

**Speech Pathology Australia's submission to the
National Disability Insurance Agency
Consultation: 'Supporting you to make your own decisions'**

10 September 2021



**National Disability Insurance Agency
Agency Policy Division**

Via email: agencypolicy@ndis.gov.au

To whom it may concern,

Speech Pathology Australia welcomes the opportunity to provide feedback to the National Disability Insurance Agency's consultation on supported decision making. As you are aware, Speech Pathology Australia is the national peak body for speech pathologists in Australia, representing more than 12,000 members. Speech pathologists are university-trained allied health professionals with expertise in the assessment, diagnosis and treatment of communication and swallowing difficulties.

Speech Pathology Australia recognises the need to support participants to make and be involved in decision making, and wish to acknowledge the consultation that the Agency is undertaking as an important first step. It is vital that the rights, preferences and will of people with disability are respected. The Association does however have several concerns regarding the proposed process, primarily how it does not address communication disability, and the ability to communicate has been confused with the level of autonomy and capacity to make decisions.

The Association strongly challenges this notion, and asserts that if a person with disability also has complex communication needs, this does not exclude them from making or being involved in making decisions. Rather, this highlights the crucial need for access to effective and personalised communication options including augmentative and alternative communication, and the right of every person to be able to communicate should be the cornerstone of the supported decision-making process.

We provide more detail on these issues below in our response to the relevant consultation questions and make recommendations that we hope the Agency finds useful. To inform our feedback we have held focus groups with our members and used their comments to augment our response. We preface this with brief background information about communication disability, communication access and the role of speech pathologists. As always, we would be very willing to meet directly with the NDIA to provide more detail of the issues we highlight in our submission and to discuss potential solutions.

In the meantime, if Speech Pathology Australia can assist in any other way or provide additional information please contact Ms Amy Fitzpatrick, Senior Advisor Disability, on 03 9642 4899 or by emailing afitzpatrick@speechpathologyaustralia.org.au.

Yours sincerely



Tim Kittel
National President

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Introduction

Speech Pathology Australia welcomes the opportunity to provide feedback to the NDIA's consultation paper: *Supporting you to make your own decisions*. The Association wishes to commend the NDIA on recognising the importance of this issue and conducting this consultation process. We have structured our feedback in response to the questions we believe are relevant to speech pathology and provide examples from our members where applicable/appropriate. We preface our comments with some background information on communication disability, communication access, and the role of speech pathologists.

About Speech Pathology Australia

Speech Pathology Australia is the national peak body for speech pathologists in Australia, representing over 12,000 members. Speech pathology is a self-regulated health profession through Certified Practising Speech Pathologist (CPSP) membership of Speech Pathology Australia. The CPSP credential is recognised as a requirement for approved provider status under a range of government funding programs including the NDIS.

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

About communication disability

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

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

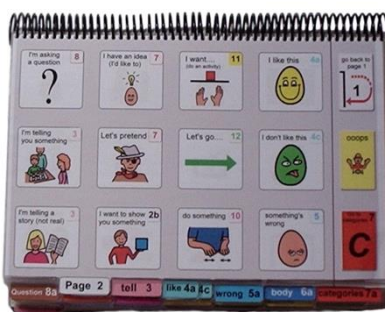
Communication disabilities can arise from a range of conditions that may be present from birth (e.g., Down Syndrome or Autism), emerge during early childhood (e.g., Developmental Language Disorder, stuttering, severe speech sound disorder), or during adult years (e.g., traumatic brain injury, stroke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

Some people with disability have complex communication needs (CCN), which are difficulties with understanding and/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 technology for phone and internet-based communication.

Augmentative and alternative communication refers to methods of communication that either support speech, where speech is difficult to understand (unintelligible) or as an alternative to speech, when speech is very limited, or the person has no speech.

AAC can include 'unaided' methods of communication such as signing and gestures, body language and facial expressions; it can also include 'aided' communication, using pictures, symbols, text and spelling with paper-based or electronic resources. Communication software on an iPad or a dedicated speech generating device can provide a voice for people. AAC needs to be sufficient to enable a person to use language – however, it is in a different form to what most people use day to day.



People with severe communication impairments include those with acquired brain injury (e.g., stroke, traumatic brain injury), neurodegenerative disorders (e.g., Parkinson's disease) and developmental disabilities (e.g., cerebral palsy, intellectual disability, autism). In Australia there are thousands of individuals with CCN who have a severe/profound core activity limitation affecting their communication. In 2018, of the 4.4 million Australians who had disability, almost 3.9 million people had a limitation with the core activities of communication, mobility or self-care and/or a schooling or employment restriction. As a proportion of the Australian population: 3.2 per cent had a profound limitation and 2.6 per cent had a severe limitation.ⁱⁱ

People who have “severe to profound” cognitive disability often rely on informal communication such as body language, facial expression and gestures to communicate their needs and wants. They may have associated challenging behaviours, such as yelling or hitting, as a result of feeling frustrated that their communication signals are not being identified, acknowledged or responded to.

Communicative participation

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

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

People with CCN experience a range of barriers to participation in community life. For example, having questions addressed to their support worker rather than themselves, being treated and spoken to like a child despite having normal intellect, being unable to use public transport because they are unable to verbally convey their destination, or being unable to order what they wish at a cafe because the waiter is too busy (or embarrassed) to persist in trying to understand what they want.

Communication access

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

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

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

Just as adjustments to the built environment help remove physical barriers faced by people with disability - such as kerb cuts - improving communication access, particularly to government services such as education, health and justice sectors helps remove the discriminatory barriers faced by individuals with a communication disability.

