



## Disability Council NSW

Preliminary Submission to  
Review of the *Guardianship Act 1987*

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## Disability Council NSW

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The Disability Council NSW (also known as 'the Council') was established under the *Community Welfare Act 1987* (NSW), and was re-constituted under the *Disability Inclusion Act 2014* (NSW) on 3 December 2014. The *Disability Inclusion Act 2014* provides a rights-based legislation framework for the Council.

The Council's main responsibilities under the *Disability Inclusion Act 2014* are to:

- Monitor the implementation of Government policy;
- Advise the Minister on emerging issues relating to people with disability, and about the content and implementation of the NSW State Disability Inclusion Plan and Disability Inclusion Action Plans;
- Advise public authorities about the content and implementation of Disability Inclusion Action Plans;
- Promote the inclusion of people with disability in the community and promote community awareness of matters concerning the interests of people with disability and their families;
- Consult with similar councils and bodies, and people with disability; and
- Conduct research about matters relating to people with disability.

The Council has 12 members, including a Chairperson and Deputy Chairperson. Each member is appointed for up to four years by the Governor of NSW on the recommendation of the Minister for Disability Services.

Members are selected to be on Council because:

- They live with a disability
- They are an expert on disability
- They want to improve the lives of people with disability.

The Council's members have a variety of disabilities and backgrounds. Members include people from Aboriginal or cultural and linguistically diverse backgrounds (CALD), young people and also people from rural and regional NSW. In addition, the Council includes members who are carers or family members of people with disability.

The Council is funded and resourced by the NSW Government through the NSW Department of Family and Community Services (FACS) and is supported by a secretariat team within FACS.

The Council members meet bi-monthly.

## Executive Summary

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There is a fundamental need for a decision-making framework that is consistent with Australia's obligations under the UNCRPD and other human rights instruments and provides a continuum of supports that people can access to assist them to make different decisions at different times. The decision-making framework should be supported by resources that actually build the capacity of people with disability to make decisions and drive cultural change to increase recognition of the human rights and decision-making abilities of people with disability.

It is imperative to note at this early stage in the review the importance of involving people with disability in the process of determining the future of the guardianship regime in NSW. This is an area where the fundamental human rights of people with disability are at stake. Any transition to new regimes must be done carefully, systematically and in consultation with people with a disability.

The Council has considered recent developments in law, policy and practice in Australia and internationally as well as results from consultations with people with disability about the NSW Guardianship and financial management regime. It has identified issues to consider in the review process and a number of characteristics that any decision-making framework should exemplify in order to enable all people to exercise capacity and make choices about all aspects of their lives.

The Council would like to see a decision-making framework that:

- is consistent with Australia's obligations under the UNCRPD and other international human rights instruments
- is underpinned by more expansive, comprehensive and human rights centred principles than the current general principles in section 4 of the *Guardianship Act*
- recognises and allows for the reality that capacity is decision-specific and can change over time
- applies on equal terms to all members of the population that may have difficulty making decisions and does not specify impairment or disability as a threshold for application.
- is clear about the relationship between guardianship law in NSW and the NDIS nominee scheme and other Commonwealth schemes
- mandates and actively promotes alternatives to substitute decision making, including supported decision making models that are drawn from local and international models of best practice
- does not over-formalise or over-regulate supported decision making arrangements
- provides a representative decision making scheme that can be implemented where a person does not have capacity to make particular decisions and will require the representative to exercise their powers to promote the personal and social wellbeing of the person
- provides mechanisms for ensuring accountability of decision makers appointed in a representative decision making scheme, including monitoring and regular review of orders and decisions
- safeguards people with disability against abuse, neglect and exploitation,
- explicitly addresses the circumstances in which the use of restrictive practices will be lawful in relation to people with a decision making incapacity

## List of Recommendations

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**Recommendation 1:** The NSW Law Reform Commission should consult with and actively involve people with disability in the development and implementation of the decision-making framework.

**Recommendation 2:** The decision-making framework should promote mechanisms for consistent data collection about supported and representative or substitute decision-making arrangements.

**Recommendation 3:** The decision-making framework should be consistent with Australia's obligations under the UNCRPD and other international human rights instruments.

**Recommendation 4:** The decision-making framework should be underpinned by principles that are more expansive, comprehensive and human rights centred than the current general principles in section 4 of the Guardianship Act.

**Recommendation 5:** The decision-making framework should establish principles and a process for assessing decision-making ability that allows for the reality that decision-making ability is decision-specific and can change over time.

**Recommendation 6:** The decision-making framework should use the term "decision-making ability" rather than disability or decision-making capacity.

