiment (at the heart of Article 12 of the CRPD) that the ability to communicate and therefore express will and preference is universal to all humans, it has largely been ignored in the NDIA support for decision making consultation documents, proposed model and key principles.

We acknowledge that to hear the voice of people with PIMD is a challenge. Those committed to supporting choice and control for people with PIMD are faced with a dilemma. As described by Grove et al. (1999) this dilemma is intensified because, unlike people with milder cognitive impairment, people with PIMD have “an inability to contradict an interpretation and therefore the dilemma is difficult to resolve” (Grove et al., 1999a p.190). However, Petry and colleagues claim supporters have a choice, “Either ignore these individuals because they cannot self-report or obtain data from proxies that may be biased or invalid” (Petry, Maes, & Vlaskamp, 2009 p.1404). Perhaps rather than questioning the value of proxy reports, there should be an increased acceptance that in many cases, their use maybe inevitable and therefore “the question that should be asked is how and by whom are the person’s preferences obtained, interpreted and shared” (Watson, 2012 p.41). In Australia and internationally there is a rich body of expertise, stemming from the field of speech pathology and augmentative communication, that can provide supporters with the tools and skills to support a person’s autonomy regardless of where they are along the human communication continuum.

### **Summary of Suggestion 2:**

#### **Acknowledge the centrality of communication in the realisation of autonomy**

We suggest a clear and explicit acknowledgment within the principles and capability framework and decision making continuum that the ability to communicate is a universal human trait, that is central to decision making. Specifically, we would like to see the policy acknowledge existing expertise in this area (e.g., Speech Pathology and augmentative and alternative communication) and direct resources to supporting this communication, not only for people who communicate formally, but for people routinely excluded from efforts to enhance self-determination, people with cognitive disability who communicate informally.

### **Suggestion 3:**

#### **Acknowledge that optimal human decision making is relational.**

Within contemporary research, practice and legislative literature focused on supported decision making there is a clear move away from decision making competency being measured as an absolute. In other words, there is a clear paradigm shift away from a person being assessed as either capable or not capable of making decisions for themselves. Like many human endeavors, decision-making is complex, and the realisation of autonomy is not a binary construct. It is rarely an individualised pursuit, but rather, dependent on numerous variables, including the social environment of which someone is a part (Arstein-Kerslake, O’Donnell, Kayess, Watson, In Press).

The support for decision making policy document describes autonomy as ‘how much you can do without help’. With its focus on individual as opposed to collective autonomy, this definition along with the proposed capability

framework and decision-making continuum does not reflect contemporary research and practice in this area. Nor does it reflect the collective and relational view of autonomy highlighted in cross-cultural studies of self-determination, positing the family, community, or village as central to decision-making (Blackhall, 1995; Chan, 2004; Fan & Tao, 2004; Iyengar & Lepper, 1999a; Shogren, 2012). Iyengar and Lepper (1999) suggest that individualized (as opposed to collective) autonomy is a western postmodern construct and is not generally desired in more “socially interdependent cultures”, such as parts of Asia and South America (Iyengar & Lepper, 1999, pp. 349-366) and in Indigenous Australian communities (Avery, 2018).

It is our view that the capability framework and decision-making continuum proposed by the NDIA has its theoretical foundations in an outdated understanding of decision-making autonomy. It is focused on a dominant conception of decision-making capacity stemming from liberal political theory that emphasise an atomistic, isolated, and independent view of autonomy and personhood. Instead, we argue for a more contemporary conception of decision making, which is relational, rather than a neo-liberal understanding of decision making as individualised and independent. We recommend the NDIA look to a body of research and practice literature incorporating relational autonomy as an important component of supported decision making particularly for people with PIMD (Arstein-Kerslake et al., In press; Arstein-Kerslake et al., 2017; Kittay, 2005; Watson & Joseph, 2011; Watson et al., 2019; Watson et al., 2017).

### **Summary of Suggestion 3:**

#### **Acknowledge that optimal human decision making is relational.**

We suggest the NDIA update the decision-making capability framework and decision-making continuum to better reflect the empirical and practice knowledge base around optimal supported decision making, that promotes a relational view as opposed to an individualised view of autonomy. We recommend that the NDIA consult further with First Peoples’ and CALD communities and people with PIMD and their supporters, to gain a better understanding of supported approaches to autonomy, with a view to co-designing a framework that is less focused on the neo-liberal construct of individualised autonomy, and more inclusive of these often-overlooked groups.

