

Women With Disabilities Australia (WWDA)

WOMEN WITH DISABILITIES AUSTRALIA (WWDA)

Review of the Applied Principles and Tables of Supports (APTOS)

NDIS Review

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ABOUT WOMEN WITH DISABILITIES AUSTRALIA (WWDA)

<u>Women With Disabilities Australia (WWDA)</u> Inc is the national Disabled People's Organisation (DPO) and National Women's Alliance (NWA) for women, girls, feminine identifying, and non-binary people with disability in Australia. As a DPO and an NWA, WWDA is governed, run, and staffed by and for women, girls, feminine identifying and non-binary people with disability.

WWDA uses the term 'women and girls with disability', on the understanding that this term is inclusive and supportive of, women and girls with disability along with feminine identifying and non-binary people with disability in Australia.

WWDA represents more than 2 million women and girls with disability in Australia, has affiliate organisations and networks of women with disability in most States and Territories, and is recognised nationally and internationally for our leadership in advancing the rights and freedoms of all women and girls with disability. Our organisation operates as a transnational human rights organisation - meaning that our work, and the impact of our work, extends much further than Australia. WWDA's work is grounded in a human-rights based framework which links gender and disability issues to a full range of civil, political, economic, social, and cultural rights. All WWDA's work is based on co-design with and participation of our members. WWDA projects are all designed, governed, and implemented by women and girls with disability.

Disabled People's Organisations (DPOs), also referred to as Organisations of Persons with Disabilities (OPDs) are recognised around the world, and in international human rights law, as self-determining organisations led by, controlled by, and constituted of, people with disability. DPOs/OPDs are organisations of people with disability, as opposed to organisations which may represent people with disability. The United Nations Committee on the Rights of Persons with Disabilities has clarified that States should give priority to the views of DPOs/OPDs when addressing issues related to people with disability. The Committee has further clarified that States should prioritise resources to organisations of people with disability that focus primarily on advocacy for disability rights and, adopt an enabling policy framework favourable to their establishment and sustained operation.¹

WWDA'S SUBMISSION: REVIEW OF THE APPLIED PRINCIPLES AND TABLES OF SUPPORTS (APTOS)

- 1. Women With Disabilities Australia (**WWDA**) welcomes the opportunity to provide feedback on the National Disability Insurance Scheme (**NDIS**) Applied Principles and Tables of Support (**APTOS**),² which set out the principles used to determine the funding and delivery responsibilities of the NDIS and other service systems. Noting that many of the principles have not been adequately implemented, and are clearly out of date, WWDA has continually called for their review for several years now.
- 2. The NDIS Review, as conducted by the Independent Review Panel, presents the ideal opportunity for the Australian Government to review and amend the APTOS to ensure better outcomes for people with disability within and outside of the NDIS, and across all service systems. We strongly recommend that the APTOS principles be reframed and updated in a human rights framework, consistent with, and reflecting the seven international human rights treaties to which Australia is a party.
- 3. In this brief Submission, as part of WWDA's contribution to the NDIS Review, we have focused on the six 'Principles' of APTOS, rather than the substantive detail of the entire APTOS document. We set out our key concerns and recommendations below, and trust that they will assist the NDIS Review Secretariat and Independent Review Panel.

Principle 1: People with disability have the same right of access to services as all Australians, consistent with the goals of the National Disability Strategy which aims to maximise the potential and participation of people with disability.

- 4. Under Article 9 of the Convention on the Rights of Persons with Disabilities, Australia is required to ensure that people with disability have access, on an equal basis with others, to the physical environment, transportation, information and communications (including information and communications technologies and systems), and to other facilities and services open or provided to the public.³ However, in practice, people with disability do not have the same access to services as people without disability in Australia. People with disability face barriers, discrimination, and ableism across all service systems and in all areas of life. This includes in relation to health; mental health; early childhood development; child protection and family support; school education; higher education and vocational education and training; employment; housing and community infrastructure; transport; justice; and aged care. It is therefore clear that Principle 1 has not been achieved for people with disability, within or outside of the NDIS.
- 5. Further barriers to accessing services arise in relation to the operation of the NDIS and its market model. Thin markets and a lack of inclusive and intersectional services impact what is available to participants of the Scheme, and in particular, participants experiencing multiple points of marginalisation. Simultaneously, there remains an absence of funded supports and services for people with disability who are not NDIS participants.

