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People with Disability Australia (PWDA)

NSW Law Reform Commission Review of the Guardianship Act 1987

Draft Proposals

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Disabled People's Organisations Australia

Contents

About People with Disability Australia 3
Introduction 3
Recommendations 5
Overarching concerns 6
Response to Draft Proposals 12
Chapter 1 – A new framework 12
Chapter 2 – Personal support agreements 13
Chapter 3 – Tribunal support orders 14
Chapter 4 – Enduring representation agreements 14
Chapter 5 – Representation orders 15
Chapter 6 – Healthcare decisions 16
Chapter 7 – Medical research procedures 17
Chapter 8 – Restrictive practices 18
Chapter 9 – Advocacy and investigative functions 19
Chapter 10 – Provisions of general application 20
Chapter 11 – Tribunal procedures and composition 21
Chapter 12 – Supreme Court 21
Chapter 13 – Search and removal powers 21
Chapter 14 – Interaction with mental health legislation 22
Chapter 15 – Adoption information directions 22
Chapter 16 – Recognition of interstate appointments 22

About People with Disability Australia

1. **People with Disability Australia (PWDA)** is a leading disability rights, advocacy and representative organisation of and for all people with disability. We are the only national, cross-disability organisation - we represent the interests of people with all kinds of disability. We are a non-profit, non-government organisation.

2. PWDA's primary membership is made up of people with disability and organisations primarily constituted by people with disability. PWDA also has a large associate membership of other individuals and organisations committed to the disability rights movement.

3. 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. PWDA was founded in 1981, the International Year of Disabled Persons, to provide people with disability with a voice of our own.

4. PWDA is also a founding member of Disabled People's Organisations Australia (DPO Australia) along with Women With Disabilities Australia, First Peoples Disability Network Australia, and National Ethnic Disability Alliance. DPO's are organisations that are led by, and constituted of, people with disability.

5. The key purpose of DPO Australia is to promote, protect and advance the human rights and freedoms of people with disability In Australia by working collaboratively on areas of shared interests, purposes, strategic priorities and opportunities. DPO Australia is made up of four national peak DPOs that have been funded by the Australian Government to represent the views of people with disability and provide advice to Government/s and other stakeholders.

Introduction

6. PWDA welcomes the opportunity to contribute to the NSW Law Reform Commission Review of the Guardianship Act 1987.

7. As PWDA has stated in our previous submissions, we firmly believe that this Review provides a key opportunity for robust legislative and institutional change in NSW. Such significant reform must result in a legal capacity

framework that is wholly compliant with the Convention on the Rights of Persons with Disabilities (CRPD).

8. A CRPD compliant legal capacity framework recognises that everyone has equal rights, including the right to equal recognition before the law. That is, all people have rights equally (legal capacity), have the capacity to act on those rights (legal agency), and to have those acts (and the decisions that lead to those acts) recognised and respected in law.[1]

9. We appreciate that the NSW Law Reform Commission has envisaged a new framework for assisted decision-making in NSW, and that the draft proposals illustrate a shift away from the current substitute decision-making framework. Legislating supported decision-making will assist this type of support to become normalised and seen as a legitimate requirement.

10. Nonetheless, we remain concerned that this proposed framework falls short. Ultimately, it fails to recognise legal capacity for people with disability, as it still offers a formal substitute decision-making model. Furthermore, the new proposed Act remains focussed on the individual in terms of 'ability', whereas the legislation should specifically identify that the measure of such 'ability' will be the quality and appropriateness of support available. The draft proposals therefore do not encompass a CRPD compliant legal capacity framework.

11. PWDA does not support the concept of representatives in the proposed *Assisted Decision-Making Act* as this concept appears to be equivalent to current substitute decision-makers or guardians. We are deeply concerned that the recommendations of the Australian Law Reform Commission's 2014 report *Equality, Capacity and Disability in Commonwealth Laws,*[2] and the CRPD General Comment on Article 12[3] are not reflected in the draft proposals. This must be urgently addressed.

12. Furthermore, we are concerned by the exclusion of people under mental health legislation from the supports offered by these draft proposals. We are also troubled by the inclusion of decisions regarding restrictive practices in the draft proposals.[4] We also have serious concerns regarding the proposed Public Advocate body.

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[1] PWDA, 2017a. *NSW Law Reform Commission Review of the Guardianship Act 1987, Question Paper 2: Decision Making Models*, People with Disability Australia.
[2] Australian Law Reform Commission (ALRC), 2014. *Equality, Capacity and Disability in Commonwealth Law: Final Report*. Available: https://www.alrc.gov.au/publications/equality-capacity-disability-report-124
[3] Committee on the Rights of Persons with Disabilities, General Comment No. 1 (2014), Article 12: Equal recognition before the law, 11th sess, UN Doc CRPD/C/GC/1, 19 May 2014. Available: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx; and
[4] For PWDA's previous comments regarding the use of restrictive practices, see French, P., Dardel, J. and Price-Kelly, S. 2009. *Rights Denied: Towards a National Policy Agenda about Abuse, Neglect and Exploitation of Persons with Cognitive Impairment*, People with Disability Australia

13. We offer our main concerns with the new framework and draft proposals in our response below, and provide varied recommendations for improvements.[5] These should all be read in light of our significant concerns regarding the inclusion of substitute decision-making and restrictive practices, and the exclusion of people under mental health legislation within this Act.