Communication access is as important as physical access to people with disability if they are to participate fully in social, economic, sporting and community life and is in line with the UN Convention on the Rights of Persons with Disabilities: Article 9 - Accessibility, which, in addition to stating the need to address barriers in the built environment also highlights the need to take into account **all** aspects of accessibility.

Communication, by definition, involves at least two people. This means that those people who are in the community and could, or will, be interacting with a person with communication disability are a significant part of the 'environment' which may require 'modification' to enable access.

Supports can be provided to improve inclusivity and accessibility around expressive communication difficulties (i.e., being able to *send* messages to others such as expressing their preferences or choices), but also to be able to *receive* or understand messages. This is of particular importance in situations whereby information about processes individuals may be involved in, options and choices that may be available to them and the potential consequences of their choices need to be successfully *sent* and *received*.

Communication access does not require a lot of money to achieve as it relies on awareness and understanding of people in the community and a willingness to adjust their interactions in line with the communication needs of the person. For example, this may be having signage that is pictorial or uses simple language (easy English), speaking directly to the person with disability (rather than speaking to a carer), indicating to the person when they have not understood what they have said, providing information in multiple formats if necessary, pointing or using other gestures, reading out information to the person, giving people time to respond and repeating information if needed.

For example, if a person with CCN is at the bank and their communication device does not have the word for "cheque" programmed within the device, then when they need a cheque made out for a particular service, and the person cannot type or write, they are completely reliant on a communication partner to interpret their message. However, in a society where communication access is prioritised, the bank teller may have the skills to ask yes/no questions and notice the way the person indicates yes and no, and might use a pictorial board with the different services listed to work together to understand what service the person is requiring.

The role of speech pathologists

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 and private services (including health, disability and education sectors and mental health services). Speech pathologists, as experts in the assessment, diagnosis, and treatment of communication and swallowing 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) differ depending on the clinical presentation and diagnosis – with speech pathology care 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 the disability sector focus their practice on the assessment and provision of communication aids for people with complex communication needs.

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

The pervasive nature of certain difficulties, varied and fluctuating presentation and high incidence of co-existing conditions requires a thorough diagnostic process that examines all aspects of development and functioning

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

An important role of a speech pathologist in the diagnostic process is the differential diagnosis of other communication-related conditions; for example, in a childhood setting this may be specific language impairment, social (pragmatic) communication disorder, language disorder, speech sound disorder (e.g., childhood apraxia of speech), and specific learning disorder (e.g., dyslexia). In addition, the speech pathologist will assist the multidisciplinary team to decide if the person's communication profile is more consistent with a description of intellectual disability, trauma, anxiety, or attention deficit disorder, or Autism in conjunction with one or more of these other conditions.

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 information and decision-making procedures and protocols. In addition to 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.

With regards to cognitive assessments, or other ways to assess decision making skills, the speech pathologist is a valuable member of the multidisciplinary team. Their role may include working with a psychologist and/or a psychiatrist to find a range of standardised assessments that would be appropriate for the person's communication ability and preference, or working with an occupational therapist to understand the role of communication in assessing executive functioning, social skills and daily living tasks.

Speech Pathology Australia's response to relevant consultation questions:

1. How can we help people with disability to make decisions for themselves?

First and foremost, communication must be the cornerstone of any supported decision-making framework. The Association has long advocated for recognition of communication access being as important as physical access to people with disability if they are to participate fully in social, economic, sporting and community life. Unfortunately, communication access is rarely thought about in relation to services, or decision-making processes.

People with disability are often assumed to have a greater level of cognitive disability than they in fact do. Assessments of their cognitive and communication abilities may be provided, but rarely modified to assess people of diverse abilities, and with no adjustments to account for, or reflect the barriers to communication faced by the individual. For instance, a person with cerebral palsy who is unable to speak, point or indicate "yes" or "no" using a conventional gesture cannot complete most formal, standardised tests of intelligence and language. This person is unable to demonstrate their language comprehension, and therefore assumed to be unable to learn or use language, let alone make decisions.

Autonomy, the concept that people have a right to make decisions and choices that impact upon their own lives is also a critical factor when discussing supported decision making. In regard to determining their supports, people with disability may have their needs discussed without them present, and potentially supports put in place that reflect the desires of the parent or carer rather than the person themselves. Participants may need additional supports and adaptations to current systems to encourage their involvement. This may involve assuming competence on behalf of the person with disability by asking for their input, and creating environments that take communication needs into consideration to assist the person with disability to respond.

Within society, negative stereotypes and misconceptions frequently prevail that a communication difficulty is synonymous with a loss of capacity and competence. This misconception can be dangerous within the decision-making space, as many people with CCN are denied opportunities, as it is assumed that they are not able to make autonomous choices, simply because they cannot communicate their choice. It is disappointing to see that the Agency's consultation paper includes this erroneous assumption.

The Association asserts that the 'Decision Making Continuum' on page 11 should be altered to remove the notion that a person who has limited or very limited capacity to communicate therefore can only have limited involvement in decision making. This directly contravenes Article 21 of the United Nations Convention on the Rights of People with Disabilities which states "*Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice*".^v Article 21 should be strongly reflected within the supported decision making framework, and communication participation and access championed, as basic human rights for all people with disability.

The estimated 1.2 million Australians who have some level of communication disability already experience a range of barriers to participation in civic, political and economic life. As discussed elsewhere in this submission, these barriers and the inequity and frustration they cause an individual is also exacerbated by demeaning attitudes displayed towards them on a regular basis. For example, being spoken over and about rather than to, having assumptions made about their choices rather than being asked, and being ignored when asking for assistance.

