



**PEOPLE WITH DISABILITY**  
**AUSTRALIA**

**A voice  
of our  
own**

# Tune Review of the NDIS Act

Submission to the Tune Review:

Improving the NDIS Experience: Establishing a Participant  
Services Guarantee and removing legislative red tape

OCTOBER  
NOVEMBER 2019

# About PWDA

**People with Disability Australia** (PWDA) is a leading disability rights, advocacy and representative organisation of and for all people with disability. We are the only national, cross-disability organisation - we represent the interests of people with all kinds of disability. We are a non-profit, non-government organisation.

PWDA's primary membership is made up of people with disability and organisations primarily constituted by people with disability. PWDA also has a large associate membership of other individuals and organisations committed to the disability rights movement.

We have a vision of a socially just, accessible and inclusive community, in which the human rights, belonging, contribution, potential and diversity of all people with disability are recognised, respected and celebrated with pride. PWDA was founded in 1981, the International Year of Disabled Persons, to provide people with disability with a voice of our own.

PWDA is a NSW and national peak organisation and founding member of Disabled People's Organisations Australia (DPO Australia) along with Women With Disabilities Australia, First Peoples Disability Network Australia, and National Ethnic Disability Alliance. Disabled Peoples Organisations (DPOs) are organisations that are led by, and constituted of, people with disability. The key purpose of DPO Australia is to promote, protect and advance the human rights and freedoms of people with disability in Australia by working collaboratively on areas of shared interests, purposes, strategic priorities and opportunities.

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# Introduction

People with Disability Australia welcomes the opportunity to provide this submission to the Australian Government's review of the National Disability Insurance Scheme Act 2013 (the NDIS Act): the Tune Review.

The Terms of Reference for the Tune review of the NDIS focus on "opportunities to amend the NDIS Act to:

- a. remove process impediments and increase the efficiency of the Scheme's administration; and
- b. implement a new NDIS Participant Service Guarantee
- c. as well as any other matter relevant to the general operation of the NDIS Act in supporting positive participant and provider experiences.

In making this submission, we note that a previous review of the NDIS Act was undertaken in 2015. However, while the recommendations of this review were accepted by the COAG's Disability Reform Council, the recommendations did not progress to changes in the legislation at the time.

PWDA believes that this current review of the legislation should include the amendments to the legislation that were recommended in 2015 and are yet to be implemented. In this submission, we have reviewed the proposed 2015 amendments and we outline why the majority of them are still current and should be adopted as part of this legislative review.

As the Terms of Reference highlight, this review must also have regard to "the objectives and principles of the NDIS Act and the experiences of people with disability, their families and carers with the Scheme's administration and decision-making, including: access, planning, review and appeal processes."

Our submission is informed by our strong and continuing support for the Objects and Principles of the Act. PWDA recognises that the NDIS represents a key plank within the broader National Disability Strategy (NDS) which seeks to deliver on Australia's commitments under the Convention on the Rights of Persons with Disability (CRPD).

PWDA notes the recently released UN Committee's Concluding Observations on the combined second and third reports of Australia (September 2019) identified the following concerns with the implementation of the NDIS:

- III.A.5.e - Disability assessment to be eligible to receive services through the National Disability Insurance Scheme (NDIS) still relying heavily on the medical model of disability and not providing older persons with disability, persons with disabilities from culturally and linguistically diverse (CALD) or Indigenous backgrounds and person with intellectual or psychosocial disabilities with equal opportunities
- III.A.5.f - Inaccessibility of the NDIS due to the complex, complicated procedures, limited publically available and accessible information, and lack of services in remote areas

- III.A.5.g - The lack of sustainably, adequately resourced continuous, individual and independent advocacy programmes.<sup>1</sup>

We also note that there are a number of other reviews related to the NDIS and its legislative instruments including:

- the Streamlined Governance Bill
- amendments to Rules relating to Special Disability Accommodation and the Quality and Safeguards Commission.

We encourage the Tune Review to our submissions made to these inquiries and note that our comments in this current submission on the review of the NDIS Act in relation focus on the matters raised through the Discussion Paper.

And finally, we note that the redevelopment of the National Disability Strategy (NDS) and the National Disability Agreement are critical to addressing significant and ongoing issues with the implementation of the NDIS and, in particularly clarifying the interface between the NDIS and the policy and funding arrangements for services and supports provided by State and Territory and local Governments.

<sup>1</sup> Committee on the Rights of Persons with Disabilities, (2019) Concluding observations on the combined second and third reports of Australia, p.2

## PWDA's expertise to make this submission – the voices of people with disability must drive the NDIS

PWDA provides advice and information; individual, group and systemic advocacy; training, research and education; and a representative voice of people with disability nationally and internationally.

Our work addresses the discrimination, marginalisation, poverty and human rights abuses that people with disability experience. As a 'cross-disability' organisation, we work with all people with disability, with a focus on people with disability in who are in marginalised and vulnerable situations.

PWDA is also a 'Disabled People's Organisation' (DPO) in that we are governed by, led by and constituted of people with disability, and have significant connections and engagement with our membership and constituents who are people with disability. As a DPO, we recognise that people with disability are experts in their own lives. As a DPO, PWDA fulfils a specific role as a Disability Representative Organisation and at the national level are funded in this specific capacity, in addition to work that might be funded through the National Disability Advocacy Program (NDAP) and through the NDIS-specific projects and programs that we run.

DPOs are recognised and valued as a rich source of information, peer networks and policy. For example:

- DPOs have been consulting and collaborating with each other, sharing information and knowledge on good practice, providing capacity building and delivering training to peers, specialist and mainstream services for decades
- DPOs provide peer to peer capacity building, supported-decision making, information provision and training that maintains and develops relationships of trust, community and empowerment between people with disability
- DPOs offer the capacity to drive policy advice, research and training that is independent and not effected by existing relationship dynamics between people with disability and service providers or government agencies, and thus avoids potential conflicts of interest
- DPOs and independent advocacy work from a human rights perspective.

It is critical to recognise that PWDA already undertakes, and has significant expertise which support access, inclusion and participation of people with disability in the NDIS.

PWDA is recognised for our expertise and value in:

- providing disability rights information, linkages and referral to inform people with disability about their rights and to connect them to the NDIS and other relevant specialist disability and mainstream supports
- providing training to local councils, State Government and disability and mainstream service providers to build capacity to effectively design best practice service delivery and enhance inclusion of people with disability

- providing advice and support to government and non-government service providers in the development of Disability Action Plans that eliminate disability discrimination and create accessible workplaces and customer service environments
- building self-advocacy capacity through peer support activities and training programs
- building and supporting local peer support groups of people with disability to share and learn from each other
- providing training to people with disability, service providers and government on specific issues, such as human rights, preventing and responding to violence and sexual assault, communication and supported decision-making
- providing supported decision-making assistance and capacity building to people with disability and service providers, including providing communication supports and developing supported decision-making tools and mechanisms
- facilitating consultation and collaboration with people with disability to enable evaluation of the disability and mainstream support system.

DPOs have a direct connection to the issues and concerns of people with disability through their membership and their constituency. As with most DPOs, PWDA's membership and constituency is largely made up of people with disability in the most marginalised and vulnerable situations and who have experienced or continue to experience significant human rights violations and hardships. These are the very same people who are the main receivers of advocacy services and who would benefit from increased access to the supports and services they need through the NDIS. For example, this includes people with disability who are in contact with the criminal justice system, living in institutions, experiencing domestic violence, being forcibly sterilised, having their children taken from them, being forced to live in segregated and congregate environments, being homeless and most likely to be living in poverty.

PWDA's submission represents the interests and views of our members and supporters. PWDA regularly engages with our members and supporters on key issues impacting the roll-out and effective operation of the NDIS in a variety of accessible formats, including survey, phone conversation, email and in person.

Many of our projects and programs are directly related to the NDIS. Whilst these projects and programs may have different funding streams, they are interrelated. These include:

- NDIA Appeals Advocacy and Information (funded through Department of Social Services) – This service provides support and non-legal advocacy to people living in NSW and QLD to appeal a decision made by the NDIA about their NDIS plans. This can range from supporting a person through the review process, assistance accessing Legal Aid services and, where the issue remains unresolved, supporting a person through conciliation and formal proceedings before the Administrative Appeals Tribunal. This service also provides information sessions across NSW and QLD on how to appeal a plan and provides tips on self-advocacy.
- Individual Advocacy (funded through the National Disability Advocacy Program or 'NDAP') – PWDA provides individual advocacy across NSW and in 5 QLD Local Government Areas. Our most recent figures show that approximately one quarter of

individual advocacy matters are directly concerned with the NDIS. The nature of NDIS matters coming through to the individual advocacy program vary greatly, but some key issues include: inadequacy of funding ; lack of casework support available resulting in NDIS participants not being able to fully utilise funding within their plans; inadequacy of support to parents with disability who are on NDIS.

