

Winner, National Human Rights Award 2001
Winner, National Violence Prevention Award 1999
Winner, Tasmanian Women's Safety Award 2008
Certificate of Merit, Australian Crime & Violence Prevention Awards 2008
Nominee, UNESCO Prize for Digital Empowerment of Persons with Disabilities 2020
Nominee, National Disability Awards 2017
Nominee, French Republic's Human Rights Prize 2003
Nominee, UN Millennium Peace Prize for Women 2000

Senator the Hon. Linda Reynolds

Minister for the National Disability Insurance Scheme

Via Email: senator.reynolds@aph.gov.au

Via Email: <u>Garry.Simpson@servicesaustralia.gov.au</u>

Via Email: Michelle.Lewis@aph.gov.au

Cc Via Email: martin.hoffman@ndis.gov.au

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29 September 2021

Dear Minister Reynolds,

I write to you from Women With Disabilities Australia (WWDA), to provide a brief Submission in response to the National Disability Insurance Scheme (NDIS) Consultation Paper on *'Supporting you to make your own decisions' (the Consultation Paper)*.¹

We thank you for the opportunity to provide this response to the NDIS Consultation Paper. This response is informed by the experiences of our membership and networks, including women and girls with disability who require support to make decisions, their families, carers, support people, friends, and representative networks. WWDA also draws on our plethora of work in the human right to decision making space to inform this response, particularly WWDA's response to the *Good Practice in Supported Decision-making for People with Disability Project*² (the project) Consultation Document, developed by the University of NSW (UNSW) Social Policy Research Centre.

As you are aware, WWDA is the only national Disabled People's Organisation (DPO)³ for women, girls, feminine identifying, and non-binary people with all types of disability in Australia; and uses the term 'women and girls' to refer to our members. WWDA is managed and run by women with disability and represents more than two million disabled women and girls in Australia. WWDA has affiliate organisations and networks of women with disability in most States and Territories of Australia and is recognised domestically and internationally for our leadership in advancing the rights and freedoms of women and girls with disability.

Universally, women are systematically under-represented in decision-making processes that shape their societies and their own lives. It is widely recognised that women and girls with disability have fewer opportunities, lower status and less power and influence than men and boys with disability.⁴

Additional to the life stages approach⁵ outlined in the Discussion Paper, WWDA takes this opportunity to discuss the importance of a gendered perspective to decision making. Women and girls with disability in Australia, particularly women and girls with intellectual and/or cognitive disability, continue to be denied their basic rights to make fully independent or supported choices about their own lives, bodies, and goals.⁶ The denial of their decision-making rights can range from small choices about what to eat and what to wear, to more important life choices, like where to live,

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with whom and whether to have a partner and/or children. These are specific issues impacting women and girls with disability and WWDA is concerned that a gender-blind approach to decision-making by the NDIA will compound the situation for many women and girls who continue to lack agency in their own lives.

WWDA cautions against the use of Support Coordinators and service providers as Formal Decision Supporters as discussed in the Discussion Paper⁷ due to the inherent conflict of interest and lack of transparency this may create. Independent advocacy needs to be in place for people who have no other options for support with decision making. Natural supports are also critical and must be acknowledged and respected.

WWDA welcomes the ideals expressed in the discussion paper where the NDIA asserts:

We have the opportunity to drive a change in decision making for people with a disability. We want to:

- challenge perceptions of decision-making capacity
- emphasise an individual's rights for decision making
- identify appropriate safeguards
- build the capability of staff and partners working with you
- encourage greater involvement in decisions
- recognise informal supports and their role
- help all decision supporters to involve you with decisions that impact your life.⁸

However, WWDA asserts that ensuring all Australian women and girls with disability (not just those in receipt of NDIS supports and services) can fully exercise their human rights will require the complete dismantling of the current systems that regulate decision-making. The safeguards that are built to replace these problematic systems must be co-designed, implemented, and monitored in full and ongoing consultation with women and girls with disability and the DPOs that represent them.

WWDA seeks further clarification and insight about how the NDIA intends to ensure the following, as stated in the Discussion Paper, particularly given many NDIS participants have formalised substitute decision makers:

"We expect as a result of implementing this policy:

- You will have increased ability to exercise choice and control.
- Our staff and partners will have increased understanding of support for decision making best practice. They will be able to support you to be more involved in decision making.
- Your capacity to making decisions in day-to-day life outside of the NDIS will increase.
- You will experience increased self-determination and autonomy leading to increased well-being.
- Decision supporters will be able to better support you in your decision making and to build their capacity.
- · Community inclusion will improve.