- 6. Pricing caps and a focus on specialised disability supports have allowed providers to capitalise on supports with a 'disability price tag', while mainstream services are not incentivised to become more accessible. NDIS participants are rarely able to use their funding for mainstream supports and, when they do, are charged a different (and greater) price than non-participants and people without disability.
- 7. People with disability in Australia urgently require the realisation of their right to access services, in both policy and practice. This requires greater investment in inclusion and accessibility across all service systems, with a focus on equity and intersectionality.

Principle 2: The NDIS will fund personalised supports related to people's disability support needs, unless those supports are part of another service system's universal service obligation (for example, meeting the health, education, housing, or safety needs of all Australians) or covered by reasonable adjustment (as required under the Commonwealth Disability Discrimination Act or similar legislation in jurisdictions).

- 8. Principle 2 is fraught for the many people with disability for whom disability and other attributes, needs and areas of life cannot be separated.
- 9. For example, for many people with disability, health and disability are inextricably linked. Article 25 of the Convention on the Rights of Persons with Disabilities requires the Australian Government to recognise that people with disability have the right to the highest attainable standard of health without discrimination.⁴ However, people with disability are often unable to obtain adequate healthcare including in relation to healthcare needs related to disability. In order to ensure that people with disability receive adequate supports and services for their disability-specific needs, the Australian Government should provide clearer guidance on which service system will be responsible for health needs that are related to or are a consequence of a person's disability. Within the NDIS, processes for determining where a participant's health needs are connected to their disability and should therefore be funded by the Scheme, should be clarified and simplified.
- 10. Further, despite the delineation of responsibilities in relation to health as set out in the Table of Supports, people with disability often have health 'maintenance' needs that are related to disability but relegated to the health system. Many NDIS participants also face significant barriers to proving the 'stability' of impairments in terms of functional capacity, which prohibits their use of NDIS funds for medical costs. This results in significant out-of-pocket costs for disability-related needs.
- 11. In addition, the evidence suggests that the NDIS and the health system are not working together at the local level to ensure service delivery or smooth transitions between service systems. Transitions between hospital settings and the NDIS are notoriously protracted, with some patients with acquired disability remaining in hospital for up to 600 days from being clinically ready for discharge, while waiting on NDIS planning processes.⁵ The use of

NDIS funding for allied health services is also problematised where participants are advised that certain services are the responsibility of the health system, even where they are related to disability-specific needs. For example, WWDA has heard that Autistic participants have been advised that they will not be allocated funding for psychology. Many participants are also charged higher rates for allied health services than non-participants and people without disability, due to the operation of pricing caps as pricing 'anchors'.

- 12. Similar difficulty arises in relation to the education system. Although the Table of Supports provides that the NDIS will fund supports that students require due to the impact of their disability on their functional capacity (and that are additional to reasonable adjustments), there are often informal understandings that the NDIS will not fund such supports. This creates a situation whereby education providers may be required to directly fund specialised disability training or school transport arrangements for students who are NDIS participants. This has tangible consequences, because education providers may use this expenditure as rationale for determining that a student's enrolment or adjustment causes 'unjustifiable hardship' for the purposes of an exception to their anti-discrimination obligations (as further detailed below).
- 13. In relation to the provision of reasonable adjustments for disability (pursuant to the *Disability Discrimination Act 1992* (Cth) or state or territory anti-discrimination frameworks), we note that this mechanism is not comparable to, or a substitute for, funded personalised supports. It is often ineffective in practice and relies on individuals with disability or their supporters to identify, request, and pursue a specific adjustment within a service system, often based on individual evidence and advocacy.
- 14. The mechanism is also undermined by the exceptions that apply and how those exceptions are used in practice. Under the Act (and equivalent legislation) discrimination may be lawful if avoiding the discrimination would impose an 'unjustifiable hardship' on the discriminator. When considering whether an unjustifiable hardship would be imposed, a potential discriminator is required to consider, among other things, the relevant financial circumstances, the estimated amount of expenditure required, and the availability of financial and other assistance to that person (or organisation). In practice, it is also often relevant whether the individual requiring the adjustment has access to financial assistance, such as NDIS funding. This creates a situation in which NDIS participants (or those with access to other funding) may be more likely to have adjustments made to meet their needs.
- 15. Further, the availability of legal remedy where a service system fails to make a reasonable adjustment for a person with disability, does not equate to the delivery of that adjustment, or the provision of some form of disability support. People with disability in Australia urgently require a new model of service delivery, in tandem with proactive and intersectional human rights legislation that protects against systemic discrimination.

