

Inquiry into Independent Assessments

Submission to the Parliament of Australia Joint Standing
Committee on the National Disability Insurance Scheme
(NDIS)

March 2021



Women
With
Disabilities
Australia
(WWDA)

PUBLISHING INFORMATION

Women with Disabilities Australia (WWDA) (2021). *'Submission to the Parliament of Australia Joint Standing Committee on the National Disability Insurance Scheme: Inquiry into Independent Assessments'*. March 2021.

Acknowledgments

WWDA acknowledges the traditional owners of the land on which this publication was produced. We acknowledge Aboriginal and Torres Strait Islander people's deep spiritual connection to this land. We extend our respects to community members and Elders past, present and emerging.

This document was written by WWDA staff members Heidi La Paglia and Vanamali Hermans for and on behalf of Women with Disabilities Australia (WWDA).

Women with Disabilities Australia (WWDA) receives part of its funding from the Australian Government, Department of Social Services.

Disclaimer

The views and opinions expressed in this publication are those of Women with Disabilities Australia (WWDA) and not necessarily those of our funding bodies.

All possible care has been taken in the preparation of the information contained in this document. WWDA disclaims any liability for the accuracy and sufficiency of the information and under no circumstances shall be liable in negligence or otherwise in or arising out of the preparation or supply of any of the information aforesaid.

This work is copyright. Apart from any use as permitted under the Copyright Act 1968, no part may be reproduced without written permission from Women With Disabilities Australia (WWDA). © 2021 Women With Disabilities Australia (WWDA).

ABN: 23 627 650 121

Contact

Carolyn Frohmader, Executive Director
Women With Disabilities Australia (WWDA)
PO BOX 407 Lenah Valley, Tasmania, 7008
Australia

+61 438 535 123
officeadmin@wwda.org.au

wwda.org.au
facebook.com/WWDA.Australia
twitter.com/WWDA_AU

Awards

Winner

National Human Rights Award 2001

Winner

National Violence Prevention Award 1999

Winner

Tasmanian Women's Safety Award 2008

Nominee

French Republic's Human Rights Prize 2003

Nominee

UN Millennium Peace Prize for Women 2000

Certificate of Merit

Australian Crime & Violence Prevention Awards 2008

Nominee

National Disability Awards 2017

Nominee

UNESCO Prize for Digital Empowerment of Persons with Disabilities 2020

ABOUT WOMEN WITH DISABILITIES AUSTRALIA (WWDA)

Women With Disabilities Australia (WWDA) is the award winning, national Disabled People's Organisation (DPO) for women, girls, feminine identifying and non-binary people with all types of disability in Australia. The key purpose of WWDA is to promote and advance the human rights and freedoms of women and girls with disability. Our goal is to be a national voice for the rights of women and girls with disability and a national force to improve the lives and life chances of women and girls 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 two million disabled women and girls in Australia, has affiliate organisations and networks of women with disability in most States and Territories of Australia, and is internationally recognised for our global leadership in advancing the human rights of women and girls with disability. As a DPO, WWDA is managed and run by women with disability, for women and girls with disability.

DPO's are recognised internationally as organisations OF people with disability that are led, directed and governed BY 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 these organisations 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.

For more information on the extensive work of WWDA, please see:

- wwda.org.au
- oursite.wwda.org.au
- facebook.com/WWDA.Australia
- twitter.com/wwda_au



CONTENTS

| | |
|--|----|
| Publishing Information | 5 |
| About Women with Disabilities Australia (WWDA) | 6 |
| Introduction | 9 |
| Background | 11 |
| Gender Inequalities in the NDIS | 13 |
| Limitations for Complex, Invisible and Psychosocial Disabilities | 15 |
| Limitations of Standardised Assessment Tools | 19 |
| Risk of Trauma | 22 |
| Concluding Comments | 25 |
| Endnotes | 27 |

Introduction



INTRODUCTION

WWDA welcomes the opportunity to make this Submission in response to the Parliament of Australia Joint Standing Committee on the National Disability Insurance Scheme: 'Inquiry into Independent Assessments' and thanks the Australian Government for the opportunity to contribute.

WWDA does so in the recognition that the current National Disability Insurance Scheme (NDIS) takes an ungendered approach to supporting participants and is limited in its ability to adequately meet the needs of women and girls with disability.