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- Public perception of people with disability will improve.
- You will exercise greater autonomy in decisions about your life.9"

WWDA warns against making statements the NDIA may not be able to live up to, given the system of substituted decision making that exists in Australia.

WWDA has undertaken significant work around supported decision-making over many years, including the development of the *WWDA Position Statement 2: Right to Decision-Making*¹⁰(the Position Statement). The Position Statement includes key evidence concerning the exclusion of women and girls with disability from decision-making processes and outlines in detail Australia's human rights obligations. The Position Statement makes seven recommendations to improve the fulfilment of women and girls with disability's right to decision-making on an equal basis with others.

WWDA believes:

- the right to decision-making is fundamental to the realisation of agency, autonomy, and self-determination.
- women and girls with disability must be afforded their full decision-making rights and opportunities in all aspects of their lives.
- women and girls with disability have the right to receive all necessary supports to make meaningful and informed decisions. Support must respect the human rights, autonomy, will and preferences of women and girls with disability and should never amount to substitute decision-making.
- accurate and accessible information is a prerequisite for the provision of active, free, and informed consent and meaningful decision-making of women and girls with disability in all matters.
- the widespread denial of the right of women and girls with disability to make decisions is continuing unabated due to paternalistic attitudes, problematic stereotypes, deep-rooted inequality, and extreme forms of discrimination against women and girls with disability.

Decision-making is a human right for all people, not a privilege reserved only for some. WWDA asserts that good practice supported decision-making guidelines must be grounded in a human rights framework. In the context of supported decision-making for people with disability, Australia is a party to seven core international human rights treaties:

- Convention on the Elimination of All Forms of Racial Discrimination 1965 ([1975] ATS 40).
- International Covenant on Economic, Social and Cultural Rights 1966 ([1976] ATS 5).
- International Covenant on Civil and Political Rights 1966 ([1980] ATS 23).
- Convention on the Elimination of All Forms of Discrimination against Women 1979 ([1983] ATS 9).
- Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment 1984 ([1989] ATS 21).
- Convention on the Rights of the Child 1989 ([1991] ATS 4).
- Convention on the Rights of Persons with Disabilities 2006 [2008, ATS 12].

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As a party to these treaties, Australia has chosen to be bound by the treaty requirements and has an international legal obligation to implement the treaty provisions through its laws and policies. The Convention on the Rights of Persons with Disabilities [CRPD) clearly mandates State Parties to recognise that persons with disabilities enjoy legal capacity on an equal basis with others and should be supported to exercise their legal capacity (CRPD Art. 12). This means that an individual's right to decision-making cannot be substituted by decision-making of a third party, but that each individual without exception has the right to receive the supports they need to make their own choices and to direct their own lives, whether in relation to medical treatment, family, parenthood and relationships, or living arrangements.11 The CRPD also requires respect for the evolving capacities of children (CRPD Art 3 and 7) and the provision of support for children with disability to express their views, and for these views to be given appropriate weight in the context of their age and maturity.

WWDA is concerned by assertions in the Discussion Paper around substituted decision making and seeks further clarity around how the NDIA intends to:

"... keep encouraging substitute decision makers to involve you in decisions about you and help you to practice your decision making. We will also try to influence substitute decision authorities to help their staff to do this too."12

Currently the NDIA has no power or mandate to enforce this.

WWDA is concerned that in the example of the decision-making process in the Discussion Paper (in Appendix B Framework for Action), substituted decision making is still considered an option. How is this different to what operates now? And how is this consistent with CRPD Article 12? The Committee on the Rights of Persons with Disabilities, in its 2019 review of Australia's compliance with the CRPD, recommended that Australia:

"repeal laws and policies the deny or diminish the right of people with disability to exercise legal capacity and implement a nationally consistent supported decision-making framework".13

If the Australian Government is to meet its obligations under the human rights treaties to which it is a party, WWDA has long advocated that it must abolish the current substitute decision-making regimes and mechanisms that deny women and girls with disability the opportunity to make their own decisions or recognise their legal capacity.