#### **Suggestion 4:**

#### **Explore and incorporate methodologies used to support decision making for people with PIMD**

The Support for Decision Making Consultation paper refers to and draws from several excellent evidence based resources and frameworks to enhance support for people with cognitive disability and mental illness to make decisions (Brophy et al., n.d.; Douglas & Bigby, 2020). However, these resources and frameworks have been developed from research that has excluded people with PIMD. We believe a focus on the supported decision-making



needs of people with PIMD is missing. We suggest a closer engagement with people with PIMD and their supporters as well as the research and practice literature, before finalising the supported decision-making policy as currently their voices are not represented.

This omission is not surprising and reflects self-advocacy and person-centred movements of the past, in which opportunities for supported decision making are disproportionately afforded to people with mild as opposed to more severe cognitive impairment, whose decision making capability are less likely to be questioned (Watson et al., 2019). This exclusion of people with PIMD may in part stem from there being a shallow evidence base around how best to provide supported decision making to this group. Additionally, an argument exists promoted by bioethicists such as Singer and McMahan that the promises embedded in the UNCRPD and Australia's NDIS have little relevance to people with PIMD, because they do not meet their criteria of what it means to be human (McMahan, 2002; Singer, 1993). This argument is centred around the challenges faced by people with PIMD in understanding and processing information and communicating formally, characteristics believed by some to define personhood. This characterisation of personhood is strongly rejected by the CRPD, and therefore should be rejected by its signatory nations such as Australia. At the heart of Article 12 of the Convention is the obligation that signatory nations embrace the notion that *all* people have a right to be seen as "full persons before the law", that all people can communicate and therefore, with support can have their will and preference reflected in decisions made about them. The proposed capability framework and decision-making continuum does not reflect this sentiment.

Due to the highly dependent nature of their lives, for people with PIMD, autonomous decision-making is obviously challenging. However, if Australia and other signatory nations to the UNCRPD are to live up to their obligations under Article 12, and the promises made within the context of the NDIS, significant questions need to be asked. Perhaps the most important of these questions is, how best to support people with PIMD to have their will and preference (rather than what is perceived to be in their best interest), drive decisions made about their lives.

The good news is there is a strong and emerging body of research and practice literature focused on how to do this. We implore the NDIA to consider this body of work in their new supported decision-making policy and capability framework. Although it is beyond the scope of this submission to share this body of work in its entirety, we ask the NDIA to review some of the methodologies that have been designed to support decision making for people with PIMD, including (Finlay et al., 2008; Grove et al., 2000; Kittay, 2005; Maes et al., 2007; Quinn et al., 2018; Ten Brug et al., 2013; Watson, 2016; Watson, 2019; Watson & Joseph, 2011).

In Australia, a resource developed by Scope Australia and authored by Watson and Joseph in 2011 and adapted in 2015, titled 'Listening to People Rarely heard' provides a training resource, supported decision making framework and a set of practice tools to support people with PIMD to live maximally autonomous lives (Watson & Joseph,

2011; Watson & Joseph, 2015). This resource is used across Australia and internationally as an alternative to guardianship (E.g. see: Brady et al., 2019).

Since 2015, Watson and her colleagues have produced, and are continuing to develop, a body of research focused on best practice in providing supported decision making for people with PIMD (Pepin et al., 2013; Quinn et al., 2018; Watson, 2016; Watson, 2019; Watson et al., 2017). Watson and colleagues characterise supported decision-making for this population as:

A process of enhancing the decision-making capacity of a person with PIMD through collaborative support from a group of people in that person's life. A person's circle of support, comprising a group of key people in the person's life, who have a good understanding of the person's life history, preferences, and personal characteristics, is an important ingredient in this process. Within this context, autonomy for a person with PIMD is viewed as a relational construct, best realized in collaboration with those in the person's life who know him or her well.

(Watson et al., 2019 p.5)

Watson and colleagues further characterise supported decision making for people with PIMD,

In terms of the existence of two distinct, played by (a) the person with a disability (supported) and (b) the circle of support (supporters) in the decision-making process. The role of the person with a disability in this dynamic is their expression of preference, and the role of supporter is to respond to this expression of preference by acknowledging, interpreting, and acting on this expression in some way. Several factors have been found to underlie supporter responsiveness, providing a focus for practice and policy efforts for ensuring people with PIMD receive appropriate support in decision-making"

(Watson et al., 2019 p.5)

The practice model characterizing supported decision making for people with PIMD is displayed in Figure below.

