

Dear Committee Chairperson,
Joint Standing Committee on the NDIS – Hearing Services Terms of Reference

I offer the following submission as an example taken from my own life experience and of countless voiceless people with a hearing loss, who are deaf or Deaf, who I work for and with.

My submission highlights area of issues and unmet needs that need to be covered under hearing services in the NDIS, so all Australian who live with hearing loss or impairment, a chronic ear disorder or tinnitus; are Deaf or deafblind; and their families can have equity in their lives and equal access to our communities and the wider Australian economy .

Yours sincerely,

As part of the committee's inquiry into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS), the committee will examine the issue of how hearing services are transitioned to, and delivered through, the NDIS.

The terms of reference.

1. That the joint committee inquire into and report on the provision of hearing services under the National Disability Insurance Scheme (NDIS), with particular reference to:
 - a. **The eligibility criteria for determining access to, and service needs of, deaf and hearing impaired people under the NDIS;**

The effects of deafness on a person, cannot always be judged by a person's medical or audiological history. One person with a moderate hearing loss may cope quite well in employment or social situations but others not. A Deaf person using Auslan may be more socially adapted than a person with a moderate to severe hearing loss. The length of time a person has had a hearing loss, if it was from birth, early childhood or in later years effects their educational standards, employment, community involvement and their ability to cope with their hearing loss are all factors that need to be taken into consideration.

If a person is able to get supports and to be proactive about their hearing loss early as it starts to decline then secondary issues are less likely to arise. These secondary issues are well documented by Australian Hearing Services reports. These can be poor health, poorer mental health and wellbeing, more likely to be unemployed or underemployed more likely to be separated or divorced, more likely to have stress at work or more likely to have lower education outcomes than the general population. A person's hearing deteriorates as they age. A person who has a mild hearing loss and is proactive about it is less likely to have problems when their hearing deteriorates over a number of years to a severe or profound level.

Recommendation

Eligibility should be related to the individual's independent and meaningful participation in the community.

Eligibility should also reflect early intervention principles.

b. Delays in receiving services, with particular emphasis on early intervention services;

Early intervention in rural areas is difficult due to the lack of appropriately trained professionals. As permanent hearing loss is not that common in children, audiologists and speech pathologists that specialize in child hearing loss are not common in regional and rural areas. Attracting such professionals in regional areas is difficult, therefore families need to wait longer for services. The cost of travel and time involved to provide services from regional cities takes funding which is frequently not accounted for. Therefore rural people have less access to trained and appropriate services and less direct therapy time when they are available.

It is an essential for children with a hearing loss to have a link and working relationship between their education and their hearing provider. Audiology and education each require specialist that can work together for the betterment of the student. At present Australian Hearing provides an excellent and qualified service with liaison with schools and kindergartens on early childhood hearing loss. This may not always be the case if changes are made to Australian Hearing services. If Australian Hearing does not support students in schools in future and it is left to private providers then delays will occur in service and the use of specialized and trained pediatric audiologist less likely to assist students.

Services in Victoria that do specialize in Deaf and hard of hearing for children are all city based. With improvement of technology outreach services are improving but children and families in rural and regional areas are badly serviced in professional and appropriately trained early intervention services.

Families use Auslan as a main communication mode or use Auslan with their deaf child are without appropriate Deaf services in rural areas.

Recommendation

Funding for services provided to rural areas need to reflect the full costs of travel including extra funding to provide outreach services

c. The adequacy of funding for hearing services under the NDIS;

Funding needs to reflect the expensive prices of assistive equipment. Quality hearing aids are expensive. Top quality hearing aids have many adaptations and extra technologies that enable the wearer to be more connected and have a better clarity of communication, which of course will have better outcomes for them immediately and in the future. These aids are usually not available under current Hearing services except if the person is able to pay extra. This can be \$1000s. The cost of the better hearing aids to the individual, including those who are currently using hearing services, is prohibitive. People who may be eligible for the NDIS, currently may not be under Hearing services, also find that quality hearing aids currently are prohibitive in cost. A person with a hearing loss typically is less likely to work in high paid professions or jobs, therefore the percentage of income needed to purchase hearing aids is high. Hearing aids can range up to \$10,000-\$12,000 and need to be replaced each 3 to 5 years.

One in six people have a hearing loss, a substantial cost to themselves, emotionally, relationship wise and financially as well as a cost to the economy. Much of this hearing loss is preventable. Awareness and early intervention proves to be the best indicator of adapting to the loss of hearing. Awareness on the part of the person with a hearing loss but also community awareness. If communication is two way then all people should be aware of communication strategies and use of equipment that can assist a person with a hearing loss.

Prevention, awareness and community inclusion is the other side of hearing loss. As much as technology and equipment assists, is vital that the community is aware and can appropriately make adaptations for a person with a hearing loss. Currently Australian Hearing and other funded agencies have little funding for such activities. Funding for inclusion of people who are deaf and hard of hearing needs to be substantial under the ILC

Recommendation

Awareness, prevention, community capacity building and community inclusion needs to be a national coordinated approach, implemented at a local level, as a part of the ILC component of the NDIS as this area will be the best way to assist the majority of people with a hearing loss.

