



Department of Social Services (DSS)

**Submission on the NDIS Act Review and NDIS Participant
Service Guarantee Discussion Paper ('Tune Review')**

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Publishing information

This document was prepared by Women with Disabilities Victoria (WDV).

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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. We acknowledge the traditional owners of the land on which this publication was produced, the lands of the Kulin Nations, and 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. This 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 Senior 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 and overview

We would like to thank the Department of Social Services (DSS) for the opportunity to comment on the Discussion Paper 'Improving the NDIS Experience', as part of the review of the *National Disability Insurance Scheme Act 2013* (NDIS Act), NDIS Rules and the development of a new NDIS Participant Service Guarantee.

Women with Disabilities Victoria works to make the NDIS relevant and responsive to women with disabilities. Due to gender inequalities in Australian society, women with disability are overwhelmingly more disadvantaged than men with disability. For example, we experience higher levels of disadvantage than men with disability in employment and in income levels and face extremely high rates of violence, particularly family violence. We strongly advocate for taking a gender-sensitive approach in the NDIS because women and girls with disability experience multiple and intersecting forms of discrimination.

Accessing the NDIS

Fixing barriers to access for women with disability

We welcome the recent announcement by Minister Stuart Robert of an increase in to the number of Australian Public Service (APS) staff at the NDIA this financial year. However, we join many others in drawing attention to the Average Staffing Level (ASL) cap as one of the main restrictions placed on the National Disability Insurance Agency (NDIA). Inadequate staffing levels at the NDIA have led to a high turnover of staff and insecure employment at the NDIA, impeding the performance and implementation of the NDIS. While we welcome this recent announcement, we call, as many others have, for the repeal of the NDIA's staffing cap and careful ongoing monitoring of this issue.

While we also acknowledge that the NDIS is a major, life changing policy reform and that the Australian Government and NDIA have initiated improvements to the NDIS, such as the Participant Pathways reform, we remain concerned about data and research that is indicating there are inequalities for women in the NDIS.

Research findings demonstrate that factors that drive inequalities, such as gender, age, class and geographic location are operating to prevent access to the NDIS and the achievement of positive outcomes.¹ We are particularly concerned about the low rates of women accessing the NDIS. The percentage of women participants in the NDIS remains at 39%, with even lower figures in some jurisdictions. This disparity is compounded for

¹ See: 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.



women from Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse (CALD) backgrounds. Only 5.7% of participants in the NDIS who have an approved plan identify as Aboriginal and Torres Strait Islander people and only 8.4% of participants are from Culturally and Linguistically (CALD) backgrounds. These figures are extremely concerning, given the higher rates of disability amongst Aboriginal and Torres Strait Islander peoples especially.²

As part of this review, the NDIA must acknowledge the access issues for multiply marginalised and disadvantaged communities, including the gendered inequalities in accessing the NDIS and take special measures to address this.

To respond to this, we recommend that the NDIA work with Disabled Peoples Organisations (DPOs), representative organisations and networks of women with disability to develop a strategy to identify solutions to these inequalities in accessing the NDIS. Providing further publicly available gender disaggregated NDIS data will also help us understand more about the issues facing women with disability within the NDIS. As part of finding solutions, we also recommend that this review respond to the need for women with disabilities in the community to have further avenues to participate in genuine co-design, collaboration and consultation with the NDIA.

Implementing more pre-access support

There is a need for further navigational and access support for women with disability to gain access to the NDIS. As has been documented elsewhere, the pressures of the NDIS transition stage have led to significant changes in the Local Area Coordination (LAC) role, initially intended for referral and the provision of navigational support to people with disability.³

LACs are usually the primary form of support for most NDIS participants in navigating the NDIS. However, most LAC time is spent preparing NDIS plans due to the way key performance indicators are tied to the completion of plans. This has meant that support with the application process and in navigating and understanding the NDIS has been under-developed.

Commonly reported reasons for people with disability not applying for the NDIS include distrust, people being too unwell to apply, a feeling of overwhelm and a lack of awareness

² In 2014-15, around 45% of Aboriginal and Torres Strait Islander people aged 15 years and over said they experienced disability. Australian Bureau of Statistics, 4714.0 - National Aboriginal and Torres Strait Islander Social Survey, 2014-15, <<https://www.abs.gov.au/ausstats/abs@.nsf/mf/4714.0>>.

