

# Response to the discussion paper: Equality, Capacity and Disability in Commonwealth Laws

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*Scope*

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## ***Executive Summary***

Scope is one of the largest providers of services to people with a disability in Victoria. Scope's mission is to support people with a disability to achieve their potential in welcoming and inclusive communities. Scope welcomes the Australian Law Reform Commission's invitation to provide input into the review of the Commonwealth's laws and legal frameworks relating to our obligations as a signatory nation to the United Nations Convention on the Rights of Person's with Disabilities (UNCRPD) (2006).

Scope has used the proposals and questions provided by the ALRC to guide this submission and it is structured accordingly. Although each of the proposals and questions put forward by the ALRC have been considered, this submission only provides commentary on decision-making support for people with cognitive impairment, particularly those with severe to profound disability. The submission is organised into themes, each relating to a cluster of questions and proposals.

This is an area of particular interest and focus for Scope. In recent years Scope has been a key contributor to national and international conversations around decision-making capacity and support (Johnson, Watson, Iacono, Bloomberg, & West, 2012; Pepin, Watson, Hagiliassis, & Larkin, 2013; Watson, 2010, 2013a, 2013b, 2013c; Watson & Joseph, 2011a; Watson, Wilson, & Hagiliassis, 2013). Scope has explored (and continues to do so) the concept of decision-making support with its service users, with a particular emphasis on those with severe to profound intellectual disability, a group of people who it believes are rarely

heard. Scope's involvement in research, practice and legislative reform make it well placed to provide commentary in this complex and important legislative space.

Arguably the most momentous advance to date, pertaining to the rights of people with disability has been the adoption of the United Nations Convention on the Rights of People with Disabilities (UNCRPD) (United Nations., 2006), which was signed by Australia in 2007 and ratified in 2008. The first principle of the UNCRPD (2006) is *"respect for inherent dignity, individual autonomy including the freedom to make one's own choices and independence of persons"* (United Nations., 2006). Article 12 of the Convention in particular emphasizes the full and equal legal capacity of all citizens including those with severe to profound intellectual disability. From this premise it then stipulates the right of everyone to receive appropriate support in decision-making. Having ratified this convention, Australia as a nation, has an unambiguous obligation to ensure this principle is upheld for all citizens. This obligation is reflected within the ALRC discussion paper, Equality, Capacity and Disability in Commonwealth Laws.

Scope commends the ALRC for its comprehensive and timely review of Australia's performance under Article 12 of the UNCRPD (2006), *'equal recognition before the law and legal capacity for people with disability'*.

Specifically, it offers this submission with a view to highlighting the specific needs of people with severe to profound cognitive impairment. These people have traditionally been considered to have no decision-making capacity, and therefore under current guardianship legislation, no right to legal capacity. While Australia continues to have an interpretative declaration in relation to Article 12,

allowing for substitute decision-making, those with the most severe to profound cognitive disability will continue to be excluded from yet another global movement toward empowerment and self-determination for people with disability. Therefore, Scope agrees with Proposal 2-1, the Australian Government should review the Interpretative Declaration in relation to art 12 of the United Nations Convention on the Rights of Persons with Disabilities with a view to withdrawing it.

Scope is supportive of the introduction of four national decision-making principles that reflect the key ideas and values upon which the ALRC's approach in relation to legal capacity is based. However, it recommends an additional set of prerequisites be added to those articulated in Proposal 3-7, around a person's decision-making capacity. These prerequisites should reflect the interdependent lives of people with severe to profound intellectual disability, and be inclusive of the necessary external supports they need to have their preferences heard.

Scope is of the view, that for Australia to live up to its obligations under Article 12, the unique needs of these people need to be carefully considered. There is a growing body of research indicating that with the right resources and supports these people can have their preferences heard through a range of supportive approaches to decision making (Grove, Bunning, Porter, & Olsson, 1999; Johnson et al., 2012; Maes & Petry, 2006; Watson, 2011; Watson, 2013b). Scope asks ALRC to consider this research and commentary within their quest to ensure Australia meets its obligations under Article 12.

## *The context for reform: Australia's obligations under Article 12*

**Proposal 2-1:**

The Australian Government should review the Interpretative Declaration in relation to art 12 of the United Nations Convention on the Rights of Persons with Disabilities with a view to withdrawing it.

Scope believes that Australia's interpretative declaration to allow for substitute decision making in relation to Article 12 has a significant negative impact on the recognition of people with severe to profound cognitive impairment before the law, and consideration should be given to withdrawing it or rewording it.

