

**Speech Pathology Australia's submission to the  
Joint Standing Committee on the National Disability Insurance Scheme's  
Consultation:  
'General Issues around the implementation and performance of the NDIS'**

**14 April 2022**



**Hon Kevin Andrews MP**  
**Chair,**  
**Joint Standing Committee on the National Disability Insurance Scheme**

Sent electronically: [ndis.sen@aph.gov.au](mailto:ndis.sen@aph.gov.au)

Dear Mr Andrews,

Speech Pathology Australia welcomes the opportunity to provide feedback to the Joint Standing Committee's standing review of general issues around the implementation and performance of the NDIS. As you are aware, Speech Pathology Australia is the national peak body for speech pathologists in Australia, representing more than 13,000 members. Speech pathologists are university-trained allied health professionals with expertise in the assessment, diagnosis and treatment of communication and swallowing difficulties, and have expertise in the prescription of assistive technology in these areas.

Speech Pathology Australia has concerns regarding several overarching issues that continue to be reported by members, predominantly related to the lack of disability knowledge of NDIA staff. In addition, there are several areas where the implementation of the scheme is not being managed adequately, to the detriment of people with disability and speech pathologists providing NDIS services. This includes the assistive technology process, and involvement of First Nations people with the scheme.

We provide more detail on these issues below in our submission and make recommendations that we hope the Committee finds useful. We have conducted numerous surveys, and interviews, and also receive direct communication from our members regarding these issues, so we have used some of these comments to augment our response. We preface this with brief background information about communication disability, communication access and the role of speech pathologists. As always, we would be very willing to provide more detail of the issues we highlight in our submission directly to the Joint Standing Committee.

In the meantime, if Speech Pathology Australia can assist in any other way or provide additional information, please contact \_\_\_\_\_, Senior Advisor Disability, on \_\_\_\_\_ or by emailing \_\_\_\_\_

Thank you for the opportunity to contribute to your inquiry.

Yours sincerely

—

**Tim Kittel**  
**National President**

## Table of Contents

<b>Introduction .....</b>	<b>4</b>
About Speech Pathology Australia .....	4
About communication disability .....	4
Communicative participation .....	5
Communication access .....	5
<b>Ongoing issues Speech Pathology Australia has identified: .....</b>	<b>6</b>
1. Systemic agency issues.....	6
2. Assessments and equity of access.....	9
3. Reasonable and necessary supports .....	11
4. Increased appeals & need for advocacy.....	13
5. Assistive technology.....	14
6. Culturally appropriate supports for First Nations participants.....	19
<b>Recommendations .....</b>	<b>22</b>

## Introduction

Speech Pathology Australia (the Association) welcomes the opportunity to provide feedback to the Joint Standing Committee's inquiry. We have structured our feedback regarding issues that are ongoing within the scheme and provide examples from our members where applicable/appropriate. We preface our comments with some background information on communication disability, communication access, and the role of speech pathologists.

## About Speech Pathology Australia

Speech Pathology Australia is the national peak body for speech pathologists in Australia, representing over 13,000 members. Speech pathology is a self-regulated health profession through Certified Practising Speech Pathologist (CPSP) membership of Speech Pathology Australia. The CPSP credential is recognised as a requirement for approved provider status under a range of government funding programs including the NDIS.

As the national body regulating the quality and safety of speech pathology practice in Australia, Speech Pathology Australia is also well placed to monitor and progress workforce developments and initiatives. The Association also manages the formal complaints process for the profession and can, if necessary, place sanctions on practice for any member who is demonstrated to contravene the Association's Code of Ethics.

## The Role of Speech Pathologists

Speech pathologists work to give people with disability a voice and connect with others in an accessible and meaningful way, assist in teaching the social communication skills required to participate in different environments, and reduce the impact of swallowing or feeding difficulties experienced by individuals and their families or support networks across the lifespan and all life activities.

Speech pathologists are the only professionals with the knowledge and skills required to comprehensively assess the core communication, speech, language, social pragmatic and eating and drinking difficulties associated with disability. The speech pathology assessment process involves multiple assessment sessions as the speech pathologist observes and assesses the individual in a range of contexts (for example, clinic, home and/or educational setting) and with a range of communication partners (e.g., family, peers or strangers). This will often include a standardised assessment and a comprehensive report addressing all areas of communication and eating/drinking.

## About communication disability

The Australian Bureau of Statistics' 2015 Survey of Disability, Ageing and Carers (SDAC), estimated that 1.2 million Australians had some level of communication disability, ranging from those who function without difficulty in communicating every day but who use a communication aid, to those who cannot understand or be understood at all.<sup>1</sup> Some people have problems with their speech, language and communication that are permanent and impact on their functioning in everyday life.

Difficulties in speech, language, fluency, voice, and social communication can occur in isolation or the person may have difficulties in more than one area and can negatively affect an individual's academic

---

<sup>1</sup> Australian Bureau of Statistics (2017) Australians living with communication disability.  
<http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features872015?opendocument&tabname=Summary&pr odno=4430.0&issue=2015&num=&view>

participation and achievement, employment opportunities, mental health, social participation, ability to develop relationships, and overall quality of life.

Communication disabilities can arise from a range of conditions that may be present from birth (e.g., Down Syndrome or Autism), emerge during early childhood (e.g., Developmental Language Disorder, stuttering, severe speech sound disorder), or during adult years (e.g., traumatic brain injury, stroke and head/neck cancers, neurodegenerative disorders such as Motor Neurone Disease) or be present in the elderly (e.g., dementia, Alzheimer's disease, Parkinson's disease). The prevalence and complexity of these disorders increase with age as both communication and swallowing functions are vulnerable to the natural ageing process; therefore, with an ageing population, prevalence and subsequent demand for supports will increase.

## **Communicative participation**

Communicative participation can be defined as 'taking part in life situations where knowledge, information, ideas or feelings are exchanged'<sup>2</sup> and measured by the ability to successfully send and receive messages with all communication partners and in all contexts in which communication occurs.

Communicative participation may take the form of speaking, listening, reading, writing, or nonverbal means of communication<sup>3</sup> and may take place for a defined social goal (e.g., establishing relationships), for a function/role (e.g., job-related), and/or in a particular context (e.g., in a restaurant or government service agency such as Centrelink).

## **Communication access**

Communication access can be simply defined as being 'when everyone can get their message across'.

It is similar to the concept of providing 'kerb cuts' for communication. Kerb cuts make it possible for people who are in wheelchairs to access their physical environment. Similar to mobility access, communication access involves the provision of the necessary environmental supports for people with communication disability to access the community and mainstream services by being able to communicate effectively. In the same way kerb cuts improve physical access for everyone, activities to promote communication access for people with communication disability can also benefit a range of other people who have difficulties with spoken or written communication (such as people with English as a second language and people with low literacy).

Communication access is a prerequisite for participation in our communities by people with communication disabilities. Supports for communication access and participation are provided by, under the direction of, or with input from speech pathologists, and draw on the knowledge and theoretical frameworks for the profession, including the World Health Organisation's International Classification of Functioning, Disability and Health. Communication accessible environments are critical if individuals with communication disability are to engage in and use mainstream services and to participate in the community, education and employment sectors.