**Recommendation 7:** The decision-making framework should clearly outline how it interacts with and relates to the NDIS nominee scheme and other Commonwealth schemes.

**Recommendation 8:** The decision-making framework should provide and promote alternatives to substitute decision-making, including supported decision-making models that are drawn from local and international models of best practice.

**Recommendation 9:** The decision-making framework should strike the appropriate balance between allowing informal arrangements that give control to the person being supported to exist and providing legal acknowledgement of and certainty for third parties about the role of supporters.

**Recommendation 10:** The decision-making framework should include resources that build the decision-making ability of people with disability and drive cultural change, including independent community based individual advocacy, education about human rights of people with disability and services that support people with disability to exercise their rights and make decisions for themselves.

**Recommendation 11:** The decision-making framework should include a representative decision-making scheme that will require the representative to exercise their powers to promote the personal and social wellbeing of the person and can be implemented in limited circumstances where a person does not have the ability to make particular decisions.

**Recommendation 12:** The decision-making framework should include safeguards against abuse, neglect and exploitation of people with disability.

**Recommendation 13:** The decision-making framework should explicitly address the circumstances in which the use of restrictive practices will be lawful in relation to people with impaired decision-making ability and establish an independent office to regulate the use of restrictive practices.

## Introduction

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The Council welcomes the opportunity to make a preliminary submission to the review of the *Guardianship Act 1987* (The *Guardianship Act*) and looks forward to making further more detailed submissions during the various stages of this review.

In 2014 the Disability Council consulted widely with people with disability about the NSW National Disability Strategy Implementation Plan (2012-2014).<sup>1</sup> In these consultations, concerns were indicating a degree of dissatisfaction with the Guardianship system. It was felt that some aspects of the system were confusing, demoralising and belittling and were not in sync with the philosophical framework of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). In short, concerns reflected the prevailing cultural norm of low expectations of the capacity of people with disability to make decisions about how they would like to live their lives.

This review should actively consult with people with disability and their representative organisations and consider what legislative changes and resources are required to enable people with disability to make decisions and exercise control over their lives.

The review of the *Guardianship Act* comes at a critical time for the rights of people with disability. Under the National Disability Insurance Scheme (NDIS), people with disability, many for the first time, will have choice and control over services and supports they need to make progress towards their goals. It is more important than ever that the decision-making framework reflects and, as much as possible, upholds the human rights of people with disability and facilitates self determination.

The Council has considered recent developments in law, policy and practice in Australia and internationally as well as results from consultations with people with disability about the NSW Guardianship and financial management regime. It has identified issues to consider in the review process and a number of characteristics that any decision-making framework should exemplify in order to enable all people to exercise capacity and make choices about all aspects of their lives. These are briefly outlined in this submission.

Underscoring the recommendations made in this submission is the fundamental need for a decision-making framework that is consistent with Australia's obligations under the UNCRPD and other human rights instruments and provides a continuum of supports that people can access to assist them to make different decisions at different times. The decision-making framework should be supported by resources that actually build the capacity of people with disability to make decisions and drive cultural change to increase recognition of the human rights and decision-making abilities of people with disability.

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<sup>1</sup> Disability Council NSW (2014) *Nothing About Us Without Us – Community Feedback Report on the NDS NSW Implementation Plan (2012-2014)* [http://www.disabilitycouncil.nsw.gov.au/\\_data/assets/pdf\\_file/0016/311290/210814-Feedback-Report-on-NDS-Implementation-Plan.pdf](http://www.disabilitycouncil.nsw.gov.au/_data/assets/pdf_file/0016/311290/210814-Feedback-Report-on-NDS-Implementation-Plan.pdf).

## **Issues to consider in the review process**

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### The need for ongoing consultation and involvement of people with disability and their representative organisations

It is imperative that people with disability and their representative organisations are involved in the process of reviewing the *Guardianship Act*. The fundamental human rights of people with disability are at stake and it is important that people with disability are given every opportunity to give their opinions and suggestions for improvement of the decision-making framework in NSW.

Any transition to new regimes must be done carefully, systematically and in consultation with people with a disability and their representative organisations. Even the most robust and appropriate scheme will be undermined if it is introduced without consulting people with disability and without support to ensure a smooth transition.

**Recommendation 1: The NSW Law Reform Commission should consult with and actively involve people with disability and their representative organisations in the development and implementation of the decision-making framework**

### The need for improved data collection about decision-making arrangements

To date, it has been difficult to obtain consistent data about the appointment of substitute decision makers. There is a clear need for improved data collection to facilitate comparisons across jurisdictions and inform policy development.

The decision-making framework must promote mechanisms for consistent data collection about supported and representative or substitute decision-making arrangements.