- Systemic Policy and Advocacy (Funded through the NSW – Systemic Advocates provide policy advice and representation on the rights of people with disability, to bring fundamental, positive change to social structures and processes that result in marginalisation, disadvantage, discrimination, exclusion and abuse of people with disability. The direction of our policy work is guided by the concerns of our members, issues and trends drawn from our individual advocacy program, and the policy and law reform opportunities that arise. The PWDA systemic advocacy program has been at the forefront of advocating for the NDIS, including advocacy on: transitional arrangements; gaps in services and supports; supports needed to live in the community, accessible housing options and the operation of Specialist Disability Accommodation (SDA), sufficient funding for transport; quality and safeguards, issues around the need for increased access to case management; and ensuring that people’s will and preference is at the forefront of the NDIS.
- NSW Disability Housing Information and Advocacy Service (funded through the NSW Department of Communities and Justice or ‘DCJ’) – The service provides information and advice to people with disability living in Specialist Disability Accommodation (SDA), their supporters and accommodation providers in NSW. This service also can provide information on dispute resolution processes, including internal complaints to the SDA provider and external complaints resolution through a Community Justice Centre.
- Disability Housing Advocacy Service (funded through the NSW Department of Communities and Justice or ‘DCJ’) – This service provides people with disability who are living in SDA with advocacy to assist them to resolve their housing concerns and enforce their rights. This may be through provision of information and advice, individual advocacy, mediation or other dispute resolution.
- Building Access NSW – This is a pilot project which aims to increase access to domestic and family violence services across NSW for women and children with disability. This project reviews accessibility of existing domestic and family violence services and provides feedback and delivers training on ways to improve accessibility of their services. The project is building best practice networks across the domestic and family violence sector in NSW to address barriers faced by people with disability in accessing the services they need to escape violence.
- Information Linkages and Capacity Building (ILC) (funded through the NDIA) – the various ILC projects undertaken by PWDA include:
  - Disability Support Organisation (DSO) Peer Connectors – This was a project which was completed in 2019, which provided peer support and built capacity in local communities raise awareness of the NDIS and support access to the NDIS through building self-advocacy within marginalised communities. The focus of the



project was on some of the most marginalised communities such as people who are Deaf-Blind and people with disability in the LGBTQAI+ community.

- Creating Access NSW Project– This project reviews accessibility of existing youth services and provides feedback and delivers training on ways to improve accessibility of their services. The project has assisted the youth sector in NSW to be more responsive, inclusive and accessible to young people with disability. The project is led by an advisory group of young people with disability and has developed a toolkit to assist the youth sector to continue to improve accessibility of their services for youth with disability.
- Wayfinder Hub– Provides a national disability information and referral service that links people with disability to the specialist and mainstream services they need. The Wayfinder service is also a central knowledge base for mainstream organisations looking for guidance on making their services accessible to people with disability.
- Enable In NSW– This project works with hard-to-reach groups across NSW to support awareness of, and access to, the NDIS. The aim of the project is to assess current and future NDIS and mainstream supports needed by the individual. The specific groups that the Enable In project work with includes: people with disability who: are homeless or at risk of homelessness; living in Assisted Boarding Houses; women in prison and due for release; living in an institution.

Additionally, PWDA represents the voices of people with disability on a number of NDIS reference groups and forums, which includes:

- NDIA Independent Advisory Group
- CEOs Forum chaired by the NDIA
- Market Oversight Advisory Group
- Specialist Disability Accommodation Reference Group.

Our experience shows that people with disability, who are our members and those accessing our advocacy supports, are often experiencing multiple forms of vulnerability regarding the NDIS, service provision, and other issues such as housing, education, child protection, abuse and neglect, or health. This collective knowledge of the lived experiences of people with disability has been built up over many years, and PWDA draws on such experience to inform this submission.

Through our work representing the voices and experiences of people with disability as well as working within a range of different individual information, referral and advocacy programs and function, we confirm for the benefit of the Tune Review that the vision for the NDIS still stands as a way of introducing a national, universal system to replace the old, broken and unfair system of past provisions of disability services.

The NDIS provides us with choice and control over what supports we need, where, when and how these supports are delivered for us. We recognise that many people with disability tell us that the NDIS is transforming their lives. However, we also see repeated circumstances and situations where people with disability tell us that access to the scheme

is too difficult, information and communication from the NDIA is not clear, decisions take too long and can be inconsistent.

There is an emerging and troubling picture that some people get good plans while others, particularly from marginalised groups or communities are left with poor quality plans, with limited access to supports and services that are included in their plans.

The way people with disability access and experience the NDIS needs to change.

The proposal to introduce a legislated Participant Service Guarantee may help to fix the delays in NDIA decision-making around access, plan development and approval and plan reviews, however, real change will not be realised until a broad range of policy and operational changes are made. These include:

- removing the staffing cap, so that the NDIA can meet participant demand
- providing one consistent contact person for all participant dealings with the NDIA
- increasing the investment in the training and development of NDIA staff, so that:
- access decisions are informed, consistent and transparent
- improving the quality of plans to realise choice and control for the person with disability and that decisions are informed, consistent and transparent
- properly considering reviews based on existing evidence rather sending the person with disability for further costly functional assessments.
- introducing a minimum quota of 51% of employment of people with disability across all levels of the NDIA to improve the culture of respect for people with disability and the understanding of the way functional assessment translate into support needs within plans
- requiring all NDIA staff, board, contractors, and Local Area Co-ordinators to be trained on disability rights, the social model of disability and the UN Convention on the Rights of Persons with Disability.
- increasing the investment in independent advocacy and supported decision-making to ensure that plans are properly developed with the person with disability at the centre
- removing the real, perceived and potential conflicts of interest between Local Area Co-ordinators (LACS) and the NDIA, and between Support Co-ordinators and Registered NDIS Service Providers
- addressing the ongoing interface issues between State and Territory services such as health, education, housing and transport and ending the buck passing between the NDIA and State and Territory agencies
- addressing market failures in rural and regional areas by establishing a provider of last resort
- moving away from a medical model of assessment to functional assessments.

We note that this is not an exhaustive list of operational issues that must be addressed to in the objectives of the Tune Review “mak[e] the participant experience with the NDIS better”.

# 1. PWDA's commitment to the NDIS

In responding to this review of the legislation underpinning the National Disability Insurance Scheme (NDIS), PWDA reiterates our commitment to advocating for systems of support that are tailored to individuals with disability, rather than driven by the efficiencies of service provision. PWDA has long supported the development of the NDIS. Indeed, much of the conceptualisation of the NDIS comes from the changes driven by the disability rights movement toward deinstitutionalisation, centring the rights and experiences of the person with disability, and removing social and environmental barriers to access.

PWDA wishes to ensure the centrality of human rights of people with disability to the legislation, policy and practice of the NDIS. We raise in particular the following areas to improve consistency with the Convention on the Rights of Persons with Disabilities (CRPD):

- Principles of autonomy and independence for people with disability
- Equality before the law and the presumption of legal capacity (meaning conditions on perceived capacity such as 'to the extent of capacity' or 'where possible' should be removed, and supports provided to understand a person's will and preference)
- The right of all people with disability to supports, including older people with disability and non-citizens
- The right to accessibility and supports (including removing barriers to access the NDIS such as the cost of assessments and improving the provision of information in easy english etc)
- Right to supports (rural and remote/ women/ CALD/ ATSI)
- Transparency of decision making.<sup>2</sup>

PWDA notes that the participant satisfaction results quoted by the NDIA have a number of shortcomings and underlying issues. There are difficulties with measuring the experience of people with disability that are not addressed by the methodology of the survey. PWDA acknowledges the participant satisfaction rates of 90 percent, at the last quarterly report, and cautiously congratulates the NDIA on this figure. We note, however, that the quarterly reports do not give complete information on the experience of those seeking access to the Scheme, because those who have access requests denied are not routinely surveyed. Of

<sup>2</sup> United Nations Department of Economic and Social Affairs *Convention on the Rights of Persons with Disabilities and Optional Protocol*, United Nations, available: <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

those who do gain access to the Scheme, 76% were happy with the process.<sup>3</sup> Access to the scheme is the source of many concerns from people with disability.

Capturing the full experiences of people with disability with either of the methods used by the NDIA is almost impossible.<sup>4</sup> The long form survey, used to formulate the satisfaction rates, is agreed to initially by phone, then conducted by phone, SMS or email. These methods of communication are inaccessible for many people with disability and it is not clear whether the surveys is available in languages other than English.<sup>5</sup> Some people with disability will be fearful of retribution or losing supports if they answer the survey honestly, due to their experiences of institutionalisation, and previous retribution from service providers or other 'supporters'. Therefore the results are likely to be skewed. We also note that the NDIA has stopped publishing data on appeals of access decisions settled outside of the AAT.

