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Speech Pathology Australia's submission to the **Australian Government's Department of Social Services' consultation:** the NDIS Act Review and NDIS Participant Service Guarantee

31 October 2019



The Speech Pathology Association of Australia Limited ABN 17 008 393 440

NDIS Consultations Department of Social Services GPO Box 9820 Canberra ACT 2601

NDISConsultations@dss.gov.au

Dear Sir/Madam

Speech Pathology Australia welcomes the opportunity to provide feedback to the Australian Government's Department of Social Services' consultation regarding the NDIS Act Review and NDIS Participant Service Guarantee.

As you are aware Speech Pathology Australia is the national peak body for speech pathologists in Australia, representing more than 9500 members. Speech pathologists are university-trained allied health professionals with expertise in the diagnosis, assessment and treatment of communication and swallowing disabilities.

We commend the Department's intent to make the NDIS process simpler and remove barriers to positive participant and provider experiences with the NDIS. While we acknowledge that there have been some attempts to address many of the system-wide issues and failings of the scheme since its roll-out, such as the NDIS Pathways reform, changes to assistive technology processes and interim plans for eligible children whose support needs are not considered complex, there remain significant issues regarding inequitable access to the scheme, inconsistent interpretation of eligibility criteria as well as shortcomings with the planning processes.

We are mindful that many of the concerns we raise below have been highlighted in numerous forums and therefore provide only brief descriptions of these issues as we feel that practical solutions and recommendations will be more useful. We do still however, where appropriate, include feedback from our members working with NDIS participants and their families/carers to illustrate these problems. Our feedback is prefaced with brief background information about communication disability and swallowing difficulties and the role of speech pathologists.

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

Once again thank you for the opportunity to provide feedback to this important review.

Yours faithfully

Tim Kittel National President

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Introduction

Speech Pathology Australia welcomes the opportunity to provide feedback to the Australian Government's Department of Social Services' consultation regarding the NDIS Act Review and NDIS Participant Service Guarantee. We have structured our comments in response to key areas of focus and topics raised in the Discussion Paper that we feel are relevant to speech pathology, and conclude with recommendations that we hope you find useful. We would say, in summary, that *all* of the suggested standards or participant guarantees are appropriate, and that none should be, or should need to be, prioritised over others. They all come together to define person centred, strengths focused and 'customer' focused service, which should be the baseline of service that people with disability should expect from the NDIS. Planners should not be the new gatekeepers to access to the reasonable and necessary supports for people with disabilities.

We preface our comments with background information on communication and swallowing disability and the role of speech pathologists.

About Speech Pathology Australia

Speech Pathology Australia is the national peak body for speech pathologists in Australia, representing over 9500 members. Speech pathology is a self-regulated health profession through Certified Practising Speech Pathologist (CPSP) membership of Speech Pathology Australia. The CPSP credential is recognised as a requirement for approved provider status under a range of government funding programs including the NDIS.

As the national body regulating the quality and safety of speech pathology practice in Australia, Speech Pathology Australia is also well placed to monitor and progress workforce developments and initiatives. Speech Pathology Australia accredits the 26 university entry-level training courses for speech pathologists in Australia, evaluates requests for recognition of overseas qualifications, administers the continuing professional development (CPD) program for the profession and provides mentoring and support programs to the significant cohort of new graduate/early career speech pathologists currently within the speech pathology workforce. The Association acts as the self-regulatory body for the profession. Quality and safety of speech pathology practice is regulated for members with requirements mirroring that required by the National Registration and Accreditation Scheme in relation to monitoring and systematic mechanisms for quality and safety in the delivery of health care. The Certified Practising Speech Pathologist (CPSP) program is the foundation of speech pathology as a self-regulated health profession.

About people with communication disability

The Australian Bureau of Statistic's 2015 Survey of Disability, Ageing and Carers (SDAC), estimated that 1.2 million Australians had some level of communication disability, ranging from those who function without difficulty in communicating every day but who use a communication aid, to those who cannot understand or be understood at all.¹

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

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

Difficulties in speech, language, fluency, voice, and social communication can occur in isolation or the person may have difficulties in more than one area. These difficulties can negatively affect an individual's academic participation and achievement, employment opportunities, mental health, social participation, ability to develop relationships, and overall quality of life.