**Recommendation 2: The decision-making framework should promote mechanisms for consistent data collection about supported and representative or substitute decision-making arrangements.**

## **Characteristics of a decision-making framework that will enable all people to exercise capacity to their full extent and make choices about their lives**

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### Consistency with Australia's obligations under the UNCRPD and other international human rights instruments

NSW laws with respect to capacity and financial management have not substantially changed since Australia ratified the UNCRPD and became a party to the Optional Protocol in August 2009. The UNCRPD represents a paradigm shift in addressing legal capacity. It recognises that people with disability “enjoy legal capacity on an equal basis with others in all aspects of life.”<sup>2</sup> A key message from the UNCRPD is that people with disability are to be regarded and respected, first and foremost, as citizens with equal rights, aspirations to live well, a capacity to contribute to the community and to make their own decisions. Reform to NSW laws is timely and critical to ensure that this paradigm shift translates to real and measurable improvements to the lives of people with disability and the extent to which their human rights are upheld.

For NSW laws to be consistent with Australia's obligations under the UNCRPD and other international human rights instruments they should, at a minimum:

- affirm that people with disability have the right to recognition as persons before the law<sup>3</sup>
- recognise that people with disability enjoy legal capacity on an equal basis with others in all aspects of life<sup>4</sup>
- provide support so people with disability can exercise capacity and realise their right to individual autonomy, independence, and freedom to make one's own decisions<sup>5</sup>
- provide appropriate, effective and proportionate safeguards to prevent abuse, neglect and/or exploitation of decision-making arrangements,<sup>6</sup> including rights to regular review and time limitations
- provide assistance and support so people with disability can manage their financial affairs<sup>7</sup>
- apply on equal terms to all members of the population that may have difficulty making decisions and not specify impairment or disability as a threshold for application
- provide “reasonable accommodation”<sup>8</sup> so people can make, communicate and participate in decisions that affect their lives.<sup>9</sup>

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<sup>2</sup> Article 12, *United Nations Convention on the Rights of Persons with Disabilities* (2008) <http://www.refworld.org/docid/45f973632.html> (UNCRPD).

<sup>3</sup> UNCRPD Article 12(1); International Covenant on Civil and Political Rights (1966) <http://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx>.

<sup>4</sup> UNCRPD Article 12 (2).

<sup>5</sup> UNCRPD Article 12 (3); Article 5(a).

<sup>6</sup> UNCRPD Article 12 (4).

<sup>7</sup> UNCRPD Article 12 (5).

<sup>8</sup> Reasonable Accommodation is defined as “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms” UNCRPD Article 2.

<sup>9</sup> UNCRPD Article 5.



**Recommendation 3: The decision-making framework should be consistent with Australia's obligations under the UNCRPD and other international human rights instruments**

Underpinning principles that are more expansive, comprehensive and human rights centred principles than the current general principles in section 4 of the *Guardianship Act*

The current general principles in the *Guardianship Act* are not expansive or comprehensive enough for a decision-making framework that will reflect and uphold the human rights of people with disability and enable all people to exercise capacity to their full extent and make choices about their lives.

The paramount consideration for guardians and administrators is currently the welfare and interests, rather than the wishes or expressed opinions of the person. This is fundamentally inconsistent with the UNCRPD as it does not respect the autonomy of the individual and places a responsibility on the guardian or administrator to act in a protective capacity.

The Council is generally supportive of the National Decision-making principles outlined by the Australian Law Reform Commission Report on Equality, Capacity and Disability in Commonwealth Laws, namely that:

- all adults have an equal right to make decisions that affect their lives and to have those decisions respected
- persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives
- the will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives
- laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.<sup>10</sup>

The Council also supports the five framing principles identified in the report, namely, dignity, equality, autonomy, inclusion and participation and accountability. All of these principles are important for a framework that enables people to exercise capacity to their full extent and make decisions about their lives.

The *Guardianship and Administration Act 2000* (QLD) provides a useful example of principles that are more expansive and reflect the key themes of the national decision-making principles. Schedule 1, part 1 to the *Guardianship and Administration Act* includes principles that presume capacity, recognise the importance of human rights and that people should be supported to maximise their participation in decision-making and minimise the use of substitute decision-making.<sup>11</sup>

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<sup>10</sup> Australian Law Reform Commission (2014) *Equality, Capacity and Disability in Commonwealth Laws* <https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>

<sup>11</sup> *Guardianship and Administration Act 2000* (Qld)

Another useful example is contained in the principles suggested in the final report of the Victorian Law Reform Commission on Guardianship.<sup>12</sup> These principles emphasise the dignity, human rights and fundamental freedoms of all people, the need to provide people with the support necessary for them to make, participate and implement decisions, take their wishes and preferences into account and significantly, that all people are entitled to take reasonable risks and make choices that other people might disagree with.<sup>13</sup>

It is important that the NSW Law Reform Commission considers the above examples and other examples of principles that guide the implementation of decision-making frameworks. These examples should be drawn on to develop principles that will guide a framework that will enable all people to make, communicate and participate in decisions that affect their lives.