Additionally, WWDA calls on the Australian Government to immediately withdraw its Interpretative Declarations on CRPD Article 12 [Equal recognition before the law], Article 17 [Protecting the integrity of the person] and Article 18 [Liberty of movement and nationality]. ¹⁴ These Interpretative Declarations restrict effective implementation of the CRPD, prevent reform and allow for human rights violations including denial of legal capacity, forced treatments, and substitute-decision making.15

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WWDA believes key elements that are essential to good practice supported decision-making include the following:

· Genuine participation by decision-maker at every stage

WWDA believes women and girls with disability should be engaged and consulted at every stage of good practice supported decision-making. However, currently women and girls with disability continue to be denied the right to participate in and remain largely excluded from decision-making about issues that affect their lives and those of their families, communities, and nations. Too often, they have their views ignored or disregarded in favour of 'experts', 'professionals', parents, guardians, and carers, as well as representatives of organisations not controlled and constituted by women with disability themselves.¹⁶

If women and girls with disability are involved in the decision-making process, it is often done as an 'after thought', right before or even after the decision is made. This leaves women and girls with disability with insufficient time to understand and consider the information, choices and potential consequences of the decision or seek support from a trusted or independent source.

Women and girls with disability who live in institutional environments, including residential group homes and other forms of supported accommodation facilities, often have limited opportunities for meaningful decision-making, and are at high risk of coercion.¹⁷ Those who have lived most of their lives in institutional or semi-institutional environments may have had limited (or no) opportunities to articulate their needs, preferences and wishes, and may be fearful about disagreeing with decisions made by others on their behalf due to prior and ongoing experiences of sexual and other forms of violence and abuse.¹⁸

Women and girls with communication impairments and/or little or no speech may also be denied or have restricted opportunities to make decisions and articulate their needs preferences and wishes.¹⁹

Access to accurate, accessible, and appropriate information

Good practice supported decision-making is dependent on access to accurate, accessible, and appropriate information.²⁰ Yet many women and girls with disability are denied the right to seek, receive and impart information about decisions affecting their lives.

For many women and girls with disability, access to information about their legal and human rights is limited, particularly for women and girls with intellectual disability, and for those who are incarcerated, hospitalised, and/or who live in other institutional or semi-institutional residential environments.²¹

Restricted and limited access to information and opportunities for education about decision-making and rights, combined with prejudicial social attitudes and systemic discrimination, reproduce social

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and gendered inequality, and contribute to women and girls with disability experiencing, and at risk of violations of their human rights.

The information needed to make informed decisions is rarely made available to women and girls with disability in timely, comprehensive, and accessible ways. Government agencies and service providers rarely provide information in the full range of accessible formats, such as in as sign language, Braille, large print, audio, Easy English, plain and/or non-technical language, captioned video, in languages other than English, or through the provision of accessible and usable web sites.²²

· Impartial information presented free from coercion

Good practice supported decision-making ensures all relevant information and options are presented in an unbiased manner.

Currently, supported decision-making for women and girls with disability is regularly limited and/or undermined by familial, institutional, and professional gatekeepers, including service providers, care/support staff and family members.²³

Many women and girls with disability can be presented with limited options when making decisions because others determine that they 'lack capacity' to understand the full range of choices. Such judgements often lead to substitute decision-making processes whereby others decide on a woman or girl's behalf what is in her 'best interests'. This is particularly the case for women and girls with intellectual disability – where the diagnosis of intellectual disability is assumed to equate with a lack of capacity to make decisions.²⁴

Substitute decision-making and 'best interests' approaches have been criticised as fundamentally contravening the CRPD and as intrinsically value laden.²⁵ In practice, the 'best interests' approach most often serves the interests of guardians and paid/unpaid carers.²⁶ This is particularly dangerous for women and girls with disability who are significantly more likely to experience domestic/family and other forms of gender-based violence, meaning decisions are often influenced or made by those perpetrating violence and abuse.

Good practice supported decision-making occurs when a person can make decisions without pressure or coercion from any other individual. Any guidelines for good practice supported decision-making must recognise and include processes to mitigate the higher risk of coercion faced by marginalised groups within the general population of people with disability. Those at higher risk of coercion include women and girls with disability, children with disability and people with disability who are reliant on carers for personal care and mobility.