³ Joint Standing Committee on the National Disability Insurance Scheme 2018a, Market readiness for provision of services under the NDIS, cited in Brotherhood of St Laurence, 'Submission to the NDIS Thin Markets Project Consultation', Department of Social Services (DSS), July 2019, p. 10.



of the NDIS.⁴ Previous focus groups we have run with women with disabilities indicated that even in NDIS launch sites there was a real lack of awareness among women about how to access the NDIS. To address this, Women with Disabilities Victoria created information on the NDIS and has run workshops for women to explain their rights under the NDIS.

At the access stage, some women experience extra hurdles based on the evidentiary thresholds of the access process and parts of the *NDIS (Becoming a Participant) Rules* that require participants to have exhausted all 'known, available and appropriate evidence-based' treatments before an impairment is considered 'permanent and significant' under the NDIS Act. Where the NDIA requests further evidence from a person with disability after receiving their access request, such requests often do not outline what further evidence is actually being sought by the NDIA to assist with its decision making.

Some groups of women with disability, particularly women with autism and chronic pain-related disability can be more likely to experience misdiagnosis or late diagnosis. These women can face significant hurdles in obtaining the diagnostic information and reports that will satisfy NDIS criteria. Furthermore, the greater poverty women with disability are more likely to experience creates significant financial barriers to obtaining reports needed for access to the NDIS.⁵ Women with psychosocial disability are also faced with a limited number of mental health professionals who have familiarity with the NDIS, its language and eligibility criteria, which would allow them to obtain reports that enable entry to the NDIS. Occupational Therapists (OTs) are currently experiencing an increase in the demand for report writing, but often lack the training in mental health to assess functionality for NDIS purposes.⁶

NDIS eligibility requirements can therefore result in privileging those with more well-defined and recognised diagnostic conditions and those with the financial means to retrieve costly reports, effectively erecting barriers for those with limited treatment histories and limited previous access to disability support. Some women with disability may not be able to access a neat diagnosis of their impairment by professionals due to a complex presentation, the rareness of their disability, and the complex interplay between

⁴ National Mental Health Commission, 'Monitoring mental health and suicide prevention reform: National Report 2019.'

⁵ Yellow Ladybugs research found that in Australia, 10% of autistic girls receive a diagnosis before the age of 3; 37% aged 3-5 years; 24% aged 6-8 years; 16% aged 9-12 years; 4% aged 13-18 years; with 9% still waiting to have their disability recognised. There are many undiagnosed females with autism in the population, as professionals are more likely to overlook the possibility of autism in women and girls, despite diagnostic criteria. See: Blakemore, M., Robertson, G., Hansford, S. *et. al.*, 'Multiple and Intersecting Forms of Discrimination against Autistic Women'.

⁶ See our submission to the Royal Commission into Victoria's Mental Health System: Australian Federation of Disability Organisations (AFDO), Disability Resource Centre (DRC), Disability Justice Australia (DJA), Women's Mental Health Network Victoria Inc. (WMHNV) and Women with Disabilities Victoria (WDV), (2019), Submission to Royal Commission into Victoria's Mental Health System, (Melbourne: Victoria).



gendered inequalities, current medical understandings and the application of diagnostic criteria.

Additionally, medical report writing does not always emphasise the permanence of conditions in the way that the NDIA requires, as medical professionals are not trained in the language of the NDIS. Currently, the onus on women with disability to gather and provide evidence in the context of the NDIS's layered statutory framework is large, especially with limited support.

As the current NDIS access process relies on a level of self-referral and the navigation of complex language and structures, this disadvantages women with disability who are currently in crisis (such as experiencing family violence and homelessness), who are not engaged with services or who would otherwise struggle to get NDIS support without an advocate or dedicated case management. For example, many people with disability currently experiencing homelessness could be eligible for the NDIS, but without dedicated outreach and support, the barriers to submitting an access request are immense.⁷

Strengthening navigational infrastructure and pre-access support is needed for women with disability to be able to access the NDIS equitably, particularly women with disability experiencing multiple, intersecting forms of disadvantage. Advocacy and peer support also act as important safeguards and can also help to support engagement with many people considered to be in 'hard to reach' populations. We recommend that the new Participant Service Guarantee make a commitment to more proactive engagement and outreach for women with disability who may be eligible for the NDIS and make recommendations to this effect.