Principle 3: Clear funding and delivery responsibilities should provide for the transparency and integrity of government appropriations consistent with their agreed policy goals.

16. Principle 3 has not resulted in transparency regarding service delivery, or clarity about where responsibility for services for people with disability lies. There remains a disconnect between the stated availability of supports for people with disability, and the actual availability of such supports. As Olney, Mills and Fallon (2022) have written:

There is a clear gap between what is promoted and what is happening in the interface between people with disability who are not NDIS participants and the NDIS.⁶

- 17. For example, while NDIS Local Area Coordinators are stated to be tasked with providing information and connecting non-participants with services and community-based supports, it appears that this does not occur in practice.⁷ Disability Representative Organisations, including WWDA, fill this critical gap despite not being funded to do so.
- 18. The majority of supports and services for people with disability outside of the NDIS are provided by unpaid family members and supporters, many of whom are people with disability themselves.

Principle 4: There should be a nationally consistent approach to the supports funded by the NDIS and the basis on which the NDIS engages with other systems, noting that because there will be variation in non-NDIS supports funded within jurisdictions there will need to be flexibility and innovation in the way the NDIS funds and/or delivers these activities.

- 19. Principle 4 has not resulted in a nationally consistent approach to the supports funded by the NDIS and by other systems.
- 20. Problematically, the approach of the NDIS to funding is at times not even consistent between different touch points for individual participants. For example, WWDA members report receiving different answers about the use of their funding each time they engage with an NDIS representative. Some members have sought prior written approval for supports, have had their claims approved for such supports, and have then been advised that the approval is rescinded and the participant must repay the funds.
- 21. While balancing the need for flexibility and innovation, people with disability urgently require clarity and transparency regarding the supports funded by the NDIS and the supports that will be provided by other service systems.

Principle 5: In determining the approach to the supports funded by the NDIS and other service systems, governments will have regard to efficiency, the existing statutory responsibilities and policy objectives of other service systems and operational implications.

22. As the Disability Advocacy Network Australia has written in its recent publication, *NDIS Review: Mainstream and Tier 2*:

Inconsistent eligibility, availability and accessibility of support across different service systems and places, out-of-pocket costs, significant gaps between supply and demand for services and support, and confusing and competing sources of information about the service landscape are preventing people from being able to find - or even begin to ask for – support outside the NDIS.⁸

23. Unfortunately, it remains unclear which disability supports and services are actually funded and available outside of the NDIS. The Australian Government must ensure that its focus is centered upon the practical reality of interactions between service systems, over and above policy objectives and statutory responsibilities. Policy objectives and statutory responsibilities must be revised, based on consultation with people with disability, to identify and address unmet needs and critical gaps in service availability and delivery.

Principle 6: The interactions of people with disability with the NDIS and other service systems should be as seamless as possible, where integrated planning and coordinated supports, referrals and transitions are promoted, supported by a no wrong door approach.