Recommendations

PWDA makes a number of recommendations that respond to the issues we raise in this submission. We recommend:

1. That the draft proposals be amended to ensure CRPD compliancy throughout.
2. That the Public Advocate must not sit alongside the Public Representative. Instead, it should be an entirely separate and independent mechanism.
3. That the NSW Government immediately review and align all legislation that relates to legal capacity (including the Mental Health Act 2007 (NSW) and Mental Health (Forensic Provisions) Act 1990 (NSW)) with a supported decision-making framework.
4. That all mentions to restrictive practices be removed from this proposed legislation. These reforms must act as a catalyst to eliminate the existing use of restrictive practices (and the ways in which these are often directly tied to views about legal capacity).
5. That the NSW Government establish an independent, regulatory framework and office for the oversight of the reduction and elimination of restrictive practices and the promotion and development of evidence-based positive behaviour support.
6. That the NSW Government appropriately resource the introduction of the new *Assisted Decision-Making Act* at all levels.
7. That the NSW Government continue to fund (and increase investment in) disability advocacy, representation and information organisations.
8. That the participation of independent advocates must be routine in Tribunal proceedings.
9. That significant work is performed in relation to overhauling the cultures and work practices of the existing guardianship mechanisms. This must include significant training on the CRPD (with particular emphasis on Article 12) and disability awareness.

[5] For further discussion of our position, see: People with Disability Australia (PWDA), the Australian Centre for Disability Law (ACDL) and the Australian Human Rights Centre (AHRCentre). 2014 *Australian Law Reform Commission (ALRC): Equality, Capacity and Disability in Commonwealth Laws Discussion Paper,* Available: http://www.pwd.org.au/documents/pubs/SB14-ALRC-Submission-PWDA-ACDL-AHRCentre.doc; PWDA 2017a, op cit., PWDA, 2017b. *NSW Law Reform Commission Review of the Guardianship Act 1987, Question Paper 3: The role of guardians and financial managers*, People with Disability Australia

Overarching concerns

14. We note that the introduction to the draft proposals outlines that the new framework reflects the CRPD.[6] While the CRPD is referred to sporadically throughout the document,[7] the new framework does not in its entirety comply with the fundamental human rights to which this important international human rights document refers.

15. Indeed, we are concerned that the review has missed the opportunity to profoundly reconceptualise the legal capacity framework in NSW. Whilst we understand that ensuring CRPD compliance is a significant undertaking, the draft proposals do not take bold enough steps to recognise legal capacity as we describe below.[8]

16. Consequently, we urge the NSW Law Reform Commission to urgently address the following key divergences from the CRPD.

Legal capacity

17. PWDA is concerned that in some instances, references to decision-making ability do not reflect a CRPD compliant understanding of legal capacity. As we have outlined in numerous submissions, everyone has the right to equal recognition before the law. We have also previously advocated that 'decision-making capacity' should never be a term used to describe an individual.

18. References to 'decision-making ability' throughout the submission are still rooted in the framework of determining and assessing the individual, rather than assessing the quality and appropriateness of the supports with which they are provided. Changing the word 'capacity' to 'ability' does not mean anything unless the measure of that 'ability' is clearly defined. This means that the question is not whether the person has decision-making 'ability', but rather what supports does the person require to exercise decision-making.

19. Under a CRPD compliant legal capacity framework all people are recognised to equally have legal capacity. Similarly, it is recognised that all people require different support to make decisions at different times in their lives. Therefore, the measure of 'capacity' or 'ability' is dependent on the quality, appropriateness and availability of support. This must be clearly defined in the new Act. The use of the term 'decision-making ability' must therefore be

[6] NSW Law Reform Commission (NSWLRC), 2017. Review of the Guardianship Act 1987: Draft Proposals. Sydney Australia. p1.
[7] Directly referenced in Proposal 1.8, and mentioned in passing in the explanatory statements of Chapters 6, 7 and 11.
[8] Nor as it is described in: Committee on the Rights of Persons with Disabilities 2014 op cit.; ALRC 2014 op cit.

reconceptualised throughout the draft proposals to clearly articulate that any assessment regarding decision-making is focused on assessing and critiquing the adequacy of decision-making supports, as opposed to assessing the individual's 'ability.'

20. Likewise, references to whether someone is likely to 'recover decision-making ability'[9] must be reframed in relation to the supports they are provided. For instance, 'recover decision-making ability' could be changed to 'adequate and appropriate supports are available for a particular decision.'

21. Similarly, the use of the phrase 'personal and social wellbeing' appears to merely replace the term 'best interests' in the current Act. This phase is used numerous times throughout the draft proposals, for instance, referring to making decisions that promote or maintain the person's personal and social wellbeing. As this phrase is not defined in the draft proposals, any judgements about 'personal and social wellbeing' would be subjective (as are judgements about best interests).

