



**Submission to the Joint Standing Committee on the National
Disability Insurance Scheme (NDIS)**

NDIS Planning

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Acknowledgment of country

Women with Disabilities Victoria acknowledges Aboriginal and Torres Strait Islander peoples as the first inhabitants and traditional custodians of the lands on which we live and work, the lands of the Kulin Nations. We pay our respects to ancestors and Elders, past, present and emerging.

A note about language

Many people with disabilities have come to refer to themselves as ‘targeted’ and ‘at risk’ rather than ‘vulnerable.’ This change of language shifts the focus away from a blaming tone towards the victim/survivor – and on to the people who choose to abuse people with disabilities and the social conditions that make this common. Such language is reflected in this document.

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About Women with Disabilities Victoria

Women with Disabilities Victoria is a membership-based organisation run by women with disabilities, for women with disabilities. Our members, board and staff live across the state and have a range of disabilities, lifestyles and ages. We are united in working towards our vision of a world where all women are respected and can fully experience life.

To advance social and economic inclusion for women with disabilities in Victoria, we act as a voice for women with disabilities, create opportunities to be visible and be heard, build partnerships and engage the community to challenge attitudes and myths about women with disabilities. Our gender perspective allows us to focus on areas of particular inequity to women with access to women's health services, gendered National Disability Insurance Scheme (NDIS) services and safety from gender-based violence. We undertake research and consultation and provide professional education, representation, information and leadership programs for women with disabilities.

We have dedicated particular attention to the issue of men's violence against women with disabilities, due to its gravity and prevalence in our lives. Since 2009, we have had a Policy Officer, funded by the Victorian Government, to focus on violence against women with disabilities. This has been a valuable resource for the community sector and government. Our representation at the Royal Commission into Family Violence in Victoria contributed to sixteen recommendations with specific disability content, and our representation to the Victorian Parliamentary Inquiry into Abuse in Disability Services resulted in a chapter on gender in the Committee's final report.

We also work to make the NDIS relevant and responsive to women with disabilities, empower women through our Enabling Women Leadership and Enabling Women Mentoring Programs and promote access to health services for women with disabilities. In focusing on these areas, we are guided by our members. We will wherever possible respond to new and emerging issues to stay relevant and reflect the concerns of women with disabilities.



Pictured: Women with Disabilities Victoria members, associate members, board, staff and supporters.



Introduction

Women with Disabilities Victoria welcomes this opportunity to contribute to the Joint Standing Committee on the National Disability Insurance Scheme's (NDIS) inquiry into NDIS planning. This submission is based on our years of research, practice experience and feedback from our members.

Women with Disabilities Victoria recently held forums for women with disabilities in order to help women prepare for, and understand, the NDIS. These forums were also opportunities to hear firsthand from women with disabilities about the issues they are encountering with the NDIS planning process. We have drawn on insights from these workshops in this submission and reflect what our members have told us is important to them.

Summary

Women with Disabilities Victoria works to make the NDIS relevant and responsive to women with disabilities. We work to influence the National Disability Insurance Agency (NDIA) to take a gender-sensitive approach to all aspects of the practical implementation of the NDIS.

We strongly advocate for using a gender-sensitive approach because women and girls with disability experience multiple and intersecting forms of discrimination. Women with disabilities are overwhelmingly more disadvantaged than men and boys with disability in similar circumstances: we experience higher levels of disadvantage than men with disabilities in employment and income levels and face extremely high rates of violence, including family violence.

While the NDIS is a life changing social reform, we are concerned about research and evidence over time that shows there are inequalities for women in the NDIS. Recent research findings have indicated that women, people with disability in rural areas and those who experience other well-known factors that drive disadvantage are missing the benefits of the NDIS.¹ We are particularly concerned about the lowered rates at which women are accessing the NDIS compared to men. Across all jurisdictions, the percentage

¹ Malbon, E., Carey, G., Meltzer, A., (2019), 'Personalisation schemes in social care: are they growing social and health inequalities?', *BMC Public Health* 19, 805. See also: Warr, D, Dickinson, H, Olney, S, et. al. (2017) *Choice, Control and the NDIS*, Melbourne: University of Melbourne.



of women in the NDIS remains at less than 39%, with some jurisdictions having even lower figures.²

A properly gendered perspective in the NDIS would help to address this clearly emerging gender inequality. For women with disabilities to have positive experiences in the NDIS planning process and opportunities to exercise real choice and control, we recommend the following as a response to key issues raised in this submission:

- That the NDIA take a gendered perspective by developing a Gender Strategy;
- That the NDIA create gender-specific resources for women with disabilities;
- That NDIA staff and planners receive violence prevention and gender equity training (including around economic abuse);
- That the NDIA establish clear processes, guidelines and training for planners in using a risk assessment tool to assess family violence;
- That the NDIA adopts processes allowing participants to see a draft of their NDIS plan;
- That the Australian Government and the NDIA address the issue of thin marketplaces for NDIS services in rural and regional areas; and
- That the Australian Government lift the staffing cap on the NDIA.

