

**Submission to the Australian Law Reform Commission**

**Response to Issues Paper 44: Equality, Capacity and Disability in Commonwealth Laws**

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## About Disability Advocacy Network Australia (DANA) Ltd

Disability Advocacy Network Australia (DANA) is the national peak body for almost 70 disability advocacy organisations across Australia. Our goal is to advance the rights and interests of people with disability by supporting our members in their targeted advocacy as well as engaging in systemic advocacy on a national level to further these objectives.

Independent advocacy agencies address the advocacy needs of those most marginalised and disadvantaged people with disabilities who are more likely to have experienced abuse, neglect and/or breaches of their fundamental human rights. They do this through a variety of delivery models that include systemic advocacy, legal advocacy, individual advocacy support by paid advocates, citizen advocacy using volunteer advocates, self-advocacy development and family advocacy development and support. Some agencies focus wholly on the provision of independent human rights focused information for people with disabilities. DANA works to a vision of a nation that includes and values persons with disabilities and respects human rights for all.

The failure of legal and societal institutions to grant equality to people with disabilities, or to recognise and support their decision making abilities, is often at the heart of the work that disability advocacy agencies undertake for their clients. DANA is therefore very supportive of the aims of this Inquiry and hopeful that it shall lead to real reforms and greater compliance with international human rights standards.

## Australia’s Interpretive Declaration in relation to Article 12 of the UNCRPD

The understanding articulated in the Australian Declaration does not comprehend the true meaning and implications of Article 12. Professor Amita Dhanda describes the drafting process and “the conservative strangleholds that have attempted to be placed on a forward looking text”.[[1]](#footnote-1) An interpretation that permits fully substituted decision-making arrangements, and legitimises frameworks that place adults under plenary guardianship orders, ignores or dilutes the universal reach of the capacity formulation in article 12(2).[[2]](#footnote-2) The paradigm shift of article 12:

“compels law reform to assume that everybody enjoys legal capacity and redirects our focus away from deficiencies (which are in fact universal and not confined to persons with disabilities) towards supports that enable individuals to make decisions for themselves and expand their capacities to do so. The notion of ‘supported decision-making’ simply builds on this universal reality and extends it to persons with disabilities.” [[3]](#footnote-3)

Although article 12 and its relationship to substitute decision making has been subject to a range of differing perspectives and interpretations,[[4]](#footnote-4) statements by United Nations bodies expressly clarify the incompatibility of guardianship laws, and other legal frameworks allowing declarations of incapacity, with the recognition of legal capacity in persons with disabilities in paragraph 2. Such perspectives undermine the validity of Australia’s declared interpretation.

For instance in 2009 the Office if the United Nations High Commissioner for Human Rights, submitted to the Tenth Session of the Human Rights Council a “Thematic Study on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities”. This report highlighted the centrality of the article to the structure of the Convention and its instrument value in the achievement of numerous other rights, and identified actions for implementation:

“In the area of civil law, interdiction and guardianship laws should represent a priority area for legislative review and reform. Legislation currently in force in numerous countries allows the interdiction or declaration of incapacity of persons on the basis of their mental, intellectual or sensory impairment and the attribution to a guardian of the legal capacity to act on their behalf. Whether the existence of a disability is a direct or indirect ground for a declaration of legal incapacity, legislation of this kind conflicts with the recognition of legal capacity of persons with disabilities enshrined in article 12, paragraph 2. Besides abolishing norms that violate the duty of States to respect the human right to legal capacity of persons with disabilities, it is equally important that measures that protect and fulfil this right are also adopted, in accordance with article 12, paragraphs 3, 4 and 5…”[[5]](#footnote-5)

As discussed in the Issues Paper, the UN Committee’s Concluding Observations[[6]](#footnote-6) and the Draft General Comment[[7]](#footnote-7) restate the need to review comprehension and eliminate misunderstandings of article 12, and make those reforms that will truly implement its human rights based principles.

### The impact on decision making arrangements

The interpretative declaration in respect of article 12 has the effect of protecting the status quo of paternalistic substitute decision making regimes, inhibiting reform and slowing exploration and implementation of supported decision-making models in Australia. By declaring the legitimacy of fully supported or substituted decision making arrangements, which dominate the relevant legislation of each state and territory, the statement has the effect of reinforcing the primacy of substitute decision making over developing models of supported decision making.