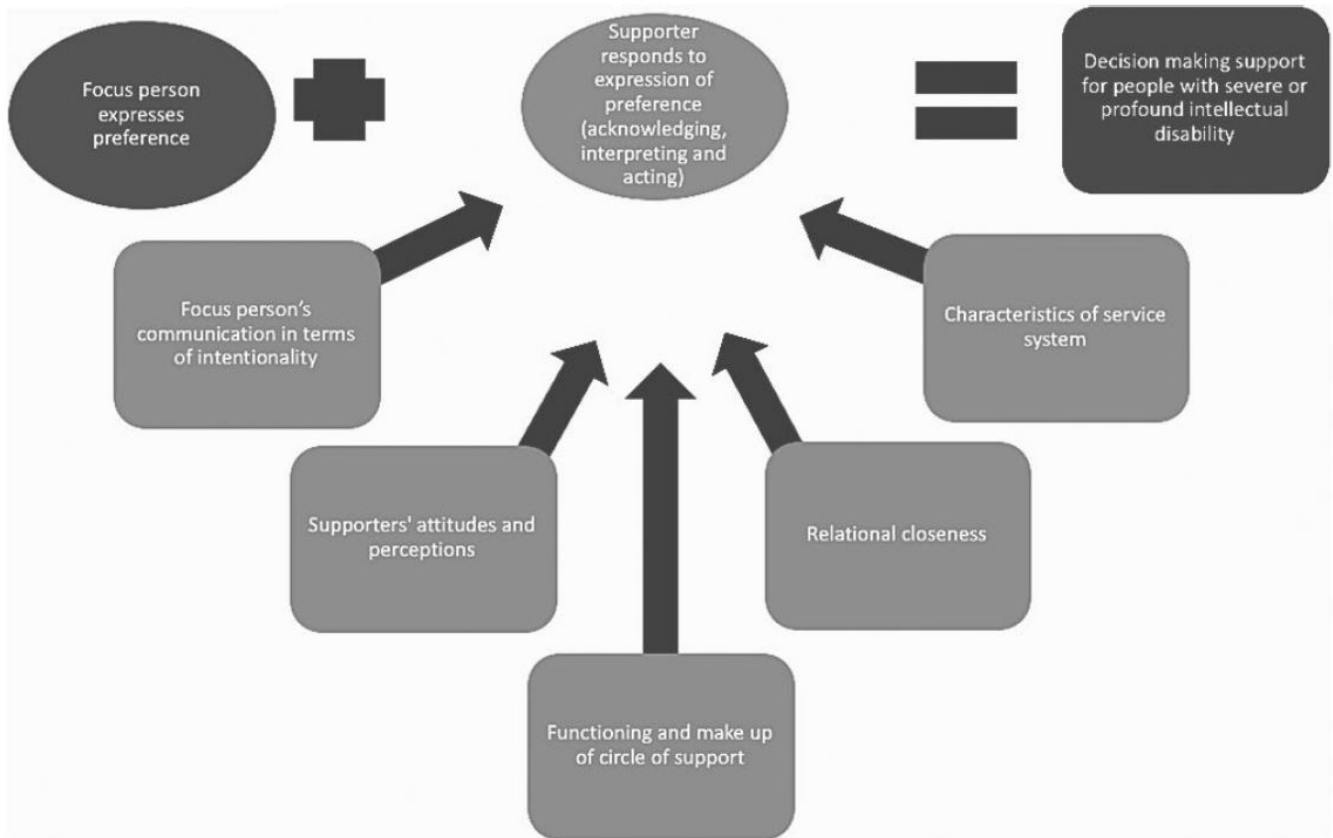


Figure 2: Practice model – Supported Decision Making for people with PIMD (Watson, Voss, Bloomer, 2019)

Although this body of work is constantly evolving, a range of public resources are available that are currently being used in Australia and internationally. A list of these resources are available in Appendix A of this submission.

**Summary of Suggestion 4:**

**Explore and incorporate methodologies used to support decision making for people with PIMD**

We suggest the NDIA explore and incorporate into their support for decision making policy, methodologies currently used throughout Australia and internationally to support people with PIMD to live self-determined lives. We have shared some of these methodologies in Appendix A.

## Suggestion 5:

### Re-design the Support for decision-making policy framework to reflect the needs of people with PIMD

- i) Eliminate the use of cognitively based decision-making assessments to determine participants' right to supported decision making.

