

The Executive Director
Australian Law Reform Commission
GPO Box 3708
SYDNEY NSW 2001

NSW Government submission

ALRC Discussion Paper 81 - Equality, Capacity and Disability in Commonwealth Laws

The NSW Government appreciates the opportunity to comment on the issues raised in Australian Law Reform Commission Discussion Paper 81, *Equality, Capacity and Disability in Commonwealth Laws*. The NSW Government supports in principle the concept of introducing a formal supported decision making framework, however there are a number of practical implications in facilitating the provision of supported decision making that warrant further consideration.

The NSW Supported Decision Making Pilot (SDMP), conducted by the Department of Family and Community Services, Ageing Disability and Home Care, in conjunction with the Public Guardian and NSW Trustee and Guardian from mid-2012 to mid-2014, is currently being independently evaluated. However, early findings from the NSW SDMP highlight some of the challenges in facilitating supported decision making. Some of the key factors that need to be taken into consideration for the proposed broad implementation of supported decision making include:

- intensive work required to build the capacity of some people with disability and their supporters to be 'decision ready';
- availability of 'natural' supporters to assist people with disability to make decisions;
- mechanisms to identify and proactively manage conflicts of interest that may emerge between decision makers and supporters;
- significant resource implications in providing the necessary support and guidance to both people with disabilities and their supporters to undertake supported decision making; and
- in parallel, the need to continuously raise awareness and promote an understanding of supported decision making throughout the community.

The ability of decision makers to readily identify supporters to assist them to make decisions emerged as a significant challenge during the NSW SDMP and requires particular consideration for any proposed wide-spread implementation of supported decision making. In part this was due to some decision makers' limited access to 'natural' supports (e.g. family and friends). However, even when decision makers were able to identify 'natural' supporters from their family and friends, many declined to take on the role due to time constraints, limited resources or carer fatigue. In these circumstances, decision makers resorted to using paid supporters or the SDMP facilitators also assumed the role of supporter for some decision makers.

The NSW Government considers that the key focus of the implementation of model laws should be on establishing a structure that provides support according to a continuum of decision making ability, with appropriate safeguards, in such a way that it does not over-formalise the system.

The NSW Government agrees that there is potential for the implementation of formal supported decision making arrangements in situations where the person with a disability has the ability to express a view as to the decision, or the person's will and preferences can be ascertained. However, as noted in the attached comments from the Guardianship Division of the Civil and Administrative Tribunal of New South Wales (The Tribunal, **Att A**), there will always be members of our community who are unable to express a view and whose will and preference cannot be ascertained due to the severity and long-term nature of the decision making impairment.

There is also a risk that the proposed terminology and language used in the Discussion Paper fails to appropriately delineate the role of supporter and representative and may lead to a blurring of roles. The Discussion Paper proposes that the representative may perform both the role of supporter and substitute decision maker, where required. This blurring continues further through the use of the term 'fully supported' which implies that the person has been fully supported by their representative to make their own decision. Therefore, as noted in the attached comments provided by the Tribunal, the NSW Government recommends that further consideration be given to ensuring that the model laws do not blur the distinction between supported and substitute decision making, especially where supported decision making is used to shield what is in reality a substitute decision.

It will be important that sufficient consideration is given to how the high level principles outlined in the Discussion Paper would be implemented, and how the proposed reforms would work in practice. The experience of the NSW SDMP and of other pilot programs operating in several states in Australia is that the application and practice of supported decision making is still in early stages of development. The NSW Government recommends that further testing and evaluation of supported decision making approaches is required to properly inform the development and implementation of a formal supported decision making framework.

National Framework for Quality and Safeguards

The National Disability Insurance Scheme (NDIS) is governed by a National governance model which reports to the Council of Australian Governments (COAG) through the Disability Reform Council (DRC). The Disability Policy Group (DPG) sits within the governance model and is responsible for progressing national design and policy relating to the NDIS, through the governance framework.

As noted in the Discussion Paper, DPG is developing a national framework for quality and safeguards, which is due to be considered by the DRC and COAG early in 2015.

DRC have also commenced work on a nationally consistent approach to the use of restrictive practices in disability services, as recommended in the Discussion Paper. Once finalised, the NSW Government will review the recommendations of the Discussion Paper in the context of the work being undertaken by the DPG, and consider where the recommendations may inform the national framework.

