

Submission
No 249

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL
DISABILITY INSURANCE SCHEME AND THE PROVISION
OF DISABILITY SERVICES IN NEW SOUTH WALES**

Organisation: Speech Pathology Australia

Date Received: 9 August 2018

Speech Pathology Australia's Submission to the

Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales

9 August 2018



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**The Director
Portfolio Committee No. 2 – Health and Community Services,
Parliament House
Macquarie Street
Sydney
NSW 2000**

Dear Sir/Madam

Speech Pathology Australia welcomes the opportunity to provide feedback to the Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales. Speech Pathology Australia is the national peak body for speech pathologists in Australia, representing more than 8500 members (2545 in NSW). Speech pathologists are university trained allied health professionals with expertise in the assessment and treatment of communication and swallowing disabilities.

Whilst the majority of speech pathologists see the immense potential of the NDIS for people with disability, many are reluctant to register as NDIS providers as the scheme's additional time and monetary costs pose a very real risk to the financial viability of many of our members' small (often solo) private practices. The recent Independent Pricing Review's initial recommendations for tiered pricing and travel reimbursement unfortunately did little to help ease our members' concerns. Supporting participant readiness can also see a speech pathologist spending many, again unpaid, hours helping and advising participants and their carers to prepare for planning meetings, access information, explaining documents and helping them to understand their individual plans; this has an emotional as well as financial impact upon providers. Finally, there are real concerns regarding the lack of knowledge and training of NDIS Planners and Local Area Coordinators, with worrying reports of them overriding the support recommendations of allied health professionals.

As the peak body regulating and representing speech pathologists, we have drawn together evidence and feedback from our members working with NDIS Participants in NSW and present these quotes to illustrate the key issues we feel relate to the Inquiry's Terms of Reference. We preface this with general background information about the role of speech pathologists in providing support for people with communication and swallowing disabilities.

As always, we would be keen to appear before the Committee to bring together leaders in the speech pathology profession with expertise and 'real life' experiences of these issues to provide more detail regarding the particular problems we highlight in our submission and to discuss potential solutions.

In the meantime, if Speech Pathology Australia can assist in any other way or provide additional information please contact Ms Catherine Olsson, National Advisor Disability, on _____ or by emailing _____

Yours faithfully

Gaenor Dixon
National President

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Introduction

Speech Pathology Australia welcomes the opportunity to provide feedback to the Inquiry into the implementation of the National Disability Insurance Scheme (NDIS) and the provision of disability services in New South Wales (NSW). We have structured our feedback in response to the Terms of Reference and conclude with recommendations that we hope the Commission will find useful. We preface our comments with general background information on communication and swallowing disability and the role of speech pathologists in improving outcomes for people with communication and swallowing disability.

About speech pathologists and Speech Pathology Australia

Speech pathologists are the university trained allied health professionals who specialise in treating speech, language, communication and swallowing problems. Speech pathologists work across the life span with infants, children, adolescents, adults and elderly persons with communication and/or swallowing problems.

Speech pathologists work in both publicly and privately funded services. In recent years, however there has been a significant shift in the location of service delivery from a previous majority government-employed to the private sector including private practice, not-for-profit and non-government organisations.

Speech Pathology Australia is the national peak body for speech pathologists in Australia, representing more than 8500 members (2545 in NSW). 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. Speech pathologists are not required to also be registered through the Australian Health Practitioner Regulation Agency (AHPRA).

About communication and swallowing disability

Some people have problems with their speech, language, communication and swallowing that are permanent and impact on their functioning in everyday life.

Difficulties in speech, language, fluency, voice, social communication and swallowing can occur in isolation or the person may have difficulties in more than one area. Communication and swallowing difficulties can arise from a range of disabilities that may be present from birth (e.g. Down Syndrome or Autism Spectrum Disorder), emerge during early childhood (e.g., cerebral palsy), or during adult years (e.g., traumatic brain injury, stroke and head/neck cancers, neurodegenerative disorders such as motor neurone disease).

Communication disorders encompass difficulties with speech (producing spoken language), understanding or using language (including oral language, reading, spelling and written expression), voice, fluency (stuttering), and pragmatics (the social use of language), or a combination of areas. There is very strong international and Australian evidence that communication disorders negatively affect an individual's academic participation and achievement, employment opportunities, mental health, social participation, ability to develop relationships, and overall quality of life.

Swallowing disorders affect the ability to safely swallow food or liquids and can lead to medical complications and a reduced ability to safely and enjoyably participate in social, employment and education experience where consumption of food and liquid is needed. Swallowing problems are common in people with complex disability.

People with communication and swallowing disability span the entire age range and the nature of their difficulties impacts on most areas of life. The clinical protocols for speech pathology treatment are evidence based and backed by strong multidisciplinary scientific evidence for efficacy. Clinical protocols for treatment (in terms of session duration, frequency of care, intensity etc.) differ depending on the clinical presentation and diagnosis – usually speech pathology care is aimed at maximising function for that person.

