

# Submission to the Joint Standing Committee Inquiry: Capability and Culture of the National Disability Insurance Scheme



[www.swanautism.org.au](http://www.swanautism.org.au)

## Acknowledgements

SWAN acknowledges the traditional owners of the land on which this submission was produced, the Wardandi Noongar people. We acknowledge the deep spiritual connection to this land and extend our respects to community members and Elders past, present, and emerging.

## Submission preparation

This submission was prepared by South West Autism Network Inc. In order to write this submission, we listened to the views, concerns and experiences of autistic people, their families and advocates, and the wider community. We researched:

- NDIS processes
- [NDIS Operational Guidelines](#)
- [The NDIS Act 2013 \(amended 2022\)](#)
- The Productivity Commission Report [2011](#) and [2017](#)
- [The Tune Review report 2019](#)
- [NDIS Participant Service Charter](#)
- NDIS Participant Service Improvement Plan [2020-21](#) and [2022-23](#)
- [NDIS Participant Service Guarantee](#)
- NDIS Provider Workshop Presentation 'Redesigning Our Systems to Improve the Participant Experience' July 2022
- [NDIS Data and Insights](#)
- [NDIS Quarterly Report to Disability Ministers](#)

## About Us

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**The South West Autism Network (SWAN) is grateful to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) for making available this opportunity to provide feedback on the Capability and Culture of the NDIS.**

SWAN is a not for profit, charitable organisation supporting autistic individuals and their families living in the south west region of Western Australia for the past 12 years. We are a Disabled Persons and Families Organisation (DPFO), currently delivering two Information Linkages and Capacity Building (ILC) projects. We have almost 2000 registered members, with hundreds more people with disability and their families accessing support from SWAN. All staff, volunteers and Board members either have a disability, are a family member of people with disability, or both.

Our role in the community is to provide information, peer support, advocacy, and connection to mainstream and disability services, building the capacity of people with disability and their families to navigate Government and non-government systems in order to meet their needs and participate in their local communities. We support people seeking diagnosis, post-diagnosis, and across the lifespan. More than 90% of SWAN's work supporting people with disability and their families involves access to, understanding, and navigating the NDIS, and appealing NDIS decisions.

## Culture within NDIA and NDIS Partners in Community

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Since early 2021, NDIS participants and families have reported increasingly negative experiences when dealing with NDIS, and as advocates this is something we have directly witnessed. Prior to 2021, the NDIS plan was built around the person. Now, the NDIS tries unsuccessfully to fit the person into the plan. Increasingly, NDIS representatives are treating NDIS participants, families and supporters as being deliberately deceptive and fraudulent when requesting funded supports to meet their disability needs. There is a lack of respect for participants and their supporters. Reasonable and Necessary support requests are often dismissed without being recorded, and we have witnessed NDIS representatives gaslighting participants and supporters when stating the impact of the disability on their function. The default stance within NDIA and NDIS Partners in Community seems to be the assumption that the participant, nominee and/or supporters are over-exaggerating or lying about their needs. Participants and families frequently report highly adversarial meetings and interactions with NDIS representatives, and SWAN is often contacted by distraught people, particularly after negative planning and reassessment meetings. Planning, Review and Reassessment meetings need to be collaborative, as per the NDIS legislation.

The culture of prioritising cost cutting over the well-being of participants, introduced in 2021, continues to impact on NDIS Participants. Concerningly, 'should represent value for money' is being prioritised over all other [Reasonable and Necessary criteria](#). There is a lack of recognition of human rights in decision-making, as evidenced by the NDIA's frequent practice of reducing or removing supports previously funded and needed by participants, and the reliance on undisclosed algorithms lacking in co-design, knowledge and understanding of disabilities to create Typical Support Package plans. Frequently we see NDIS Plans bearing no resemblance to the supports discussed in the planning or reassessment meeting. It's apparent that much of the input of participants, their supporters and existing supports (including professional therapists) is often ignored.

NDIS Representatives increasingly assume that therapist recommendations are excessive in order to increase profits. These assumptions about therapist reports are particularly ludicrous when there is an ongoing national shortage of therapists, and most (if not all) therapy providers have either long waiting lists or have closed their books. Further, **there is still no appropriate guidance, standard or format from the NDIA to therapists on how to write and present progress reports and Functional Capacity Assessment reports to be deemed acceptable evidence for NDIS to approve the recommended supports.** Participants and families are frequently informed that they need to provide more evidence, but no information is given to explain what that evidence looks like, or how it should be phrased. It should also be noted that whilst NDIA commonly demand therapist reports as evidence to support all requests for funded supports, the decision-makers within NDIA are typically bureaucrats with no allied health qualifications, and are often unable to accurately understand or interpret reports by therapists.

