Submission to the Independent NDIS Review August 2023

South West Autism Network Inc (SWAN)

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 disability 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 Data and Insights
- NDIS Quarterly Report to Disability Ministers

About Us

The South West Autism Network (SWAN) is grateful to the Independent NDIS Review for the opportunity to provide feedback on the experience dealing with NDIS for participants and their supporters.

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.

Autism and the NDIS

We understand that there is a misconception in the community that autism is over-diagnosed in Australia, and that most autistic children require minimal funded support. While SWAN is unable to comment on the situation in other states, in Western Australia autism is significantly under-diagnosed. Due to extreme staffing shortages and stringent diagnostic processes, WA families are waiting up to 2 years to access a paediatrician and up to a further 2 years to access formal diagnostic assessment. Accessing autism diagnostic assessment in WA is arduous, traumatic, and actively discouraged by too many paediatricians. Families with the financial means to pay privately for autism diagnostic assessments are able to source diagnosis and access support much faster, but are still delayed by the requirement for referral by Paediatrician to access the Medicare rebate.

Naturally this means that families experiencing financial hardship are unable to access reasonable and necessary funded supports for their autistic child for up to 4 years, unless the developmental delay was identified before their child turned 6 years of age. Families experiencing domestic violence, homeless and severe financial hardship are rarely connected to services able to identify these needs, or difficulties relating to autism may be incorrectly assumed to be trauma-related. As per the NDIS Demographic Chart Data for Autism, the proportion of WA NDIS participants with a primary diagnosis of autism is only 9%. Data for South Australia matches this statistic, whereas New South Wales (30%), Victoria (27%) and Queensland (21%) all have significantly higher proportions of NDIS participants with a primary diagnosis of autism. Tasmania (2%), Northern Territory (1%) and ACT (2%) all have a very low proportion of autistic participants.

We note also that autistic children typically receive very low funding in their NDIS plans. For 7-14 year old autistic kids, we routinely see NDIS plans with Capacity Building – Improved Daily Activities funding only, with amounts between $4,000 and $11,000 per year, the average being around $5,000. For context, $5,000 per year equates to **less than one hour of therapy per fortnight**. It's well established that autistic children benefit from multi-disciplinary therapy, requiring Psychology and Occupational Therapy as a bare minimum, with many also requiring Speech Pathology and sometimes Physiotherapy. Autism is a spectrum condition, impacting each individual differently.

> "*Delivery related to supporting a child's development of functional skills in one or more developmental domains should involve practitioners with allied health and/or education qualifications that correspond with those domains (e.g., occupational therapy for enhancing participation and engagement in childhood occupations, physiotherapy for gross motor skills, psychology for cognition and mental health, speech pathology for communication).*" (Autism CRC 2022)

For many autistic kids, repetition and consistency are vital for building skills, and this simply cannot be achieved with such low funding. Under-funding supports for autistic kids impacts long-term sustainability of the NDIS – autistic adults whose support needs were not met in childhood will require substantially more support throughout their lifespan.

Culture within NDIA and NDIS Partners in Community

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, and we continue to see significant problems regarding this issue. Too many NDIS representatives are still 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'* continues to be 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 (TSP) 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. Too often we see NDIS plans featuring goals which do not reflect the goals requested by the participant and their supporters, breaching the NDIS Act 2013. We also commonly see that the 'About Me' section of the plan is rarely updated during plan reassessments, which means that the plan does not accurately represent the person and their current circumstances – increasing the issue of inappropriate plans. Another common issue is seeing copy and pasted plans, where a different participant's name appears in parts of the NDIS plan.

NDIS Representatives continue to assume that therapist recommendations are excessive in order to increase profits. These assumptions about therapist reports are particularly ludicrous when there remains an ongoing, national shortage of therapists, and most (if not all) therapy providers have either long waiting lists or have closed their books. In the south west region of WA, the wait time to access therapy providers ranges from 8 months to more than 3 years, depending on the type of therapist being sought and the age of the person. 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 rarely able 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 consistently ignoring the recommendations made in these reports. Expensive reports are also being required to justify relatively inexpensive supports. Examples include:

- Requiring a $2,000 Occupational Therapy Driver assessment to justify $650 additional driving lessons for autistic participants and participants with Intellectual Disability.
- Requiring a $1,600 Occupational Therapy risk assessment to justify a $2,000 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 concerning when NDIS representatives are routinely denying funding for 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.