---

<sup>2</sup> Eadie TL, Yorkston KM, Klasner ER, Dudgeon BJ, Deitz JC, Baylor CR, Miller RM, Amtmann D. Measuring communicative participation: a review of self-report instruments in speech-language pathology. *Am J Speech Lang Pathol.* 2006 Nov; 15(4):307-20.

<sup>3</sup> Eadie T. et al, Measuring Communicative Participation: A Review of Self-Report Instruments in Speech-Language Pathology, *Am J Speech Lang Pathol.* 2006 Nov; 15(4): 307–320



## Ongoing issues Speech Pathology Australia has identified:

### 1. Systemic agency issues

#### Frequent changes to the scheme

Despite the scheme being in its ninth year, it is far from stable. Changes are frequently made by the Agency across multiple aspects of the scheme, including compliance, pricing, billing procedures and what is covered under a participant's plan. These changes can (and do) occur at any time and are most often released with little to no notice before they must be implemented, creating significant challenges for providers.

Our members report that this constant shifting of parameters result in extensive administrative burden to update service agreements and NDIS processes within their businesses. There are multiple reports of experienced private practice owners having to employ additional administrative staff, purely to manage the NDIS burden. Speech Pathology Australia members have also expressed in surveys that this 'plane being built as it is flown' approach causes unnecessary stress and uncertainty when providing services to NDIS clients, particularly in regards to compliance.

"As a NDIS registered provider I have had to employ an extra full time admin person, therapy staff spend a large amount of time on NDIS paperwork, we have outstanding payments that my admin has spent hours on the phone and via email chasing, I personally have had to reduce my caseload from 4 days per week to just 2 so that I can stay on top of all the NDIS requirements."

This impacts upon the willingness of providers to register, and contributes to the thin market for therapy supports, particularly for Early Childhood. The weight of responsibility for ensuring that all changes are implemented as quickly as required, and constant monitoring for these changes is entirely upon the provider and requires significant vigilance. Whereas un-registered providers can for the most part run their businesses in a more stable manner, registered providers are beholden to the ever changing requirements and processes of the NDIA in addition to the standard requirements for speech pathologists as an already well regulated profession. It should also be noted that the Association is also unable to receive answers regarding issues affecting our membership, due to not being a registered provider.

"Within my work hours I can see clients and earn income to support my family OR do the paperwork and set up policies and procedures and all the other matters required by the NDIS BUT I cannot do both."

"The forever changing rules around pricing, travel, cancellations and now the safeguard commission have forced us to let our registration lapse. It's not feasible for small businesses [who] are not predominantly NDIS providers"

#### Lack of transparency and communication with the sector

The issues described above are compounded by the lack of transparency within the agency, which at times appears to border on obfuscation. Major changes that have direct impacts upon providers and participants alike are implemented without any lead time or prior information. The rules shift frequently, but then are not communicated to the sector, placing the onus on the provider to notice a shift in wording, change their processes or documents and communicate this to the participants they work with.

Consultation with the sector is often piecemeal in nature, and frequently the Association has been invited to a stakeholder consultation, only for there to be limited opportunity for change or influence over what is being suggested. For example, regarding the independent assessment process, several peak bodies were asked to give feedback on this process, only to discover that the assessment tools had already been determined, and group members were not able to have input into this critical process that would significantly impact upon participants. This sequence of consulting only after a decision has been made or

is already in process defeats the purpose and is not in the spirit of co-design, as it is simply informing the sector of what is going to occur, rather than truly allowing feedback to be considered.

Communication with participants is also particularly poor, and in conjunction with an overly complex system, providers must engage in extensive unpaid work to support participant's navigation of the system. For instance, plans are not written in accessible language and are most often unwieldy documents that are difficult to understand - regardless of whether the participant has cognitive or literacy difficulties, or comes from a culturally and linguistically diverse background.

One regularly occurring example that causes significant and unnecessary difficulty is communicating how a participant is managed. This is not clearly explained to participants, and their understanding is not ensured by NDIA staff, therefore frequently agency managed participants are engaging unregistered providers, because they do not understand the system. This leaves the provider out of pocket for the services that have been provided, as the families are unable to pay for this service themselves. This also occurs with plan managed clients believing they are self-managed, and not understanding that they need to independently source a plan manager.

"Clients often don't understand the terminology, and have difficulty understanding how payments are made. Often providing mis-information as a result of misunderstanding or language issues. We have had cases of payments/ accounts exceeding \$3000 waiting for payment from plan management providers. Often as a result of client indicating that the accounts are "Agency managed". Not enough time is being spent with [planners] running through the terminology and as service providers we are left spending hours on end explaining everything to families when we don't have the time to do so (out of session)."

The enormous frequency of these difficulties resulted in the Association developing its own document to explain the differences between the plan management types for speech pathologists to provide to participants. To date no document of this kind has been developed by the NDIA. Additionally, there are no guides to being plan managed, or agency managed for participants, only self managed, and this is not communication accessible.

### Inadequate staffing

In 2017 the Productivity Commission, as part of its investigation into the costs of the NDIS, suggested that the Agency itself would take up 7-10% of the overall operating budget of the scheme in order to operate effectively<sup>4</sup> and it was suggested that there would be 10,500 public sector staff employed by 2019<sup>5</sup>. Unfortunately the NDIA continues to run drastically under these estimates, employing only 4,852 public sector employees (as at December 2021<sup>6</sup>) to the detriment of the quality of their services. For example, the original intention of Local Area Co-ordinators (LACs) was to link participants in to supports within their community<sup>7</sup>, however due to taking on more duties within the planning process (as a result of the lack of planners), this is simply not possible.

It is unclear as to exactly why the Agency does not simply employ more public sector staff. It seems counterproductive to running a national multi-billion dollar scheme that affects the lives of 500,000 people to so severely limit the number of people able to implement it. It also affects the financial sustainability of the scheme to employ so many labour hire staff (sitting at 1,530 at December 2021).

Under-staffing also has negative impacts upon the staff that are employed. In the Joint Standing Committee's hearing regarding the NDIS workforce plan, evidence was given that NDIA staff are significantly over worked, with high levels of burn out, and people with disability employed by the Agency

<sup>4</sup> <https://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs-overview.pdf>

<sup>5</sup> [https://parlinfo.aph.gov.au/parlInfo/search/display/display\\_w3p;adv=yes;db=COMMITTEES;id=committees%2Fcommint%2F25062%2F0006;orderBy=customrank;page=0;query=NDIS%20Dataset%3AReportInt.comJoint%20Dataset\\_Phrase%3A%22commint%22;ec=14;resCount=Default](https://parlinfo.aph.gov.au/parlInfo/search/display/display_w3p;adv=yes;db=COMMITTEES;id=committees%2Fcommint%2F25062%2F0006;orderBy=customrank;page=0;query=NDIS%20Dataset%3AReportInt.comJoint%20Dataset_Phrase%3A%22commint%22;ec=14;resCount=Default)

<sup>6</sup> <https://www.ndis.gov.au/media/4063/download?attachment>

<sup>7</sup> <https://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-executive-summary.pdf>

especially impacted. It was described that this results in cutting corners regarding planning, so that plans are automatically rolled over, or processes not followed as there aren't enough staff or time to follow standard procedures<sup>8</sup>.