The planning process

Women with disabilities we speak to often tell us that they can be left feeling like their planners do not understand their disability or their needs. It is common to hear women with disabilities speak about not feeling understood or listened to by their planner. At Women with Disabilities Victoria, we repeatedly hear from women with disabilities that they feel like they must 'speak up' and become more assertive before they are heard.

Some women said that they would like it if the NDIA had more planners with specialised understanding of their disability type. Some women felt that their planner had drafted their plan based on a limited knowledge of their needs and circumstances. One woman we spoke to observed that despite being prepared for her planning meeting, her NDIS planner did not take very many notes during the planning meeting. The woman's plan came back several months later, with little resemblance to what her support needs were, giving her the sense that the planner did not really remember who she was. It is all too common for women to receive an NDIS plan that does not reflect the discussion in their planning meeting or does not accurately reflect support needs.

² Women with Disabilities Australia, Election Platform. Women are 39% of all NDIS participants in Victoria. See: NDIA, Quarterly Report 2019, COAG Disability Reform Council, Quarterly Report, 30 June 2019, p. 154.



More and better training for NDIA planners and Local Area Coordinators (LACs) is needed to improve the quality of NDIS plans. Providing participants with a draft version of their NDIS plan would provide an opportunity for participants to correct any inaccuracies and ask questions. This would also mean minor changes could be made before initiating a lengthy plan review process. As a result, we recommend that the NDIA adopt the practice of providing participants with draft plans.

Changing an NDIS planner

Women with Disabilities Victoria lets women know that they have the right to feel comfortable with who their planner is and that they can request a different planner, if they want to. We also make it clear that women have the right to have their planning meeting where they feel comfortable and can request to have their meeting in this location. Some women spoke about feeling frustrated about the process of requesting a new planner. Other times, this was helpful.

Women with Disabilities Victoria also reiterates to women that they have the right to choose whom they want, or do not want, to be at their planning meeting. This includes being able to have a friend or support person present, or being able to speak without a family member or carer present, if this is what they want. The drive of people with disabilities for independence from family members must be respected in NDIA practice, acknowledging that, in some cases, family members can seek to serve their own interests above those of family members with disabilities. A woman's request about who they want to be at their meeting should be respected. Additionally, situations of family violence (including economic abuse) should be screened for as part of the planning process.

“ We need to make sure that people are not asked, for example, ‘are you happy with your mother being your administrator,’ in front of their mother. That people are fully briefed about their rights and are able to speak privately.” – Sandra.³

The right to choose the gender of a support worker is a key issue raised by our members and stakeholders. This choice is important for women's feelings of safety, comfortability

³ Sandra's comments are from a focus group held in 2015 regarding NDIS Quality and Safeguarding processes. See: Women with Disabilities Victoria (2015), Inquiry into an NDIS Quality and Safeguards Framework – Submission to Department of Social Services, on behalf of the Disability Reform Council and COAG (Melbourne: Victoria).



and, in some cases, cultural and religious reasons. We recommend that the NDIA create gender-specific resources for women with disabilities, in a range of accessible formats, to let women know they have these options.

“ *Sometimes I am, but sometimes I am not, asked about my gender preference for support workers and services. I do not always think this is seen as being as important as it really is.*” - Mira.⁴

Plan gaps

After the initial planning meeting, many women we speak to are waiting months before receiving their NDIS plan. Many are unable to find out about the status of their plan, feeling that it has entered “a black hole” and waiting for several months. No timeline is provided for when participants can expect to hear back from the NDIA or their Local Area Coordinator about their plan. Many women said that this process and the level of uncertainty was incredibly stressful and emotionally distressing. This uncertainty and disruption has the potential to exacerbate existing mental health condition(s) and/or impact upon psychosocial disabilities.