The proposed support for decision making policy requires participants to give consent to participate in supported decision making. The NDIA propose that a person's ability to give this consent using cognitive capacity assessments, is based on "how much [a person] can do without help". The NDIA have explicitly focused on cognitive parameters as indicators of someone's ability to make decisions: "You should be able to weigh up the positives and negatives for each option and consider alternatives... for real decision making, you must also be able to consider the consequences of each option and then decide which one is best for you' (p. 10). This is an outdated approach to assessing decision making capacity. This approach is routinely reserved for people with cognitive disability and does not reflect the reality of human decision-making which is not linear nor dependent on cognitive abilities such as those outlined.

Such an individualistic approach to assessing decision making capacity is problematic, as it explicitly excludes people who are unable to give consent in this traditional (but outdated) sense, such as people with complex communication support needs who communicate informally and are the focus of this submission, people with PIMD. Article 12 of the CRPD, clearly states a universal right to supported decision making, and therefore contradicts this approach. There is a growing acknowledgment that instruments designed to test an individual's capability are found wanting because they are weighted toward individual cognitive capacity and generally fail to evaluate the substantial role of environmental support in human decision-making

In addition, the impact of a negative assessment of decision-making capacity should be acknowledged. There is an increasing body of research supporting the importance of assuming capacity. Negative perceptions of a person's ability to make decisions is increasingly acknowledged as a key barrier to self-determination for people with PIMD (Knox et al., 2013; Watson, 2019). This negative perception of decision-making capability is particularly apparent for people with the most severe cognitive disability, people with PIMD. The value of supporters having a positive perception of people with intellectual disability's decision-making capability 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 capability to participate in decisions (Antaki et al., 2009; Finlay et al., 2008).

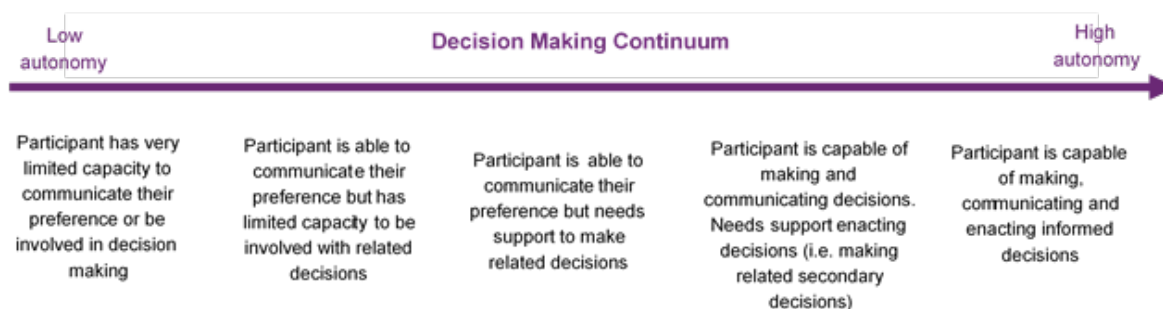
Traditional decision-making capacity assessments are structured around the premise that decision-making capability is characterised by a set of individual cognitive abilities serving as prerequisites for decision-making capability. Such tools are used within jurisdictions that maintain guardianship law. For example, within the current Victorian Guardianship system, various types of specialist psychology reports (usually neuropsychology)

