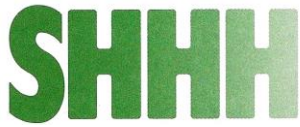


**Submission  
No 177**

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL  
DISABILITY INSURANCE SCHEME AND THE PROVISION  
OF DISABILITY SERVICES IN NEW SOUTH WALES**

**Organisation:** Self Help for Hard of Hearing People (Hearing Matters Australia)  
**Date Received:** 8 August 2018

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9 August 2018

Dear Director

### **Implementation of the National Disability Insurance Scheme and the provision of disability services in NSW**

Thank you for the opportunity to contribute to the Upper House inquiry into the implementation of the National Disability Insurance Scheme (NDIS) and provision of disability services in New South Wales.

Self Help for Hard of Hearing People (Shhh), soon to be known as Hearing Matters Australia, is a consumer organization representing adults living with hearing loss.

SHHH is an unfunded volunteer organisation, established in the 1980s, which is focused on conditions and causes of hearing loss, and which provides support and guidance to consumers in the management of hearing loss. In its role as a consumer advocacy organisation SHHH has no connection to retailers of hearing devices. Instead, our efforts are directed towards hearing loss support and encouragement, advocacy, education and the provision of accurate and up to date information pertaining to hearing loss and related conditions.

We strive to raise consumer awareness relating to

- the recognition (and acceptance) of hearing loss and it's possible consequences;
- making informed choices in terms of obtaining a correct and unbiased diagnosis of the condition;
- living with hearing loss and developing techniques to minimise its impact on lifestyle and social interactions, and
- current research on hearing loss and related conditions.

We produce a regular print magazine that educates the public about hearing loss and related matters. We also work closely with Macquarie University and a few independent audiologists to administer a hearing aid bank to those living in Australia who are need and who do not have access to the publicly funded scheme – the hearing services programme (HSP).

Shhh / Hearing Matters Australia has contributed to numerous inquiries into hearing services in Australia over the past few years. We welcome the opportunity to contribute to the NSW inquiry into the delivery of services both within and outside of the NDIS.

We wish to raise three main points in relation to the provision of services both within and outside of the NDIS in NSW:

1. Eligibility criteria
2. NDIS access
3. Hearing device provision vs hearing rehabilitation – role for NSW

### Eligibility Criteria

It is axiomatic that hearing impairment without treatment results in communication difficulties, leading to increasing isolation and to challenges for the individual in family, social and workplace environments. It is well documented that it can also lead to on-going health conditions such as depression, increased incidence of falls and cognitive decline, which are costly to society and the health care system. Being prescribed a hearing device is only part of the solution to the communication problem. Further, for most people, hearing devices do not completely rectify the hearing loss and some communication challenges remain. A process of rehabilitation is necessary for the new hearing device user to maximise the benefits achieved and become accustomed to living with the device(s). Rehabilitation includes learning communication strategies and techniques to make the most of the enhanced hearing capability as well as to minimise the impact of remaining communication deficiencies. Note that it is not only the new device user that needs this support but also their family, social and work groups. Without support, users of hearing devices frequently fail to achieve the full benefits of their devices.

The NDIS, despite declaring that funding decisions are determined by function and need, applies an impairment measure to determine eligibility for those with hearing loss. Eligibility criteria have been set for the NDIS that are dependent on age and degree of hearing impairment. Those under 26 years of age are eligible for support from the NDIS, regardless of type or degree of hearing loss. For those over 26, only those with average hearing loss levels of 90 dB or higher in their better hearing ear (described as profound deafness) are automatically eligible for NDIS funding. Those with lesser degrees of deafness, if associated with other conditions may be eligible. By far most people with debilitating hearing loss fall outside of the range of those who are automatically covered by the NDIS.

The quantified impairment-based cut-off point adopted by the NDIS means that some Australians with milder degrees of hearing impairment are being excluded from NDIS funding, despite having substantially reduced ability to participate effectively in activities or perform tasks or actions in an environment where do not know how to adapt their communication and even whilst also using specialised equipment. Even with hearing devices, many with hearing loss, regardless of degree of impairment, have significant impacts on social participation and ability to work, which are lifelong. In addition, there is often deterioration in both degree of hearing loss and function when communication situations become increasingly demanding.