**Recommendation 4: The decision-making framework should be underpinned by principles that are more expansive, comprehensive and human rights centred than the current general principles in section 4 of the Guardianship Act.**

Assessment of decision-making ability that allows for the reality that decision-making ability is decision-specific and can change over time

The ability to make decisions is a fluid concept that may vary from time to time and from decision to decision. It is fundamentally important that assessments of decision-making ability are not based on a person's disability but on a proper inquiry into a person's ability to make specific decisions. The term "decision-making ability" is deliberately used here. As suggested by the ALRC, this directs reform towards supported decision-making and removes connotations of previous decision-making regimes.<sup>14</sup> This is more appropriate than "decision-making capacity" as "ability" has more positive connotations and reduces the chance of confusion with the concepts of legal capacity and mental capacity which are very different to decision-making ability.

The decision-making framework should establish principles and a process for assessing decision-making ability. The final report of the Victorian Law Reform Commission on Guardianship recommended that Guardianship legislation should contain the following decision-making assessment principles:

- (a) A person's decision-making ability is specific to the decision to be made.
- (b) Impaired decision-making capacity may be temporary or permanent and can fluctuate over time.
- (c) An adult's inability to make a decision should not be assumed based on their age, appearance, condition, or an aspect of their behaviour.
- (d) A person should not be considered to lack the ability to make a decision merely because they make a decision that others consider to be unwise.

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<sup>12</sup> Victorian Law Reform Commission (2012) *Guardianship Final Report* [http://www.lawreform.vic.gov.au/sites/default/files/Guardianship\\_FinalReport\\_Full%20text.pdf](http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20text.pdf).

<sup>13</sup> Ibid.

<sup>14</sup> Australian Law Reform Commission (2014) *Equality, Capacity and Disability in Commonwealth Laws* <https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>.

- (e) A person should not be considered to lack the ability to make a decision if it is possible for them to make that decision with appropriate support.
- (f) When assessing a person's decision-making ability, every attempt should be made to ensure that the assessment occurs at a time and in an environment in which their decision-making ability can most accurately be assessed.<sup>15</sup>

These principles reflect the fluid nature of decision-making ability and may help to ensure that any limitations on decision-making are proportionate, that is, limited in scope or targeted to the specific issues or issues of concern, and time-limited to the period in which support is required.

It is also important that legislation does not specify impairment or disability as a threshold or essential basis for application. This is inconsistent with the UNCRPD as it disqualifies or limits the exercise of legal capacity because of a particular status (disability).<sup>16</sup> It would be more appropriate to use the term "decision-making ability" in the guardianship and financial management regime rather than disability or decision-making capacity as recommended in the terms of reference.

**Recommendation 5: The decision-making framework should establish principles and a process for assessing decision-making ability that allows for the reality that decision-making ability is decision-specific and can change over time.**

**Recommendation 6: The decision-making framework should use the term "decision-making ability" rather than disability or decision-making capacity**

#### Clarity about the relationship between guardianship law in NSW and the NDIS nominee scheme and other Commonwealth schemes

Current laws relating to decision-making across Australia are complex because they permit a range of substitute decision-making appointments under different legislative schemes. The NSW decision-making framework should clearly outline how it interacts with and relates to the NDIS nominee scheme and other Commonwealth schemes.

There is a potential for conflict between the NDIS Nominee Scheme and a state based decision-making framework that emphasises supported decision-making and only employs substitute decision-making as a last resort. Section 86 of the *National Disability Insurance Scheme Act 2013* allows the National Disability Insurance Agency (NDIA) to appoint a plan nominee to act for a participant on request of a participant or on the NDIA's own motion. Under section 78, a plan nominee can do anything relating to the preparation, review or replacement of the participant's plan; or the management of the funding for supports under the participant's plan<sup>17</sup> that the nominee considers the participant is not capable of doing.

This a very wide scope that may be greater than what a supporter or representative may have under informal or formal state-based arrangements. There may be a need for legislative provisions to clarify who can be appointed as an NDIS nominee and what steps

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<sup>15</sup> Victorian Law Reform Commission (2012) *Guardianship Final Report* [http://www.lawreform.vic.gov.au/sites/default/files/Guardianship\\_FinalReport\\_Full%20text.pdf](http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20text.pdf).