Since 2021, NDIS has been requiring extensive and expensive reports to justify all requested supports, and then regularly ignoring the recommendations made in these reports. Expensive reports are also being required to justify relatively inexpensive supports. Examples include:

- Requiring a \$2000 Occupational Therapy Driver assessment to justify \$650 additional driving lessons for autistic participants and participants with Intellectual Disability.
- Requiring a \$1600 Occupational Therapy risk assessment to justify a \$2000 footpath to enable a wheelchair user to check his letter box and access his electricity meter. This request was then rejected as 'not value for money', requiring the participant to



obtain a further \$400 report from their Occupational Therapist, which finally resulted in approval of the support. These reports doubled the cost of the footpath.

The increase in demand for Occupational Therapist reports from NDIS representatives has significantly impacted on the availability of Occupational Therapists to provide actual therapy supports for participants. This is particularly galling when NDIS representatives are increasingly refusing to fund other allied health supports such as psychology, speech pathology and physiotherapy – instead funding Occupational Therapy only. Many participants have been waiting 18mths to 3 years thus far to access an Occupational Therapist.

Prior to June 2021, participants and families who contacted SWAN primarily sought assistance with preparing for NDIS planning meetings and implementing their plan. Since July 2021, the most common reason people with disability and families have contacted SWAN has been to gain support to seek an Internal Review of Decision or Change of Circumstances Reassessment because they received insufficient funding in their NDIS plan to meet their needs. Many people experienced a 30-60% reduction in funding, and this issue is continuing to occur. A common issue we have seen at Reassessment, is a participant's 1 year plan being turned into a 2 year plan, with the funding remaining the same – that is a 50% cut to funding.

NDIS systems and processes are overly complex, with each new amendment to processes increasing complexities, rather than simplifying or streamlining processes. Participants and families are trying to comply, but the rules and Operational Guidelines keep changing. Ask one NDIS representative, you get one answer. Ask another, and you get a different answer. Of note, a change was made to the NDIS Operational Guidelines for S100 Internal Reviews of Decisions which occurred approximately September-October 2021. NDIA removed the requirement for Internal Reviewers to contact participants or their nominees direct, and conduct the Internal Review **with** the participant. In January 2022, we started to hear from NDIS participants and families who had received an outcome letter from the NDIA Internal Review team confirming the original decision, with no other contact from the agency. All but two of the people who contacted SWAN regarding this issue had already missed the deadline to submit an appeal to the Administrative Appeals Tribunal (AAT). Each person advised that they were so **devastated** by the outcome letter that they couldn't face yet another fight. In these circumstances we supported them to gather more evidence, and submit an S48 Change of Circumstances Reassessment. In each of these cases, the S48 was accepted, but the outcome was still less funding than was recommended in the Functional Capacity Assessment report. This led to supporting those people to then submit another S100 Internal Review of Decision request. **This is hardly an efficient use of the NDIA's resources.**

## NDIS Operational Guidelines

The NDIA has created an external website for the NDIS Operational Guidelines at <https://ourguidelines.ndis.gov.au/>. There is no centralised, integrated menu for the more than 508 webpages located on the site, and being an external website separate to the primary website of <https://www.ndis.gov.au/>, the site remains unknown to most NDIS participants and families. Concerningly, however, participants and nominees are being expected by NDIA and NDIS Partners in Community to comply with Operational Guidelines which are overly complicated, and without being advised of their existence. NDIA continuously add to and alter the webpages at <https://ourguidelines.ndis.gov.au/>, with no notification being given to participants and families of changes occurring.

In an attempt to be able to locate relevant Operational Guidelines, SWAN's CEO spent 16 hours collating an Excel spreadsheet of the 508 webpages. This time was entirely spent collating a list of the webpages, not reading the actual content. In order to track the changes made to the content, we are spending 3-5 hours each month using the search function on the website to date-search for new and altered webpages for that month. This is increasingly difficult and time consuming, as of November 2022 the search function will only search by month and year, not date, and only displays changed landing pages rather than new or changed sub webpages. Frustratingly, we are dedicating time to staying abreast of the extremely complicated Operational Guidelines in order to build the capacity of participants and families we support, but NDIS Partners in Community and NDIA Delegates are often less knowledgeable about these changes, or interpret the Guidelines inappropriately.