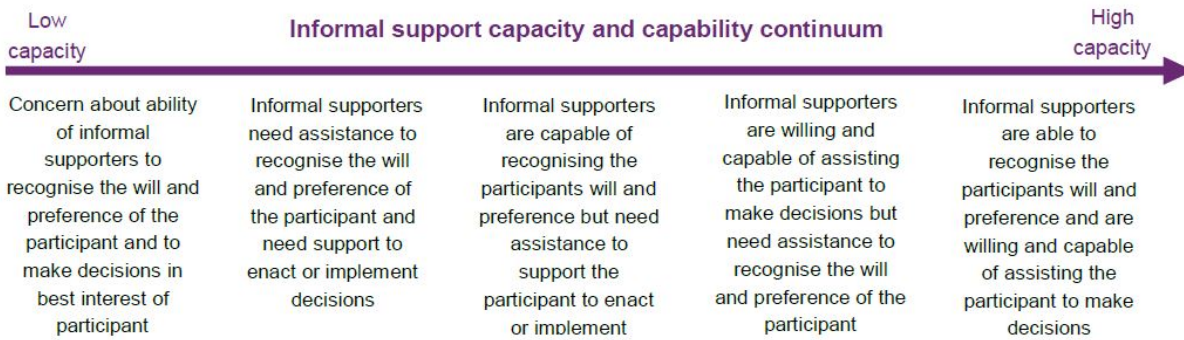
submitted to the Victorian Civil Administration Tribunal (VCAT) continue to form a central component of the evidence the tribunal considers when deciding whether someone can make a decision. Such reports are written to assess and report on a person’s capability at a particular time, predominantly taking into consideration cognitive factors such as problem solving, memory function, rationality and language. These skills are predominantly assessed independent of environmental factors such as support from family, friends and support staff. Due to the narrow nature of these assessments, people with PIMD who come before the tribunal, are usually assessed as having no or very limited mental or decision-making capability (Watson et al., 2020). In most jurisdictions, the legal response to this assessment is to deny legal capacity, and permit a third party, in Victoria known as a legal guardian, to make decisions on behalf of the concerned person. Donnelly (2010), discussing approaches to guardianship in current western society, suggests that one of the reasons for such a black and white view of legal capacity within the guardianship arena is “the ease with which this particular ethical concept can be converted into legal doctrine” (Donnelly, 2010 p.47). However, as argued by Clough (2014) “this ease comes at the cost of nuance, and that the individualistic conception of the person fails to accord with the reality of human interdependence” (Clough, 2014 p.131).

Human rights scholars are increasingly highlighting the profound impact of such formal assessments of decision-making incapacity. Perlin and the European based Mental Disability Advocacy Centre, characterize it as a form of “civil death” (Mental Disability Advocacy Center, 2013; Perlin, 2012). A system of law is increasingly being promoted that moves away from the focus on cognition in denying legal capacity and therefore personhood, to one that recognises that a person’s ability to make decisions (and therefore be recognised as a person) does not rest on their individual cognitive capability but on the quality of support available to help them to make decisions (Alford, 2015; Bach, 2015).

- ii) Redesign the Decision-making continuum to reflect the relational as opposed to the individual components of human decision making.

See suggestion 3, which highlights the importance of relational approaches to decision making support as opposed to individual approaches. Specifically, we propose a reworking of the decision-making continuum (Figure 2 in NDIS document) and the Informal support capacity and capability continuum (Figure 4 in NDIS document), both illustrated below.





We suggest the NDIA replace both these with just one figure of a supported decision-making continuum, removing any reference to capacity and best interest, and emphasising relational as opposed to individualised autonomy. Drawing on the work of Watson and colleagues discussed above, we have drafted a possible continuum below.