Women still make up only 37 per cent of participants,<sup>6</sup> despite prevalence being similar for males and females.<sup>7</sup> People from CALD backgrounds are 7.7 percent of participants, despite a stated NDIA goal of 20 per cent CALD participants. Aboriginal and Torres Strait Islander people are 5.4 percent of participants or about 9000, despite around 60,000 Aboriginal and Torres Strait Islander people in Australia having a severe or profound disability. Any Participant Service Guarantee must consider and deliver for all people engaging with the NDIS, and consider all stages of engagement with the NDIS.

<sup>3</sup> COAG Disability Reform Council Quarterly Report, June 2019, National Disability Insurance Scheme, <https://www.ndis.gov.au/about-us/publications/quarterly-reports> p.36

<sup>4</sup> National Disability Insurance Scheme, 'Have your Say', available: <https://www.ndis.gov.au/community/have-your-say#the-long-form-outcomes-survey>

<sup>5</sup> Ibid.

<sup>6</sup> COAG Disability Reform Council Quarterly Report, June 2019, National Disability Insurance Scheme, <https://www.ndis.gov.au/about-us/publications/quarterly-reports> p.81

<sup>7</sup> Australian Bureau of Statistics, 4430.0 - Disability, Ageing and Carers Australia 2018: Summary of Findings <https://www.abs.gov.au/AUSSTATS/abs@.nsf/0/C258C88A7AA5A87ECA2568A9001393E8?Opendocument>

## 2. Objects and principles of the NDIS Act

PWDA reiterates our overall support for the Objects and principles of the NDIS Act 2013. However, as outlined in the Disability Rights Now 2019: Australians Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities: UN I Review 2019<sup>8</sup>, we reiterate the comments made in the report that there are limited opportunities for people with disability and their representative organisations to monitor and evaluate the NDIS.

We propose and support, in line with recommendations from the Joint Standing Committee on the NDIS that a principle be added to the NDIS to ensure that the NDIA collaborates with people with disability in the development of its operational plans and guidelines.<sup>9</sup>

As we have highlighted in our 2013 submission to the Senate Community Affairs Legislation Committee's Inquiry into the National Disability Insurance Scheme Bill 2012, we believe the Objects can be strengthened by the recognition and inclusion of the language that highlights the role of the act in realising the human rights of people with disability.<sup>10</sup>

Accordingly, in Chapter 1, Part 2.3.1(c), the objects should include reference to supporting the independence and social, economic, *political and cultural* participation of people with disability.

Under Chapter 1, Part 2.4.2 and Chapter 1, Part 2.4.8 should remove references to "the extent of their ability" and "to the full extent of their capacity". The reasons for this are discussed in full in Section 5 Planning and Plans.

**Recommendation:** That the NDIS Act be amended to include a principle for collaboration with people with disability and their representative organisations.

**Recommendation:** That the NDIS Act be amended to include references to political and cultural participation in the line with the Convention on the Rights of Persons with Disabilities.

**Recommendation:** That the NDIS Act be amended to remove references to phrases that diminish and place limits on 'capacity' and 'ability' of people with disability.

<sup>8</sup> Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities (2019) <https://dpoa.org.au/wp-content/uploads/2019/08/CRPD-Shadow-Report-2019-English-PDF.pdf>

<sup>9</sup> *ibid*, p.14

<sup>10</sup> PWDA 2013 Submission to the Senate Community Affairs Legislation Committee re the National Disability Insurance Scheme Bill 2012.

# 3. Approaches to a Participant Service Guarantee

PWDA recognises the need for and broadly supports the development of Participant Service Guarantee (PSG) for the NDIS.

Since the establishment of the NDIS in 2013, our consultations with PWDA's membership, our work with people with disability through our individual advocacy programs and several ILC projects have highlighted that NDIS participants experience delays across the system including:

- access to the scheme
- getting plans developed
- getting plans reviewed, whether that is part of an annual scheduled review, an unscheduled review, or a request for an internal review.

Our individual advocates report the delays from the NDIA in access, planning and review processes continue to create a range of pressures and stresses for participants who are supposed to be beneficiaries and supported by the scheme. For example, due to delays with the NDIA decision-making and approval processes:

- Participants may have plans that are due to expire and face the real possibility of being left without the necessary supports to live safely. When this occurs, people with disability may seek support from advocates to lodge a complaint or seek to escalate the matter to the "escalations" team within the NDIA.
- Participants may contact their local Federal Member of Parliament for support - the Member of Parliament is able to lodge a complaint through the Members and Senators Contact Officer (MASCO) who triages the complaint and may refer it back to the Escalation Team, the Early Solutions (Resolution) Team, the NDIA complaints officers and/or make a referral to the NDIS Quality and Safeguards Commission
- Participants, because of ongoing frustrations with access, plan development and plan review processes, may decide to make a complaint to the Commonwealth Ombudsman as the oversight body for the NDIA or to take their case to the Administrative Appeals Tribunal (AAT) to seek justice and remedy.

At the same time, we know that many people with disability may not have the personal resources and supports, including access to individual advocacy, to take up their complaints directly with the NDIA, their local Member of Parliament, the Ombudsman or pursue their case through the AAT. Instead, they may settle with not accessing the scheme or for poor quality plans that do not give the person with disability the choice and control in how they realise their short and longer term goals through their NDIS plan.

This situation falls far short of the Objects and Principles of the NDIS and does not meet the expectations of the disability community and the wider Australian community for the NDIS and how it should be improving our lives.

Particular concerns with the implementation of the NDIS were highlighted in May 2018, by the Commonwealth Ombudsman in its report on the NDIA's challenges with completing plan reviews within reasonable timeframes. The Ombudsman revealed that some people with disability were waiting up to nine months for their review to be completed.<sup>11</sup>

The Ombudsman's report outlined a number of shortcomings in the NDIA's system for handling:

- Scheduled plan reviews
- Unscheduled plan reviews (at the request of the participant due to changing circumstances)
- Internal reviews.

The Ombudsman made a number of recommendations. One of the longer term recommendations was for the NDIA to:

- Establish KPIs or agreed service standards for completion of unscheduled plan reviews and internal reviews, and communicate these publicly.<sup>12</sup>

PWDA recognises the development of the PSG will seek to address recommendations from the Commonwealth Ombudsman regarding delays in review processes, and it will also go further to legislate and mandate timeframes for NDIA decision-making processes for a number of key steps in access to and participating in the NDIS.

Based on the outline in the Discussion Paper, PWDA understands that the Participant Service Guarantee will cover three key aspects of the NDIS:

- A clear timeframe for the NDIA to tell a person with disability if they are eligible to access the scheme - based on the application that is provided to the NDIA by the person with disability
- A clear timeframe for the NDIA to approve a person with disability's plan
- A clear timeframe for the NDIA to review a person with disability's plan if they seek a review.

PWDA supports the establishment of clear timeframes for these steps and we make more specific comments in following sections of this submission about the way in which the legislation should be amended to realise these changes.

However, based on the outline of the PSG in the Discussion Paper, PWDA is concerned that the PSG will not address the full suite and wide-ranging issues with the day-to-day operations of the NDIS and, in particular, how people with disability experience the processes of:

<sup>11</sup> Commonwealth Ombudsman, 2018, Administration of review under the National Disability Insurance Scheme Act 2013: Report on the National Disability Insurance Agency's Handling of Reviews.

<sup>12</sup> Ibid., p.15.

- access the NDIS
- plan development that delivers choice and control and does not see critical supports downgraded or removed from the plan, because the NDIA determines, with limited evidence or transparency that these the supports are not “reasonable and necessary”
- plan reviews, whether scheduled or unscheduled, that are embraced by the NDIA as a way to achieve the best outcomes for the person with disability and are acted upon within agreed timeframes and agreed quality standards for how NDIA will perform its work
- seeking an internal review because the NDIA decisions are unclear and/or lack transparency or sufficient evidence.

For a PSG to be effective and improve outcomes for people with disability who are entitled to the NDIS, the PSG must cover more than improving timeframes and create a far stronger focus on NDIA’s overall ‘quality of service delivery’.

