

Speech Pathology Australia's Submission to the

Joint Standing Committee on the National Disability Insurance Scheme

Transitional arrangements for the National Disability Insurance Scheme

24 August 2017



Hon Kevin Andrews MP
Chair
Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6100
Parliament House
Canberra
ACT 2600

Dear Mr Andrews

Speech Pathology Australia welcomes the opportunity to provide feedback to the Joint Standing Committee on the National Disability Insurance Scheme's Inquiry into the Transitional arrangements for the National Disability Insurance Scheme (NDIS). Speech Pathology Australia is the national peak body for speech pathologists in Australia, representing more than 8000 members. Speech pathologists are university trained allied health professionals with expertise in the assessment and treatment of communication and swallowing disabilities.

As the peak body regulating and representing speech pathologists, we have drawn together evidence from our members working with NDIS Participants from all states and territories of Australia using member surveys and interviews. We preface our comments relating to the Inquiry's Terms of Reference with background information about the role of speech pathologists in providing support for people with communication and swallowing disabilities.

We would like to draw to the attention of the Committee, two very significant and urgent issues with the transition arrangements:

1. The recent decision by the NDIA to no longer fund meal time supports for people with swallowing, eating and drinking problems associated with their disability. Advice from the NDIA is that this support should be funded through the health system. There are no formal (or informal) agreements in place to transition funding or service delivery of this traditionally disability sector support to any health system in Australia. We have written to all Ministers for Disability and Ministers for Health this week to raise this issue and we will provide supplementary material to the Committee if responses are received.
2. The current inconsistent and inappropriate arrangements for the funding and provision of communication devices for NDIS Participants. The NDIA is not operating a functional system for Participants with communication disability to access appropriate, evidence-based or effective communication devices for people with complex communication needs. Delays of many months for a Participant to access an effective communication device precludes these people from participating in the 'choice and control' tenets of the NDIS and acts as a 'gag' to prevent them from complaining directly to the NDIS through the verbally mediated complaints mechanisms.

We are keen to appear before the Committee to explain these particular problems and to discuss realistic, feasible and cost effective solutions. We would be pleased to bring together leaders in the speech pathology profession with expertise and 'real life' experiences of these issues to inform the decision making of the Committee.

Yours faithfully

Gaenor Dixon
National President

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Speech Pathology Australia's Submission to the Joint Standing Committee on the National Disability Insurance Scheme's Inquiry into the Transitional arrangements for the NDIS

Speech Pathology Australia welcomes the opportunity to provide feedback to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) Inquiry into the Transitional arrangements for the NDIS. 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 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 the elderly with communication and swallowing problems.

Speech pathologists provide services in the acute care (hospital), sub-acute care, rehabilitation and primary care sector (including community health, general practice and mental health services) as well as within other sectors such as disability, residential and community based aged care, education, juvenile justice, prisons and community settings.

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 8000 members. Speech pathology is a self-regulated health profession through Certified Practising Speech Pathologist (CPSP) membership of Speech Pathology Australia. Speech pathologists are not required to also be registered through the Australian Health Practitioner Regulation Agency (AHPRA).

The CPSP credential is recognised as a requirement for approved provider status under a range of government funding programs including the NDIS, Medicare, all private health insurance providers, some Commonwealth aged care funding, Department of Veteran Affairs (DVA) funding, Betterstart for Children with Disability (BetterStart) and Helping Children with Autism (HCWA) programs.

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 conditions that may be present from birth (e.g. Down Syndrome or Autism Spectrum Disorder), emerge during early childhood (e.g., 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).

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. These people frequently require interventions and supports from multiple areas of public service (including health, the disability and education sectors and mental health services). 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.

Currently there is limited available data regarding the prevalence of communication and swallowing disorders within the Australian population. Conservative estimates indicate there is in excess of 1.1 million Australians who have a communication disorder and one million who have a swallowing disorder.

There is an overlap of incidence between the different types of communication disorders and swallowing disorders, with some Australians experiencing both due to developmental, disease or injury processes (for example, individuals with Down Syndrome or cerebral palsy). It is also clear that these prevalence figures will likely increase exponentially as the population ages.

About NDIS Participants with communication disability

Detailed data regarding the functional needs and supports accessed by NDIS Participants is not, as yet, publicly available, thus there is no quantifiable evidence 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.

There is good quality information however, that would suggest that a large proportion of NDIS Participants have communication disability. The most recent information from the Australian Bureau of Statistics 2015 Survey of Disability, Ageing and Carers (SDAC) indicates that 1.1 million Australians use equipment and/or aids to communicate (including 700,000 using hearing equipment/aids). This reflects about a quarter (25.9 per cent) of all people with disability. Information from the ABS SDAC 2015 indicates that some 235,800 people with disability use either electronic or non-electronic communication aids for reading, writing and speaking (this figure does not include hearing aids). Whilst this figure is unlikely to capture all people with communication disability who are eligible for the NDIS, it is probable that the majority of these people will be eligible for NDIS due to their complex communication needs.