Describing hearing loss as mild, moderate, severe or profound, and basing those categories on audiometry only without also recognising the degree of functional impact is outdated. Consequently Shhh/Hearing Matters Australia, as a partner of the Ida Institute, is examining the terminology is used to describe hearing (dis)ability. We know that the devastating effects of hearing loss on communication, psychological and social functioning, employment and participation in society are very often underestimated and overlooked, with deafness often described as the “invisible handicap”(Punch, 2016).

To illustrate how important intervention is, we illustrate a case study from our President, Christine Hunter, as shared with the Inquiry into the hearing health and wellbeing of Australians undertaken in 2017.

#### CASE STUDY – Christine

*I was diagnosed with a mild sensorineural hearing loss at age 5 following a bout of measles. My parents were told that nothing could be done to restore it. Throughout my schooling my hearing loss didn't really impact on me significantly but I compensated for the loss by sitting at the front of the classroom and received some external coaching in English and Mathematics to fill in some of the gaps emerging in my learning. I left secondary school after achieving my HSC in the late 1960's with the aspiration to be a secondary teacher. I gained a scholarship to Teacher's College and was the first member of my family to enter into tertiary education. At the end of the first year the College became aware of my reduced hearing and withdrew the scholarship as they considered I would be unable to manage classes. I was told I would be “a danger to children”. There was no Disability Discrimination Act in place back then!*

*I proceeded to work for several years in office clerical roles that did not require much face to face interactive communication with my workmates or the public. Following my marriage and the birth of three children I was persuaded at age 30 to try a hearing aid. With just one aid I began to realise what I had been missing in terms of sounds. As examples, I was able to hear the phone ring, birds sing in trees and was better able to hear the activities of my young children. I decided to try again for a tertiary qualification and began a TAFE course in which I excelled. This success gave me further confidence to enrol in a Bachelor of Education.*

*I completed 4 years of full time study and graduated with Distinction as top of my year. This would not have not been possible without the confidence and increased communication ability gained from the use of just one hearing aid, the help of my classmates and the communication strategies I had acquired over the years. By the time I graduated I found that my hearing was deteriorating and consulted an audiologist who assessed that it had dropped to the moderate range of hearing loss. I was fitted with 2 hearing aids which helped me get a more balanced, all-round sound reception and which helped improve my ability to cope. I was able to gain employment as a teacher in both state and private schools, rising to Head of Department in a highly regarded Sydney private secondary school. I taught all levels of students in my subject area, including HSC, and retired after 22 years as an educator. In retrospect, without the initial assistance of just one hearing aid I would not have been able to contemplate undertaking tertiary studies. Also, as my hearing continued to deteriorate to a severe level, without the assistance of 2 hearing aids I would not have been able to work and contribute to the community as an effective teacher for 22 years. This aspect is quite apart from these devices also providing me with improved interpersonal communication ability with family, friends and in everyday life situations. However, the hearing aids did not completely compensate for my hearing loss as although they amplified sounds they didn't always improve the sound clarity. Also the background noise in the classroom situation was often problematic.*

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*I became very good at lip reading, and I utilised new technology as it became available, such as going from analogue to digital hearing aids and then incorporating features such as Bluetooth for television and mobile phone usage as it developed (which needed top of the line hearing aids to work!). However I had to actively manage the way I communicated in the classroom and in meetings. I found meetings particularly stressful as I needed to try and centralise my position so I could hear more easily and I often needed to enlist the help of others to fill in any gaps that I had missed. I was forever very conscious of perhaps giving an inappropriate answer in a group situation as I could not always see the speaker or understand what was being said if I could not lip read. No other assistive technology was offered in my workplace environment which also added to my stress levels.*

*Communication strategies are one of the things that SHHH seeks to help its members develop in order to increase the effectiveness of their assistive devices. Over that 22 year career and as technology improved I upgraded my hearing aids 3 times at 5 or 6 year intervals. During this time I spent over \$40,000 on my hearing aids and received less than one tenth back from my health fund.*

*Overall for me, hearing aids were an essential tool of trade and although they were not the complete answer on their own, without their use my ambition would not have been realised and instead of being able to contribute meaningfully to society I could well have become an added burden to public health.”*

SHHH Australia Inc (Self Help for Hard of Hearing People) Submission to the Inquiry into the Hearing Health & Wellbeing of Australia

Christine's history is pertinent to the NDIS inquiry. In the 1960s, little support was available for those with hearing loss. Christine did not even have the benefit of hearing aids during her school years. In 2012, we are fortunate to be better informed, so that all Australians, up to the age of 26 are supported for any degree of hearing loss through the NDIS. However, to remain productive and to avoid any burden to the health and welfare system support is needed both for those who will remain eligible for NDIS support beyond the age of 26 years, as well as those who will not. In addition, those who acquire a hearing loss, often progressive in nature meaning that it starts as a mild loss of hearing that gradually worsens, experience greater and greater impact on everyday life. Hence early intervention and support is required to prevent stigma, denial, miscommunication, relationship breakdown, employment difficulties and social disconnection that can occur when hearing loss is not supported. We advocate for services to be available to all with hearing loss and their families, whether or not they are eligible for the NDIS.