The need for a more expansive PSG is highlighted in the Ombudsman’s most recent Annual Report 2018-2019 which demonstrates that the complaints about the NDIS were broader than simply delays in timeframes.<sup>13</sup> The Commonwealth Ombudsman notes:

Complaints to our Office in 2018–19 covered many aspects of participants’ experiences with the NDIS, as well as providers’ experiences. The most common complaint issue was the NDIA’s handling of reviews of plans and decisions. Other common complaint issues included:

- Difficulty and delays in navigating the assistive technology process, and having funding for assistive technology included in plans for things like home and vehicle modifications.
- Dissatisfaction with the NDIA’s handling of complaints made to its complaints service.
- Delays in deciding requests for access to the NDIS and confusion about timeframes for receiving an NDIS plan after access to the scheme is granted.
- Dissatisfaction with the process and outcome of planning meetings.<sup>14</sup>

The Ombudsman’s report provides a breakdown of the type of complaints:

- Review - 33%
- Planning - 13%
- Service Delivery- 7%
- Complaints service - 10%
- Access request - 10%
- Request for assistive technology 13%

<sup>13</sup> Opcit, p.62.

<sup>14</sup> Ibid. p.61.



- Provider payment 7%
- NIDA service partners 2% (such as LACs)
- All other issues 5%<sup>15</sup>

While the complaints to the Ombudsman do not capture all the complaints and issues that participants of the NDIS experience, this summary demonstrates that to meet the Tune review’s objectives of “making the participant experience with the NDIS better”, the PSG will need to cover more than the timeframes by which participants can expect the NDIA to make decisions.

We note that the “possible principles for NDIA service standards” suggest that the PSG may, in fact, entail more than mandated or legislated timeframes. However, the Discussion Paper, does not provide detail on the type and scope of the services standards to which these principles would be applied.

PWDA notes that the draft principles are very “high-level” and provide no detail on how “delivering on these principles” would be measured and assessed. Further development of the principles and the subsequent service standards should be fully co-designed with people with disability.

In the current form, PWDA would suggest that the following principles are redeveloped to include a stronger focus on realising the rights of people with disability.

Principle	Comment
Timely	Include references to accountability (including sanctions and compensation) when the NDIA does not meet the legislated timeframes
Engaged	Include clear references to the models of consultation and how the NDIA will consult with and act on matters raised by people with disability on a regular and national basis
Expert	Include a clear reference that all staff will have training in disability rights including supported decision-making, application of the social model of disability and recognition of the impact that the environment can have on the experience of disability
Connected	Include a reference to the voices and experiences of people with disability at the centre of NDIA policy development and operations
Valued	Include references to respectful communication and behaviour, including behaving as a Model Litigant in the AAT

<sup>15</sup> Ibid., 62.

Decisions are made on merit	Add a separate principle that directly addresses Transparency and that decisions will reflect the Objects of the Act
Accessible	Add “women” to the description

PSGs that are used in other organisational contexts are generally focussed on delivering “customer satisfaction”, and a Service Guarantee generally creates obligations on the organisation to deliver on particular benchmarks or indicators of quality. A Service Guarantee will also include reporting requirements, sanctions (penalties) and/or compensations when the organisation does not meet the agreed standards.

An example of a well-developed Quality Framework/Accreditation system, which includes legislated requirements for service delivery as well as quality standards is the National Quality Framework for early childhood education and care services.<sup>16</sup>

A PSG for the NDIA must legislate for clear and full services standards that outline not only when work will be completed but the standards to which the work will be undertaken by the NDIA.

We recognise that the NDIS Quality and Safeguards Commission is overseeing registration/accreditation of service providers under the NDIS and is developing comprehensive practice standards for service providers.

A PSG for the NDIA must operate as a companion to the standards developed for service providers and must include more than set of timeframes for NDIA decision-making. The PSG should consider the “whole experience” for a person with disability engaging with the NDIA from initial processes of seeking to access the Scheme, including engagement and interactions with all parties engaged with the service system from Local Area Co-ordinators who may provide information and support regarding how to make an application to the scheme, through to the application process including gathering evidence to support the person with disability’s access to the scheme.

### Case Study: Adrian’s Story

*Recently, many NDIS participants have been notified by their service provider that they are no longer able to claim transport costs from their service provider under core supports. The notification came from the service provider and it was simply noted that the NDIA has recently clarified the rules for claiming transport costs within plans. Adrian did receive any direct communication from the NDIA. In addition, Adrian has been advised that they may need to “Request a review of your NDIS Plan so that some of your support budget is moved to be able to fund transport (the budget support line item for Transport is 02\_051\_0108\_1\_1)”.*

*For Adrian the unexpected change means that they will need to find around \$300.00 per month to fund their transport to travel to ongoing therapy appointments to realise goals in their plans.*

<sup>16</sup> <https://www.acecqa.gov.au/nqf/about>

*Adrian is extremely concerned about what this means for him. It is unclear how a PSG solely focussed on “improving timeframes for NDIA decision-making” would improve Adrian’s experience of the NDIS.*

*Adrian’s story shows how the NDIA has made a major policy change which impacts on his plan and there has been no direct consultation with NDIS participants like him.*

*When Adrian was asked how they would assess the service of the NDIA in relation to this change to the funding in his plan, he said he would rate the Service as “poor”.*

*A key question for the development of the PSG would be how it would prevent and/or improve the quality of participant experience in this circumstance?*

## **Penalties, sanctions and compensation when the NDIA doesn’t meet benchmarks in the PSG**

PWDA notes that the Discussion Paper does not provide any outline or questions on what kinds of penalties or sanctions will be created and imposed, if the NDIA fails to meet the standards to be mandated through legislation or other secondary mechanisms.

To provide certainty for people with disability, a PSG must include specific provisions for consequences and sanctions when the NDIA misses a mandated deadline or falls short of agreed quality standards or key performance indicators. For example, a PSG should include details on:

- the penalties or fines that the NDIA must pay
- compensation for the NDIS participant
- actions that the NDIA will take to remedy the breaches of the PSG - it is not appropriate for the onus to be placed on the participant to seek a remedy to pursue a claim for a missed deadline or other such shortfall within the PSG caused by the NDIA.

### **Recommendation:**

That the PSG not only addresses timeframes for NDIA decision-making but is expanded to include the full suite of quality service standards that a person with disability has a right to expect from engaging with the NDIA and its contractors such as Local Area Co-ordinators and Support Co-ordinators.

# 4. The experience of people with disability with the administration of the NDIS

## Functional assessments must be used to improve assess and planning within the NDIS

PWDA notes that we have continually raised concerns in various policy statements and submissions that the NDIA relies upon a medical model of disability in its access decisions as well as in planning for reasonable and necessary supports. Participants are often called upon to give medical evidence that is expensive and unnecessary.

While we support the use of assessment, this should be reflective of the human rights model of disability, which looks at the interaction between environment, rights and impairments.

Thus, a functional assessment, which considers the environment and the impact of the impairment on function, rather than diagnosing the impairment or seeing disability as solely inherent to the person, is appropriate. In response to these and other concerns repeatedly raised by people with disability, the NDIA recently conducted a functional assessment trial, the results of which have not been released.

## The interpretation of permanence and “substantially reduced capacity”

One of the Objects of the Act is to give effect to Australia’s obligations under the CRPD, and so the Scheme is premised on the recognition that people with disability are entitled to support in order to enjoy their rights on an equal basis as others as required by Article 12 of the CRPD.<sup>17</sup> Therefore, there should be no barrier to accessing the Scheme when a person with a disability meets the age, resident and disability requirements under sections 22-24 of the Act.

The CRPD is also clear that disability is conceptualised as long-term rather than permanent. The NDIA itself acknowledges this here:

The term 'disability' is described in Article 1 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) as follows:

"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may

<sup>17</sup> United Nations Department of Economic and Social Affairs *Article 12 – Equal Recognition Before the Law*, United Nations, available: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html>

hinder their full and effective participation in society on an equal basis with others."<sup>18</sup>

From our experience, sections 24(1)(b)-(e) of the Act poses significant barriers through the National Disability Insurance Agency's (the Agency) flawed interpretation of these sections. This is driven by a lack of sufficient guidance in both the primary legislation (the Act) and secondary legislation (the Rules), and made worse by similarly insufficient guidance at the policy level (*Operational Guidelines*).

Section 24 of the Act currently reads:

## 24 Disability requirements

(1) A person **meets the disability requirements** if:

(a) the person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition; and

(b) the impairment or impairments are, or are likely to be, permanent; and

(c) the impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities:

(i) communication;

(ii) social interaction;

(iii) learning;

(iv) mobility;

(v) self-care;

(vi) self-management; and

(d) the impairment or impairments affect the person's capacity for social and economic participation; and

(e) the person is likely to require support under the National Disability Insurance Scheme for the person's lifetime.

The barrier to access stems from the effect of section 24(1)(e) requiring a prospective applicant to the Scheme to be "likely to require support ... for the person's lifetime".

