



people with disability
ABN 98 879 981 198

People with Disability Australia Incorporated

Postal Address: PO Box 666
Strawberry Hills NSW 2012

Street Address: Tower 1, Level 10
1 Lawson Square
Redfern NSW 2016

Phone: 02 9370 3100

Toll Free: 1800 422 015

Fax: 02 9318 1372

TTY: 02 9318 2138

Toll Free TTY: 1800 422 016

NSW Law Reform Commission Review of the Guardianship Act 1987

People with Disability Australia (PWDA)

**Submission
March 2016**

Contact:

Ngila Bevan
Human Rights Advisor
People with Disability Australia
PO Box 666 Strawberry Hills NSW 2012
Tel: 02 9370 3100
Fax: 02 9318 1372
ngilab@pwd.org.au

About People with Disability Australia (PWDA)

Our vision is of a socially just, accessible and inclusive community, in which the human rights, citizenship, contribution and potential of people with disability are respected and celebrated.

1. PWDA is a leading disability rights, advocacy and representative organisation of and for all people with disability. We are a NSW and national, cross-disability peak representative organisation and member of the Australian Cross-Disability Alliance. We represent the interests of people with all kinds of disability. We are a non-profit, non-government organisation. PWDA's primary membership is made up of people with disability and organisations primarily constituted by people with disability. We have a vision of a socially just, accessible and inclusive community, in which the human rights, citizenship, contribution, potential and diversity of all people with disability are recognised, respected and celebrated.

Introduction

2. PWDA warmly welcomes the opportunity provided by the NSW Law Reform Commission to consider reform of the NSW Guardianship Act 1987. Indeed there has been considerable international and domestic developments in the conceptualisation of legal capacity over recent years which makes reform of the Act necessary. However, it will not be enough to merely tweak the existing legislation. The overall framework for the way legal capacity is addressed in NSW legislation must be reconsidered if we are to comply with our international legal obligations and create a system that works to meet the needs of people with disability in practice.
3. As this is only at the beginning of the consultation process we have confined our response to the most pressing questions in the terms of reference - this submission does not go into full detail about what a new model for legal capacity in NSW should look like. However, PWDA has made numerous submissions on this topic over many years and some of these are referenced throughout or listed at the end as additional information.

Creating a disability neutral model

4. In our 2014 submission to the Australian Law Reform Commission (ALRC) Inquiry into Equality, Capacity and Disability in Commonwealth Laws, we laid out our reasons against the formulation of an "ability test"¹. Similarly, a change of language to "decision making capacity" as proposed in this consultation still infers that the person themselves is being tested or is required to meet a specific standard in order to have their legal capacity recognised. This type of formulation does not realise equality before the law for people with disability, and would not go far enough in establishing and implementing the regimes of support necessary to adequately support people with disability to exercise their legal agency.
5. PWDA broadly agrees with the National Decision Making Principles as laid out by the ALRC in its Report (Recommendation 3-1). However, PWDA is concerned that the Support Guidelines (Recommendation 3-2) do not fully implement Article 12 of the CRPD. 2(c) states that, 'a person's decision making capacity must be considered in the context of available supports', to which we would agree, noting that this is the key element of the paradigm shift to supported decision in that it is the quality of supports available that enables a person to exercise their capacity. The rest of that Recommendation, however, goes on to discuss 'decision making ability' of the person without making it clear that the variable is the quality of supports not the matter in issue or consideration of dignity or risk. It is the availability of appropriate supports that 'fluctuates over time' and enables or disables a person from being able to participate in decision making, not the capacity of the person themselves that fluctuates. This clarification is essential to make as only when appropriate supports cannot be offered is the threshold for representative decision making met.

