



Women
With
Disabilities
Australia
(WWDA)

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

Mr. Martin Hoffman
Chief Executive Officer
National Disability Insurance Agency
GPO Box 700
Canberra ACT 2601

Via email: martin.hoffman@ndis.gov.au
Cc: engagement@ndiscommission.gov.au
Cc: senator.reynolds@aph.gov.au

Date: 18 May 2021

Dear Mr Hoffman,

I write to you as the CEO of Women With Disabilities Australia (WWDA) in response to the National Disability Insurance Scheme (NDIS) Consultation Paper on '*Interventions for Children on the Autism Spectrum*' (the Consultation Paper).¹

We thank you for the opportunity to provide this response to the NDIS Consultation Paper. This letter is informed by feedback from our membership, including Autistic women and girls, their parents, carers, support people and representative networks. In line with the communities preferred terminology, we use the term 'Autistic' to refer to individuals on the Autism Spectrum.

As you may be aware, WWDA is the only national Disabled People's Organisation (DPO)² 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.

While we understand and welcome the need for a more effective and evidence-based approach to supporting Autistic children through the NDIS; we are concerned that the approach reflected in the

¹ National Disability Insurance Scheme (2020) [Consultation paper: Interventions for children on the autism spectrum](#), *National Disability Insurance Agency*.

² DPOs are organisations made up and governed by people with disability for people with disability.



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

Consultation Paper is inconsistent with both the views of the Autistic community and with the evidence base that it refers to. In addition, we hold significant reservations about the ability of the proposed approach to address the complex needs of Autistic girls, who already have low participation rates in the NDIS compared to men and boys, despite Autism Spectrum Disorder (ASD) being the largest primary disability category in the NDIS.³

Across Australia, Autistic NDIS participants make up 29% of total participants, but among these, only 14, 854 (22%) are women and girls, compared to 51, 007 (76%) men and boys;⁴ a gap which is even wider for participants under 14 years.⁵ While NDIA reports claim that this participation gap is due to the higher rate of Autism in men and boys, compared to women and girls;⁶ evidence suggests that the perceived higher prevalence of boys with a diagnoses is due to gender biases in diagnostic processes; rather than a actual significant difference in numbers.⁷

Rather than addressing these biases, WWDA is very concerned that the approach to supporting Autistic children that is presented in the Consultation Paper is a gender-blind one that not only ignores the gender inequality inherent in the identification of Autism, but also threatens to exacerbate the discrepancy in participation rates and deny access to the limited supports that are currently available. In addition, WWDA is concerned that the proposed approach to 'supporting' Autistic children sits in contradiction with Australia's responsibilities under Article 6 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which requires states parties to take measures to ensure women with disabilities can access "the full and equal enjoyment - of all human rights and fundamental freedoms."⁸ Our reasons are explained in the remainder of this letter.

Inconsistencies in decision-making

Throughout the Consultation Paper, the NDIA refers to the need to only fund and support early interventions that are backed up by "research evidence."⁹ However, the references used to sites such as the Better Health Channel and the Raising Children website, are inconsistent with

³ National Disability Insurance Scheme (2020) '[Outcomes for participants with Autism Spectrum Disorder.](#)'

⁴ Ibid, p. 22

⁵ National Disability Insurance Scheme (2019) [Analysis of Participants by Gender](#), National Disability Insurance Agency, p. 8

⁶ National Disability Insurance Scheme (2019) [Analysis of Participants by Gender](#), National Disability Insurance Agency, p. 15

⁷ See e.g. Haney, JL (2016) [Autism, females, and the DSM-5: Gender bias in autism diagnosis](#), Social Work in Mental Health, Vol. 14, no 4, pp. 396-407.

⁸ Committee on the Rights of Persons with Disabilities (2016) General comment No. 3. Article 6: Women and girls with disabilities. UN Doc. No. CRPD/C/GC/3.

⁹ National Disability Insurance Scheme (2020) [Consultation paper: Interventions for children on the autism spectrum](#), National Disability Insurance Agency, p. 4, 7, 10, 11, 14, 16, 21, 23 etc.