Other specific issues with the NDIS Operational Guidelines we have identified to-date include:

### **When Would We Decide Not To Change Your Plan?**

<https://ourguidelines.ndis.gov.au/your-plan-menu/changing-your-plan/when-would-we-decide-not-change-your-plan>

Several statements in this Operational Guideline are both offensive to NDIS participants and families, and harmful in how they are interpreted by NDIS Partners in Community and NDIA Delegates.

*"If your request is only about wanting more funding, or supports that other participants have"*

The primary reason that NDIS participants and families seek a Plan Reassessment or Variation is due to insufficient funding to meet their needs. Additionally, people new to the Scheme, and to having a disability, typically have limited knowledge about suitable Reasonable and Necessary supports to request at their planning meeting. Commonly, people learn about funded supports to meet their needs and improve their quality of life through peer networks. The statement above implies that NDIS participants and families are unnecessarily seeking more funding, or are somehow greedy and jealous, rather than genuinely seeking the Reasonable and Necessary supports they need.

*"[If informal, community or mainstream supports can meet your needs]... would reasonably expect family or friends to do for you, such as short-term care if the family members who usually support you are sick."*

The above statement is concerning in that NDIS Partners in Community and NDIA Delegates have increasingly been placing more responsibility on informal carers to provide the majority of support to participants. Consequently, they are reducing funded supports, particularly in the Core budget for children and adolescents, most of whom have little or no Core funding. For NDIS participants being cared for by a single parent with no extended family support, this typically means that if the parent carer is hospitalised, there is no one able to step in and care for the participant. With little or no Core funding, this also means that Short Term Accommodation cannot be used. This statement also neglects to consider the situation for single parents caring for multiple children with disability.

When single parents of children without disability become unwell (e.g. hospitalisation), extended family, friends or neighbours are sometimes willing to step in and provide care. For children, youth and adults with disability, there is often no one in the community who

feels sufficiently confident and capable to step in and provide care. This is a Reasonable and Necessary support which should be the responsibility of NDIS.

We are especially concerned by how both statements are interpreted by NDIS Partners in Community, NDIA Delegates, and how these kinds of statements reflect the culture within the NDIS.

### **Leaving the NDIS – How much time will you have to give us more information?**

<https://ourguidelines.ndis.gov.au/home/becoming-participant/leaving-ndis/are-you-still-eligible-ndis/how-much-time-will-you-have-give-us-more-information>

This webpage refers to NDIS participants for whom the NDIA has decided to reassess eligibility for the scheme. Concerningly, this Operational Guideline states that the NDIA will *“usually give you 28 days from the date of our first letter, so you can explain if you think you meet the requirements. This will give you an opportunity to give us any extra information or evidence to help us make the right decision.”* As we have previously noted, wait times with all therapy providers and most medical practitioners are excessive, so allowing a mere 28 days to supply additional evidence of eligibility is unreasonable. In contrast, the [NDIS Participant Service](#) Charter states *“Allow sufficient time for prospective participants to provide information, after the NDIA has requested further information - 90 days”* for participants applying for Access to the scheme.

### **Would We Fund It – Generators**

<https://ourguidelines.ndis.gov.au/would-we-fund-it/assistive-technologies/generators>

When the electricity fails, most people light some candles and pull out the old Monopoly boardgame to wait for the power supply to return. For some people with disability, who are reliant on electronic life support equipment, a loss of electricity means the [loss of their lives](#). Whilst supply of electricity is indeed the responsibility of State Governments, this Operational Guideline fails to take into consideration the reality experienced by people with disability living in regional and remote areas of Australia, where electricity supply is commonly unreliable. It also fails to take into consideration unforeseen power interruptions, caused by motor vehicle accidents, storms, flooding, bushfire, and vandalism. Regardless of the intention, this Operational Guideline is typically interpreted by NDIS Partners in Community and NDIA Delegates as a blanket ‘No’ for requests to fund generators for life support equipment. As the generator needs to activate automatically during power outages, the cost is likely out of reach of Disability Support Pension recipients.