For women with disability, a common example of 'questionable supported decision-making' occurs around the use of contraception. While there are many contraception choices available, women with disability, particularly women with intellectual and/or cognitive disability, are often steered towards

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either long-acting contraceptives, such as Depo-Provera injections or Intrauterine devices (IUDs) or encouraged to undergo sterilisation. While a woman may 'agree' to this, their decision is made without an informed understanding of the long-term consequences or the benefits of other available options. This is supported decision-making at its worst as it is often the result of pressure from family, carers, guardians and/or medical professionals.

Access to independent advocacy supports

Women and girls with disability should have access to independent support and advocacy to ensure good practice supported decision-making.

For many women and girls with disability, families are not always a natural safeguard. While many families can be very supportive, families can also be a site of violence, exploitation, and abuse for people with disability.

While education is needed for informal supports such as parents, family, and carers to understand and facilitate good practice supported decision-making under the right circumstances, DPOs and independent advocacy supports should be viewed as the preferred safeguard for people with disability.

The role of independent advocacy, including individual, systemic, and self-advocacy, is critical to ensuring women and girls with disability can fully exercise their right to decision making.

The importance of 'independent' advocacy should be understood in the context of implementation of the CRPD,²⁷ including that:

- independent advocacy is a critical, interconnected component of progressing the human rights of people with disability and supporting Australia's international human rights obligations
- in the changing disability service landscape advocates are often the only constant independent support for people with disability
- NDIS participants and people with disability not eligible for the NDIS must have equal access to independent advocacy supports
- advocacy support that is owned and managed by Aboriginal and Torres Strait Islander peoples and communities should be developed and resourced
- independence from service systems and disability support agencies is critical to ensuring that advocacy support is free from conflicts of interest and always puts the rights, will and preference of people with disability at the forefront
- investment, funding and resourcing for representation and independent advocacy needs to be available from both Commonwealth and State and Territory Governments.

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However, in its 2019 review of Australia's compliance with the CRPD, the CRPD Committee expressed concern at the lack of sustainably, adequately resourced continuous, individual, and independent advocacy programs, and recommended that Australia:

"Ensure that all persons with disability have access to continuous, sustainable and adequately resourced individual and independent advocacy programmes, particularly outside the NDIS."²⁸

The Interim Report of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability,²⁹ released on 30th October 2020 highlighted similar concerns:

"We have heard from many advocacy and representative organisations that increased advocacy is a key measure to address violence, abuse, neglect and exploitation and would lead to a more inclusive society. We have also heard that there is a lack of advocacy services, including for First Nations people with disability and people with complex needs, and that existing advocacy services are under-funded."³⁰

Additionally, WWDA continues to call on state, territory, and federal governments to increase core funding for DPOs and independent advocacy supports to ensure people with disability can assert and exercise their right to decision-making.

Well-resourced supports provided by trained professionals

All people working with people with disability, particularly women and girls with disability, should be adequately trained to understand and facilitate good practice supported decision-making. However, workforce training and development around supported decision-making remains inadequate. Training for disability support workers, health professionals and community service providers is too often based on a medical model of disability and lacks the human rights principles that support the rights and autonomy of people with disability.

Inadequate resourcing for supports, particularly for people with intellectual and/or cognitive disability and people living in institutional settings, also leads to poor supported decision-making processes. Women living in institutional or semi-institutional settings report that disability support workers, health professionals and community service providers are often unable to provide good practice decision-making support due to being understaffed or not being allocated sufficient time for one-on-one support.

WWDA acknowledges the work the NDIA is undertaking to ensure a Supported Decision-Making model for NDIS participants. Embedding good practice supported decision-making processes in state and national legislation is key to ensuring the human rights of women and girls with disability are upheld. Given the increased barriers, discrimination and violence experienced by women and girls with disability, WWDA believes the NDIA must explicitly acknowledge and seek to mitigate gender inequality in supported decision-making.

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The NDIA's framework for supported decision making must be based on Australia's legal obligations under human rights treaties. The framework must also seek to address the current gaps in supported decision-making provision, including ensuring women and girls with disability can genuinely participate at every stage of the process with access to accurate, accessible, and appropriate information; impartial information presented free from coercion; independent advocacy services, and supports delivered by trained professionals.

Thank you again for the opportunity to provide feedback on the NDIS Consultation Paper on 'Supporting you to make your own decisions'.

Our organisation looks forward to continuing to collaborate with you and the NDIA.

