

Speech Pathology Australia's Submission to the Australian Government Department of Communications and the Arts Communications Accessibility: 2016 and Beyond

6 May 2016



The Manager Communications Accessibility PO Box 13310 Law Courts Melbourne VIC

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Dear Manager,

Speech Pathology Australia is the national peak body for speech pathologists in Australia, representing more than 6900 members. Speech pathologists are the allied health practitioners who specialise in diagnosing and treating communication disorders and swallowing difficulties (dysphagia). There are an estimated 1.1 million Australians who have a communication disorder and one million with swallowing difficulties. Our submission to the review of the National Relay Service (NRS) focuses on the needs of people with communication impairments to access Australia's communication infrastructure.

Difficulty in communicating impacts on all areas of life. Without communication, we cannot relate socially to one another or work together to develop, create or refine our world. Communication disability occurs when one or more of the areas of communication are ineffective or disordered, leading to a restriction in communicating in a spoken, written, or symbolic form.

Communication difficulties can arise from a range of conditions and may be present from birth (e.g., cleft palate, cerebral palsy), emerge during early childhood (e.g., stuttering), or during adult years (e.g., traumatic brain injury, stroke, progressive neurological conditions and head/neck cancers) or be present in the elderly (e.g., dementia, Alzheimer's disease, Parkinson's disease).

Many people with disability have Complex Communication Needs – which 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. People with Complex Communication Needs will have very specific requirements in relation to their use of the NRS and their potential to adopt mainstream communication methods as an alternative to NRS. There is also a high coexistence of physical disability and Complex Communication Needs.

While communication problems affect people across the lifespan, the prevalence and complexity of these disorders increase with age. Any increase in age related communication impairment therefore has the potential to increase the demand for services such as the NRS.

Speech Pathology Australia welcomes the opportunity to provide comment to the Department of Communications and the Arts' consultation on Communications and accessibility: 2016 and beyond. We preface our response to the options and questions posed with background information about the role of speech pathologists in providing care for people with communication problems and general comments regarding the use of the NRS by people with expressive communication problems.

Of note, our overarching concern regarding the proposed models to improve the financial sustainability of the NRS is that they presume a sophisticated understanding of usage and demand patterns for each service model – patterns for which evidence was not provided in the discussion paper. This information is required to determine which proposals are most likely to *appropriately* reduce demand without disadvantaging or unfairly restricting the use of the NRS by people with differing abilities and needs.

On behalf of our profession and people with communication difficulties, we hope that you find our comments and suggestions useful in your deliberations.

Yours faithfully

Gaenor Dixon, National President

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Speech Pathology Australia's Submission to the Communications accessibility: 2016 and beyond About speech pathologists and Speech Pathology Australia

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

Speech pathologists provide health services in the acute care (hospitals), 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 pathology care assesses, improves and maintains communication and swallowing functions, with a focus where necessary to prevent further loss/deterioration of function in a patient with a complex and ongoing condition. It is important to recognise that for many of these people, speech pathology treatment does not (nor is it purported to) provide a 'curative' return to function – it provides an important support to complement the medical care they are also receiving. For many people with these conditions, speech pathology care helps to maximise their communication and swallowing functions to allow them to have the highest possible quality of life that they are able to given their condition or disease.

Speech Pathology Australia is the national peak body for speech pathologists in Australia, representing more than 6900 members. . Speech pathologists undertake a four year undergraduate degree or a two-year graduate entry Masters degree to be qualified as speech pathologists. Speech pathology is a self-regulated health profession through Certified Practicing Speech Pathologist (CPSP) membership of Speech Pathology Australia and practitioners are not required to also be registered through the National Registration and Accreditation Scheme.

About communication impairment

Communication – the process of being able to understand and to be understood – is something most of us take for granted as part of our daily lives. It is one of the crucial components of human evolution and development and arguably is one of the defining characteristics of the human race. Through communication we participate in our communities, in education, in employment, in cultural and social spheres. Communication also enables us to access the public services and supports that we are entitled to in Australia, for example, medical care and social services. Difficulty in communicating impacts on all areas of life. Without communication, we cannot relate socially to one another or work together to develop, create or refine our world.

Communication disorders encompass difficulties with expressive 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.