Concrete and comprehensive data regarding the total number of children with communication and/or feeding and/or swallowing difficulties is unavailable at present. It is estimated that there are approximately 250,000 – 300, 000 Australian children living with a disability¹. 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.

The Intermediate Report of the Evaluation of the NDIS highlights two groups of NDIS Participants who are not experiencing improved outcomes. Firstly, people with disability who are 'unable to effectively advocate for services on their own behalf, including people with psychosocial disability and/or those people who struggle to manage the new and sometimes complex NDIS processes'ⁱⁱ.

It is highly likely that Participants with communication disability are disproportionately included in this group of NDIS Participants who are unable to effectively advocate on their own behalf.

The second group of Participants which the NDIS Evaluation indicated are faring poorer within the NDIS are those facing difficulties accessing disability supports for which they have received funding – primarily due to a lack of local providers, lengthy waiting lists and lack of quality provision.

The Intermediate Evaluation Report repeatedly acknowledges the unmet demand for allied health, including speech pathology services currently experienced within the NDIS. It is the view of Speech Pathology Australia that this second group of NDIS Participants who need (and have NDIS funding for), but are unable to access speech pathology services are also likely to be facing poorer outcomes under NDIS.

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

a) The boundaries and interface of NDIS service provision, and other non-NDIS service provision, with particular reference to health, education and transport services

Speech Pathology Australia has members who work across multiple sectors including the NDIS, education, aged care and health. As such, speech pathologists provide services under unique circumstances to understand the interaction, and in some cases, the disconnect between NDIS and mainstream services – including for the same individual NDIS Participant.

There are significant problems now in relation to the interface between education, health and the NDIS, with some cost-shifting apparent, and gaps appearing in access to services. This may be a reflection of this particular point in time, in which the Scheme is still in the midst of transitioning in the different states and territories of Australia. The issues are further complicated, as other sectors which interact with the disability sector are also undergoing significant reform. Whilst it can be argued that time is needed to allow the reforms to 'settle' and new systems of services in health, education and disability to be established, there are some areas of service provision where our members are identifying particular issues, and urging an immediate focus and the facilitation of collaborative problem solving.

The first of these is around provision of mealtime supports for people with disabilities. Many NDIS participants need an assessment of their eating, drinking and swallowing function in order to determine and address their support needs, so that they are able to have safe, effective and enjoyable mealtimes, and avoid or reduce the risk of choking, medical complications such as malnutrition or chest infections.

There are significant risks around people with disabilities being moved into new residential accommodation settings, resulting in a change in the environment in which they are having their meals, (including who is providing them with support). Workers need up to date documentation and training to be

able to provide supports in a safe, respectful and appropriate way. It is of concern if there is no clear pathway to access an assessment and a mealtime care plan, or for there to be a delay while it is determined if a health sector employed speech pathologist or a NDIS funded speech pathologists should conduct this assessment. This is particularly problematic, given that the NDIS is creating a situation where participants may be changing their place of residence, or the provider of their direct supports.

The second area of speech pathology service provision, which is at particular risk during transition, is the provision of assistive technology to augment or provide an alternative to speech (Augmentative and Alternative Communication, or AAC), for people whose communication difficulties mean that they have little or no expressive speech. Most of the States and Territories have established and funded services to support provision of AAC Assistive Technology (AT), including allied health teams with specialised skills and experience and a clinical focus in this area. While there is some variation, the supports offered through these services have included:

- a library of AAC technology to use for assessment, trial and short term replacement of devices
- a store of devices so that people with disabilities can simply keep a device which has been individualised to meet their needs, following a successful trial
- an information hub, able to provide information, training and troubleshooting support to allied health providers, people with disabilities and those who are providing support to them
- 'scaffolded supports' to 'primary' allied health providers from the disability, education and health sectors, supporting them to develop their knowledge and skills in order to be able to support the provision of AAC AT in the environment/s that the person with disabilities is in
- A service to provide non-electronic aided AAC, such as communication books or boards

These supports have been identified by Speech Pathology Australia members as critical components of an efficient, high quality, evidence based service system for provision of AAC AT, but it is difficult to see how these will be funded through individualised funding. There is currently no apparent consideration of how these might be funded through Information, Linkages and Capacity (ILC) component of the NDIS. Disruption to these services holds the risk of putting service provision back to what it was twenty years ago, and eroding the work and achievements of the AAC community over many years.

Clarifying the roles and responsibilities between education, health and the NDIS therefore needs to be addressed by government as a matter of urgency.

Education/NDIS interface

In the education system, issues can arise for individual students when they have multiple agencies providing services. There are students who will always straddle the inter-sectoral government jurisdictions (education departments, human services, community services, mental health, health, juvenile justice) and non-government organisations. Speech Pathology Australia has members who provide services under all these different government funding streams, and who are reporting considerable confusion over service delivery responsibilities. The risk is that each sector will assume needs are being managed by the other sector – to the detriment of the child or young person concerned.