¹ See [PWDA Submission to Australian Law Reform Commission \(ALRC\): Equality, Capacity and Disability in Commonwealth Laws, Discussion Paper May 2014](#)

6. Ideally, NSW should develop a regime that recognises that all people have legal agency, but that some people require support to exercise it. When this premise is genuinely accepted, the question then shifts to how to create a mechanisms through which a person can express their will and preferences, and have those expressions of legal agency recognised as decisions before the law. What is required is a universally applicable mechanism of support provision which fulfils the requirements of any person who needs it in order to exercise their legal agency. Thus, the reform required is not solely of the Guardianship Act or in disability legislation and policy per se, but should focus on how NSW laws and policies should operate to recognise legal capacity in general, and enable the realisation of fundamental rights in a fair, accessible and non-discriminatory way.
7. Therefore, the legislative language used should be *disability neutral, albeit disability responsive*. This would acknowledge that all people have equal recognition before the law, all people utilise supported decision making to some degree, and that any person may experience impairment that means they require support to exercise their legal agency at some point in their life. This may be as a young adult with disability, during a period of chronic ill health, or towards the end of a person's life if they have developed dementia for example.
8. Any new legislation governing the exercise of legal capacity should be a mainstream instrument, outlining the principles and processes relevant to the entire spectrum of ways to exercise legal agency. These are:
 - Independent exercise of legal agency
 - Exercise of legal agency with support, including decision making support
 - Exercise of legal agency through an agent, such as power of attorney or advance directive
 - Representation
9. A person should be able to exercise their legal agency using one or a combination of these methods at any one time. There should be only one piece of legislation governing the whole spectrum of ways to exercise legal agency as opposed to the myriad that we currently have (Guardianship Act 1987, The NSW Trustee and Guardian Act 2009, The Power of Attorney Act 2003, The Mental Health Act 2007).

UN Convention on the Rights of Persons with Disabilities (CRPD)

10. The understanding of Article 12 of the CRPD which underlies this submission is that:
 - Every person has the right to equal recognition before the law. This includes the capacity to have rights and the capacity to act on those rights (to exercise legal agency) as well as to have those acts recognised by the law.
 - This is a non-derogable civil and political right requiring immediate implementation.²
 - Legal agency is exercised when will and preference is expressed.
 - Every person has the right to support to express their will and preference if required. For some people this may include decision making support.
 - The State is obliged to provide the support necessary for a person to express their will and preference. As equality before the law is a civil and political right there is no limit to the level of support that must be provided to achieve this.

² By virtue of Article 5 and 12 of the CRPD.

- Failure to provide adequate support, including the inadequate resourcing of support options, may constitute discrimination.
 - Where there is no formulation of support that can determine will and preferences then legal agency is not being exercised. In this circumstance a representative may be appointed to make decisions based on the previously expressed will and preference of the person and/or their human rights as applicable to the situation.
 - NSW must amend legislation to fulfil the obligations of Article 12 in its entirety.
11. To summarise, the onus is on the support to facilitate the expression of a person's will and preference and hence their legal agency. Any test of a person's ability to exercise their legal agency is actually *a test of whether the supports provided to the person are adequate and appropriate to the task in hand*. If not they should be altered until will and preference can be expressed, or it becomes apparent that this is not possible. The CRPD does not provide for a circumstance whereby a person is tested on their ability or impairment type.
12. There are three significant financial implications of this:
- a) there must be a greater investment in and availability of communication aids and equipment and supports such as Auslan interpreters for example;
 - b) awareness must be raised of the provisions of other legislation that provides for people with disability to participate on an equal basis as others using communication or decision making supports e.g. NSW Evidence Act 1995 and the Criminal Procedure Act 1986³; and
 - c) NSW must build upon the [Supported Decision Making \(SDM\) Pilot](#) and develop a supported decision making regime that recognises the role of informal and formal decision making support particularly for people with cognitive impairments or psychosocial disability.
13. Strengthening SDM in NSW will require resourcing of Disabled Person's Organisations (DPOs) to build the capacity of individuals with disabilities, families and supporters, and raising awareness within the community. At present it is unclear whether the Information Linkages and Capacity Building (ILC) stream of the NDIS will provide funds for some of this work. Nevertheless, supported decision making may be required for many other people in NSW who are not part of the NDIS such as those over the aged of 65 or those with a chronic illness requiring short term assistance.