<sup>16</sup> UNCRPD Article 5 and Article 12.

<sup>17</sup> *National Disability Insurance Scheme Act 2013* (Cth) s 76(1)(a); s 76 (1)(b).

they must take to involve the participant and recognise their decision-making ability as much as possible as part of their role as a nominee. These may also need to clarify how a nominee is to decide whether a person is capable of doing things relating to the preparation, review or replacement of their plan or the management of their plan. It is also important to note that an independent review of the *NDIS Act* took place in late 2015<sup>18</sup> and the *NDIS Act* may imminently change in response to the recommendations of this review.

The ALRC has recommended that all state and territory governments review legislation that deals with decision-making to ensure consistency with the National Decision-making Principles and the Commonwealth Decision-making Model that emphasises a supporter and representative scheme rather than substitute decision-making. It is important the NSW Law Reform Commission, in the first instance, considers this scheme as other jurisdictions are likely to review their decision-making regimes and use the recommended principles and model to inform any new decision-making regimes. This may contribute to greater consistency and cross-jurisdictional recognition of decision-making arrangements.

**Recommendation 7: The decision-making framework should clearly outline how it interacts with and relates to the NDIS nominee scheme and other Commonwealth schemes.**

Provision for and promotion of alternatives to substitute decision-making, including supported decision-making models that are drawn from local and international models of best practice

Effective supported decision-making should be mandated and promoted in order to ensure compliance with the UNCRPD and promote increased participation of people with disability in decisions that affect their lives. By introducing a wider range of decision-making arrangements and recognising supporters in legislation, the decision-making framework may become a positive means of promoting the decision-making ability and human rights of people with disability rather than just a protective mechanism that is in place to mitigate risk.

A supported decision-making model can reflect the fluctuating nature of decision-making ability and acknowledges that different people will need different levels of support to make different decisions. It can also be an integral component to the NDIS by empowering people with disability to make their own decisions and exercise choice and control over their life. Supported decision-making processes “prioritise personal autonomy and recognise that individuals should be empowered with information to make decisions – even bad ones (acknowledging the dignity of risk).”<sup>19</sup>

Under a supported decision-making model, the essential question is not “does the person have capacity to make the decision?” but rather “what supports are needed to ensure that this person can best exercise their rights?”<sup>20</sup> In this way it supports personal autonomy,

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<sup>18</sup> National Disability Insurance Agency (2015) *Independent Review of the NDIS Act* <http://www.ndis.gov.au/about-us/governance/legislation/ndis-act-review>.

<sup>19</sup> McSherry, B. ‘Legal Capacity Under the Convention on the Rights of Persons with Disabilities’ (2012) 22 *Legal Issues* 23.

<sup>20</sup> Bach, M. & Kerzner, I. (2010) *A new paradigm for protecting autonomy and the right to legal capacity* <http://www.lco-cdo.org/disabilities/bach-kerzner.pdf>.

authority and control that people have over their lives, develops decision-making skills and can increase support networks.

Common elements of supported decision-making schemes include:<sup>21</sup>

- Guiding principles that emphasise rights to self-determination and autonomy, the presumption of decision-making ability and the right to decision-making supports
- Recognition of a person's will, intent and preferences in the decision-making process
- Recognition that decision-making assistance is required, including by way of an interpreter, facilitated communication, assistive technologies, plain language etc.
- Processes to support individuals exercise their decision-making ability, including providing information and advice, spending time to determine a person's preferences and wishes and building informal relationships of support between a person and their social networks.<sup>22</sup>
- Clear guidance on the role of supporters
- Carefully structured provisions and safeguards so they do not over-regulate the lives of individuals and become burdensome
- Access to safeguards and monitoring of supported decision-making arrangements
- Mechanisms to identify and manage conflicts between people and their supporters

It is clear that there are many advantages and benefits that flow from the implementation of supported decision-making. What is still unclear is the best way to facilitate and ensure more widespread implementation of supported decision-making. Recently there has been a number of trials and implementation of supported decision-making models and suggestions for how to provide a statutory framework for supported decision-making.

