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NSW Law Reform Commission Review of the Guardianship Act 1987 Question Paper 1: Preconditions for Alternative Decision Making Arrangements

People with Disability Australia (PWDA)

Submission
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[redacted]

About People with Disability Australia (PWDA)

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 Disabled Peoples Organisations Australia (DPO Australia) 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 with pride.

Introduction

2. PWDA welcomes the opportunity to contribute to the NSW Law Reform Commission Review of the Guardianship Act 1987. This submission to Question Paper 1 should be read in the context of our preliminary submission[1] to this process, which outlines the need for fundamental reform, rather than a tweaking of the existing legislation. In our submission to this question paper we respond from that premise.

3. We reiterate our concern that this process is being undertaken within the context of the current framework for the way that legal capacity is addressed in NSW. Rather, we see the need for substantial legislative and institutional reform of all arrangements relating to legal capacity in NSW, to ensure it conforms to human rights standards and is consistent with international best practice.

4. This review process is being undertaken during a period when significant, and much needed, shifts are occurring in both Australian and international law and practice, to progress the implementation of Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD)[2].

5. In practice, supported decision making models are already being used by many people with disability. This practice is increasingly being used to either replace or delay the appointment of substitute decision makers. This is a welcome development, made possible by the growing recognition, in theory and practice, that with the right resources and supports people with disability can, and should, direct their own lives.

6. However, the issue remains that Commonwealth and State legislation remains focused on the concept that the exercise of capacity should be limited or denied for people with

[1] PWDA's preliminary submission (March 2016) to the NSW Law Reform Commission can be accessed here http://www.pwd.org.au/pwda-

[2] United Nations Convention on the Rights of Persons with Disabilities, Article 12, Equal Recognition before the Law http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx#12. This submission is based on the interpretation of Article 12 outlined in the submission made by PWDA, the Australian Centre for disability Law and the Australian Human Rights Centre, to the Australian Law Reform Commission (ALRC): Equality, Capacity and Disability in Commonwealth Laws, Discussion Paper May 2014 found here http://www.pwd.org.au/pwda-publications/submissions.html

disability in particular circumstances, as opposed to supported and encouraged. We trust that the intention of this review is to develop a robust system to support the latter.

7. Moreover, the introduction of the National Disability Insurance Scheme (NDIS) is providing people with disability, many for the first time, access to the quality supports they require to take control over decisions that affect their lives. With adequate supports in place, including decision making supports (as permissible and encouraged within NDIS plans), many people who are currently under guardianship orders, having people making decisions for them, are instead building their skills to independently exercise their own legal agency. This is a development that must be celebrated, and this review process is an opportunity to consolidate these progressive developments into NSW law and policy.

8. These changes will undoubtedly take time, and be an incremental process. We therefore recommend that this review be repeated within a maximum period of 5 years, to ensure that NSW law is informed by domestic and international experience in this area and is developing in a way that reflects best practice.

3. The concept of "capacity"

Question 3.1: Elaboration of decision-making capacity

Should the Guardianship Act provide further detail to explain what is involved in having, or not having, decision making capacity?

9. *Decision-making capacity* should never be a term used to describe an individual. The Guardianship Act must recognise, as an essential starting point, that all people have decision making capacity. That is, all people, equally, have rights, have the capacity to act on those rights (legal agency), as well as to have those acts recognised by law.

   If the Guardianship Act were to provide further detail to explain what is involved in having, or not having, decision making capacity, how should this be done?

10. All people make decisions of different levels of complexity, at different times in their lives. All people utilise support to make those decisions to some degree, and any person may experience impairment that means they require different, or additional support to determine and express their will and preference at some point in their life (thereby exercising their legal agency).

11. When this is the starting point, the framework shifts from the assessment of an individual's 'decision-making capacity', to a focus on the quality and appropriateness of the supports that an individual is provided with. If the right support is in place, then a person should be able to express their will and preference. Any measure of capacity is therefore that of the supports, not of the individual.