The narrow scope for representative decision making

14. The ALRC report does not clearly separate the roles of Supporter and Representative yet the distinction is essential especially as it impacts upon the role of guardians or what may in the future be called Representatives. Recommendation 4-7 of the Report states that 'a Representative assists a person who requires support to make decisions or, where necessary, makes decisions on their behalf'. However this unnecessarily conflates the role of Supporter and Representative creating potential conflicts of interest and a grey area as to which decisions are supported and which were made by the Representative. In our view the role of Supporter and Representative are mutually exclusive roles. If a Representative has been appointed then by definition it is not possible to support the person to participate in decision making any longer, the representative is working based on previously raised will and preferences and balancing of rights.
15. Any future Representative authority must invest heavily in training and public awareness initiatives to adequately address the magnitude of the shift from 'best interest' substitute decision making by guardians to representative decisions based on a balancing of human

³ See [PWDA and NACLC submission to Australian Law Reform Commission \(ALRC\): Equality, Capacity and Disability in Commonwealth Laws, Discussion Paper May 2014 re Access to Justice for more information.](#)

rights. This latter task requires an expertise and understanding of human rights that people who are currently eligible to be guardians do not necessarily have, it is a different role.

16. Moreover, any future NSW SDM authority should also be responsible for the guidance and training of potential informal and formal support people, providing information about support options for the general public, public services and mainstream services, awareness raising about the regime, capacity building of disability support organisations, and training of government agencies in the facilitation of supported decision making. This would also assist in consolidating the move away from the medical approach to legal capacity and towards the social model of supporting the exercise of legal capacity.
17. Application of a CRPD compliant legal capacity framework will require new thinking in a variety of areas currently dealt with through the Guardianship Act. In general though the process is simple and applicable across issue areas: is the person being adequately supported (where required) to participate in decision making about the issue at hand? If yes process continues with support and safeguards. If no, question whether all support options have been exhausted? If yes then person cannot be supported to participate in the decision making and a Representative is appointed. Due to the fluctuating availability and quality of supports the appointment of this Representative must stay under review.
18. This framework should apply to issues currently dealt with under Guardianship legislation in NSW such as consent to dental or medical treatment (including sterilisation for therapeutic purposes⁴), participation in clinical trials, and regular review of financial management orders. As regards the NDIS and other Commonwealth legislation PWDA advocates for the adoption of a national system of support for the exercise of legal capacity so that all people are supported to exercise legal capacity. The presumption of capacity is written in to the NDIS legislation and support packages should include decision making support for those who need it. Our position is that the provisions in the NDIS Act providing for the NDIA CEO to appoint substitute decision makers outside State and Territory guardianship processes should be repealed. If an NDIS participant cannot be supported by the Scheme to participate in decisions about their lives they should go through existing, or reformed, NSW SDM, guardianship or Representative decision making authorities.
19. As regards restrictive practices a Supporter would be required to assist a person to participate effectively in processes to address “behaviours of concern”⁵ and a Representative would be required to make a decision balancing the rights, will and preferences of the person; in both cases noting that in general the law does not provide for people (with or without disability) to consent to practices which may cause them physical or psychological harm or deprive them of liberty. Representatives would likely be lacking in the skills and knowledge required to make a decision about a restrictive practice based on a balancing of human rights as well as previously expressed will and preference. Therefore, it would be essential that they were assisted in this exercise by an independent and suitable person, such as the role of Senior Practitioner as formulated in Queensland and Victoria.
20. However, our position is that restrictive practices may constitute torture and ill-treatment which are prohibited in international law and that are frequently justified through the operation of regimes that fail to recognise and engage with the legal capacity of people with disability. The new model for recognising legal capacity must be a mechanism to challenge

⁴ For more information on our position relating to sterilisation see [PWDA Submission to the Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia](#).

⁵ For a detailed account of our position relating to the interrelationship between legal capacity and restrictive practices see [PWDA's joint submission to the ALRC Inquiry with the University of Sydney](#).

the use of restrictive practices and move towards their elimination throughout the community not solely in the disability service sector.

21. Similarly, this new model of conceptualising and recognising legal capacity must apply equally to people with psychosocial disability, including those who may at present fall under the Mental Health Act (2007). The same concept of informal and formal Support for decision making, testing the adequacy of support as opposed to testing the ability of the person, appointing Representatives and providing safeguards including regular review of the adequacy of support available must apply. The CRPD does not differentiate between psychosocial disability and other kinds of impairment and models to support the exercise of legal capacity must be inclusive of all people with disability without discrimination.

We thank the NSW Law Reform Commission for the opportunity to contribute to this Inquiry, and we would welcome invitations to participate in further consultation on any of the matters raised in this submission.

Additional materials include:

- [Accommodating Human Rights](#), PWDA 2003
- [Rights Denied](#), PWDA 2010
- [Everyone, Everywhere](#), PWDA 2009