There is an overlap of incidence between the different types of communication disorders and swallowing disorders, with some Australians experiencing both due to their disability (for example, individuals with Down Syndrome or cerebral palsy).

About NDIS Participants with communication disability

While detailed data as to the number of NDIS Participants who have communication or swallowing disability or who have access to speech pathology services as part of their NDIS Plan is not yet readily available, there is good quality information that would suggest that a large proportion of NDIS Participants have communication disability. For example, the most recent information from the Australian Bureau of Statistics, based on the 2015 Survey of Disability, Ageing and Carers (SDAC)ⁱ estimates 1.2 million Australians have 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. It is probable that the majority of these people will be eligible for NDIS due to their complex communication needs. 'There were 278,100 children with disability, of whom almost half (46.0% or 127,900 people) had some level of communication disability. The majority (86.5%) of these children had profound or severe communication disability.' It is unclear how many of these children would be eligible for NDIS under the full scheme (post age seven) or through the Early Childhood Early Intervention (ECEI) stream.

With regards to access to the NDIS and reported outcomes, the final report of the evaluation of the NDIS shows that:

The NDIS was identified to work best for participants and families who were able to strongly advocate for themselves. In contrast, poorer outcomes were reported for NDIS participants with intellectual disability, psychosocial disability and complex needs or with older carers facing their own health issues. The qualitative evidence also indicated that some people with disability were experiencing poorer outcomes under the NDIS and were receiving a lower level of services than previously. NDIS participants from CALD backgrounds and living outside urban areas were similarly considered to be disadvantaged under the NDIS.ⁱⁱ

It is likely that NDIS Participants with communication disability are disproportionately represented in the group reportedly experiencing poorer outcomes.

Speech Pathology Australia's specific comments relating to the Inquiry's terms of reference

In order to highlight specific issues relating to the provision of NDIS services in NSW, we have drawn together evidence and feedback from our NSW members using the findings of two NDIS related surveys as well as reports made directly to the Association from our members or families of NDIS participants via email or telephone.

The first of these member surveys was carried out in November 2017, and of the total 1029 respondents, almost one third (326) were NSW based. The second survey, which was undertaken in March 2018, saw an even greater percentage of NSW based respondents, some 44% (280) of the total 634 respondents.

(a) the implementation of the National Disability Insurance Scheme and its success or otherwise in providing choice and control for people with disability

Speech Pathology Australia and its members have a number of major concerns regarding the implementation of the NDIS and its ability to provide choice and control.

Firstly, the inconsistencies in eligibility and access, which are often the result of NDIS Planners and Local Area Coordinators (LACs) making decisions without adequate knowledge or training. Our members report situations where a Planner has determined that an individual that a member has referred, is not eligible for the NDIS, yet another person the member has also referred, with the same condition and similar functional needs, is determined to be eligible by a different Planner. This has been particularly problematic, but not exclusive to, children in the Early Childhood Early Intervention (ECEI) stream of the NDIS where it is unclear if the functional problems experienced by the child will be permanent.

"There are just too many inconsistencies and too little understanding from the Planners. Decisions are being made that the [Planners] are not qualified to make and go against the notion of choice and control...."

"It seems that many LAC[s] have limited experience in disability services, and I wonder how they are able to make a proper decision/recommendations for a funding amount. This [has] created massive frustration among my clients."

Our members have also repeatedly raised concerns regarding the allocation of funds in NDIS Participants' plans. Funding decisions appear to reflect a lack of understanding by NDIS Planners of evidence based supports that would meet the outcomes and needs identified by Participants. There are reports of omissions and inconsistencies, whereby NDIS Plans for Participants with similar functional needs do not include key supports that are reasonable and would be considered necessary by anyone familiar with these specific disabilities. In addition, there are many reports of over-funding or significant underfunding of supports and therapy. Whilst we appreciate the need to consider the budget/financial implications of the level of support, resource allocation needs to be made with an informed understanding of the evidence relating to specific supports. For example, Planners are making decisions about 'how much support' for therapy is provided in NDIS Plans for children without advice from technical advisors/experts (including speech pathologists) about what would be needed in order for the child to achieve their goals. This has led to numerous instances where the number of speech pathology sessions listed in a child's plan is far above or below that which the evidence recommends for clinical efficacy (and change in functional status) for that child's condition. There are also cases of Planners overturning or

ignoring professional recommendations for equipment and services, as well as not reading the reports for planning meetings.

“Unqualified staff are using invalid assessments to measure level of need. Refusal to fund the intervention with the strongest evidence base for ASD [and a] strong bias towards larger organisations”

“I also am concerned with NDIS putting caveats on my therapy, as I have had issues with NDIS trying to dictate service delivery which were not in the best interests of my client, nor did they fit my client's presentation or goals... I would prefer to work directly with the client and their family to decide what is best for them, and what fits in with the way that I am able to work with them. After all, the client nominated me as their therapist for the reason that they like the way we work together, so I believe that should be respected.”