NDIS Plans are increasingly prescriptive in nature. It's extremely common to see NDIS plans stating Capacity Building – Improved Daily Activity budgets describing $3,879.80 (20 hours) for Speech Pathology and $4,849.75 (25 hours) for Occupational Therapy, for example. While the plans sometimes state that this budget is flexible, participants and families are often reprimanded at plan reassessment if they claimed Psychology to support their autistic child with developing emotional regulation and social skills, rather than Occupational Therapy as decided by NDIS. This is despite substantive evidence that Psychologists are the allied health professional to support autistic children in building the necessary skills in this area; with Psychology having been well established as the primary allied health support for autistic children, youth and adults for more than 30 years. It's necessary to emphasise here that Occupational Therapy is in such high demand due to being prioritised by NDIS over all other allied health professionals, that participants struggle to access this support.

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 – either due to the Typical Support Package being grossly inadequate for autistic children, or due to funding being cut. 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.

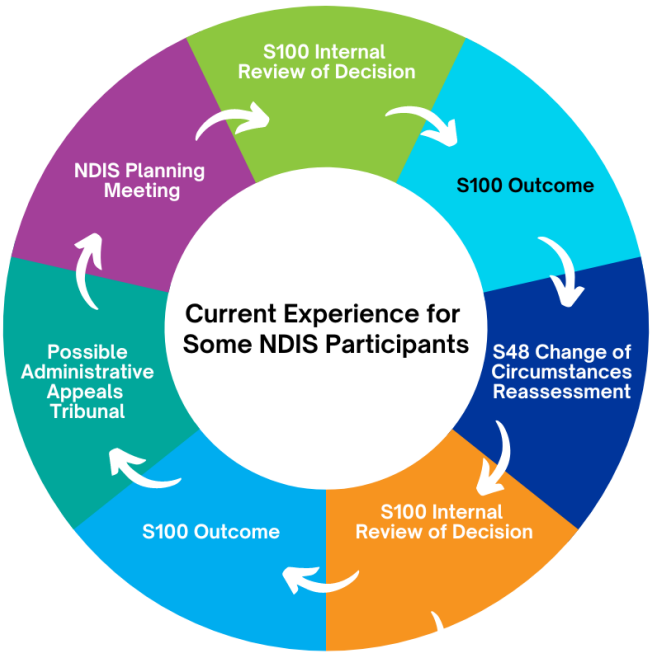
The largest funding cut we have seen was a reduction of 83%, which occurred in February 2023. The new plan was issued as a 3 year plan with only $2,000 per year allocated in the Core and in the Capacity Building budget, for an autistic adult with physical disabilities; the plan was essentially unusable. The 83% plan cut occurred because the NDIA delegate claimed there was no documentation in the participant's file, and they also ignored the previous NDIS plan expenditure of 97%. The participant's file contained 2 comprehensive

Functional Capacity Assessments dated 2 years apart and 6 progress reports over the course of their 4 years as a NDIS participant. Despite formal complaint to NDIA and internal escalation to the NDIA's WA Participant Solutions Team, it took 4 weeks to rectify the plan.

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.**

Whilst we are hearing that participants are more frequently contacted by the NDIA's Internal Review team to discuss their S100 request, in late 2022 – early 2023 a new issue emerged. SWAN are now supporting participants and families to submit S100 Internal Review of Decision requests after grossly underfunded plans were issued, and they are receiving outcome letters stating that the requested supports were not asked for during the original planning meeting, and the participant needs to submit an S48 Change of Circumstances Request. We have then supported the participant to submit an S48 Change of Circumstances Request, the participant has received a slightly improved plan, and SWAN have then supported them with another S100 Internal Review of Decision request.