22. Instead, in line with the CRPD, the person's will and preferences must be upheld, and if the supports are inadequate for their will and preferences to be known, then subsequent decisions must be based on promoting or maintaining the person's human rights.[10]

23. Under the CRPD, equality before the law is a civil and political right. Such rights cannot be restricted, and are not subject to progressive realisation. There is no limit to the level of support that must be provided by the State to achieve equality before the law. However, the new framework does not explicitly state this, and in numerous sections outlines that if less intrusive or restrictive measures are unavailable or not suitable then representation will be appointed (with representation being equivalent to current guardianship arrangements).

24. However, according to the CRPD, the State is obliged to fill that service delivery gap to ensure that appropriate and quality supports are available to an individual. Indeed, the unavailability of adequate supports may be particularly prevalent in regional or rural areas that do not have the same levels of support or service infrastructure as metropolitan areas. Consequently, the NSW Government must perform significant service scoping ahead of establishing this new supported decision-making regime, to ensure appropriate supports exist and are adequately resourced across the state. Moving forward, PWDA would hope that the identification of service or support gaps would be readily addressed by the NSW Government to ensure that they

[9] As outlined in draft proposal 7.2 for instance.
[10] Committee on the Rights of Persons with Disabilities, 2014 op cit.

would be able to be provided in the future (thus rendering representation orders void where supports were subsequently adequate).

25. Finally, all new terminology must be clearly defined in the new Act and any related documentation. For instance, in the draft proposals the Assisted Decision-Making Division of the Tribunal, any representative, supporter, person responsible or witness to an agreement are considered to be the 'decision-maker'.[11] This is inherently problematic. By referring to these entities and individuals as the 'decision-maker', this yet again implies that supported and represented people are not the decision-makers in their lives. This is fundamentally untrue, and a denial of legal capacity as it reflects a substitute decision-making arrangement.

26. Similarly, the functions of supporters must also be reconsidered to reflect that the supported person remains the primary decision-maker. Functions provided in draft proposals 2.8 (4) and 3.9 (4) that allow supporters to sign and do all things necessary to give effect to their functions on behalf of a supported person are inappropriate. Instead, the supported person must consent to this occurring.

27. PWDA argues that support agreements instead outline that the supported person must consent to the supporter signing or acting on their behalf on each and every occasion. Such an approach would be similar to the process performed by independent advocates, whereby specific and restricted consent forms are required for them to assist in various elements of the individual's life. These consent forms would offer a safeguard, and would also ensure that supporters are actively supporting and upholding their responsibilities appropriately (rather than simply acting on behalf of the supported person).

Restrictive practices

28. The use of restrictive practices and involuntary treatments, such as seclusion, solitary confinement, and physical, mechanical or chemical restraint, violate fundamental human rights.[12] All people, including those requiring decision-making support, have an equal right to be free from torture or cruel, inhuman or degrading treatment or punishment. Nevertheless, people with disability and older people remain routinely subjected to restrictive practices that can

[11] As outlined NSWLRC 2017 op cit., p5, and as used in draft proposals 1.1, 1.14 and 1.15

[12] As outlined in the CRPD and the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. For more information see: CRPD Civil Society Parallel Report Project Group, 2012, *Disability Rights Now: Civil Society Report to the United Nations Committee on the Rights of Persons with Disabilities,* August 2012, p91. Available: http://www.pwd.org.au/issues/crpd-civil-society-shadow-report-group.html; French, P., Dardel, J. and Price-Kelly, S. 2009. Op cit., pp 72, **Error! Bookmark not defined.**; Lea, M., & Sands, T., 2017, '*Disabled People's Organisations Australia (DPO Australia) Submission to the Australian Law Reform Commission Discussion Paper: Protecting the Rights of Older Australians from Abuse'*, DPO Australia, Sydney, Australia.

cause physical pain and discomfort, which deprive them of their liberty or alter their thoughts or thought processes.[13]

29. Currently, as the NSW Law Reform Commission will be aware, the use of restrictive practices is often justified through existing frameworks that fail to recognise and engage with the legal capacity of people with disability.[14]

30. In order to fundamentally reform and improve the legal capacity framework in NSW, it is therefore vital that the new decision-making framework challenge the use of restrictive practices.

31. There must be no opportunity for people with disability to voluntarily consent to practices that may amount to severe breaches of their basic human rights.[15] Indeed, '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 their liberty'.[16]

32. Furthermore, all supporters and representatives (regardless of whether they have been personally selected through an agreement or appointed by an order) must likewise be unable to support someone to make or otherwise make a decision regarding the use of restrictive practices.

33. Challenging the use of these discriminatory practices that fundamentally violate the human rights of those they are used upon is an important (and necessary) move towards eliminating restrictive practices throughout NSW (in the disability, aged care and mental health sectors, as well as in the broader community).[17] Consequently, the NSW Government must commit to developing an evidence-base around positive behaviour support to contribute towards the elimination of restrictive practices.

34. Importantly, the NSW Government must establish an independent, regulatory framework and office for the oversight of the reduction and elimination of restrictive practices and the promotion and development of evidence-based positive behaviour support. Such frameworks exist in other jurisdictions, such as Queensland and Victoria, and provide greater protections of human rights than the current NSW policy approach to this issue.[18]

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[13] PWDA and The University of Sydney (USYD), 2014. *Submission to the Australian Law Reform Commission Equality, Capacity and Disability in Commonwealth Laws Inquiry.* See also: PWDA and the Mental Health Coordinating Council, 2009. *Submission to the NSW Legislative Council: 'Substitute Decision-Making for People Lacking Capacity.'*

[14] Lea and Sands 2017 op cit., p11.