Case study 1:

In October 2017 the mother of a child with moderate intellectual disability, severe apraxia and ASD who is non-verbal calls the Association. The child uses ProLoQuo2Go [voice output software] on an iPad, and Auslan [the signed language of the Deaf community]. The child was determined to only have ‘mild to moderate’ needs under NDIS, and only allocated \$11,000 in total across all areas including equipment and therapy supports. The mother worked out this was equivalent to one hour of therapy a week, and nothing for equipment and was going to tribunal to dispute this.

*The mother reported being told the following by the Planner:
(Before the planning meeting)*

“Just to let you know, I don't believe in therapy, I usually suggest that people just go through early intervention support programs.”

(During the meeting)

“What do you mean, you want BOTH [types of AAC]?! Why don't you just use one?”

“With all of her needs, as if she can possibly sign, I don't believe that”

“Why on earth do you want her to sign? How is that going to help her in the community? What, do you want her to talk to Deaf people?”

Finally, with regards to the provision of equipment/Assistive Technology, there are a number of additional concerns beyond whether an item will be funded. For example, there is the added pressure and concern about having to find a registered provider who sells the required item under the NDIS in time before funding is ‘lost’ and also examples of where funding for an iPad App is approved but not the iPad. Clear guidelines as to what can/will be funded are required to ensure consistency and equity.

“Different planners from different regions have different standards. I have applied for the same equipment in the past for different clients and have had different results due to different interpretations of their own policies.”

(b) the experience of people with complex care and support needs in developing, enacting and reviewing NDIS plans

As mentioned above, NDIS planners are making decisions regarding supports with little experience or knowledge of disability which not only impacts on whether the appropriate level of support is included in

an individual's Plan, but also results in many Plans having to be reviewed, which is a lengthy and in some cases, avoidable, process.

"It all depends on the planner you get. If you get a planner who understands the client's needs and can meet the requests made by therapists then the experience is good. Other planners don't understand and will approve an electric wheelchair but decline a non-electric wheelchair as they see it as too much rather than appreciating that you always need a low tech option for when the electric option breaks down"

"planners often have limited understanding of specialist areas but who make final decisions about funding, sometimes based on their 'own assessment of the situation' (a direct quote from a planner) increase[ing] the burden of reporting - review assessments are falling through the cracks and families become exhausted by the process of fighting for funding - leaving less energy for focusing on the NDIS participant in their care."

Supporting participants to understand the support options available and the evidence base would ideally be part of the role of Planners/Local Area Coordinators/Early Intervention partners. However, providers often have to help participants navigate the NDIS system as participants and/or their families/carers may not know what to ask for, or where to look to get information to assist with their decision making process, or where to find providers of certain services once needs are established. Speech pathologists are spending many unpaid hours helping and advising participants and their carers to prepare for planning meetings, access information, explaining documents and helping them to understand their individual plans. As you can appreciate, this can have an emotional toll on providers and families alike.

"Difficulties in supporting parents going through the planning process, review process, managing being rejected from the scheme, with limited information ourselves and an obvious lack of consistency... Scheduled plan reviews not being held on time - managing this from an administration point of view is time consuming and difficult - especially if they are NDIA managed"

"Each client's package is so different and some really lose out with little hours to provide what is needed...feels like being asked to provide a service while gagged and tied to a chair. Families are angry, frustrated and feel cheated and we cop the brunt of this. Social work was not my career. Family support is not what I want to spend my time doing when the client's communication and practical daily survival are at stake here."

(c) the accessibility of early intervention supports for children

In addition to the aforementioned issues regarding eligibility to the ECEI stream of the NDIS, there are also major issues regarding the timely access to planning and services for eligible children under early intervention. These accessibility issues are primarily due to the lack of ECEI partners in NSW coupled with the cessation of government-funded services, leading to extensive waiting times. For example:

"The 3 ECEI providers in Newcastle (RIDBC, Firstchance and Aspect) have been told they are not to be early intervention planners anymore because it is a conflict of interest. They have been told they are absolutely definitely going to stop providing access and planning services to 0-6-year-olds from 30th June [2018]. There is no known replacement and no information has been provided about how to refer 0-6-year-old children or request planning meetings after this date. The NDIA have "unofficially" told them there will probably not be any referral or planning service until October - so the kids will be in limbo"

"Service for [Early Intervention] is non-existent in Newcastle. We have reached our 'cap' for early intervention participants and they are now on a wait list for any type of service. The need for service continues to remain high, complex and crucial for change."

“Current ECEI providers in my area have all disappeared (CPA closed local office with no notice, ASPECT never physically come here, Mission Aus. will only see children with NDIS funding despite the fact they are registered as ECEI providers - and they have no access to therapists) therefore hideous situation - children under 7 not having access to services.”

