PEOPLE WITH DISABILITY
AUSTRALIA

PO Box 666
Strawberry Hills
NSW 2012

Toll free 1800 422 015
pwd@pwd.org.au
www.pwd.org.au

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Committee on Ageing and Disability
Parliament of New South Wales

Submitted via **ageingdisability@parliament.nsw.gov.au**

Dear Committee on Ageing and Disability

Inquiry into Supported Decision-Making for adults with Disability and Older people in NSW: Further clarification of responses made during the hearing by PWDA

On review of the transcript, I have considered that further clarification of some of my responses made during the hearing of Monday 11 May 2026 may be of assistance to the Committee. I thank the Committee for the opportunity to provide this clarification.

Page 7 of the transcript: I am asked by **the Chair** as to how a supported decision-making framework might operate in practice

1. PWDA believes that any supported decision-making framework must be grounded in clear principles. We support in principle the 10 supported decision-making principles identified by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC) in recommendation 6.6 of its Final Report. We have some concern with Principle 6 in the recommendation which states that the ‘will and preferences of people who may require supported decision-making must direct decisions that affect their lives.’ We believe that ‘rights’ alongside ‘will and preferences’ must also direct decisions. In our view, this is reflected in the wording of article 12(4) of

the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) and is subsequently confirmed by the United Nations Committee on the Rights of Persons with Disabilities (the Committee) in its *General Comment No. 1* on Article 12. We note that Australian Law Reform Commission in its Equality, Capacity and Disability in Commonwealth Laws Report (ALRC Report 124) developed four National Decision-Making Principles. The DRC recommendations are influenced by these. In contrast to principle 6 in DRC recommendation 6.6, the ALRC National Principle 3 states that '[t]he will, preferences ***and rights*** of persons who may require decision-making support must direct decisions that affect their lives' [*emphasis added*].

2. Clear legislated guiding principles, based on CRPD rights, are important to bring consistency across multiple spaces such as health, guardianship, financial administration, justice and education. All agencies in those spaces should adopt clear policies based on those principles which are designed to support a person with disability to engage meaningfully with that agency, record the views (will and preferences) of the person with disability, and for that agency to respond in a way that respects and demonstrably considers that person's rights, will and preferences. All agencies must recognise all rights outlined in the CRPD and give effect to them through policy and practice. All agencies must provide supported decision-making assistance (consented to), if a person with disability does not have access to their own supporters.

3. The issue, as alluded to in my initial responses is how supported decision-making can operate in contexts where there are actual legal questions at issue – in the civil justice space this may result in the appointment of a litigation guardian for example. In other cases, a guardian or financial management order may be applied. There are contexts where a person with disability may be prevented from engaging in legal decision-making – such as entering a contract, because of assumptions about capacity.

4. It is helpful to think of 'little decisions' and 'big decisions' (I note these terms come from research with children and young people with disability where they used those terms – they do not indicate that 'little' decisions are inconsequential – they are critical to developing personal identity). Supported decision-making can work very well when we are supporting a person to think about 'little decisions' which may be related to lifestyle for example (think food choices, recreational activities etc), or future goals (work, study etc) or relationships.

5. ‘Big decisions’ on the other hand can relate to things such as entering actual legal relationships – contracts for example, moving into independent accommodation, and even medical procedures. They may relate to a legal matter, finances and so on. How the law currently works here in relation to supported decision-making is challenging. Supported decision-making can operate to assist the person with disability to understand what is going on and participate. And that is essential. But it has little impact currently on any actual legal outcome. In other words, decisions made (via the expression of will and preferences) in those contexts by a person using supported decision-making are generally not considered *actual decisions* made by the person with disability for the purpose of the law. Their will and preferences (and rights) can be ignored and overridden. Critically, ableist assumptions continue to prevent people with disability from being recognised as persons before the law, with the right to enjoy full legal capacity on an equal basis with others in all aspects of life – this is a breach of our human rights as identified in CRPD article 12(1)-(2).

6. There may be reasons – and we have touched on the dignity of risk previously, and there is no suggestion this is not relevant (within a strict principled approach). However more needs to be done to see how supported decision-making can be utilised to ensure that more people with disability are able to express their legal capacity and have decisions they make through supported decision making recognised as a decision recognised by the law as a decision of themselves. This is, in my view, the current ‘frontier’ in supported decision-making.

7. It is relevant to note that some Courts in Australia are looking at ways to explore how supported decision-making type relationships may be able to replace some instances where previously a Litigation Guardian was appointed – this is partly in response to difficulties in finding suitable litigation guardians, delaying justice.

8. In other instances, Tribunals and Courts have attempted some reforms to how Litigation Guardians may operate. For example, section 67 of the *Administrative Review Tribunal Act 2024* (Cth) now refers to ‘litigation supporters’ and notes that the Tribunal must inter alia, consider the party’s will and preferences or likely will and preferences regarding the appointment of a litigation supporter.