However, while we understand and welcome the need for systemic reforms to the NDIS that improve the ability of people with disability to access the scheme and the supports they receive, WWDA and its members hold significant concerns about the efficacy of the proposed changes to the NDIS and how they will address the very diverse and complex needs of women and girls with disability.

Across Australia, women and girls currently only make up less than 37 percent of all NDIS participants,¹ and this has remained unchanged since the Scheme became operational. Less than 30 percent of female participants are under 14 years of age.² WWDA is very concerned that many of the new changes to the NDIS, including the introduction of Independent Assessments, is a gender-neutral move that not only ignores the gender inequality inherent in the NDIS, but also threatens to exacerbate the discrepancy in participation rates.

In this submission, WWDA draws on research, as well as case studies from WWDA members, to illustrate our concerns. In particular, WWDA strongly urges the Joint Standing Committee to recommend that the Australian Government urgently reconsider mandating standardised independent assessments as part of the NDIS.

Background



BACKGROUND

In 2013, the National Disability Insurance Scheme (NDIS) was implemented in Australia to support people with disability to access the resources and supports they need to participate in society. However, while the NDIS has had a positive impact on many people with disability who have been able to access the Scheme, it is well known that the NDIS has been limited its ability to meet the support requirements of all individuals.

Among other issues, restrictive criteria, and inaccessible, confusing access processes have limited the NDIS to including only 10 percent of Australia's people with disability;³ and of those who do meet the criteria, many have reported frustration and dissatisfaction with the processes required to access much needed funding and supports.⁴

In 2018, the National Disability Insurance Agency (NDIA) determined it would run an Independent Assessment Pilot and Review in response to the inconsistent and inequitable access to the NDIS, which was creating difficulties for both participants and potential participants.⁵

For NDIS purposes, an 'Independent Assessment (IA)' is an assessment of functional capacity, using standardised assessment tools by a 'qualified health care professional' not known to, or familiar with the individual.⁶

The first stage of the independent assessment pilot ran in 2019 in nine regions in New South Wales, with 513 participants with disability. It is acknowledged that there were significant limitations with this pilot. The second stage of the pilot was set to take place in the first half of 2020 but was discontinued in March 2020 due to the impact of the COVID-19 pandemic.

Following the first pilot, the 2019 review of the National Disability Insurance Scheme Act 2013 (commonly known as the Tune Review) was released,⁷ which has since been cited as the basis for the decision to mandate the introduction of Independent Assessments for all current and future NDIS participants.

However, while the Tune Review indicated that the pilot resulted in 'more consistent decisions and more equitable plan outcomes for participants,'⁸ it did not recommend the universal and mandatory roll out of Independent Assessors without participant choice or control over who would be assessing them.

Conversely, the Tune Review identified that the implementation of Independent Assessments (IAs) would be problematic for particular cohorts such as Aboriginal and Torres Strait Islander people, Culturally and Linguistically Diverse (CALD) communities and women and girls with disability; and recommended that their implementation be preceded by extensive consultations with people with disability.

In addition, the Tune Review specifically recommended that the roll out of IA's should be accompanied by protections for participants, including, the right to choose an assessor that is appropriate for their personal circumstance and the right to challenge results after assessments; neither of which have been included in the reform plans released by the NDIS to date.

In absence of protections and flexibility for participants, WWDA is extremely concerned that basing funding decisions on a standardised assessment conducted by an entirely impartial assessor who does not know the individual, will likely result in an incorrect evaluation of an individual's capacity, and in turn, a denial of supports that are required.

Gender Inequalities in the NDIS



GENDER INEQUALITIES IN THE NDIS

Across Australia, women and girls only make up less than 37 percent of all NDIS participants, and less than 30% of participants are girls under 14 years of age. As women and girls with disability already have disproportionately low representation in the NDIS, WWDA holds significant concerns that the introduction of Independent Assessments has not been accompanied by a strategy to address the Schemes' existing gender inequalities.

It has been argued that IA's would provide a means to capture 'consistent and equitable information about the 'functional capacity' of people with disability'.⁹ However, the fact that the proposed assessments are to be standardised across people of all races, cultures, ages and genders will further exacerbate inequities, when considering that people of different identities have differing experiences and presentations of the same conditions.