The disruption to the previous state based early intervention, coupled with the NDIS excluding some children based on the interpretation of the Early Intervention (EI) eligibility criteria as meaning children must require input from more than one allied health provider, has led to uncertainty about what services children are able to access, and from which sector. There should be consistency regarding the services available, including a suite of evidence based, family focused, capacity building programmes which fit with the Early Intervention Best Practice guidelines. At the moment, what is and isn't offered by the ECEI partners is variable which leaves providers in the market uncertain of what 'offers' they should have, which complement what is provided by the ECEI partner. The lack of clarity regarding the EI pathway and the different Provider options needs addressing.

“The wait between clients accessing NDIS can impact on the family and early intervention. The transition to NDIS for some families that are already registered with other funding (i.e. fahcsia) is unclear. There [needs] to be specific guidelines for what information is required in reports/recommendations for families that may be eligible for NDIS”

“Not all staff give correct information Some parents were told they don't help under 8 year olds”

There are also reports of 'funneling' of NDIS Participants to providers who are 'preferred' by the ECEI partners.

“ECIA approach in our area is not evidence based, is used as an all in one fits, and support coordinators also act as therapists (conflict of interest)”

“Pressure being put on families to switch providers by organizations (EI) during the planning process”

“ECEI to intervention' pipeline shuttling EI participants to the former larger [not for profits] away from smaller providers.”

Case Study 2:

In May 2017 a SPA member submits an access request for a 5 year old indigenous girl with a severe receptive and expressive language delay impacting upon her learning. The child's mother is illiterate and so the speech pathologist is the nominee for the family (upon their request). In August it is established that this paperwork has been lost by the NDIA, and so the member hand delivers the access request. The request is denied in February 2018, and the member then appeals the decision and makes the following complaint:

"I followed up the referral at the beginning of this year and was told her application had been unsuccessful. Even though I am the contact person for this family, no-one had told me her application was unsuccessful until I rang. This was an unexpected outcome given her age (5 years old) and severe developmental language disorder. So I asked why she was not accepted. The NDIS call centre said that only the assessor could answer and she could not get through to her. She said her name was "Kate" and that she would return my call in 3 days. This was over two weeks ago and I have rung twice more since this time. Every time I am told someone will contact me and no-one does.

It is a shame that the most vulnerable in our society, who cannot follow-up and advocate for their children, are the group that are most disadvantaged in accessing NDIS funding. "

In March 2018 the member is advised that the review was successful and the client is now a Participant. In April 2018 First Chance (the ECEI partners for the area) advise that they had not heard that the client had been accepted. In May 2018 the member discovers that the family have been discharged from the ECEI planning waitlist as they had been unable to contact the parents. With further follow up the member is then able to have the family reinstated on the waiting list and arrange a planning meeting for the 29th May 2018.

A planning meeting was arranged more than twelve months after initially submitting the request, requiring eleven instances of written contact, and numerous phonecalls. This advocacy was entirely unpaid.

(d) the effectiveness and impact of privatising government-run disability services

The 'market' of allied health professionals is particularly affected by uncertainty regarding which clients will and won't get access to NDIS plans/funding, which impacts on the demand (or lack of it) for their services, and therefore the value and importance of expanding their businesses. The uncertainty and fluctuation in NDIS decisions as to what will be funded affects the provider market. For example, the potential shifting of supports for oral eating and drinking from Disability to Health means businesses which are 'specialists' in this area are now uncertain about whether or not they will have a client base (or whether these supports will indeed be shifted to Health). There is also a need for clarity regarding the provision and funding of 'infrastructure' services such as those that underpin Augmentative and Alternative Communication Assistive Technology (AAC AT) services, i.e. the trialling and maintenance of equipment. These additional but essential related services are unlikely to be effectively provided by the

market, and could lead to Participants purchasing AAC AT that is not actually required or not the most appropriate system for them.

In addition, the change from a social justice and needs based framework to a business/market driven framework does not sit well with some disability providers.

"I am extremely upset by the changed nature of our work. Suddenly it has become competitive and money-focussed, rather than collegiate and service-focussed. This is the biggest change of all - and I have been in private practice for 30+ years. Organisations that were once charities are now profit-making competitors, and still claiming charitable status. How is that right? And 2 of these organisations have made statements to my clients that if they want the benefit of their services (e.g. for OT, Psychology etc), then the client MUST become a client for Speech Pathology as well. This was never the way NDIS was meant to work! Less choice for the client not more, purely to achieve a financial bottom-line"

Government services have been reduced or removed, but other providers are not moving into the market to replace them. This is particularly problematic in rural and remote areas, and for Participants with complex support needs whose NDIS Plan funding simply doesn't address their high level support needs.

"I work for a large NGO but in a regional/rural specialist team. In the last 2 years our region covered has shrunk to about 10% of our pre-NDIS region. Our client numbers are 20-25% of pre-NDIS and our actual workload significantly smaller again. Our direct line manager is based out of our region, and is actively reducing hours allocated to the staffing. We have a physio vacancy unserved since May 2017 (so clients miss out on that service altogether). Our main fear under the old/existing pricing is that the organisation will not continue to absorb such large financial losses and will cut all positions to unviable part-time roles or close the team altogether."