It is highly likely that this will worsen with the advent of the participant planning guarantee and associated key performance indicators with planning timelines. The NDIA as an employer must look at workloads, and appropriate staffing levels as a matter of urgency, given the lack of capacity for current staff to enact the responsibilities of their original roles.

#### Limited knowledge of disability

Speech Pathology Australia has on several occasions highlighted to this Committee, in both written submissions or at public hearings, our concerns about the lack of knowledge and understanding of disability displayed by many NDIA planners and its impact on NDIS participants. Due to the lack of transparency discussed above, it is unclear what training NDIA staff receive, however it appears from the inconsistency of decisions, and reports of inappropriate remarks that it is severely inadequate.

One member reports:

[My client was] rejected. Needed a new report from Paediatrician stating that he still has Downs Syndrome (6 month wait and \$500 here). Another client- 19 years old with Profound [intellectual disability] recently had funding slashed to \$8000. Mum was verbally told "She's had so much therapy in her life, you'd think she'd be fixed by now".

Another member discussed the behaviour of a planner towards a family attempting to advocate for their child with Autism, who is not speaking, to have speech therapy in their plan:

"[the mother] got told by the planner to get a grip on reality... I believe he even swore at her while doing so. So many planners without the necessary skills trying to make judgements in areas that are outside their knowledge base."

As planners are the nominated delegates for provision of supports in plans, it is imperative that they are provided with the skills, tools and supports, including supervision and support, needed to be able to consider and make informed and appropriate decisions. Planners who are inexperienced with disability or lack knowledge of a condition need to be adequately trained and supported to ensure they are effective in their role.

Due to the staffing issues described above LACs are also fulfilling a role that involves extrapolating the needs of participants and conveying these accurately to planners, as well as discussing what supports might be possible with participants. Given that they can be employed regardless of their previous experience or employment background, this is a significant responsibility. Greater training around disability, cultural sensitivity, and accessibility that is implemented nationally for all planners, LACs and Early Childhood Early Intervention Co-ordinators is desperately needed to ensure they have the knowledge relevant to the decisions they are supporting participants to make as well as enabling more consistent planning decisions. Speech Pathology Australia has offered to consult regarding this training, or provide it directly, however this has not been taken up by the Agency.

#### Lack of alignment with the Commission

Following the inception of the NDIS, the NDIS Quality and Safeguards Commission (the Commission) was established in December 2017 to ensure the independent governance of NDIS providers and quality and

---

<sup>8</sup>[https://parlinfo.aph.gov.au/parlInfo/search/display/display\\_w3p;adv=yes;db=COMMITTEES;id=committees%2Fcommjnt%2F25062%2F0006;orderBy=customrank;page=0;query=NDIS%20Dataset%3Areportjnt.comJoint%20Dataset\\_Phrase%3A%22commjnt%22;ec=14;resCount=Default](https://parlinfo.aph.gov.au/parlInfo/search/display/display_w3p;adv=yes;db=COMMITTEES;id=committees%2Fcommjnt%2F25062%2F0006;orderBy=customrank;page=0;query=NDIS%20Dataset%3Areportjnt.comJoint%20Dataset_Phrase%3A%22commjnt%22;ec=14;resCount=Default)



safety of services for participants. As a regulatory body, it is required to be completely autonomous from the NDIA, however there is also a lack of communication and alignment between the two, which has significant impacts upon participants and providers alike.

Prior to the creation of the Commission, registration of providers occurred through the NDIA, and they continue to be responsible for payment and billing practices. The process of transferring registration to the Commission was meant to happen automatically, and despite varying lead times for different states and territories so that this did not occur all at once, there were numerous administrative errors. Several Speech Pathology Australia members reported being registered as a completely different professional, such as an art therapist or counsellor. Members found it very difficult to establish how these errors occurred, and how to have them altered quickly so that it did not affect their service provision and billing.

However, the poor communication between the Commission and the Agency is most apparent in regards to the new dysphagia standards that commenced on 15 November 2021. Lack of alignment has meant that the necessary processes have not been put in place by the Agency to allow for the corresponding changes to services for participants. Specifically, the new standards mean that support workers will be required to have additional training, and in some instances organisations providing mealtime supports will need to be registered for that specific high intensity skill module.

This has a knock on effect to participants who will potentially require more highly skilled support workers who have completed the required training and can actually charge a higher rate under completely different line items. As a result, participants may need additional funds placed within their plan for an updated mealtime assessment, training of new support workers and to employ support workers at the different rate. Organisations will most likely need to rescind existing service bookings and create new ones, which may not be possible until the changes are made from the NDIA to the participant's plan. Members are also reporting that some organisations are delaying completing mealtime assessments in order to delay having to register within another category.

This is a huge logistical issue, and one that has the potential to affect thousands of participants, on a daily basis, in a very significant way. Speech pathologists are key stakeholders in this process, as a diagnosis of severe dysphagia would trigger the need for a review, however the Association was informed of the changes at the same time as the general public. The changes were in effect immediately, and the Commission have not responded to requests for a meeting, or the provision of specific information sessions for speech pathologists working in the sector.

When the Commission was asked for clarification regarding whether those who were not registered for the relevant high risk category would be required to gain registration prior to providing mealtime support for identified participants, they responded that decisions around the level and types of support are the responsibility of the NDIA, and they do not have a role in those decisions. Nevertheless, the rules that they have put in place- seemingly without notifying or working with the NDIA- directly impact these decisions and need for these supports. Strong communication between these two bodies and alignment of processes/changes, with lead time to ensure smooth roll out is desperately needed to lessen the impact upon participants.

## **2. Assessments and equity of access**

### Inconsistent access & planning decisions

Speech Pathology Australia has noted significant inequity for people with complex communication needs in accessing the NDIS, seemingly due to a boundary on the provision of funding within the communication domain. Speech Pathology Australia has engaged in direct advocacy with the NDIA around specific lifelong conditions that affect communication as the primary domain, such as Childhood Apraxia of Speech (CAS) and Developmental Language Disorder (DLD). Whilst Agency representatives have acknowledged these

communication disabilities within meetings with the Association, there continues to be significant variation in access decisions for these diagnoses, particularly for those over the age of 7.

A member discusses a recent example:

"I am working with a young boy with DLD. As he has just turned 7 he received an eligibility reassessment letter after only recently having a plan review and implementation. I wrote a letter stating his diagnosis of DLD and going into detail about what this means and how it affects him and will affect him. We then received a letter confirming his ongoing eligibility and they completed yet another plan review in the last few weeks, only to have NDIS send another eligibility reassessment letter (the same one). Mum called and the NDIS representative told her that DLD isn't considered a permanent disability."

Additionally, access decisions for participants with other impairments that are often communication specific, such as stuttering and those with cleft lip and/or palate are also negatively impacted by a reported attitude amongst NDIA staff that it is 'just' communication. Communication is a basic human right, however difficulties in this domain can also impact upon almost every other domain within the NDIS disability criteria, including social interaction, learning, self-care and self-management. Communication disabilities should therefore be recognised by the NDIA and training and consistent information provided to Agency staff.