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

academic protocols which consider research evidence to be only papers that are peer reviewed and published in academic journals.¹⁰

In addition, the proposal to only support interventions that are backed by "research" is not consistent with the NDIS aim of providing choice and control to participants. For example, on page 15 of the Consultation Paper, it is stated that supports must be "evidence based and have measurable outcomes;"¹¹ meaning that interventions that are not measurable will not be supported by the NDIS. The Consultation Paper gives the example of weighted blankets, which Autistic children and their parents commonly find beneficial for anxiety and sleep habits. In this instance, the Consultation Paper states that a weighted blanket would be considered an everyday expense that is not funded by the NDIS, because of a lack of research evidence on their efficacy; even though therapists, parents, carers and participants find that weighted blankets are helpful.¹²

Limitations of Evidence base

While WWDA understands the need to consider research backed evidence, we are concerned that the proposed approach undermines the Scheme's ability to adequately support participants, as well as Article 7 of the CRPD, which asserts that any decisions made that affect children with disabilities should consider the interests of the child to be the highest primary consideration.¹³ In contrast with Article 7, the prioritisation of 'research evidence' risks dismissing the interests of Autistic children, in favor of a narrow base of research which is rapidly becoming outdated.

In recent years, it has become widely acknowledged that research-based understandings of how Autism and the support needs of Autistic children are identified, are based on a cohort of predominantly white, male participants.¹⁴ As limited research has been done on non-white, non-male Autistic individuals; some researchers have suggested that current diagnostic processes are an inaccurate means of identifying the diagnoses and support needs of Autistic children who are Aboriginal and Torres Strait Islander, Culturally and Linguistically diverse (CaLD), gender diverse or female.¹⁵ While the emerging research base is not developed enough to offer alternative

¹⁰ Golbeck, -Wood, S (1999) [Evidence on peer review—scientific quality control or smokescreen?](#), BMJ, Vol. 318, no. 7175, pp. 44–45.

¹¹ National Disability Insurance Scheme (2020) [Consultation paper: Interventions for children on the autism spectrum](#), National Disability Insurance Agency, p. 15

¹² National Disability Insurance Scheme (2020) [Consultation paper: Interventions for children on the autism spectrum](#), National Disability Insurance Agency, p. 15

¹³ Committee on the Rights of Persons with Disabilities (2016) Article 7: Children with disabilities.

¹⁴ Becerra, TA et al (2014) Autism Spectrum Disorders and Race, Ethnicity, and Nativity: A Population-Based Study, Paediatrics, Vol. 134, no. 1, pp. e63–e71.

¹⁵ See: e.g., Ratto, AB et al. (2018) What About the Girls? Sex-Based Differences in Autistic Traits and Adaptive Skills, J Autism Dev Disord, Vol. 48, no. 5, pp. 1698–1711; Welterlin, A & LaRue, RH (2007) [Serving the needs of immigrant families of children with autism](#), Disability & Society, Vol. 22, pp. 747-760



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

mechanisms for diagnosis; it does suggest the need to look at other identifiers such as the views of families and carers, to determine interventions that may be helpful.

Exacerbation of inequalities based on Culture, Race and Gender

Instead of trusting participants and their families to make decisions about support interventions however, the proposed strategy for supporting interventions for Autistic children is to categorise non-research supported interventions as "everyday expenses" that parents must pay for, without compensation.¹⁶ This approach is extremely concerning for WWDA, as it not only threatens to further deny Autistic girls' access to NDIS support; but threatens to reinforce broader inequalities in the NDIS based on culture, race and gender.

Additionally, placing the responsibility of expenses on parents is inequitable for children who live in single-parent or low-income households. When taking into consideration that women on average, earn less than men;¹⁷ it is clear again, that the proposed strategy is blind to gender.

