



Self Help for Hard of Hearing People

SHHH Australia Inc.

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Productivity Commission
Disability Care and Support
disability-support@pc.gov.au

Dear sir/madam,

SHHH Australia Inc.

SHHH Australia Inc. is a voluntary, non-profit educational organisation dedicated to helping Australians with a hearing loss and whose primary method of communication is through speech. It was founded in 1983 in NSW by a hearing impaired person who felt strongly that hearing impaired people needed more than lip reading and hearing aids. SHHH has since grown and expanded, and now gives information and advice to hearing impaired people and their families, while promoting community understanding about hearing loss. SHHH believes that knowledge is essential to becoming a successful consumer. As its name suggests, its aim is to assist each hearing impaired person to make informed decisions about their own best alternatives for their hearing management.

The proposed National Disability Insurance Scheme

SHHH supports the proposal for a NDIS and commends the Productivity Commission for providing a plan for all Australians to be insured against the adversity of disability. The vast majority of Australians now gamble that they and their children will not suffer disability, as the cost of maintaining some quality of life for people with disability is beyond the means of ordinary people. This is a gamble with no winners, because those who avoid disability can have no guarantee of protection for their families or themselves in the future. Insurance again is a lottery in which people who are “lucky” enough to establish fault will be rewarded with some compensation, less whatever their lawyers take.

The potential of the hearing impaired (HI)

Although hearing impairment is strongly associated with the elderly, a significant number of people are born with hearing loss or acquire a hearing loss during their childhood or working years. Hearing loss has a significant adverse consequences on the education, employment and mental health of most HI children and working age adults. The cost to the community of the unemployed and

underemployed HI working adult population is enormous.

Now the potential exists for HI people to be fully rehabilitated and integrated into the education system, workforce and society. A wide range of technological, educational, medical and social resources exist to enable full rehabilitation.

Universal neonatal screening programs enable HI babies to be identified within the first few days of life. Medical and educational interventions are then available to assist the HI baby to hear and to obtain educational assistance to keep up with their hearing peers. Hearing aids and cochlear implants are being fitted at a very young age. Technology is available to assist with the home and classroom, so that children can communicate with their parents and teachers. This technology is constantly developing and improving.

Employers need motivation to employ and provide reasonable adjustment to hearing impaired staff. HI people with a good education and a healthy psychological profile are able to work as well as those who do not have a disability. Generally HI employees are more stable and loyal to their employers than people who don't have a disability

Why do so few HI people achieve full rehabilitation?

The first problem is that HI is the “invisible handicap” and is frequently overlooked when disability is considered. Politicians and bureaucrats are so much more impressed by disabilities that leave people in wheelchairs, using sign language or canes. The large group of working age HI Australians is very much overlooked. Some working age HI Australians have managed well to overcome the disadvantages of their disability because they were lucky enough to have the right help, the resources to pay for technology, the support of family and friends and a robust psychological profile. It is this group of successful HI people who tend to be most noticeable. The majority of working age HI Australians are not so visible if they have become socially isolated, depressed, antisocial and reclusive.

The second problem is that HI is dominated by the elderly cohort. Rehabilitative responses to HI have been focused on pensioners. The Office of Hearing Services voucher scheme is a well-run government program that has assisted hundreds of thousands of eligible elderly Australians to have quality of life in their senior years. But there is nothing comparable for working age HI Australians.

The third problem is that there are some programs and resources that help the HI and governments and bureaucrats simply assume that these programs and resources are accessible to all. In reality, the reach and success of programs varies tremendously. Factors such as location, age, money and determination are all relevant to the rehabilitation outcome. Organisations like Centrelink provide little or no direction toward hearing rehabilitation.

The need for universal provision of hearing aids

Hearing aids are expensive. A pair of hearing aids typically cost between \$2500 and \$12,000. This is beyond the means of many low income people. HI people may not be able to afford hearing aids, which results in their being cut off from normal communication. As a result, they may not be able to gain an education, get a job, develop normal relationships or live a healthy life. The failure to provide hearing aids is likely to result in an unnecessary burden on welfare and social services, extra health costs and more.

Because the HI are numerous, the cut-off criteria for NDIS eligibility will be difficult to determine. A

simple reference to the severity of hearing impairment (e.g. mild, moderate, severe, profound) is inadequate, because of complicating factors such as tinnitus, word discrimination, balance disorders etc. Query whether the International Classification of Functioning, Disability and Health, referred to on page 49 of the draft report will be appropriate for the classification of the HI.

SHHH supports a program that will enable everyone who needs a hearing aid to be able to get one. This may not require an extension of the voucher scheme to all working age Australians. It may be sufficient to have means-tested provision of hearing aids to those people who cannot afford to buy them on the private market.

Cochlear implants are a costly but highly effective alternative to a hearing aid for some HI people. Invented by an Australian, we remain one of the leading countries in the development and application of these wonderful devices. At present there are significant differences in access to cochlear implants depending on location and circumstances. A national disability scheme has the potential to standardize availability.

The need for assistive listening devices

Often overlooked, assistive listening devices (ALDs) fill in many gaps where hearing aids are inadequate. A handheld microphone can enable a HI person to hear what is said in a noisy setting. A looped room can enable the hearer to understand the speaker at a meeting by using the telecoil on their hearing aid. A student may be able to participate in a normal classroom setting with assistance from a remote captioner.

For some people, various forms of amplification and captioning provide more suitable alternatives to hearing aids. An amplified classroom can assist a group of Aboriginal children to hear. An amplified phone may help a person with a mild hearing loss. Some products are inexpensive but others can cost thousands of dollars. Better access to ALDs needs to be an essential part of the Disability scheme.