[15] PWDA and USYD 2014 op cit., p5.

[16] Ibid.

[17] PWDA, 2016. *Submission to the NSW Law Reform Commission Review of the Guardianship Act 1987*, p7, People with Disability Australia.

[18] French, P., Dardel, J. and Price-Kelly, S. 2009 op cit., pp95-98.

Interaction with mental health legislation

35. People with psychosocial disability and people subject to mental health legislation must be guaranteed the same rights to the new supported decision-making framework as others. To suggest otherwise is inherently unfair and discriminatory.

36. Put simply, in their current form the draft proposals in relation to mental health legislation directly contravene Articles 5, 12 and 25 of the CRPD, and would directly contribute to a range of forced treatments and deprivation of liberty in contravention of Articles 14, 15, 16, 17 of the CRPD.[19] The CRPD does not differentiate between psychosocial disability and other types of disability, and thus the proposed legal capacity framework must apply equally and be inclusive of all people with disability without discrimination.

General comments

37. PWDA is working from the assumption that all documentation and forms associated with this new framework will be available in fully accessible formats, including but not limited to Easy English, large print, Braille, Auslan and video. Supported and represented people must have a clear understanding of the agreement they are making or the order to which they are subject. Similarly, they must be provided with clear and accessible information about how to end or suspend agreements or orders. This may include decision-making support.

38. PWDA also asks for clarification regarding the eligibility requirements for supporters and representatives. For instance, the draft proposals appear to indicate that a person is eligible to be an enduring representative with financial functions even if they have been bankrupt or convicted of a dishonesty offence, provided they have disclosed this prior to their appointment. While we understand that requiring disclosure of such offences allows individuals to make informed choices about who is supporting or representing them, PWDA is keen to ensure that such representatives (or personally selected supporters, as they are subject to similar eligibility requirements) would be subject to appropriate levels of oversight with regards to the financial decisions being made.

39. In relation to oversight mechanisms, it is pertinent to state that PWDA has serious concerns with the proposal that the Public Advocate sit alongside the Public Representative. We are troubled by the potential conflict of interest inherent in this proposed arrangement, and offer our specific concerns below.

[19] Committee on the Rights of Persons with Disabilities, 2014 op cit.

While we do see the merit in having a Public Advocate in NSW, this body must be thoroughly independent, and must have robust investigative and advocacy functions that are rooted within a CRPD compliant supported decision-making framework.

40. Even with an independent Public Advocate, there remains an ongoing need for independent individual and systemic advocacy from DPOs such as PWDA. Resourcing DPOs to build the capacity of people with disability who may require decision-making support is a vital aspect of this. Mentioned throughout the draft proposals is the importance of building the 'decision-making ability' of individuals. This must be understood as ensuring the person has appropriate supports. It is vital that DPOs and/or Disability Support Organisations (DSOs)[20] are involved in not only the provision of these supports, but also assessing whether existing supports are adequate. DPOs and DSOs should also be funded to train supporters and representatives on how they can assist in this process.

41. Furthermore, DPOs and independent advocacy organisations are important safeguards, with significant expertise working not only to prevent violence, but also to improve responses to violence and abuse.[21] PWDA is concerned by the general inattention to proper oversight mechanisms throughout these draft proposals. For instance, what tangible safeguards will be implemented to ensure that all supporters and representatives are adhering to their responsibilities as outlined in the new Act? Inadequate oversight (including through independent means) could place supported or represented people at significant risk.

42. This leads us to raise concerns with the Tribunal review mechanisms of agreements and orders that are proposed in Chapters 2-5. We are troubled that the Tribunal is not bound to review support or representation agreements or orders if the request does not disclose grounds that warrant a review, or if they have previously reviewed the agreement or order. We believe that a request for review from a supported or represented person must always be upheld. Circumstances change, and there are many reasons (often relating to violence, abuse, neglect and exploitation) that could contribute to a supported or represented person not disclosing the exact reason why a review has been requested.

[20] DSOs foster peer support networks of people with disability, and often develop information and capacity building resources for participants. Furthermore, DPOs, of and for people with disability, are essentially peer support organisations that may also undertake independent advocacy.

[21] For further information about the safeguarding role of independent advocacy organisations, see: Parliament of Victoria, Family and Community Development Committee, 2016. *Inquiry into abuse in disability services: Final Report*, Victorian Government Printer.

Response to Draft Proposals

43. We preface these responses by reiterating our above concerns. We are fundamentally opposed to the continuation of substitute decision-making regimes in NSW that do not uphold the human rights of people with disability.

44. Bearing in mind these overarching concerns, PWDA would like to offer some specific comments on each of the chapters of the draft proposals document. We note that these comments are not exhaustive, as it would be impractical to reference every instance in which the draft proposals depart from the CRPD and from previous recommendations about supported decision-making.[22]

Chapter 1 – A new framework

45. PWDA urges the NSW Law Reform Commission to consider the new framework in light of our abovementioned concerns. As we have previously outlined, best practice regarding supported decision-making is still evolving,[23] yet starting from a completely CRPD compliant framework must be prioritised. However, if our overarching concerns are not addressed and substitute decision-making is to be performed by a representative as outlined in this legislation, we offer the following comments.