Communication disabilities can arise from a range of conditions that may be present from birth (e.g. Down Syndrome or Autism 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). The prevalence and complexity of these disorders increase with age as both communication and swallowing functions are vulnerable to the natural ageing process; therefore, with an ageing population, prevalence and subsequent demand for supports will increase.

Some people with disability have complex communication needs (CCN) which are difficulties with understanding or the expression of communication, associated with additional physical, cognitive or sensory impairments. Many people with CCN benefit from the provision of alternative or additional methods of communication, including aided Augmentative and Alternative Communication (AAC) such as communication books, boards, speech generating devices and accessible IT for phone and internet-based communication.

The role of speech pathologists

People with communication and swallowing disability span the entire age range and the nature of their difficulties impact on most areas of life. These people frequently require interventions and supports from multiple areas of public service (including health, disability and education sectors, and mental health services). Speech pathologists, as experts in the assessment, diagnosis, and treatment of communication disorders are essential members of multi-disciplinary teams providing services to people with disability.

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. Speech pathologists use their diagnostic capacity to provide tailored and individually targeted intervention solutions to achieve functional outcomes. Some speech pathologists working in disability focus their practice on the assessment and provision of communication aids for people with complex communication needs (CCN). This is a specialised area of the NDIS workforce. Speech pathologists working in this specific area of clinical focus typically develop their skills over many years working with people with CCN.

Speech pathologists also provide valuable contributions to the assessment of decision-making capacity and the facilitation of supported decision making for people with communication support needs. This includes developing communication accessible health information and decision-making procedures and protocols. In addition to identification of disease/disorder, assessment and intervention, speech pathologists can also provide counselling/support to families and caregivers, education of other professionals, case management, consultation, and advocacy. Communication partner training, including staff training, is considered an essential part of a speech pathologist's work.

Speech Pathology Australia's specific comments relating to relevant topics and questions raised in the Discussion Paper

Eligibility and access to the NDIS

Since the initial rollout of the NDIS we have consistently received feedback from our members highlighting significant challenges facing not only NDIS participants accessing the supports they need, but also for some people with disability being deemed ineligible to join the scheme.

Access issues for those deemed ineligible

The current Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability's defines 'neglect' as '*depriving a person with disability of the basic necessities of life such as food, drink and <u>medical care and treatment</u> (highlight added).*

We concur with this definition and argue that the existing eligibility criteria and its interpretation, which is resulting in many individuals who we feel should be supported through the NDIS being excluded from the scheme, is a form of neglect. Eligibility criteria need to change, not only to ensure everyone with a disability, regardless of its complexity, is able to participate in the scheme but criteria also need to be unambiguous, so it is not subject to interpretation.

We have received many reports of inconsistencies in access whereby a planner has determined that an individual referred to the NDIS by a Speech Pathology Australia member, is not eligible for the scheme, 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 for, 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.

Furthermore, interpretation of the eligibility criteria by planners that a child MUST have therapy needs from more than one allied health profession and/or in more than one functional area, has restricted access to ECEI for children who have life-long conditions such as Developmental Language Disorder and Childhood Apraxia of Speech. These are children whose communication is severely compromised and who will go on to have lifelong communication disability, but at this point in their development may require therapy from only one discipline e.g. speech pathology. But planners are interpreting a section of the definition of developmental delay in the Act that it *results in the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services that are of extended duration and are individually planned and coordinated as meaning that to be eligible they must require multidisciplinary supports. Children who only require support from a single therapy area are being excluded from the NDIS ECEI.*

This is denying timely access to early intervention for children aged under 7 years, which not only seems contrary to the insurance principles of the NDIS, but also represents a costly missed opportunity to potentially address some of the significant risk factors these children face for longer term issues with literacy, learning, emotional and social well-being and the subsequent impact on their vocational and mental health outcomes.

Another group who are facing challenges in accessing the NDIS are people with mental health conditions. It is likely that this is due to difficulties with understanding written and other forms of information, and reduced capacity to manage the process of gathering and submitting the 'right' amount and type of evidence to support their application. Greater supports are therefore required to help people with mental

health conditions, and any support partners they may have, to undertake the application process. This can be done by using accessible language, providing information in a range of modes including Easy English.

