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NSW Law Reform Commission Review of the Guardianship Act 1987 Question Paper 2: Decision Making Models

People with Disability Australia (PWDA)

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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). 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, belonging, 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 provides further context to PWDA's overarching position outlined in both our preliminary submission, and response to Question Paper 1¹.
3. We reiterate that, given the major disability reforms currently underway in Australia, there is an opportunity for the NSW Law Reform Commission to lead the way in legislative and institutional change, which conforms to the human rights standards embodied within the UN Convention on the Rights of Persons with Disabilities (CRPD) and is consistent with international best practice.
4. As outlined in our previous submissions, we believe that this inquiry must not just tinker at the edges of the current system, but instead entirely reframe the concept of capacity in terms of decision making within the legislative and policy environment.
5. All people have decision-making capacity; in that all people have rights equally, have the capacity to act on those rights (legal agency), and to have those acts (and decisions that lead to those acts) recognised and respected in law.
6. If this is the starting point in legislation, then subsequent policy and practice would shift to the pursuit of all avenues of support to enable and encourage a person to exercise their legal agency, rather than limiting or denying this right based on an assumption or judgement that they lack or have limited capacity based on disability.
7. We have outlined in our previous submissions, that an overarching framework is required that encompasses the principles and processes for the entire spectrum of ways to exercise legal agency, and recognises this spectrum in law. Within that framework formal and informal support will take different forms, depending on the method a person is using at that time in order to exercise legal agency e.g. communication support, or the type of decision being made e.g. routine or life changing. One of these formal and informal supports will be supported decision making.
8. This new framework requires a restructure of current policy and practice, to establish a holistic and comprehensive assessment of the adequacy of support a person is being provided with, before the initiation of any formal process to provide, recommend or appoint

¹ See our responses here <http://www.pwd.org.au/pwda-publications/submissions.html>

a supported decision maker, or in some cases a representative decision maker. As we outlined in our response to Question paper 1, we believe an independent body should be established to take on this advice and information, quality assessment of supports, and referral role in terms of identifying and meeting support needs.

9. Being mindful of current resources, time, and the need for this to be an ever evolving process (particularly as international best practice further emerges), we propose an incremental model which looks at the potential suitability of different entities to take this role. This may include community and non-government agencies, with specific skills and expertise in the assessment of adequacy of support. This independent body would then make recommendations to the tribunal if individuals support arrangements required legal recognition.
10. This independent body could either be a formally associated arm of the tribunal, or administered externally. Ultimately the goal would be to shrink the formal Guardianship regime, and move towards a structure of supported decision making recognised in law that pursues all alternatives and reduced the instances whereby representative decisions makers are appointed.
11. The first priority for reform therefore, should be the recognition in law that all individuals have decision-making capacity. This will require a reframing of the Principles of the Act, to align with a CPRD compliant legal capacity framework.
12. Next, there needs to be recognition in law that all people have the right to support to exercise their legal capacity on an equal basis.
13. Supported decision making is one a number of different forms of support an individual may access. We have responded to this discussion paper with the structure outlined about as a starting point.

Question 5.1: Formal supported decision-making

- **Should NSW have a formal supported decision-making model?**
 - **If there were to be a formal supported decision-making model, how can we ensure there was an appropriate balance between formal and informal arrangement?**
 - **If there were not to be a formal supported decision-making model, are there any ways we could better recognise or promote informal supported decision-making arrangements in NSW law?**
14. Supported decision-making should be formally recognised in legislation, including anti-discrimination legislation, as an essential form of support that a person has the right to access in order to exercise their legal agency. The right to a supported decision maker should be conceptualised in the same way as the right to large print for a person with vision impairment for instance, or other forms of support such as communication devices and easy English materials.
 15. Formal legal recognition of supported decision-making would legitimise and normalise this form of support in the community, and across the full spectrum of decisions to be made, and situations in which they are made. Where an individual has in the past had their decisions undermined or refused because of institutional concerns around risk or liability (such as by a financial institution, or health care professional), the role of supported decision makers may help to ensure that the individual's decision is respected in these

circumstances, However, the appointment of a supported decision maker must not be overly prescriptive in that it undermines the rights of the individual. It must not lead to an assumption that a supporter need be appointed for a decision to be legitimate.