46. The definition of decision-making ability provided in draft proposal 1.12 must include scope for the person to be able to access support (such as an independent advocate) to assist them with making sense of potentially quite complex information. The new Act must clearly provide that appropriate and adequate support must be provided to ensure that a person can exercise their legal capacity and decision-making ability.

47. Draft proposal 1.14, outlining the assessment of decision-making ability, must be founded upon the provision of support in the first instance, and the assessment must therefore be of the supports and the quality of supports available that enable a person to exercise their legal agency.

48. PWDA is unclear what changes will occur to the existing guardianship infrastructure (other than the name changes outlined in draft proposal 1.3). Extensive work must be done internally to change the existing substitute decision-making culture, and the existing ways of working. Each agency involved in this process would likely require significant training on the CRPD and legal capacity within this, the new Act, the roles of supported and

[22] Including those previously mentioned by the ALRC 2014 op cit., and the Committee on the Rights of Persons with Disabilities, 2014 op cit.
[23] PWDA 2017a op cit., p 3.

representative decision-making, and on disability awareness. People with disability through their representative organisations must be involved in designing and delivering this training.

49. In particular, there must be substantial investment in training for the Public Representative to ensure an appropriate shift from best interests, substitute decision-making by guardians to representative decision-making based on the rights, will and preferences of represented individuals.

50. Finally, PWDA is unclear how the new framework will be resourced. We recommend that significant attention be paid to awareness building activities, including investment in community engagement around the role of supported decision-making. We also recommend that increased funding be dedicated to the availability and quality of communication aids, equipment and supports such as Auslan interpreters and independent advocates.

Chapter 2 – Personal support agreements

51. Individuals must be able to appoint supporters on their own volition, choosing individuals with whom they have trusting relationships. It is important that both parties enter into the arrangement freely, and are aware that the agreement can be revoked at any time. As mentioned earlier, information about ending personal support agreements must be freely available and fully accessible.

52. To protect supported people from abuse, appropriate oversights and safeguards must apply in instances whereby paid care workers, volunteers and others involved in providing medical, accommodation or other daily services are appointed as supporters. PWDA is concerned that supporters who work at the organisation or company from which the supported person receives services may not be able to impartially provide the necessary level of support. Similarly, we hold concerns that such potential conflicts of interest could lead to abuse and exploitation in some circumstances.

53. Nonetheless, PWDA concurs that the criteria for appointing personal supporters should not be overly prescriptive. We recommend that supporters receive basic information about the CRPD, legal capacity and supported decision-making, and have a clear commitment to the social model of disability. Other essential criteria would be knowing the supported person well, having a trusting relationship with them, and being able to communicate in a way that the individual can understand.

54. Independent advocates often provide informal decision-making support, have established relationships with people with disability and are able to understand and support their decision. This includes supporting them to make

and communicate their intention to make risky decisions. Independent individual advocates should thus should be considered to be eligible to act as personally appointed formal supporters.

55. As outlined in our above concerns, supporters should not have any power to enact a decision on behalf of the individual they are supporting. This must hold true for all decisions. They should also have no authority to seek or share any personal information relating to the supported person without the supported person's prior and informed consent.

Chapter 3 – Tribunal support orders

56. PWDA believes that Tribunal mandated support orders must only occur in circumstances in which personal appointments are not possible. It is unclear in the draft proposals how the Tribunal would make such an appointment, including how these supporters would be found or recruited, what training they would have or whether they are required to have an existing relationship with the supported person. It would appear to be the role of the Public Advocate (operating independently of the Public Representative) to determine who would best support the individual requiring decision-making support.

57. PWDA reiterates our concerns regarding the Tribunal appointing paid workers to act as supporters. Ultimately, we oppose these appointments. However, if they are to go ahead, there would need to be clear guidance and robust oversight in such instances, as well as training in the CRPD, legal capacity and supported decision-making.

58. A review mechanism must be in place to ensure that the appointment meets the expectations of the supported person in terms of the quality and quantity of support offered to them.

Chapter 4 – Enduring representation agreements

59. An individual has the right to choose whomever they like to be their representative once they cannot be supported to express their will and preferences themselves. As we have said in previous submissions, representation must always be a last resort.

60. As previously outlined, we do not support the change of terminology to representatives when these representatives perform similar roles to current guardians. However, if these concerns are not addressed, it is vital that any enduring representation agreements only come into effect once all support options have been exhausted, and it is not currently possible to support the

individual to make their own decisions. From this position, it is clear that there must be ongoing monitoring of enduring representative agreements (and representation orders alike), to ensure that these remain the least restrictive option and apply for the least amount of time possible.