### **Would We Fund It – Swimming Lessons in Early Childhood**

<https://ourguidelines.ndis.gov.au/would-we-fund-it/improved-health-and-wellbeing/swimming-lessons-early-childhood>

Families of autistic children frequently request funding for the difference in cost between private and group swimming lessons. The reason for this request is because many autistic children are unable to learn the life-saving skills of swimming in group settings, and require private swimming lessons throughout the year, often ongoing for many years in order to learn and retain this vital skill. Many autistic children are drawn to water, have limited or no understanding of risk or protective behaviours, and many are ‘runners’. Autistic children are at a [significantly higher risk of drowning than their peers](#). Again, this Operational Guideline is typically being interpreted by NDIS Partners in Community and NDIA Delegates as a blanket ‘No’ on funding the cost difference between private swimming lessons and group swimming lessons.

After the devastating [death by drowning](#) of a 6yr old autistic and non-speaking child in WA on 27/03/22, the SWAN CEO wrote to former NDIA CEO, Martin Hoffman, former NDIS Minister, Linda Reynolds, and then Shadow Minister Bill Shorten regarding the NDIA's Operational Guideline for funding of Swimming Lessons, and how it is interpreted and applied by NDIS representatives. Only Mr Hoffman responded.

Excerpt from Martin Hoffman's letter dated 20/04/22 (attached):

*"For the NDIS to fund the cost difference for a child to attend private swimming lessons compared with group swimming lessons, we would firstly need to understand how the child's disability directly impacts their ability to participant in group swimming lessons. We also need to know how private lessons will help the participant meet their goals, facilitate their social participation, and represents value for money in relation to both benefits of the support and the cost of similar supports. We must also consider what families and other informal supports would usually provide. You can learn more about this criteria in the reasonable and necessary guideline.*

*We recognise the importance for all children to have the chance to take part in group activities. Group swimming lessons are a social activity and promote vital water safety learning and development of skills in children. We would not typically fund private swimming lessons as swimming lessons are considered a day-to-day living cost. Everyone has to pay for them whether or not they have a developmental delay or disability. Australian parents and carers are responsible for the costs associated with making sure their children are safe in and around water.*

*If due to a child's disability, they cannot attend group swimming lessons, we might fund the developmental delay or disability-related supports or assistive technology to help the child have the same opportunities as their peers. This means we may cover supports the child needs to take part in swimming lessons or water safety awareness activities.*

*Reasonable adjustments can also be explored for swimming lesson options within the local area of the child. For example, any existing capacity building budget within a child's NDIS plan can be used to work with their early intervention team to develop and share strategies with a qualified swim instructor. This can help the child be included in swimming lessons in a group setting."*

Concerningly, in his response, the former NDIA CEO prioritised the benefits of participating in a group over learning to swim, and this Operational Guideline reflects this viewpoint. The purpose of swimming lessons is to **learn to swim in order to prevent drowning**. There are many other more suitable opportunities for children with disability to benefit from participating in group activities. Further, there is no acknowledgement in the former NDIA CEO's letter of our expressed concern that the guideline is being interpreted by most NDIS representatives that the cost difference between private and group swimming lessons is not to be funded.

### **Would We Fund It – Mental Health Supports**

<https://ourguidelines.ndis.gov.au/would-we-fund-it/improved-health-and-wellbeing/mental-health-supports>

Despite all case studies in this Operational Guideline describing participants with psychosocial disability, requests for funding for psychologists to support participants with Intellectual Disability, Autism and developmental delay are being routinely denied, both by



NDIS Partners in Community and by NDIA Delegates. Participants with these diagnoses are instead told to visit their GP for a Mental Health Care Plan, disregarding the fact that these diagnoses are neuro-biological in nature, not mental illnesses. Moreover, they are not listed as eligible diagnoses under the Medicare funded Better Access Initiative. For autistic people in particular, psychology has been considered the primary therapy support for more than 25 years, yet NDIS are routinely denying this reasonable and necessary support.

These 'Would We Fund It' examples clearly show that codesign and expert disability advice were lacking in the development of the Operational Guidelines. **All** of the 'Would We Fund It' examples are problematic in nature, and it's questionable as to whether they comply with the NDIS legislation (see examples in [Team DSC article](#)). They show a lack of expertise and understanding of the disabilities described, and a failure to take into consideration how the guidelines would be interpreted by operational staff. Overwhelmingly the 508 webpages describe scenarios that NDIS would **not** fund. There are very few case studies describing requested supports that NDIS approved, and only one webpage 'What **does** NDIS fund' which details the NDIS Reasonable and Necessary criteria before yet again detailing what the NDIS won't fund. Particularly disturbing is the fact that most NDIA Delegates and NDIS Partners in Community are viewing the Operational Guidelines as rules, when many appear to be non-compliant with the NDIS legislation (as per evidence given by Naomi Anderson of [Villamanta Disability Rights Legal Service](#) to the Joint Standing Committee Hearing in Geelong on 17<sup>th</sup> November 2022).