One population for whom this is of particular concern is children and young people who have speech, language and communication difficulties that are 'stand-alone' conditions i.e. not associated with differentiating conditions (such as Cerebral Palsy or Down Syndrome). It is unclear if, and how, these children will be eligible for NDIS services. While Speech Pathology has engaged with the NDIS around this issue on a number of occasions, it is unclear whether these children will be able to access NDIS funding for provision of speech pathology interventions, both in ECEI or in NDIS Plans. At present, members are reporting variable (inconsistent) access for these children across Australia. These communication disabilities have profound consequences for participation in activities that involve a communication interaction – which includes learning and recreational activities, as well as social interaction and behavioural and emotional development and regulation. In the absence early intervention

services prior to school entry, the educational system is likely to be required to make even more significant (and costly) adjustments for the student to access/participate in the curriculum.

There is also a presumption by the NDIS 'system' that the education sectors are able to effectively support students with disability. Recent federal and state based inquiries into educational supports for students with disability reflect considerable variation in their ability to do so across states and territories, across school systems (public, independent and Catholic) and for students with different types of disabilities¹. While it is understood that it is not the responsibility of the NDIS to fund supports for student with disabilities that relate directly to curriculum access, it is important that there is discussion and clarification around whether supports are for school access vs participation in the education environment (as for any other environment) vs curriculum access and learning supports – it is only when there is a nuanced understanding of these differences that decisions can be made about which sector is most appropriately responsible for funding the needed support.

There is now widespread reports of schools across Australia restricting all access to NDIS providers to students during core learning times, school hours and in some cases on school premises. This barrier to the Participant accessing best practice support within an educational setting, or at worst no service at all, is concerning.

Schools are in the business of 'educating', and their priorities need to be to support access and participation in the learning environment for a student with disability. Individual schools, principals, teachers and speech pathologists are placed in positions where they need to make local, individual judgements about who is responsible for what type of support for a student. Clear guidance is needed from the Governments and the Departments of Education about the interface between the NDIS and the education system; where the provision of reasonable educational adjustments finish and where the provision of reasonable and necessary disability supports start.

Health/NDIS Interface– dysphagia and meal time supports

Given speech pathologists often work across health and disability services, they are in a position to not only identify problems with the interface between health services and disability services for the NDIS, but also contribute to the development of solutions, such as clinical pathways and processes to support continuity and consistency of care across both sectors.

The most problematic interface between mainstream health and NDIS services relates to the provision of speech pathology services to people with swallowing disability and the provision of mealtime management supports.

Some people with complex disability have difficulties eating and drinking that arise from their disability. They may rely on others to provide them with support, both with preparation for eating, and provision of meals (i.e. physical support to get food or fluids into their mouths, rate of eating or drinking, assistance to interact with others during mealtimes). Speech pathologists are the allied health practitioners who specialise in assessing and diagnosing eating, drinking and swallowing problems (dysphagia) and determining what supports the person needs to allow them to eat and drink as effectively, as well as safely, as possible. These are typically called provision of 'mealtime supports'.

¹ For example see the Senate Inquiry into Current levels of access and attainment for students with disability in the school system, and the impact on students and families associated with inadequate levels of support in 2015, the South Australian 2015 Inquiry into Access to the Education System for Students with Disability and the currently underway inquiry in NSW 2017, inquiry into student with disability or special needs in New South Wales Schools.

Problems in being able to effectively swallow food and liquids (dysphagia) can lead to medical complications such as malnutrition, dehydration, chest infections/pneumonia and choking – including choking incidents causing death.

However, for people with disability, as for all of us, eating and drinking is a key functional activity of every day life (i.e. meals at home or out, with family and friends, while attending work). Eating and drinking are more than a means to sustain life – they are integral components of social participation in our society.

Usually, health and hospital services conduct the instrumental diagnostic assessments of swallowing (dysphagia) for people with and without disability. Often if a person is having significant problems associated with swallowing and eating and drinking, they will be referred for a diagnostic assessment of their swallow function (a videofluoroscopy assessment that is usually performed in a hospital and is like a moving x-ray of how someone swallows). Speech pathologists are part of the health team in a hospital conducting this assessment. Dysphagia can occur for people associated with medical conditions (for example Motor Neurone Disease) and also for people associated with an underlying disability (for example Down Syndrome).

When the problems with eating and drinking arise from a disability, speech pathology services for meal time supports in everyday environments (home, work etc) have historically been provided through the disability sectors. Speech pathologists are key members of the team (often including Occupational Therapists, Physiotherapists, Dietitians and support workers) who provide solutions to enable persons with disabilities to participate in mealtimes which are safe, effective and enjoyable, as part of their everyday lives (at home, work or school).