61. As outlined previously, representative decision-makers should have a firm commitment to the social model of disability and must clearly understand and adhere to Article 12 of the CRPD. We agree that service providers and certain members of the person's family must not act in an enduring representative role. However, we are concerned by the inclusion under draft proposal 4.3 that 'the appointment does not lapse if an enduring representative (or their spouse, child, brother or sister) is subsequently engaged to provide for fee or reward healthcare, accommodation or other support services to the represented person'. While we understand why an individual may engage their enduring representative (or one of their family members) to provide other support services, such a change in circumstances would warrant review or close monitoring at the very least.

62. Finally, draft proposal 4.9(2c) speaks to enduring representatives providing decision-making support. However, if a person can be supported to make a decision, they clearly do not require a representative, but instead require a supporter.

Chapter 5 – Representation orders

63. The following comments are important to consider if our concerns regarding substitute decision-making are not addressed.

64. Tribunal appointed representation orders must always be a last resort. There must be clear evidence that all other support alternatives have been pursued and have been proven to be unsuitable or ineffective. As with enduring representatives, representation orders must always remain under close review, including a full assessment of supports available. Furthermore, the Public Advocate could have the role of supporting and overseeing all appointed representatives, providing particular support to representatives between the ages of 16 and 18.

65. We concur that the Public Representative or NSW Trustee should only be appointed as a last resort, in cases in which the individual does not have suitable people in their lives who could possibly be appointed as a representative.

66. We are pleased to note that the powers and functions of representative decision-makers appointed by the Tribunal are consistent under the draft proposals. We are unclear regarding how Tribunal ordered representative decision-makers will give effect to the will and preferences of represented people.

67. PWDA is also pleased that the changes proposed in this chapter will make financial management arrangements time limited and reviewable. This is vital, as the purpose of financial management is not about controlling every aspect of a person's life, and nor is it about behaviour management (as some financial managers currently seem to understand their role, based on our experience). Tribunal ordered representative decision-makers should be obliged to support all reasonable alternatives to financial management for represented people.

68. PWDA is concerned regarding draft proposal 5.16 in relation to enforcing the decisions of representatives. This draft proposal outlines actions that a representative, specified person or person authorised by the representative may take to ensure the represented person complies with any decision of the representative in the exercise of their functions. As we see it, a representative must make decisions based on the rights, will and preferences of the person. It is not clear why there should ever be the need for force.

Chapter 6 – Healthcare decisions

69. PWDA is concerned about the draft proposals in relation to healthcare decisions for 'patients who do not have "decision-making ability"' for such decisions.[24]

70. For instance, draft proposal 6.17 explains when the Tribunal may authorise a representative to override a patient's objection to major or minor healthcare. This remains rooted in the 'best interests' framework of the current Act. Decisions about what would promote the patient's personal and social wellbeing are purely subjective and no different to the 'best interests' approach. It is important that the decisions – their will and preferences – of supported and represented people are respected and upheld.

71. We are also opposed to the reclassification of some major treatments, particularly the reclassification of oral and injectable contraceptives and the contraceptive implant. It is important that supported and represented people have access to appropriate and accessible information or education about contraceptive options that may be available to them. PWDA is aware of many

[24] NSWLRC 2017 op cit., p43.

instances in which contraceptive medications have been used without consent to suppress menstruation in women with disability in residential settings. In many cases, such contraceptives are administered as a first and only response to inappropriate behaviour (such as removing sanitary pads in public or not disposing of them appropriately).[25] We are deeply concerned that by reclassifying certain contraceptives as minor treatments they will be more easily available to representatives or others seeking to deny the reproductive and human rights of people with disability.

72. PWDA understands that the Tribunal may consent to special healthcare (which includes any healthcare that is intended to or may render the patient permanently infertile) in instances where such healthcare is necessary to save the patient's life or prevent serious damage to their health. However, we are extremely troubled by how this will be applied in practice, given the language used in the draft proposal. For instance, in relation to healthcare intended or reasonably likely to cause permanent infertility, the draft proposals outline that: '"serious damage to the patient's health" includes serious and persistent health problems associated with menstruation (for example, seizures or anaemia).'[26] While seizures or anaemia can be persistent health problems, these conditions can be associated with many other health concerns other than menstruation.

73. We have grave concerns about current practice that interprets 'serious damage to health' broadly, and in effect enables forced sterilisation to be permitted. Sterilisation should not be performed to address a serious health issue where this would not be acceptable for a person without disability.

74. PWDA remains strongly opposed to the involuntary or coerced sterilisation of people with disability.[27] We therefore agree with draft proposal 6.27 (3) that 'a person must not take another person without decision-making ability outside Australia to obtain an unauthorised sterilisation procedure.'

Chapter 7 – Medical research procedures

75. As has been previously outlined, it is important that this new framework is completely CRPD compliant. This chapter makes reference to the CRPD, stating that participation in healthcare and medical research procedures is implicit in the CRPD.

[25] PWDA, 2013. *Submission to the Senate Standing Committee on Community Affairs: Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia*, People with Disability Australia.
[26] Proposal 6.8(2.a) p47.
[27] See: PWDA 2013 op cit.

76. Provided that the overarching concerns that PWDA has with this framework are addressed and that a supported person is able to consent to these practices,[28] they should be able to participate in medical research procedures.

Chapter 8 – Restrictive practices

77. NSW requires a strong regulatory framework to oversee restrictive practices,[29] including their elimination, and to progress positive behaviour support, as noted above. Supporters and representatives must not be making decisions or providing consent for the use of restrictive practices.