## Redesigning NDIS Systems

Codesign and consultation by the NDIA continues to be problematic. The NDIA's Community Engagement Division has been renamed 'Co-design and Engagement', but continues to operate in the same manner - regular updates to community service organisations with no engagement with participants and families. The NDIA Participant First Team continue to invite consultation via Expression of Interest form which typically asks only for name and whether the person is a participant or family member, and whether they have experience in the issue to be discussed. This results in consultation panels lacking in diversity. The two that SWAN's CEO personally participated in were heavily populated by people living in Sydney and Melbourne. The Expression of Interest form also needs to ask:

- Are you Aboriginal or Torres Strait Islander?
- Are you from a Culturally & Linguistically Diverse background?
- What state do you live in?
- Do you live in a regional / remote location?
- What is your disability?

**To build systems and processes which consider the diverse needs of NDIS participants living all over Australia, NDIA needs to listen to the diverse voices of NDIS participants living all over Australia.**

From 27<sup>th</sup> April 2022, the NDIA hosted Provider Workshops titled 'Redesigning our systems to improve the participant experience'. The third slide details the system changes to be introduced with NDIA's new customer relationship management system – PACE. Of concern is the statement '*Release of funding in stages over the life of a participant's plan.*' SWAN's CEO was a member of the NDIS Independent Assessments (IA) Working group from November 2020 until the decision was made that Independent Assessments would not proceed in July 2021. Release of funding in monthly or quarterly increments was a 'non-



negotiable' change that NDIA proposed to introduce along with the raft of changes planned for the introduction of Independent Assessments.

**All members of the IA Working Group advised that release of funding in quarterly increments would only work for some participants, but that for most participants, particularly individuals with episodic disability or complex needs, the change would put them at risk.** Anyone needing Short Term Accommodation during the first month of their NDIS plan would likely be unable to access this support. Likewise, if a provider is behind on their billing and charges an unexpectedly large invoice, then the participant would be left with inadequate funds to use other supports. With the thin markets experienced in many parts of Australia, especially in regional areas, the potential impact of this is providers removing participants from active client status, and placing them back on the bottom of the provider's waitlist. In the south west, those waitlists are typically 6-24mths long for providers who haven't yet closed their waitlist to new clients. For this change in release of funding to proceed, it must be optional. Preferably, with NDIA insisting on longer length NDIS Plans of 2-5 years, dispersal of funding in annual increments would enable participants to meet their fluctuating needs, manage billing by providers, and have choice and control, without being overwhelmed by trying to manage consistent spending of 2-5 years' worth of funding.

In October 2017 NDIA announced the piloting of a new [Participant Pathway](#), with the plan to improve the experience of NDIS participants through the planning process. The new Participant Pathway was widely promoted by the NDIA and Partners in Community, and a [Pilot](#) of the new process commenced mid-December 2017 in two regions in Victoria. The Pilot involved three separate meetings between the NDIS Participant / Nominee and their NDIA Delegate, LAC or ECA Coordinator, with a working document version of the NDIS Plan being shared openly and negotiated between them over the course of the three meetings. Anecdotal feedback about the Pilot from participants was positive, but no report on the outcomes of the Pilot was ever made public, and no further mention of the New Participant Pathway has been made. **It's important to note that in this Pilot, participants received a draft copy of their NDIS Plan, with the opportunity to make amendments and negotiate the final version of the Plan to their satisfaction.**

The planning process as used in the Pilot above has been requested by Participants, nominees, and advocates since the commencement of the scheme. In the WA State-based version of NDIS, participants underwent a similar process, with participants or their nominee being required to sign the plan in order for it to be finalised. This process resulted in significantly fewer complaints and reviews than is the experience in the national version of the NDIS.