We know from what women tell us that plan gaps have major impacts. We have heard of one woman’s impairment deteriorating significantly due to not receiving a piece of equipment during the gap between NDIS plans. The impacts of gaps between plans includes general stress, anxiety and impacts on mental health and psychosocial disabilities. In one woman’s words, the NDIS is “*a rollercoaster of emotions, one minute it is good, the other it is bad.*”

NDIS reviews and appeals

The process for seeking a review of a decision made by the NDIA is still lengthy, complicated and stressful for the many women with disabilities we hear from. The process is also experienced differently depending on a person’s disability type and a range of other circumstantial factors, including the amount of support a person has to initiate an appeal or review process.

We also observe the many mental health and wellbeing impacts associated with the NDIS review process. The high need for assistance with NDIS appeals and reviews is also having an impact on the disability advocacy sector. Due to the high demand for assistance

⁴ Name has been changed.



with NDIS issues, many Victorian disability advocacy organisations current have waiting lists for independent advocacy and assistance, which are completely full.

“ *As women with disabilities, if you do not speak up and really tell people what you need, you will not get the full amount of support available. It is easy to say, “Oh, okay, I guess I’ll have that.”* Cara.⁵

Family violence and the NDIS planning process

Women with Disabilities Victoria continues to align our NDIS work with the recommendations of the Victorian Royal Commission into Family Violence and their implementation. One of our concerns is that planners in the NDIS do not have sufficient training in recognising and responding to family violence.

Women with disabilities need staff at the NDIA and in Local Area Coordination to be equipped in understanding, recognising, responding and referring women to appropriate agencies such as family violence, legal and sexual assault services. These are priority issues for us because the rate, length and severity of violence against women with disabilities is extremely high, as confirmed by Victoria’s Royal Commission into Family Violence, among other significant investigations.⁶

Women with disability experience significantly higher levels of all forms of violence and experience it from a greater number of perpetrators. While women with disability face many of the same forms of family and sexual violence as women without disability, women with disability are at more risk of particular forms of violence, such as forced sterilisation, seclusion and restrictive practices.

We also experience violence in a range of institutional and service settings, such as in residential institutions or hospitals. The Convention on the Rights of Persons with Disabilities (CRPD) requires that state parties recognise that women and girls with disabilities are at a particularly greater risk of violence, abuse and exploitation.

⁵ Name has been changed.

⁶ The Victorian Royal Commission into Family Violence found that women with disabilities experience all kinds of violence at higher rates, increased severity and for longer than other women. Dowse et al., (2013); Didi et al., (2016) cited in Maher, J. M., Spivakovsky, C., McCulloch, J., McGowan, J., Beavis, K., Lea, M., ... Sands, T. (2018), ‘Women, disability and violence: Barriers to accessing justice: Final report’ (ANROWS Horizons, 02/2018). Sydney: ANROWS.



As such, we recommend that NDIA planners and service delivery staff receive violence prevention and gender equity training, developed and delivered by people with expertise in gender equity.

The NDIA must institute clear processes and training around using a risk assessment tool to assess family violence for women with disabilities. If family violence is disclosed or suspected, NDIA staff should take all possible steps to uphold participants' safety, rights and interests. The new NDIS workforce must be trained in understanding gendered violence and applying the principles of good practice to uphold the safety of women with disabilities. These processes should also be applied for participants who require Supported Independent Living (SIL) supports in their plans.

Resource: You Can Ask That

[You Can Ask That](#) is Women with Disabilities Victoria's video produced as part of an NDIS module for Enabling Women, our community leadership program for women. The video is an accessible resource that provides viewers with peer-to-peer advice and information, based on first-hand knowledge, skills and experiences about being an NDIS participant.

Conclusion

Improvements to the NDIS planning process are critical for women with disability to fully experience the benefits of the NDIS. We need an NDIS that considers the impact gender makes and acknowledges the rights of women with disabilities to live free from violence. To this end, women with disabilities expect more and better training for the NDIS workforce around both gender and disability and a removal of the staffing cap on the NDIA, to allow for better access to the scheme and better quality plans.

Women with disabilities in the NDIS have the right to ...

- Be listened to.
- Be safe and feel safe.
- Have accessible information.
- Have supports that respect our dignity as women and our privacy.
- Have supports that do what was agreed to in our NDIS plan.
- Choice about who provides us support (e.g. if we want to have a female worker).
- An advocate or a support person in a planning meeting.
- To have our planning meeting somewhere we feel relaxed and comfortable and help the NDIS planner understand our life.