Access issues for NDIS participants

Our member feedback highlights many examples of NDIS participants being unable to access the necessary supports they require in a timely manner. The major access challenges facing NDIS participants include:

- Significant delays we are aware of participants having to wait, often for months, for Access requests to be considered and a determination made on whether a Plan is appropriate, planning meetings to be scheduled, plans to be provided and then made active and available on the Portal, and for NDIA decisions on reviews of reviewable decisions.
- Various problems with Plan 'build', including: levels of therapy included in plans falling outside of what has been identified by the provider, or the person providing the supporting documentation, as 'reasonable and necessary', omissions, funding being allocated to support items which neither the participant nor the relevant provider are able to access, and significant inconsistencies regarding the levels of service/therapy being included. The NDIS claims that these differences in Plans reflects individual differences in participants – but our members' observations are that it seems more to reflect individual differences in planners.
- Difficulties in accessing appropriate Assistive Technology equipment. We understand that a new process, including an AT Assessor, has been piloted, but there has been no further information about the pilot, its outcomes or whether and when it will be implemented more broadly. SPA has serious concerns about how the AT Assessor panel would be able to access the necessary knowledge, skill or expertise to assess whether and what type of Augmentative and Alternative Communication Assistive Technology may provide the optimal solution for a participant, and how the role of the AT Assessor will intersect with that of the speech pathologist and other allied health providers supporting the participant.
- Planners' lack of knowledge/training regarding the types of activity and participation barriers experienced by people with communication disabilities, how speech pathology supports can ameliorate or eliminate these, and what type and quantum of supports may be required to enable the participant to achieve their social, economic and other participation goals and outcomes.
- Recommendations from skilled and experienced allied health practitioners are being ignored or overturned by planners.
- Unnecessary and stressful reassessments for those with developmental disorders to in effect 'prove' that they have a long term/permanent disability.

These issues are discussed in more detail in the following section as they are often a consequence of problems with the planning process

Challenges faced by NDIS participants in the planning process - creating, using, reviewing and amending plans.

Significant delays

We are aware of participants still having to wait, in some cases for months, either for plans to be submitted, for NDIA decisions and/or reviews. For example, we have received a report whereby an ECEI planning meeting was delayed by a year as the NDIS planner(s) continually contacted an Indigenous family who had literacy difficulties by mail, despite the family having specifically requested at the onset of their engagement with the NDIS, that the provider – in this case a speech pathologist – be contacted to arrange and lead the planning process on their behalf. The lack of response from this vulnerable family resulted in their being 'taken off the list' by the ECEI partner organisation and the speech pathologist having to follow up and appeal the process on their behalf, at a cost of many unpaid hours, and significant emotional burden. Another issue that has caused delays to access NDIS supports and services, and unnecessary added frustration and administrative burden to families, is the loss of ECEI applications/files. This seems to be occurring for several reasons including NDIA IT problems, administrative lapses or communication breakdown, indeed one family has reportedly had their application "lost" <u>six</u> times.

"I am in the process of applying for my son. They have lost the forms 6 times and I ended up hand delivering them to the local NDIS office. I follow up each email two days later to ensure that the documents have been received and can be opened"

We understand this to be a nationwide issue, however it was particularly notable in the Melbourne area when children's files were being transferred from ECIS services, but the following quote is from a Speech Pathology Australia member based in Queensland forwarded to the Association as recently as August 2019:

"I have had an increasing number of children whose parents have applied for the NDIS for them, wait for months, contact the NDIS and are unvaryingly told their applications have been lost and they need to do the whole thing again"

Inadequate levels of therapy being included in plans, omissions and inconsistencies regarding levels of service/therapy.

There have been numerous examples of plans having inadequate levels of therapy, not including key supports that are reasonable and would be considered necessary by anyone familiar with these specific disabilities. There are omissions and inconsistencies regarding levels of service/therapy prepared for individuals with similar functional needs and even overfunding of supports and therapy. Planners are making decisions about 'how much support' for therapy is provided and what would be needed in NDIS plans for the participant to achieve their goals, without reference to the advice from technical advisors/experts (including speech pathologists). This has led to numerous instances where the number of speech pathology sessions listed in a plan is far above or below that which the evidence recommends for clinical efficacy (and change in functional status) for that condition.