Communication difficulties can arise from a range of conditions and may be present from birth (e.g., cleft palate, Down Syndrome), emerge during early childhood (e.g., stuttering), or during adult years (e.g., traumatic brain injury, stroke, progressive neurological conditions and head/neck cancers) or be present in the elderly (e.g., dementia, Parkinson's disease).

A communication disability can be temporary or permanent. It can be mild, moderate or severe. It can be present across the lifespan, from birth to old age - and may be developmental in nature or acquired through disease or injury. It can encompass non-verbal aspects of communication - for example, being able to read social cues or understand tone and gesture.

People who have complex communication needs are unable to communicate effectively using speech alone. These people may require augmentative or alternative communication methods in order to communicate.

A person with complex communication needs uses a multi-modal approach and may communicate using:

- vocalisations and speech that is hard to understand
- atypical behaviours known only to familiar communication partners
- gestures, signs, pictures, words or spelling
- a non-electronic communication book, board or resource
- a computer, a dedicated speech generating communication device and /or a smart phone or tablet.

Australians with communication difficulties span the entire age range and the nature of their difficulties impacts on most areas of life. These people frequently require health and disability interventions and support that span multiple areas of the health system (including general practice care, acute and subacute), community health, mental health and disability sectors.

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

While communication problems affect people across the lifespan, the prevalence and complexity of these disorders increase with age. Communication functions are vulnerable to the natural ageing process with changes in cognition, anatomy, physiology, sensory and motor functioning leading to reduced function. The body's natural ageing process can impact on memory, processing speed, voice, hearing, and speech processes which can have an effect on how effectively the older person can communicate. It is important to note that even subtle age-related changes in communication skills such as voice have been demonstrated to have a significant impact on a person's everyday life and social participation. There is of course the added possibility of disease or disorder in older Australians, and many common age related conditions including stroke, dementia and Parkinson's disease have a high prevalence of communication and swallowing problems associated with them. The communication problems associated with ageing vary significantly in type and severity.

It is clear that these prevalence figures for communication disability will likely increase exponentially as the population ages.

In terms of service use data, the ABS Survey of Disability and Carers reports that around 40 per cent of people with a severe or profound core activity limitation require assistance with communication; approximately 215,000 Australians aged under 65. This high prevalence is replicated in data from services provided under Commonwealth and State/Territory Disability Agreements, where 42 per cent of users require support for communication, and a further two per cent need communication aids or devices. Twelve per cent of disability service users have little or no effective communication (2011-12). Across Australia, around 6,900 people use electronic speaking aids to communicate, and over 15,000 use non electronic communication aids. ii,iii

In recognition of the prevalence of communication and swallowing problems and in accessing speech pathology services in Australia, in 2014 the federal 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.

The use of NRS by people with communication impairment

People with communication impairment (specifically expressive communication problems) are likely to rely on the National Relay Service as a key support to access Australia's telecommunication infrastructure. People with expressive communication problems (from any cause) are likely to predominantly use the following NRS:

- 1. Speak and Listen service
- 2. Type and Listen service
- 3. SMS Relay
- 4. Video Relay (to a lesser extent)
- 5. Internet Relay (to a lesser extent)

It is important to consider users of these options with communication disability are not a homogeneous group with similar needs in relation to accessing telecommunications systems. This has implications for the proposed reforms to the NRS and which options would unfairly restrict access to the NRS for particular cohorts of people with disability. Consider for example the needs of the following people to use the NRS:

- Someone who has complex communication needs who is also unable to physically use a standard smart phone or computer.
- Someone with complex communication needs whose electronic communication aids are unable to 'link' with standard telecommunications systems
- Someone with more moderate communication problems who requires assistance to be understood on the phone/through video
- Someone who has an acquired communication impairment (perhaps through head injury or stroke) and who is unable to effectively learn to use mainstream text based communication devices
- Someone with expressive communication problems who has low literacy
- Someone who is older and has problems expressing themselves but is resistant to the use of mainstream devices (tablets, smart phones)
- Someone who either through age (over 65 years) or nature of disability (moderate impairment) is ineligible for individualised funding through the National Disability Insurance Scheme (NDIS).

Any increase in age related communication impairment has the potential to increase the demand for services such as the NRS.