Funding under the NDIS needs to reflect the high costs for technology and equipment.

d. The accessibility of hearing services, including in rural and remote areas;

In rural areas of Victoria where I work there is not a wide choice of service providers outside the regional cities. This puts people in rural areas at a disadvantage in costs of hearing aids and well as services. At present Australian Hearing travel to smaller towns as does one private audiologists and one hearing aid franchise, however it is not financially sustainable for a full time presence or for service providers to be competitive.

Hearing services in rural areas also need to be tailored by the need for intervention, prevention, education, screening, follow up in indigenous communities, not only in remote areas but rural and regional Victorian communities. This is an essential specialized area which may not be financially viable for providers unless special provisions are provided.

The lack of services effects if a person continues to wear hearing aids. A very common issue is that people who get hearing aids discontinue using them. This is for a number of reasons. However if there are available services, follow up and back up, it is more likely that people will make effective use of their hearing aids. Without local services this backup does not occur.

At present repairs to hearing aids happens in capital cities. In a rural area, if you need a hearing aid repaired and you have to wait until the service provider comes to your town, then wait for the aids to be sent off and repairs to be done. Then you have to wait until the service provider returns to your area, unless you want to pay \$150.00 priority. This effectively puts you without effective communication for almost two weeks. This adversely effects your life, your relationships, and your work.

Recommendation

That funding from the NDIS reflects the substantial extra cost incurred by rural hearing services in providing services to rural people with hearing loss.

e. The principle of choice of hearing service provider;

It is important that there is a choice but also important that the person with a hearing loss knows the service provider and staff are appropriately trained and accredited with a professional Australian Audiology Association or similar. Hearing aid companies and hearing aid franchise are beginning to dominate the market and people are wary of places that diagnose your hearing loss, then suggest expensive hearing aids. Continued work is needed on guidelines to the practice of audiology and audiometric practitioners. Continued competition and service from Australian Hearing, a trusted provider with qualified practitioners for specific and minority groups. I.e. children and indigenous, is also needed.

In rural areas of Victoria where I work there is not a wide choice of service providers outside the regional cities. This puts people in rural areas at a disadvantage in costs of hearing aids and well as other hearing services, screening, and repair, follow up. At present Australian Hearing travel to smaller towns as do two private audiologists, however it is not financially sustainable for a full time presence or for other service providers to compete.

Recommendation

Continued work is needed on guidelines to the practice of audiology and audiometric practitioners.

Continued competition and service from Australian Hearing, a trusted provider with qualified practitioners for specific and minority groups. I.e. children and indigenous, is also needed.

f. The liaison with key stakeholders in the design of NDIS hearing services, particularly in the development of reference packages;

Recommendation

The Deafness Forum is the peak body that represents the majority of organizations and a large number of individuals with hearing loss, deafness or hearing health issues. Deaf Australia represents Deaf people who have overlapping but sometimes different needs. These two peak bodies understand the issues from a participant's point of view and should be the main contact.

I believe that although technology and equipment is a major assistance for people who are deaf and hard of hearing, it is not a cure. Even the best hearing aids have their limitations, people choose not to use them, including Deaf people who communicate through Auslan. Therefore emphasis on equipment should not be the only assistance discussed when developing reference packages. Technology and hearing aid companies should not be key stakeholders but agencies like Conex Foundation, who put the appropriate technology into accessible forms, are more important to have input.

ILC. What community supports are available? What community infrastructure is needed? What community awareness is needed? These are questions that need to be asked as hearing loss affects communication and communication happens in the community. This information is more likely to be gained from the Deafness Forum. In Victoria the DHHS Deaf Access a Building Inclusive Communities program works to ensure that Deaf and Hard of hearing people are included in their communities. This program goes beyond technology and works with communities to be inclusive for deaf and hard of hearing people.

g. Investment in research and innovation in hearing services;

Recommendation

Technology in this area of disability and community access is changing rapidly. Independent research and innovation needs to be in keeping with this change so participants of the NDIS have access to these initiatives.

h. Any other related matters.

The importance the ILC shall have for people with a hearing loss.

Most people with a hearing loss will not receive funding under the NDIS. Once hearing aids or equipment is purchased very little else is given in the way of assistance for hard of hearing people. They still have a disability, they still are discriminated against, and they are still not given equal access in the community or at work. Community spaces, public, educational, commercial or business, are not designed for effective communication. Public and private agencies do not use effective communication strategies for hard of hearing. Why do I need to ring up to book my hearing assistance dog on the Tasmanian ferry? To me that is not sensible and most disheartening especially when my mishearing made me agree to incorrect dates and I needed to re ring when I received written confirmation that showed I had made a mistake. As an individual I can complain but this does not change their systems. This type of problem is common where communication is designed for hearers only. Who shall make business, companies, government aware of these barriers and work towards overcoming them? Adequate funding under the ILC is essential for the inclusion of deaf and hard of hearing people into their communities.

Movie theatres when they do advertise captions do then not have useable equipment, hearing loops that don't work, community consultations held in inappropriate meeting spaces, meetings, radio and television that allow more than one person to talk at once, only free to air television having captions. Community Capacity Building under the ILC would be able to assist in most instances. These are bigger systematic issues that if broken down will greatly improve a hard of hearing or deaf person's community participation with all the physical and mental health and wellbeing that ensues.

Recommendation

That the ILC is funded so all people with a hearing loss, the few NDIS participants and many, many others, will benefit from the ILC community capacity building through increased community participation. .