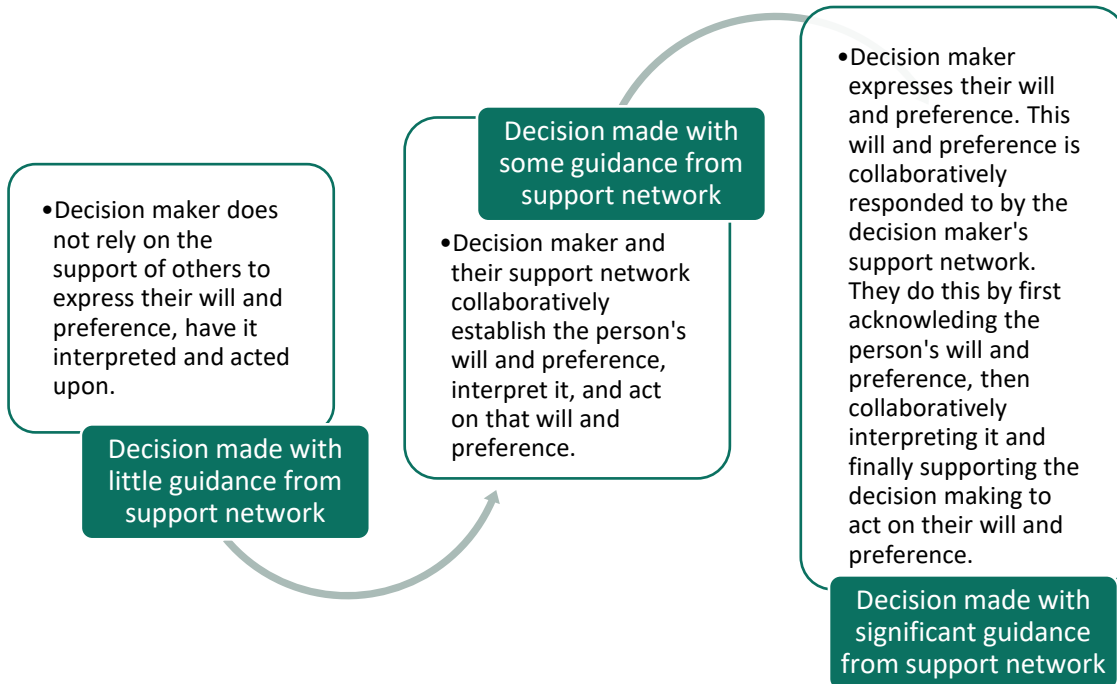


Figure 3: Proposed supported decision-making continuum (Watson, 2021)

## Summary of Suggestion 5:

### Re-design the Support for decision-making policy to reflect the needs of people with PIMD

We suggest that NDIA abandon the use of cognitively based decision-making assessments to determine participants' right to supported decision making. In addition, we propose a re-design of the Decision-making continuums to reflect the relational as opposed to the individual components of human decision making. We have suggested an alternative continuum for consideration.

## Conclusion

As discussed, over the past decade there has been a strong legislative and practice research focus on supported decision making, both within Australia and internationally. This extensive body of evidence has informed supported decision principles throughout the world in a variety of legislative, policy and practice contexts. Although it has been acknowledged that “this proposed policy has been developed with ideas from the Independent Advisory Council (Council), as well as other Support for Decision Making frameworks, peak bodies, and advocacy organisations” (NDIS, 2021, p. 8), we believe that the principles, policy and framework are not adequately informed by contemporary research and therefore are not reflective of a contemporary evidence base in this area.

In addition, although the paper states that the proposed “principles are... supported by The Australian Law Reform Commission in its report *Equity, Capacity and Disability in Commonwealth Laws* (ALRC Report 124), there has been little acknowledgement or reference to this substantial piece of evidence based work, which was commended by the United Nations' Committee on the Rights of Persons with Disabilities in a recent evaluation of Australia's performance regarding its commitment as a signatory nation to the UNCRPD.

Specifically, we are concerned that the proposed principles and policy are not designed to accommodate the unique needs of people with PIMD, who according to Article 12 of the Convention, like all Australians, have the right to be supported to have their will and preference reflected in the decisions made about their lives. We are concerned that the emerging body of practice and empirical literature relating to supported decision making for people with PIMD have not been considered in the proposed policy and principles. We welcome further

consultation to ensure the policy, principles and framework is inclusive of people with PIMD, a group historically excluded from self-determination movements and mechanisms such as the NDIS.



Dr Jo Watson  
On behalf of Deakin's Disability and Inclusion Team  
School of Health and Social Development  
Deakin University