We are aware of at least 8 cases to-date where this has occurred. The participant / nominee requested specific supports during the planning meeting, but the LAC did not forward these requests to the NDIA Delegate – a clear breach of the NDIS Act 2013. Again, this is not an efficient usage of NDIA's resources, nor of advocacy and ILC funding. SWAN remind the Panel that we are a small, regional DPFO. If we have witnessed 8 cases of this occurring, this issue is likely to be significant.

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 were dedicating time to staying abreast of the extremely complicated Operational Guidelines in order to build the capacity of participants and families we support, but this is no longer practicable. Due to the extreme complexity, NDIS Partners in Community and NDIA Delegates are often less knowledgeable about these changes, or interpret the Guidelines inappropriately.

Examples of 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. Drowning accounts for 46% of all injury deaths among autistic children, which translates to 160 times the chance of dying from drowning compared with other children (Autism Swim 2016). 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 to SWAN dated 20/04/22 :

> *"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 30 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 17th November 2022).

Whilst there is a new senior executive team at the NDIA, and we welcome this change, these Would We Fund It Guides and Operational Guidelines remain in place.

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 27th 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 below 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"*. SWAN note that the NDIA's existing IT

systems do in fact permit the sharing of draft copies of participant plans, having witnessed a draft plan being provided to the participant who experienced the 83% funding cut.

NDIS Participants and families have been promised draft copies of their NDIS Plans since prior to 2017, yet in 2022, when the NDIA was commencing work to transition to a new IT system with the opportunity to develop a user-friendly 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 NDIS representatives are consistently and systematically failing to meet these standards. While there are some minor signs of culture shift within the NDIA under the new senior executive team, shifting the culture within the NDIS can be likened to turning around the Titanic when it's already touched the iceberg.

What needs to change to fix the NDIS?

Recommendations

1) Any and all changes to the NDIS considered by the Independent NDIS Review must be fully co-designed with participants, supporters, Disability Representative and Carer Organisations (DRCOs) and Advocacy Organisations. We emphasise that co-design processes must include diverse voices, and take particular consideration of the unique barriers and difficulties faced by people with disability in regional and remote Australia, and ensure their voices are included.

2) In order to address the cultural issues within the NDIA and Partners In Community, we recommend targeted recruitment of people with disability as part of the Government's budget priority to build the NDIA's Workforce Capability. Ensuring that NDIA develop staff's expertise in specific disability types rather than having minimal general knowledge of all disabilities would significantly improve outcomes for participants. Further, we strongly recommend that all staff and partner organisations ensure all staff undertake training in:
   - Trauma Responsive Practice
   - De-escalation skills
   - Conflict resolution
   - Incidental Counselling

3) All communication from the NDIS must be provided in formats accessible to the participant. Culturally and Linguistically Diverse (CaLD) participants must be provided an NDIS plan in their language, or funding included in the plan for a translator to do this. Vision-impaired and blind participants must be provided a copy of their plan in large text or braille if required, and the NDIA must ensure that the rollout of PACE will enable screen readers to accurately read the plan. Participants requiring Easy Read versions of their NDIS plan must be provided the plan in this format, or funding included to produce an Easy Read version. Plain English must be the minimum standard for all communication from the NDIS. We note also that Easy Read documentations must be released at the same time as standard versions, not weeks or months later (or not at all).

4) 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. We note also, that getting the plan right in the first place will immediately address the issue of inter-plan and intra-plan inflation.

5) NDIS representatives must check the accuracy of participant information on file – directly with the participant and their supporters regularly. SWAN's advocacy work is increasingly identifying very significant errors in NDIS participant records which seriously impact participants. We are uncovering errors such as NDIS Access Requests being entered into the NDIA's operating system incorrectly, diagnoses listed incorrectly (e.g. diagnoses missing from the participant's file), and more. In April 2023 SWAN's CEO sought feedback in several NDIS related peer support groups on whether NDIS representatives are checking that participant information on file is correct. These polls identified that **more than 80% of participants have never had their information checked for accuracy by NDIS representatives**.

6) 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.