12. The NSW Capacity Toolkit goes some way to addressing this. However, the reference in the Toolkit to assessing a person's 'decision making ability' should be strengthened, making it explicit that this refers to an assessment of the supports available to the person to make a decision. It is the quality and appropriateness of the support that enables decision making ability and the provision of this support is pivotal to the passing of the ''test''. For example, a deaf person may not pass the test if they didn't have the support of an Auslan interpreter, a

person with autism may not pass the test if it was conducted in a chaotic environment, a person with intellectual disability may not pass the test without a support person to explain the information. The form of impairment or type of disability is immaterial to the assessment of capacity; the support provided is the key.

13. Currently, guardianship arrangements are put in place when a person is deemed to have 'lost' decision making capacity. Our view is that the Tribunal has a role to play in appointing Representative decision makers (similar to the recommendations made in the Australian Law Reform Commission (ALRC) report 'Equality, Capacity and Disability in Commonwealth Laws'[3]), but that this should be a last resort. There is a role, as yet unfilled, for an independent body to assess and make orders regarding the appointment of supports, which would enable a person to exercise their capacity. The provision of these supports, including decision making support, would endeavour to avoid the need for an individual to progress to the Tribunal and therefore avoid the need for the appointment of a Representative decision maker. The logic being that when a person is appropriately supported they do not 'lose' their capacity, this loss only occurs when supports are unavailable or denied, and it is the result of a disabling environment, as opposed to a disabled person.

14. Acceptance of this paradigm shift would also require removal of section 3(1) of the Guardianship Act, which says that a guardian may be appointed for a person with disability where they are ''totally or partially incapable of managing his or her person''. A Representative decision maker should only be appointed if it is not possible for an individual to be supported to make his or her own decisions.[4] If the Tribunal were presented with a person whom in their view presented as ''totally or partially incapable'' then the first questions should be, ''what supports are being provided? Who by? Are these meeting the individual's needs? How do we know? Can these be altered to support the person to exercise capacity? Let's try x, y or z first." This assessment of support should be a formal step put in place before an order is considered.

15. Consideration of these kinds of questions could be inserted into the Guardianship Act through an amendment of section 4, which lists the matters the Tribunal must have regard to. In practice it may be that the Tribunal already factors questions such as these into their deliberations, as there is certainly overlap with existing provisions. However, it must be made explicit in order to elevate the significance of the right of a person to receive support to make decisions and participate in the community.

16. If a person were an NDIS participant, then these questions would flag the need for a review of their supports, as they may be inadequate. This review process is not the function of the Tribunal, but it may be useful if an order could be made to ensure that this review occurred. Similarly, if a person were over 65 this would be a flag to consult with aged care services. Either way, the path towards representative decision making, or guardianship, should not be automatic.

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[3] Australian Law Reform Commission (ALRC) *Equality, Capacity and Disability in Commonwealth Laws* (ALRC Report 124), published 24 November 2014 https://www.alrc.gov.au/publications/equality-capacity-disability-report-124

[4] This position was further elaborated on in PWDA submission to the ALRC inquiry found here http://www.pwd.org.au/pwda-publications/submissions.html

17. Ideally, there would be a body in place to ensure that these questions are being asked before a person appeared before a Guardianship Tribunal, and this is a gap that needs to be filled. This body could be formally related to or part of the Guardianship Tribunal, or alternatively could be a function fulfilled by an external third party (see also section 3.9). What is clear is that the fact a person is presenting before the Tribunal may point to deficiencies in care and support programs elsewhere.

18. It should never be the role of the Tribunal to limit a person's rights and appoint Representative or substitute decision makers due to failures in service provision. On the contrary, it can be the role of the Tribunal to raise awareness of systemic failures and initiate processes to correct failures of service provision so that a person does not have their freedoms curtailed.

19. Support for decision making lies within the community and the supports, attitudes and behaviours that a person with disability experiences as they go through their life. The function of the Guardianship Tribunal should be to address the situations that occur when these supports are no longer adequate or have broken down, leaving a person vulnerable to decisions being made on their behalf without their consent.