In a number of recent forums attended by representatives from Speech Pathology Australia, some NDIA staff have made comments that seem to imply that it is not intended for the NDIS to provide enough funding to address **all** of the participants' needs and that 'choice and control' over what they spend their funding on is increasingly meaning an either/or choice. For example, it seems that the NDIA position is that participants with communication and swallowing disabilities will continue to receive the same level of

funding for capacity building supports, and will need to 'choose' between accessing supports to be able to eat and drink enjoyably, effectively and safely, *or* therapy that helps them learn communicative strategies to be able to participate more fully in their family and community.

The shift from block grant funded providers to individual participant funded plans under the NDIS seems to be resulting in a shift in who is responsible for making decisions about the 'rationing' of funding for services and equipment. This would be in complete contradiction to the intent of the scheme and the recommendations of the Productivity Commission: to 'fix' what was considered a broken system and create a new way of providing disability services by which Australia is able to meet its obligations under the United Nations Convention on the Rights of Persons with Disabilities.

Difficulties in accessing appropriate Assistive Technology equipment

Regarding the provision of aided Augmentative and Alternative Communication (AAC) Assistive Technology, planners are not adequately trained, and/or are without the necessary competencies, to understand and apply the NDIS guidelines appropriately or effectively. For example, planners are reporting to participants that the NDIS does not purchase iPads because they are considered mainstream technology, so are refusing to fund the purchase of a tablet/iPad, but approving the cost of the iPad communication App. This has led to providers having to recommend (often much more costly) dedicated electronic AAC devices because the family or participant are not able to purchase the cheaper iPad, the sole purpose of which is to support communication and participation. Planners are therefore inadvertently making decisions which are completely contrary to the NDIS principle of value for money. There is also the added pressure and concern about having to find a registered provider who sells the required piece of AAC equipment under the NDIS in time before funding expires. This is one of many examples where planners are trying to implement a 'directive' or operational 'rule', rather than demonstrating an ability to interpret and apply the 'reasonable and necessary' criteria in a flexible way based on a true understanding of the principles.

Planners lack of knowledge/training regarding the support requirements of people with communication disabilities

It seems that planners are frequently making decisions about the provision of speech pathology supports, including the model of service delivery, based upon simplistic and reductionist views about what speech pathology interventions are or should be. Many planners are making important decisions regarding eligibility and supports with little or no experience or knowledge of disability and the complex needs of some participants.

While we would not expect NDIS planners to have in-depth knowledge of <u>all</u> types of disability, we would expect criteria guidelines and protocols within the scheme to help planners access professional input and advice when required. For example, the distinction between developmental delay and disability in early childhood is clinically complex and not straightforward even for clinicians. The current inability of planners to understand and address complex needs is causing delays for participants to access the scheme as their eligibility is being queried and more information sought. It also results in inappropriate levels and types of support being approved. Not only are these consequences stressful for participants and their families but also results in unnecessary appeals.

"a 5 year old with virtually no speech who takes 6 months to be deemed to meet [ECEI] criteria is a joke. a 3 year old with a genetic duplication that has a 97% chance of having an intellectual disability, ASD, mental health disorder etc etc to be asked for further information when the paediatric letter says he has little language, is a joke. I have many other examples of long waiting times to meet criteria for these little ones - kids that have obvious needs. They have turned the family centred approach of Early Intervention into a bureaucratic nightmare particularly for many families who are less able to negotiate and advocate for their kids"

"One of my speechies' NDIS families has been told by a planner that speech therapy does not work in Downs Syndrome folk over the age of 15."

"I had a client who called up about her daughter's application and was told it had been "closed" due to "not enough evidence". This child is 3.5, has an Autism diagnosis, and is non-verbal. We were in disbelief. They hadn't even told the family that it had been closed, the [family] thought they were waiting on a planning meeting. So they are starting again".