As the NRS website highlights, many clients of speech pathologists are 'prime beneficiaries of the NRS as it helps people with speech impairments, as well as those with hearing impairments, to have successful phone conversations and live a more independent, connected life. It's a great option to help them stay in touch with friends, family and the outside world, and also reach emergency services when needed'.iv

The consultation draft indicates that the increase in usage for the NRS has predominantly been in the SMS relay, video relay and captioned relay service options. However data has only been presented on usage by number of call minutes.

A more sophisticated analysis of demand and usage of the NRS is needed to determine what cohorts of users are driving the increase in demand. For example, is it that existing users are using the NRS more frequently or for longer, or is the increase in demand reflecting an increased number of new individual users? Is demand being driving by people with acquired hearing or communication loss? Of the current NRS users, who would be eligible for individualized funding through NDIS?

Without further evidence of which cohorts of NRS users are driving the increase in demand for the NRS, it is difficult to comment on the appropriateness of the reform options proposed in the Discussion Paper for people with expressive communication impairments. What may seem to be a 'sensible' option for reform of the NRS may in fact, inappropriately, and unfairly restrict a particular cohort of people from accessing Australia's telecommunication infrastructure (particularly if they do not have an alternative option).

The ability to 'switch' to mainstream options

Speech Pathology Australia acknowledges that there have been significant advances in mainstream telecommunication technology and that many individuals may choose to use these options over the NRS. For example video call options such as Skype and FaceTime are useful for people with Complex Communication Needs as communication boards and facial expressions can be seen during calls which enhances how the person can communicate.

As telecommunication technology continues to advance it may well result in mainstream devices becoming so sophisticated that the assistive technology they provide is equivalent to or even an improvement on the current NRS. In this case, it is likely there will be a natural switch to mainstream as people value the enhanced options for communication the mainstream options provide. Until this happens those individuals who do not want to, or cannot use, mainstream options should continue to have access

to the NRS not just as a 'safety net to access emergency services' but as a service to allow them to use the existing Australian telecommunications infrastructure to the same degree as people without disability are able to access it.

The Consultation Paper states that voice calls are declining in the general population but demand for NRS is increasing. There is an assumption in the Discussion Paper and reform options proposed that a switch to mainstream options is the best way of controlling demand for the NRS. This is a problematic assumption as without ascertaining exactly 'who' is using the service there may be important barriers to individuals switching to mainstream options. Evidence about cohorts of people with disability who have specific needs for the different service options available through the NRS was not presented in the paper. As such, it is difficult to predict if reform options that promote a switch to mainstream options would actually be suitable for the people using some of the NRS services.

For example, there are a range of issues that need to be considered such as a physical disability (a person with expressive speech problems may not be able to use a keyboard or mouse), literacy issues, memory or cognitive issues that will impact if people are able to switch to mainstream options. There are also factors associated with the cost of internet access and/or its availability (not just the quality of service in rural and remote areas but access for individuals in nursing homes and Community Residential Units) that create a context that means 'switching' to mainstream options may not be viable.

If the NRS is able to determine cohorts of people with disability who are high users of the different service options, then it would make it easier to understand their communication needs and whether they are a group who cannot, or should not, be encouraged to switch from the NRS to mainstream options. Where the possibility of a switch to mainstream options seems viable, then it is likely that they will need information, support and training to use mainstream options.

The role of the NDIS in supporting people with communication disability

It is a challenge for the Department that the review of the NRS is being conducted at a time when the roll out of the NDIS is still occurring. There is much uncertainty and inconsistency across the trial sites as to eligibility for individual NDIS funding and the framework for the Information, Linkages and Capacity Building (ILC) component of the NDIS has still not been finalized. It is the view of Speech Pathology Australia (and many others in the disability sector) that the ILC has not been adequately funded to meet the needs of Australian's with disability.

Not every person with disability in Australia will be eligible for individualized targeted funding. It is likely that people with Complex Communication Needs (requiring communication devices) will be eligible. It is also likely that people with more moderate communication disability and those over the age of 65 years will not be eligible for individual funding and will need to rely on generalized supports provided through the ILC.