SWAN is deeply concerned to note the deletion of a requirement for NDIS to provide draft copies of the participant's NDIS Plan on page 3 of the NDIA's Participant Service Improvement Plan as follows:

## [2020-2021 NDIS Participant Service Plan:](#)

### Communicating with us

- You will have a **current contact** name for all your interactions with us
- We will put the **name** of a real person on our letters to you
- You will be able to use **online forms and services** where you want to
- You will be able to **track** where your application or inquiry is up to **online**
- **The website and portal** will be clearer and easier to use
- **The call centre** will give you more helpful and consistent information.

### Getting information from us

- Our decision letters will have **reasons** for why

### Making your plan

- We will support you, if you want, to build **goals** in your plan that are clearly defined, realistic and attainable
- If you want, you will be able to have a **face-to-face meeting** with the person who makes a decision about your plan supports and funding
- We will also support more **video-conference** planning meetings
- You will get **plan summary statements and draft plans** before your plan is approved so you can check your information is right and there are no surprises
- We are working to build more **do-it-yourself online plan tools**.

### Using your plan

## NDIS Participant Service Improvement Plan 2020-21 page 3

## [2022-2023 NDIS Participant Service Plan:](#)

### Our commitments to you



#### Communicating with us

- You will have a **current contact** name for all your interactions with us
- We will put the **name** of a real person on our letters to you
- You will be able to use **online forms and services** where you want to
- You will be able to **track** where your application or inquiry is up to **online**
- **The website and portal** will be clearer and easier to use
- **The call centre** will give the right information the first time where possible.



#### Getting information from us



#### Gaining access to the NDIS

- You will be able to apply to the NDIS in the way you want, including using an **online form**
- We will make sure you are connected to other mainstream and community supports and services as well, even if you don't gain access to the Scheme.



#### Making your plan

- We will support you, if you want, to build **goals** in your plan that are clearly defined, realistic and attainable
- If you want, you will be able to have a **face-to-face meeting** with the person who makes a decision about your plan supports and funding
- We will also support more **video-conference** planning meetings
- We are working to build more **do-it-yourself online plan tools**.

## NDIS Participant Service Improvement Plan 2022-23 page 3

We refer also to the recommendation in the [2019 Tune Report](#):

The Participant Service Guarantee should require the NDIA, when requested by a person with disability, to provide an explanation of an access, planning or plan review decision in an accessible format of their choice. This would be consistent with best practice administrative decision-making principles, reinforce robust planning practices, and ensure the NDIS remains accountable to the people it was designed to support.¶

The Participant Service Guarantee should also empower participants to be able to review and consider a full version of their draft plan before it is approved, inclusive of the estimated plan budget. The provision of a whole draft plan is an important mechanism to ensure decision-making processes are transparent and for keeping the participant at the centre of the planning process.¶

### **Tune Report 2019 page 11**

The NDIA has repeatedly stated that the agency's IT systems do not permit the sharing of draft copies of participant plans. Considering the NDIA is in the process of transitioning to a new IT system, PACE, it's alarming to see the removal of the statement *"You will get plan summary statements and draft plans before your plan is approved so you can check your information is right and there are no surprises"*.

NDIS Participants and families have been promised draft copies of their NDIS Plans since prior to 2017, yet in 2022, when the NDIA is transitioning to a new IT system with the opportunity to develop a system to enable this process, NDIA has removed this goal from the NDIS Participant Service Improvement Plan.

In comparing the [NDIS Participant Service Charter](#) standards

- **Transparent**
- **Responsive**
- **Respectful**
- **Empowering**
- **Connected**

with NDIS processes and interactions with participants and supporters, it is our observation that the current culture and capability of NDIS is consistently and systematically failing to meet these standards.