Other impacts of privatising government-run disability services include the loss of clinical governance for allied health service provision. ADHC previously had a significant role in the provision of 'capacity building' supports within and across sectors. Examples of within sector 'capacity building' included facilitating positive student placements and providing training/supervision to community based providers to ensure high quality supports in areas of clinical focus for people with disability such as Augmentative and Alternative Communication. An example of cross sector capacity building would be supporting educators to adapt the curriculum to support literacy development for children with little or no speech, or to provide 'generic' training to student support officers regarding barriers to and facilitators of effective, enjoyable and safe mealtimes for children while at school, or at out of school hours care.

ADHC had developed resources, such as the Augmentative and Alternative Communication Practice Guide, which were available to community-based providers. SPA put in an expression of interest to act as the auspicing agency for these resources into the future, in order to ensure that they were kept up to date based on current and emerging research and practice principles, and to ensure their availability to allied health professionals working in this area. It is unclear where these resources now sit, and whether and how they will continue to be accessible for providers in the community.

While there have been attempts to develop models and frameworks for the continuation of these kinds of activities, there is significant concern about their sustainability, in the absence of responsibility being explicitly identified, and funding being provided for provision of these supports.

Given that the role of the National Quality and Safeguarding Commission includes assuring quality of service provision, it is possible that the types of clinical governance activities previously undertaken by government agencies, and the larger government funded organisations, will be part of the remit of the

Commission, but it is not at all clear at this point that this will be the case, nor where this responsibility is seen to sit if it is not the case.

“My issue with rural services is that, as the only speech pathologist in my area, I am getting referrals for much more complex children than I used to. I am having to quickly skill myself up in AAC that is more than an iPad and ProLoQuo2Go [voice output software]. Once upon a time I could have called on the assistance of an ADHC NSW therapist, but now they are my competition. Now I am trying to provide the service in consultation with suppliers who really want to sell you their product”

Finally, last resort arrangements are also needed from a range of service providers, to ensure NDIS participants with very complex and costly support needs are supported, especially at times of crisis. The level of demand for such services is potentially so low that they are unlikely to be profitable, meaning the government will have to provide, or subsidise, such services and supports if the market fails to provide them.

(e) the provision of support services, including accommodation services, for people with disability regardless of whether they are eligible or ineligible to participate in the National Disability Insurance Scheme

There is a distinct lack of free or low cost services available to those ineligible to participate in the NDIS. This severe access issue has come about not only because of the aforementioned cessation of government funded support services, but also due to former not for profit providers becoming NDIS providers and shifting their service focus to NDIS Participants only.

“Nowhere to send clients without funds as the NDIS has changed the structure of service provision and there are no free (to the client) services they can access now”

(f) the adequacy of current regulations and oversight mechanisms in relation to disability service providers

Regulation is required to ensure there is no conflict of interest in cases where large organisations that provide planning or support co-ordination, also provide therapy so can in effect refer clients to themselves. This obviously affects client choice.

“[I’m] concerned about conflicts of interest with large providers referring work to themselves, and not giving clients true choice”

Regulation is also lacking regarding Allied Health Assistants and/or students who are being seen by Planners as a cheaper option to a qualified therapy provider. Whilst this is concerning from the point of view of expertise and quality service, it is also ineffective and potentially dangerous when no support or funding is included to provide for a qualified therapist to oversee them. This practice is yet another example of insufficiently trained NDIS staff making decisions about an individual’s support needs, which may be complex and require specialist assessment. This has the potential to impact negatively on an individual Participant if they are not receiving support from a suitably qualified and experienced provider.

“[I’m] concerned about comments from NDIS staff that untrained workers will be able to do the work of therapists”

“Insufficiently trained NDIS staff [are] making clinical decisions that they are not qualified to make and impact[ing] on the potential that clients can reach for example recommending that people with severe communication and behavioural difficulties use 'student' speech pathologists or untrained helpers”

Case Study 3

In October 2017, the Association is contacted by a grandmother of three children who are deaf. Their mother is also deaf and therefore the grandmother is making inquiries on her behalf. At the planning meeting for the family the planner asked the mother if she couldn't possibly 'cut back on speech therapy', or alternatively 'find a cheaper therapist', as it was going to be very expensive (implied too expensive) to have both speech therapy and all of the required equipment (hearing aids, assistive devices for the home) in their packages. Currently only one of the children is receiving speech therapy, and that is at \$160 an hour, so not even at the NDIS price limit.

A specific example of the loss of an oversight mechanism in relation to disability service providers is that of the overarching cross-sectoral system overseeing risk factors for the provision of supports to people with oral eating and drinking difficulties. This, too, was provided through the Clinical Innovation and Governance sector of Ageing Disability and Home Care, and ensured the quality and provision of training to workers providing mealtime supports regarding their duty of care, balancing duty of care with dignity of risk, and managing Occupational Health and Safety issues for workers (associated with providing direct mealtime supports).