In NSW, the NSW Trustee and Guardian, the Public Guardian and the Department of Family and Community Services ran Supported Decision-making Trial called *My Life, My Decision* to explore what supported decision-making might look like in practice in the NSW context.<sup>23</sup> It involved 26 people with disability in area with a high level of diversity, and each person was assigned a supporter to help them make both small everyday decisions and major life decisions. Supporters were family members, friends, paid service providers or paid advocates. The pilot also included the development of written resources for participants and their supporters which could be used to help them make decisions. The project team facilitators also assisted with the establishment of decision maker/supporter relationships, provided training and access to tools to support the decision-making processes. Results from the pilot evaluation indicated that supported decision-making could be successful for a diverse group of people with a disability and varied support needs and circumstances.<sup>24</sup>

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<sup>21</sup> Office of the Public Advocate South Australia (2010) *Submission to the Productivity Commission Inquiry into Disability Care and Support* <http://www.publicadvocate.vic.gov.au/advocacy-research/ndis>.

<sup>22</sup> Australian Law Reform Commission (2014) *Equality, Capacity and Disability in Commonwealth Laws* <https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>.

<sup>23</sup> Department of Family and Community Services NSW (2015) *My Life, My Decision: An Independent Evaluation of the Supported Decision Making Pilot* [http://www.adhc.nsw.gov.au/\\_data/assets/file/0009/346194/sdm\\_pilot\\_project\\_evaluation\\_report.pdf](http://www.adhc.nsw.gov.au/_data/assets/file/0009/346194/sdm_pilot_project_evaluation_report.pdf).

<sup>24</sup> Ibid.



In South Australia, the Office of the Public Advocate ran a supported decision-making project aimed at enabling people with a cognitive disability to make individual decisions about a variety of life choices.<sup>25</sup> It was based on the Stepped Model which describes different intermediate steps between autonomous decision-making and substitute decision-making. It was a non-statutory model that involved setting up an agreement between a person with disability and a supporter. The supporter was either a family member or close friend who would help make decisions about an individual's healthcare, accommodation and lifestyle. An agreement was also made with an independent party to be a monitor who would keep track of how the arrangement was going. The evaluation of this project indicated that participants felt an increased level of confidence in making decisions and a level of growth in support networks, but that the infrastructure was not developed enough to make this a viable alternative to the guardianship system.<sup>26</sup>

The Victorian Law Reform Commission in its final report on Guardianship suggested the development of a supported decision-making and co-decision-making structure.<sup>27</sup> This would provide recognition to supporters – trusted persons providing support and assistance to an adult who needs help in making a decision – and external oversight by the Victorian Civil and Administrative Tribunal (VCAT). The co-decision maker would act jointly with the adult, appointments would be made by VCAT, and the range of decisions for which the person needs support could be those previously covered by guardians and administrators. Safeguards in this system include online registration of co-decision-making orders, regular review on a range of grounds and options to renew, amend or revoke the order.<sup>28</sup> This is an example of a statutory supported decision-making model that could be implemented in NSW.

In Victoria, amendments to the *Powers of Attorney Act* mean that people can now appoint a supportive power of attorney who can enable them to give effect to his or her decisions with support.<sup>29</sup> A supportive attorney must act honestly, diligently, and in good faith and must exercise reasonable skill and care, but is not able to receive remuneration for acting as a supportive attorney. This is another statutory model NSW may consider implementing in order to facilitate supported decision-making.

For supported decision-making to be effective, according to the ALRC, it must be facilitated by appropriate legislative recognition of supporters. This is particularly important where a person does not have access to respectful, trusting, natural relationships and formal supporters are required. The Supporter Model proposed by the ALRC recommends a formal appointment process for supporters and recognition of the role and duties of supporters in legislation.<sup>30</sup>

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<sup>25</sup> Wallace, M. (2012) *Evaluation of the Supported Decision Making Project* [http://www.opa.sa.gov.au/resources/supported\\_decision\\_making](http://www.opa.sa.gov.au/resources/supported_decision_making).

<sup>26</sup> Ibid.

<sup>27</sup> Victorian Law Reform Commission (2012) *Guardianship Final Report* [http://www.lawreform.vic.gov.au/sites/default/files/Guardianship\\_FinalReport\\_Full%20text.pdf](http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20text.pdf).

<sup>28</sup> Ibid.

<sup>29</sup> *Powers of Attorney Act 2014* (Vic) s 86.

<sup>30</sup> Australian Law Reform Commission (2014) *Equality, Capacity and Disability in Commonwealth Laws* <https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>.

It must be acknowledged, however, that many supported decision-making relationships operate very effectively informally, and there is a risk that in over formalising supported decision-making that control is taken away from people who are being supported because the provisions may be too prescriptive about how arrangements should operate, who can be a supporter and what a supporter can do. The decision-making framework should strike the appropriate balance between allowing informal arrangements that give control to the person being supported to exist and providing legal acknowledgement of and certainty for third parties about the role of supporters.