16. All people use informal decision-making supports to make decisions in their lives. For example, we seek advice and guidance from friends and families regarding our finances and health care choices. This is an important function that should not be overly formalised. Unfortunately, many people with disability lack the networks that provide this informal support, and other more formal arrangements may be needed. In more and more cases decision making support is being provided through support workers, disability advocates or others such as community volunteers. Although made by agreement, these processes remain relatively informal as often the arrangements sit outside specific legislation.
17. When it is identified that a person may require more formalised support with decision-making, this support should be provided. PWDA advocates for a centralised independent body (as described above) to provide; advice, information, referrals, capacity building, training, adequacy of existing support assessments, and access to a database of decision making supporters for people who require them. This body may require legislation for its establishment or could be an arm of a reformulated guardianship tribunal.
18. As models of supported decision-making are evolving, and best practice is identified, legislation must not be restrictive in terms of the means and modes of supported decision-making. Legislation should, however, provide parameters around the role of decision-making supporters, and safeguards to prevent undue influence and abuse including a conflict resolution mechanism.
19. An individual may utilise both formal and informal arrangements at the same time, depending on the decision, situation, or availability of support. However, legislation must ensure that the person with disability agrees to the support arrangement whether it be formal or informal in advance.

Question 5.2: Key features of a formal supported decision-making model

- **Should NSW have formal supporters**
 - **if so, should NSW permit personal or tribunal appointments, or both?**
 - **Should NSW have formal co-decision-makers?**
 - **If so, should NSW permit personal or tribunal appointments, or both?**
 - **What arrangements should be made for the registration of appointments?**
20. NSW should provide the opportunity for people with disability to appoint formal decision-making supporters of their own volition. These supporters should be of people with disability's own choosing, whom they believe they can build a trusting relationship with over time.
 21. Similarly, NSW should provide for a person with disability to be appointed with a decision making supporter when an unmet support need is formally identified by what we call "the independent body" described above. In this case there must be a processes in place for the person with disability to consent to the appointment and choose the most suitable person available in order to maximise the productivity of the relationship. Due to the trusting relationship that must be built between the person with disability and supporter, it is

unlikely that a system that merely appointed any available supporter to a person with disability would function well in the majority of cases.

22. We agree that all options for supported decision making should be investigated before any representative decision making arrangement are considered, and we acknowledge that co-decision making models are in place in Canada as a step to avoid substitute decision making. However, we strongly urge the Commission to review the effectiveness of these co-decision making models in terms of their role in a CRPD legal capacity framework. If a person can be supported to 'co-make a decision' (i.e. they are fully informed, understand the decision to be made and can determine their own will and preference), then we question the requirement for a co-decision maker. This person is surely being supported to make the decision themselves.
23. We are concerned that co-decision making arrangements may be put in place for the benefit of third parties (financial institutions/health care providers as mentioned above), who, rather than recognising a decision made by an individual themselves who has been informally or formally supported, require an additional authorisation from a third party who is deemed to have more 'capacity'. This has the potential to undermine the rights of the individual, and the very purpose of supporting decision-making.
24. For any form of formal supported decision-making arrangement, the independent body we propose would devise parameters around the appointment to ensure that it meets the specific needs of the individual and is neither onerous nor overly flexible. The body would also ensure that the individual has agreed to this arrangement being put in place, and that they are aware that they can revoke this arrangement at any time they choose.
25. A review mechanism should also be in place, which would ensure that the arrangement was meeting the expectations of the person with disability in terms of quality and quantity of support. It could also act as a trigger mechanism for more formal capacity building of either or both parties.
26. On a practical level we do not necessarily view registration of support arrangements to be workable. This would be overly restrictive if the purpose was to provide legitimacy for the decisions being made, and we do not require this for the provision of other types of support that influence decision-making. There may often be situations in which a person utilises the support of a formal supporter, an informal supporter or an ad hoc supporter interchangeably depending on who is available at the time – the important part is that their support need was adequately met by someone. To make a comparison with other kinds of disability support, a Deaf person may require an Auslan interpreter but they are not required to have only one, they use whoever is available to meet their needs in the situation whether it be at work, at school or at hospital etc. The decisions they make are not judged based on a formal agreement between the Deaf person and the interpreter.
27. What may be required is registration of people who work as formal decision making supporters to ensure that they have the skills, qualifications and values required to be effective in that role and should not be disqualified for any reason. Again, this would be a matter for the proposed independent body.