Submission endorsed by Deakin University Disability and Inclusion Team



## References

- Antaki, C., Finlay, M., & Walton, C. (2009). Choices for People With Intellectual Disabilities: Official Discourse and Everyday Practice. *Journal of Policy & Practice in Intellectual Disabilities, 6*(4), 260-266.
- Arstein-Kerslake, A., O'Donnell, E., Kayess, R., & Watson, J. (In press). Relational Personhood: A conception of legal personhood with insights from disability rights and environmental law [Invited manuscript]. *Griffith Law Review*.
- Arstein-Kerslake, A., Watson, J., Browning, M., Martinis, J., & Blanck, P. (2017). Future directions in supported decision making. *Disability Studies Quarterly, 37*(1). <https://doi.org/http://dx.doi.org/10.18061/dsq.v37i1.5070>
- Arvio, M., & Sillanpää, M. (2003). Prevalence, aetiology and comorbidity of severe and profound intellectual disability in Finland. *Journal of Intellectual Disability Research, 47*(2), 108-112.
- Avery, S. (2018). *Culture is inclusion: a narrative of Aboriginal and Torres Strait Islander people with disability*. Sydney: First Peoples Disability Network Australia.
- Brady, A. M., Burke, M. M., Landon, T., & Oertle, K. (2019). Siblings of adults with intellectual and developmental disabilities: Their knowledge and perspectives on guardianship and its alternatives [Article]. *Journal of Applied Research in Intellectual Disabilities, 32*(5), 1078-1087. <https://doi.org/10.1111/jar.12597>
- Brophy, L., McSherry, B., Kokanovic, R., Moeller-Saxone, K., & Herrman, H. (n.d.). *Guidelines for supported decision making in mental health services* <https://healthtalkaustralia.org/wp-content/uploads/corporate/Guidelines-for-Supported-Decision-Making-in-Mental-Health-Services.pdf>
- Douglas, J., & Bigby, C. (2020). Development of an evidence-based practice framework to guide decision making support for people with cognitive impairment due to acquired brain injury or intellectual disability. *Disability & Rehabilitation, 42*(3), 434-441. <https://doi.org/10.1080/09638288.2018.1498546>
- Finlay, W., Antaki, C., Walton, C., & Stribling, P. (2008). The dilemma for staff in 'playing a game' with a person with profound intellectual disabilities: Empowerment, inclusion and competence in interactional practice. *Sociology of health & illness, 30*, 531-549. <https://doi.org/10.1111/j.1467-9566.2007.01080.x>
- Grove, N., Bunning, K., Porter, J., & Morgan, M. (2000). See What I Mean: Guidelines to Aid Understanding of Communication by People with Severe and Profound Learning Disabilities. *BILD*.
- Kittay, E. (2005). At the Margins of Moral Personhood \* [research-article]. *Ethics, 116*(1), 100-131. <https://doi.org/10.1086/454366>
- Knox, L., Douglas, J. M., & Bigby, C. (2013). Whose decision is it anyway? How clinicians support decision-making participation after acquired brain injury. *Disabil Rehabil, 35*(22), 1926-1932. <https://doi.org/10.3109/09638288.2013.766270>
- Maes, B., Lambrechts, G., Hostyn, I., & Petry, K. (2007). Quality-Enhancing Interventions for People with Profound Intellectual and Multiple Disabilities. *Journal of Intellectual & Developmental Disability, 32*, 163-178. <https://doi.org/10.1080/13668250701549427>
- Pepin, G., Watson, J., Hagiliassis, N., & Larkin, H. (2013). Chapter 12: Supporting People's Decision-making. In K. Stagnitti, A. Schoo, & D. Welch (Eds.), *Clinical and Fieldwork Placement in the Health Professionals*. Oxford University Press.
- Quinn, G., Gur, A., & Watson, J. (2018). Ageism, Moral Agency and Autonomy: Getting Beyond Guardianship in the 21st Century. In I. Doron. (Ed.), *Aging, Ageism and Law in Europe*. EE Publishing.
- Rousseau, M., Mathieu, S., Brisse, C., Motawaj, M., Grimont, E., Auquier, P., & Billette de Villemeur, T. (2015). Aetiologies, comorbidities and causes of death in a population of 133 patients with polyhandicaps cared for at specialist rehabilitation centres. *Brain injury, 29*(7-8), 837-842.
- Ten Brug, A., Van Der Putten, A. A. J., & Vlaskamp, C. (2013). Learn and apply: Using multi-sensory storytelling to gather knowledge about preferences and abilities of children with profound intellectual and multiple disabilities - Three case studies [Article]. *Journal of Intellectual Disabilities, 17*(4), 339-360. <https://doi.org/10.1177/1744629513508384>
- Watson, J. (2016). Assumptions of Decision-Making Capacity: The Role Supporter Attitudes Play in the Realisation of Article 12 for People with Severe or Profound Intellectual Disability. *Laws, 5*(1), 6. <https://www.mdpi.com/2075-471X/5/1/6>
- Watson, J. (2019). The role of speech-language pathology in supporting legal capacity. *Journal of Clinical Practice in Speech-Language Pathology, 21*.
- Watson, J., Anderson, J., Wilson, E., & Anderson, K. L. (2020). The impact of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) on Victorian guardianship practice. *Disability and Rehabilitation, 1*-9. <https://doi.org/10.1080/09638288.2020.1836680>
- Watson, J., & Joseph, R. (2011). *People Leading Lives they prefer through Supported Decision Making: "Listening to those rarely heard". A training package developed by Scope with funding from the 2009 Capacity Building for People with a Disability: Information, Tools and Resources grant (Disability Services, Victorian Department of Human Services)*. Scope.
- Watson, J., & Joseph, R. (2015). People with severe to profound intellectual disabilities leading lives they prefer through supported decision-making: Listening to those rarely heard. A guide for supporters. A training package developed by Scope. (Version 2). In. Melbourne, Victoria, Australia: Scope.
- Watson, J., Voss, H., & Bloomer, M. J. (2019). Placing the preferences of people with profound intellectual and multiple disabilities at the center of end-of-life decision making through storytelling [Journal Article]. <https://doi.org/10.1177/1540796919879701>
- Watson, J., Wilson, E., & Hagiliassis, N. (2017). Supporting end of life decision making: Case studies of relational closeness in supported decision making for people with severe or profound intellectual disability. *J Appl Res Intellect Disabil, 30*(6), 1022-1034. <https://doi.org/10.1111/jar.12393>