Furthermore, the Association has long held the view that the suggested 'postcode lottery' of planning amounts is not dependent purely upon geography, but also deeper societal issues, and a lack of accessibility. Reports of inconsistency between planners are a common complaint amongst our members and participants who contact the Association, who frequently identify that it is the families or participants with greater capacity to advocate for themselves who obtain greater plans that meet their needs. Participants and families who are from culturally and linguistically diverse backgrounds, have complex communication needs or low literacy, or those parents of children with a disability who have a disability themselves are consistently disadvantaged by an overly complex system.

It is imperative that the communication needs of the person with disability (and their families) are taken into account as part of any and all NDIS processes. This must occur at all levels, for example in ensuring that the planning process, including all information relating to the plan, and how they might utilise it is communication accessible; and in provision of the necessary communication supports for the person to express their choice/s in their preferred modality.

#### Inappropriate assessments

The estimated 1.2 million Australians who have some level of communication disability already experience a range of barriers to participation in civic, political and economic life. The Association has long advocated for recognition of communication access being as important as physical access to people with disability if they are to participate fully in all aspects of society. Therefore, it is extremely concerning that functional assessments used by the Agency do not contain questions relevant to the communication difficulties that participants might experience, and are not communication accessible.

Additionally, the Association (and other peak bodies) raised concerns during the discussion around Independent Assessments that many of the proposed assessments (including the WHODAS and PEDICAT that are already in use) were not fit for purpose, or designed to be used to correlate to funding levels. Whilst the Independent Assessments process is no longer going to be implemented in its suggested form, following sector wide outcry, the NDIA has stated that they are planning to create some type of replacement assessment process.

Due to the aforementioned lack of transparency it is unclear what this will be, however given the previous tight timeline for roll out and lack of co-design with the sector, Speech Pathology Australia would highlight this as an issue where drastic improvements are needed. Allied health professionals, along with people

with disability and their advocates should be involved from the stage of first principles to ensure that the negative and difficult experiences in the Independent Assessment trial are not repeated.

#### Questioning provider reports

There are consistent accounts of NDIA staff questioning the expertise of experienced allied health professionals in their reports. Families have also discussed with members that NDIA staff have disclosed they have not even read the reports, or that they have been lost. It is concerning that planners are making decisions about how much support for therapy is provided and what would be needed in NDIS plans in order for the participant to achieve their goals, without reference to the advice from technical advisors and allied health professionals (including speech pathologists).

“I had someone making the final financial decision on services after the planner had submitted their report call me to justify my request for speech therapy and then wanted to know what speech paths and OTs do.”

It is also distressing for the highly trained speech pathologists who may have known the person or participant applying for considerable time to have their professional opinion questioned by NDIA staff who frequently have limited knowledge of disability and have never met the participant. This is worsened when there may have been many hours invested in the assessments and applications for funding which may go unpaid due to a perceived ethical obligation to the client.

“The entire process takes away from our professionalism - why are we asked to provide our professional opinion when completely uninformed, unprofessional and uneducated people (in our profession - in one case we were dealing with a planner who was a motor mechanic) decide and make judgements about our professional opinion? Most of this is expected to be done unfunded -this is not a sustainable model of provision. We cannot bear to see our families so stressed and unsupported.”

“I had a situation with a brand new planner who had just finished a uni degree in human resources, was 21, and told the family that there was no need for OT and SP because they ‘did the same thing’. This child was having meltdowns at school where his whole classroom had to be evacuated because the other children were at risk. This was right before Christmas, and this planner put them (and me) through hell, demanding more and more supporting information and documentation, because they didn’t understand Autism. I have worked with this family for 3 years under NDIS, but still on Christmas Eve I had to write a third report, free of charge as they had run out of funding by that point, just explaining that yes, SPs do work with children with Autism, simply because the NDIS planner doesn’t understand Autism, or different allied health professions.”

### **3. Reasonable and necessary supports**

#### Undefined concepts

One of the most critical aspects of the scheme, and one that frequently determines the type of supports a participant is able to access is the definition of reasonable and necessary. Unfortunately, it is also one of the most opaque concepts, that is poorly explained by the Agency, despite it being a common reason for denying supports within a plan. To combat this, in 2021 the NDIA published a new section of the website called ‘Would we fund it’ with several case studies and scenarios.

These case studies are still very complex, are not communication accessible, and do not always clearly align to the reasonable and necessary criteria<sup>9</sup>. The website is generally difficult to navigate as often they use technical terms such as ‘enteral nutrition’, and have different scenarios listed under their funding terminology, e.g. ‘Consumables’ rather than simple terms like ‘nappies’ or ‘formula’. The main issue

<sup>9</sup> <https://ourguidelines.ndis.gov.au/how-ndis-supports-work-menu/reasonable-and-necessary-supports/how-we-work-out-if-support-meets-funding-criteria/does-support-meet-reasonable-and-necessary-criteria>

however is that these appear to be justifications that planners would use to approve or refuse funding for very specific things, there is still limited information regarding what 'reasonable and necessary' actually entails.

The lack of a clear definition, and clear principles underpinning decision making around what constitutes reasonable and necessary significantly affects participants being able to receive the supports they have requested. It also circumvents the ability of allied health professionals to write supporting documents addressing these criteria. Policy priority two in the Australian Government's new National Disability Strategy is "*The NDIS provides eligible people with permanent and significant disability with access to reasonable and necessary disability supports*"<sup>10</sup> Therefore it is reasonable to expect greater clarity around what constitutes reasonable and necessary supports and for them to be funded by the NDIS.

### Inappropriate application of criteria

At present the limited transparency around reasonable and necessary supports, and associated confusion means that certain aspects appear to be over zealously applied. This is frequently reported around the ongoing nature of some supports, and the concept of 'value for money' where the clinical opinions of professionals are questioned, despite NDIA staff not having knowledge of certain principles that might be considered foundational and obvious.

One member discusses a case where in order to prove value for money for a low cost app (less than \$300) they were asked to provide significant clinical information regarding options they did not intend to use. Effectively they were asked to estimate how long it would take to teach a language they weren't planning to use to multiple people.

"We are applying for an iPad based AAC. We needed to trial 2 other AAC's (sign and PECS). We need to show that the iPad option is value for money... The LAC says we need to work out how many hours it would take to teach the child to be a "proficient" signer as well as parents, educators etc."

Another member discusses a situation that has subsequently been escalated to the Administrative Appeals Tribunal (AAT) around the lack of understanding about the importance of speech therapy to build the capacity of communication partners, and it not being a once off support.

"Just having access to a comprehensive communication system is not the same as a wheelchair... or more accurately a microwave... where if you show the communication partners once you are set until the next system comes along, and therefore should not spend extra time coaching the communication partners in supporting and expanding communication.

[I] have provided references on efficacy of communication partner training for individuals using AAC but questions are being asked of why this is required if it was done last plan!"