Question 5.3: Retaining substitute decision-making as an option

28. Substitute decision-making should not be retained in the reformulated Guardianship Act. Representative decision makers (as outlined in previous PWDA submissions and supported

by the ALRC inquiry report) play a role in giving effect to what a person with disability would likely want, based on all information available, including consulting with the persons formal, and informal supporters and a balancing exercise of their human rights in the given situation.

29. Representative decision-making must be a last resort, and only pursued when all other support options have been exhausted. Wording to the effect of the Mental Capacity Act 2005 (UK) s.1(3) would be preferred: a person is not to be treated as unable to make a decisions unless all practical steps to do so have been taken without success.”

Other issues

30. In formal and informal supported decision-making arrangements, there is the potential for exploitation. The system cannot always rely on people to make complaints or raise concerns themselves, as they may not identify that the relationship is becoming inappropriate.

31. The independent body we propose could have a role to provide education, information and capacity building to people with disability seeking decision making support around avoiding, recognizing and reporting potential exploitation. The NDIS Quality and Safeguarding Framework is making initial steps in this regard. The body could also have a role of monitoring supported decision making arrangements where there are reasonable grounds for concern.

Supporters and co-decision-makers

Question 6.1: When supporters and co-decision-makers can be appointed

- **What requirements should be met before a person needing support can appoint a supporter or co-decision-maker?**

32. All people have the right to access support to make decision, and we caution against specifying overly restrictive requirements around the appointment of supporters, as this has the potential to over formalise the process.

33. Pre-requisites for personal formal appointments should be that a person enters the arrangement freely, without influence, and that they are aware they can revoke that arrangement at any time.

- **What requirements should be met before a court or tribunal can appoint a supporter or co-decision-maker?**

34. As outlined above, pre-requisites should be that an un-met need has been identified, the person with disability consents to the arrangements, and that the person with disability consents to the specific person being appointed, having had the opportunity to meet and assess the potential of the relationship.

35. All parties must agree to enter into the arrangement freely, and the appointment should be subject to review. The individual in need of support should be able to revoke the arrangement at any point.

Question 6.2: Eligibility criteria for supporters and co-decision-makers

- **What, if any, eligibility criteria should potential supporters and co-decision-makers be required to meet?**

36. Personally appointed supporters should not have overly prescriptive eligibility criteria. The individual has selected them themselves, and specific criteria may undermine this choice. The person must have a commitment to the social model of disability and a clear understanding of Article 12 of the CRPD including the rights, will and preference standards.
37. However, the essential elements of a supporter would include knowing the individual well or having the capacity to develop a trusting relationship over time, and being able to communicate information relating to a decision in a way that the person can understand.
38. Formal supporters appointed by the tribunal on recommendation from the independent body, should have specific eligibility criteria, which includes having specific skills in reflective practices.
39. There must be a commitment on behalf of supporters to commit to the relationship over the long term, as effective supported decision making depends on a deep understanding of an individual, and how they best wish to receive information about a decision to be made, and communicate their will and preference.

Question 6.3: Characteristics that should exclude potential appointees

- **What, if any, characteristics should exclude particular people from being supporters or co-decision-makers?**

40. It is difficult to come to firm decisions regarding exclusion criteria as decision-making support is a personal relationship and a criminal record, for example, may not preclude a person from being an excellent support person. However, we would advise that criminal checks should be undertaken and considered. We would not support appointment of a person with a conflict of interest such as an existing disability support provider, or a person who has had a supporter relationship revoked because of concerns by either a court or tribunal. We refer the Commission to the NDIS Quality and Safeguards Framework, specifically the risk-based worker screening tool for developing guidance in this area.

Question 6.4: Number of supporters and co-decision-makers

- **What limits, if any, should there be on the number of supporters or co-decision-makers that can be appointed?**

41. An individual may access informal support from different people depending on the type of decision being made and the level of support that they need at that particular time to make that decision. Therefore it is important to reiterate that the role of a supporter is decision dependent, not ongoing, and can change depending on circumstances.