Referral pathways for those deemed ineligible for the NDIS

We know anecdotally that there is limited referral onwards to other available supports for women deemed ineligible for the NDIS and a lack of integrated pathways to other kinds of services. Currently, navigating both NDIS-funded and non-NDIS funded support is fragmented, with multiple systems operating in a siloes, as limited collaboration is fostered under the NDIS's current pricing structure.

As noted previously, because the role of LACs in providing information, linkage and referrals to other services and connecting people with disability to other supports in their community has changed, initiatives are required to provide a system for much-needed referral, collaboration and inter-agency work in the NDIS. Increased coordination and collaboration between the NDIS and other services is essential for providing people with disability ineligible for the NDIS with warm referrals to other services.

⁷ Council to Homeless Persons (CHP), 'Homelessness and the National Disability Insurance Scheme – Challenges and Solutions.'



Recommendation: that as part of the review and amendments to the NDIS Act, the NDIA, Partners in the Community (LACs) and people with disabilities come together to reassess and refine the LAC role within the NDIS, including the support needed to submit access requests and to navigate the NDIS.

Recommendation: that the NDIA work with representative organisations and networks of women with disability to develop a Gender Strategy to respond to the emerging gender inequalities within the NDIS.

Recommendation: that the Participant Service Guarantee include a right for participants to receive and expect a gender-sensitive and safe experience while engaging with the NDIS.

Recommendation: that the Participant Service Guarantee include a right for people with disability, including women with disability, to expect opportunities for genuine co-design, collaboration and consultation with the NDIA.

Recommendation: that all monitoring of how well the NDIA is delivering on the Participant Service Guarantee is gender disaggregated (i.e. data on outcomes is collected and reported separately according to gender).

The planning process

Plan quality

Issues with the quality of NDIS plans is longstanding and well documented elsewhere. Too many women we represent tell us about feeling overwhelmed, confused and unheard during the planning process. Wait times before plans are approved are inexcusably long, often many months without any contact or updates from the NDIA. Women report experiencing anxiety or the exacerbation of existing mental health issues because of the uncertainty, as no indication of timeframes for approval are given. In the words of one woman at a recent forum: *“I am tired of the word ‘wait’, I am sick of waiting.”*

Receiving poor quality plans is also far too common; and whether a person receives a satisfactory or poor quality plan partly depends on chance - whether the first allocated LAC planner has the skills, knowledge and understanding to develop a sufficient first plan in respectful coordination with the participant *and* in agreement with the NDIA delegate tasked with approving the plan.

Inadequate plans affect the NDIA’s own efficiency and as well as participant outcomes, with many poor quality plans going straight into the review stage, filling up the NDIA’s already existing review backlog. Many elsewhere have previously highlighted and reported on the internal overreliance on Typical Support Packages (TSPs) in the



development of participant plans as a source of many of the inadequacies in the current planning process.

We recommend that this review and any new Participant Service Guarantee ensures that the planning process return to executing the NDIS Act's legislated intention of providing person-centered, individualised planning, focused on an individual's unique set of needs, circumstances and goals. Planning should be a respectful, meaningful and collaborative investigation of a person's support needs. While we understand the focus around participant intake in the transition period, a focus on getting plans right in the first instance will prevent the need for reviews. A new Participant Service Guarantee is an important opportunity to re-center the person-centered values at the heart of the scheme's original design.

There would be considerable benefit in including a right and standard practice for participants to view a copy of their draft NDIS plan and have further discussion about the plan before a plan is agreed to and 'locked in'. We would also recommend that this review provide a new right and regular practice of providing participants with draft plans in the NDIS.

Training of planners

Too often, we hear from women with disabilities we represent that their planners do not understand their disability, their support needs, or that they do not feel listened to. We repeatedly hear from women with disabilities that they feel like they must 'speak up' and become more assertive before they are heard and respected.

In discussions and focus groups, women with disabilities often say that the NDIA must have more planners with specialised understanding of their disability, specific training, the right values and knowledge and sensitivity around issues that affect women with disability, such as experiences of gender-based violence.

Some women we spoke to felt that their planner had drafted their plan based on a limited understanding of their needs and circumstances, despite what was provided as part of the access process, a planning conversation and in reports. One woman we spoke to observed that despite preparing extensively for her own planning meeting, her NDIS planner took minimal notes during her 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 even remember who she was. Most of the time, participants do not get to meet or build a rapport with the delegate tasked with approving their plan. This can lead to a sense of mistrust, a feeling that the NDIA is 'faceless' and that there is a lack of transparency in the plan approval process.