## What needs to change to fix the NDIS?

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### Recommendations

- 1) NDIS Planning meetings must be held with the actual decision-maker, not with LACs / ECA Coordinators. Currently, too many LACs and ECA Coordinators are acting as gate-keepers, refusing to draft plans which accurately reflect the supports requested by participants and families. When the participant or their nominee submit an S100 Internal Review Request, we are increasingly seeing the requested changes rejected because there is no record of the original support being requested. Outcome letters from the Internal Review team state that the support was not requested at the planning meeting, and to request an S48 Change of Circumstances Reassessment. Further to this, LACs and ECA Coordinators are submitting S100 Internal Review Request forms without the input of the participant, and failing to provide the participant with a copy of the submitted form. If the participant is forced to appeal to the Administrative Appeals Tribunal, they then need to request release of their information from NDIS, which takes as long as 5 months to receive. Notably, this information generally includes only the case file notes, but doesn't include the S100 form.
- 2) Participants must be given the full name and contact information of the NDIS representative responsible for negotiating and finalising their NDIS Plan, **prior** to the NDIS planning meeting. Failing to do this results in participants being unable to submit further evidence, including written details of the supports they are requesting. This enables gate-keeping and limits participants' opportunity for successful S100 Internal Review requests. This is because the Internal Review team are now only reviewing the notes submitted by the NDIS Partner in Community or NDIA Delegate at the planning meeting, and comparing this with whatever was submitted in the S100 Internal Review request form. Currently, the only email address most participants have for submitting documentation is [enquiries@ndis.gov.au](mailto:enquiries@ndis.gov.au), which generally takes 6 weeks to be processed. This isn't an option when many participants are given as little as 2 days' notice of their meeting. With more than half a million participants as well as providers using the one email address, there is also the issue of emails to [enquiries@ndis.gov.au](mailto:enquiries@ndis.gov.au) not being actioned.
- 3) NDIS must shift from a focus of keeping funding in participant plans as low as possible to a focus on ensuring that the participant's NDIS plan accurately reflects their needs and reasonable and necessary supports. **NDIS needs to get the participant's plan right – the first time, wherever possible.** Planning meetings need to be conducted by NDIA Delegates, and need to be a negotiation between the participant / nominee and the Delegate. This can be achieved by providing a draft of the plan to the participant / nominee, and have them sign their approval of the plan in order to finalise it. This system was successfully used in the WA trial sites for the State version of NDIS.
- 4) NDIA must cease all use of algorithms in determining funding for NDIS Participants. Planning, Review and Reassessment processes must be returned to individualised, person-centred and collaborative processes, acknowledging and respecting the lived experience of the participant and their supporters.
- 5) NDIA's use of 'Primary Disability' for NDIS participants must cease. Participants and supporters are never informed which of their diagnoses have been approved for NDIS eligibility, but are expected to only claim supports for the diagnoses NDIA has decided are eligible. The NDIS Act 2013 (amended 2022) does not include the terms 'diagnosis',



'diagnoses' or 'diagnosed' anywhere in 307 pages. We ask the Joint Standing Committee whether NDIA's cherry-picking of participant diagnoses, and not advising them of this, is compliant with the Legislation. Further, NDIS representatives appear to randomly select a diagnosis to list as the 'Primary Diagnosis', again without advising participants. This selection of 'Primary Diagnosis' then impacts the algorithms used to determine funding budgets.

- 6) As per the [NDIS Participant Charter](#) standard 'Connected', ensure that participants and nominees are contacted according to their expressed preferred method of communication. If a participant has requested email, then contact should be via email. If a participant is blind or vision impaired, then contact should be made using accessible documents.
- 7) The website <https://ourguidelines.ndis.gov.au/> must be deleted. All Operational Guidelines must be reviewed to ensure compliance with the legislation, and be co-designed with people with disability, advocates and disability representative organisations.
- 8) The [3 NDIS Participant booklets](#) need to be redesigned to ensure that participants and supporters are able to easily submit information about their needs and requested supports in writing. A more user-friendly system would be to have 1 booklet explaining NDIS processes, 1 booklet for preparing for the first planning meeting, and 1 booklet for preparing for a plan Reassessment. Further, a separate version should be developed for families of children aged 0-6 years accessing the Early Childhood Approach.
- 9) Participants and families need access to a single NDIS contact person for support, rather than having to tell their life story to a dozen random people. LAC Partners in Community are no longer assigning an LAC to specific participants. Since late 2021 it has been luck of the draw as to which LAC will conduct your planning meeting, and if you are lucky enough to be provided plan implementation support, another random LAC **might** contact you about this. Participants are given a generic email address and phone number for the LAC Partner in Community organisation on the front page of the NDIS Plan, but this number and email address are not listed anywhere else. The participants and families contacting SWAN consistently complain that they have no idea who their LAC is, or how to contact them.
- 10) Sub-contracting, outsourcing and casualisation of the NDIS workforce greatly reduces the accuracy of information being supplied to participants and families, while increasing operational costs. We need to build the necessary expertise within the NDIA, and retain this expertise by ensuring that staff have full employee benefits.
- 11) All participants, regardless of age, must have a minimum Core budget in their NDIS plan which can be used flexibly to meet their needs. The majority of children and teens, particularly in the south west region, have no Core budget, or as little as \$100-\$300 for Core supports. Typically we see Capacity Building – Daily Living only NDIS Plans for 7-14yr old children of \$4500-\$9000 per year. To illustrate the inadequacy of this, \$5000 equates to **less than** 1 hour of speech pathology or occupational therapy per fortnight, with no funding allocation for assessments, writing of reports required by NDIS, or therapist travel costs. NDIA persistently misrepresents the amount of funding in participant plans.