(g) workforce issues impacting on the delivery of disability services

Our members highlight workforce issues impacting on the delivery of disability services that relate to providers but also workforce issues within the NDIA itself.

From the provider perspective, the increased administrative demands associated with the NDIS have required some businesses to employ more administrative staff, and others give up therapy time in order to deal with admin related issues.

“the administration time needed to manage our small business (of 1 full-time and 2 part-time therapists) has gone from approximately 4hrs per week to at least 15hrs per week due to dealing with NDIS clients. This does not include clinical reporting for NDIS clients, but simply the work needed to ensure compliance and payments.”

“The stress that it has caused for myself and my staff is beyond anything we have experienced. My business partner had to go on indefinite stress leave last year when the portal issues were happening. The rules keep changing with no communication, they are making it harder and harder for small private practices to keep up with all the admin requirements. I have to put more admin staff on to meet the requirements.”

“We are at a turning point with our business. I have invested heavily to be able to provide the best possible services for my clients and to meet the demands of the area. The current rate is \$175.57 - it seems a lot of money and it is, however, as an 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."

There is also a shortfall in the supply of experienced providers, and with the admin/billing/business pressures associated with the NDIS, there is not enough time to be able to adequately train/supervise new graduates or therapists who may be working in a new area of practice.

"The area that we work in has long waiting lists for participants and there are not enough experienced therapists providing services."

"Our multi-disciplinary practice has built its reputation and has heavily invested in skilling staff specifically around early intervention, and complex disability. It is a requirement of the new safeguard and quality commission that we remain registered to provide services to this ECEI population, as well as invest in the TPV process. We would otherwise elect to de-register, and see those clients exercising choice and control using self managed funds. We would be unable to provide the level of service our clients currently enjoy, as we are currently committed to many "behind the scenes" practices that we engage in to ensure quality and specific service. At the moment we set our billable hours at 5 hours per day, where staff are employed for 8.5 hours. This additional "non billable" time allows us to prepare and advocate for our clients."

There seems to be a very high turnover of NDIA/LAC staff which results in a loss in continuity with regards to staff supporting Participants. The reported high workload of NDIA staff also impacts on their ability to respond to provider/Participant enquiries which cause delays and in the case of Planners and LACs can cause service gaps if a Participant's plan expires before renewal – see example below in response to ToR (h) regarding a LAC *"being too busy"*.

"The NDIS staff seem to change very regularly and there is no funding for client caseworker support...Not enough NDIA staff."

"High turnover of LAC's with no handover or transition of allocation to a new LAC for participants."

"Half my clients had plans run out last week. I have been contacting the NDIS since early March to organised review meetings. They happened 2 weeks ago. The LAC said he would be in contact about continuity of plans. I contacted several times before I was due back at the school on Weds. They did not return any contact attempts (e-mail or phone). As a result, I did not go to work on Weds because I did not know if the children had funding. I rang again on Weds and he said, "oh yeah, all the kids have had a 3 month extension because I am too busy."

(h) challenges facing disability service providers and their sustainability

The majority of private speech pathology practices are small or sole provider organisations, with limited infrastructure and resources.

Our members have reported an increased administration burden of providing services through the NDIS (in comparison to other funding streams including BetterStart for Children with Disability, Medicare, Department of Veteran Affairs and private health insurance). This has resulted in our members either delaying registration, deciding to only see self-managed Participants, or withdrawing from the NDIS altogether as it is proving to be financially unviable. A survey of our members, undertaken in November 2017, showed that 42 per cent of respondents had considered withdrawing from the NDIS in the last six months.

We also surveyed our members in March 2018 to gauge the potential impact of the proposed tiered payment system recommended in the McKinsey & Company's Independent Pricing Review for the NDIS, and almost 10 per cent of the 634 respondents said they would have to close their business. Approximately 12 per cent said they would de-register and no longer see NDIS clients, 36 per cent said they would also de-register but still see self-managed NDIS clients and 22.5 per cent said they would remain registered but would need to prioritise only complex (higher payment level) clients to remain financially viable. Only 13 per cent of respondents said that the new payment system would not impact their service provision.

"I currently spend more (excessive) amounts of time doing admin rather than direct face to face intervention...The amount of hoops that are required to be jumped through to be able to provide an expert clinical opinion is ridiculous. I feel the NDIS does not respond in a timely manner. The planners themselves lack knowledge about key health issues and are often cruel and negative in [their] refusal of requests."

"My business spends a significant amount of time liaising with NDIS when this really is the NDIS' issue. Claims processing as clients reach the end of their plan periods and transition to new plans we are unable to claim. [We] spend significant amount of administration time sorting through this unnecessary process."

In addition to inadequate remuneration for non face-to-face service provision there is often inadequate funding in individual plans for therapy provision.

"LOTS and LOTS of money going to administration and organisation planners and a small amount of funds going to the actual therapy. I've seen a child that had a severe disability and had \$1,300 in therapy to be divided between OT and Speech and the management company got \$5,000. This is not in the best interest of the client."