This attitude can be seen within group homes or residential facilities, when there is any difficulty in communicating with a resident there is a tendency to turn to an alternative decision maker, typically a parent or paid person providing support. It is the position of Speech Pathology Australia that this is neither

adequate nor an appropriate way to ensure the rights of people living with communication disability are upheld. By deferring to a representative when a facility or service needs/wants information, there is insufficient attention to providing supports to residents with communication impairments to initiate discussion regarding their care, needs or preferences.

Therefore, it is imperative that the communication needs of the person with disability are taken into account as part of any and all decision-making processes. This must occur at all levels, for example in the evaluation of the person's capacity being modified as necessary for the participant to access; in ensuring all information relating to the decision is communication accessible; and in provision of the necessary communication supports for the person to express their choice in their preferred modality.

There must be a shift in culture, so that people with disability have the right to autonomy, and the expectation is that everyone can make their own decisions, some people with disability may just need more supports to do so. Decision making is also not a simple, fixed skill, and people with disability, particularly those with complex communication needs require opportunities to develop these skills over time. Starting with young children and increasing in an appropriate developmental order, participants should be asked about their preferences so that this is seen as an ordinary part of life, i.e., there is a presumption of capacity to make decisions for everyone, not something that is 'extra' for people with a disability.

Concurrently there will need to be capacity building for families, support workers, and organisations to have the knowledge and tools to support people with disabilities to make decisions for themselves, as there is presently poor information regarding how to support choice making. In particular, acknowledging that capacity is not a binary yes/no question, rather there is wholistic life-long learning around the steps within making a decision. Decision making is complex and nuanced - there may be a continuum of being able to make a decision at a particular level, in certain contexts, but there is a need for increased supports for other types of decisions or situations, e.g., being able to express a preference at home with known communication partners, but requiring support to do this in a food court in the community.

For this reason, in order to effectively and appropriately support people with a disability to make their own decisions, both time and resources must be allocated. Adults, in particular, may never have had access to communication options, or been involved in making their own decisions. Additionally, they may have never had any assessment of their capacity, rather this may have been a historical judgement made by health staff. Alternatively, adult participants may have been brought up to be compliant and please others, not expressing their preferences or will. Therefore, it may take months or longer for an individual to fully understand their options and this may involve discussing the decision/options multiple times in various ways, or even trying different activities several times.

Again, the Association would like to stress the importance of ensuring people with disability are given every opportunity and support to be able to develop a method of communication, as this may directly impact upon their decision-making skills. Communication difficulties affect communicative development and communicative participation opportunities. For example, parents of children with limited expressive speech often modify their interactions with their children, including anticipating children's needs, being more directive in their communication style, and having fewer, and shorter, back and forth interactions with their child. Though well intended, these modifications effectively mean that children have reduced opportunities to develop their communication skills and express their preferences and will.

It is likely that these changed experiences of communication interactions will also affect children's development of their self-concept – leading to them seeing themselves as having limited rights, or ability, to impact on their world, including to have a voice in their own care, and exercise choice and control across any and all aspects of their own lives. They become passive consumers of life and are therefore less likely to be able to have experience in making decisions. This is particularly concerning when the person has capacity to be involved in decisions, but not the means of communication to do so.

One member describes:

“A young boy who had a very severe medical condition spent the first 12 years of his life in hospital...When he moved to a residential facility and started attending a special school, he had a new communication assessment by a speech pathologist with extensive knowledge of AAC strategies... He demonstrated the ability to learn to use a PODD communication system, using a partner-assisted scanning method to access the vocabulary. Until this was introduced, this boy had only been able to make basic choices with a limited selection of pictures available in his environment and to answer “yes” and “no” questions. He would have been capable of learning to use an AAC language system much earlier, but this was not provided within the tertiary healthcare setting where he spent the early years of his life.”

Part of the role of speech pathologists is to build the capacity of parents, and other communication partners, so that they are providing the best possible developmental and learning opportunities for children. This includes supporting the use of alternative and augmentative communication. It is critical that the Agency acknowledges the need for, and value of, speech pathology supports for participants. Cost cutting exercises such as substituting therapy assistants for qualified allied health professionals will not suffice.

Many children have been denied their potential to communicate because of insufficient access to appropriate speech pathology supports, and therefore many people with disability enter adulthood without having had their communication, speech and language needs met. Their reduced communication skills and development continues to impact upon the opportunities that are available to them as adults. The absence of formal communication ability also leads to an increased reliance upon support people and/or family in any decision-making processes. It cannot be emphasised enough, the ability to develop communication and receive information in communication accessible formats is crucial to learning how to make and express choices and decisions. If a strong foundation in this area is achieved, then many other issues within the decision-making space will be naturally addressed.

As one member states:

“I don’t think we can stress the importance of communication [enough] in this process, near enough is not good enough. This is where the system has failed many people with disabilities, not just those with communication impairments.”

5. How can we make sure the right people are helping?

At present, due to pervasive societal attitudes that see people with disability as ‘different’ and ‘other’, and do not value alternative forms of communication, they often lack the opportunity to self-advocate for their choices or goals. Frequently it is non-disabled people who are presenting for, or making choices on behalf of, the person with disability. This might be a parent, or someone within a care-giving capacity, or it may be an advocate from an organisation such as a support co-ordinator.

It is very common for able-bodied people to make assumptions which lead to discrimination against people with disabilities, particularly cognitive disabilities, resulting in reduced/inadequate supports being provided to enable people with cognitive disability to develop their communication skills, or to be able to participate communicatively. Disability support workers, in particular, have often been placed in the decision supporter role, but not trained adequately.