Page 7 of the transcript: I am asked by **Mr Nathan Hagarty** about what is and isn't working in other jurisdictions.

9. Two critical items regarding supported decision-making, are firstly, that the right to supported decision-making (which flows from article 12 of the CRPD and is defined further by the Committee on the Rights of persons with Disabilities in *General Comment No. 1*) must be embedded in legislation. Secondly, the legislation must then work to give effect to realising that and other rights. This includes embedding a requirement that the agencies are obligated to provide that support when required.

10. What works is ensuring that decision makers have a clear legislated rights framework to reference, and that they *must* demonstrably consider these rights and principles in their decision making. The legislation must empower this where it does not do so already.

11. What we do know is that engaging with people with disability, ensuring that they are able to express their will and preferences, that their will and preferences are to be the primary consideration at all times, and that other inclusive and accessible practices and processes are implemented to support participation (as much as they may like) in any proceedings does result in better decisions and participant wellbeing. This can work across diverse spaces we noted previously – health and mental health, guardianship and financial management, justice, and education for example.

12. Relevantly, a key concept to note regarding supported decision-making is the difference between 'informal' supporters and 'formal' supporters. Informal supporters may be described as family members, carers, and friends and similar. Formal supporters are those supporters appointed by or recognised through a process by an agency to assist the agency in giving effect to rights. They can be an informal supporter who is then 'formally' recognised by an agency with authority operate in a narrow-defined context only. In practice they have much less scope than a current legally recognised 'guardian.' But being 'recognised' (approved after review) by the agency they have now more scope to act for the person requiring support than as just an informal supporter. Examples at a Federal level include the NDIS 'Plan Nominee' relationship. Victoria has perhaps made the greatest progress in this space - Part 4 of the Victorian *Guardianship and Administration Act 2019* allows for the appointment of a 'supportive guardian'. There are also options for a 'supportive administrator' in the case

of financial management matters. There are similar examples in Victoria regarding a ‘supportive attorney’ under the *Powers of Attorney Act*, and formalised ‘support persons’ and ‘nominated persons’ in the health and mental health space. A purpose of these is to minimise persons going straight to full guardianship by offering other options. The ‘supportive guardian’ option (as opposed to full guardianship) in Victoria appears to still be underutilised and not well understood.

13. These kinds of relationships are worth exploring further in New South Wales. What hasn’t worked well, is that those formal ‘supportive’ relationships are currently confined to the jurisdiction and agency that recognises them. This can explain in part why the Victorian supportive guardian option appears underutilised. It is not recognised anywhere else outside of the Tribunal. This is a not insignificant limitation for engaging with other spaces including the consumer space. As being registered as a ‘Plan Nominee’ for a person under the NDIS or as a ‘Supported Guardian’ under guardianship legislation is not currently recognised anywhere else as a formal ‘legal’ relationship, this forces those people with disability to still enter formal guardianship relationships to engage with some services and agencies, even when they may not be needed elsewhere, and when they are not wanted by the person with disability (and their family and carers for example) to start with.

14. To reduce reliance on formal guardianship, NSW should explore how a formal ‘supportive’ relationship can be implemented across all spaces, and how these formal relationships recognised by a Tribunal or the NDIS (for example) can be recognised across other agencies and jurisdictions, and indeed within the consumer sphere as well.

15. There are issues around safeguarding for both informal and formal supporters. And this is not the current context to discuss that in depth. However, it is worth noting that not all people with disability have access to informal support decision-making and support networks to start with. There is a potential inequity here. All people with disability need to be able to access supported decision-making if they choose.

Page 8 of the transcript: I am asked by **Ms Abigail Boyd** about the importance of enshrining the right to supported decision-making in legislation, including in the context of restrictive practices reforms.

16. The right to supported decision-making (with its basis in CRPD article 12 and developed by the Committee on the Rights of Persons with Disabilities in *General Comment No. 1*) is regarded as a critical 'foundational' right, from which the realisation or enabling of all other rights flows.

17. Article 12 highlights the critical importance of individual autonomy and inherent dignity as being central to what it means to be human. Autonomy is expressed through making decisions. It is recognised that we all have inherent legal capacity – this includes having legal standing (being recognised as a person with rights), and legal agency (the ability to act on those rights). It means that decisions we make must be respected. Ignoring our will and preferences means that our autonomy and legal capacity is being ignored. In short, it means our human rights are being fundamentally denied, which in turn means that our very recognition as a human being is threatened.

18. This is why supported decision-making is so critical and must be enshrined in legislation - it is rights affirming and human affirming. It is central to personal, social, legal and political identity. It cannot just be an aspiration or consideration. It must be a legal requirement. Indeed, CRPD article 12(3) places obligations on Australian governments to provide supported decision-making. If rights are not placed in legislation, then there is a real risk they can be ignored, let alone enforced.