One of the most common and telling instances of this occurs in women and girls with Autism Spectrum Disorder (ASD), who have significantly low participation rates in the NDIS compared to men and boys, despite ASD being the largest primary disability category in the NDIS.¹⁰ While the current assessments that precede a diagnosis of ASD and support access to the NDIS are similarly the same for all genders, it has been well documented that these standardised assessment processes overlook the support needs of women and girls, who are socialised to 'mask' or hide their differences.¹¹

It is these gender inequalities in the NDIS that remain unaddressed by the proposal to implement mandatory Independent Assessments, despite ongoing calls from both domestic and international human rights bodies to the Australian Governments to address the poor status of women and girls with disability in Australia.¹² The Committee on the Rights of Persons with Disabilities (CRPD), through CRPD General Comment 3 [Article 6: Women with Disabilities], for instance¹³ has provided clear and authoritative guidance to States Parties (including Australia) regarding the imperative to employ targeted, extra and specific measures to ensure that women and girls with disability can realise and enjoy their rights on an equal basis as others.¹⁴ This includes their right to access and receive services and programs – including through the NDIS.

As a clear object of the NDIS Act (2013) is to give effect to Australia's obligations under all articles of the Convention on the Rights of Persons with Disabilities (CRPD), including Article 6: Women with Disabilities, WWDA re-iterates our long-standing recommendation to the NDIA that the Agency act to develop an NDIS Gender Strategy, in consultation with women and girls with disability, and their representative organisations.

Limitations for complex, invisible and psychosocial disabilities



LIMITATIONS FOR COMPLEX, INVISIBLE AND PSYCHOSOCIAL DISABILITIES

In addition to evidence that standardised assessments are not a suitable method to identify functional capacity across genders, WWDA's concerns about the efficacy of Independent Assessments are supported by peer reviewed research that shows how invisible and complex disabilities can be misjudged or overlooked by unfamiliar assessors.

For example, there has been countless accounts of people with invisible or chronic illness being diagnosed with psychosocial conditions, due to an overlap of symptoms, or misinterpretation of a person's presentations.¹⁵ One extremely common example among women with disability is women with endometriosis being diagnosed with a different physical health condition such as Irritable Bowel Syndrome (IBS) or a co-morbid psychosocial disability.¹⁶ Another example is commonly reported from neurodivergent women with ASD or Attention Deficient Hyperactive Disorder (ADHD), who have received adult diagnoses after having one or multiple psychosocial disabilities such as depression, anxiety, obsessive-compulsive disorder (OCD) and eating disorders that are often co-morbid among neurodivergent girls and women, but often occur as a result of a misunderstanding or lack of support for their experiences.¹⁷

Even in the short time since the NDIS introduced the concept of IA's, individuals with invisible and complex disabilities, and their advocates, have already experienced difficulties in the standardised assessment processes. For example, in a pilot Independent Assessment session, the son of the Autism Awareness Australia's Chief Executive Officer (CEO), Nicole Rogerson was left 'embarrassed' and 'confused'.¹⁸ In reporting on her son's experience, Rogerson explained that the assessment didn't have the level of sophistication needed to really understand her son, Jack's experiences or 'explore what opportunities there are to increase his independence'.¹⁹ While Jack is only one individual, his experience falls directly in line with the broader concerns being raised by organisations and advocates about the mandating of IA's. In a public statement about the announcement, the Australian Autism Alliance stated that they do not believe an 'NDIA contractor conducting a very time-limited assessment of an autistic person they are meeting for the first time' can adequately understand their experiences.²⁰

In response to the roll-out of Independent Assessments, people with other invisible and complex disabilities have also raised similar concerns. When WWDA asked its members for their input in relation to IA's, many of our members expressed their fear and concerns. Examples of some of the responses communicated to WWDA include:

"I am concerned especially as someone with a less known and understood disability that these (Independent Assessments) will not help at all. I need specialists who are trained in and understand my disability. There are many professionals who don't understand it, have outdated ideas and would be biased towards me because of that. It's so important to have people assess you who are experts in your disability! I faced this bias when my application for inclusion into the scheme was assessed by an ex-nurse who had outdated, biased views of my disability and therefore denied by access. This was overturned on internal appeal as my assessments by my specialists showed I well and truly met access requirements." – JR

"I'm terrified. My history is extremely complex & even my GP of 30yrs often defers to me on my ideas about what might be happening inside my body. What makes them think ANY independent assessor can comprehend what challenges my disabilities pose when even the DOCTORS at the top of

their fields defer to the patient rather than guessing & judging based on an argument from ignorance?” – KA

“Having to explain 10 years of what my specialist already knows seems problematic with an independent assessor who may not specialise in a field relevant to my disabilities” – EM

“If cognitive biases occur when industry funds research, then cognitive biases occur when Governments pay Medical Practitioners to review claims for people with disabilities” – DS.