At present, it is unclear and inconsistent if the NDIS will fund some communication devices that are needed by people with disability. For example, if tablets/ipads are deemed necessary to support an individual NDIS participant to meet their planned goals, they may be funded through the NDIS. However this is not occurring consistently across the trial sites. Funding for training and/or ongoing support for the use of the devices is also not being consistently funded through the NDIS.

As such, the Department needs to consider carefully any reliance on the use of NDIS supports and funding to assist people to switch to mainstream communication devices. Until such a time as formal agreements are made between the NDIS and the Department, it is recommended that changes not be made to the NRS that *presume* NDIS support for people to access mainstream communication technology.

Response to consultation questions:

Option 1: Increase the funding allocation available for the NRS to sustain its delivery over the life of the current contracts

The NRS is an important public good and access should not be restricted for Australians with disability. In the short term, funding should be increased to cover operating costs whilst medium to longer term strategies are put in place to manage demand and ensure longer term financial sustainability. As discussed previously, without evidence of the characteristics of the demand (beyond blunt descriptions of which services have increased in demand) it is unclear which service options could *appropriately* be restricted without also disadvantaging those people with disability who genuinely need those service options.

Option 2: Introduce measures to manage demand

From the evidence provided in the Discussion Paper, it is unclear if there is a genuine problem in unfair use or inappropriate use of the NRS by people with disability. Without this evidence, we cannot agree to any recommendation to cap specific services or introduce fair use controls – these may inappropriate reduce access to Australia's telecommunication system by people with communication impairment who have no other options. The NRS as a critical support for people to access the Australian telecommunication systems should not be restricted to 'part time' options for non-emergency communication – other Australians do not face these restrictions in use of telecommunications. As stated earlier in our general comments, identifying which groups or individuals are the high users is paramount to understanding their needs and reliance on the service. This should be established before any change in service or measures to encourage a switch to mainstream options are implemented.

Option 3: Introduce more specific requirements to support access to the NRS including greater enforcement of fair use policies

The Discussion Paper proposed a range of options relating to registration and verification of disability of users of the NRS. Whilst not opposed to users needing an 'account', we are concerned that any process of verification of disability will be a burden on individuals with disability and on health and disability providers (including speech pathologists) who may be called on to establish evidence of disability. Reliance on eligibility for NDIS individual funding packages is not an appropriate mechanism to establish eligibility for NRS as many people with disability in Australia will not be eligible (or need) individualised funding packages yet will still have a genuine need to use the NRS.

It is recommended that the Department establish evidence of any non-genuine use of the NRS prior to requiring people to demonstrate evidence of communication disability to be eligible to use the NRS.

Option 4: Refocus the existing NRS outreach program

The outreach programme could be refocused to encourage mainstream option use in appropriate circumstances for appropriate cohorts of users. However, targeting of increased education and information through the outreach program is needed in order for these efforts to be effective at encouraging people to adopt mainstream services only in circumstances where they are able to do this. Whilst 'encouragement and information' may be a focus, the outreach program may need to consider how it provides 'training' to assist particular cohorts of existing NRS users to use these mainstream services. The Department should not rely on, or presume that the NDIS will provide this training and support for NDIS participants – it remains unclear if the NDIS will consistently provide support and training for communication using mainstream devices.

Option 5: Review the range of services options and technologies available to sustain delivery of the NRS in the future

We would not encourage any phasing out of technology or equipment until a suitable substitute service is readily available and easy to provide to an individual. This includes support and mentoring where required to assist the person to transition to an alternative option.

The NRS will always be chosen, and therefore should be available, if there is no mainstream option offering the same service/outcome for an individual or where other barriers (including communication, physical, cognitive, literacy or cost) make an alternative option not viable.

Option 6: Remove specific telecommunication regulations in place from disability equipment programs

Where specialist equipment is required and is the only option available for a person to utilise Australia's telecommunication system, then this should continue to be provided and subsidised. In circumstances where other mainstream communication devices can be used instead then this may be promoted by the NRS as an alternative. It should be noted that not all 'new' equipment is suitable for every person currently using the NRS.

Of significant concern is any proposal to repeal regulation that requires telecommunication providers to provide disability equipment programs. Reliance on the Disability Discrimination Act (DDA) to ensure telecommunications companies are meeting the needs of people with disability presumes that they are aware of, and understand in detail what their obligations under the Act are for their particular industry and services. Of concern, reliance of the DDA puts the onus on the person with disability to make a formal complaint (after the fact) of breaches of the Act through a complaints system that is telephone based.