There is an expectation that providers will continue to provide therapy services during 'gap' periods between plans, this is obviously a financial risk to businesses and causes yet further administrative burden having to claim fees for back dated services. Similarly, there are delays when there are changes to plans and service bookings associated with price changes and/or Plan reviews.

"I've been told to continue to see clients for intervention and that plans will be concurrent (e.g. the old plan will meet the new plan), however this is not always the case and then a debt builds up to the extent where I have to discontinue services."

"unbelievable expectations that providers will continue to provide uninterrupted services when plans run out with no knowledge of when or IF a plan will be renewed allowing for payment to be processed."

"Most difficulties are in the interim periods between plans. NDIS guarantees payments until new plan is established or funding is cancelled. But this doesn't happen easily. I have spent over 20 hours on the phone, in emails etc claiming 10 hours of fees from one interim period for one child."

The aforementioned lack of consistency regarding which Participants (and/or supports) will continue to be funded, and at what levels, not only makes Participants and their families/carers feel insecure regarding ongoing future supports, but also impacts upon businesses. Practices that have a focus on disability, where NDIS Participants potentially make up a large portion of their business are unable to forward plan, as funding streams are not guaranteed.

“local therapy services and many, many small businesses have worked overtime for several years now to allow our clients to access services and many of these businesses are now very vulnerable to changes in funding. Business planning is almost impossible.”

“Our business plan was based on the fees that the NDIS currently pays and has been paying. I’m at a loss. I am gambling my family’s life savings doing this and will invest over \$300,000 of borrowed money. Do I risk my house, or cut my losses now and forget it... I don’t want to give up, I have many families that I [k]now really need this facility and the services we offer, but I have to put my family’s future first.”

Another area of concern is advocacy, not only with the funding cuts to organisations that provide such support, but also the amount of support and advocacy now being provided by individual providers on behalf of Participants. The NDIS has created a system whereby individuals are finding themselves having to take their cases to the Administrative Appeals Tribunal when they, unfortunately, need greater advocacy and support. At a provider level, our members report having to spend many unpaid hours advocating on behalf of their clients, which is both time consuming and emotionally taxing.

“I do all the access work for the families unpaid; however the bigger problem is that I do not have the time or energy to keep up this level of advocacy. I will probably fold my business. Too hard and too soul destroying. We are 5 years into NDIS here in Newcastle and we all agree it is getting worse.”

(i) incidents where inadequate disability supports result in greater strain on other community services, such as justice and health services

Speech Pathology Australia has been raising concerns regarding the proposed shift of mealtime support from Disability to Health and its potential impact on people with oral eating and drinking difficulties, since 2016. Not including supports for functional oral eating and drinking in Participant Plans and the absence of an agreed decision based on a shared interpretation of the Principles to Determine the Responsibilities of the NDIS and other Service Systems is leading to increased barriers to effective, enjoyable and safe mealtimes in everyday environments. We provide two de-identified NSW case studies.

Case Study 4

Client is a young man (in his 20’s) with a progressive syndrome who is presenting with late stage symptoms. He received insufficient hours in his initial NDIS plan – when we requested a review the NDIA assured us that hours would be provided in the event of a decline. He has since experienced a decline in his condition, and his hours have been exhausted managing his risk of aspiration.

X’s dysphagia is a direct result of his disability - a Mealtime Management Plan is in place not only to prevent aspiration pneumonia, but also to manage his comfort, capacity to eat textured foods, choices around mealtimes, behaviours related to mealtimes and many other participation related functions. To prevent aspiration pneumonia it is essential that X is assessed and reviewed by a suitability skilled and disability-trained speech pathologist, and this should occur in X’s own environment as explained as his usual chair is not able to be transported.

Health services in the client’s area do not have an outpatient service (aside from oncology), and have stated that they are unable to provide home visits. The client has since had a further decline in swallow function and is demonstrating signs of aspiration – the family are now in a position where they need to transport him to hospital (20 mins away) and present to the Emergency Department for an assessment. The client is unable to travel in a standard seat and so this will require transport in a wheelchair taxi. He can have significant behaviours, particularly in unfamiliar environments.

Case Study 5

Speech Pathologist first met family of Child, almost 8 years old, with Chromosome deletion in February 2016, at the time they had limited therapy services from ADHC [since disbanded] and the Feeding Clinic at a local children's hospital. The Child's feeding skills were delayed [and]

- *Mum feeding child for all meals. No clinical signs of aspiration (difficulties swallowing) and no history of chest infections.*

Child then received monthly reviews both at home or school, lots of joint collaboration with OT and teacher's aide to support feeding skills.