“My biggest concern is whether the assessor will have a good understanding of the disability that is being assessed. For those with invisible disabilities it can make things very difficult. I also query how that person can take into account the emotional and mental toil your disability takes on your body. This is something I fear will be ignored. How can they assess someone with a disability they do not understand?” – HP

“I am worried that for those with psychosocial disabilities and Autism, the areas of skill will be focused on too much and the actual need will be overlooked.” – MJ

“I have an aggressive form of a common neuro degenerative disorder, but my presentation does not fit the normal pattern. This change will affect people like me.” – TS.

For many of these women, access to the NDIS has only been obtained with the support of information and reports from long-standing relationships with trusted practitioners, and in many cases, advocates. The specific, and often unique needs of many people with disability cannot be ‘assessed’ and summarised by an unknown practitioner, in a mandated timeframe using standardised assessments. As people with disability are extremely diverse, the options to provide evidence should reflect this, as well as recognise the complexity of understanding those with multiple, invisible and/or complex disabilities.

This is particularly the case for individuals who have psychosocial disabilities, especially when their psychosocial conditions accompany one or more physical disabilities. For these individuals, having an assessment with an unfamiliar independent assessor will almost inevitably result in a focus on only their physical capabilities, at the expense of any less obvious disabilities. For those with fluctuating psychosocial conditions who do not have visible disabilities, there is also the risk that an assessment conducted on a ‘good’ day will inaccurately assess the level of support required and/or potentially conclude that they do not meet the criteria to access NDIS supports.

Additionally, it must be recognised and acknowledged that many people with intellectual and cognitive disabilities who live in institutional settings, such as group homes, will often not have the agency or support to actively participate in consultations. In these highly structured and institutionalised environments, it is extremely common for individuals, especially women, to be taught and ‘rewarded’ for unquestioning compliance, making it impossible for an external assessor to understand the full scope of their situation through a one-off ‘assessment’.

While the IA process allows people with disability to have an additional person, such as a support person or family member, take part in the assessment, this requirement is likely to work against, not for, those who many who live in institutional settings. Despite the fact that to make one’s own choices and to control one’s own life is enshrined in a range of international human rights instruments, including the International Covenant on

Civil and Political Rights to which Australia has been a party since 1980, women and girls with disability living in institutional settings have been categorically denied the support they require to make decisions about any matter that affects their lives. In contrast, these women are often coerced into language and patterns of behaviour that are not in their best interests through controlled and calculated 'reward' offerings, such as access to certain meals, outings or spending money. For these individuals, undergoing an assessment with an unknown practitioner may not only risk that assessor undermining their support needs; but could also create a situation where their carers, guardians or support persons have even more power and control over their circumstances.

Limitations of Standardised Assessment Tools



LIMITATIONS OF STANDARDISED ASSESSMENT TOOLS

Across the disability sector in Australia, a number of concerns have been raised about the ability of standardised assessment tools to accurately assess an individual's support needs. In the statement released by the Australian Autism Alliance for instance, it was noted that “no single assessment tool solely meets the nuanced and individual needs of all autistic people;” and concern was raised about “whether NDIA-commissioned assessments will be consistent with the National Guidelines for Assessment and Diagnosis of Autism.”²¹

As part of the introduction of the Independent Assessment process, the NDIA has selected 6 assessment tools through research and testing coined the ‘Assessment Toolkit’. As part of the Independent Assessment, the NDIA has stated that participants will be assessed according to whether they meet the ‘normal functional abilities’ for their age using one or multiple of these assessment tools.²² However, while these tools have been identified as being adaptable to different disabilities,²³ concern has been raised about whether they can assess differences in a person's capacity in different areas. For example, for people with disabilities like Autism Spectrum Disorder or Fetal Alcohol Spectrum Disorder (FASD), it is often common to have a standard or even above average capacity in one area, while experiencing severe limitations in another.²⁴

For people with more than one disability ‘type’, the concerns are similar. As the NDIA currently plans to continue recording one primary disability for each participant, it is difficult for any NDIA appointed standardised assessment to identify the impact of or interaction between multiple or varying disabilities. While someone with Osteogenesis, who uses a wheelchair for example, would be assessed according to how this disability impacts their physical abilities, the same assessment could not accurately assess the impact of co-morbid fluctuating conditions such as Irritable Bowel Syndrome (IBS) or psychosocial disabilities.