42. However, we do believe that in a formal capacity, the number of supporters should be limited, given that the quality of the relationship between the individual and their supporter is key to ensuring the most effective decision making support.

Question 6.5: Public agencies as supporters or co-decision-makers

43. We do not believe that public agencies should have a formal role to play in supported decision-making.

44. However, a register of community supporters could be established to provide people with the option of engaging a registered formal supporter with specific training and skills in supported decision-making.

Question 6.6: Paid workers and organisations as supporters and co-decision-makers

45. Having paid workers and organisations appointed as supporters poses risks of conflict of interest, and potential abuse and exploitation in some circumstances. However, we advocate that individual staff of organisations may be supporters, and supporters should also be paid for their services where it is provided as such. However, it may be a conflict of interest if the paid support was from the same service provider that the person with disability uses, or a worker at a residence where a person lives.
46. Independence is central and NSW should invest in developing the disability support industry to promote the role of decision-making supporter as a core skill and/or attractive career option. We would again refer to the NDIS Quality and Safeguards Framework for developing guidance in this area.
47. We recognise that informal support is likely to occur in these circumstances however, given that a person may lack other informal networks in their community and their care worker may in fact be the person who is closest to them. This reinforces the importance of ongoing education and training for both workers, and individuals around avoiding, identifying and reporting exploitation and abuse.
48. We support the findings of the Victorian Law Reform Commission that advocates be permitted to act as formal supporters.

Question 6.7: Volunteers as supporters and co-decision-makers

49. As mentioned above, we believe that there could be benefits in the establishment of a community support program, which involves volunteers who can act as supporters when all other avenues have been investigated. A formal training and registration process would need to be in place, and these supporters would need to commit to a relationship long term. This program could be managed through the independent body.

Question 6.8: Powers and functions of supporters

- **What powers and functions should the law specify for formal supporters?**

50. The Guardianship Act must specify that the function of a formal supporter is to: facilitate the expression of the will and preference of a person with disability through assisting them to access and interpret all necessary information to make and communicate a decision themselves, rather than make decisions on their behalf.
51. Supporters should make all efforts to build the decision-making skills and experience of the individuals they are supporting.
52. Supporters should have certain restrictions placed on them, particularly given the level of personal information they may be privy to in order to assist a person to make a decision. In Alberta legislation it is specified that a supporter:
 - may use and disclose the information only for the purpose of exercising the authority granted to them, and
 - is to take reasonable care to ensure the information is kept secure from unauthorised access, use or disclosure.

- **What powers or functions should the law specifically exclude for formal supporters?**

53. Supporters should not have any power to enact a decision on behalf of the individual they are supporting. Supporters should not be able to enter into any arrangement, and there

should be no recognition in law for this provision. This should include all financial and personal matters.

Question 6.9: Powers and functions of co-decision-makers

54. As outlined above, we question the role of co-decision makers, and warn against the implementation of this function until the Commission has reviewed the effectiveness of this arrangement in other jurisdictions.

55. If an individual were, of their own free will, to appoint a person as a co-decision maker, this should be recognised and respected. However, a co-decision maker should never be appointed without the individual's consent.

56. A co-decision maker should not be able to make any decision on behalf of an individual, and the individual's decision should always take precedence over the co-decision maker.

Question 6.10: Duties and responsibilities of supporters and co-decision-makers

57. Formal supporters (including co-decision makers) have the responsibility to:

- support an individual with accessing all necessary information in order to make a decision.
- Help the individual to interpret that information and come to their own conclusion
- Support the individual to communicate that decision to relevant parties
- Maintain confidentiality at all times, and only share personal information if authorised by the individual being supported, and directly for the purpose of decision making
- Commit to building the decision making skills and experience of an individual

What duties and responsibilities should the law specifically exclude for formal supporters and formal co-decision-makers?

58. Formal supporters and decision makers should have no authority to make a decision on behalf of an individual, or seek or share any personal information relating to an individual without their prior consent.

We thank the NSW Law Reform Commission for the opportunity to contribute to this review process. We welcome the opportunity to participate in further consultation on the matters raised in this submission.