From PWDA's perspective, there are two clear impacts of the references to 'requiring, or likely to require', a lifetime of support:

<sup>18</sup> <https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/access-ndis-disability-requirements>

1. the threshold to meet the overall disability requirements under section 24 becomes too high and onerous for people with disability, due to the evidentiary burden placed on them, and
2. people with disability are forced to demonstrate substantially reduced capacity in more than one activity domain under section 24(1)(c), in order to meet the high threshold.

## Case Study - Carlo's Story

*Carlo is a 62 year old man who has fibromyalgia, type 2 diabetes, chronic obstructive pulmonary disorder, generalised anxiety disorder and major depressive disorder. Carlo receives the Disability Support Pension and is living in social housing. He has previously experienced homelessness and is estranged from family and friends, and has been hospitalised regularly. Carlo has a long term GP and community support services, but has variable levels of engagement due to his psychosocial disabilities.*

*Carlo has already tried to access the Scheme before, but was knocked back as he did not have enough evidence. In fact, the evidence in his hospital records and his DSP application were used as evidence that his support needs were incorrectly due to his health conditions and not his disability. In desperation, Carlo contacts a previous support worker who knows him well. The support worker advises Carlo to focus on how his disability impacts his capacity to socially interact with others, self-care and self-manage. Carlo doesn't know how to communicate this, and so he seeks an advocate. The advocate liaises with Carlo's GP who advises the GP on how to demonstrate how his capacity is substantially reduced. As a result, Carlo's access request is approved.*

The need to demonstrate “substantially reduced capacity” and “permanence” can be hard for someone like Carlo. The episodic nature of his psychosocial disability, is often seen as evidence that his disability does not require, or is not likely to require, lifetime support. While his long-term GP could potentially demonstrate he meets the disability requirements under section 24, his GP may not be confident, or know what evidence is needed. This means, Carlo may be forced to rely on hospital records and his DSP application to demonstrate he meets the requirements, but these records may contain information that could be used by the assessor to wrongly misattribute his support needs to his health conditions.

To overcome this barrier, Carlo would stand a better chance of accessing the Scheme if he could demonstrate “substantially reduced capacity” in more than one activity domain as a way to prove the permanence of his disability. However, this requires Carlo to first have a good relationship with his support workers and/or the support and money to gather the evidence needed. It also requires a Local Area Co-ordinator to have sufficient training and skill to understand how to support Carlo to gather the information necessary.

Carlo should not need to demonstrate “substantially reduced capacity” in more than one activity domain to simply prove permanence, or face other barriers to gather the evidence he needs for his access request. This is in direct contrast to the *Operational Guidelines*

guidance which states: “it is sufficient for a prospective participant to have substantially reduced functional capacity in relation to one activity”.<sup>19</sup> Not only is this approach to assessing functional capacity deficits-based, it can be traumatising and distressing for people to gather evidence that essentially seeks to demonstrate they are “less than” in order to simply access the Scheme designed for them.

The legislative barrier to access is then made worse when both the *Operational Guidelines*, and primary and secondary legislation, provide insufficient guidance on how to interpret the meaning of permanence and “substantially reduced capacity”.

The *NDIS (Becoming a Participant Rules) 2016* provide only three instances where the “substantially reduced capacity” threshold will be deemed to have been satisfied (Rule 5.8), while the *Operational Guidelines* under-defines what “substantially reduced capacity” means by merely listing a limited number of examples under each of the activity domains in section 24(1)(c).<sup>20</sup>

As the primary and secondary legislation and policy guidelines provide insufficient direction for the meaning of “substantially reduced capacity”, there is not a general criteria an assessor can use to judge whether an impairment substantially reduces capacity for a person with disability. This further contributes to the evidentiary burden placed on the person with disability to meet the high threshold of section 24.

The same applies to the meaning of permanence. Currently the meaning of permanence is too vague and restrictive. Rule 5.4 in the *NDIS (Becoming a Participant Rules) 2016* simply states an impairment is permanent or likely to be permanent “only if there are no known, *available and appropriate* evidence-based clinical, medical or other treatments that would be likely to remedy the impairment”. Not only is there no definition of what ‘available’ or ‘appropriate’ means, is also does not account for the episodic nature of disability.

Therefore, people with disability whose impairment changes on a periodical basis are particularly vulnerable cohort, and are more likely to have their disability assessed as not meeting the high threshold under section 24.

From our experience, applicants are similarly required to demonstrably prove their disability is permanent by extrapolating and mapping out clearly the specific impacts of their disability in their daily lives. However, in order to do this well depends on three factors:

1. whether the applicant knows they need to demonstrate “substantially reduced capacity” in at least one of the activity domains
2. whether the applicant has the capacity to and/or has the support to demonstrate “substantially reduced capacity” in at least one of the activity domains

<sup>19</sup> See section 8.3 of the Operational Guidelines here: <https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/access-ndis-disability-requirements#8.3>

<sup>20</sup> *ibid*

3. the quality of functional assessment reports from medical and/or allied health professionals that adequately meets the criteria the assessor seeks.

If these three factors are satisfied, the legislative barrier caused by the Agency's flawed interpretation of the sections is reduced. However, if one or more of these factors, (especially access to support to meet the evidentiary burden) is missing, then it is our experience access decisions rely on the knowledge (or lack thereof) and quality of the individual assessor who is judging the access request of a prospective applicant.

Access to the NDIS should not be reliant on an individual assessor to make an access decision when there is insufficient direction from the primary and secondary legislation and policy guidelines.

Therefore, to address the above issues we recommend the following:

**Recommendation:** That section 24(1)(e), which relates to a lifetime requirement be removed from the Act, and insert a provision noting that where an individual currently has substantially reduced capacity but is likely to improve, they should be admitted as an early intervention participant under section 25 of the Act.

**Recommendation:** That the *NDIS (Becoming a Participant Rules) 2016* be amended to provide full definition of the relevant life domains and to define generally applicable criteria for substantially reduced capacity.

**Recommendation:** That the Act be amended to clearly state the meaning of impairments which are, or are likely to be, permanent.'

**Recommendation:** That the *NDIS (Becoming a Participant Rules) 2016* be amended to clarify what 'available' and 'appropriate' treatment means. The amendment should have regard to whether the treatment is available at a location reasonably accessible to the person, is available at a reasonable cost, can be expected to result in substantial improvement in functional capacity, is regularly undertaken and performed, has a high success rate and carries a low risk to the person.

**Recommendation:** That the Act be amended to include a provision that provides for access to advocacy support when accessing the Scheme.

## The legislation leads to additional barriers

Noting the issues with the interpretation of the meaning of permanence and "substantially reduced capacity" discussed above, the legislation also leads to other barriers to access to the Scheme by remaining silent on the following:

- how the Agency can formally help individuals secure evidence until they are granted "prospective participant" status
- how the Agency could exercise its powers to assist prospective participants from low socio-economic, hard-to-reach and/or priority groups to secure diagnoses or evidence to address the high threshold requirements under section 24
  - how the Agency can formally train, develop and support Local Area Coordinators and assist prospective participants.



By formally extending the power of the Agency to address the above additional barriers, the Local Area Coordinators can play a central role in the positive initial experiences of people with disability accessing the Scheme. By formally training, developing and supporting Local Area Coordinators, the evidentiary, cost and access issues would greatly improve.

These additional barriers could be addressed under Section 6 of the Act, which provides for a broad and general power for the Agency to provide support and assistance. Currently, section 6 reads:

## **6 Agency may provide support and assistance**

To support people with disability to exercise choice and control in the pursuit of their goals, the Agency may provide support and assistance (including financial assistance) to prospective participants and participants in relation to doing things or meeting obligations under, or for the purposes of, this Act.

Therefore we recommend the following:

**Recommendation:** That section 6 of the Act be amended to extend the power of the Agency to provide support and assistance to applicants secure evidence at all stages of the access process.

**Recommendation:** That section 6 of the Act be amended to ensure the Agency has the express power to help prospective participants from priority, hard-to-reach and low-socioeconomic groups.

**Recommendation:** That the operations and resources for Local Area Coordinators (LACs) be reviewed to improve access supports for people with disability to access the Scheme, including transfer of oversight of quality and safety to the NDIS Quality and Safeguards Commission, rather than the Commonwealth Ombudsman as is currently the case.

## 5. Planning and plans

Planning centred on the person with disability, using a social or human rights model of disability, is critical to the success of the NDIS. An Object of the Scheme, laid out in the Act, is to:

*(e) enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports;*

This process of planning, and the outcome, is essential to people with disability, so that we not only have a positive experience of the NDIS, but receive the supports we need and have our human rights to independence, support and upheld. For this to happen, a number of key areas need to be ensured:

Our will and preference is upheld, not undermined by conditional statements that rely on our capacity or default to substitute decision making

- Supports are provided to us in a timely manner
- Informal supports are not assumed to meet our needs without evidence that they are able and willing to do so
- Assessments are of our functional needs and do not rely on the medical model of disability
- Reasonable and necessary should be more clearly defined in a way that recognises the rights of the participant
- Reviews are our right.