As safeguards are generally built into guardianship and administration regimes the interpretative declaration suggests that current systems should be accepted as human rights respecting. However, evidence demonstrates that substitute decision making legislation and procedures are often problematic in operation and tend to unnecessarily restrict the autonomy and choices of individuals with disabilities, or ignore the will and preferences of the person in question.[[8]](#footnote-8)

Guardianship laws have been undergoing review and reform in various states and territories, and trials of supported decision making are underway, yet the acceptance of substitute decision making in the declaration supports its continuation, and arguably weakens the demand for greater human rights scrutiny. In the absence of legislative provision for supported decision making, or other formal recognition, the burgeoning awareness of supported decision making practices has not yet disturbed the general use and expectation of substitute decision making arrangements. Therefore the latter is not truly being employed as a last resort, as the interpretative declaration requires, as options for decision support are not being fully explored.

### The impact on recognition before the law and exercise of legal capacity

The maintenance of outdated models of decision making impacts greatly on the recognition of people with disabilities and their exercise of legal capacity. The effects of the Interpretative Declaration on decision making arrangements have significant consequences for how people with disabilities interact with the law and the legal decisions they make. These legal limitations may directly disrupt and impinge on the individual’s life, autonomy, and choices, and broadly influence (and reinforce) public perceptions and self-perceptions of people with disabilities and decision making impairments. Substitute decision making regimes authorise the discriminatory removal of a person’s right to make decisions and exercise control over his or her own life, and contribute to the disempowerment of people with disabilities in Australia. Wrongful and overly-restrictive applications of guardianship law, often influenced by paternalistic attitudes and assumptions about people with cognitive impairments, further undermine the self-determination of people with disabilities. As the Issues Paper recognises, the incomplete implementation of article 12 has numerous implications for myriad areas of law and policy, which this Submission shall not specifically address.

DANA submits that reform to the legislative and regulatory framework is vital and must be prioritised. As recommended by Disability Rights Now,[[9]](#footnote-9) and affirmed by the Concluding Observations of the UN Committee on the Rights of Persons with Disabilities,[[10]](#footnote-10) the Government should review and withdraw its Interpretative Declaration, and establish alternative models to replace substitute decision-making to effectively implement the standards contained in article 12 of the United Nations the CRPD*.* To retain the Declaration and continue to accept the status quo would substantially diminish Australia’s progress in disability rights and undermine its position as a State committed to advancing the inclusion, participation and wellbeing of people with disabilities, in our country and overseas.[[11]](#footnote-11)

## National Disability Strategy 2010-2020

When the National Disability Strategy was developed, DANA applauded Australian Governments for recognising the social, economic, and human rights imperatives and committing to a unified, national approach. The vision and principles of the Strategy rightly reflect the aspirations of the CRPD. The National Disability Strategy provides a framework for Australia to address its CRPD obligations, particularly in establishing a coordination mechanism (as recommended in article 33) to facilitate implementation in different sectors and at different levels. However, the future areas for action should incorporate CRPD obligations with greater specificity, clarity and strategic direction. Though progress has been made since ratification, Australia remains a long way from full implementation.  Disability Rights Now identifies current inadequacies in implementation and monitoring.[[12]](#footnote-12)

Furthermore, the text of the Strategy foregrounds supporting and enabling people with disabilities to participate as equal citizens, yet does not clearly identify the particular challenge of ensuring people with disabilities can exercise legal capacity. Chapter 2 on Rights Protection, justice and legislation considers “effective access to justice...on an equal basis with others” in Policy Direction 3, and decision making and legal capacity are indirectly raised by Policy Direction 2: “Remove societal barriers preventing people with disability from participating as equal citizens”. Article 12 themes emerge in the Areas for Future Action; (for instance, 2.7: Provide greater support for people with disabilities with heightened vulnerabilities to participate in legal processes on an equal basis with others). However, legislative reform in this area is not mentioned and the wording of Area 2.12 reflects a flawed and inconsistent understanding of article 12, despite Area 2.1 highlighting “compliance with international human rights obligations”. The regulatory focus on safeguards and accountability does not indicate an awareness of a positive obligation to ensure access to decision making supports exists for people who need them.