Some further concerns about the limitations of standardised assessments are illustrated in the below comments from WWDA members:

“This topic has concerned me greatly. I feel that those who designed this approach have not really understood the ramifications. Nearly everyone with a disability will tell you there is so much more to their disability to what is seen on the surface.” – HP.

“as someone with multiple issues that do not fit into standard ‘textbook’ tick boxes, I have a history of falling through the gaps and have been traumatised, so I am very fearful of standardised one size fits all blanket assessments that do not take into account people's individual needs and circumstances.” – JS.

“I too am deeply concerned about this. This is going to have serious concerns for many girls and women, particularly who have multiple conditions that are already misunderstood by misogynistic medical models and outdated medical education” – LS.

The reasons given for the implementation of the proposal to use independent assessors reference two short pilots between November 2018 and March 2020, as well as recommendations from the 2019 review of the National Disability Insurance Scheme Act 2013 (the Tune Review)²⁵. However, while the Tune Review itself identified that implementation of Independent Assessments would be problematic for particular cohorts,

there has not been any information provided on how the Independent Assessment process will be adapted to meet the needs of people with complex or multiple disabilities, nor for individuals from culturally diverse communities; for whom there is no cited reliable tool for assessing disability.²⁶

WWDA holds serious concerns over the accuracy and appropriateness of standardised assessment tools, given the limitations they hold when accounting for diverse experiences of disability, and more concerningly, their inherent prejudices towards marginalised cohorts of people with disability, including disabled women, girls and non-binary people. It is well known that many standardised assessment tools used by government and health professionals to assess disability, centre experiences of being white, of being middle-class, and of being a man, as if they were 'universal' categories.

This means that many standardised assessment tools do not account for the experiences of people who fall outside of these 'categories', failing to accurately capture the needs and strengths of people with disability who do not meet these 'norms.' In particular, WWDA draws attention to the fact that many standardised assessment tools do not meet the needs of women, girls and non-binary people from culturally diverse backgrounds who may not speak English or who may conceptualise disability differently; as well as the needs of disabled Aboriginal and Torres Strait Islander women, girls and non-binary people who often have different experiences of disability informed by both culture and the ongoing impacts of colonisation.

In Stephens and Bohanna's investigation of Acquired Brain Injury (ABI) in Cape York and the Northern Territory²⁷ it was found that for Aboriginal and Torres Strait Islander people there was 'no reliable, culturally appropriate instruments to measure and assess the extent of one's impairment, without which, eligibility for the NDIS would be difficult to establish.' Given the lack of culturally appropriate assessment tools for these communities, the introduction of IA's run the very real risk of further disenfranchising Aboriginal and Torres Strait Islander women, girls and non-binary people with disability from accessing the NDIS. This community is already disproportionately underrepresented within the scheme, with Aboriginal and Torres Strait Islander people with disability making up less than 5.7% of all active NDIS participants.²⁸

Whilst rarely spoken about, WWDA also emphasises the impact of 'fatphobia' within standardised assessment tools, and the way this prejudice may harm and lead to inaccurate judgements of disabled women, girls and non-binary people. There is a growing evidence base that suggests bias within institutional policies and assessment tools have created significant health barriers for 'fat' women, leading to growing disparities within health and disability care, as well as medical mismanagement and misdiagnosis.²⁹ Similar to the earlier concerns this submission has raised in regards to the misdiagnosis of disabilities such as Autism Spectrum Disorder within the population of women and girls, WWDA fears introducing IA's may result in mischaracterising the disabilities and needs of 'fat' women and girls, with assessors using tools that focus on the impacts of one's body mass index (BMI) at the expense of other experiences of disability.

Risk of Trauma



RISK OF TRAUMA

There has been a considerable lack of clarity around whether the individual allied health practitioners appointed as assessors will be matched to the cultural and safety needs of disabled people; which is particularly concerning for women and girls with disability.