7) We **strongly** discourage the Panel from recommending that participant budgets be decided prior to the planning meeting. This methodology fails to acknowledge the expertise of participants and supporters, is not individualised, and will not meet the unique support needs of most participants. Whilst this method would reduce costs, the risk to participants is extreme. Further, this places participants at the mercy of the whims of future Governments. All Australians with disability need certainty about the future of their supports, and this is **not** the way to achieve that.

8) 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, 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 not being actioned.

9) NDIS participants must be provided an explanation of all decisions made by the NDIA about them and their supports, without the requirement of the participant or their supporters to submit a Freedom of Information request.

10) 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. The Typical Support Package (TSP) lacks evidence and external scrutiny to ensure efficacy, and is entirely unsuitable in determining funded supports.

11) 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 NDIS Review Panel 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.

12) 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 to be contacted by email, then contact should be via email. If a participant is blind or vision impaired, then contact should be made using accessible documents.

13) 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.

14) In order to ensure holistic support for children and young people with disability, we recommend that mainstream services such as Education, Health, Mental Health and Allied Health be invited to participate in NDIS Planning meetings where appropriate. Since the rollout of NDIS in the south west region, we are increasingly observing a siloed approach to support for children and youth with disability. This has the effect of families being pinged back and forth between mainstream services and the NDIS, unable to access the supports which are desperately needed. There needs to be a more collaborative approach to supporting youth with disability, ensuring greater understanding of what supports NDIS can provide, and what supports mainstream services can provide. There is a higher rate of young people with disability (particularly autistic kids) disengaging from mainstream schools due to insufficient support. Whilst this is not the responsibility of NDIS, a more collaborative approach and shared responsibility is beneficial in improving outcomes for youth with disability.

15) 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.

16) 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.

17) 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. There are currently NDIA contracted organisations not tasked with LAC and ECA services phoning participants for check-ins. This is a huge breach of the participant's privacy, as well as being extremely confusing for participants and supports. SWAN wish to draw your attention to how this practice puts participants at higher risk of being scammed or defrauded. All communication to participants about the NDIS needs to come from the NDIA direct – using their preferred communication method.

18) 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 of WA, 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 $4,000-$9,000 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.

19) 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. We note also that there are self-managed participants successfully direct employing support workers (not via ABN) at significant cost saving to the NDIS. One of our members is direct employing 2 support workers as permanent part time employees with superannuation, leave entitlements and insurances – and still saving the NDIS in excess of $30,000 per year.

20) To address issues of Quality and Safeguarding, rather than limiting supports to registered providers, NDIA 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 unacceptably high numbers of participants who have not heard from any NDIS representative for up to 4 years, with 12 month plans auto-extending each year.

21) Further to recommendation (9), the Government should provide a free audit process and support 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.

22) 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.

23) 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.

Recommended amendments to the NDIS legislation:

1) Removal of risk assessment in deciding whether participants can have their funding Plan Managed. This is urgently needed for participants in regional and remote Australia, where there is extremely limited or no access to NDIS registered providers. Participants living in thin market areas with Agency (NDIA) Managed funding are trying to manage with limited or no supports, which is entirely unsustainable.

2) Amendment to ensure that the NDIA's Compliance Team's decision that a participant has incurred a debt is a reviewable decision. Currently, if the NDIA decides that a participant has incurred a debt, the only recourse a participant has is to request that the debt be waived by the NDIA. If the NDIA refuse to waive the debt, that decision can be reviewed. However, the record of the debt remains on the participant's file, with potential to impact the participant and how their funding is managed long-term. Participants, nominees and child representatives must have legislative right to challenge the NDIA decision that a debt has been incurred. Whilst the current NDIA's Compliance Team have advised that they are researching Administrative Appeals Tribunal decisions to aid them in decision-making, there is no legislated requirement for them to do so. This part of the legislation must be amended to protect the rights of participants in future. As has been evidenced in the very recent past, there is high risk of this process being changed in the future.

Conclusion

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 in 2022, we believe this statement continues to accurately reflect the experience of participants navigating NDIS processes. As an organisation with more than 14 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 Independent NDIS Review Panel if requested.

On behalf of SWAN members and the wider disability community, we are grateful to the Independent NDIS Review Panel for investigating 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 Panel Members conducting the Review.

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