## Appendix A

### Publicly available resources that have informed this submission.

#### Publicly available Talks/Webinars on supported decision making

Watson, J. (2016) Decision making capacity. Invited 'Ted Inspired' talk delivered at Financial Counselling Australia Conference. Adelaide, Australia.

Can access talk here: <https://www.youtube.com/watch?v=qMerG7CULJE>

Watson, J (2017) Supported decision making for people who communicate differently. Invited workshop presented at the 9<sup>th</sup> International disability and law summer school, 2017, National University of Ireland, Galway.

Can access talk here: <https://www.youtube.com/watch?v=D5gMlrUXmzk>

Watson, J (2017). Invited keynote presentation: Reykjavik, Iceland - Listening to people rarely heard: Supporting decision making for people who communicate informally.

Can access talk here: <https://www.youtube.com/watch?v=4C-q4Z5u-AE>

Watson, J. (2020). *Invited webinar: Communication supports for informal communicators – realising legal capacity*. Hosted by Communication Disabilities Access Canada (CDAC). This webinar forms part of a larger training package commissioned by the Canadian government to build the nation's capacity to implement Article 12 of the UNCRPD.

Can access webinar here:

<https://courses.cdacanada.com/lessons/communication-supports-informal-non-symbolic-communicators/>

#### Podcasts:

Inform Podcast (2020): *Dr Jo Watson on Supported decision making* -

<https://www.independenceaustralia.com.au/podcast-episode/supported-decision-making-podcast/>

ASID Research to Practice Podcast - Season 2 Episode 1 (2017): Dr. Jo Watson on Supported Decision Making for people with unconventional communication <https://player.whooshkaa.com/episode/?id=246102>

#### Publicly available supported decision-making resources

Watson, J., & Joseph, R. (2011). Listening to those rarely heard: a training video. Melbourne: Mclure Multimedia.

<https://vimeo.com/21176882>

#### Publicly available research publications

Watson, J., Anderson, J., Wilson, E., & Anderson, K. (2020). The impact of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) on Victorian guardianship practice. *Disability and Rehabilitation, October*. doi: 10.1080/09638288.2020.1836680

Can access the paper here: <https://pubmed.ncbi.nlm.nih.gov/33096002/>

Watson, J., Voss, H., & Bloomer, M. J. (2019). Placing the Preferences of People with Profound Intellectual and Multiple Disabilities at the Center of End-of-Life Decision Making Through Storytelling. *Research and Practice for Persons with Severe Disabilities*, 44(4), 267–279. <https://doi.org/10.1177/1540796919879701>

Can access the paper here: <https://journals.sagepub.com/doi/full/10.1177/1540796919879701>

Watson, J. (2019). The role of speech-language pathology in supporting legal capacity *Journal of Clinical Practice in Speech-Language Pathology*, Vol 21 (1).

Can access the paper here: <https://speechpathologyaustralia.cld.bz/JCPSLP-Vol-21-No-1-2019>

Watson, J., Wilson, E., & Hagiliassis, N. (2017). Supporting end of life decision making: Case studies of relational closeness in supported decision making for people with severe or profound intellectual disability.

*J Appl Res Intellect Disabil*, 30(6), 1022-1034. doi:10.1111/jar.12393

Can access the paper here: <https://pubmed.ncbi.nlm.nih.gov/28815814/>

Arstein-Kerslake, A., Watson, J., Browning, M., Martinis, J., Blanck, P. (2017) Future directions in supported decision making. *Disability Studies Quarterly*, 37(1). DOI: <http://dx.doi.org/10.18061/dsq.v37i1.5070>

Can access the paper here: <https://dsq-sds.org/article/view/5070/4549>

Watson, J (2016). Assumptions of decision-making capacity: the role supporter attitudes play in the realisation of Article 12 for people with severe or profound intellectual disability, *Laws*, Vol 5 (1) DOI:10.3390/LAWS55010006

Can access the paper here: <https://www.mdpi.com/2075-471X/5/1/6>