78. PWDA is aware of numerous instances in which restrictive practices have been used against people with disability who were subject to guardianship orders. In particular, the atypical use of antipsychotics has been reported, and in many instances, such drugs have been used without any mental health diagnosis. In many cases, people are subjected to a mixture of medications that amounts to medical experimentation and maladministration of medications.[30] These medications are used in this way to chemically restrain people with disability and to keep people quiet and passive in boarding houses, aged care facilities and other institutional settings.[31]

79. As explained above, PWDA is extremely concerned by the ongoing inclusion of restrictive practices within this proposed framework. Supporters and representatives would likely have insufficient skills and knowledge about restrictive practices and positive behaviour supports to make informed decisions about their use. Furthermore, supporting someone to make or making decisions to use restrictive practices would be in direct conflict with the responsibility of supporters and representatives to uphold the human rights, will and preferences of the person they are supporting or representing.

80. The new model of recognising legal capacity in NSW must therefore offer a robust challenge to the use of restrictive practices, and must make tangible steps towards their elimination throughout the community as a whole. Such steps could involve the NSW Government committing to developing an evidence-base around positive behaviour support to contribute towards the elimination of restrictive practices.

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[28] Particularly our concerns regarding the independence of the Public Advocate, given the draft proposal that the records of medical research are to be filed with the Public Advocate.
[29] For more information, see: French, P., Dardel, J. and Price-Kelly, S. 2009. Op cit.
[30] Ibid.
[31] For further information about the use of these drugs, see for instance: New South Wales Parliament, Legislative Council, General Purpose Standing Committee No. 2, 2016, *Elder abuse in New South Wales,* Sydney NSW, available: https://www.parliament.nsw.gov.au/committees/DBAssets/InquiryReport/ReportAcrobat/6063/Report%2044%20-%20Elder%20abuse%20in%20New%20South%20Wales.pdf

81. PWDA fundamentally disagrees that the proposed Public Advocate functions be carried out by the Public Representative. The separation of powers and responsibilities is vital in this area. Distinct entities and clear cut responsibilities would help to ensure that the rights of people who are being supported or represented in their decision-making are adequately upheld.

82. One key concern is the potential for conflict of interest that such an arrangement would pose. For instance, if the Public Representative makes decisions regarding the use of restrictive practices for an individual, how would the Public Advocate support the rights of that individual and successfully prevent the use of these practices? While there have been positive reviews of this combined system functioning effectively in Victoria,[32] human rights abuses against people with disability in Victoria still remain rife.[33]

83. Furthermore, combining the Public Representative and Public Advocate does not allow for adequate delineation of responsibilities. Indeed, having the same agency involved in both representation and advocacy could subsequently lead to the silencing of a significant number of people who would benefit from external and independent assistance and advocacy support. Enabling the NSW Ombudsman to investigate complaints about the Public Advocate is not an adequate safeguard.

84. There is a clear ongoing need for robust and independent advocacy in relation to supported and representative decision-making. PWDA is of the firm belief that such advocacy must be totally separate from government institutions and agencies, including the Public Representative, the Public Advocate and the National Disability Insurance Agency. Independent advocacy is vital. For example, PWDA's individual advocates work with people with disability to assist with critical meetings and court appearances, to assist with decision-making, and to support them to have their views heard in various forums.

85. Currently, however, independent advocates often encounter difficulties with their existing relationships with the NSW Office of the Public Guardian. It is not uncommon for guardians to attempt to cease an advocate's involvement, denying people with disability access to advocacy. Such attitudes towards advocacy are troubling. If similar attitudes towards independent advocacy supports persist when the Public Guardian becomes the Public Representative, this will have hugely negative impacts on represented people.

[32] NSWLRC 2017 op cit., p61.
[33] See for instance Parliament of Victoria, Family and Community Development Committee 2016 op cit.

86. PWDA therefore recommends that if a Public Advocate is to be established in NSW, this body must be entirely separate from the Public Representative. This new and distinct body should perform some of the proposed functions outlined in chapter nine, with some exceptions (where for instance, independent advocacy organisations and Disabled People's Organisations are already performing these roles effectively. In such cases these existing organisations should be adequately funded to continue such functions). The representative functions of the Public Guardian should remain the sole remit of the Public Representative. This is particularly important as no details are provided regarding how the Public Representative would be supported or resourced to take on the additional Public Advocate role.

87. If this separation of Public Advocate and Public Representative were to occur, the Public Advocate could perform the functions we have in previous submissions attributed to an independent supported decision-making body. This arm of the Public Advocate would be responsible for the guidance and training of potential informal and formal support people, providing information about support options for the general public, disability services and mainstream services, awareness raising about the regime and the training of government agencies in the facilitation of supported decision-making.[34] The independent body would also assess the adequacy of supports being provided to an individual, or could initiate such assessments through existing structures such as the NDIA or aged care systems.

88. However, in the event that the Public Representative and Public Advocate sit alongside each other, it is even more vital that the role of independent advocacy be significantly strengthened. Indeed, even with its long-established combined model Office of the Public Advocate, Victoria is increasing funding to independent advocacy.