### Will and preference

A core principle in the CRPD is autonomy and independence, and this is best articulated under Article 12, Equal recognition before the law.<sup>21</sup> This means we have the right to make decisions based on our will and preference, rather than have others make decisions for us based on 'best interests', or have our capacity questioned. We have the right to all necessary supports to make decisions. Despite the rhetorical emphasis on choice and control, these principles of autonomy and independence are not currently fully reflected in the Act. In relation to principles for participation in the scheme, Section 17a of the Act states:

*(1) People with disability are assumed, so far as is reasonable in the circumstances, to have capacity to determine their own best interests and make decisions that affect their own lives.*

<sup>21</sup> Op.cit.

*(2) People with disability will be supported in their dealings and communications with the Agency so that their capacity to exercise choice and control is maximised.*

Contradictorily, it then also states:

*(3) The National Disability Insurance Scheme is to:*

- (a) respect the interests of people with disability in exercising choice and control about matters that affect them; and*
- (b) enable people with disability to make decisions that will affect their lives, to the extent of their capacity; and*
- (c) support people with disability to participate in, and contribute to, social and economic life, to the extent of their ability.*

The ambiguous language “extent of their capacity” and “extent of their ability” is potentially confusing, and COAG agreed in its response to the 2015 legislative review that this language should be removed.<sup>22</sup> Despite this it remains in the Act, and PWDA supports its removal.

The conceptualisation of decision making articulated in this section of the Act, as being premised on ‘capacity’, is contrary to Article 3, general principles of the CRPD, which include individual autonomy and independence of persons, and full and effective participation in society.<sup>23</sup> This is best articulated in Article 12, Equal recognition before the law, and General Comment No. 1 on this Article.<sup>24</sup> Article 12 states that “persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life”.<sup>25</sup> Entitlement to legal capacity is not dependent on the characteristics of the person, but rather means that people are holders of rights, and are entitled to exercise those rights, on an equal basis with others, with whatever supports are required. This means that the wording of section 17a potentially limits the rights of people with disability and should be removed.

PWDA has concerns, as stated above, regarding conditional language that potentially limits the decision-making capacity of the participant and their will and preference regarding their plan. Therefore we recommend the following amendments:

<sup>22</sup> Department of Social Services, COAG response to the independent Review of the National Disability Insurance Scheme Act 2013, available:

[https://www.dss.gov.au/sites/default/files/documents/03\\_2017/coag\\_response\\_to\\_the\\_independent\\_review\\_of\\_the\\_national\\_disability\\_insurance\\_scheme\\_act\\_2013\\_pdf.pdf](https://www.dss.gov.au/sites/default/files/documents/03_2017/coag_response_to_the_independent_review_of_the_national_disability_insurance_scheme_act_2013_pdf.pdf) (p.1)

<sup>23</sup> United Nations Department of Economic and Social Affairs Article 12 – General Principles, available:

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-3-general-principles.html>

<sup>24</sup> Committee on the Rights of Persons with Disability, 2014, General Comment no.1 (2014) Article 12: Equal Recognition before the law, available:

[https://tbinternet.ohchr.org/\\_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en)

<sup>25</sup> Op.cit.

**Section 31** *The preparation, review and replacement of a participant’s plan, and the management of the funding for supports under a participant’s plan, should so far as reasonably practicable:*

*(d) where possible, strengthen and build capacity of families and carers to support participants who are children; and*

*(k) Provide the context for the provision of disability services **supports** to the participant and, where appropriate, coordinate the delivery of disability services where there is more than one disability service provider.*

The current modifier ‘so far as reasonably practicable’ prior to principles including:

*(g) be underpinned by the right of the participant to exercise control over his or her own life;*

is unnecessary and removes the primacy of this important principle.

Similarly, Section 43(5) states:

*If the funding for supports under a participant’s plan is to be managed to any extent by a registered plan management provider specified by the Agency, or by the Agency, the CEO must, so far as reasonably practicable, have regard to the wishes of the participant in specifying who is to manage the funding for supports under the plan to that extent.*

PWDA recommends the removal of this term, in particular, and all such terms throughout the Act. We note that the CRPD principles of autonomy and independence, and right to legal equality, commit states’ parties to have regard to will and preference and not the best interests model, despite the dominance of this model internationally. We hold the same view regarding Section 44, which states:

**44 Circumstances in which participant must not manage plan to specified extent**

*(2) The statement of participant supports in a participant’s plan must not provide that the participant is to manage the funding for supports under his or her plan to a particular extent if the CEO is satisfied that management of the plan to that extent would*

*(a) present an unreasonable risk to the participant; or*

## Plan agreement timeframes

Regarding section 32, PWDA proposes consideration of a timeframe for the NDIA to approve participants’ first plans. This would address the ongoing concerns regarding wait times from approval to receiving support for participants.

In 2015, the Independent review of the NDIS suggested: “[t]he next review of the NDIS Act should consider the costs and benefits of amending the legislative framework to stipulate a timeframe in relation to plan preparation.”<sup>26</sup> A guarantee of support within a specific timeframe would relieve stress and provide much needed reassurance for people with disability.

**Section 33(1)** A participant’s plan must include a statement (the *participant’s statement of goals and aspirations*) prepared by the participant that specifies<sup>27</sup>

PWDA believes a timeframe should be placed on the NDIA to agree to plans, and proposes the following wording:

*33 (4) The CEO must endeavour to decide whether or not to approve the statement of participant supports **within 28 days** as soon as reasonably practicable, including what is reasonably practicable having regard to section 36 (information and reports).*

This would provide participants with certainty regarding timelines, but as noted by others,<sup>28</sup> these timeframes need to be both firm, and used by the NDIA to retrieve necessary information that supports the participants’ plan.

PWDA is concerned by reports from our community that people are being denied supports on the basis of what informal supports planners and LAC’s believe are ‘reasonable’. Therefore we recommend the following amendment:

**Section 34** *For the purposes of specifying, in a statement of participant supports, the general supports that will be provided, and the reasonable and necessary supports that will be funded, the CEO must be satisfied of all of the following in relation to the funding or provision of each such support:*

*(e) The funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community **are willing and able to provide, and what the participant wants;***

## Reasonable and necessary

Many of the issues that people with disability experience with the scheme stem from the contested concept of ‘reasonable and necessary’ supports. Reasonable and necessary supports should be more clearly defined, compliant with a human rights model of disability, which includes the right to support in and outside of the home, to access transport, community, services, and information. The NDIS was envisioned as a beneficiary scheme

<sup>26</sup> Op.cit. p.47

<sup>27</sup> Amend throughout legislation where applicable.

<sup>28</sup> Darren O’Donovan, 2019, *Submission to the Tune Review on the National Disability Insurance Scheme Act and Rules*, [https://www.academia.edu/40802395/ODonovan\\_Tune\\_Review\\_submission](https://www.academia.edu/40802395/ODonovan_Tune_Review_submission)

that would serve people with disability and provide us with lifelong, reliable care and support. This vision remains, but the detail and supports we need are regularly denied and contested. We recommend that in depth consultation be undertaken with people with disability about their experiences of denial of reasonable and necessary supports. However, we also recommend specific clarification in legislation and associated rules and regulations that reasonable and necessary include the following:

- Assessment processes needed for planning, whether they concern the person or their environment, are to be funded
- Participants are not responsible for covering the gaps in services between the NDIS and mainstream state or federal services. Where these gaps cause harm or risk of harm to the participant, the gap should be covered by the NDIS
- Support coordination should be supplied when participants are found not to be utilising supports funded in their plans
- Plans should allow for ad hoc reasonable and necessary supports as needed, such as rainy day transport and assistive technology repairs, without causing gaps in the participant's plan. Such ad hoc needs can cause and should
- Transport to access supports and services in our plans.

## Assessments

Similarly to assessment during the access phase, any assessments called for under the planning phase should have functional options. Currently, the Act notes that the CEO may request assessments including medical, psychiatric, psychological or other. We recommend that this language be removed.

*(2) The requests the CEO may make are as follows:*

*(b) that the participant do either or both of the following:*

*(i) undergo an assessment and provide to the CEO the report, in the approved form, of the person who conducts the assessment;*

*(ii) undergo, whether or not at a particular place, a medical, psychiatric, psychological or other examination, conducted by an appropriately qualified person, and provide to the CEO the report, in the approved form, of the person who conducts the examination.*

## Right to review

Participants should have a legislated right to review at all times. As we pointed out in consultations on the drafting of the Bill, it is inappropriate that this is worded as a request.

