Level 1 / 114 William St T 61 3 9642 4899 Melbourne Victoria 3000 F 61 3 9642 4922

 $office @\, speech pathology australia.org. au$ www.speechpathologyaustralia.org.au



Speech Pathology Australia's Submission to the

Senate Community Affairs References Committee:

Inquiry into the delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities

27 April 2017



Senator Rachel Siewert, Chair Senate Standing Committees on Community Affairs PO Box 6100 Parliament House Canberra ACT 2600

Dear Senator Siewert

As you are aware, Speech Pathology Australia is the peak body representing over 7500 speech pathologists in Australia. Speech pathologists are the allied health practitioners who specialise in speech, language and communication and swallowing difficulties (dysphagia).

Approximately one million Australians have disabilities that effect their ability to communicate, the most recent information from the Australian Bureau of Statistics 2015 Survey of Disability, Ageing and Carers (SDAC) indicates that 1.1 million Australians use equipment and/or aids to communicate (including 700,000 using hearing equipment/aids).

These Australians experience a range of barriers to participation in civic, political and economic 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. Of critical concern, people with communication disability face significant barriers to being able to report abuse, neglect or mistreatment, because they are not provided with the opportunity or the means to do so in a way that 'fits' with their communication abilities.

These Australians require 'communication access' to participate in community and economic life. Communication access is a similar idea to providing 'kerb cuts' for communication. Kerb cuts make it possible for people who are in wheelchairs to access their physical environment. Similarly, communication access involves the provision of environmental supports for people with communication disabilities to access their community.

Communication access is a vital pre-requisite for people with communication disability to participate in community life. The almost exclusive focus on physical access in the built and natural environments at the expense of the consideration of communication access undermines the ability for the National Disability Strategy 2010-2020 to achieve its goals.

Speech Pathology Australia welcomes the opportunity to provide comment to the *Inquiry into the delivery* of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities. We preface our comments relating to the Terms of Reference with background information about the need to build communication inclusive and accessible communities, this is in line with our written request to you, dated 2 February 2017, to include this equally essential but distinctive addition. We conclude our submission with a set of recommendations for consideration.

Finally, should the Committee wish to discuss communication access and how this relates to the National Disability Strategy's aspiration for inclusive and accessible communities then representatives from our Association would be very pleased to appear at a hearing for your inquiry. On behalf of our profession and individuals with communication and swallowing disabilities, their families and carers, we hope that the Committee finds our comments and suggestions useful.

Yours faithfully

Gaenor Dixon

National President

Speech Pathology Australia's Submission to the Inquiry National Disability Strategy 2010-2020 Inclusive and Accessible Communities

About speech pathologists and Speech Pathology Australia

Speech pathologists are the university trained allied health professionals who specialise in diagnosing and treating speech, language, communication and swallowing problems. Speech pathologists work across the life span with infants, children, adolescents, adults and the elderly with communication and swallowing problems. Speech pathologists undertake a four-year undergraduate degree or a two-year graduate entry Masters degree to be qualified as speech pathologists.

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

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

Speech pathology was recently recognised as a key unmet demand in the NDIS, alongside occupational therapy and psychology – in the Intermediate Evaluation of the NDISⁱ.

Speech Pathology Australia is the national peak body for speech pathologists in Australia, representing more than 7500 members. Speech pathology is a self-regulated health profession through Certified Practicing Speech Pathologist (CPSP) membership of Speech Pathology Australia. Speech pathologists are not required to also be registered through the National Registration and Accreditation Scheme.

About communication and swallowing disability

When considering the achievements of the National Disability Strategy 2010-2020 to build inclusive and accessible communities, it is critical to remember that not all Australians with disability have physical or mobility limitations.

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

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

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

Swallowing disorders affect the ability to safely swallow food or liquids and can lead to medical complications including chest infections/pneumonia and choking. Swallowing difficulties impact on a person's health and wellbeing and can lead to social isolation, poor nutrition and medical complications (including choking and death).