- 24. The failure to adequately implement Principle 6 has had severe implications for people with disability, with the NDIS and other service systems remaining difficult and in some cases impossible to navigate.
- 25. In a 2022 study of access to support for people with disability without individual NDIS funding, almost all participants reported that the support or services they accessed were not adequate to meet their needs.⁹ Cost, inability to access what they needed, not knowing where to look for what they needed, feeling that their needs were not understood, and negative prior experiences were the most commonly cited reasons for this response.¹⁰ These barriers were also the most commonly cited reasons for not using supports or services at all, alongside rigid eligibility requirements, and finding the services too difficult to engage with.¹¹ Similarly, WWDA members consistently report that their interactions with the NDIS and other service systems are laborious, inaccessible and traumatising. The examples reported by WWDA members include:
 - NDIS application processes taking multiple years to complete, and requiring thousands of dollars of expenditure;
 - Being met with judgmental and/or misinformed attitudes from frontline workers of the NDIS who often act as gatekeepers to critical supports and services;
 - Being unable to apply for the NDIS in accessible ways (i.e. verbally), despite advice to the contrary on the NDIS website; and
 - Being unable to enter the local NDIS office because it does not have ramps.

- 26. Planning, coordination, referrals and transitions are often not integrated or supported in practice, and it is common for people with disability to be referred back-and-forth through multiple organisations with no resolution. WWDA regularly receives calls for crisis support or referrals, notwithstanding that we are not funded to provide crisis services, auspicing, or individual advocacy. Many of these calls are from services directly, who do not have funding, resources or capacity to assist.
- 27. Disability Representative Organisations have long called for a 'no wrong door approach' to services and supports, but people with disability continue to experience what is better described as an 'all wrong doors' approach. Many WWDA members report giving up on their search for supports and services, or being deterred after observing others' experiences. For a number of WWDA members who are women with disability themselves, seeking support for their disabled children has been traumatising, and deters them from seeking support for themselves.
- 28. Principle 6 should be revised to include that the interactions people with disability have with service systems should be accessible, culturally safe and trauma-informed. Principle 6 must then be urgently implemented.

ENDNOTES

4 UN General Assembly (2007) Convention on the Rights of Persons with Disabilities. United Nations General Assembly. A/RES/61/106.

5 Cubis, L., Ramme, R.A., Roseingrave, E., Minter, E., Winkler, D., & 1,2 Douglas, J. 1,2 (2022). Evaluating the discharge planning process: Barriers, challenges, and facilitators of timely and effective discharge for people with disability and complex needs. Melbourne. Australia: Summer Foundation.

6 Olney S, Mills, A & Fallon L (2022) The Tier 2 tipping point: access to support for working-age Australians with disability without individual NDIS funding. Melbourne Disability Institute, University of Melbourne.

7 Disability Advocacy Network Australia (2023) NDIS Review: Mainstream and Tier 2 Discussion Paper. Disability Advocacy Network Australia.

8 Disability Advocacy Network Australia (2023) NDIS Review: Mainstream and Tier 2 Discussion Paper. Disability Advocacy Network Australia.

9 Olney S, Mills, A & Fallon L (2022) The Tier 2 tipping point: access to support for working-age Australians with disability without individual NDIS funding. Melbourne Disability Institute, University of Melbourne.

10 Olney S, Mills, A & Fallon L (2022) The Tier 2 tipping point: access to support for working-age Australians with disability without individual NDIS funding. Melbourne Disability Institute, University of Melbourne.

11 Olney S, Mills, A & Fallon L (2022) The Tier 2 tipping point: access to support for working-age Australians with disability without individual NDIS funding. Melbourne Disability Institute, University of Melbourne.

¹ Committee on the Rights of Persons with Disabilities, General Comment No. 7 on the Participation of Persons with Disabilities, Including Children with Disabilities, through Their Representative Organizations, in the Implementing and Monitoring of the Convention, UN Doc CRPD/C/GC/7 (9 November 2018).

² See: <u>https://www.dss.gov.au/sites/default/files/documents/09_2021/ndis-principles-determine-responsibilities-ndis-and-other-service-1.pdf</u>

³ UN General Assembly (2007) Convention on the Rights of Persons with Disabilities. United Nations General Assembly. A/RES/61/106.