As an independent review of the operation of the Commonwealth *NDIS Act 2013* is due to commence in 2015, the NSW Government will await the outcomes of this review before providing a position on any suggested amendments to the Commonwealth *NDIS Act 2013*.

ENDS



**Submission: Australian Law Reform Commission Inquiry
 Equality, Capacity and Disability in Commonwealth Laws
 Discussion Paper May 2014**

The Civil and Administrative Tribunal of New South Wales ('the Tribunal'), and in particular its Guardianship Division, welcomes the opportunity to contribute to the NSW Government response to the Australia Law Reform Commission inquiry into Equality, Capacity and Disability in Commonwealth Laws Discussion Paper 81 (May 2014).

The Tribunal has limited its comments to address the practical impact of the implementation of the proposed Commonwealth scheme, in the context of the issues raised in Chapter 10 of the Discussion Paper, and the suggestion that the inquiry may present an opportunity to review State and Territory legislation. The Tribunal considers that the key focus of the implementation of model laws should be on establishing a structure that provides support according to a continuum of decision making ability, with appropriate safeguards, in such a way that it does not over-formalise the system.

The Tribunal has focused its comments on:

- The potential implementation of the National Decision Making Principles in NSW and the difficulties with a reliance on the language of supported decision making.
- The current use of informal decision making supports compared with formal substitute decision making arrangements in NSW and the potential impact of the Commonwealth model in terms of the risk of over-formalising the current system.
- Practical questions concerning the implementation of the supporter/representative model in NSW, including:
 - The appropriateness of certain categories of appointees as supporters and representatives who are likely to have a conflict of interest, and
 - The shift to decision making guidelines based on human rights principles rather than best interests considerations.
- The potential issues surrounding the interaction between Commonwealth and State-based schemes, as exemplified in the Tribunal's experience in its Guardianship Division with NDIS-related applications for guardianship orders.

The language of 'fully supported decision making'

In Chapter 2 at page 43, the Discussion Paper identifies a lack of 'conceptual clarity' about the roles of supported and substitute decision makers in relation to the interpretation of article 12 of the UN Convention on the Rights of Persons with Disabilities. The Tribunal agrees that there is potential in NSW for the

implementation of formal supported decision making arrangements in situations where the person with a disability has the ability to express a view as to the decision, or the person's will and preferences can be ascertained. However, the Tribunal notes that there will always be members of our community who are unable to express a view and whose will and preferences cannot be ascertained due to the severity and long-term nature of the decision making impairment.

There will also be situations where the person's human rights will only be able to be ensured by the appointment of a substitute decision maker with the authority to make decisions on the person's behalf, including decisions that may be contrary to the person's expressed will and preferences. This may arise, for example, in cases of financial elder abuse where a person is influenced to appoint another person (for example an acquaintance or neighbour) under an enduring power of attorney, and the attorney misappropriates funds from the estate of the person for his or her own benefit. The principal may express the view that he or she still wants the attorney to continue to act, without the necessary insight or understanding to realise that their estate is being depleted to the point that he or she is at significant personal risk. In these circumstances, the appointment of a financial manager with authority to act as a substitute decision maker, by reference to appropriate guiding principles, may be essential in order to give effect to the person's right to be free from exploitation and abuse (UN Convention on the Rights of Persons with Disabilities, Article 16(1)).

If the Commonwealth model were to be implemented, in both the national and NSW contexts, the proposal to create a scheme of appointed representatives who must make decisions by reference to human rights principles appears to be, in all practical and legal effect, the appointment of a substitute decision maker. In circumstances where the person with a disability lacks the ability to express a view and there is no opportunity for the representative to ascertain what the person would have wanted, the Tribunal considers that the use of the term 'fully supported' may be misleading, as it implies that the person has been supported to make their own decision. The term 'substitute' appropriately recognises the legal and fiduciary nature of the relationship between the decision maker and the person. This relationship should not be diluted or blurred through non-specific language with the risk of consequently diluting the importance of the duties that the decision maker owes to the person.

The issue of restrictive practices exemplifies the potential problems associated with the use of the language of supported decision making where the decision is, in effect, made without reference to the will and preferences of the person due to the degree of decision making incapacity. In NSW, the implementation of a restrictive practice may require the consent of a guardian with the appropriate function, whose appointment is regularly reviewed by a Tribunal or a Court.