Question 3.2: Disability and decision-making capacity

How, if at all, should a person's disability be linked to the question of his or her decision making capacity?

20. Principle 1, of the National Decision Making Principles proposed by the ALRC report states that '*all adults have an equal right to make decisions that affect their lives, and to have those decisions respected*'[5].

21. In line with recommendation 3-2 (2) (a) '*A person must not be assumed to lack decision-making ability on the basis of having a disability',* NSW legislation and policy should be disability neutral, albeit disability responsive. This should assume 'universal' legal capacity in accordance with Article 12 of the CRPD[6], promoting personal autonomy, authority and control for all people over their lives.

22. Contrary to Section 3(1) of the Guardianship Act there is no causal link between a person's impairment, disability or medical diagnosis and their legal capacity or decision making ability. All references to such a link must be removed. For example, a diagnosis of dementia must not automatically lead to an application for a representative decision maker or guardian, nor should the acquirement of a brain injury automatically lead to a decision making capacity assessment. In both these cases emphasis should remain on what supports can be put in place to ensure that the person is able to participate fully in all aspects of their lives without restrictions, including making their own decisions.

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[5] Australian Law Reform Commission (ALRC) *Equality, Capacity and Disability in Commonwealth Laws* (ALRC Report 124), published 24 November 2014 https://www.alrc.gov.au/publications/equality-capacity-disability-report-124, proposed National Decision Making Principles, Recommendation 3.1, P. 11

[6] For interpretation of Article 12, see P. 4 of the submission made by PWDA, the Australian Centre for disability Law and the Australian Human Rights Centre, to the Australian Law Reform Commission (ALRC): Equality, Capacity and Disability in Commonwealth Laws, Discussion Paper May 2014 found here http://www.pwd.org.au/pwda-publications/submissions.html

Question 3.3: Defining disability

If a link between disability and incapacity were to be retained, what terminology should be used when describing any disability and how should it be defined?

23. As above, no terminology should be retained that links disability to decision making capacity. Incapacity is only relevant in terms of the quality and appropriateness of the support provided to a person i.e. the regime of support available to an individual may be limited in capacity, not the individual.

24. An individual may not be able to adequately express their will and preference because of limitations in the available support, not because of disability. We strongly oppose the retention of a link between disability and incapacity. This would be contrary to the UN CRPD, the National Disability Strategy and the NSW Disability Inclusion Act.

Question 3.4: Acknowledging variations in capacity

Should the law acknowledge that decision making capacity can vary over time and depend on the subject matter of the decision?

How should such acknowledgements be made?

25. A person's ability to determine, and express, their will and preferences **will** vary over time, and **will** depend on the subject matters of that decision. Decisions vary in complexity and importance, and to some degree we will all require support to make certain decisions over our lifetime. This is no different for a person with disability.

26. It is critical that NSW legislation acknowledge this, and recognise that this variance comes not purely from an individuals' state of health or cognition but also from:

- The support that is available to an individual at a given time, and for a particular decision;
- The quality and appropriateness of that support to enable the individual to express their will and preference, and whether support of the same of similar type has been used before; and
- The complexity of the particular decision and whether decisions of a similar type or consequence have been made before.

27. By recognising this variance, legislation then acknowledges that people can change their decision over time, if the level and quality of support they are provided with changes. In fact, a person is likely to become more confident to make decisions of different types over time, not less.

28. The presumption that people with disability will have deteriorating ability to participate in decision making must be reversed. Like other abilities, decision making is a skill which a person can lose if underused, or develop with practice. For many people with disability, especially those who have been used to a lack of choice and control in their lives, the fact that supported decision making options are more readily available provides an opportunity to expand their lives to previously unimagined levels of independence. Legislation must be

drafted in a way that reflects support for decision making as both positive and ordinary, a tool like any other to assist a person to navigate their lives.

If the definition of decision-making capacity were to include such an acknowledgement, how should it be expressed?

If capacity assessment principles were to include such an acknowledgment, how should it be expressed?