Across Australia, it is well known that women and girls with disability experience significantly higher rates of violence than men with disability or people without disability and are particularly susceptible to specific forms of violence, including violence and abuse perpetrated by carers, support people, healthcare practitioners and government personnel. This violence takes place not only in the home, but in institutions including group homes, hospitals and prisons. For this reason, it must be recognised that there is significant risk of trauma inherent in the process of requiring women with disability to undergo an assessment by someone unknown to them.

For women with intellectual, cognitive and psychosocial disabilities, as well as Aboriginal and Torres Strait Islander women with disability, there is a specific risk of trauma associated with being subject to an assessment with a government appointed assessor. Many of these individuals have had negative experiences with government legal and justice systems, including histories of child-removals and incarceration.³⁰ For these women, there exists a very real fear of having their lives scrutinised by someone who does not fully understand their experiences. Being subjected to an IA with an unknown government assessor could undoubtedly be traumatising and may result in marginalised women with disability, such as Aboriginal and Torres Strait Islander women, deciding to disengage from the NDIS entirely to protect themselves and their families from being split up or institutionalised.

For a variety of reasons, the Tune Review identified that the implementation of Independent Assessments would be problematic for particular cohorts, and that measures should therefore be taken to ensure that the diversity of assessors is sufficient enough to mitigate concerns.³¹ For these reasons, WWDA has called for the NDIA to urgently reconsider mandating Independent Assessments for all participants, and re-design the roll out in a way that ensures adequate choice for participants in relation to their assessors and assessments, including the choice to have assessors that match their gender, culture and Indigeneity.³²

Furthermore, it has been raised by advocates that mandatory Independent Assessments risk not meeting the (currently in progress) national trauma-informed disability practice guidelines; a concern that has also been echoed by WWDA members.

“It took 10 years for me to even cope with having a hair dresser cut my hair and a similar length of time for my dentist to engage with me. I would not have capacity to engage with a stranger in 20 minutes. This is not safe and not trauma informed or trauma sensitive best practice. The requirement to be subjected to this assessment on an annual basis would impose a barrier that is not disability appropriate or safe for me. I would therefore not have capacity to engage or participate and disengage. Further, stress and other factors trigger flares in my conditions. Flares cause permanent damage to my bones, organs, connective tissue. I do not want to end up in hospital because of these unsafe proposals.” – KM.

“I query how that person can take into account the emotional and mental toil your disability takes on your body.” – HP.

“I am concerned for my daughter who is funded for mental illness. The trauma and anxiety of having to convince a stranger of her impairment will increase her already high suicide risk” – JW.

“One cannot necessarily understand the profundity of individual situations in a short two-hour session without the participants having to retell their stories and retraumatise or add to existing trauma.” – JS.

“The Independent Assessment process is not trauma informed in any way, is all about my deficiencies & I believe is in breach of my rights” – AB.

For women who have developed disabilities as a result of violence, this risk is further compounded. Across the globe, it has been well documented in research that asking survivors of violence to re-tell their stories over and over to different professionals, risks unnecessarily re-traumatising the individual.³³ To mitigate this risk, research informed therapeutic interventions are almost always centred on giving agency and control back to the survivor;³⁴ which is exactly what the IA process denies.

WWDA acknowledges concerns about the safety of individuals with a history of trauma have been briefly addressed in the NDIS ‘Access and Eligibility Consultation Paper’ in section 3.7 ‘Exemptions from independent assessments,’ where it states that: ‘The delegate may decide that an applicant does not need to complete an independent assessment where there is a risk to safety or an assessment is deemed inaccessible or invalid.’³⁵ However, WWDA remains concerned that it is not the individual being assessed who will be empowered to make these decisions; especially in cases where individual women have already been denied agency by guardians, family members and professionals.

The danger of mandating Independent Assessments is further exacerbated by the requirement that additional people take part in the assessment. For many women with disability, violence and abuse is perpetrated by their direct carers, support people, and third parties (such as public guardians) in the form of practices such as forced-sterilisation, forced-contraception and control through medication; and is supported by substitute decision-making regimes which are seen to be acting in the persons best interests.³⁶

While WWDA has consistently raised the fact that these non-consensual practices require urgent action, they have not been subjected to any form of national or consistent oversight, monitoring or review.