At the time of review – December 2017 - child had achieved the following:

- *No longer on bottle, using a sippy cup to drink milk, trying to wean this to a straw*
- *Using a straw to drink water at school and diluted juice at home*
- *Starting to chew foods but fatiguing quickly*
- *Still relying on mashed food for nutrition but eating pieces of egg for breakfast, soft pieces of steamed vegetables and fruit as well as bite dissolve foods for school lunch box*
- *Starting to self-feed yoghurt in a bowl – some behavioural issues around holding spoon*
- *Working with family to slowly increase variety of soft easy chew foods in diet at home*
- *School focus for 2018: to move towards "cruskit sandwiches" or similar that child can pick up and hold, also working on increase awareness around tongue movements and chewing strength.*
- *Other therapies: started walking, working on toilet training and using AAC device and signing quite efficiently, also started to make vocalisations and move tongue to copy movements children in mainstream class. All of this achieved through NDIS funding.*

Upon review NDIS funding for feeding was denied based on weight and nutritional reasons – suggestion to see Dietitian. Child has NO nutritional or weight issues – she is growing well, her mashed food contains everything she needs nutritionally. Issues are specific to oral motor speech pathology feeding support.

(j) policies, regulation or oversight mechanisms that could improve the provision and accessibility of disability services across New South Wales

There needs to be a more streamlined review process and 'quick fix' review options to correct minor errors or make minor changes to NDIS plans.

"There needs to be a system where parents can get minor errors on plans fixed. I have several parents that are waiting six months for a simple fix between [1]NDIS pays my provider and [2]NDIS will pay my support provider."

Some kind of client liaison/information service is also required for families to help them navigate the NDIS and lessen the burden on therapists. Supporting participants can see a speech pathologist spending many unpaid hours helping and advising participants and their carers to prepare for planning meetings,

access information, explaining documents and helping them to understand their individual plans; this has an emotional as well as financial impact upon providers.

“Clients aren't being told what to do or how to do it and it's the service providers left to help them through the system.”

(k) any other related matter

There are recurring complaints relating to a lack of appreciation of the time and financial costs regarding travel and appropriate reimbursement for providers. Low levels of reimbursement have a knock-on effect to services provision in rural/remote areas.

“Travel - under the NDIS formula I would be charging more for travel than for therapy. I have been told to just include more therapy time and claim as a whole; however, this uses up the client's therapy allocation. There is NO recognition of the time/distance required to travel to see clients in rural/remote areas.”

“Claimable travel time (cost) seems to be based on areas where there is no major traffic jam. I have to drive all over Sydney, and it sometimes takes 1 hour only for 6 kms at peak time.”

There are also a number of issues with the Equipment/Assistive Technology request and review process. These include delays in equipment being provided, often due to repeated requests to providers for additional information or clinical justification. Planners lack knowledge and understanding of a Participant's 'reasonable and necessary' equipment support needs meaning either no equipment or inappropriate equipment is approved, and there is no funding to support training to use the new equipment.

“There is no way to change equipment so you end up taking unsuitable equipment that is funded as a 'carry over' until you get to plan review to request the correct equipment, the Equipment Appeals [processes] are taking over 12 months for a decision”

“Massive delays in providing clients rationale for declining to fund essential equipment. A 5-year-old with CP [Cerebral Palsy] and approx. 5 verbal words has waited 9 months to find out why she was declined the recommended speech output system, despite numerous complaints from the family. When the rationale was given, it seemed to be a general blanket rationale that did not take into account the information supplied.”

Recommendations

We request the Committee consider the following recommendations:

1. Provide Planners with the necessary resources and training to ensure appropriate knowledge and understanding to help improve the overall planning process and quality of individual plans, as well as minimise the need for reviews. In addition, provide ongoing support so they can easily access expert input and assistance as and when required.
2. Clarify what will be funded in individual NDIS plans – these instructions need to be clear and not open to interpretation which has led to confusion and inconsistencies about what can be included.
3. Decrease the costly (time and monetary) administrative burden on providers. This can be done by ensuring NDIS online systems and forms are clear, quick and easy to use, and information for providers and Participants is accurate and easy to understand. In addition, reduce the amount of changes to rules and processes that have shown to be both time consuming and confusing.
4. Re-examine travel expenses/rulings and work with providers and peak bodies to determine consistent and practical solutions to facilitate access to services, particularly in rural and remote areas
5. Provide system-wide funding and structural supports for services such as speech pathology to be delivered via telepractice within the NDIS. This could offer a key solution to addressing some of the issues with the supply of speech pathology services in rural and remote areas.
6. Ensure adequate, appropriate and ongoing information and support is available to Participants rather than relying on providers having to support their clients.
7. Clarify the exact roles, responsibilities and service delivery parameters of state/territory Departments of Education, Health and Disability Services.
8. Establish mechanisms to support provision of Clinical Governance for allied health services funded through the NDIS.
9. Consider establishing a 'provider of last resort' to provide rapid response for NDIS participants who experience urgent and unanticipated need for speech pathology supports.

If Speech Pathology Australia can assist in any other way or provide additional information please contact Ms Catherine Olsson, National Advisor Disability, on 03 9642 4899 or by emailing disability@speechpathologyaustralia.org.au

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