19. Relevantly, supported decision-making is an important safeguard against violence, abuse, neglect and exploitation by giving voice to the lived experience of people with disability. It is a powerful tool for self-advocacy. Lived experience must inform all decisions made that impact people with disability.

20. Restrictive practices are problematic as they directly challenge key elements of what it means to be human noted above – they restrict autonomy. They are overwhelmingly used against people with disability and are in practice inherently discriminatory. They are routinely used without the consent of the person experiencing restrictive practices, ignoring will and preferences and in turn rights. They are by their nature, a form of 'legalised' or state sanctioned violence. Evidence before the Disability Royal

Commission showed that too often, they are used as a default option to respond to a situation causing further harm and trauma. Supported decision-making is one strategy, along with other rights affirming processes and practices, that must be utilised before there is any consideration of restrictive practices (I note PWDA has a longstanding position calling for the abolition of all restrictive practices). The goal is to understand what the person with disability needs, to support them to understand options, respond in a way that affirms that person's rights, including to their own safety and well-being, acknowledge their experience and understanding of the response, and adapt our engagement as necessary to ensure dignity is upheld. The aim is to reduce and eliminate the use of any restrictive practices.

21. If we are to reform restrictive practices frameworks to align them better with human rights-based principles and drive their full elimination over time (we note numerous recommendations have been made including from the DRC to immediately eliminate some of the most egregious, violent and dehumanising practices), then it is critical that legislated guidelines and policies around the use of supported decision-making as a process are implemented to frame and guide a conversation around rights, will and preferences. This must occur with the person with disability prior to any consideration about using restrictive practices. Again, the point of supported decision-making is to inform, support, de-escalate and build capacity and capability in the decision-making of the person with disability over time.

Page 8 of the transcript**: Mr Geoff Provest** asked me about barriers to supported decision-making for youth.

22. I note previously the comments I made regarding informal and formal supporters. Currently much supported decision-making goes on 'informally' – in homes for example, and within a developed peer or friendship group. We know from research that building the capacity of families, parents, carers and so forth to engage in supported decision-making in a proper rights affirming and structured way is still developing. We know from research that there are important safeguarding considerations around informal support relationships – the extent of undue influence for example may be hard to discern. So, a 'barrier' in a sense is the quality of understanding of supported decision-making by an informal supporter. But that shouldn't detract from most families, parents, and carers doing the best they can with limited resources to provide

incredible support in nurturing environments to children and young people with disability.

23. Importantly, we know from the research that having access to some kind of informal supporter network, based on some kind of trusted relationship, is far better than having access to no informal network. So, a key barrier to start with is the existence or not of an informal supporter network. The quality of the network becomes secondary (though no less important). Work on improving quality is ongoing and must be pursued within a multi-agency approach – children, young people, older people, First Nations, culturally and linguistically diverse etc. Supporting our children and young people better to develop and express autonomy results in adults with a clearer sense of identity and rights awareness, and strong decision-making confidence.

24. Another barrier which is not always recognised is where a child or young person with disability or older person with disability might engage in different spaces, but understanding of supported decision-making and human rights generally are not understand in the same way across each setting. So, for example, a child's parents or carers may be very focused on providing opportunities for decision-making practice and appreciate concepts such as 'evolving capacity' and dignity of risk. They have read lots of materials. But the child's teacher, or the coach at the sports club or a medical professional, or a police officer they ask for help or similar may have a different view of disability, perhaps one still rooted in ableism. Many people with disability encounter this within the employment space. So, the person with disability is confronted with these differing approaches at odds with what they have been taught at home for example. Human rights are really a whole of community concern – this is why we need consistency of understanding. That lack of consistency in approaches to rights, capability and participation restricts realisation of a positive community normative framework and is a barrier to inclusion. Everyone should understand rights and supported decision-making.

25. It is the case that there are significant numbers of children and young people with disability who do not have access to trusted informal supported decision-making relationships. This is concerning. These children may be living in Out of Home Care (OOHC) spaces. They may be in a Youth Justice Centre or other closed setting. They may be homeless. There is academic literature in this area examining the extent to which young people in OOHC were supported to make decisions about their lives, and

especially how they were supported to transition from OOHC (out of statutory care) and into ‘adulthood.’ Being completely reliant on care workers for that support (who may lack qualifications or not be in the position for very long before moving on) assistance was problematic and left young people with disability feeling very daunted and unprepared to transition from statutory care to adult independence.

26. The workers in those spaces can be better characterised as a kind of formal supporter. Those spaces need to be resourced to guarantee that all children and young people with disability have access to stable long term support workers so that real relationships of trust can be developed. More work needs to be done to ensure that people working with children and young people with disability in those settings above receive ongoing training (including in understanding intersectional identity matters, and cultural safety) and professional support to assist them to recognise and deliver rights and identity affirming opportunities for decision-making and participation in life planning.

We thank you again for the opportunity to provide some further clarification to our responses.

Yours sincerely

Julian Laurens
Senior Policy Officer
People with Disability Australia