In particular the over extension of the 'most appropriately funded by the NDIS' aspect does not effectively take into account the intersection of the NDIS with other sectors. For example, once there is any mention of a person with disability needing to access the health system, it is reported that the immediate response is that the NDIS is not responsible to provide any supports. There are reports including from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (RCPWD)<sup>11</sup> that poor integration can have significant impacts upon the participant's quality of care and wellbeing if there is not appropriate handover and transition between the health care system and community based supports. The NDIA needs to develop processes to help planners to understand their responsibility to fund core supports for people with disability where they face additional barriers or have additional needs in order to participate

<sup>10</sup> <https://www.disabilitygateway.gov.au/document/3106> pg 20

<sup>11</sup> <https://disability.royalcommission.gov.au/news-and-media-releases/royal-commission-details-violence-abuse-neglect-and-exploitation-people-disability-interim-report>

in an episode of care within the health system. This is separate from the responsibility of the health system to fund health services and supports for people with disability just as they would for any other citizen.

#### Evidence based practice

The Association would like to draw the Committee's attention to a safeguarding issue that has been reported by several Speech Pathology Australia members. At present there is no requirement on behalf of the NDIA for providers to provide evidence-based practice, or provide evidence to support certain treatment claims. Qualified allied health providers are required to use evidence to inform practice and not make unsubstantiated claims regarding the benefits of services they offer, as they are bound by their relevant codes of conduct, codes of ethics, and requirements of governing bodies such as the Australian Health Practitioner Regulation Authority (AHPRA) and Speech Pathology Australia. However, non-qualified service providers are not subject to any similar oversight or regulation. The NDIS code of conduct, which does apply to all providers, is silent on the subject of evidence-based practice and advertising.

This puts participants and families, particularly those who are more vulnerable, at risk of wasting their funds on non-evidence based, and in some cases potentially harmful practices due to unfounded promises and emotive advertising. There is also an opportunity cost in that they may miss out on therapies that are evidence-based and may have been of assistance in critical early intervention periods while accessing inappropriate services.

The Association would therefore suggest an expansion of the NDIA safeguarding processes and/or fraud taskforce to include instances whereby a non-registered provider, who does not have any qualifications or is otherwise not subject to any other regulation, is still subject to complaints raised by a participant or a qualified professional. Additionally, a code of conduct regarding advertising to NDIS participants to be developed, potentially based upon the National Law, AHPRA guidelines, Speech Pathology Australia's Code of Ethics - Advertising policy, and endorsed by the Australian Competition and Consumer Commission.

### **4. Increased appeals & need for advocacy**

#### Lack of advocacy supports

Participants and their families express that trying to gain access to the NDIS and requested funding in their plans is a 'battle'. Speech Pathology Australia members report that despite being already stretched clinically, with large caseloads, they are now often playing the role of advocates, writing review letters about whether a participant with a disability has tried all available treatment options, gathering evidence about whether their disability is disabling enough to gain funding, and then assisting families to apply to the AAT.

Certainly, it appears from the figures released within the quarterly reports that the numbers of decisions being taken to AAT are increasing, particularly across 2021. In June 2021, only 0.78% of active participants were appealing decisions at the AAT, this doubled to 1.55% in six months and only reflects participants, not appeals regarding access. By December 2021 there were 1,910 active appeals regarding the NDIS made to the AAT<sup>12</sup>, indicating that participants' dissatisfaction with NDIS decisions is increasing. There is now a specific page on the AAT website dedicated to information for NDIS participants<sup>13</sup> and a dedicated NDIS appeals service<sup>14</sup>.

It should be noted that the NDIA will not fund advocacy services or supports, up to and including denying funding for support co-ordinators to attend planning meetings. As discussed in the RCPWD, the NDIS

<sup>12</sup> <https://www.ndis.gov.au/media/4063/download?attachment>

<sup>13</sup> <https://www.aat.gov.au/steps-in-a-review/national-disability-insurance-scheme-ndis/assistance>

<sup>14</sup> <https://www.dss.gov.au/disability-and-carers/programs-services/for-people-with-disability/ndis-appeals>



system in itself does not support self advocacy well<sup>15</sup> meaning that it is frequently those participants or potential participants who have strong family supports, or external parties able to advocate on their behalf who are able to lodge successful appeals.

It is important to acknowledge that the appeals process is lengthy, complex, and can also be traumatic for people with disability and their families. The majority of the issues with the process are discussed extensively in the August 2021 submission by 20 different advocacy organisations to the Committee for their interim report on the enquiry into General Issues Affecting the Implementation and Forecasting of the NDIS (Submission 83<sup>16</sup>). Therefore, the Association would like to support the issues raised within Submission 83 and add the issue of communication accessibility.

Frequently those who use augmentative and alternative means of communication are denied access to their right to complain, particularly when their communication mode is non verbal. The appeals process is not communication accessible, and there are limited avenues for participants with complex communication needs to be given the opportunity and supports to directly discuss what they may wish to change about their plan or appeal. This is a denial of their rights, and the appeals process, including being able to complain about the NDIA and their plan should be modified to be communication accessible, including Easy English as a minimum.

### Review processes

Whilst key performance indicators with regard to suggested timeframes have been proposed as part of the participant service guarantee, presently there is no requirement for the NDIA to conduct an unscheduled plan review in an expedient manner. They must respond to the request for a plan review in regards to whether they will or will not conduct one within 21 days, however there is no timeline as to when the review itself must occur. The new participant service guarantee has this listed as 28 days for a plan variation, but 60 days for an unscheduled plan review. This seems to be an unreasonable penalty to be experienced by participants when requesting rapid reviews of NDIS plans as a result of changes to a person's care needs – including to enable them to get to and safely and effectively participate in necessary health care. They are also unable to escalate a matter to the AAT until the internal review has been completed.

Additionally, there has been requests for some time to have the option of a so called 'light touch review' for when there are minor errors in the plan, or an administrative error on the part of the NDIA (such as placing the plan under the incorrect management type). This was misconstrued within the proposed changes to the NDIS legislation to allow for changes to the plan to be made without the participant's consent. This would be inappropriate, and rather the process that has been requested - namely a light touch review that does not require a full plan review but does require participant consent - should be implemented.

## **5. Assistive technology**

### Unreasonable delays & hidden costs

Speech Pathology Australia members consistently raise concerns about the length of time participants are having to wait for their assistive technology to be approved. Communication is a basic human right, and as per article 21 of the United Nations Convention on the Rights of Persons with Disability<sup>17</sup>, participants have a right to be able to communicate in the form of their choosing. Significant delays in the approval and receipt of assistive technology for augmentative and alternative communication (AAC) denies the participant

<sup>15</sup> <https://disability.royalcommission.gov.au/publications/interim-report>

<sup>16</sup> [https://www.aph.gov.au/Parliamentary\\_Business/Committees/Joint/National\\_Disability\\_Insurance\\_Scheme/GeneralIssues/Submissions](https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/GeneralIssues/Submissions)

<sup>17</sup> <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-21-freedom-of-expression-and-opinion-and-access-to-information.html>

access to communication and limits their freedom of expression. The Association has multiple reports of cases of participants waiting nine months or more to receive their vital assistive technology, during which time they may not be able to communicate.

“For example, since March I have been attempting to organise an augmentative communication system for a child with a degenerative condition. I have submitted the same information at least 4 times. Just last week [November] it was approved and now we wait for the order to be filled. In the meantime the child is frustrated!”

There are no monitoring processes for either participants or providers that provide tracking information regarding where an application sits, however there appear to be two main bottlenecks creating lengthy delays for assistive technology (AT). Firstly, in the approval for the supports to be included within the plan. This is due in no small part to the complexity of the process.