Recommendations from skilled and experienced allied health practitioners are being ignored or overturned by planners

There are also cases of planners overturning or ignoring professional recommendations for equipment and services, as well as feedback that they are not reading provider reports and are therefore ill-prepared for planning meetings. We are aware of cases whereby a recommendation made by an experienced speech pathologist has been denied outright for the participant or where a type of AAC equipment has been denied and an alternative approved without consultation with the speech pathologist as to its appropriateness for the individual participant.

"I've had a client knocked back for a LAMP app (which he uses functionally to communicate). I didn't apply for a dedicated device because all those requests were getting knocked back, so I tried to help NDIS and suggest a cheaper option. The reason the planner gave her was "children under six shouldn't be using that sort of technology to Communicate, they are too young". Who are these people? What is their background in AAC? I'm a disability clinician, but I am starting to think this is all too hard now that NDIS is in town."

Many members have also reported incidents where planners have made incorrect decisions which impact on timely access to reasonable and necessary supports, based on outdated operational guidelines which our members are aware have been modified. In these situations, it is often extremely difficult, if not impossible, to be able to correct, or even raise a question about the planner's decision.

Unnecessary and stressful reassessments for those with developmental disorder to in effect 'prove' that they have a long term/permanent disability.

Our member feedback regarding the reassessment process shows that it mainly applies to children as they turn seven years of age and shift from ECEI services to the mainstream NDIS. Those with developmental disorder often must go through a reassessment process to 'prove' that they have a long term/permanent disability. This is an unnecessary and stressful process as families face the possibility of being told that their child is ineligible for the scheme and that their funding and support will therefore cease. It is a similar situation for children who have been given an initial short-term NDIS plan for six months, as the NDIA appears to be waiting to see if the child is still considered eligible (i.e. they 'still have a disability') six months later. This is putting families, many of whom are already vulnerable and under a huge amount of stress, into an added state of uncertainty and anxiety.

The review process and amendments to plans

"Scheduled plan reviews are not being held on time - managing this from an administration point of view is time consuming and difficult - especially if clients are NDIA managed"

Feedback from our members indicates that requests to review a plan outside of the standard one-year cycle are taking a minimum of six months, leaving participants in limbo, and creating significant distress. There should be delineation between scheduled plan reviews, and those which are requested by the participant or their family due to an error, or because there has been a request for a review of a decision.

A process to 'triage' plan review requests needs to be developed and consistently implemented. It would save time and participant frustration and anguish to distinguish between reviews which are 'significant' and those which are less complex. For example, changing the way a plan is being managed should, in most cases, be a simple process and quickly implemented but it seems that all reviews are just put on the list and addressed in date order. Plan errors, such as funding being placed in the incorrect category, should also be managed quickly and efficiently to lessen the impact of such administrative glitches upon the participant.

Additionally, if the planning process is improved and participants receive plans that meet their needs, and do not contain errors, then hypothetically this would result in a reduction in unscheduled plan reviews, and subsequent complaints and escalations to the Administrative Appeals Tribunal (AAT).

"We are 8 months into zero response to a review of a reviewable decision and a complaint. We've been to pollies. We've been everywhere. No one will help until the NDIS have completed their internal review. But they seem to be getting around that by just not doing it"

We therefore concur with the suggestion in the Review Discussion Paper to introduce 'plan amendments' to avoid the need for every change to go through a full review process, and we would recommend that <u>all</u> straightforward changes can be changed through a plan amendment. Tight timeframes must be set for 'rapid reviews'. We would recommend a one week turnaround.

Appealing a decision

We would argue that a shift in focus from one that prioritises applying a restrictive and arguably detrimental focus on the scheme's financial 'sustainability' to focus instead on providing relevant and adequate 'reasonable and necessary' supports, would help reduce the number of appeals to the Administrative Appeals Tribunal (AAT). Ensuring the scheme is responsive and efficient will require the provision of clearer guidelines and training to ensure that participants receive the supports they need in a timely manner and are not having to appeal decisions regarding eligibility and/or where required supports have been denied, excluded or delayed.

This constant focus on budget is not only causing anguish, and in some extreme cases actual harm to some of society's most vulnerable, but also placing an unnecessary cost burden on the scheme. Money that should be used to provide the services and supports participants need in the first instance, is being wasted on administrative appeals against poor decisions and inappropriate allocation of funding.