People with communication and swallowing disability span the entire age range and the nature of their difficulties impacts on most areas of life. These people frequently require interventions and supports from multiple areas of public service (including health, the disability and education sectors and mental health services). The clinical protocols for speech pathology treatment are evidence based and backed by strong multidisciplinary scientific evidence for efficacy. Clinical protocols for intervention (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.

A communication disability can be mild, moderate or severe, and may be developmental in nature, acquired through disease or injury, or from an unknown origin. Often communication and swallowing disorders are invisible (*even silent*), especially to the untrained eye, as the person may have no obvious 'outward' signs of their disability. This results in poor understanding by the general community of the experiences of people with communication disability in Australia. This can significantly affect individuals' access and participation in the wider society, and have negative impacts on their social and emotional wellbeing, and quality of life outcomes.

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

Additional or alternative methods of communication, termed Augmentative and Alternative Communication (AAC) methods include symbol and text based boards, electronic tablets and Apps, and access supports such as mounting and switches. Information from the ABS SDAC 2015 indicates that some 235,800 people with disability use either electronic or non-electronic communication aids for reading, writing and speaking (this figure does not include hearing aids).

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

Currently there is limited available data regarding the prevalence of communication and swallowing disorders within the Australian population. Conservative estimates indicate there is in excess of 1.1 million Australians who have a communication disorder and one million who have a swallowing disorder. The most recent information from the Australian Bureau of Statistics 2015 Survey of Disability, Ageing and Carers (SDAC) indicates that 1.1 million Australians use equipment and/or aids to communicate (including 700,000 using hearing equipment/aids). This reflects about a quarter (25.9 per cent) of all people with disability.

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

In recognition of the prevalence of communication and swallowing problems and in accessing speech pathology services in Australia, in 2014 the Senate Community Affairs References Committee held an inquiry into the prevalence of speech, language and communication disorders and speech pathology

services in Australia. At the time of writing, the Australian Government's response to the Senate Committee's recommendations is still forthcoming.

Communication access and participation are critical for Australians with disability

If the National Disability Strategy 2010-2030 is to achieve its aspirations of creating inclusive and accessible communities, then investment needs to be made in how our communities can be accessible for all people with disability – not just those with physical or mobility limitations.

Governments need to acknowledge, and invest in addressing issues of communication access for the one million Australians who have speech, language and communication disabilities.

Over a quarter of a million Australians with disability (278,000) report to need assistance with communication. The recent 2015 ABS Survey of Disability and Carers found that 89.9 per cent of people with disability who need informal assistance and support (from family or carers) to participate in social and economic life needed it for communication. For those people who needed formal supports (from organisations or government services), 43.5 per cent indicated they needed these formal supports to communicate.

Australians with disability report a need for support to communicate with others in their personal and wider community contexts. Some people with disability have speech that is difficult for others to understand, have no speech or may use other means to communicate such as pointing or facial expressions. Some may also have difficulty understanding what others are saying to them. Some may use communication aids such as speech generating devices of picture/symbol boards.

These Australians 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. Of critical concern, people with communication disability face significant barriers to being able to report abuse, neglect or mistreatment, because they are not provided with the opportunity or the means to do so in a way that 'fits' with their communication abilities. These Australians require 'communication access' to participate in community and economic life.

Communication access is a relatively recent concept in the disability sector internationally and in Australia. 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 in the community (prams, bikes, etc.), 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 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 with regard to programs such as the NDIS whereby information about processes that NDIS participants may be involved in, options and choices that may be available to them and the potential consequences of their choices needs to be successfully *sent* and *received*.

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

Communication access does not require a lot of money to achieve, but 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.

Communication access is a prerequisite for participation in our communities by people with communication disabilities. Communication participation is defined as "taking part in life situations where knowledge, information, ideas, or feelings are exchanged. It may take the form of speaking, listening, reading, writing, or nonverbal means of communication." Communication participation 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).