Planners also require an understanding of the needs of parents with disabilities, as the needs of parents with disability are often an overlooked as a specific group. Appropriate



antenatal and postnatal care support for mothers with disability is often lacking and the overall disproportionate representation of parents with a disability in the child protection system reflects the absence of much needed support. There is need for further education and training, including across the NDIS workforce, to develop the knowledge of available accessible information and family support services in order to better support parents with disability.

Training for planners should focus on how to provide best practice, person-centered planning, with training in conducting family violence risk assessments and education on gender equity issues for women with disabilities, including experiences of violence and abuse. We continue to voice the need for increased resourcing of planners and more and better training to improve the quality of NDIS plans. While there is a need for improved training, we also stress that there is also a need for more planners, particularly planners who are APS staff, with the right delegation to approve plans and serious measures to address the issues underlying high staff turnover at the NDIA.

A single point of contact

Many women note that they do not always know whom to contact for information about the status of their plan, or their request for a review, or experience significant delays in being able to contact staff. A single point of contact is a welcome development, as long as participants are still able to change their single point of contact, for any reason, at any time, without this jeopardising the level of support they receive.

We inform women with disabilities that they have the right to request a different planner, for any reason, or to request a female planner, if this feels more comfortable. Women with disabilities should have the right to a single, trusted point of contact. While single points of contact are a needed improvement, however, no participant should be unable to request that their planner or point of contact change.

Communication

At all stages of the NDIS experience, the NDIA needs to commit to improving its communication with participants and internal communication processes by using plain and simple language. For example, we have heard from several women who have not received their plans in accessible formats or in language that they do understand. As part of the Participant Service Guarantee, the NDIA must seriously commit to improving its own internal language and aligning all communications with simple and easy to understand forms of English, Easy English and providing resources in languages other than English. When it comes to internal communication, the NDIA should establish mechanisms to improve internal communication between the NDIA delegates approving and reviewing plans and LAC staff members.



Recommendation: as part of the Participant Service Guarantee, that the NDIA commit to greater accessibility and improved communication; providing all resources and communications in simple English and Easy English for participants and in the language that participants prefer, including languages other than English.

Recommendation: that participants have a right to review a draft of their NDIS plan and have further conversations about it with their planner before it is agreed to.

Recommendation: that the Participant Service Guarantee include the principle that participants have a right to receive and expect person-centered and respectful planning at all stages of their NDIS journey.

Recommendation: that more and better training is provided for NDIS planners, designed and delivered by people with disability, with a focus on information and referral, family and parenting services for parents with disability, conducting family violence risk assessment and specialised knowledge of disability.

Plan reviews, internal reviews and NDIS appeals

Participants are often receiving inadequate plans that do not reflect the discussion in their planning meeting or their support needs, often leaving them with no choice but seek either a plan review or request an internal review (a 'review of a reviewable decision').

The process for seeking a review of a reviewable decision made by the NDIA is lengthy, complicated and stressful for the many women with disabilities we represent. Legislated time limits for the completion of an internal review should be implemented to address this. Currently, participants are waiting extremely long periods before receiving an outcome on their request for an internal review, up to many months.

The process is also experienced differently depending on a person's disability type, life experiences and a range of other contextual factors, including the amount of support a person has to initiate an appeal or review process, including whether they have an advocate to assist them with the process. Participants often need support with the review process, such as the assistance of an advocate, due to impacts on their wellbeing, the complexity of negotiating their way to needed supports and understanding complex and confusing language and legislation.

The growing demand for assistance with navigating the NDIS appeals and review process is also having an impact on the disability advocacy sector. Due to the high demand for assistance with NDIS issues, many Victorian disability advocacy organisations currently have waiting lists for independent advocacy and assistance that are completely full. In Victoria, the advocacy sector does not have funding security beyond June 2020.



Despite the stress and difficulty of the NDIS reviews process, there is an emerging understanding that complaints and appeals are a necessary part of the process for obtaining much needed supports, or a response, with some participants resorting to contacting their local Member of Parliament. As one woman in a recent community forum put it: *'[a]s women with disabilities, if you do not speak up and really tell people what you need in the NDIS, you will not get the full amount of support available. It is easy to say, "Oh, okay, I guess I'll have that.'*

Any changes to the review process should be grounded in an understanding that the principle task is to get plans right in the first instance, with good quality planning meetings, reducing the need for unscheduled reviews and reviews of reviewable decisions.