For an example of the lack of recognition of an individual’s right to communicate their preferences, and appreciation of how they best communicate, we refer the Agency to the following witness testimony from Ms Sam Peterson presented at the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability’s Melbourne Public Hearing 10.09am, Friday, 6 December 2019 – Ms Peterson uses an augmentative and alternative communication device.^{vi}

“The added avalanche of verbal words from support workers when they were supporting me was impossible to keep up with. They told me stuff when I was getting dressed and couldn’t respond as I didn’t have my communication devices. I told them to stop it but they would forget. Some support workers didn’t seek my input about what I needed and what I’m okay with. If I really wanted my speech device I could always get it but sometimes I risked them going away to work with someone else while I wrote. They could be gone for ages.

The result was that I was reluctant to assert my right to communicate. I had to choose between communicating and getting dressed. When the support workers would dress me, often they would have three people doing it at once. They would all ask me things at once and I couldn’t respond to all three of them without my speech device. They saw it as being efficient but I saw it as taking my say away.”

Disregarding Ms Peterson’s need to access her speech device and not respecting the time needed for her to communicate with them effectively, thereby restricting her ability to communicate her wishes and respond to their questions, highlights a lack of understanding by the support staff. As Ms Peterson clearly states in her testimony “they saw it as efficient, but I saw it as taking my say away.” Support workers should receive training to assist them in understanding that this is not appropriate, and neglects the person with disability’s rights and autonomy.

Therefore, it is possible that any range of different people might be the ‘right’ person but this is critically dependent on having the knowledge and skill to ensure that they are supporting the person with disability appropriately. They must understand the underlying principle of autonomy as well as the specific support needs of the participant they are helping and actions they need to take to provide appropriate support for that person.

Therefore, there is a critical need to ensure education and skill development for the people helping. This may include (but not be limited to):

- Supporting, to whatever extent possible, engagement of the person with disability in the decision making about their own care, including considerations around balancing dignity of risk and duty of care.
- Understanding the communication needs of the participant and providing information in a communication accessible format, in addition to providing them with options to respond in their chosen modality.
- Managing situations where there is the potential for another person to make decisions which are in their own self-interest and/or are not in the best interest of or reflecting the apparent preferences of the person with disability.

A frequent theme that was expressed by members was that a decision supporter needs to know the person with disability well, a concept that is paramount in the La Trobe Support for Decision Making Practice Framework Learning Resource^{vii}. By knowing the person with disability well, this assists in knowing their preferences and underlying will, assisting in the decision supporter being able to facilitate a decision, rather than make it on behalf of the participant.

As one member, who is also a NDIS participant states:

“I don’t want anyone who doesn’t know me to tell me how I am and who I am”

Another aspect to ensuring the right people are helping is to ensure that there are robust safeguarding processes in place. Participants must have avenues to feedback and complain through communication accessible pathways, and these must be widely communicated to the entire disability sector. The Agency might refer to the accessibility and inclusion strategy for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability^{viii} for examples.

6. What should decision supporters know about so they can help people make decisions?

Throughout Australian culture, ableism is a significant issue. Ableism can be defined as the discrimination or prejudice against people who have disabilities. It can take the form of ideas and assumptions, stereotypes, attitudes and practices, physical barriers in the environment, or oppression on a more systemic level. Therefore, the attitudes and biases that able-bodied people have towards people with disability can have dramatic impacts, even if these are unconscious or unintentional.

For example, it is often assumed that if an adult has failed to develop a means of expressing themselves using any alternative modes of communication (including using symbols or signs) during their school years, it is impossible for them to develop their communication skills or to learn as adults. Correspondingly, it may be assumed that someone who does not use expressive speech cannot communicate, has a cognitive disability and/or does not have anything to say. These attitudes at a higher level may mean that the wishes of people with a disability are ignored, or they are not consulted regarding aspects of their care or life, but at a basic level may mean that people communicate with a carer or able-bodied person rather than the person with a disability at all.

It is the position of Speech Pathology Australia that these issues are exacerbated by, or directly result from, barriers to communicative development and participation for people with disability, and the lack of understanding of, and support for, communication access across the disability sector. Because communication involves at least two people, the behaviours of support workers as communication partners is a vital component of communicative participation, which in turn is a vital element in providing a truly person-centred supported decision-making framework.

There are some basic guidelines which communication partners can adopt to make communication interactions with people with complex communication needs (CCN) more successful, and ultimately improve their ability to self-advocate but unfortunately there is very limited understanding and awareness of what these are or why they are important within most environments.

For example, people with CCN routinely report that communication partners:

- Direct their questions and information to support workers or family who do not have CCN, by default.
- Assume that they have severe cognitive impairment and are unable to participate in any way in communication interactions.
- Fail to seek, provide, or use their AAC, or any of the many evidence-based aided AAC supports which could support their communication.

In some communication interactions therefore, some people with complex communication needs may require support from a trained and experienced communication partner, who is able to help co-construct the communication messages while also ensuring that the message is that of the person with CCN.

Providing better supports for communicative participation – to help prepare the person for later decision making, to enable the people around the participant to understand the person's needs around communication, and to support the person to feel that their messages are being identified, acknowledged and responded to – are an important component of addressing these issues.

As well as the developmental impacts, people with disability also experience ongoing differences in their everyday communication interactions which result in reduced opportunities to express themselves and to exercise choice and control. Furthermore, there is widespread misunderstanding about the nature of communication disabilities and communication needs, and a lack of knowledge about the range of supports, including AAC, available to help people to communicate and participate to their full potential.

It should be noted that even if people with severe to profound communication disability *do not* have the opportunity or capacity to learn to use representational systems using symbols or signs as part of their communication, most people with disability will, at the least, use some informal means of communication. People with disabilities may also understand more than they can demonstrate. People using informal

means of communication are therefore more reliant on the people around them to optimise their communication opportunities and to interpret their facial expressions, body positioning, vocalisations and behaviours to indicate their wants, needs and preferences, but not completely without autonomy.