In these activities, while we are interacting with people we share the same modes of communication and are competent as communicators and as such, we can be successful in getting our message across to each other.

For people with communication disability, to be able to successfully get their message across, they may need their communication partner to know and do something more and different within the interaction than they would with someone without communication difficulties. This is sometimes referred to as contributing to 'co-construction' of communication.

Australia is the home of some of the world leading activities in the area of communication participation and access. One such initiative by Scope in Victoria is the development and endorsement of a registered symbol to denote communication accessibility, similar to the familiar wheelchair accessible and Hearing Impairment accessible symbols. See figure below. Scope offer an accreditation program for organisations/businesses to be assessed as communication accessible. Notable public services who have achieved communication access under the Scope scheme include the Victorian regional public transport system (VLine¹) and the Bass Shire Community Information Centres².



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 WHO 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.

¹ See https://www.vline.com.au/Fares-general-info/Additional-pages/Communications-Access

 $^{^2\ \}underline{\text{http://news.basscoast.vic.gov.au/communication-accessible-visitor-information-cent}}$

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.

Speech Pathology Australia and the speech pathology profession has reaffirmed its commitment to advocating for communication accessible communities through the profession-wide landmark project Speech Pathology 2030. The project outcomes reaffirmed the vision of our profession that

"we will ensure through building communication accessibility that everyone is treated with dignity and respect; communication partners are skilled listeners and talkers (e.g. they provide extra thinking and talking time, they know not to finish off someone's sentences etc.) and other methods of communication (e.g. communication boards, speech-generating devices, switches and eye-tracking devices etc.) will be understood, and if required, their use supported™.

Communication access and participation as a human right

The National Disability Strategy 2010-2020 acknowledges the importance of Australia ratifying the United Nations (UN) Convention on the Rights of Persons with Disability (in 2008) and states that one of the purposes of the Strategy is to give visibility to disability issues and ensure they are included in the development and implementation of public policy.

Participation, education, employment, access to public services and expression are all basic human rights. Without communication access, people with disability are denied an important component of their human rights, as recognised in the UN Convention on the Rights of Persons with Disabilities. To access their communication rights, people with disability need a range of specific and additional supports to be implemented in the environments in which they interact.

However, thousands of people in Australia may have these rights compromised on a daily basis because a foundational right - the opportunity to communicate - has not been met. This failure is mirrored in services and supports at both federal and state and territory level, and can be attributed to a lack of acknowledgment of the critical role of communication to participation and quality of life in Australia.

Not only is communication a human right, it is the essence of what makes us human. The rights of people with communication disability should be explicitly acknowledged within major public policy and strategy documents, across health, disability, aged care, education and early childhood, and justice sectors. Policies should acknowledge and seek to redress issues relating to availability and accessibility of services and supports for people with communication disability. There is a need for greater acknowledgement of the rights of people to communicate to their full potential, in order for the barriers to full participation in society for people with communication disability to be addressed. The 2014 federal Senate inquiry into the prevalence of communication disorders and speech pathology services also acknowledged the important role governments have in addressing issues relating to speech and communication disorders in the development of public policies and programs – and made a specific recommendation that public policy should address this issue.

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, see in particular part two detailed below (with emphasis added) from the Article.

UN Convention on the Rights of Persons with Disabilities Article 9 - Accessibility

- 1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:
 - (a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;
 - (b) Information, communications and other services, including electronic services and emergency services.
- 2. States Parties shall also take appropriate measures to:
 - (a) Develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;
 - (b) Ensure that private entities that offer facilities and services which are open or provided to the public **take into account all aspects of accessibility for persons with disabilities**;
 - (c) Provide training for stakeholders on accessibility issues facing persons with disabilities:
 - (d) Provide in buildings and other facilities open to the public signage in Braille and **in easy to read and understand forms**;
 - (e) Provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;
 - (f) Promote other appropriate forms of assistance and support to persons with disabilities to ensure their **access to information**;
 - (g) Promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;
 - (h) Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

The Delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities – terms of reference:

- a. the planning, design, management, and regulation of:
 - i. the built and natural environment, including commercial premises, housing, public spaces and amenities.
 - ii. transport services and infrastructure, and
 - iii. communication and information systems, including Australian electronic media and the emerging Internet of things;

The National Disability Strategy 2010-2020 is a critical cross-government policy framework that provides a vision for all Australians to live in a society that is inclusive and enabling of people with disability and that 'people with disability live in accessible and well designed communities with opportunity for full inclusion in social, economic, sporting and cultural life'. This vision is one that Speech Pathology Australia heartedly endorses.

The Strategy explicitly acknowledges that people with disability face challenges in access and participation in relation to communication and information. However, the Strategy itself has significant shortcomings in how it conceptualises an 'inclusive and accessible community' – with an almost exclusive

reference to physical access in the built and natural environment as being the primary barrier for people with disability to have the opportunities for full inclusion in social, sporting and cultural life.

Modification/design of the physical and natural environment is important to assist people with disability to physically access and negotiate the physical space in our communities. However, it has limited value on its own in helping achieve the aspirations of the National Disability Strategy for people to life in inclusive and accessible communities.

A much stronger emphasis needs to be made on the way in which our communities, services and programs can enable access and inclusion through 'communication access'.

- It is of limited value if you can wheel your chair up a ramp into the local Council office if the Council Officer is unable to communicate with you so that you can organise for a new recycling bin to be delivered.
- If is of limited value if you can park in the 'disabled parking spot' near the entrance to the pool, yet you and the pool attendant are unable to communicate that you need to buy a 10 visit pass card.
- It is limited value if you need to respond to a Centrelink letter by calling a toll-free number and speaking to a customer service operator if you do not have verbal communication.
- It is of limited value if a lift has been put in at the train station, if the customer service officer is unable to communicate with you when you ask to buy a ticket and for directions to your platform.
- It is of limited value if the brand new, custom designed general practice has great signage for pathology, treatment rooms and a height adjustable bed in every consultation room if you and the receptionist are unable to communicate about how long an appointment you need.
- If is of limited value if there is a disabled change room yet the retail assistant in the clothes shop
 is unable to understand that you would like to try on a different size of the item you have selected.
- It is limited value if your health care team can provide palliative care, if you and your clinical care team are unable to communicate with them about your end-of-life choices.
- It is of limited value if the stairs at school are all contrast highlighted to improve visibility, if in the classroom the teacher doesn't allow you to use your Alternative and Augmentative Communication device.
- It is of limited value if your residential aged care facility has appropriate floor coverings to minimise tripping hazards, but staff are too busy to wait for you to communicate with them that you would prefer tea to coffee for your afternoon tea.
- It is of limited value if you receive your 'voting instruction' letter in the mail if the written instructions are too complicated for you to understand how you are to vote in your state elections.
- It is of limited value in your new place of employment, if the self-opening doors lead to a meeting where you have not had a chance to see the agenda prior to the meeting and program your voice-generating device with the contributions you wish to make to the discussion.
- It is of limited value to you, if you are able to attend an NDIS planning meeting, but the Planner is
 unable to communicate effectively with you so that you can participate in making decisions about
 your Plan.

Even the most ideal physical environment, designed with the most cutting edge physically accessible features will be of little value in enabling people with communication disability to engage in social, economic, sporting and cultural life, if that environment is filled with other people who are unwilling, unable or do not know how to alter the way they communicate with people with communication disability. Even the most ideal physical environment designed to facilitate access can act as a barrier if the people

working in it are operating within systems, stuctures and processes that do not allow them to modify the way they interact with people with disability (e.g. taking more time with that customer, writing down instructions, taking stock out of packaging to 'show' rather than to explain verbally).

