Joint Standing Committee on the National Disability Insurance Scheme
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Parliament House
Canberra ACT 2600
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30 January, 2017

Dear Sir/Madam

Re: Provision of hearing services under the National Disability Insurance Scheme (NDIS)

Thankyou for the opportunity to make a submission to the current inquiry.

Background

I present these comments based on my personal experience, observations and opinion.

I am an audiologist with almost 30 years experience in a range of remote, regional and urban settings. Since 2008, my clinical work has centred on outreach audiological services across the Top End of the Northern Territory (NT) and to a lesser extent in Central Australia. I do not perform this work fulltime and am part of a team delivering these services from Darwin or Alice Springs. I have spent between 24-28 weeks per year working and traveling to various remote regions of the NT (split into 4 blocks across the year).

My employment since 2008 has been with different agencies (including both Australian Hearing and to a lesser extent the NT Hearing Health Program) for a wide range of age groups from young infants up to elderly adults. This has mostly been tertiary re/habilitative hearing services but also primary health care, prevention and education for ear and hearing health, and secondary diagnostic hearing services (including the audiological component of tele-otology or Ear-Nose-Throat service delivery). The majority of this outreach clinical caseload has been Aboriginal infants, children and adults with conductive and mixed hearing losses associated with otitis media (ear infections and ear disease). In addition the caseload has included other eligible Australian Hearing clients (infants, children and adults) living in the remote communities and towns visited and with sensorineural hearing loss, other complex hearing disorders and hearing loss with other disabilities.

In the Northern Territory, NDIS was introduced in the Barkly region (Tennant Creek) as a trial site in 2014 and has now commenced in East Arnhem region in January 2017.

Comments

Although I have very limited personal experience with NDIS to date, I am interested how the NDIS is further rolled out and implemented in NT and across Australia. I wish to draw the Committee's attention to a number of issues related to the following terms of reference and to highlight my concerns.

I understand some of these issues would already be familiar to NDIS and agencies working in the Transition Plan [1]. I wish to further emphasise their importance so there is confidence no-one would be potentially worse off at the full roll out of NDIS.

(a) The eligibility criteria for determining access to, and service needs of, deaf and hearing impaired people under the NDIS

The current criteria for determining eligibility for hearing impairment under NDIS is:

> *Deafness/hearing loss – a 45 decibels or greater hearing impairment in the better ear, based on a 4 frequency pure tone average (using 500, 1000, 2000 and 4000Hz).*

This definition precludes mild hearing impairment and also people with asymmetrical hearing loss which may be mild in the better ear but a potential moderate, severe or profound hearing loss in worse ear.

It is currently unclear how longer term fluctuating conductive hearing loss would be regarded.

I understand in the transition to the full NDIS roll out, ongoing consultation regarding some of these aspects may be expected.

I believe there needs to be flexibility in the eligibility criteria. A figure of an average hearing loss in the better ear does not adequately capture all those who cannot effectively participate in life without assistance or modifications. Other measures which indicate the degree of impact of impairment of hearing or auditory disorder and related capacity (activity limitation) and performance (participation restriction) measures would assist justifying a need for hearing services.

Young children and students who may fall outside the current NDIS criteria and who may be at risk of not having audiological and communication needs adequately met if they do not have the financial means or access to an appropriate service should be addressed by NDIS. An appropriate hearing services plan for them would optimize speech and language development, communication skills, educational attainment and later employment opportunities. Once gainfully employed, such people deemed to not fall within current NDIS criteria should have ongoing access for some service provision to maintain employment based on additional criteria or functional assessment tools rather than simply a figure from an audiogram and average hearing loss in better ear. (For example, a child with a mild hearing loss in one ear and a cochlear implant in the other worse ear has an ongoing need for services and some of which are quite expensive such as implant speech processor repairs or replacement).