Autonomy is central to decision making. Decision supporters require training and potentially supports themselves to be able to provide enough support to an individual and avoid substituted decision making.

As one member discusses:

“It’s important that they can speak for themselves, and not have others speak for them. If they need support from another person, it needs to still reflect their ideas and goals and dreams. [It’s] important others are careful to represent them respectfully and without changing their ideas too much.”

Other important concepts for decision supporters to be aware of are that of capacity and dignity of risk. Capacity is the ability to consent at a particular point in time - this may be fluid, and decision specific, as decision making is a skill that is learned and must continually be extended. Communication ability alone does not determine capacity. The consultation paper is silent on how capacity might be assessed and determined for people with disability, and this is a critical process to get right, potentially requiring the assessment of both cognitive and language skills by skilled psychologists and speech pathologists respectively. It is vital that decision supporters know about different levels of decisions, what the person with disability’s strengths are and where they would particularly benefit from support, both in regard to, and outside of their communication needs.

Dignity of risk refers to the notion that all people, regardless of their age and/or ability, have both the self-determination and right to take risks in order to preserve their dignity and self-esteem^{ix}. It is therefore essential that decision supporters acknowledge and accept the dignity of risk associated with the participant’s preferences and will.

Additionally, decision making is not a one off occurrence, or a case of one decision or preference determining all other decisions into the future. A person may require ongoing adjustments to ensure their participation in the process, e.g., vocabulary in their communication system may need to be updated and specifically taught. It may be that full informed consent is not possible without support at one particular point, however it is still possible to gain ascent from the person with disability that an action is permissible, or they are happy with a particular choice. This would be determined by the person’s capacity at that time.

8. What is the best way to support people with disability to make decisions about their NDIS plan?

At present one of the main obstacles to participants making decisions about their NDIS plan is the complexity and lack of transparency regarding the planning and plan implementation process. The inaccessibility of the NDIS processes is a significant barrier, both related to, and in addition to, making decisions. People with disability and their caregivers struggle to navigate the NDIS, often as a result of inadequate health literacy or proficient English language skills. Those who do not have effective advocacy, or understanding of the NDIS, are disadvantaged in regard to being able to make informed decisions.

The planning process must be broken down, made communication accessible, and explicitly explained to participants. Plans should be written in Easy English, with the process for making changes, or appealing decisions, clearly communicated to participants, families, and providers, with consistent information provided by NDIA staff. The lack of consistency with information, and frequent changes which are not communicated effectively to NDIA staff, or the wider community, also impacts upon participants’ decisions being upheld.

Our members discuss:

“There are just too many inconsistencies and too little understanding from the planners. Decisions are being made that the people are not qualified to make and go against the notion of choice and control.”

“NDIS does not communicate with participants much at all unless the participant hounds the NDIA, and is on the phone to them consistently to get answers. Depends on who you speak to as to what story you get - different planners say different things.”

“Sometimes it is hard to get accurate info and sometimes conflicting info is given - lots of learning new systems with not much guidance...I would love a manual with step by step guidelines on how to apply for AT devices, what evidence is needed etc.”

The reasonable and necessary criteria, in particular, is overly complex and presented very differently to self-managed participants, compared with providers, compared with the operational guidelines. The Association has heard numerous reports from members who are working with NDIS participants that have been denied a particular support or request, which directly contradicts the information that has been provided by other Local Area Coordinators or NDIA staff over the phone. One frequent example is when a participant or their nominee wishes to change the way that their plan is managed, one might be told that this is able to happen internally, and this change is subsequently made, another is told that they will have to have a full plan review, and risk losing some of their funding. This removes control and choice from participants, and the obfuscation of information creates unnecessary barriers to requesting particular items, supports, or changes to their plan. It also furthers the power imbalance and lack of control for participants when compared to Agency staff.

As one member describes:

“I had two families living on the same street who both had Autism level 3. One received therapy supports for \$2,000 and the other for \$10,000. One was a migrant family living in Commission housing and one wasn't. When this was questioned, I was told that \$2,000 was the limit for that age group. I provided a de-identified copy of the other child's plan with the family's permission, and was able to get the amount matched.”

If the NDIA wishes to support participants to make decisions about their NDIS plan, then correspondingly there must be avenues for these changes to be made, and choices to result in actions. It would be disingenuous for the Agency to ask participants to make choices about their plans, that are not able to be enacted, or subsequently ignored. There must be a shift in attitude and policy within the Agency to provide information for people with disability to know what is possible to change, and what is forming the basis of the NDIA decisions regarding utilisation of their plans and reasonable and necessary criteria decisions. There must be pathways for people with disability to express their preferences and decisions and have them be respected and upheld.

9. Are there different things to consider for people with different disabilities or cultural backgrounds?

The Association has discussed several factors that must be addressed, which apply to all people with disability, but particularly those with cognitive impairments and/or complex communication needs. Nevertheless, intersectionality must also be considered, in particular if the decision supporter is influenced by cultural attitudes that may be negative or biased in some way. People from differing cultural backgrounds have different understandings of what constitutes a disability, and differing perspectives on long-term outcomes for people with disabilities, which can influence how support for people with disabilities is managed.

Some cultures and communities may stigmatise disability, perceiving it as a 'curse', which also impacts on how the person is supported and how their capacity to make decisions is perceived within that cultural community. These factors must be acknowledged and addressed within any supported decision-making process, including developing cultural sensitivity training for support workers and decision supporters, as well as translated resources about the process, and liaison between the decision supporter and the participant's community to establish trust and culturally safe practices.