The first Implementation Plan in 2012,[[13]](#footnote-13) included some progress being made and planned, but momentum and focus is likely to be lost without clear commitments to specific actions and the achievement of tangible outcomes. The Concluding observations of the UN Committee offer valuable direction for the next phase of the Strategy. Relevantly, the Committee recommends taking immediate steps to replace substitute decision making with supported decision making, other measures conforming to article 12 rights to autonomy and capacity.

Incorporation of reform plans into the text of the strategy shall of little value if these pronouncements do not lead to real and concrete changes to Australian law and policy. Continual monitoring and evaluation of progress made, and ongoing engagement and consultation of Australians with disabilities will be vital. People with disabilities, through their representative organisations, including independent advocacy agencies, must be adequately resourced to participate in the Strategy’s development and monitoring. As State and Territory disability plans are developed, their consistency with the vision the Strategy and the CRPD must be ensured and the respective responsibilities of different levels of government should be further clarified.[[14]](#footnote-14)

## A uniform approach to legal capacity

DANA is supportive of the development of a uniform approach to defining capacity and assessing a person’s ability to exercise their legal capacity. Inconsistency between states and territories and different areas of law is incoherent and promotes unfairness and inefficiency. Overseas examples demonstrate the viability of developing a consistent approach and an Australian model should draw on the best legislative and practical examples from the United Kingdom, Ireland and Canada.[[15]](#footnote-15) People With Disabilities Australia Inc has long advocated for a uniform definition and more standardised and accurate testing of capacity, in order to avoid of confusion, discrimination, and subjective interpretation, and to promote greater legal certainty and understanding of the meaning of capacity.[[16]](#footnote-16) Disability advocates generally support an approach that is decision-specific, recognising that capacity depends on the interaction of the underlying impairment and the relevant circumstances.[[17]](#footnote-17) The dignity of risk, including the opportunity to take chances when making rational and informed choices, is an important component of decision making.[[18]](#footnote-18)

## The role of advocates in supporting people to exercise legal capacity

A number of advocacy agencies (and Public Advocates) have strongly promoted the shift to a supported decision making paradigm in Australia.[[19]](#footnote-19) The integral role disability rights advocates have played in driving research, creating resources and raising the profile of this model is unsurprising, as core aims of advocacy overlap with the principles and values of supported decision making. As stated in the National Disability Strategy, “disability advocacy enables people with disability to participate in the decision making processes that safeguard and advance their human rights, wellbeing and interests.”[[20]](#footnote-20)

The Draft General Comment recognises that advocacy may fall within the “support” referred to in article 12, paragraph 3, stating that in this context support:

“encompasses both informal and formal support arrangements, of varying types and intensity. For example, persons with disabilities may choose one or more trusted support persons to assist them in exercising their legal capacity for certain types of decisions, or may call on other forms of support, such as peer support, advocacy (including self-advocacy support), or assistance with communication.”[[21]](#footnote-21)

Despite certain dynamic, practical intersections between advocacy and decision support practices, such as providing and explaining information on a person’s rights or supporting a person to consider, evaluate and express their preferences, equating the activities too closely may confuse distinct conceptual and practical functions.

In decision making regimes, advocacy can fulfil an important role in ensuring integrity, as advocates will “typically be independent and therefore freer of conflicts of interest...very aware of the person’s situation and vulnerabilities, and be working on meeting their fundamental needs.”[[22]](#footnote-22) Incorporation of access to independent advocacy into decision making models and accompanying legal frameworks would function as a safeguard against decision support being unduly or improperly influenced by family, carer or service provider interests or perspectives.

## Nominee provisions in the National Disability Insurance Scheme

Section 88 of the National Disability Insurance Scheme Act 2013 allows the National Disability Insurance Agency (NDIA) to appoint a nominee to act for a participant on request by the participant or on the NDIA’s own motion. The general principle is that nominees should only be appointed where it is not possible for participants to be assisted to make decisions for themselves. Nominees may either be appointed as a plan nominee, or a correspondence nominee; each involving specific duties and actions. The Agency may only appoint a person as a nominee with the written consent of the person to be appointed and after taking into consideration the wishes of the participant.