Chapter 8 of the Discussion Paper suggests that a person may be able to be 'supported' to give consent to the use of restrictive practices. In reality, if a person were able to be supported to the extent that he or she could give or withhold consent to the use of a restrictive practice, the person may have developed a level of insight into their behaviour so that the restrictive practice would not need to be implemented.

A distinction should be maintained between the lawful substitute consent to the use of the restrictive practice and the support provided to the person. If the distinction is not maintained, the danger is that the restrictive practice may be implemented without lawful consent. The use of ‘fully supported’ decision making terminology may not appropriately preserve this significant legal distinction.

Use of formal and informal decision making supports in NSW

The 2012 ABS Survey of Disability, Ageing and Carers reported that over 18% of the NSW population had a disability; 6.4% having a profound or severe disability that affected one or more core activities of living.¹ In 2012 the population of NSW was over 7.2 million, meaning approximately 1.3 million people in NSW identified as having a disability. The survey does not distinguish between purely physical disabilities and disabilities that give rise to a cognitive or decision making impairment. 18.4% of the 1.3 million were identified as having a ‘mental or behavioural disorder’ (which included dementia, mental illness, and intellectual disability) and a further 2.8% had identified physical disabilities which may also be associated with cognitive impairment, such as stroke or acquired brain injury.²

For the financial year 2012-13, the Tribunal received:

- 2,794 applications for guardianship (1,382 orders made),
- 2,847 applications for financial management (1,956 orders made) and
- 356 applications to consent to medical or dental treatment (274 consents granted).

The relatively low number of applications contrasted with the high number of people with a disability that affects cognition may be influenced by a number of factors, including but not limited to:

- The use and acceptance of informal support networks, such as family and carers, when engaging with services.
- The existence in Part 5 of the *Guardianship Act 1987* (NSW) of the automatic substitute decision making hierarchy of ‘person responsible’ for consent to medical and dental treatment where the patient does not have capacity to provide or withhold his or her own consent.
- The use of personally appointed substitute decision making arrangements such as enduring guardianship and enduring powers of attorney.

The NSW Guardianship Act includes provisions to ensure that substitute decision making orders, such as guardianship orders, should only be used as a last resort, tailored to the person’s circumstances and are regularly reviewed. Orders are generally only made in circumstances where a person has no informal support network or where the network has broken down. It is a requirement in the Guardianship Act that the Tribunal consider the practicability of services being provided without the need for an order (s 14(2)(d)).

¹ ABS, Disability, Ageing and Carers, Australia: Summary of Findings, Table 4, 2012. Available at: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features12012?OpenDocument>

² ABS, Disability, Ageing and Carers, Australia: New South Wales, Table 12, 2012.

Given the relatively low number of appointments of substitute decision makers compared with the high number of people accessing services and support, an inference may be drawn that informal arrangements are the current method of support for the majority of people with cognitive disability in NSW. In Chapter 4 of the Discussion Paper, the proposed Commonwealth model for supporters is via a formal appointment process undertaken by the principal. The implementation of the model should ensure that it does not have the effect of ‘over formalising’ or inappropriately replacing these current support networks.

The Tribunal considers that both the supporter and the representative models must include a mechanism to resolve disputes between appointees (where more than one may be possible), between appointees and other key people involved in the person’s care, and between appointees and the person themselves. The kinds of disputes that may develop are currently clearly exemplified in the Tribunal’s jurisdiction to review enduring guardianship and enduring power of attorney documents.

Conflict of interest and supporters/representatives

Throughout the Discussion Paper there are suggestions that paid carers, organisations and professional advocates could act as supporters or representatives under the model. The Tribunal’s experience in appointing guardians and financial managers, and reviewing appointments of enduring guardians and attorneys, is that these categories of appointees often face a conflict of interest and duty. There are provisions in the NSW Guardianship Act that prohibit the appointment of paid carers and other persons with a conflict of interest as substitute decision makers (see ss 6B(2), 17(1)(b), 25M(1)(a)). If such appointments were allowed under the model Commonwealth scheme, there would need to be appropriate supervision and support from an independent body; with powers to seek the removal of supporters and representatives if required (and the principal no longer had the ability to do so themselves).