The National Disability Insurance Agency (NDIA) has recently informed Speech Pathology Australia that the NDIS will not fund meal time supports as part of individualise plans into the future – the rationale being that this support is primarily to prevent a health risk (pneumonia or choking) and therefore the Health sector should finance it. It is Speech Pathology Australia's view that this ignores the important role eating, drinking and sharing a meal play in family and social life for people with disability. It also fails to acknowledge the fact that day-to-day provision of supports for mealtimes is part of the responsibility of disability support workers, often as part of provision of specialist disability supports. These workers have typically been provided with training by speech pathologists working within the disability sector about dysphagia and mealtime supports generally, and about the support needs of the Participant they are working with.

It is our understanding that no agreements are currently in place between the NDIA and any Health Minister or Department for the transition of community based meal time support services from Disability to Health.

There are currently no alternative funding streams for meal time support services provided by a speech pathologist (or multidisciplinary team) for people with disability through the health systems. Current MBS item numbers for speech pathology services are not structured appropriately or adequately to fund this service.

The transition of such a fundamental meal time support from the disability sector to the health sector is going to be very complex from policy, funding, workforce and service delivery perspectives.

It is unacceptable that people with disability will bear the risks associated with an ill-considered and unplanned cost shifting of a service from the disability sector to the health sector

In addition to the very real and very serious risks of people with disability dying from choking related incidents because they have not received appropriate support to eat and drink at home, there are also risks that Participants will be restricted from participating in their usual social, educational and employment activities because they and/or their support workers have not received the appropriate meal time supports.

Speech Pathology Australia has recently written to all Ministers for Health and Ministers for Disability to raise this issue and seek urgent clarification on how this essential service for people with disability will be funded and delivered. Any response from state and territory Ministers of federal Ministers to these requests will be communicated to the Committee to keep the Members and Senators up to date on this issue.

b) The consistency of NDIS plans and delivery of NDIS and other services for people with disabilities across Australia

Inconsistency in eligibility and access

Feedback to Speech Pathology Australia from speech pathologists working within the NDIS system indicate that there is considerable inconsistency and uncertainty regarding eligibility for the NDIS – as determined by individual Planners. Speech Pathology Australia members have reported repeated problems with access to the NDIS. For example, members report situations where a Planner has determined that one individual they have referred is not eligible for NDIS, yet another person with the same condition and similar functional needs is determined by a different Planner to be eligible. This has been particularly problematic in the case of children in the Early Childhood Early Intervention stream of the NDIS (but not exclusive to this NDIS stream) where it is unclear if the functional problems experienced by the child will be permanent. Speech Pathology Australia has made a submission to the Committee's concurrent Inquiry in the Early Childhood Early Intervention Approach which detailed the experiences and expertise of speech pathologists working with young children both within and outside of NDIS early intervention funding.

Even when provided with evidence from multidisciplinary practitioners (including speech pathologists) regarding the functional needs of the person (that is considered to demonstrate clear eligibility for NDIS) Planners, who are the "gate keepers" who determine eligibility, make decisions that are at odds with specialist advice. Speech Pathology Australia members have been told by Participants of Planners who openly reject or denigrate the advice the speech pathologist has provided.

Speech Pathology Australia supports the recommendations made recently by the Productivity Commission's Position Paper into the NDIS Costs that recommend significant changes to the planning process and Planner understanding in order to improve consistency and efficiencies in NDIS plans and service delivery.

It is the view of Speech Pathology Australia that the eligibility criteria set out in the NDIS Act are appropriate for the Scheme, however it is the interpretation of this eligibility by Planners that is inconsistent and has also varied over time. This would seem to suggest an insufficient knowledge of disability conditions and functional needs, and pose the most significant risk for the NDIS to meet its goals.

There is also confusion around what exactly the Early Intervention Access Criteria provide access to – consideration for eligibility to the NDIS Individualised Plan versus the provision of short to medium term supports from the Early Childhood Intervention Partner.

Issues with the development of Plans

Whilst it is acknowledged that the recent transition to full Scheme has placed enormous pressure on the Planning process, some of the efforts that have been made to streamline and speed up this process have come at the expense of personalisation of Plans. This includes the move to using telephone based planning. Members with experience in early intervention for people with disabilities, both lifelong and acquired, are concerned that the NDIA has failed to understand the importance, value, complexity and the time that is required to develop a relationship with (and build the capacity of) Participants. This capacity building needs to occur in relation to the Planner's understanding of disability, their goals and aspirations, the supports that may be needed to help the person achieve these goals. Planners need to have this understanding to build the capacity of Participants so that the Participant is an informed consumer in the 'market'. Speech Pathology Australia (along with other allied health professional peak associations) can inform the development of improved processes for engaging with Participants, including the ways in which providers can collaborate in preparing Participants for the planning process, and providing information to inform the determining of supports in the plan.

Inconsistency in funding in plans

Speech Pathology Australia members have consistently and repeatedly raised concerns regarding the allocation of funds in NDIS Participant's plans. Funding decisions appear to reflect a lack of understanding by the NDIS Planners of supports that are evidence-based to meet the outcomes identified by Participants.