#### Access to the NDIS and success in providing choice and control for those who are Deaf or Hard of Hearing

Many Australians with hearing loss or who are Deaf struggle to understand how to access the NDIS and obtain suitable supports via the program. The application process needs to be made accessible for those with communication difficulties and oversight needs to be exercised to monitor the success of the program in achieving choice and control for those who are Deaf or have hearing impairment in NSW.

One of the obstacles to gaining NDIS supports is that participants are unclear of what to discuss with their planner. Those with a regular audiologist to support them can obtain audiological advice, understand the HSP voucher system prior to their NDIS planning session. This is greatly beneficial in understanding what the voucher will cover and to recognise what additional supports are needed in their particular circumstance.

Those who are not familiar with the HSP voucher scheme will not have that valuable starting point to discuss what is available through the voucher and the NDIS. Participants may believe that the voucher is adequate to cover all their communication needs, whereas in fact the voucher is focussed on device distribution and access to a base level of technology that may not meet the needs of all participants. The usual process is that participants have little discussion of their specific needs in their initial planning session and are instead given a standard item of funding in their initial plan to undergo an assessment by an allied health professional or therapist to help assess goals and supports. In fact, it should be made clear to those with hearing loss that they can undergo an audiology consultation to discuss hearing needs and potential supports available. Additionally many Deaf or hearing impaired participants already have audiology support and don't realise that they can use this existing support to develop their goals and determine their needs. Audiologists as university qualified and accredited hearing health professionals are best placed to help assess hearing goals, make recommendations of devices and habilitation required to meet needs. It is important to note that a full audiological consultation with a qualified audiologist is required. Many companies advertise free hearing screenings or hearing checks that are often mistaken for audiological consultations. An audiological consultation can be expected to include a full discussion of history and needs, and a full audiological test battery undertaken by a university qualified audiologist who will be able to identify supports and services required beyond hearing device fitting.

In the current system many are not able to state clear goals or make informed requests for required supports in their initial planning session. This means that once they eventually obtain an HSP voucher and realise after appropriate consultation what support they require they must then submit a request for assistive technology or higher-level supports following their first approved plan, triggering a "plan review" which can take many months as there is a back log of review requests. This process is not efficient as it creates more administration and delays access to much needed equipment and services.

Additionally, meeting with planners who themselves usually have little knowledge of hearing loss or what potential supports would be beneficial and do not fully grasp the limitations of hearing device technology has resulted in vague and basic plans that pass responsibility on to an allied health professional, often an Occupational Therapist, who also is not necessarily a hearing and communications expert. We are aware of NDIS participants who, as a result of this convoluted system have not had access to sufficient information to exercise choice and control. Additionally they wait many months for essential safety equipment such as smoke alarms and urgent replacements for old and lost amplification devices. To improve choice and control for those who are Deaf or have hearing impairment we would like to see services in NSW vastly improved with better training for Local Area Coordinators (LAC) and Planners in the field of hearing loss management. As an organization, Shhh/ Hearing Matters Australia would welcome the opportunity to engage with the NDIS to develop appropriate training materials for NDIS employees. NSW can take a leading role in developing training for planners and LACs, that could be adopted nationally. Training should cover the impact of hearing loss, the hearing services available under the HSP to NDIS participants. Areas of training required include: how to access an HSP voucher, what is covered under the voucher, the differences between services offered by audiologists, audiometrists, retail hearing aid sales, what constitutes comprehensive aural rehabilitation, what is available to those eligible for Australian Hearing Community Service Obligation programs, and what rehabilitation is available in the private sector.



## Hearing rehabilitation – role for state governments

We understand that state services are meant to provide support for those not covered by the NDIS. State funded services for those with hearing loss in NSW are lacking. To date, hearing services in Australia have largely been addressed by Federal government and have mainly focused on hearing device provision. State hospitals and rehabilitation programmes offer very few audiology services. NSW can develop world class audiological services for the one in six NSW residents living with hearing and balance disorders. Community based interventions such as appropriate town planning, public address systems, noise standards, audiology services in state hospitals and on all multidisciplinary healthcare teams are all areas that are not necessarily covered as supports by the NDIS. NSW state services can also develop these to support those who are Deaf or have hearing loss who are not eligible for the NDIS.