There are four levels of assistive technology within the NDIS, often grouped almost interchangeably into two levels, but three budget designations. Levels 1&2, low cost and low risk generally fall under \$1500 and therefore do not require an assistive technology request, then Levels 3/4, which are high risk or high cost, generally covering the mid cost budget range of \$1,501- \$15,000 and high cost of \$15,000+.

High cost AT (and until very recently mid-cost as well) requires a provider to submit an assistive technology request form. This was also often required for items that were deemed ‘high risk’ even if they were low cost, a classification that was frequently applied to any communication device or app, regardless of cost. It should be noted that the general AT form is 18 pages long in its blank state, and members report that they will spend a minimum of 5-6 hours completing it, or ensuring the required information from the form is included within their report. This can often be at least partially unpaid, as there are insufficient funds included within the plan to cover the amount of time required to complete the request process.

“We have had excruciating experiences with some planners trying to get assistive technology budgets approved for children who are non-verbal and who require a communication system to be put in place. In some cases we have spent 10 hours writing up letters/ reports of support after our initial (detailed and more than adequate support letters) have been submitted and knocked back, up to 4 times!! This level of work is unsustainable and I don't feel that planners have a realistic expectation of the time commitment or the demands they are placing on service providers. We have had to wear the brunt of this cost as we feel terrible charging families for this (other than our usual report writing times).”

There are also accounts of an expectation, applied inconsistently, that the participant will have trialled multiple different options. This is problematic within the AAC space for several reasons. Many of the technology items are applications that are tablet based, and are purchase only, without any free, or even paid trial options. Even if the programs have a trial option, there are no opportunities to trial the tablets themselves. Members report that the best way around this is for the speech pathologist working with the client to have a version of the program on a tablet to then be able to trial with participants in sessions themselves- a solution that must be self funded by the therapist.

For more expensive pieces of equipment, some companies may offer trial periods, however these are limited, often have long waiting lists and frequently have a cost. Trial costs are reported to rarely be included within plans, disadvantaging those participants who cannot pay out of pocket. Additionally, as each piece of equipment or aspect of the request must be trialled there is a complex organisational process to co-ordinate trial periods for different technology (for instance, a communication device, and then the eye gaze equipment to access it), which may simply not be possible, particularly with current postal and delivery delays. Often this co-ordination falls to the treating provider, and is frequently unpaid.

Whilst it is reasonable to expect that technology will be recommended based upon clinical evidence of its benefit to the client, with the complexities involved, it may be that the ‘best’ option is the only one that is trialled, and if it is successful, it is reasonable to expect it to be funded. Instead there are multiple accounts

of AT being denied because only one trial was conducted, or the provider was not able to provide extrapolated clinical information about hypothetical options.

“The time it takes to review and approve assistive technology is exorbitant and can put the person at risk. Assistive technology that has been recommended as the optimal tool to support communication is often declined due to ‘cheaper options’ available, even though the cheaper option hasn’t been recommended for a reason.”

“[I’m experiencing] significant difficulties with the process of Communication AT applications (from a very experienced clinician who has been successful previously in applications.). Applications sent back with requests for increased trialling of equipment or trialling of alternate equipment over and above what was previously accepted.”

This reflects the lack of knowledge of NDIA staff, and is often seen when speech pathologists request AAC devices- either they are told that the NDIA does not fund iPads (which is incorrect<sup>18</sup>) or alternatively that they will *only* fund an iPad, against the clinician’s recommendation for a dedicated device. This issue has been raised numerous times with the Committee and the Agency themselves, but continues to be experienced by Speech Pathology Australia members.

“I had an 11 month fight to get a client a dedicated robust device when NDIS insisted they should have an iPad instead (even though I provided extensive photographic and receipt evidence that the client regularly damaged iPads).”

“We have NDIS AT Advisors returning AT forms with “try an iPad”. Even getting a trial of a dedicated device is becoming difficult - concern regarding the timeframe between plan, service and then approval of AT - in WA in the old system it was 2 weeks, now on average it is 6 months”

This lack of understanding regarding technology is frequently resulting in an ongoing combative process for requesting funding for AAC within plans, which contributes to the delays involved as the application must be resubmitted each time, often to a generic email address. These delays can have a domino effect as they mean that originally submitted quotes expire, requiring new quotes to be gathered, and potentially a whole new application to be submitted. It also costs significant time for the speech pathologist to provide ongoing information, which can further affect the participant’s budget.

“It has already cost more than the device in \$/time to write the AT application, and now it’s going to cost more than that again to fight the decision...The additional stress caused to families, and the additional wait time for this child to receive their AAC device (he was distressed for some time when the AAC trial finished) is not okay.”

“This year I have submitted 3 applications on the: 27/4/21, 30/4/21 and 2/6/21. To date [late August], none of these applications have been processed and no decision has been made. I called the NDIS on 2/7/21 to enquire and was told all documents had been uploaded to the correct location and no further information was available. I called again today and spent nearly 2hours on the phone to 3 different staff at the NDIS to be told that all documents had been sent to the regional offices and were “in progress”. For all 3 clients, their quotes are now redundant as Apple has released next generation devices and stock of the devices requested are disappearing/no longer available. Furthermore, the size of the new devices are slightly different and as yet, most manufacturers of protective cases/accessories have yet to release updates that will fit.”

These delays can be particularly detrimental for participants with degenerative conditions or changing needs, as it can significantly impact upon the possible benefits of the technology.

“One particular client, with degen[erative] disease: recommended AAC, funding available however needed to be released. Unable to be released to my company because we are not AT provider registered. Other company was registered as AT provider, however they were not granted access to

---

<sup>18</sup> <https://ourguidelines.ndis.gov.au/would-we-fund-it/assistive-technologies/smart-devices-tablets>

funds. When they were, they were only granted funds to supply iPad and not AAC app. Recommendation was given in February. They have only just been provided with a solution from NDIS [in November]. Client's voice has changed completely and hopes of voice banking are now gone. Client is understandably livid, likely to have only 12 months use of the device now."

The second major bottle neck being reported is the delay in having the funding actually placed within the participant's plan after the assistive technology is approved. It appears that if the assistive technology request and information can be submitted at the time of the plan being developed it can assist in shortening this process, however many participants require funding in order to access a speech pathologist to provide this information in the first place. If the participant does have funding within their plan for an AT assessment and report, they can still experience the abovementioned delays, which are compounded if the funding is placed under the wrong area, or type of management.

"I have recently submitted AT applications for another 3 participants. For one, I have written the AT application in full prior to their initial planning meeting in an attempt to stop a repeat happening of my previous experience. This was done pro bono because the family could not afford to pay for the time and they are not yet on a plan."

One member discusses her experience regarding a paediatric participant who had been waiting for four and a half months for their device:

"This is despite me submitting reports and recommendations prior to the plan development...The NDIS staff member I spoke to following my complaint acknowledged the significant impact this delay was having on the child's development and was made aware of the sum of money being spent on a loan device in the interim and the limited availability of this loan. He had promised to have the AT application sorted within 2 weeks – before the loan agreement expired. This expired on the 20th September [3 weeks ago]."