Speech pathologists repeatedly report that they see Plans for NDIS Participants with similar functional needs that do not include key supports (that are reasonable and would be considered necessary by anyone familiar with specific disabilities), over-fund certain supports or significantly under-fund certain supports. Many examples have been provided where even the Participant does not understand what the supports funded in their Plans are intended to achieve or why they would wish to use them. Most recent examples include the significant (and disproportionate) allocation of funds for Support Coordination.

The My First Plan process and use of benchmark packages are efforts to create standardisation of Plans – however there should not be a 'one size fits all' approach to disability support planning. These processes on their own are not problematic, but when coupled with other structural aspects of the NDIS (not the least of which is the disability sector skills and expertise of the Planning workforce) - it creates a planning process that is inflexible and unable to be responsive to the individual needs of Participants.

Funding of Assistive Technology – Augmentative and Alternative Communication

Many people with disability have Complex Communication Needs (CCN); these are defined as difficulties with understanding or the expression of communication, which occur as a result of, or in association with, other sensory, cognitive or physical impairments. Individuals with complex communication needs may have little or no speech or have unintelligible speech. Many of these people benefit from the provision of additional or alternative methods of communication such as aids and devices.

Additional or alternative methods of communication, termed Augmentative and Alternative Communication (AAC) methods include symbol and text based boards, electronic tablets and Apps, and access supports such as mounting and switches.

Most people whose functional communication is compromised such that they would benefit from AAC will likely fit the eligibility criteria for the NDIS. Many, however, will not seek or require individualised funding across their lifetime. For many people, particularly those with acquired communication difficulties, it may be possible to provide them with a functional communication system (AAC) which meets their medium term and/or their longer term needs at one point in time.

For people with CCN the need for specialist assessments and intervention by speech pathologists is essential. Australian Institute of Health and Welfare data indicates that nine per cent of users of disability services have little, or no effective communication.ⁱⁱⁱ

There are currently very significant problems associated with access to AAC and associated supports for NDIS Participants with complex communication needs.

Speech pathologists report that the NDIS Planning process and the decisions made by the NDIS Planners themselves generally demonstrate a lack of understanding of the complexity of needs for individuals with disability and the complexity involved in developing an outcomes based plan for supports and services. Whilst the need for improved understanding of disability by Planners was recognised in the recent recommendations made by the Productivity Commission – this lack of understanding is particularly problematic when it relates to communication devices for Participants.

Reports from Speech Pathology Australia members relating to access to AAC for Participants with communication disability indicate the following (though there is the usual variation and inconsistency between Planners/NDIS regions):

- Repeated examples of Planners overriding clinical recommendations made by speech pathologists for particular AAC equipment to meet the individual needs of a Participant. In these cases, the recommendation has been denied outright for the Participant or the 'type' of AAC has been denied and an alternative approved (without input from the speech pathologist as to its appropriateness for the individual Participant).
- Seemingly arbitrary 'caps' placed on the amount that can be spent on AAC. A 'cap' of \$1000 is common – and is seen to reflect an erroneous (nor evidence based) presumption by Planners that any Participant with a communication need can have their needs met through the provision of an 'iPad' with Apps (equating to approximately \$1000).
- An assumption by Planners (despite appeals by speech pathologists and families) that an iPad with communication Apps will meet the Participant's communication needs. There are multiple problems with this, the least of which is that Participants with physical limitations may be unable to physically use an iPad.
- Planners refusing to fund the purchase of a tablet/iPad, and only approving the cost of the communication App within the Plan.
- Lengthy and administratively burdensome processes for speech pathologists (in conjunction with Participants and families) to appeal decisions made not to fund a particular AAC device. Speech pathologists are not funded to participate in appeals processes on behalf of Participants when seemingly arbitrary decisions have been made about funding specialised equipment by Planners who have limited (if any) knowledge about AAC.

- The listing of an AAC device in a Participant's Plan occurs during the Plan development stage, in isolation from any recommendations from experts in AAC provision, and is therefore not informed by expert advice. Due to current problems in reviewing Plans mid-cycle, there is a significant delay if the AAC device in the Plan needs to be adjusted based on a thorough assessment of their communication needs by a speech pathologists.
- An insistence that only one AAC device only will be funded through the NDIS. This presumes that a person's communication needs will be met in all circumstances by the one device. It is common for an individual to have a range of solutions that are part of their overall communication system. For example a person may have two electronic aided (speech generating) devices; for example, a more complex system for indepth conversation with family, along with a simpler system such as a single switch device with some 'quick' messages, to use when at a café, or catching public transport.
- This 'one item for the same purpose' principle has also meant that Participants who require both a non-electronic and an electronic aid are required to choose only one of these. This is at odds with best practice principles and can mean that participants may be left without a voice – for example when their electronic system 'fails', or when it is not appropriate to use (for example, when camping with their family or while at the pool).
- The variation in length of time to approve expenditure on an AAC device can be considerable. In some cases, approval has taken many months. This is unacceptable for Participants who have no other form of functional communication.
- Confusion and inconsistency by the NDIA about if a Participant can use their AAC device in a school setting. Speech Pathology Australia members have provided reports of Participants being told they are unable to use their device for 'educational purposes' (which the NDIS will not fund), demonstrating a lack of understanding of the purpose of AAC for people with communication disability. It is unworkable to have a child learn to communicate effectively with a particular AAC device in one environment (home for example), and then restrict them from using it in another setting, simply because it happens to be an educational setting. This is equivalent to not allowing a child with mobility issues to use their wheelchair at school.
- An incongruence between funding of AAC within one year's plan and the lifespan of the AAC. For example, an expensive (but appropriate) AAC device might be funded in the Plan for 2017 but may 'last' over ten years for that Participant. In regards to AAC, there appears to be no mechanism for spanning the cost of the item over the lifespan of the item within the NDIS Plans.