Inclusion of National Decision-Making Principles in NSW

The Tribunal is of the view that the proposal of an externally appointed representative, who is unable to ascertain the views of the person and must make decisions according to human rights principles, is closely aligned with the current substitute decision making scheme in NSW. The Tribunal acknowledges that decision making principles that highlight ‘best interests’ considerations are due for reform in light of the UN Convention on the Rights of Persons with Disabilities. The need for reform was also identified in the NSW Standing Committee on Social Issues inquiry into ‘Substitute Decision Making for People Lacking Capacity’ in February 2010. However, a new decision making framework based on a rights based approach rather than best interests would need to be explicit in terms of the appropriate considerations to guide decision making. For example, it may be of benefit that any model Commonwealth legislation expressly provides the list of ‘human rights’ considerations, as found (in part) on page 70 at paragraph 3.76 of the Discussion Paper.

Interaction between State and Commonwealth Schemes

The Tribunal considers that some of the important issues to be addressed in the interaction between state and Commonwealth Schemes include:

- Whether state-based appointees should automatically be appointed under the Commonwealth scheme.
- If different persons are appointed, whether a Commonwealth appointee's authority would override the authority of a state-based appointee where the scope of their appointments may intersect (for example, would a decision by a representative under the NDIS affecting a person's accommodation override a decision by a state-based guardian in relation to accommodation?).
- The mechanism for resolution of disputes between Commonwealth appointees and state-based appointees. It is important to recognise that state-based appointments include both Tribunal/Court appointed and principal-appointed arrangements, such as enduring guardianship.
- The institution of double-duties upon appointees under both Schemes and whether this might make people reluctant to be appointed.
- The recognition of Commonwealth appointees in State-based legislation and vice versa.

The Tribunal does not propose solutions to each of these issues. However, the Tribunal's current experience of the operation of the National Disability Insurance Scheme (NDIS) provides a useful example of the current interaction between a Commonwealth Scheme and state-based legislation. The NDIS launch site in the Hunter region, including Newcastle, Maitland and Lake Macquarie, has been operating in NSW since July 2013. It is anticipated that about 10,000 Hunter region residents will be covered by the NDIS by 2016.³ This has presented the Tribunal with a unique perspective on the interaction between the NDIS and state-based decision making arrangements.

The Guardianship Division of the Tribunal has received over 85 applications for the appointment of a guardian for a person who is or will become a participant in the NDIS. Evidence received at a hearing in March 2014 was that the National Disability Insurance Agency (NDIA) had not yet appointed a nominee for any of the 1,731 participants in the scheme in NSW.⁴ The implication of this evidence is that where the participant is not able to self-manage their plan, the NDIA is managing the plan on the participant's behalf.

Applications to the Tribunal for a guardianship order have been made by family members or care providers raising concerns about the operation of the NDIS. Where the person has an active informal support network and strong advocate in a family member or friend, the Tribunal had, to date, dismissed the application. In [KTT \[2014\] NSWCATGD 6](#), the Tribunal commented that:

The Tribunal was cautious about pre-empting the NDIA processes by making a guardianship order so that Mrs LBU was all the more likely to be appointed nominee by the NDIA. [29]

³ NDIS, *Information for service providers in NSW*, undated.

Available at: <http://www.ndis.gov.au/document/375>

⁴ [KCG \[2014\] NSWCATGD 7, \[61\].](#)

By contrast, in [KCG \[2014\] NSWCATGD 7](#) the Tribunal determined to make a guardianship order for Miss KCG, appointing the Public Guardian, as she did not have a friend or family member involved in her care. The Tribunal commented:

The irony in reaching this conclusion is that a state based appointment is required for a person in Miss KCG's circumstances to ensure that her interests in relation to a Commonwealth scheme are protected, as it seems there is no Commonwealth equivalent of a Public Guardian, a Public Advocate or other independent body who could be appointed as a nominee on her behalf [69].

The practical reality as evidenced in this case is that where the NDIA is managing the plan on a participant's behalf, and the person has no capacity to provide a view and no family or friends to advocate on his or her behalf, the decisions being made by the NDIA are in the nature of substitute decisions with no independent monitoring or scrutiny.

These applications clearly demonstrate that a number of the tensions raised in the Discussion Paper concerning the model laws are already being experienced in relation to implementation of the NDIS. The Tribunal wishes to emphasise that the model laws should be careful not to blur the distinction between supported and substitute decision making, especially where that supported decision making is used to shield what is in reality a substitute decision. Whilst the concept of introducing a formal supported decision making regime in NSW has merit, the role that substitute decision makers play for people with disability who are unable to be supported to make their own decisions should continue to be expressly recognised.

Malcolm Schyvens
Deputy President
Division Head, Guardianship Division

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