If participants do not have their AT needs accurately reflected within their plan they must ask for a full review of their plan, and in some cases submit a change of circumstances request in order for this review to be considered. As discussed elsewhere in this submission, the NDIA do not currently have any fixed timelines regarding when they will conduct an 'unscheduled plan review', even if the issue with the plan is due to an error made by the NDIA themselves.

Whilst the NDIA often make changes to the AT process and systems in attempts to lessen delays, the frequency of changes and poor communication simply results in further confusion amongst their staff and providers. Furthermore, these changes rarely address the core issues that seem to impact upon the significant delays experienced by participants namely:

- Limited staff available to appropriately evaluate and assess applications
- Lack of a dedicated email address for applications and information regarding them to be sent
- Lack of knowledge regarding assistive technology by the NDIA staff making the decisions as to whether or not it will be funded
- No tracking system or information to allow participants or providers to know how the application is progressing

#### Disadvantage for agency managed participants

The Association would also like to draw the Committee's attention to policies which unfairly disadvantage agency-managed participants in accessing assistive technology. If a client is self managed, they are able to use their funding to purchase recommended or approved AT items, or be reimbursed for items that are determined to be appropriate and meet criteria. This is also the case for the most part for plan managed participants. Although there are some reports of plan managers acting outside of scope and denying that

NDIS funds can be used to purchase recommended AT, generally a participant or provider is able to submit a request for payment for an item and have it reimbursed.

For agency managed participants however, they are only able to purchase assistive technology - regardless of the level of cost or risk- from registered providers. This is particularly problematic in regards to AAC apps and tablet devices- as there are only one or two registered companies that provide these items, and often they must be purchased as a bundle of items. Previously some NDIS registered organisations would assist with the purchase of apps using iTunes cards, however when the NDIA changed their ability to claim an administrative fee for this service, this has for the most part been discontinued.

This has placed further pressure upon registered speech pathologists to purchase the apps or tablet themselves and then seek reimbursement from the NDIA. Similarly to the participants, providers often can not afford this initial outlay, or take this financial risk if there is any delay in the funding being released- particularly for multiple participants on an ongoing basis.

Despite these restrictions being part of the NDIA's own approach to assistive technology, planners are also reported to make decisions that then make it impossible for participants to purchase equipment. For example:

"NDIA managed participant who has AT approved in their plan for an iPad, rugged case and LAMP [communication app]. The planner has not approved the Zytech [a dedicated equipment company] bundle and has said we need separate quotes for each item from other outlets like JB HiFi. Obviously the family cannot purchase from JB as they are not a registered provider."

This unfair disadvantage for agency managed participants should be ameliorated, with all participants able to have their capital budgets be either self or plan managed, even if they are agency managed for all other aspects of their plan.

#### Concerns regarding responsibility for equipment

It has recently come to the attention of Speech Pathology Australia that in the event a piece of prescribed assistive technology should no longer meet the client's needs, the responsibility for replacement of the equipment would lie with the prescriber. This is not dependent upon the reason why the equipment is no longer appropriate, such as a change in the participant's needs or disability. There are also no limitations regarding the length of time since the prescription, or whether the participant is now working with a different therapist.

In conjunction with the significant delays in the funding of assistive technology, this is an unrealistic burden to be placed upon the prescribing therapist. As described above, there may be extensive time between the initial assessment and determination of the most appropriate equipment and the item/s subsequently being able to be purchased. When such lengthy delays are being experienced, it is highly possible that assistive technology may no longer meet the participant's needs particularly young children or those with progressive conditions, creating a higher risk profile for those working with these types of participants.

This policy disadvantages those people with progressive disabilities, who may have fluctuating needs, or those who have more complex factors influencing prescription whereby the Agency is able to deny replacement of their equipment, instead expecting this to be claimed from the prescriber's insurance. The Association has concerns that by having this risk be wholly assumed by the initial prescriber, this will further deter allied health providers from entering the prescriber market, which is already extremely thin.

The Association has grave concerns that this policy, in conjunction with the new change that participants only require a letter of support to purchase equipment up to \$15,000 will place many providers at risk. The complete shift from requiring multiple trials and justification to none, means that there is no



safeguarding process in place to ensure appropriate equipment prescription. Whilst the intent behind this change to the mid cost AT process is to streamline the provision of AT, and lessen delays, this is likely to have significant unintended consequences.

When the low cost equipment process was introduced in 2020 to assist participants to purchase equipment for telehealth services there was an enormous amount of pressure put upon allied health providers to write support letters because participants were informed they were able to get an iPad. In some cases, this was appropriate, but there were reports of numerous cases where participants or families purchased equipment when this was not recommended by an allied health professional, but rather a plan manager or support co-ordinator. Speech pathologists were placed in the very difficult position of being forced to deny the provision of letters that were being demanded in the cases where they had not seen the participant for some time, or they were not receiving telehealth services, as this would be a breach of the Speech Pathology Australia Code of Ethics.

Without parameters around this new mid cost process, and strict training regarding scope of practice for support co-ordinators and plan managers it is feared that there will be a repeat of the 2020 wave of requests, on a grander and more expensive scale. Greater clarification is also required regarding the supports that, due to their level of risk, should still involve an assessment by a qualified allied health professional. It should be noted that as part of a new process there will be 'assistive technology mentors' providing services without a relevant allied health qualification, and therefore no corresponding governance or regulation. Whilst the potential lived experience that these mentors are proposed to have may assist some participants, it is not a substitute for assessment by a qualified allied health professional.

These changes leave participants vulnerable to wasting large amounts of plan funding on inappropriate and potentially harmful assistive technology. Even if the AT is not actively dangerous, there may still be an opportunity cost whereby the participant loses time that could be spent achieving positive outcomes if something more appropriate had been put in place.

## **6. Culturally appropriate supports for First Nations participants**

### Lack of data

The NDIA published their Aboriginal and Torres Strait Islander engagement strategy in 2017 and a progress report in July 2021, with the strategy due to be 'refreshed' during 2022. Akin to the Agency's consultation with the disability sector as a whole, it is unclear as to how consultation regarding the updated strategy is to occur and with whom. It is greatly disappointing to see that frequently consultation and discussion papers put out by the NDIA regarding different topics (e.g. the recent shared decision making and pricing review papers), do not actually ask about these issues in regards to the experience of Aboriginal and Torres Strait Islander peoples. This is a missed opportunity for the specific needs, stories, and ways of doing of First Nations people with disability to be shared, but also limits true consultation from occurring.

Additionally, there is limited evidence regarding how the priorities from the current strategy are being implemented, or their outcomes. It should be noted that the progress reported within the 2021 report is somewhat vague and often outdated, for instance under *Priority 3- Sharing best practice* there is a discussion of a consultation with First Nations people that occurred in 2017, presumably when the strategy was first developed. Therefore, it would appear that there has been no progress or further work being done or reported on in regards to best practice from a First Nations perspective.

In regards to other outcomes, the only data presented is quantitative in the form of numbers and percentages of Aboriginal and Torres Strait Islander peoples participating in social and community activities and employment. It could be argued that these figures do not necessarily indicate positive outcomes, as there is no qualitative data available. What kind of social and community activities? Are they activities that non NDIS participants are also part of (e.g. is this part of their Community way of

doing, rather than reflective of any support provided by through their plan)? Is their employment positive, and fitting with their needs? Is it culturally safe?