People in the disability sector with expertise in communication disability (including Participants themselves) are clear that these issues demonstrate a lack of understanding by the NDIS. This lack of understanding is about the unique needs of these Participants, the variable support options that should be made available, and of the standard recommended approaches to provision of aided AAC.

Problems with timely access to appropriate communication aids and equipment for NDIS Participants with communication disability essentially acts to 'gag' these Participants from complaining about the NDIS through the NDIA's verbally mediated complaints mechanisms.

Participants cannot communicate their complaint to the NDIS if they have not been provided with an appropriate communication device – but more importantly, they are unable to truly build their capacity and take the opportunities to exercise their choice and control across all aspects of their lives.

The Intermediate Report of the Evaluation of the NDIS indicated that a group of Participants who were not faring as well under the NDIS were those that find it difficult to advocate for themselves. Unfortunately,

Speech Pathology Australia has to report that the NDIS funding and rules related to AAC provision are likely contributing to the barriers experienced by this group of participants, through the restrictions that are being created to timely access to appropriate and evidence based communication aids.

c) The rollout of the Information, Linkages and Capacity Building Program

The proposed range and type of services, to be funded under the Information, Linkages and Capacity (ILC) program, appears to be consistent with the goals of the NDIS. The current processes for seeking applications for funding under the ILC does create a real concern that the ILC supports which are eventually established will be a random 'patchwork', designed according to the particular areas of focus and capacity of current organisations which have the wherewithal to apply for funding. There is a concerning potential for there to be many significant 'holes' in ILC supports. The NDIA has a role to play in providing a level of stewardship in the development to the ILC through the identification of areas of previously unmet need and emerging gaps. Most importantly, this needs to be informed by a dynamic and ongoing consultation with the sector, both service providers and people with disability.

Speech Pathology Australia members have reported that Participants need a greater depth of information about the types of interventions that may be appropriate for them than what is currently conveyed. Speech pathologists with considerable experience in the disability sector have identified that providing this information for people with disabilities, their families, natural supports and paid supports has often been part of an extensive process, embedded within a trusting relationship. The ILC needs to address the needs for participants to develop a shared understanding of the potential interventions that could address their needs, their benefits and any risks, including risks if they are not implemented, so that participants are able to make informed decisions. Communication accessible information which provides the evidence base for different approaches will enable participants to truly exercise choice and control, and help them identify the provider best able to provide high quality interventions that are relevant for them.

Also of concern is the allocation of a minimal amount of funding to the ILC and Local Area Coordinators (LAC) components of the NDIS. It is a widely reported view from the disability sector that there is a significant under-funding of the ILC in order to meet the needs of people with disability. Of particular concern is the significant component of this overall funding that has been allocated to LAC functions.

The parameters and value of the LAC functions to the overall Scheme, even in areas that are well advanced in their roll out of the NDIS, is unclear. The LAC function is variable across Australia and it is not clear what skills, qualifications and experience personnel who are employed as LACs should have.

It is understood that part of the role of LAC is to refer people with disability, who do not qualify for individual support under the Scheme, back to mainstream services. It is unclear if and how these mainstream services are meeting the needs of people with disability who are ineligible for NDIS. There is a presumption that these mainstream services exist and have capacity to meet the needs of these people, however there are significant access barriers to speech pathology services within education based settings, community health and rehabilitation as well as in early childhood intervention programs. These access barriers were extensively investigated by the Senate Community Affairs References Committee in their 2014 Inquiry into the Prevalence of different types of speech, language and communication disorders and speech pathology services in Australia.

Speech pathologists who work in mainstream services report to Speech Pathology Australia that planning and service design for their services presumes that the NDIS will 'pick up' the majority of people with

disability previously accessing their services. Some services are deliberately restricting their services for people they (the mainstream service) consider suitable for support under the NDIS – meaning – anyone with a permanent disability. Examples include redesigning the Child and Adolescent Mental Health Service in South Australia or the Child Development Service in the ACT. There is a vested interest in these mainstream services referring people back to the NDIS if they consider that they could be eligible under the NDIS funding stream for services. There may be a further financial imperative to do this if their operating budgets have been further retracted with an assumption of reduced demand due to transfer of demand to the NDIS.