**Recommendation 8: The decision-making framework should provide and promote alternatives to substitute decision-making, including supported decision-making models that are drawn from local and international models of best practice**

**Recommendation 9: The decision-making framework should strike the appropriate balance between allowing informal arrangements that give control to the person being supported to exist and providing legal acknowledgement of and certainty for third parties about the role of supporters.**

#### Resources that build the decision-making ability of people with disability and drive cultural change

It is clear from the UNCRPD that state parties are obligated to positively act and invest in supports so people with disability can exercise capacity and realise their rights.<sup>31</sup> In NSW there has been significant investment in the guardianship regime but no similar investment in decision support services, leading to a situation where people who might otherwise be able to make decisions for themselves (with the right support) may have a guardian appointed. Simply eliminating or reducing the practice of substitute decision-making will serve no purpose unless there are quality and appropriate supports available that empower people to make decisions.

Any legislative or policy change to the way people are facilitated to make decisions should be complemented by sufficient resources, supports, education and guidance that will better enable people to exercise their rights and make decisions for themselves. This may include independent community based individual advocacy, education about human rights of people with disability and services that support people with disability to exercise their rights and make decisions for themselves. It should also include adequate resourcing for advocacy groups that represent people with a disability. Funding of advocacy groups is a contentious issue under the NDIS but should be resolved and guaranteed in order to ensure people are best supported to make decisions about all aspects of their lives.

For some people with disability from culturally and linguistically diverse backgrounds (CALD), increased support and effective advocacy may be needed to assist people to negotiate and establish an independent life in the community which may be different from that conceived by their family or their community, where strong views may be held that do not reflect the values of modern Australian life, nor the independence of people with disability.

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<sup>31</sup> UNCRPD Article 5.

Legislative or policy change should also be complemented by more widespread information, education and awareness campaigns about the human rights of people with disability. This should assist in driving the cultural change required to overcome the prevailing cultural norm of low expectations of the capacity of people with disability to make decisions about how they would like to live their lives.

**Recommendation 10: The decision-making framework should include resources that build the decision-making ability of people with disability and drive cultural change, including independent community based individual advocacy, education about human rights of people with disability and services that support people with disability to exercise their rights and make decisions for themselves.**

A representative decision-making scheme that can be implemented in limited circumstances where a person does not have the ability to make particular decisions and will require the representative to exercise their powers to promote the personal and social wellbeing of the person

It is important to note that the Committee on the Rights of Persons with Disabilities has commented that “the development of supported decision-making systems in parallel with the retention of substitute decision-making regimes is not sufficient to comply with Article 12.”<sup>32</sup> However, it can be argued that this ignores the practical reality for some people with severe impairment and that there will always be a role for representative or substitute decision-making regimes for people who cannot make decisions even with support.

A representative decision-making scheme should only apply in limited circumstances. The Mental Disability Advocacy Centre noted that a representative decision-making scheme should only apply when<sup>33</sup>:

- supports have been exhausted (including creative communication techniques, building relationships, accessible information) and they have not lead to a decision
- the individual’s will and preferences cannot be clearly and unambiguously ascertained or there appears to be substantial conflict between preferences
- the individual has not previously expressed his or her will and preference (e.g. in planning documents)

Representative decision-making may be appropriate in cases where people with disability are being abused, neglected, exploited or overprotected and are unable to recognise these breaches or assert themselves in responding to these breaches, and in cases where there are disputes within families or between families and others about what decisions should be made. It is important, however, that representative decision-making is not imposed on someone who is expressing an unpopular or unorthodox will or preference or a will or preference that is contrary to medical advice or the advice of mental health professionals.

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<sup>32</sup> United Nations Committee on the Rights of Persons with Disabilities (2014) *General Comment No 1 (2014) on Article 12 of the Convention—Equal Recognition before the Law* [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en)

<sup>33</sup> Mental Disability Advocacy Centre (no date) *Supported Decision-Making: An Alternative to Guardianship* [http://mdac.info/sites/mdac.info/files/English\\_Supported\\_Decision-making\\_An\\_Alternative\\_to\\_Guardianship.pdf](http://mdac.info/sites/mdac.info/files/English_Supported_Decision-making_An_Alternative_to_Guardianship.pdf).



Under the Commonwealth Decision-making Model suggested by the ALRC, a person may choose someone else to make decisions for them or someone may be appointed to make decisions for another person.<sup>34</sup> The representative would first attempt to support the person to express their will and preferences in order to make a decision. Where it is not possible to determine the person's will and preferences, the representative would make a decision based on what the person would likely want, or on the basis of the person's human rights relevant to the situation. This model would only be invoked as a last resort, and would be as confined in scope and duration as is reasonably possible and would be subject to accessible mechanisms for review.