Interventions to manage the impact of hearing loss for individuals, families and communities in Australia have been shown, through inquiries and investigations, to be device-centric. Regardless of the age at which intervention is offered, hearing devices) are typically offered by service providers (medical specialists, allied healthcare practitioners, early interventionists) as the primary and often only intervention. Making use of hearing devices is highly desirable *if* foundational interventions are in place or offered simultaneously (Getty & Hetu, 1991; Hetu & Getty, 1991). Understanding and making use of supplementary communication cues or using accessible languages such as Auslan; understanding and adapting to the psychological and cultural / social implications and knowing how to adapt environments for optimal communication should all be part of every intervention programme, preferably offered before or at least simultaneously with device provision. Such interventions are commonly referred to as rehabilitation.

For holistic intervention to be planned, assessments need to incorporate in-depth investigations. Communication abilities of the individual and others; psychosocial functioning of individuals and their communities as well as tests of auditory function and auditory processing ability are needed.

Funding models do not currently pay for individually determined assessments that investigate the full impact of hearing loss on individuals, their communication partners, families, schools and workplaces. Instead, a common model is for hearing tests or screening to be offered for free, under arrangements that bundle the cost of devices with services, those being focussed in device functionality, rather than personal and/or family functioning. For those with limited benefit from devices, in-depth investigations might eventually be undertaken, and advice provided under a hearing device fitting package, but such intervention is typically offered only if individuals and/or their families are very persistent. Rarely are such interventions offered ahead of any decision about device fitting as a first or only intervention (Collingridge, 2009). For those who give up on hearing services due to disappointment with devices, the opportunity to deliver supplementary and alternative interventions is lost when only devices are focussed on initially.

In many hearing clinics, regardless of age of the individual with a hearing difficulty, assessments are undertaken to determine eligibility for hearing devices as a first or only step.

Decisions such as implantable vs conventional hearing devices; or wearing one or two devices are made before other interventions are considered, which unrealistically raises expectations that technology will solve communication and social difficulties. When these expectations are not met, disappointment with devices, disillusionment with service providers and device abandonment is not unusual (the Australian Society of Rehabilitation Counsellors, 2017 report that a third of all devices owned are not used regularly), leading to frustration within families, social isolation, difficulty in school or the workplace.

For adults, untreated hearing loss (which includes abandoned devices without any other interventions) is recognised as a contributor to dementia (Livingston et al., 2017). Abandonment of devices and failure to take up any other interventions is common in Australia. Typically, the most common solution offered in hearing clinics is to trial yet more sophisticated or differently branded hearing devices, rather than to look more broadly for social, communication and environmental support – all of which serve as the foundation to effective communication and are recognised as interventions that can be offered with or without devices (Manchaiah & Danermark, 2016). Rehabilitation is recommended early in intervention programmes (Öberg, Bohn, & Larsson, 2014) whether or not devices are recommended. Where devices are an option, early intervention and counselling can assist with understanding devices so that they are more likely to be effective, when taken up (Hickson & Meyer, 2014).

### Call for NSW State Support

Enabling the holistic intervention requires state government to support research and services that are not given priority yet.

To this end, we call on government to work with consumer groups, including our own to achieve:

1. NSW to develop comprehensive training for NDIS planners, LAC and the public as to how to the effects of hearing loss on communication, services that are available and community supports required in order to help deaf and hearing impaired participants exercise choice and control over their programs. To this end, the NSW government is urged to nominate hearing as a health priority for Australia, supporting COAG decision making to enable this initiative and to develop public education programmes accordingly.
2. . NSW government to re-establish comprehensive audiology services in State hospitals, community centres and as part of multidisciplinary teams across NSW.
3. NSW government to recognise hearing devices as just one part of rehabilitation, which are helpful to most (but not all) with auditory and related disorders and very rarely are fully beneficial without additional support – including communication training, counselling, support for significant others, environmental adjustments.



We thank you for the opportunity to provide comment to the inquiry into the NDIS and delivery of disability services in NSW. We would welcome any opportunity to contribute to further discussions and to engage with the NSW government to develop hearing services to supplement those offered by the NDIS.

Yours sincerely

*Christine Hunter*

Christine Hunter

Shhh / Hearing Matters Australia President

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