An inclusion of the interpretative declaration of Article 12 means that there is continued exclusion of people with severe to profound intellectual disability from their right to enjoy legal capacity, based on traditional views of decision-making capacity and communicative competence. These people have traditionally been regarded as lacking decision-making capacity and, within a legal context, are usually subjected to guardianship.

Scope believes that the well-established benefits of self-determination should be afforded to all Australian citizens, not just those with mild to moderate cognitive impairment, who are less likely to be subjected to guardianship than those with more severe disability. Although some researchers (e.g., Brown & Gothelf, 1996; Singer, 1993; Stancliffe & Abery, 1997) argue that people with severe to profound cognitive impairments are not capable of self-determination, there is growing acknowledgment that the exclusion of this group from the self-determination movement is related to a misconception of decision making capacity, which does not take into account the interdependent lives of this group (Bach & Kerzner, 2010;

Pepin et al., 2013; Wehmeyer, 1998, 2005). Scope believes that decision-making capacity can be an achievable goal for this group when it is re-defined to better reflect the realities for this group of people, who by the very nature of their disability need to live interdependent as opposed to independent lives. Articulating Scope's view, Bach and Kerzner (2010) make the point that human beings do not exercise their *"self-determination as isolated, individual selves, but relationally, interdependently and inter-subjectively with others"*, and call for a greater legal recognition of interdependent decision-making and supports within their nation of Canada's guardianship laws (Bach & Kerzner, 2010 p.40).

Scope welcomes the ALRC's focus on the United Nations' Committee on the Rights of Persons with Disabilities meeting in September 2013 to evaluate Australia's performance regarding its commitment as a signatory nation to the UNCRPD (2006). Although the Committee has welcomed the ALRC's inquiry into barriers to equal recognition before the law and legal capacity for persons with disability, it has expressed concern about the maintenance of the regime of substitute decision-making. The Committee has called for Australia to broaden its definition of supported decision making to ensure Article 12's promises are relevant to all Australian's stating:

*"The Committee recommends that [Australia] take immediate steps to replace substitute decision-making with supported decision-making and provide a wide range of measures which respect the person's autonomy, will and preferences"* (United Nations Committee on the Rights of Persons with Disabilities., 2013 par.25).

***National decision making principles: A consistent approach to SDM***

**Proposal 3-1:**

Reform of Commonwealth, state and territory laws and legal frameworks concerning decision-making by persons who may require support in making decisions should be guided by the National Decision-Making Principles and Guidelines, set out in Proposals 3-2 to 3-9

**Proposal 3-2 National Decision-Making**

**Principle 1:** Every adult has the right to make decisions that affect their life and to have those decisions respected.

**Proposal 3-3 National Decision-Making**

**Principle 2:** Persons who may require support in decision-making must be provided with the support necessary for them to make, communicate and participate in decisions that affect their lives.

**Proposal 3-4 Support Guidelines**

(a) Persons who may require decision-making support should be supported to participate in and contribute to all aspects of life.

(b) Persons who may require decision-making support should be supported in decisions.

(c) The role of families, carers and other significant persons in supporting persons who may require decision-making support should be acknowledged and respected.

**Proposal 3-5 National Decision-Making**

**Principle 3:** The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

**Proposal 3-6 Will, Preferences and Rights Guidelines**

(c) Supporting decision-making:

- A person's will and preferences, so far as they can be determined, must be given effect;

- Where the person's will and preferences are not known, the representative must give effect to what the person would likely want, based on all the information available, including communicating with supporters; and

- If it is not possible to determine what the person would likely want, the representative must act to promote and safeguard the person's human rights and act in the way least restrictive of those rights.

**Proposal 3-7 Representative Decision-Making Guidelines**

Any determinations about a person's decision-making ability and any appointment of a representative decision-maker should be informed by the following guidelines:

(a) An adult must be presumed to have ability to make decisions that affect their life.

(b) A person has ability to make a decision if they are able to:

- Understand the information relevant to the decision and the effect of the decision;

- Retain that information to the extent necessary to make the decision;

- Use or weigh that information as part of the process of making the decision; and

- Communicate the decision.

(g) A person's decision-making ability be considered in the context of available supports.

Scope is generally supportive of the introduction of the National Decision-Making Principles and Guidelines as articulated in the discussion paper.