It is of significant concern that the NDIA has not acknowledged the perceived conflicts of interest between organisations funded to provide LAC services who are also NDIS providers. It appears to be a systemic failure of the NDIS that organisations have been funded to provide LAC and supports funded in individual plans. Participants have reported a variety of different scenarios to Speech Pathology Australia members, each of which is of concern for different reasons. For example, members have reported that participants have been told by their LAC that they must: receive all of their supports from a particular service; reduce the number of providers they are seeing or discontinue seeing their regular therapist (even though they are an NDIS provider, and in many cases has been providing a service to them over a number of years).

d) Any other related matters

Administration and regulatory burden on speech pathology private practices

The speech pathology NDIS provider market reflects a small but specialised disability service within the NDIS market.

Speech pathologists in private practice are being actively discouraged from being NDIS providers due to burdensome administrative and regulatory processes. Administrative burden continues to be experienced in relation to the Provider Portal, communication with the NDIS and registration processes.

The breakdown of the NDIS My Place Portal in June – September 2016 had a profound and negative impact on the existing speech pathology NDIS workforce and has left many of the remainder of the speech pathology workforce feeling very reluctant to enter the NDIS provider market.

During the My Place Portal problems, speech pathologists were restricted from lodging claims for payment of services due to technical problems associated with the setup of their provider accounts or the setup of the participant's accounts. Delays in payment over a number of months was unable to be absorbed by many small practices and Speech Pathology Australia had reports of speech pathology business' closing, laying off staff, placing staff on unpaid leave and refinancing their businesses in response to the delays in payment for services already rendered to NDIS Participants.

Speech pathologists have consistently been financially disadvantaged (or directly 'out of pocket') as a result of poorly considered or communicated decisions by the NDIA. For example, a number of speech pathologists have reported that, after continuing to provide services to participants during the 'gap' between plans (as explicitly encouraged by the NDIS) they have been told that they will not receive payment for these service because the participant has been refused a further plan/funding. In other instances, speech pathologists have purchased items of equipment for participants after being told that they would be able to claim payment for these items from the therapy or transdisciplinary support part of the Participant's Plan, only to find that the support item which they used to claim against no longer exists on the Portal. After spending many hours trying to get information from the NDIS, they were finally

informed that a decision had been made to change the processes for claiming several weeks earlier, and they would not be reimbursed for resources purchased for the Participant.

Members have reported the 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). Many practices have resorted to employing additional administrative staff to work solely on NDIS administration processes in the transition. The additional excessive administrative burden cannot continue to be absorbed into the per hour NDIS fee for speech pathology services for many private practitioners. Speech Pathology Australia receives regular communication from speech pathologists who are delaying entering the NDIS market, reducing the share of their practice case load of NDIS clients and/or restricting service to self managed clients to avoid the costs associated with excessive administrative burden.

In line with the nationally consistent quality and safeguarding framework for the NDIS and per the bi-lateral agreements, each jurisdiction is currently managing a process of registering applicants to be NDIS providers. The current requirements for organisations to register for the different types of disability provider supports vary considerably across jurisdictions. Speech pathologists in WA, Victoria (VIC) and South Australia (SA) whose businesses are smaller single or multi-professional allied health practices are facing significant barriers to becoming registered as NDIS providers. We have received concerning feedback from many of our members seeking to be registered as NDIS providers in these states that they are being prevented from registering in a timely and efficient manner due to 'new' registration requirements that are administratively burdensome, and inappropriate when applied to private practitioners or single-therapy service providers. This registration process involves lengthy delays and are of significant direct cost for practitioners to meet the various requirements.

After detailed examination of the requirements of this process in each state and territory it is the view of Speech Pathology Australia that the requirements have been designed (and are entirely appropriate) for assessment of larger disability specific organisations. When these requirements are applied to small or solo allied health businesses, they act as a significant disincentive for speech pathologists to become NDIS registered providers within some states.

Similar problems have been experienced in some other states – with alternative arrangements now made for small speech pathology and occupational therapy practices within New South Wales (NSW) and in Northern Territory (NT).

We are supportive of processes that ensure that Australians with disability are protected and that services chosen and purchased through the NDIS are of high quality and are safe. We do not wish to see these safeguards 'watered down' – we do however believe that there is a need to streamline the assessment of suitability of small/solo speech pathologists in private practice to provide NDIS supports in WA, VIC and SA.

Travel costs

The Intermediate Report of the Evaluation of the NDIS acknowledges that there are concerns in the sector regarding the funding of therapist travel^{iv}. The NDIS decision to cap the funding each therapist can claim for travel has led to a range of access issues and administrative challenges for speech pathologists. It has led to reduced frequency of services for many rural and outer metropolitan Participants.