On the contrary, Australian Government’s remain of the view that substitute decision-making on matters such as reproductive health is an acceptable practice, provided that it results in the person’s ‘best interests,’ as determined by their support person, who could easily also be their abuser.³⁷

Under these circumstances, there is huge potential for the inclusion of an additional person in IA’s to force women with disability to undergo the assessment in front of their abuser, and/or, be denied their right to have their views, experiences, will and preferences fully considered.

As a Disabled People’s Organisation (DPO), WWDA strongly trusts that people with disability are the best source of expertise on how their disability affects them and understand that the views of family members, carers, support workers, and guardians can often conflict with the reality of the disabled person’s experiences.

Concluding Comments



CONCLUDING COMMENTS

Overall, people with disability and our representative organisations are extremely concerned that the introduction of Independent Assessments (IAs) appears to be a major step away from a human rights approach, which positions people with disability as the expert in their own experience.

Whilst the NDIS is framed by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and aims to give more 'choice and control' to people with disability; it appears that the proposed changes are removing all choice and control from individuals on how information is provided to the NDIS about their disability.

To ensure the NDIS retains its own purpose of empowering people with disability to have more 'choice and control' in their lives, WWDA calls on the NDIA to:

1. Immediately cease the rollout of compulsory Independent Assessments as currently planned for 2021.
2. Undertake a robust, independent and transparent outcome evaluation of the current pilot of the new assessment process. This evaluation must be led by experts and co-designed with people with disability, their families and the organisations that represent them.
3. Undertake robust and transparent trials of rolling out optional Independent Assessments whilst also retaining an individual's choice to opt for alternative approaches – such as asking their health professionals of choice to provide evidence.
4. Once the trials and evaluations are complete, engage in a meaningful co-design process with people with disability, their families and the organisations that represent them to ensure a consistent, fair and representative approach to both access and planning for NDIS participants.
5. Additionally, WWDA reiterates our long-standing recommendation to the NDIA that the Agency act to develop an NDIS Gender Strategy, in consultation with women with disability and their representative organisations.

Endnotes



ENDNOTES

- 1 National Disability Insurance Scheme (2019) [Analysis of Participants by Gender](#), National Disability Insurance Agency (NDIA).
- 2 National Disability Insurance Scheme (2020) [‘Young People in the NDIS,’](#) National Disability Insurance Agency, p. 12
- 3 National Disability Insurance Agency (2020) COAG Disability Reform Council Quarterly Report 31 March 2020, National Disability Insurance Agency (NDIA).
- 4 Tune, D (2019) [Review of the National Disability Insurance Scheme Act 2013: Removing Red Tape and Implementing the NDIS Participant Service Grantee](#), Department of Social Services, Australian Government, p. 7
- 5 Ibid, p. 65
- 6 National Disability Insurance Scheme (2020) Consultation paper: Access and Eligibility Policy with independent Assessments, National Disability Insurance Agency, p. 7
- 7 Tune, D (2019) [Review of the National Disability Insurance Scheme Act 2013: Removing Red Tape and Implementing the NDIS Participant Service Grantee](#), Department of Social Services, Australian Government.
- 8 Ibid, p. 31
- 9 Ibid, p. 65
- 10 National Disability Insurance Scheme (2020) [‘Outcomes for participants with Autism Spectrum Disorder,’](#) National Disability Insurance Agency.
- 11 Autism Spectrum Australia (2020) [‘Girls and Women on the Autism Spectrum.’](#)
- 12 See for eg: CEDAW/C/AUS/CO/8; E/C.12/AUS/CO/5; CRPD/C/AUS/QPR/2-3; CRPD/C/AUS/CO/1; CEDAW/C/AUL/CO/5; CEDAW/C/AUS/CO/7; E/C.12/AUS/CO/4; CCPR/C/AUS/CO/5; CAT/C/AUS/Q/5; CEDAW/C/GC/35; CCPR/C/AUS/CO/6; CRPD/C/GC/3
- 13 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.
- 14 Ibid
- 15 Standford, D Et al. (2020) ‘Mental Illness Misdiagnosed: Increasing Awareness of Obscure Physical Illnesses,’ Journal of Psychosocial Nursing and Mental Health Services, Vol. 58, no. 10, pp. 2-3.
- 16 Bontempo, A & Mikesell, L (2020) [‘Patient perceptions of misdiagnosis of endometriosis: results from an online national survey,’](#) PubMed, Vol. 26, No. 2, pp. 97-106.
- 17 Bargiela, S Et al. (2016) [‘The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype,’](#) Journal of Autism and Developmental Disorders, Vol. 46, No. 10, pp, 3281–3294.
- 18 Moore, A (2021) [‘NDIS autism assessment pilot leaves young man embarrassed,’](#) ABC Breakfast.
- 19 Team DSC (2021) [‘Test Drive or Crash Test? Independent Assessments,’](#) DSC.
- 20 Australian Autism Alliance (2020) [‘Statement on the proposed introduction of mandatory NDIA determined assessments in the NDIS.’](#)
- 21 Ibid