The NSW Council of Intellectual Disability questions whether a person's will and preferences should bind their representative and whether human rights are a sufficient basis for decisions.<sup>35</sup> The Council shares these concerns as people's will and preferences could be influenced by their limited ability to understand options and consequences and wish for order, routine and predictability, and human rights are a complex concept that not all people will understand or be able to apply. The Victorian Law Reform Commission in their final report on Guardianship recommended that representatives should be required to exercise their powers "in a manner that promotes the personal and social wellbeing of the person."<sup>36</sup> This requirement should be imposed as an alternate or additional requirement to the requirement to consider a person's will and preferences.

**Recommendation 11: The decision-making framework should include a representative decision-making scheme that will require the representative to exercise their powers to promote the personal and social wellbeing of the person and can be implemented in limited circumstances where a person does not have the ability to make particular decisions.**

#### Safeguards against abuse, neglect and exploitation of people with disability

Any decision-making framework must include mechanisms for ensuring accountability of supporters in a supported decision-making scheme and representatives in a representative decision-making scheme. Safeguard mechanisms could include:

- time and task specific appointments
- the ability to revoke appointments at any time
- police checks
- monitoring and regular review of orders and decisions
- the ability to appoint a monitor to oversee appointments
- automatic review of financial management arrangements every two years
- accessible appeal and complaints avenues

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<sup>34</sup> Australian Law Reform Commission (2014) *Equality, Capacity and Disability in Commonwealth Laws* <https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>.

<sup>35</sup> NSW Council for Intellectual Disability (2015) *Supported decision making YES! But what role for substitute decision-making?* <http://nswcid.blogspot.com.au/2015/06/supported-decision-making-yes-but-what.html>.

<sup>36</sup> Victorian Law Reform Commission (2012) *Guardianship Final Report* [http://www.lawreform.vic.gov.au/sites/default/files/Guardianship\\_FinalReport\\_Full%20text.pdf](http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20text.pdf).

- civil penalties for abusing, neglecting or exploiting a person with impaired decision-making ability<sup>37</sup>
- an online register of appointments<sup>38</sup>

Proportionate safeguards are necessary given the possibilities of undue influence, abuse and exploitation in any decision-making framework. However, it is also important to avoid excessive regulation as this could unduly interfere with relationships between the person and supporter and undermine the trust that the supporter relationship is built on.

**Recommendation 12: The decision-making framework should include safeguards against abuse, neglect and exploitation of people with disability.**

Legislative provisions that explicitly address the circumstances in which the use of restrictive practices will be lawful in relation to people with impaired decision-making ability

In NSW, the use of restrictive practices is regulated by a lengthy policy directive.<sup>39</sup> There is a need for legislation to properly regulate, and more importantly, reduce the need of restrictive practices. The legislation should:

- apply in all situations of informal support (e.g. in the family context), in the specialist mental health, brain injury and disability service systems, and in the commercial disability service sector
- provide that the use of restrictive practices is exceptional, short term and must be justified as necessary to protect the safety and interests of the person with disability
- provide that certain restrictive practices are entirely prohibited, including practices that are experimental, cause pain or discomfort, are cruel, inhuman, degrading or humiliating, physical restraint, seclusion and/or result in emotional, psychological or other harm
- provide for independent expert approval and oversight of the use of restrictive practices
- require regular independent review of the use of restrictive practices
- require that any authorisation of restrictive practices is time limited

Legislative provisions that address the use of restrictive practices are particularly important in NSW given the transition to the NDIS and transfer of all government run disability services and accommodation to the non government sector. It is important that effective mechanisms are in place to ensure the human rights of people with disability are upheld and the use of restrictive practices is the exception rather than the rule.

**Recommendation 13: The decision-making framework should explicitly address the circumstances in which the use of restrictive practices will be lawful in relation to people with impaired decision-making ability and establish an independent office to regulate the use of restrictive practices.**

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<sup>37</sup> Victorian Law Reform Commission (2012) *Guardianship Final Report*

[http://www.lawreform.vic.gov.au/sites/default/files/Guardianship\\_FinalReport\\_Full%20text.pdf](http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20text.pdf).

<sup>38</sup> Ibid.

<sup>39</sup> Department of Family and Community Services Ageing, Disability and Home Care NSW (2009) *Behaviour Support Policy and Practice Manual Part 1 and 2* [https://www.adhc.nsw.gov.au/sp/delivering\\_disability\\_services/behaviour\\_support\\_services/behaviour\\_support\\_policy\\_and\\_practice\\_manual](https://www.adhc.nsw.gov.au/sp/delivering_disability_services/behaviour_support_services/behaviour_support_policy_and_practice_manual).

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