Also there is no systematic method of assessing and prescribing appropriate assistive listening devices. In order to access hearing aids, ALDs and other rehabilitation services, a HI person would need to be assessed as to their needs by an audiologist with specialist training in rehabilitation.

Hearing rehabilitation

There is much focus on hearing aids and cochlear implants. These devices enable HI people to participate in the wider community. Children with hearing aids or cochlear implants are often able to attend mainstream schools or acquire a mix of hearing and signing skills in special schools.

However, hearing aids are not the complete solution to the challenges of the HI. Clinical outcomes vary between individuals. Some people are able to hear on the telephone and communicate in most settings with hearing aids. Others are not and struggle to pick up just a few words. The cochlear implant is a wonderful Australian invention, but descriptions such as “miracle ear” can falsely give the impression that a cochlear implant will “cure” hearing loss.

There are many choices and options available for the HI. The proposal for a national system of information and referral is a welcome one. Many HI people do not avail themselves of the best in rehabilitation because they are not aware of what is available.

But the market is not always easy to navigate, particularly for the vulnerable HI person who may have severe limitations on their ability to communicate, and also be suffering from mild depression.

We have already seen a massive marketing push by hearing aid manufacturers and dispensers. Much of the marketing information is very good. However some advertising is overly optimistic and some is simply misleading. Hearing aid technology is very good, but the touted outcomes can be unrealistic for most consumers. The result is that a significant proportion of hearing aids are not used.

Whilst HI people do value choice, it is important that appropriate constraints are placed on an eager service industry that may be more focused on quick profits than providing a genuine outcome for the disabled. This is an issue that is relevant to all aspects of the proposed national Disability scheme. There needs to be an emphasis on quality outcomes as well as consumer choice.

Also needed is a more integrated system of rehabilitation that combines technology with counselling, education, information and ongoing support to ensure the best outcome for the hearing impaired person. For those of working age, there needs to be a stronger focus on gaining and keeping employment.

Many HI people of working age are either unemployed or underemployed. The piecemeal range of employment programs for the disabled vary considerably in effectiveness. Bearing in mind that the majority of HI people who are unemployed are struggling with depression and other mental health challenges, the prospect of an endless stream of job rejections is often too great to persist with job-seeking efforts. The proposed national disability support system offers them the hope of getting and keeping a real job.

A public awareness campaign

It is important that all Australians value the NDIS scheme. We propose that any introduction of such a scheme be preceded by a public awareness campaign that highlights the random and unexpected way in which disability can be acquired. The Commission has rightly identified fault to be a poor determinant of need. However, the public awareness campaign needs to go further than criticizing the shortcomings of the current fault-based compensation system. It needs to go further than highlighting the possibility of catastrophic injury. It needs to highlight the random nature of acquisition of disability.

Children

The HI disability group is one area where this can be highlighted. A baby born with a hearing impairment needs to be detected at an early age through neonatal screening. Then interventions must be available at a very young age, followed by educational support that will enable the child to keep up with her peers, and assistance to get into the workforce. A great outcome is possible. Contrast this success story with the child whose HI is not detected until they are in primary school, by which time the child is behind educationally, and will never catch up with her peers. The HI child will have greatly reduced employment and life opportunities simply because the system was not good enough to help her at an early age.

The NDIS means that prospective parents can have children who may be born with disability knowing that there will be support for their child. They should consider the alternative, which is unaffordable insurance. Also potential grandparents should think of the potential benefits to their grandchildren.

The elderly

We agree that the NDIS should be a separate program to those currently available for the aged. Most people of retirement age are able to afford hearing aids and the current system focuses on provision of aids to pensioners. It is likely there will be significant differences in the eligibility of people under the NDIS and aged care programs and the proposal to allow NDIS consumers the choice means that they will not be at a disadvantage when they reach pensionable age.

Co-payments

Under the voucher system for hearing aids, a modest co-payment is required annually, which covers the cost of repairs, batteries and replacement. This co-payment is set at an affordable level for pensioners and reduces the use of the service by pensioners who may not value their hearing aids sufficiently to make the co-payment. Collection of the co-payment is the responsibility of the service providers and this encourages ongoing interaction between them and the consumer. Consumers can discuss their concerns when visiting the service provider to get batteries, make the co-payment etc and have their devices checked. There is a good argument for a modest co-payment when expensive devices like hearing aids are provided as part of a disability service.

Employment assistance

Integration with employment assistance programs is also important. Employment services are often best able to identify what assistance a disabled person needs and other information that will be useful to other service providers. At present there is no structure to facilitate communication between employment services and disability service providers. Communication may depend on the consumer or an ad hoc system of communication.

Research

Hearing loss has a high incidence and prevalence in the population and more research is needed as to the most effective way to protect the hearing of future generations. Also, more research is needed about rehabilitation and the reasons why so many HI people are unable to get suitable work. Is it just inevitable, or are there reasons that could be overcome with appropriate rehabilitation and assistance?

Mental health

There is a strong link between disability and psychological problems such as depression. Ideally the NDIS will have a focus on the implementation of preventative programs that will reduce the number of consumers who receive no assistance until the psychological problems have developed. For example, HI adults are less likely to develop depression if they join a peer support group and receive lifeskills education soon after being identified as having the disability.

Workplace rehabilitation

Consideration must be given to the overlap between the NDIS and workplace rehabilitation schemes. Many working age adults suffer hearing loss as a result of noise injury and receive hearing aids and lump sum compensation. But arguably they will be better off under the NDIS scheme which is more focused on whole person rehabilitation than a lump of cash and a couple of hearing aids. Will the NDIS scheme partially replace the worker's compensation scheme and if so, how will eligibility be determined?

Please do not hesitate to contact SHHH if you require further information.

Yours faithfully,

Richard Brading

RICHARD BRADING
PRESIDENT