While the consultation infers that one way to avoid the financial barrier of paying for non-NDIS funded supports is for parents or family members to provide therapeutic supports to children directly; another barrier that should be considered is the likelihood that parents of Autistic children may also be Autistic, and therefore face unique barriers to providing interpersonal supports to their dependents. In addition, the assumption that parents can provide therapeutic supports to their children, is contradictory with the Consultation Paper itself, which states that interventions should be "delivered by, or supported by, appropriately qualified and experienced professionals."¹⁸

Assumption of community-based supports

Another concerning aspect of in the Consultation Paper is the suggestion that NDIA must ensure NDIS funded supports must not duplicate supports that exist in mainstream community settings or that would be considered a form of support that would usually be provided by families or parents.¹⁹ Examples of community supports include sensory friendly shopping hours and quiet spaces at events. At the end of the Consultation Paper, a case study is also given as an example which explains that the NDIA would not fund private swimming lessons for an Autistic girl because

¹⁶ National Disability Insurance Scheme (2020) [Consultation paper: Interventions for children on the autism spectrum](#), National Disability Insurance Agency, p. 15

¹⁷ Workplace Gender Equality Agency (2021) [Australia's Gender Pay Gap Statistics 2021](#), Australian Government.

¹⁸ National Disability Insurance Scheme (2020) [Consultation paper: Interventions for children on the autism spectrum](#), National Disability Insurance Agency, p. 14

¹⁹ National Disability Insurance Scheme (2020) [Consultation paper: Interventions for children on the autism spectrum](#), National Disability Insurance Agency, p. 15, 36



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

swimming lessons would usually be provided by informal supports such as parents, and because providing private lessons could, from the perspective of the NDIS, reduce the child's community participation.

While WWDA understands the need for the NDIS to support the rights of people with disability to take part fully in the community, it needs to be recognised that many individuals need disability specific supports to fully participate. For example, while an Autistic child may be able to attend swimming lessons in a group setting, they may not be able to fully participate due to a lack of community understanding of Autism. In this instance, the NDIS providing funding for Autism specific swimming lessons may be the only way to provide the child with the skills necessary for participation in community activities, such as school swimming carnivals, when they are older, rather than being excluded from such activities because they cannot swim.

In addition, the assumption that Autistic children benefit from community-based initiatives ignores gender differences in experiences and support needs. For example, while sensory friendly shopping hours may benefit some Autistic children, they may not be adequate for children with symptoms of Anorexia Nervosa or other eating disorders, which are extremely common among Autistic women and girls. In this instance, adequate supports may include the accompaniment of support worker who understands Autism in girls to the supermarket, as well as appointments with a nutritionist or child psychologist.

Regardless of the specific circumstances however, it must be considered that many Autistic children require individualised supports to participate fully in the community. While these support needs may sometimes dissipate with time or age periods, it must be understood that every Autistic individual is different.

In addition to the assumption that all Autistic children can all benefit equally from community initiatives, the Consultation Paper appears to suggest that NDIS funded supports should always work towards a goal of participant self-sufficiency. While this may be OK in some instances, it ignores the need for flexibility as circumstances change, such as when children reach school age.

Overall, WWDA is concerned that the proposed approach to making decisions about interventions for Autistic children is part of a much broader attempt to reduce funding levels for participants and in turn, deny supports that would be beneficial. In line with our previous submissions, WWDA urges the NDIA to reconsider its recommendations for interventions for Autistic children, pending extensive community consultation with the Autistic community and their representative



Women
With
Disabilities
Australia
(WWDA)

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

organisations. Additionally, we re-iterate our long-standing recommendation to the NDIA that the Agency act to develop an NDIS Gender Strategy, in consultation with women with disability.

Thank you again for the opportunity to provide feedback on the NDIS Consultation Papers. Our organisation looks forward to continuing to collaborate with the NDIA.

Yours sincerely

Carolyn Frohmader
Executive Director
Women With Disabilities Australia (WWDA)

Women With Disabilities Australia (WWDA)

wwda.org.au

Ph: +61 438 535 123

PO Box 407, Lenah Valley, 7008 TASMANIA

WWDA has Special Consultative Status with the Economic and Social Council of the United Nations