It is the view of Speech Pathology Australia that the intent of the National Disability Strategy 2010-2020 to focus on outcomes relating to inclusive and accessible communities does intend to focus on addressing more than physical access barriers. However, it is disappointing that the Inquiry's Terms of Reference also has such a strong focus on examining the delivery of outcomes under the Strategy primarily in relation to physical access. As we have highlighted above, communication access is of critical importance to people with disability if they are to participate in 'inclusive and accessible communities'.

Communication disability has long remained in the 'too hard' basket resulting in people with communication disability being excluded from participating in aspects of Australian life that they have a right to participate in (e.g. voting, education, employment, health care). There is a need for greater acknowledgement of the rights of people to communicate to their full potential, in order for the barriers to full participation in Australian society for people with communication disability to be addressed.

The rights of people with communication disability should be explicitly acknowledged within major public policy and strategy documents, across health, disability, aged care, education and early childhood, and justice sectors.

Whilst it is recognised that the National Disability Strategy 2010-2020 has specific outcomes relating to the justice system, education and employment and health services – the same barriers relating to communication access apply in all these sectors of Australian society.

b. Potential barriers to progress or innovation and how these might be addressed

The key barrier to progress on making Australian communities inclusive and accessible is an almost exclusive focus on physical access barriers by governments and within the National Disability Strategy 2010-2020. Significant focus needs to also be made on communication accessibility and ensuring communication access for people with disability to participate in civic, political and economic life.

A strong message from governments on the importance of both physical and communication access in public policy would be an important start to having the Australian Government meet its commitments under the UN Convention on the Rights of People with Disability, as well as to reframe some government policy attention on the meaning of 'access' in the National Disability Strategy.

Importantly, government and private investment into disability access may be considerably less when considering communication access as it is unlikely to require large scale infrastructure changes (like ramps, self-opening doors etc). Increased awareness in the community of communication disability would go a considerable way in improving the public's general understanding of communication disability and how they can interact with a person with communication disability in a way where everyone 'can get their message across'.

Government services may need to undergo some system changes to ensure they are communication accessible – but again, this may not require a large investment. Providing information on services in easy English or pictorial options, training for staff and development of information resources may be more feasible to achieve in many situations than improving physical access (for example retrofitting heritage buildings with ramps).

Speech Pathology Australia is not advocating for a focus on communication access at the expense of improving physical access – however it is important that communication access be considered as a critical factor in ensuring that our communities are accessible and inclusive for all Australians – including those with disability.

Recommendations

In summary, Speech Pathology Australia asks that the Senate Community Affairs References Committee consider the following recommendations:

- That communication access be acknowledged by the Committee in their final report as an important contributing factor in the ability for the National Disability Strategy 2010-2020 to meet its aspirations for inclusive and accessible communities.
- That state and federal governments explicitly acknowledge the importance of communication access in public policy documents.
- State and federal government programs and services should undergo a 'communication access audit/check' to identify changes that are needed to the systems of service delivery that would improve communication access. A focus could be made on the following services in the short term:
 - o The NDIS Planning process
 - Centrelink processes
 - Electoral processes
 - Complaints and Feedback mechanisms (particularly for health, disability and aged care systems)
 - The Australian government to work with Speech Pathology Australia (and other stakeholders) to
 develop information resources to assist public and private services to understand and become
 more communication accessible. This would reflect a targeted public awareness campaign. The
 resources could be focused in the short term on the following sectors that are known to have
 significant communication barriers for people with disability:
 - Justice systems
 - Primary health services (including general practice)
 - o Hospital systems
 - Aged care services (including residential aged care and community based aged care services)
 - Local government consumer-facing services (information centres etc)

If Speech Pathology Australia can assist the Committee in any other way or provide additional information please contact Gail Mulcair on or contact by emailing

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viihttp://www.aph.gov.au/Parliamentary Business/Committees/Senate/Community Affairs/Speech Pathology/Report