First Nations people often have negative experiences with service providers in other areas/systems, and consequently may be wary of engaging with any mainstream services, including the NDIS. First Nations people also experience discrimination (e.g., being accused of substance abuse when in fact their behaviour is related to a disability). These negative experiences, such as discrimination, poor quality services or denial of access can make it difficult to establish trust with any mainstream systems.

Inadequate access to disability services means that First Nations people are less likely to have had appropriate developmental supports to develop their communication skills and will therefore face greater barriers to understanding their rights and being able to express their will and preferences.

There is a lack of funding for Aboriginal health workers/liason officers, who have similar lived experiences to the person with disability. These workers help to bridge the cultural gap, which includes differences in communication interaction styles and behaviours, but there are not enough within health and disability services. Non-Indigenous staff are often not provided with adequate cultural knowledge and sensitivity training. This lack of training makes it difficult for them to bring the competencies needed to the process of supported decision making in a culturally sensitive way.

Additionally, rural/remote communities experience a lack of appropriate services and infrastructure. There may be a cultural expectation that the person with disability will be supported by family. However, people with disability may have complex family and individual issues. When the family support systems fail, there may be minimal services available. Additionally, people from remote locations often need to travel and leave family in order to access services and supports. Therefore, there may need to be a specific strategy developed for First Nations participants, possibly that is Community based, and it is vital that this is co-designed with Community and First Nations people with disability.

In addition to culturally sensitive practices and processes listed above, there is a need for better access to interpreters, for all NDIS participants who might require one. At present interpreters are not funded in NDIS plans per se, unless the need for the interpreter directly relates to the person's disability (as in the case of Deaf or Hard of Hearing participants who use Auslan). Otherwise, only registered providers are able to access interpreters for NDIS participants. This significantly disadvantages plan and self-managed clients who choose to use non-registered providers, and is a source of inequity amongst participants.

10. How can we help reduce conflict of interest?

A process must be developed where the support needs of the person with disability are known and catered for, so that their decision is informed using information tailored to their understanding, and also the expression of their decision is clear. Their decision must be what is acted upon, not the thoughts of others about 'what is best' and other paternalistic thinking, or what is the most expedient for the people around the participant.

Better education and governance of plan managers and support co-ordinators is desperately needed, particularly if the latter is to have a significant role within this framework. At present, the NDIS Quality and Safeguards Commission (the Commission) regulates all providers through the NDIS Code of Conduct and registered providers must also meet the NDIS Practice Standards. Whilst providers of therapy supports appear to be strictly regulated, there have been significant gaps identified in the Commission's regulation of other professionals within the NDIS space. Support coordinators and plan managers are poorly regulated with no required qualifications, and little to no recourse to report poor conduct. There is significant potential

for conflict of interest when large organisations are filling these roles in addition to providing therapy or daily living supports.

As one member describes:

“This conflict of interest is HUGE and it does cause families to be inappropriately pressured and to not have their needs really met when the service co-ordinator is also wanting to access funds for their own therapy provision...people with NO training or experience becoming support co-ordinators for private practices also offering therapy services ie the son in law of the owner of the business who has no experience whatsoever!”

Support co-ordinators and plan managers should at a minimum be held to the same standards as providers of therapy supports, with a process to direct complaints and provide feedback to the Commission. Additionally, if one organisation is already providing numerous types of support to the participants, perhaps the decision supporter may need to be employed by an independent body. If this is not possible, then a robust checking mechanism that is independent would be needed, perhaps via a specific process as part of auditing and surveillance through the Commission.

11. How can we help reduce undue influence?

People with disabilities can often be reliant on others for their daily care. They are frequently under the direction of others and not provided with many, or any, opportunities to exercise choice and control in their lives. This limited experience and opportunity makes them more vulnerable to violence, abuse, neglect or exploitation in society in general, including within the disability system. Reduced life experiences and difficulty with fully understanding what they are being asked to do or agree to, can make people with cognitive disabilities and/or communication disabilities ‘easy targets’ for people to scam or to bully.

This vulnerability is exacerbated by the barriers which people with CCN face to being able to complain. If they are able to raise a complaint about their care and wish to pursue a legal compensation case, they will also face barriers within the legal system, associated with their means of communication.^x

Therefore, if the supports are in place for the person with a disability to truly understand their choices and express their decisions, so that there is no need for substituted decision making in the guise of supported decision making, or ‘interpretation’ of what they are deciding, then this will automatically reduce the opportunities for undue influence. Concurrently, care must be taken to educate participants, and build their knowledge of their rights, choices, and ways to speak up. Complaints and feedback processes must be communication accessible, and robust, with several redundancies built in, so that the person with a disability has multiple pathways to report poor conduct.

12. What are your concerns (if any) around people with disability being more involved in decision making for themselves?

Whilst the Association feels that the involvement of people with disability in making decision affecting their lives is a positive, allowing them to exercise their rights, there are some impacts that may need to be addressed. There is a high level of ignorance at a population level about disability and disability rights, and about the concepts of autonomy, capacity, and dignity of risk. This lack of understanding and awareness is also prevalent amongst workers in the disability system, stemming from a lack of knowledge about disability, limited prior experience relating to people with disabilities, and a range of fears about people with disabilities themselves, as well as about how to manage an interaction with a person with disability.

If the people around the participant have previously made decisions for the person with disability, this may be a significant shift, which might affect their relationship with the person. Therefore, the people around the

participant will need to be supported to live with the dignity of risk, understanding that a truly informed decision by the individual, which may be different to what they think should happen is not a 'wrong' decision, and needs to be respected.

Additionally, they may need supports to assist them to process shifting dynamics, and potentially significant changes as a result of the person with disability perhaps expressing a preference or will that is different to what has historically been in place, or believed to be true. Families and significant people in the participant's life may therefore need access to counselling services, or particular training similar to support workers to build their capacity in supporting and respecting the preferences and choices of the person with disability.