- 12) Participants must retain the choice to use registered OR non-registered providers, and minimum qualifications must **not** be required. The Cert III in Individualised Support is an extremely general course with graduates still needing extensive training to understand the individual support needs of each person they work with. Values and ethos are far more important factors, and those are innate. Allied Health professionals are already registered with appropriate professional bodies, such as AHPRA. A push for all providers to be registered creates significant risk for regional and remote participants - many towns have no registered providers, which means that many people in regional and remote Australia would be left with no support at all.
- 13) To address issues of Quality and Safeguarding, rather than limiting supports to registered providers, NDIS need to conduct regular check-ins with participants. Check-ins should ensure they are able to access the supports they need, monitor the participant's satisfaction with providers, how they are billing and the quality of the support being provided. Check-ins need to ensure participants understand their rights when negotiating with providers, how to complain, identifying signs that participants and families need more support – triggering a Variation to include funding for Support Coordination in the participant's plan. Vitally, check-ins must engage directly with the participant in order to check for signs of violence, abuse and neglect. Currently, there are high numbers of participants, including within my own family, who have not heard from any NDIS representative for up to 3 years.
- 14) Further to recommendation (9), NDIS should provide a free audit processes for providers to become NDIS registered providers. Auditors should interview current and past users of the service as part of Quality and Safeguards monitoring. It's important to find out why participants left a service, as well as why they chose to stay.
- 15) The NDIS website should incorporate Google translate to enable access to all content for people from Culturally and Linguistically Diverse backgrounds. [www.positivepartnerships.com.au](http://www.positivepartnerships.com.au) is a great example of the effectiveness of this option.
- 16) Funding for advocacy, the National Disability Strategy, and for Information, Linkages and Capacity Building (ILC) must be expanded. People with disability and their families rely on Disabled Persons and Families Organisations (DPFO) for independent information, support, advocacy and referral. Ensuring the sustainability of DPFOs to meet the ongoing needs of people with disability and their families is vital to improving outcomes for people with disability and ensuring the effectiveness of the NDIS. The National Disability Advocacy Program must be opened to new applicants, and management of ILC needs to be returned to NDIA. Since the ILC program was transferred to DSS in 2020, there has been a loss of connection and information sharing between ILC providers and NDIA. Prior to the change, ILC providers were able to quickly contact their NDIA grant manager and discuss issues and concerns identified in the community. There was opportunity for feedback direct to NDIA, and to work with NDIA to address systemic issues at a local level. This connection has been lost to the detriment of both NDIS participants and how NDIS operates.
- 17) NDIA, Commonwealth and State Governments to work together to address the issue of thin markets, particularly in the allied health space. A significant increase in University places for Allied Health courses is urgently needed, with improved access for prospective students living in regional and remote Australia – without the requirement and additional cost to relocate to capital cities. These courses must also be amended to include co-designed disability content.

## Conclusion

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David Tune reported in 2019 that “*the NDIS Act is broadly fit for purpose, but there are a number of areas that can be amended to remove red tape and improve the participant experience*”. In light of the amendments to the legislation made this year, we believe this statement continues to accurately reflect the experience of participants navigating NDIS processes. As an organisation with more than 13 years’ experience advocating, negotiating and working in the disability sector, supporting thousands of people with disability living in regional WA, SWAN has an excellent understanding of the difficult reality faced by people with disability and their families in gaining and maintaining access to the NDIS and to Reasonable and Necessary funded supports. SWAN can provide case studies to the Joint Standing Committee if requested.

On behalf of SWAN members and the wider disability community, we are grateful to the Joint Standing Committee for continuing to investigate the systemic barriers and difficulties experienced by NDIS participants and their supporters. SWAN is deeply concerned about the increasingly negative effects of inconsistent and inefficient NDIS processes on people who are already amongst the most disadvantaged in Australia. As the peak body supporting autistic people in the south west region of WA, we would be happy to discuss the issues further with the Members conducting the Inquiry.

## Contact Details

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