If the pure figures are reviewed, it is clear that the outcomes for non-Indigenous 15-25 year olds in regards to participation are outstripping those of First Nations young people. The proportion of Indigenous participants 25 years and over in paid employment has actually decreased on average<sup>19</sup>. Whilst these numbers are not the only metric of success, and indeed not necessarily reflective of success from a First Nations perspective, they are also not reflective of positive outcomes within themselves.

#### Need for specificity and cultural responsiveness

First Nations people often experience 'double discrimination' in regards to underlying racism and bias in addition to the issues related to their disability (e.g., being accused of substance abuse when in fact their behaviour is related to a disability). It must be acknowledged that due to this intersection, First Nations people have specific needs, and the NDIS process should be tailored appropriately, to ensure that services are culturally safe. At present there are reports, including through the RCPWD<sup>20</sup> that despite the specific strategy, in practice there is no focus on culturally responsive practice for Aboriginal and Torres Strait Islander participants or potential participants.

There are issues apparent from the very base levels of the NDIS process, in that they are not accessible. It should be noted that for Indigenous peoples, accessibility encompasses more than just physically having an office they can travel to, but a process that is culturally responsive. Filling in forms, and rigid systems that require families to engage in a particular paperwork trail, in a specific order and time frame are not responsive.

One member submitted a particular case study where she spent over a year attempting to assist her five year old Indigenous client to gain access to the NDIS. This included the access paperwork being lost by the Agency, and written letters being sent to the family several times, despite it being explained that they were not literate. Once the child had been accepted to the NDIS, there was a delay of three months to receive a planning meeting. This was because the family had been deleted from the ECEI partner's list, due to a lack of contact.

First Nations people often have negative experiences with service providers in other areas/systems, and consequently may be wary of engaging with any mainstream services, including the NDIS, therefore the planning process must be tailored to take this in to account. Unfortunately, NDIS system requirements pre-determine service providers to assess participants clinically which excludes and under-values Aboriginal ways of being, knowing and doing implicit within participants needs and context.

Standardised assessments are often grossly inappropriate for First Nations people, and may inflate their disability, or create it where it doesn't exist due to cultural and linguistic difference. Additionally, research suggests that the disability may not necessarily be seen as a disability in Community. It may be socially accepted, in that they are who they are, and the family and community do not wish to change them, but rather they are embraced and supported<sup>21</sup>. In this way the deficit model, integral to the planning system being imposed on the community may be experienced as traumatic.

Whilst there is mention within the strategy of a planning resource developed for use with First Nations people, culturally responsive practice involves tailoring ways of doing that reflect the specific needs and customs of that community. It is not a case of one size fits all, where there can be one resource that is used with everyone. For this process to be truly responsive, it takes time to build trust and wrap around

---

<sup>19</sup> <https://www.ndis.gov.au/media/3445/download?attachment>

<sup>20</sup> <https://disability.royalcommission.gov.au/publications/interim-report>

<sup>21</sup> Lilley R, Sedgwick M, Pellicano E. Inclusion, acceptance, shame and isolation: Attitudes to autism in Aboriginal and Torres Strait Islander communities in Australia. *Autism*. 2020;24(7):1860-1873. doi:[10.1177/1362361320928830](https://doi.org/10.1177/1362361320928830)

supports to get a true picture and move forward with respect for the context of that particular group of First Nations people.

There is a need for localised supports and workers or guides who are familiar with communities, languages, customs, and opportunities for sharing and learning, however there is a lack of Aboriginal and Torres Strait Islander peoples employed by the NDIA. If this is to change, culturally responsive practice must also be embedded within the employment strategies implemented by the Agency in order to engage with local people in a safe way and champion working within the sector as being good for the whole community.

## Recommendations

In summary, Speech Pathology Australia recommends the following:

- The NDIA publish clear and communication accessible information regarding planning, how the scheme works and planning decisions, ensuring this information is consistently provided to participants by NDIS staff.
- The lack of equity around access to the scheme for those with communication disabilities to be addressed.
- The Agency to be staffed adequately to allow staff such as Local Area Coordinators to perform their roles as intended.
- Mandatory training to be provided for NDIS staff regarding disability (particularly communication disability, accessibility, cultural sensitivity) with an emphasis on improved quality and consistency of decision-making during planning.
- Adequate lead time to be given, prior to major scheme decisions and processes being implemented, with opportunities for true consultation and feedback to be provided by peak bodies and other stakeholders.
- Strong communication and alignment processes between the Agency and the Commission need to be established to ensure that rules put in place by the Commission correlate with the necessary NDIS changes
- Allied health professionals should be involved in the development of any assessment protocols from first principles to try and ensure they are fit for purpose
- The clinical opinion and reports of professionals providing supports to the participant should be taken into account and held in high regard by NDIA staff when determining the level of funding within a plan.
- The concept of reasonable and necessary should be defined, with clear, communication accessible examples. When supports are denied within plans, an explanation should be given as to how and why they were not determined to be reasonable and necessary.
- Acknowledgement of the intersection between the NDIS and other sectors, such as the healthcare system with supports to be funded that are appropriate for the participant to ensure effective care.
- Establish a code of conduct regarding advertising of services for NDIS providers
- The NDIS complaints and appeals process to be made communication accessible.
- A 'light touch' review process that still requires participant consent to be created, with a reasonable time frame set for unscheduled plan reviews in line with other NDIS reviews of 28 days maximum.
- The true cost of recommending assistive technology to be covered within participant's plans, including adequate report writing time and trial costs, capacity building supports for families, and an emphasis on best practice assessment.
- Ensure that 'qualified assistive technology assessors' are appropriately skilled and trained to be able to make decisions regarding recommendations made by allied health professionals.
- Core issues regarding the delays within the AT process to be addressed by:
  - Creating a dedicated email address for applications
  - Employing more qualified and knowledgeable staff to evaluate and assess applications
  - Creating a tracking system that is accessible by both providers and participants to track the progress of their request

- That funding for assistive technology be automatically self or plan managed, even for participants who are agency managed for other aspects of their plan.
- Clear delineation of responsibility of providers for equipment is required. There should be a limit regarding the time since prescription, and caveats regarding fluctuating needs and reasonable clinical assessment.
- Training to be provided for support co-ordinators, plan managers and NDIA staff regarding the rules around the new mid-cost process and their scope of practice.
- Develop specific pathways and processes to address the needs of people with disability who are also culturally and linguistically diverse, and First Nations people.
- Develop specific arrangements within a culturally sensitive and responsive planning process to address the needs of First Nations people with disability to enable greater service intensity when appropriate and wrap around supports. This should be co-designed with Community and First Nations people with disability.
- Develop targeted culturally responsive resources for Indigenous peoples, rather than retro-fitting existing resources.
- Ensure that culturally responsive practice is embedded within the NDIS as a whole, including improved employment strategies to specifically encourage Aboriginal and Torres Strait Islander peoples to work for and within the scheme.

We hope you find our feedback useful. If Speech Pathology Australia can assist in any other way or provide additional information please contact \_\_\_\_\_, Senior Advisor Disability, on \_\_\_\_\_ or by emailing \_\_\_\_\_