Speech Pathology Australia would also like to again draw the Agency's attention to the issues and factors discussed in the response to the first question regarding how people with disability can be supported to make decisions. This would need to be a process, and it should be noted that it might cause the participant distress to be expected to suddenly make decisions with none of the necessary supports in place, and no experience. This is not a reason to deny participants this experience, but to suggest that the process of learning to make decisions, and building experience in this area may take time, and should be prioritised for people with a disability who may be transitioning to a different life stage, or have an important upcoming decision to equip them appropriately. As an example, members have reported to the Association that the NDIA has automatically changed the nominee arrangements for young people with disability as soon as they turn 18. This may not be an appropriate process to occur without notification and supports being put in place, and participants would need to be prepared for this transition.

13. What else could we do to help people with disability to make decisions for themselves? Is there anything missing?

The main component that is missing from the consultation paper, as discussed throughout this submission is the necessary attention and focus on communication. This includes the provision of communication supports, including access to speech pathology services, as well as appropriate pathways for people with complex communication needs to participate in the decision-making process.

Changes in the service delivery landscape have also contributed to the challenges facing people with disability in being provided appropriate supports for decision making. For example:

- Legacy providers are no longer in place.
- New providers have entered the market.
- People with disability are choosing and changing their providers.
- There is considerable turnover in the support workforce, including disability support workers in residential accommodation services.
- With the shift to individualised and more 'compartmentalised' funding, it may be difficult or not possible for a worker to be paid to assist the person for the length of time needed to ensure they fully understand the issue.

These changes have contributed to a reduction in the opportunities for workers to understand and support the communication needs of the individuals they support, in particular those who may rely on informal communication. It has also led to a decrease in the likelihood that there is information documented about how to support the communicative participation of people with disability.

While the NDIS has filled service gaps which existed previously for some participants, including access to sufficient and timely speech pathology services at times, there are still many service gaps being reported by our members. Furthermore, the market has failed to provide some services which were previously provided through block funding, such as the jurisdictional specialised AAC Assistive Technology (AT)

Services. These services not only supplied AT equipment, they also contributed to building the capacity of primary providers and others, which as we have discussed is critical for those with CCN.

Without access to expert supports, there is a tendency for educators, health professionals and others in their lives to hold out lower expectations and to reduce the communicative development and participation opportunities, including around making decisions for people with complex communication needs. An important role for speech pathologists is to build capacity for people to provide communication learning and participation positive environments.

Unfortunately, the importance and value of supporting communication development all too often is not recognised or funded adequately, and as a consequence many children fail to develop their literacy and communication skills to their full potential. This impacts on their participation across the lifespan and in all environments – including their experiences with decision making and in relation to their perception of their rights.

There are also some additional gaps within the consultation paper regarding specific cohorts, for instance people with disability who are also parents, potentially in the situation where the child also has a disability. There appears to be no mechanisms to address this added layer of complexity, when the nominee, or default decision supporter, may also require supports around decision making.

Similarly, the needs of people with a disability within the justice system may require a tailored approach. People with psychosocial disability are over-represented within the justice system, and many of the people with disabilities within the justice system may have concurrent cognitive disabilities^{xi}. The NDIA would therefore need to look at the intersection of supported decision making with regards to a legal framework to better serve this community. It would be prudent to look at the pre-existing communication intermediary programs that are currently being utilised in several states including Victoria, New South Wales and Queensland, where speech pathologists are employed to assist people with complex communication needs in their interactions with the justice system.

14. Do you have any feedback on our proposed actions in Appendix C of this paper?

Whilst the Association strongly supports the centring of people with disability in the suggested implementation plan, as this submission has highlighted, the issues regarding communication access, and appropriate communication supports must first be addressed. This strong foundation is critical to establish prior to the other steps, as it will inform and directly contribute to the success of supported decision making for all participants, rather than just those who can express themselves verbally.

Related to this, the concept of 'complex cohorts' should be reviewed, as it only lists cognitive and psychosocial needs. The Association would argue that participants with complex communication needs should also be included within this group. Additionally, it should be acknowledged that there are numerous factors that may contribute to the complexity of the decision-making situation for the participant which are not related to their disability. This includes, but is not limited to, those people with disability under care arrangements, those who do not have any family or significant persons who know them well, those involved in the justice system, and those who are from culturally and linguistically diverse backgrounds.

As one member describes:

“Firstly, people on the NDIS are, by any definition, already 'complex' as they have a significant disability. There are no 'easy' or even 'less complex' people with disability, at all. It is simply the mix of complexity that changes. Secondly, the disability is not the only thing that contributes to complexity, often all the other things make a client complex, such as family support and engagement with services, literacy level of family and other supports, access to other services including both other support services and general community services, level of rurality or remoteness which impact on things such as isolation, limited disability support workforce, limited basic community supports and transport issues, trauma, behaviour,

siblings, other pulls on the family such as other family members that need support, transiency which can be a big issue with many families with disability. The actual disability is generally the least complex issue.”

The Association also wishes to raise concerns with the notion of ‘business intelligence’/ data driven system alerts, due to the significant risks of trying to automate such a complex process. Data points reduce people with a disability to a number, ignoring the nuance and specifics that are essential to an actively person-centred framework. Similarly, any operational framework must be flexible, and move beyond simple check boxes to ensure policies and procedures are supportive of the individual participant’s needs. If the NDIA proposes to have a supported decision-making framework that truly allows people with disability to express their preferences, and make decisions about their own lives in a way that does reflect their will, then it is essential that this is not streamlined in an attempt to simplify the process. The process may be complex, because it needs to be, as this complexity is inherent in decision making itself.