Yours sincerely

Carolyn Frohmader **Executive Director**

Women With Disabilities Australia (WWDA)

Finalist, 100 Women of Influence Awards 2015 Australian Human Rights Award (Individual) 2013 State Finalist Australian of the Year 2010 Inductee, Tasmanian Women's Honour Roll 2009 Australian Capital Territory Woman of the Year Award 2001

Endnotes

¹ National Disability Insurance Scheme (2021) Consultation Paper: Supporting you to make your own decisions. National Disability Insurance

Final Report found here: https://apo.org.au/node/313465

³ DPOs are organisations made up and governed by people with disability for people with disability
⁴ Women with Disabilities Australia (WWDA) (2010) 'Gendering the National Disability Care and Support Scheme: WWDA Submission to Stage One of the Productivity Commission National Disability Care and Support Inquiry'. Available online at: http://wwda.org.au/wp-

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⁶ Frohmader, C. (2013) 'Dehumanised: The Forced Sterilisation of Women and Girls with Disabilities in Australia', Women with Disabilities Australia (WWDA), Rosny Park, Australia

National Disability Insurance Scheme (2021) Consultation Paper: Supporting you to make your own decisions. National Disability Insurance Agency. p. 15.

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10 Women with Disabilities Australia (WWDA) 'Position Statement 2: Right to Decision-Making'. WWDA, September 2016, Hobart, Tasmania. Available at: https://wwda.org.au/publication/confpaps2016-4/.

¹¹ Frohmader, C. (2013) 'Dehumanised: The Forced Sterilisation of Women and Girls with Disabilities in Australia' - WWDA Submission to the Senate Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia; ISBN: 978-0-9876035-0-0. Available online at:

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The Committee on the Rights of Persons with Disabilities (2019) Concluding observations on the combined second and third periodic reports of Australia, adopted by the Committee at its 511th meeting (20 September 2019) of the 22nd session; UN Doc. CRPD/C/AUS/CO/2-3.

The Committee on the Rights of Persons with Disabilities (2019) Concluding observations on the combined second and third periodic reports of Australia, adopted by the Committee at its 511th meeting (20 September 2019) of the 22nd session; UN Doc. CRPD/C/AUS/CO/2-3. legal capacity on an equal basis with others in all aspects of life. Australia declares its understanding that the Convention allows for fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards; **CRPD Article 17**: Australia recognizes that every person with disability has a right to respect for his or her physical and mental integrity on an equal basis with others. Australia further declares its understanding that the Convention allows for compulsory assistance or treatment of persons, including measures taken for the treatment of mental disability, where such treatment is necessary, as a last resort and subject to safeguards; **CRPD Article 18:** Australia recognises the rights of persons with disability to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others. Australia further declares its understanding that the Convention does not create a right for a person to enter or remain in a country of which he or she is not a national, nor impact on Australia's health requirements for non-nationals seeking to enter or remain in Australia, where these requirements are based on legitimate, objective and

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15 Committee on the Rights of Persons with Disabilities, General Comment No.1 – Article 12: Equal recognition before the law, 11th sess, UN Doc CRPD/C/GC/1 (19 May 2014).

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²¹ Frohmader, C. & Sands, T. (2015) OpCit.

²² Women with Disabilities Australia (WWDA) and People with Disability Australia (PWDA) (2015) Joint Submission to the Committee on the Rights of Persons with Disabilities - Draft General comment on Article 6: Women with Disabilities. Prepared by Carolyn Frohmader for and on behalf of

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25 Australian Human Rights Commission (2014) Draft General Comment on Art. 12 CRPD, AHRC Submission to the UN Committee on the Rights of Persons with Disabilities, AHRC, Sydney. See also: Frohmader, C., & Sands, T. (2015) OpCit.

26 Juan E. Mendez, Special Rapporteur, 'Report of the Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment, 22nd session, UN Doc A/HRC/22/53 (1 February 2013).

27 Women with Disabilities Australia (WWDA) (2020). 'The National Disability Strategy Beyond 2020: WWDA Response to the NDS Position Paper'. November 2020. WWDA: Hobart, Tasmania.

²⁸ Committee on the Rights of Persons with Disabilities (2019) Concluding observations on the combined second and third periodic reports of Australia, adopted by the Committee at its 511th meeting (20 September 2019) of the 22nd session; UN Doc. CRPD/C/AUS/CO/2-3. Retrieved from

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