Chapter 10 – Provisions of general application

89. PWDA concurs that it should be simpler and cheaper to take action against an appointed decision-maker for abuse, misuse of power or failure to perform duties. District Courts must therefore be provided significant training on the new decision-making framework to ensure they are making decisions that are framed from the presumption of legal capacity.

90. As we have previously outlined, we do not necessarily see registration of all support arrangements to be practically appropriate. Such registration requirements could be overly restrictive. Furthermore, people may use

[34] PWDA 2017a op cit., PWDA 2017b op cit.

informal supporters, formal supporters or ad hoc supporters interchangeably in order to meet their support needs.[35]

91. However, as we suggested in a previous submission,[36] there may be benefits in registering the individuals working as formal decision-making supporters. This would ensure that they have the appropriate skills, qualifications and values to be effective supporters. As outlined in our preliminary submission, such responsibilities would fall to an independent supported decision-making body (an independent Public Advocate, for instance) that could oversee supported decision-making arrangements.[37]

92. PWDA generally agrees with the other provisions mentioned in this chapter, noting of course the overarching concerns outlined above which are relevant to all aspects of the draft proposals.

Chapter 11 – Tribunal procedures and composition

93. With regard to Tribunal procedures and composition, PWDA urges that NSW should be obliged to provide independent advocacy support for the person with disability. Such advocacy support could ensure that the least restrictive path is taken, and could assist with the review of support arrangements where appropriate.

Chapter 12 – Supreme Court

94. PWDA concurs with the draft proposals to govern interactions between the Supreme Court and the Tribunal. Processes should be streamlined and logical, to ensure that supported people and represented people can easily understand the processes to which they themselves, their agreements or orders may be subject.

Chapter 13 – Search and removal powers

95. We agree that it is not appropriate for the Tribunal or the representative to execute a search warrant. This would be the role of the independent Public Advocate.

96. PWDA is also concerned that the draft proposals give those with search and removal powers the discretion to 'use such force as is reasonably necessary in the circumstances.' As there is no definition of what constitutes 'force' or

[35] PWDA 2017a op cit., p5.
[36] Ibid.
[37] PWDA 2016 op cit.

'reasonably necessary', this inclusion is troubling (particularly given, outlined in draft proposal 13.1(2), that people acting in accordance with such orders are not held liable for these actions).

Chapter 14 – Interaction with mental health legislation

97. PWDA maintains our position that there should only be one piece of legislation governing the exercise of legal agency. This would clarify and streamline the involvement of people with psychosocial disability within legislation and would ensure that these individuals have access to the same protections and supports as do others.

98. As outlined earlier, we are very concerned that the draft proposals outline that matters addressed by orders under mental health legislation will prevail over orders or agreements for supported decision-making or representation. It is vital that people with psychosocial disability are included within the supported decision-making provisions referred to in the draft proposals. The same concept of informal and formal decision-making support and testing the adequacy of such support must be applied.[38] The fact that these individuals are not automatically included is discriminatory, and persists with the false assumption that people with psychosocial disability have global incapacity to make or be supported to make decisions.

Chapter 15 – Adoption information directions

99. Bearing in mind our overarching concerns with the proposed framework, PWDA agrees that adjustments should be made to the existing provisions to bring them into line with a supported decision-making framework. Where necessary, people should be adequately and appropriately supported to make decisions about obtaining information regarding adoptions.

Chapter 16 – Recognition of interstate appointments

100. When considering the recognition of interstate appointments, PWDA re-emphasises our support for the development of a nationally consistent framework that guides the processes and principles relevant to exercising legal agency.[39] The guiding principles of this framework would clearly

[38] PWDA 2016 op cit.
[39] PWDA, ACDL and AHRCentre 2014 op cit.

articulate the different ways that a person may be provided with or use support.[40]

101. This national shift to supported decision-making and the presumption of legal capacity across state and territory lines would ensure that formal supported decision-making arrangements made in other states and territories would be able to be automatically recognised in NSW. The presumption would be that the individual who made the enduring personal appointment had been adequately supported to do so, and that their legal capacity, their rights, will and preferences were being appropriately exercised.

102. In such cases, it would be appropriate to automatically recognise enduring personal appointments, and perhaps even those appointed by an interstate court or tribunal order (while noting our continued opposition to substitute decision-making representatives). However, until such time as the presumption of legal capacity is underpinned in a national CRPD compliant framework and each state and territory has a CRPD compliant legal capacity framework, considerable caution must be exercised.

103. Consequently, NSW should ensure that formal assisted decision-making arrangements made in other states and territories (and overseas) abide by the general principles of the proposed *Assisted Decision-Making Act*. An assessment should be performed to ensure that these arrangements have been made in appropriate ways, and that people have been appropriately supported to make these decisions. Where these arrangements are in place, it should be determined that all other possible supports have been exhausted in the state, territory or country from which these individuals hail. This would ensure that the existing arrangement is the least restrictive and has been implemented as an absolute last resort.

PWDA would like to thank the NSW Law Reform Commission for the opportunity to provide feedback on these draft proposals, and welcomes any further consultation on this topic.

[40] As recommended in ALRC 2014 op cit.