DANA is concerned that this appointment power is largely unfettered, as the Act gives the CEO/NDIA considerable freedom to appoint or cancel appointment of a nominee with or without the agreement of the participant or respect for the participant’s wishes, with or without regard for any existing guardianship, power of attorney or other substitute decision-making arrangement for the participant, and most importantly with or without first seeking to support and enable the participant to make the required decisions for him/her-self. This appointment power appears to give little regard to enabling the decision-making capacity of participants.

DANA is considerably concerned that the Act empowers an appointed nominee, particularly in the case of plan nominee, to make decisions and act for the participant with few safeguards for the participant. Specifically the Nominee may do: “*Any act that may be done by a participant under, or for the purposes of, this Act that relates to:*

1. *the preparation, review or replacement of the participant’s plan; or*
2. *the management of the funding for supports under the participant’s plan;”[[23]](#footnote-23)*

In making these far-reaching decisions for a participant, a nominee is required only to “*ascertain the wishes of the participant and to act in a manner that promotes the personal and social wellbeing of the participant”* (Section 80). The Act does not prescribe a requirement for a nominee to support a participant to make the required decisions or to participate in decision-making. The nominee is required only to act in a manner which the nominee believes will promote the *personal and social wellbeing of the participant*. This appears to contradict the Principles of the Act (sections 4, 5) and appears to allow the continuation of a disempowering best-interests based approach to decision making for people with disability.

DANA believes it should be an explicit Object of legislation in the disability area, such as the National Disability Insurance Scheme Act 2013, to promote the decision making capacity of people with disability, to build the capacity of people with disability to make decisions and participate in decision making, and to enable access to decision making support for all people with disability whose decision making capacity is impaired. Although positive aspirations to maximise choice and control are included in the Objects and General Principles of the NDIS Act, the Nominees provision may serve to replicate within the scheme the discriminatory operation of external substitute decision making regimes, and undermine the intended human rights framework of the NDIS.

If the Act’s [objects](http://www.advokit.org.au/general-information/ndis-objects/) and [principles](http://www.advokit.org.au/general-information/ndis-principles/) of maximised choice and control are not being realised in practice (for instance, a participant is presumed to not possess legal capacity without a genuine exploration of the person’s capabilities), independent [advocacy](http://www.advokit.org.au/general-information/independent-advocacy/) should be available to help protect the right to self-determination and prevent the person’s decision making being unfairly or unreasonably limited. Specifically, advocacy may be needed to protect the rights of a person with disability to take reasonable risks, and determine his or her interest’s which are strengthened by the [principles guiding actions](http://www.advokit.org.au/general-information/ndis-principles/#principles-guiding-actions-under-this-act) under the Act.  Advocacy and other forms of support may also assist person engaging in [supported decision making](http://www.advokit.org.au/decision-making/supported-decision-making/) to gather information, understand their rights and options under the NDIS and communicate preferences and aspirations.[[24]](#footnote-24) As the NDIS is trialled and implemented, practical access to decision support and independent advocacy shall be vital and DANA would like stronger guarantees that these supports shall be available to all NDIS participants to protect their entitlements and human rights.

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2. Ibid, 461. [↑](#footnote-ref-2)
3. Council of Europe Commissioner for Human Rights. (2012). *Who Gets to Decide? Right to legal capacity for persons with intellectual and psychosocial disabilities.* Issue Paper. Strasbourg: Council of Europe. 7 [↑](#footnote-ref-3)
4. Phillip French, ‘Final Report to the Australian Government Department of Families, Housing and Community Services and Indigenous Affairs, and the Attorney-General: Consultations with Australian Representative Organisations Governed by Persons with Disability, Disability Advisory Councils, and the Disability Legal Services Network on the Impact of Ratification of the *Convention on the Rights of Persons with Disabilities*’ (Report, Disability Studies and Research Institute for the Australian Taskforce on CRPD Ratification, March 2008) 20. [↑](#footnote-ref-4)
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