The current scheme is so flawed that some participants and their families are being forced to take extreme action, including unnecessarily involving the Administrative Appeals Tribunal or tactics (as described in the member feedback below) simply to get original unfair decisions reversed. As this feedback also highlights, the most vulnerable are not able to self-advocate, placing them at a disadvantage regarding their levels of support. Participants and their families should never be placed in a

situation whereby they have to act so forcefully to be allocated the appropriate funding for the supports that they require, which are often in the end deemed to be reasonable and necessary.

"I had a parent do this exact thing last week with her severely complex child - 4 hrs in the NDIS office with her child eventually led to an immediate change in plan and a meeting scheduled with a very high up person in the NDIA."

"It has been the ones that are prepared to fight and advocate tirelessly who end up having their requests met by the NDIA. I had a particularly tenacious parent who told me she refused to leave the office until her plan was increased. She told me she sat there for hours until they eventually came around! I find stories like these particularly disturbing as [it] shows how inconsistent it can be. It also leaves our most vulnerable clients (low levels of literacy, low SES backgrounds, minimal English skills, etc.) in a position where they're more likely to accept whatever is given to them. "

"I applied for an internal review, they upheld their original decision, I applied to AAT, about 2 weeks before the scheduled mediation meeting they started contacting me to discuss things and the day before the meeting we reached agreement on a new plan. I got everything he needed. "

The legislative framework – recommendations to streamline processes and remove barriers and suggested amendments to the wording of the Act

Recommendations to streamline processes and remove barriers

Eligibility and access

- Information about the Scheme, its role and purpose, and the Access criteria needs to be available in communication accessible formats, including in Easy English, and via face to face exchange with knowledgeable, respectful and trusted providers.
- Much of the language which is currently used within the NDIS is not easily understood by many
 potential participants. It is highly recommended that the terminology used within the NDIS is modified
 to make it more meaningful and accessible. This would also have the added benefit of helping to
 clarify for ALL stakeholders the aims and intent of the Scheme.
- Ensure that planners have the skills to be able to apply the eligibility and access criteria in an appropriate way, which allows for the huge variation in the goals and outcomes people with disability wish to achieve, the range of activity and participation barriers they may face, and the depth and breadth of supports which can be offered including by speech pathologists to help them to achieve their goals. As an example, the current ECEI criteria requires a more sophisticated understanding of early childhood delay and disability than currently exists by those making eligibility decisions. Speech Pathology Australia would be happy to assist the NDIA to help clarify what 'types' of children and functional problems would benefit from what type of service and support through the ECEI.
- The early intervention developmental delay criteria are currently being applied by the NDIS in a way which excludes children who are experiencing significant barriers to their development, and impairment of their functioning. The Access criteria need to be modified so that these children are able to access a Plan and be provided with the services they require, despite the fact that the model of service delivery which they need may not be a 'key worker transdisciplinary' model. Specifically, children under seven years of age, with a diagnosis of Developmental Language Disorder (DLD) and/or Childhood Apraxia of Speech (CAS) should not be deemed unable to access the NDIS simply because they are not necessarily best served by the transdisciplinary/key worker, or multiprofessional allied health services model, provided they meet the other Access criteria.
- As functional impacts associated with DLD and CAS can and do persist into adulthood, we
 recommend that children aged over seven years, adolescents and adults who have these diagnoses,
 may also experience functional impacts on participation which also meet the criteria for access to the
 NDIS and to a Plan, based on the COAG principles and the NDIS Act Disability Requirement.
- The KPI for Access needs to be flexible and correspond with the needs and context of the
 participant in some cases there should be an option for an 'urgent' Access decision, whilst in others,
 it may be appropriate to take longer in order to enable true engagement and involvement in decision
 making with the participant.
- The current approach by the NDIS to accessing adequate and relevant evidence to make appropriate
 and informed access decisions seems to reflect an anxiety that people will provide inaccurate or false
 information in order to provide Access for participants who may not actually fit the criteria in the Act.