Scope is particularly supportive of proposal 3.6, *'wills preferences and rights guidelines'*, which emphasises the importance of ascertaining wills and preferences of those who do not communicate traditionally (e.g., those with severe to profound cognitive impairment).

Scope cautions against Proposal 3–7 Representative Decision-Making Guidelines, which proposes a set of pre-requisites to determine decision-making capacity. These pre-requisites are unachievable for people with severe to profound intellectual disability on their own. Although the Proposal considers the availability of supports in point (g), a person's decision-making ability must be considered in the context of available supports, Scope believes that the importance of these supports should be made more explicit. Scope suggests the individually orientated pre-requisites articulated in 3-7(b) be augmented with others that reflect the interdependent lives of people with severe to profound intellectual disability.

Additional pre-requisites that could be considered in determining decision-making capacity include:

- They are supported by two or more people who they have a very close relationship with;
- Supporters know their history and life story;
- Supporters have knowledge of the communication system of those they support;
- Supporters see them more than once a week;
- Supporters have a collective knowledge of their likes and dislikes; and
- Supporters are willing and able to work together



Scope would like to see strengthened use of circles of support as a way of achieving more collaborative and representative decision-making. An advantage of this approach is that it shifts the decision-making responsibility from a single individual to a group of people representing the wishes of the person with the disability. Because a circle of support comprises a team of people important to the person with a disability, it allows for broad representation from family, friends, advocates, and support workers.

Despite the value of collaborative approaches to decision making support, Scope is aware that many of those it provides services to do not have an existing unpaid network of people in their life to support them through a decision making process. This is a sad reality for many people, particularly those who have been institutionalized from a young age and, as a consequence, have limited (if any) community supports. Scope calls for additional attention and resources for the establishment, training and nurturing of circles of support. Additional resources are critical because existing community based organizations do not have the capacity to expand their workload. Scope suggests that any additional resources focus on establishing, strengthening and extending the natural supports that might be present in a vulnerable decision maker's life, rather than substituting them by professional services. In particular, consideration must be given to schemes such as volunteer social advocacy (sometimes referred to as "citizen advocacy"), whereby a support network is intentionally established to act as a support, provide information, advice, and a voice for the person's decisions.

## ***Supported Decision-Making in Commonwealth Laws***

### **Proposal 4–12**

The Australian Government should ensure that Australian Public Service employees who engage with supporters and representatives are provided with regular, ongoing and consistent training in relation to the roles of supporters and representatives.

There is a need for the development of training and support materials about supported decision making for those who assist vulnerable decision makers lead lives of their preference. Without a commitment to further training and support, it is unlikely that the culture shift, as the one alluded to in the UN Convention is possible.

This means providing resources and supports to build capacity in using supportive approaches/frameworks to decision making for this group. An evidence base is growing that supports the notion that all people, regardless of their level of cognitive impairment, can have their preferences heard through highly collaborative, detailed and lengthy supported decision making processes (Grove, Bunning, Porter, & Olsson, 1999; Watson, n.d). These processes are reliant on strong circles of support that work collaboratively to support people to participate in decisions that reflect their preferences. An example of one of these processes is Scope's *'Listening to those rarely heard'* resource, a training package for people providing support to those with severe to profound intellectual disability (Watson & Joseph, 2011b). A video that accompanies this package can be viewed at <http://vimeo.com/21176882>. This resource is currently being evaluated within a PhD research study (Watson, n.d).

## ***The National disability insurance scheme (NDIS): The role of SDM within the NDIS***

### **Proposal 5-1**

The objects and principles in the National Disability Insurance Scheme Act 2013 (Cth) should be amended to ensure consistency with the National Decision-Making Principles.

### **Proposal 5-2**

The National Disability Insurance Scheme Act 2013 (Cth) and NDIS Rules should be amended to include supporter provisions consistent with the Commonwealth decision-making model.

### **Proposal 5-3**

The National Disability Insurance Scheme Act 2013 (Cth) and NDIS Rules should be amended to include representative provisions consistent with the Commonwealth decision-making model.

Scope supports Proposals 5-1, 5-2 and 5-3, each of which propose integration of the National Decision-Making Principles into the NDIS.

A detailed submission regarding Scope's recommendations regarding incorporation of these principles into the NDIS is beyond the scope of this submission. However, Scope's 2013 submission to the NDIS Rules Consultation paper provides some information about the role of supported approaches to decision making within the NDIS, and is available on request (Watson, 2013a).

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