29. As we have outlined, 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. Capacity assessment principles therefore, would only be relevant so far as to assess the integrity of support provided to a person, not the person themselves.

Question 3.5: Should the definitions of decision-making capacity be consistent?

Should the definitions of decision-making capacity within NSW law be aligned for the different alternative decision-making arrangements?

30. 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).

If the definitions of decision-making capacity were to be aligned, how could this be achieved?

31. All NSW laws and practices should align under a coherent framework, which guides principles and processes relevant to the entire spectrum of the 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, enduring guardian or advance directive
- Representation

32. Legislation must recognise that a person may exercise their legal agency using a combination of these methods at any one time.

Question 3.6: Statutory presumption of capacity

Should there be a statutory presumption of capacity?

33. A statutory presumption of capacity is not required. Legislation should be disability neutral and thus inherently recognise equality of all before the law. Amendments should only be made to remove references to mental capacity, legal capacity, unsound mind, ability, competence or any other discretionary exclusions based on actual or perceived disability.

Question 3.7: What should not lead to a finding that a person lacks capacity

Should capacity assessment principles state what should not lead to a conclusion that a person lacks capacity?

If capacity assessment principles were to include such statements, how should they be expressed?

34. No, a person should not be found to lack capacity. Rather, a conclusion could be made that it is not possible to support a person to exercise their capacity at the current time.

35. An individual should be provided with the support that they require to make a decision themselves. This would be inclusive of any person with an impairment who requires information in alternative formats; people who need augmentative communication devices to communicate their decision, people who need accessible environments in order to participate in decisions about their life, and people with cognitive impairment who may require supported decision-making.

36. Holistic supports should be put in place until an individual can express their will and preference, and an ongoing pursuit of quality and adequate support should be undertaken.

37. Decision making principles would therefore never find a person lacks capacity, but rather would find that having exhausted all possible support options, it is not currently possible to obtain an expression of will and preference from the person on a particular matter or matters.

38. It should be implicit that Tribunal members do not base their decisions based on references to behaviours, appearances and beliefs as referred to on page 26 of Question Paper 1 for this review,[7] as this would amount to discrimination. These characterises should have no bearing on the operation of the legislation and if they must be addressed then this should be done within guidance notes for Tribunal members. The only relevant consideration is that a lack of capacity cannot be established merely by reference to disability – all other characteristics are prejudicial inferences often based on an intersection with negative stereotypes pertaining to people with disability.

Question 3.8: The relevance of support and assistance to assessing capacity

Should the availability of appropriate support and assistance be relevant to assessing capacity?

If the availability of such support and assistance were to be relevant, how should this be reflected in the law?

39. As expressed throughout this submission, the entire onus of this reform should be based on a fundamental recognition of the pivotal role that supports play in the exercise of legal agency. Any test of a person's ability to exercise 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

[7] **NSW Law Reform Commission Review of the Guardianship Act 1987, Question Paper 1: Preconditions for alternative decision-making arrangements, P. 26** http://www.lawreform.justice.nsw.gov.au/Pages/lrc/lrc_current_projects/Guardianship/Have-your-say-conditions-for-alternative-decision-making-arrangements-.aspx

apparent that this is not possible. The CRPD does not provide for a circumstance whereby a person is tested for qualification of a right based on their ability or impairment type.

Question 3.9: Professional assistance in assessing capacity

Should special provision be made in NSW law for professional assistance to be available for those who must assess a person's decision-making capacity?

How should such a provision be framed?

40. As we have outlined in section 3.1, we believe that there is an immediate need for the establishment of a body to uniformly assess the adequacy of supports being provided to an individual, or to initiate such assessments through existing structures such as the NDIA and aged care systems.

41. This body would remove the authority of doctors, courts, tribunals or other agencies to make decisions about whether a person is or is not able to exercise legal agency. In part, this is because an assessment of the quality of support arrangements a person has is far beyond the scope of the training and experience of these professionals. They simply are not in a position which would qualify them to be making these judgements.