Reflecting this complexity, it would not be appropriate to only formally assess a person’s capacity at the beginning of their journey as proposed in Appendix C. As discussed elsewhere in this submission, capacity is not necessarily static or fixed, there may need to be ongoing evaluation of capacity if there are concerns, at a minimum at different time points when significant decisions need to be made. Concurrently, the ‘formal assessments’ would need to be tailored to the needs of the participant, with acknowledgment that these areas may not be able to be formally assessed, or not without modification. It is also vital that any assessments conducted within the framework that influence the process of decision making are communication accessible and reflect the communication needs of the person with disability.

In order to centre communication, adequate speech pathology supports will need to be included in plans, with the development of communication plans or training around the participant’s communication needs made a priority as part of the supported decision-making framework.

Any training provided to decision supporters, support workers, families and significant people within the person with disability’s life should be developed in consultation with peak bodies, including Speech Pathology Australia, disability organisations and advocates, and people with disability themselves. The Association would also draw the NDIA’s attention to several excellent pre-existing resources, including the work of Dr Joanne Watson (including her doctoral thesis on this topic), the La Trobe Support for Decision Making Practice Framework Learning Resource modules produced by the Living with Disability Research Centre, the research using Talking Mats to assist people with complex communication needs to express choices^{xii}, and the communication accessible resources on supported decision making produced by Scope^{xiii} amongst others.

Recommendations

In summary, Speech Pathology Australia recommends the following:

- The notion of complex communication needs correlating with an inability to make decisions and low autonomy in the 'Decision Making Continuum' to be altered.
- Ensure that communication participation and access is at the centre of all supported decision-making processes, at every level.
- The NDIA publish clear and communication accessible information regarding its planning processes, including but not limited to:
 - Reasonable and Necessary criteria and decision making;
 - Pathways to appeal decisions & timeframes on these processes;
 - Previously established planning decisions around what supports have/will be funded.
- The clear expectation, enshrined in policy and clearly disseminated to NDIA staff and providers, that decisions and choices made by people with disability within the supported decision-making framework will be upheld.
- Establish a working party to identify and implement strategies to facilitate provision of communication supports for people with complex communication needs e.g., development of a consistent and downloadable template for a 'communication plan' which can support communication partners to provide a communicative participation supportive environment i.e., identify and interpret the communicative participation of the person with disability, whatever their modes of communication and communicative ability.
- Facilitate disability services to become communication accessible e.g., develop and fund training about complex communication needs and communication accessibility for workers and ensure all services and facilities are made communication accessible (as they would be made physically accessible) as standard.
- Build the capacity of the NDIS sector through targeted training around augmentative and alternative communication and communication accessibility to improve interaction with people with complex communication needs using communication modes and methods that suit the needs of individuals with communication disabilities. Enhance the opportunities for disability support workers to be trained and develop an understanding of the communication modes of the people they support, in particular for people with disability who use informal means of communication.
- Implement systems to improve communicative development opportunities across the lifespan for children and adults with complex communication needs. These include access to speech pathology services and facilitation of collaboration and coordination across the disability and education sectors in relation to the provision of supports in the education setting. Associated recognition that communication development, including literacy, is the most important and far-reaching learning outcome that can be provided to people with disability.
- Develop pathways to allow people with disability to experience making decisions, and express their preferences across the lifespan, to build their capacity.
- Develop targeted supports for families, support workers, and significant people around the participant to better support and respect the decisions of participants. This would need to include specific training around autonomy, capacity, and dignity of risk.
- If formal decision supporter roles are established, they would need to be as independent as possible and practicable, with robust checking mechanisms in place, potentially through the NDIS Quality and Safeguarding Commission.

- Organisations, providers and workers within the disability sector must develop communication accessible complaints and feedback processes, with pathways clearly communicated to people with disability.
- Include mandatory modules on ableism, communication access, including informed choice and control for people with complex communication needs in the 'NDIS Worker Orientation Module' package.
- The scope of the Commission regarding complaints & governance to be extended beyond just therapists to plan managers and support co-ordinators.
- Increase Indigenous workers across both the disability sector, and First Nations liaison officers who can work with support workers, carers, and people with disability, to help them access services and participate in decision making.
- Provide cultural sensitivity training to all non-Indigenous staff working in the disability sector to help raise their understanding and awareness of the effects of trauma, discrimination, lack of sense of belonging and identity.
- Increase access to interpreters to include all NDIS participants, regardless of how they are managed, or whether the provider is registered.
- Review the notion of what constitutes complex cohorts, acknowledging complex communication needs, as well as external factors beyond the person's disability.
- Develop specific pathways and processes to address the needs of people with disability who are also culturally and linguistically diverse, or First Nations people, or involved with the justice system.
- Build flexibility into the framework to allow for supports to be tailored to participant's needs, reflecting the complexity of decision making rather than attempting to streamline or automate it.
- Ensure the concept of formal assessments is flexible so that the evaluation of capacity and level of supports needed for decision making is fluid and ongoing, associated with the needs of the person with disability and their individual life factors. Any assessments must be communication accessible and take the person's communication needs into account.
- Any training regarding a supported decision-making framework and implementation plan to be developed in consultation with peak bodies; disability organisations and people with disability. The previous work and resources in this space to be acknowledged and reviewed by the NDIA, with consultation embedded with researchers and academics in this field.

We hope you find our feedback useful, if Speech Pathology Australia can assist in any other way or provide additional information please contact Ms Amy Fitzpatrick, Senior Advisor Disability, on 03 9642 4899 or by emailing afitzpatrick@speechpathologyaustralia.org.au.

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