Additionally, this review of the NDIS Act is an invaluable opportunity to achieve a better and clearer distinction between a plan review (section 48) and a review of a reviewable decision (section 100). The language around the review process should be made clearer and simpler – and this language is presently confusing for participants; furthermore, participants are sometimes give incorrect information regarding their review rights and process by NDIA staff. We would suggest that the reviewers of the legislation consider ways to simplifying the language around both of these processes to ensure better clarity for participants, staff and advocates.

Recommendation: legislate time limits in line with similar provisions in NDIS legislation (21 days) for receiving an outcome on a request for a section 100 internal review.

Recommendation: as part of a commitment to values of transparency and timeliness, that the NDIA commit to recording and publishing NDIS review data in Quarterly Reports, including the current number of outstanding reviews.

Recommendation: that the NDIA set a target for reducing reviews and works towards this as a matter of priority.

Recommendation: efforts and initiatives are put in place by the NDIA to provide consistent and accurate information about review rights.

The need for greater flexibility in NDIS plans to deal with crisis

Conducting family violence risk assessments

Women with Disabilities Victoria continues to align our 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 and abuse.

This is a priority issue for us because the rate, length and severity of violence against us as women with disability is extremely high, as confirmed by Victoria's Royal Commission



into Family Violence, (among other significant investigations).⁸ This is why women with disabilities need staff at the NDIA and in Local Area Coordination that are equipped in understanding, recognising, responding and referring women to appropriate agencies such as family violence, legal, sexual assault and counselling services.

The NDIS Act provides that, in determining what constitutes ‘reasonable and necessary’ supports in a plan, ‘what it is reasonable to expect families, carers, informal networks and the community to provide’ should be considered by the NDIA. In the way this is interpreted, there is often an underlying assumption or a belief held, as information provided about the kinds of supports a participant needs to achieve their goals is reviewed, that ‘informal supports’, such as the support provided by carers, family or friends, is always a positive form of support. This is dangerous for women experiencing family violence and has highly a highly gendered impact on women with disability who are also carers for other people with disability themselves.

NDIS planners must be equipped as part of their training and regular practice to recognise and assess the risk factors for violence and abuse in order to uphold the safety of women with disabilities. Planners should be trained in using a risk assessment tool to assess the risk of family violence and ensure that family are not present during this assessment. If family violence is disclosed or suspected, planning staff should take all possible steps to uphold participants’ safety, rights and interests.

One of the key recommendations of the Royal Commission into Family Violence in Victoria was that the Commonwealth Government and the NDIA work to ensure that all disability service workers involved in assessing needs and delivering services to people with disability have successfully completed certified training in identifying family and domestic violence and response.

Another key recommendation of the Royal Commission provided that in the transition to full scheme, the NDIA should aim to provide flexible support packages that are responsive to people with disabilities experiencing family violence, that incorporate crisis supports and assistance for recovering from family violence. We support and strongly encourage the NDIA to implement measures that respond to these recommendations as part of the NDIS Act review and in development of its Participant Service Guarantee.

Plan amendments, as outlined in the Discussion Paper, could be appropriate in some contexts where a participant is in crisis or requires an urgent (but minor change) to their

⁸ 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.



plan and supports, or where participants require slight corrections of errors in their plan. The NDIA should always ensure that the appropriate systems and training are in place that allow it to provide flexible, timely and appropriate crisis support and assistance in women's NDIS plans.

Recommendation: as part of the Participant Service Guarantee, participants can know that NDIA staff have adequate training and the capacity to identify and respond to violence and abuse when a woman presents to the NDIS workforce.

Recommendation: that all NDIA planners and service delivery staff receive violence prevention and gender equity training, that is developed and delivered by people with expertise in gender equity.

Conclusion

General improvements to the NDIS access, planning and review process are critical for women with disability to fully experience the benefits of the NDIS. To this end, women with disabilities should be able to expect more and better training for the NDIS workforce, better pathways for accessing the scheme and better quality plans. However, we also need an NDIS that considers the impact gender makes and acknowledges the recognised rights of women with disabilities to live free from violence.

Only a properly gendered perspective in the NDIS will help to address some of the clearly emerging gender inequalities. 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 as a matter of urgency:

- 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 a Gender Strategy be developed in partnership with women with disability to address inequalities in accessing the scheme.

We wish to thank DSS for the opportunity to provide our submission on the Discussion Paper on improving the NDIS experience. We would welcome any further consultation on any of the matters we have raised.