- 22 National Disability Insurance Scheme (2020) Independent Assessment Paper:
Selection of Assessment Tools, National Disability Insurance Agency (NDIA), p.4
- 23 Ibid, p. 22
- 24 NOFASD Australia (2020) [‘Changes to the NDIS. Independent Assessments.’](#)
- 25 Tune, D (2019) [Review of the National Disability Insurance Scheme Act 2013:
Removing Red Tape and Implementing the NDIS Participant Service Grantee,](#)
Department of Social Services, Australian Government.
- 26 Stephens, A & Bohanna, I (2013) [‘Why Indigenous Australians need a properly
funded NDIS,’](#) The Conversation.
- 27 Ibid.
- 28 National Disability Insurance Scheme (2019) [Aboriginal and Torres Strait Islander
participants: 30 June 2019,](#) National Disability Insurance Agency.
- 29 Lee, JA & Pause CJ (2016) [‘Stigma in Practice: Barriers to Health for Fat Women,’](#)
[Frontiers in Psychology,](#) Vol, 7, p. 2063.
- 30 Australian Women Against Violence Alliance (AWAVA) (2020) [Submission to the
House Standing Committee on Social Policy and Legal Affairs in response to the
Inquiry into family, domestic and sexual violence,](#)
- 31 Tune, D (2019) [Review of the National Disability Insurance Scheme Act 2013:
Removing Red Tape and Implementing the NDIS Participant Service Grantee,](#)
Department of Social Services, Australian Government, p. 67
- 32 C, Frohmader (2021) [‘WWDA calls on Minister to cease roll-out of Independent
Assessments,’](#) Women With Disabilities Australia.
- 33 E.g. Arnzen, A (2014) [‘Stuck in the Trauma Story: The Construction and
Consequences of Narrative Liminality in a Domestic Violence Center in Cape Town,
South Africa,’](#) Trinity College Digital Repository
- 34 E.g. Maher, J. M, Et al. (2018).Women, disability and Violence: Barriers to Accessing
Justice: Final Report, Australia’s National Research Organisation for Women’s Safety
(ANROWS), Sydney; Ferencik, D. S & Ramirez-Hammond, R (2013) [Trauma-Informed
Care: Best Practices and Protocols for Domestic Violence Programs,](#) Ohio Domestic
Violence Network (ODVN).
- 35 National Disability Insurance Scheme (2020) Consultation paper: Access and
Eligibility Policy with independent Assessments, National Disability Insurance
Agency, p. 21–22
- 36 Women With Disabilities Australia (WWDA) (2016) [WWDA Position Statement 2: The
Right to Decision-Making.’](#)
- 37 Community Affairs References Committee (2013) [Involuntary or coerced sterilization
of people with disabilities in Australia.](#) Australian Government.



Women With Disabilities Australia (WWDA)

Women With Disabilities Australia (WWDA)
PO BOX 407 Lenah Valley, Tasmania, 7008 Australia

+61 438 535 123
officeadmin@wwda.org.au

wwda.org.au
facebook.com/WWDA.Australia
twitter.com/WWDA_AU

Awards

Winner

National Human Rights Award 2001

Winner

National Violence Prevention Award 1999

Winner

Tasmanian Women's Safety Award 2008

Nominee

French Republic's Human Rights Prize 2003

Nominee

UN Millennium Peace Prize for Women 2000

Certificate of Merit

Australian Crime & Violence Prevention Awards 2008

Nominee

National Disability Awards 2017

Nominee

UNESCO Prize for Digital Empowerment of Persons
with Disabilities 2020