### **48 Review of participant's plan**

*(1) A participant may request has a right to have that the CEO conduct a review of the participant's plan at any time.*

*Section 50 (2) The requests the CEO may make are as follows:*

*(a) that the participant, or another person, provide information that is reasonably necessary for the purposes of reviewing the participant's plan; or*

*(b) that the participant do either or both of the following:*

*(i) undergo an assessment, **the cost of which will be funded by the NDIA**, and provide to the CEO the report, in the approved form, of the person who conducts the assessment;*

## 6. Reviews and appeals

The Commonwealth Ombudsman has noted how the inaccurate classification of review requests creates issues for participants, by requiring them to await an outcome before they have access to external merits review.<sup>29</sup> This is driven by the complexity of the internal review process, which in turn causes further delays in review decisions being made by the Agency.

From our experience, the complexity in the internal review process is caused by confusion with the following review processes:

- a review being sought when a decision has been made to not reassess a participant's plan under section 48(2) of the Act
- a review being sought when a decision to not approve a statement of supports under section 100(6) of the Act
- when a participant requests an internal review for a change of circumstances under section 48(1), and
- when the CEO of the Agency decides not to conduct the review as per the CEO's power under section 42(2).

In the above situations, a participant has a right to appeal the CEO's decision to not conduct the review under section 100, but this does not mean the substance of the statement of supports that give rise to a change of circumstances can also be reviewed. The opposite can also be true, where a request for an unscheduled plan review under section 48 is misinterpreted by the Agency to be a review of the statement of supports in a participant's plan, as was the case in the case of *LQTF*.<sup>30</sup>

To address the confusion resulting from sections 48 and 100, and the complexity of the internal review processes, we support the submission made by the Public Interest Advocacy Centre. Therefore, we reiterate their recommendation below:

**Recommendation:** That the Act be amended to reduce the complexity between plan reassessments under section 48, and internal reviews under section 100. All requests under section 48 should be treated as both a request for reassessment and review.

### Severe delays cause severe consequences

From our experience the confusion in different types of reviews and appeals is made worse for people with disability because there is no recourse when there are severe delays. Take the case of the Monti family below:

<sup>29</sup> Commonwealth Ombudsman, *Administration of reviews under the National Disability Insurance Scheme Act 2013* (Report, May 2018):

<sup>30</sup> *LQTF and National Disability Insurance Agency* [2019] AATA 631 at [13] in the judgment



## The Monti family's story - the impact of severe delays

*The Monti family has five children with psychosocial disability. All five of the children have an NDIS plan, but three children do not have enough funding in their plans for allied health services. The allied health services are needed to meet the children's behavioural support needs. The parents have requested a review of the three plans, to ensure there is sufficient funding for allied health. The family have so far waited six months for the review to happen. During this time the allied health services were cut, two children were expelled from school, and one parent had to quit their full time job to provide support. Despite one parent providing full-time informal support, the family still required additional support and they paid for allied health services out of their pocket.*

The Monti family wanted a review of the statement of supports, as they felt it did not adequately provide for the reasonable and necessary allied health services needs of the Monti children. Having put in a request for review, the Monti family would have expected a decision on the review to be made within a "reasonably practicable" timeframe as required by section 48(3). However, the time to review the decision has been six months, with no clear indication of when the review decision can be expected. From the experience of our individual advocates, the time it takes to review a decision, regardless of what is being reviewed, is approximately four months.

The Monti case demonstrates that unreasonable delays can have severe consequences. The consequences are unjustifiable hardships that people with disability should not have to endure, especially when their support needs have already been determined to be reasonable and necessary under the Act. Having two children expelled and having a parent quit a full-time job, due to insufficient funding in the Monti children plans, should not happen.

## The need for a circuit breaker to resolve unreasonable delays

What would have prevented the outcome with the Monti family is if they had access to external merits review. A right to external merits review would give participants a means of enforcing a decision when a delay becomes unreasonable. Further, by providing certainty that a decision can be forced when a delay is unreasonable, it would also clarify the current ambiguity raised in the cases of *LQTF*<sup>31</sup> and *KRBG*.<sup>32</sup> In these cases, it was highlighted that it is unclear if the Administrative Appeals Tribunal have the jurisdiction to intervene in severe delays.

We do not anticipate that having a clear right to access external merits review at the Administrative Appeals Tribunal would necessarily increase the number of appeals at the Tribunal, given that section 48 decisions are already subject to limited appeals. Rather, we view the creation of a right to access external merits review would simplify the appeals process by eliminating the jurisdictional issues currently being raised as mentioned above.

Therefore, to address the above issues and confusion caused by the complexity of the internal review process, we recommend the following:

<sup>31</sup> *LQTF and National Disability Insurance Agency* [2019] AATA 631

<sup>32</sup> *KRBG and National Disability Insurance Agency* [2019] AATA 144

**Recommendation:** That section 100(6) of the Act be amended to specify a timeframe in which a decision must be made in accordance with section 100(3).

**Recommendation:** That section 100 of the Act be amended to ensure cases of unreasonable delay in deciding on internal reviews can be referred to the Administrative Appeals Tribunal for external merits review.

Further, as was the case with the Monti family, when an unreasonable delay causes a participant, their family, or their carer, to pay for support from their own funds, we also recommend the following:

**Recommendation:** That the Act be amended to insert a provision that:

- (a) where a participant's statement of participant supports is varied or set aside and substituted on review or appeal, including during any settlement of a pending appeal, and
- (b) the variation or substitution is to grant that participant funding for a requested support which was originally denied or only partially funded by the Agency, and
- (c) during the course of the review or appeal process, the participant, their family or carer paid for the support with funding outside of the Agency, then
- (d) the Agency is to reimburse the participant, their family or their carer, as the case may be, for the expenditure.

# 7. Recommendations from the 2015 Independent Review of the NDIS Act

Following the 2015 Independent Review of the Act, the Council of Australian Governments (COAG) agreed to 20 amendments to the NDIS Act. We were particularly pleased to see the COAG agreed amendments attempted to:

- introduce the concept of centrality and importance of people with disability being involved in the design of the NDIS
- recognise and value lived experience on the NDIA Board
- recognise the need to explicitly refer to lesbian, gay, bisexual, transgender and intersex status of people with disability alongside the cultural and linguistic circumstances and the gender identity of people with disability

However, we note the the agreed amendments generally needed to better reflect the language of human rights, and ensure the Act only serves people with disability, their representative disability organisations and their families and loved ones. Therefore, we continue to express concern over references to carers in the agreed amendments.

PWDA makes the following comments and recommendations below on 18 of 20 of the agreed amendments.

Section to be amended	Description and PWDA Comments/Recommendations
Subsection 4(2) and subsection 4(8)	Amend the general principles in section 4 to remove moderating language (e.g., ‘to the extent of their ability’ and ‘to the full extent of their capacity’). Section 4 intends to guide actions; however some of that guidance is qualified and it is unclear why.  <i>Comment</i> - PWDA strongly supports this amendment.
Subsection 4(9)(a)	Add new principle to reflect the centrality of people with disability and their inclusion in a co-design capacity. The concept of centrality and the importance of people with disability being involved in the design of the NDIS is already recognised in the NDIA’s corporate plan, but there is benefit in enshrining this as a principle in the NDIS Act.

	<p><i>Comment</i> - PWDA strongly supports this amendment. We reiterate the comments we made in our 2013 submission to the Senate Community Affairs Legislation Committee's Inquiry into the National Disability Insurance Scheme Bill 2012.</p> <p>We recommend the following additional changes to section 4 to better reflect the centrality and importance of involving people with disability in the design of the NDIS:</p> <p><b>Recommendation</b> - That subsection 4(2) be amended to read: "People with disability should be supported to participate in and contribute to political, social, economic and cultural life".</p> <p><b>Recommendation</b> - That subsection 4(3) be amended to read: "People with disability should have certainty that they will receive the care and support they need over their lifetime".</p> <p><b>Recommendation</b> - That subsection 4(8) be amended to read: "People with disability have the same right as other members of Australian society to be able to determine their own interests, including the right to exercise informed choice and engage in decision making that will affect their lives".</p> <p><b>Recommendation</b> - That subsection 4(11) be amended to read:</p> <p style="padding-left: 40px;">"Reasonable and necessary supports for people with disability should:</p> <ul style="list-style-type: none"> <li>(a) Enable people with disability to exercise their political, social, economic, and cultural rights;</li> <li>(b) Be age, gender and culture appropriate;</li> <li>(c) Support people with disability to lead fulfilling lives and maximise their independence; and</li> <li>(d) Support the capacity of people with disability to undertake activities that enable them to participate in the community and in open employment".</li> </ul>
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	<p><b>Recommendation</b> - - That section 4 be amended to include a subsection that provides for free independent advocacy support.</p> <p><b>Recommendation</b> - - That section 4 be amended to include a subsection that acknowledges and respects the role of people with disability as stakeholders as well as participants.</p> <p><b>Recommendation</b> - That section 4 be amended to include a subsection that provides for a nationally, consistent co-design policy and guidelines that are developed and agreed with people with disability and their representative organisations.</p> <p><b>Recommendation</b> - That section 4 be amended to include a subsection stipulating reasonable and necessary supports are to be provided without means testing of any kind.</p>
Subsection 4(15)	<p>Amend subsection 4(15) to reflect the importance of a diverse and sustainable market that provides choice and control and high-quality supports to people with disability.</p> <p><i>Comment</i> - PWDA strongly supports this amendment. This amendment would be further strengthened by recognising the effectiveness in the provision of supports is strongly influenced by the intersectionality of one’s disability with other protected attributes under Australian discrimination. To address this, we recommend:</p> <p><b>Recommendation</b> - That the Act introduce a further subsection under section 4(15) promoting a service delivery environment that recognises one’s disability intersects with other protected attributes under Australian discrimination law.</p>
Subsection 5(d)	<p>Amend principle to include a reference to lesbian, gay, bisexual, transgender and intersex status of people with disability, so that their experience is recognised alongside the cultural and linguistic circumstances and the gender of people with disability.</p> <p><i>Comment</i> - PWDA strongly supports this amendment. To strengthen this amendment, we recommend the</p>