Option 7: Encourage development of more affordable data-rich plans by retail service providers

Data on the use of internet based communication by people with communication disability is not currently available. As such, it is unclear if improvements in plans provided by retail service providers would meet the needs of current users of the NRS as a viable alternative option to the NRS.

The number of households with access to the internet at home increased, reaching 7.7 million in 2014—15, representing 86 per cent of all households (up from 83 per cent in 2012—13). Households located in major cities were more likely to have internet access at home (88 per cent) than those in remote or very remote parts of Australia (79 per cent). In 2014—15 most households who accessed the internet did so through a desktop or laptop computer (94 per cent), followed by households who accessed via mobile or smart phones (86 per cent) and households who accessed via tablets (62 per cent).

There were 1.3 million Australian households without internet access at home in 2014–15 (14 per cent). In 2014–15, information about the main reasons for a household not having internet access at home were: no need (63 per cent), lack of confidence or knowledge (22 per cent), and cost (16 per cent) In 2014–15, 85 per cent of people were internet users, with the older age group (65 years and over) having the lowest proportion of internet users (51 per cent). Reasons for accessing the internet by older people were the same as for all internet users: banking (50 per cent); and social networking (43 per cent).

If demand for the NRS is being driven by the older cohort of users, then there may be additional barriers to adoption of mainstream options than those related to their impairments. Issues of reluctance to adopt new technologies in the general older population may need to be addressed by the NRS as well as, issues relating to barriers relating to their impairments. The most critical need will be training, support and mentoring to use any mainstream service by people with disability.

Option 8: Encourage initiatives to improve digital literacy and the availability of mainstream text and video-based communication options

Encouraging people to use mainstream technologies will involve providing not just equipment but digital literacy training and mentoring. The NDIS has the potential to play a big role in supporting people with disability in this area but at this point in time, there is uncertainty about what will be funded (equipment but also training and support).

Whilst it may be appropriate to encourage the use of direct text and other text based mainstream options for current users of NRS services who have communication impairment – it is important to remember that text based methods will not be appropriate for all current users. Specific barriers relating to digital literacy are important, however of significant concern is considerations of low literacy (inability to effectively use text based systems) and barriers for people with complex communication needs who may not be able to easily physically use text based systems.

Recommendations

It is recommended that the Department consider the following when reviewing the National Relay Service:

- 1. That the NRS be recognised as a critical support to enable people with communication impairments to use Australia's existing communications infrastructure.
- 2. An in-depth analysis of the usage patterns for the NRS service options is needed to determine appropriate strategies for long term sustainability. The increased in demand may be by cohorts of users whereby a switch to the use of mainstream options may not be viable/realistic.
- 3. In the short term, funding should be increased to cover operating costs of the NRS whilst medium to longer term strategies are put in place to manage demand and ensure longer term financial sustainability
- 4. Until such a time as formal agreements are made between the NDIS and the Department, it is recommended that changes not be made to the NRS that *presume* NDIS support for NDIS participants to access mainstream communication technology (and support for its use) through their individualized funding.
- Consideration needs be given to the need of the NRS by people with communication disability
 who will not be eligible for individualised funding through the NDIS. This will include older
 Australians (over 65 years of age) and those with more moderate expressive communication
 impairments.
- 6. It is recommended that the Department establish evidence of any non-genuine use of the NRS prior to requiring people to demonstrate evidence of communication disability to be eligible to use the NRS
- 7. The outreach programme could be refocused to encourage mainstream option use in appropriate circumstances for appropriate cohorts of users. Targeting of increased education and information through the outreach program is needed in order for these efforts to be effective at encouraging people to adopt mainstream services only in circumstances where they are able to do this. This relies on higher quality information about the drivers of demand currently facing the NRS.
- That current specific telecommunication regulations regarding disability equipment programs be retained.

If Speech Pathology Australia can assist in any other way or provide additional information please contact National Office on 03 9642 4899 or contact Dr Ronelle Hutchinson, Manager Policy and Advocacy by emailing policy@speechpathologyaustralia.org.au.

Evidence cited in this submission

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