Unfortunately, this has meant that professionals supporting families have been left 'guessing' what information is useful or necessary, and this in turn leads to instances where participants who do in fact meet the Access criteria are either denied access, or their access is delayed. Increased information and support for professionals to understand the types of evidence that should be provided, including an openness about explicitly seeking further supporting evidence would reduce delays and also enable professionals to better support applicants to the Scheme.

- Explore the use of the International Classification of Functioning and Disability (ICF) and the
 International Classification of Functioning and Disability Child and Youth (ICFCY) as the framework
 for determining access and contributing to determining support needs. The ICF and ICFCY offer the
 potential to provide a more consistent and objective basis for determining the level of functional
 impact of a person's disability whereas the current assessments being used by the NDIS lead to a
 focus on 'burden of care' and 'deficit'.
- It has been suggested that ECEI partners have 'quotas' for the percentage of children who present to them who are then given access (i.e. Plans). If this is the case, it is of great concern. There must be clear and consistent evidence that Access is based on reasonable and necessary need, NOT quotas.

Planning

- Ongoing training and professional development of planners is essential to ensure they have adequate knowledge to be effective in their role so that participants have timely access to the support and services they need. We would be more than happy to support and advise the NDIA to help upskill their planning workforce to have a better understanding of communication disabilities, swallowing disorders and supports such as AAC devices, as well as raise awareness regarding the roles of speech pathologists. (This offer has been made many times).
- Provide increased professional supervision and support for Planners in relation to both their Access
 decisions, the supports provided in Plans, Plan builds and responding to review of a reviewable
 decision.
- Improve processes for change management within the NDIS. There are many instances where Planners continue to make decisions which are based on now outdated and inappropriate operational guidelines.
- Create more targeted 'specialist' Planner teams and/or Planner Advisors including for participant groups with specific developmental and acquired disabilities (Cerebral Palsy, Motor Neurone Disorder, Cerebrovascular Accident etc) to provide improved processes to determine the 'reasonable and necessary' supports where there is potential for this to be very varied and/or rapidly changing.
- Delineate between scheduled plan reviews, and those which are requested by the participant or their family due to an error, or because there has been a request for a review of a decision. A process to 'triage' plan review requests needs to be developed and consistently implemented. We concur with the suggestion in the Review Discussion Paper to introduce 'plan amendments' so that <u>all</u> straightforward changes to plans can be made without a full review process.
- Reduce the complexity of Plans and access to supports and provide better quality and more
 accessible information for participants about the different plan management options and the benefits
 and potential costs associated with each along with improving communication with participants about
 how their Plan is structured.

Governance

- There is currently no means to assess the adequacy (or not) of supports provided in Plans, and consequently, no accountability for planner decisions and the NDIS. Given the incredible impact on participants of planners' decisions about the level of supports provided, creating more robust means to evaluate that Plans are providing supports in the most efficacious way, and are leading to intended outcomes particularly in allied health service delivery is a much-needed component of providing appropriate Clinical governance for the NDIS.
- Improved data collection processes are required to facilitate determination of allied health services being sought by (and provided to) participants via their capacity building supports. Currently this is only available for physiotherapy and psychology.

Suggested amendments to the wording of the Act

To address the issue of eligibility criteria being interpreted by planners as meaning that a child must require intervention from more than one therapy discipline (currently resulting in children who require therapy from only one type of therapy discipline being excluded from the scheme), we would recommend deleting '(c)' under the definition of *developmental delay* as highlighted below. Alternatively, the wording in the Act could be modified such that it more clearly and consistently achieves its purpose i.e. to provide access to the ECEI partners and/or to an NDIS plan for children who either do not yet have a diagnosis, or whose diagnosis is not (currently) on List D - particularly when they would otherwise meet the Disability Access criteria.

Part 4—Definitions

9 Definitions

In this Act:

developmental delay means a delay in the development of a child under 6 years of age that:

- (a) is attributable to a mental or physical impairment or a combination of mental and physical impairments; and
- (b) results in substantial reduction in functional capacity in one or more of the following areas of major life activity:
 - (i) self-care;
 - (ii) receptive and expressive language;
 - (iii) cognitive development;
 - (iv) motor development; and
- (c) results in the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services that are of extended duration and are individually planned and coordinated.