	<p>following:</p> <p><b>Recommendation</b> - That subsection 5(d) be amended to read:</p> <p style="padding-left: 40px;">“(d) the cultural and linguistic circumstances, and the sex, gender, gender identity, sexual orientation and intersex status of people with disability should be taken into account”.</p> <p>However, we also note that the Preamble to the CRPD recognises the unique circumstances of Aboriginal and Torres Strait Islander people with disability. Therefore, to ensure the full inclusion of the diverse backgrounds of all people with disability, we further recommend:</p> <p><b>Recommendation</b> - That subsection 5 include specific recognition of the situation of Aboriginal and Torres Strait Islander people with disability, and the unique cultural and social factors that concern Aboriginal and Torres Strait Islander people with disability should be respected and acknowledged.</p>
<p>Section 8, section 9, Chapter 6 heading and subsection 117(1)</p>	<p>Replace the NDIA’s legal name, the "National Disability Insurance Scheme Launch Transition Agency" with the name it is known as in the Australian community "National Disability Insurance Agency" to reduce confusion amongst stakeholders.</p> <p><i>Comment</i> - PWDA supports this amendment.</p>
<p>Sections 9, 31, 33, 36, 37, 41, 47, 48, 49, 50, 55, 78, 79, 96, 99 and 104</p>	<p>“Review” is used in two different ways in the NDIS Act, which is a source of confusion for stakeholders and the NDIA. “Plan review”, is a review of the supports in a participant’s plan to ensure they continue to meet the participant’s needs, whereas “review of decisions” refers to a merits review of a decision.</p> <p>To clarify their different purposes, “plan review” will be renamed “plan reassessment” (or some other term to be agreed).</p> <p><i>Comment</i> - PWDA agrees with this amendment in part. While we recognise the issue, changing the terminology to “plan assessment” still has the potential to mislead. On this issue, we support in full the comments made by the Public Interest Advocacy Centre in their submission,</p>

	<p>and we reiterate their recommendation below:</p> <p><b>Recommendation</b> - That the Act be amended to reduce the complexity between plan ‘reassessments’ under section 48, and internal ‘reviews’ under section 100. All requests under section 48 should be treated as both a request for ‘reassessment’ and internal ‘review’.</p>
<p>Subsection 14(a)</p>	<p>Provide greater definition of Information, Linkages and Capacity Building in the legislative framework. As the nature and scope of ILC was not agreed when the NDIS Act was drafted, the current definition of ILC is both brief and broad.</p> <p>A new definition should expand the NDIA’s funding power to fund persons or entities to provide information relating to disability and disability supports; and to provide assistance to build capacity amongst providers and people with disability and their families.</p> <p><i>Comment</i> - PWDA agrees with this amendment in part. While we support a new definition that expands the NDIA’s funding power as described above, we remain generally concerned about the wording of section 14.</p> <p>Section 14 should better reflect the concept of centrality and the importance of people with disability being involved in the design of the NDIS, as discussed above.</p> <p>When legislating this amendment, we suggest the amendment be split to also include another amendment that implements the following recommendation:</p> <p><b>Recommendation</b> - That subsection 14(a) be amended to read:</p> <p>“(a) For the purposes of enabling those persons or entities to assist people with disability to:</p> <ul style="list-style-type: none"> <li>(i) Realise their potential for physical, social, emotional, intellectual, sexual and spiritual development;</li> <li>(ii) Exercise their political, social, economic and cultural rights;</li> <li>(iii) Obtain independent information about the National Disability Insurance Scheme, and</li> <li>(iv) Obtain independent advocacy support”.</li> </ul>

Subsection 17A	<p>Require the NDIA CEO to take into account the guiding principles in section 4 including that people with disability have the same right as other members of Australian society; people with disability should be supported to contribute to social and economic life; and people with disability should be supported to receive reasonably and necessary supports. This amendment will ensure that all people acting under the NDIS Act, including the CEO, are guided by the same principles.</p> <p><i>Comment</i> - PWDA strongly supports this amendment.</p>
Subsection 31(d)	<p>Remove "where possible" from the paragraph, as the words are redundant due to the presence of the words "as far as reasonably practicable" in the introduction to the section.</p> <p><i>Comment</i> - PWDA supports this amendment.</p>
Subsection 48(2A)	<p>Insert a subsection to allow the Minister to make a Rule that would provide greater guidance to the NDIA CEO on the rights of participants to request a review of their plan.</p> <p><i>Comment</i> - PWDA supports this amendment with reservations. While we support better guidance for the NDIA CEO on the rights of participants to request a review of their plan, we require a draft of the proposed rule before we can support a proposed amendment in full.</p>
Section 55	<p>Broaden the powers of the NDIA CEO to obtain information about people who have not yet made an NDIS access request to ensure the integrity of the NDIS. The use of personal information and the need to obtain a person's consent are still covered by federal and jurisdictional privacy laws</p>
Subsection 60(1) and section 61	<p>Remove subsection 60(1) and section 61, which relate to protected information as they have no application, as the <i>Privacy Act 1988</i> (Cth) already permits the NDIA to collect the information this subsection provided.</p> <p><i>Comment</i> - PWDA supports this amendment.</p>
Section 90	<p>Insert a discretionary power for the NDIA CEO to suspend or cancel one or more of a nominee's appointments, if that nominee ceases to be the guardian</p>



	<p>of the participant.</p> <p><i>Comment</i> - PWDA supports this amendment.</p>
Subsection 127(2)(a)	<p>Clarify that Board members can be appointed on the basis of having “lived experience of disability”, regardless of if they have experience in operating insurance schemes, financial management or corporate governance.</p> <p><i>Comment</i> - PWDA supports this amendment. This amendment would be further strengthened by embedding the value of lived experience on the Board through the below recommendation:</p> <p><b>Recommendation</b> -That the proposed amendment further clarifies that the majority of Board members be appointed on the basis of having lived experience of disability</p> <p>The value of lived experience on the Board would also be strengthened by implementing the following recommendations in respect to section 127:</p> <p><b>Recommendation</b> -That section 127(6) be amended to read: “In appointing the Board members, the Minister must ensure that the Board members collectively possess an appropriate balance of skills, experience and knowledge in the fields mentioned in subsection (2)”.</p> <p><b>Recommendation</b> -That the Act be amended to include a subsection under section 127 that provides that the Minister must ensure at any time there are at least two Board members with lived experience of impairment or impairments that result in substantially reduced functional capacity as defined in the Act.</p>
Section 174	<p>Amend the timeframe for the NDIA to produce its Quarterly Reports from "1 month" after the end of the quarter to "6 weeks", to allow the NDIA more time for in-depth data analysis.</p> <p><i>Comment</i> - PWDA supports this amendment.</p>
Subsection 174(5)	<p>Remove this subsection as it relates to the publishing of the first NDIA Quarterly Report and has no further application.</p> <p><i>Comment</i> - PWDA supports this amendment.</p>

Subsection 182(2)(c)	<p>Amend 182(c) to clarify that a provider is entitled to claim payment, if a participant dies before the provider was paid for providing a support to them.</p> <p><i>Comment</i> - PWDA supports this amendment.</p>
Subsection 209(3)	<p>Clarify that the Minister must consider all the objects and principles of the NDIS Act when making NDIS Rules, not only financial sustainability.</p> <p><i>Comment</i> - PWDA strongly supports this amendment.</p>



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