42. The consideration of whether a person's supports are or are not adequate is between the person, their support or supporter, and this new body. Third parties may wish to raise concerns as to the adequacy of support, or provide information as to the legal context in which support may be required, but they do not have the expertise to be making decisions about support arrangements.

43. This new structure is required to implement a universal approach and to adequately address the magnitude of the shift from 'best interest' substitute decision making by guardians to supported decision making and representative decisions based on a balancing of human rights.

44. As referred to earlier in paragraph 17, it may be that the Guardianship Tribunal has a stake in the operation of this body (especially as better support arrangements should over time mean less work for the Tribunal) or a close relationship with it. Alternatively, and preferably, NSW could legislate for an independent body or government agency. Either way this body should also be responsible for 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.

4. Other preconditions that must be satisfied

Question 4.1: The need for an order

Should there be a precondition before an order is made that the Tribunal be satisfied that the person is "in need" of an order?

If such a precondition were required, how should it be expressed?

45. Yes, the precondition is that the Tribunal has found that support options have been exhausted and there is no regime of supports currently available to support the decision making capacity of the individual. The Tribunal would receive advice in this regard from the independent body we propose in question 3.9. Therefore, a Representative decision maker should be appointed subject to ongoing reviews of decision making support regimes. This is not just a precondition, but should in fact be the only reason for the making of an order of appointment of a Representative.

46. Given that any decision to appoint a Representative decision maker would be dependent on the adequacy of available support at that particular time, any representative decision making process should be least restrictive of the person's human rights, be subject to appeal, and ongoing, regular monitoring and review. This review would include an active, and ongoing assessment of alterative or additional support that could be made available to the person.

Question 4.2: A best interests precondition

Should there be a precondition before an order is made that the Tribunal be satisfied that the order is in the person's "best interests"?

If such a precondition were required, how should it be expressed?

What other precondition could be adopted in place of the "best interests" standard?

47. The best interest of a person is to make a decision themselves as is their right, and the legislation should be built upon this premise.

48. So no, all reference to decision making based on a substitute decision makers view of best interest should be removed from the legislation. Representative decision makers (as outlined in previous PWDA submissions and supported by the ALRC inquiry report) would be authorised to give effect to what the person would likely want, based on all information available, including consulting with the persons formal, and informal supporters.

49. If it is not possible to determine what the person would likely want, then a decision should be made based on promotion and safeguarding of the person's human rights, and be least restrictive of those rights.

Question 4.3: Should the preconditions be more closely aligned?

Should the preconditions for different alternative decision-making orders or appointments in NSW be more closely aligned?

If so, in relation to what orders or appointments and in what way?

50. An overarching framework is required, which acts as a mainstream instrument outlining principles and process relevant to the entire spectrum of ways to exercise legal agency, and therefore the different ways that a person may utilise, or be provided with support.

5. Other factors that should be taken into account

Question 5.1: What factors should be taken into account?

What considerations should the Tribunal take into account when making a decision in relation to:

(a) a guardianship order
(b) a financial management order?
(c) should they be the same for all orders?

Are there any other issues you want to raise about the factors to be taken into account when making an order?

51. As outlined throughout this submission the considerations taken into account by the Tribunal should focus on whether the persons has been provided with the support they require in order to make their own decisions about their lives. Application of a CRPD compliant legal capacity framework will requires new thinking in a variety of areas currently dealt with through guardianship orders and financial management orders.

52. However, in general 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 the process regarding the issue continues with support and safeguards. If no, questions should be raised as to whether all support options have been exhausted. Orders should be made to further pursue alternative support options (as suggested, these stages could be administered by a different body or different function of the Tribunal before a formal guardianship hearing is reached). If yes, all support options have been exhausted, then the person cannot be supported to participate in the decision-making at that time and a Representative can be appointed. Due to the fluctuating availability and quality of supports the appointment of this Representative must stay under close review.

We thank the NSW Law Reform Commission for the opportunity to contribute to this review process, and will elaborate further on some of the aspects raised in this paper when responding to forthcoming question papers. We welcome the opportunity to participate in further consultation on the matters raised in this submission.