Funding rules and decisions relating to travel are emerging as a critical 'pain point' for speech pathology providers in the NDIS – with significant implications for the supply of speech pathology services to rural and remote areas. The allocation of travel costs needs to be balanced, ensuring the financial sustainability of the system while also considering the principles of choice and control upon which the

NDIS is based. The way in which funding decisions regarding travel are impacting speech pathology providers and Participants is complex and varied and needs immediate inquiry by the NDIA to resolve issues and to develop consistent and practical solutions to determining travel. These solutions need to be developed in consultation with provider organisations to ensure any policy changes are actually 'workable' for providers. Speech Pathology Australia and other allied health peak professional bodies are not direct providers of service (and as such, have no direct financial interest in the changes) and can work with the NDIA to develop solutions to the current 'travel cost' crisis.

Waiting times and service gaps

It is of significant concern that service gaps have emerged during the Trial and transition to the full scheme that have left particular groups of people with disability with no access to speech pathology services (and presumably other supports they require).

The most notable service gaps are appearing in relation to early childhood intervention supports as state-funded services offered through Community Health are retracted in anticipation that demand will be reduced as clients transition to become NDIS Participants and/or where Community Health allied health staff are directed to provide to NDIS participants on a fee for service basis. For example, in SA, the Early Childhood Intervention Services prior to the NDIS were limited (and significantly different in structure from those in VIC and NSW). Community health services in rural parts of SA are now being directed to prioritise NDIS participants aged 5–8 years of age (sometimes on a fee for service basis), younger children are no longer being seen by Community Health. This means that these children no longer able to see a practitioner to demonstrate 'evidence of disability' or 'evidence of developmental delay' which is required to access the NDIS. Families who are unable to afford private practice fees and cannot get in to see Community Health practitioners are consequently left in limbo.

In the ACT, the system has evolved differently with the closure of Therapy ACT and the opening of government funded Children Development Service (CDS). Reports from speech pathologists in the ACT indicate that the CDS's triage young children into the NDIS as a priority, with minimal services remaining to provide to children who are not eligible for NDIS. Reports indicate that the CDS has not been adequately resourced to keep up with the significant demand for children not eligible for NDIS, and as such, significant waiting times and restriction of service (a small number of consultations are offered only) are currently being experienced.

Other notable service gaps have emerged with the retraction of state-funded disability services in NSW where the state government Ageing Disability and Home Care (ADHC) has been retracted significantly; it is difficult for the market to provide and therefore for Participants to access services which were previously provided by (ADHC) speech pathology, in particular:

- Assessment, trial, prescription and intervention support for provision of electronic and non-electronic aided Augmentative and Alternative Communication (AAC)
- Information, training and direct support to facilitate the communicative participation of children with complex communication needs while at school (e.g. their ability to ask questions, or contribute to discussion, or direct their support worker, or engage in interactions with other children etc.)
- Contributing as part of a multi-professional team to development of positive behavioural support plans for people who use informal means of communication (i.e. use behaviours communicatively)

- Advocacy with and support for mainstream services to facilitate participation of people with communication and swallowing disabilities e.g. developing systems to ensure that people attending hospital have information available about how they communicate, and the supports they require at mealtimes.
- Multi-disciplinary team based assessment of oral eating and drinking difficulties
- Referral to and support for instrumental assessment of swallowing by health sector, and where appropriate the provision of recommendations
- Person centred communication accessible negotiation around mealtime supports
- Information and training for support workers around specific and individualised mealtime interventions and strategies to support safe, enjoyable and effective mealtimes

The reported transition of funding and service delivery for meal time supports from disability to the health sector does not offer a solution to this service gap at this point in time.

Recommendations

We request the Committee consider the following recommendations:

1. That the NDIA recognise the variability of supports required for people with complex communication needs requiring Augmentative and Alternative Communication (AAC) and seek advice from Speech Pathology Australia to develop processes to determine appropriate guidelines for the funding of AAC.
2. Clarification be provided urgently regarding the roles, responsibilities and service delivery parameters of State/Territory Departments of Education and the NDIS in supporting students with disability.
3. Urgent clarification be provided regarding the roles, responsibilities, funding and service delivery parameters of State/Territory/Federal Departments of Health and the NDIA in supporting people with meal time needs associated with their disability.
4. The NDIA examine travel expenses/rulings specifically and work with providers and peak bodies to determine consistent and practical solutions to facilitate access to services.
5. Carry out an audit of the NDIS planning and complaints process to determine if it is communication accessible for people with communication disability.

If Speech Pathology Australia can assist the Committee in any way or provide additional information please contact Dr Ronelle Hutchinson, Manager of Policy and Advocacy

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- i Australian Bureau of Statistics (2012) Australian Social Trends – Using Statistics to paint a picture of Australian Society
- ii Mavromaras, K., Moskos, M., and Mahuteau, S. (2016) Evaluation of the NDIS, Intermediate Report, National Institute of Labour Studies, Flinders University. Adelaide. Pg 11
- iii Australian Institute of Health and Welfare (2015) Disability Services National Minimum Data Set (DS NMDS) collection, accessed 28 February 2017, <http://www.aihw.gov.au/disability-data-cubes/>
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