Chronic or recurring otitis media (ear infections and chronic ear disease) is a known health issue for some at risk populations – for Aboriginal and Torres Strait Islander children and adults, and for people with conditions such as Down's Syndrome or congenital cranio-facial abnormalities (eg cleft palate). The

[1] Hearing Services Program NDIS Transition Plan, Dept of Human Services, Office of Hearing Services
http://www.hearingservices.gov.au/wps/portal/hso/site/about/national%20disability%20insurance%20scheme/ndis_transition_plan/!ut/p/a1/jY_dCoJAEEZfRR8gdpKUbpdAyp-kC8v2RiYzHdBV3C2op2-NbjPnbmbOx8dhgmVMSHxQhZo6ic24Cy8PD6633IETro-JD5zv0yjwVw4kYIDzBADuvDz8GA7_8sGMAmeIN3HFRI-6XpC8dSyTX0HrSgov1JB-WiTVfUBZlJYq6rItDWW-uTY3RSOe9w1KdmJisnN0_gATUn2bZq9oC8Rt-w0WyxUo/dl5/d5/L2dBISEvZ0FBIS9nQSEh/

nature and effects of conductive hearing loss from chronic or recurring otitis media in Aboriginal and Torres Strait Islander communities are well known. [2]

From an overview discussion in Audiology Australia's *Chronic Otitis Media and Hearing Loss Practice (COMHeLP) - A Manual for Audiological Practice With Aboriginal and Torres Strait Islander Australians (Hearing Loss – Its Effects, Pages 21-22):*

> *Hearing loss caused by ear disease varies with ear disease stage/state. The hearing loss associated with otitis media with effusion (OME) or acute otitis media (AOM) is conductive in nature and generally averages 15-30dB. In ears with perforated eardrums (chronic suppurative otitis media – CSOM - or dry perforations), the hearing loss is often greater and can be as much as 70dB.*
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> *Hence, an…average hearing loss… often used as a measure in audiological practice and based upon a single assessment could underestimate the degree of impairment. Moreover, the usual classifications of degrees of hearing impairment are based on pure-tone audiometry on a single test day and do not take into account other exacerbating factors.*
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> *In Aboriginal and Torres Strait Islander children… there are exacerbating factors…which would be likely to contribute to significant disability and handicap as a result of otitis media (OM) and associated hearing loss.*
>
> *Factors which might exacerbate adverse outcomes include: disease severity...social environment …language environment... learning environment.*

The challenges for a young remote Aboriginal child with a history of ear disease, fluctuating mild or mild-moderate conductive hearing loss and its impact on their speech and language development in their first (and second) language, readiness for enrolling at school, capacity to learn English as a subsequent language and attainment of literacy at school cannot be understated or simplified. Their auditory needs need to be managed in the full NDIS implementation.

(b) Delays in receiving services, with particular emphasis on early intervention services

Although I have limited NDIS experience to date, my concern is at full rollout and a moderate-high risk of timely access to services frequently experienced by people living remotely. The challenge is how the risk may be mitigated, particularly where demands for NDIS services could be higher than expected and opportunities to consult a visiting provider in remote areas are only very occasional.

I understand that a person would go through a registration, consultation and approval process with NDIS planners before hearing re/habilitation may commence. I am concerned at the prospect of any delay and bureaucratic barriers which may occur, particularly in a remote context. I can envisage lost opportunities and delays if a provider is visiting a remote location for other clients but the dilemma of a new person recently diagnosed with hearing impairment and known to be in need of service yet without

[2] Chronic Otitis Media and Hearing Loss Practice (COMHeLP) - A Manual for Audiological Practice With Aboriginal and Torres Strait Islander Australians, March 2012, Audiology Australia http://audiology.asn.au/index.cfm/resources-publications/professional-resources/

appropriate NDIS approvals in place. What provision may there be for a provider to help fast-track or cut through a systemic delay when the prospect for the next clinical consultation is not anytime soon?

(By historical illustration, it was a welcome change many years ago when Aboriginal adults living remotely and holding a Pensioner Concession Card could immediately enter the Community Services Obligation (CSO) stream of the Hearing Program upon the audiologist verifying pension status rather than completing a Hearing Services Voucher application form, wait for a voucher to be processed and then issued before funded services could formally commence. This flexible arrangement was not extended to non-Indigenous pensioners living remotely and initially entering the Hearing Services Program through the Voucher Scheme to then be classified as 'remote' and able to then access the CSO stream - they would have to wait for a voucher first. Fortunately, the more recent introduction of the Office of Hearing Services (OHS) on-line portal has helped overcome this processing barrier to a large extent. NDIA need to consider such remote scenarios with closer scrutiny.)

I envisage any delay with NDIS processes may be compounded when more remote people who have English as a subsequent language need to understand and engage with the NDIS system and its requirements (and then potentially make a choice if different providers are available in their area). This approval to determine eligibility for NDIS would appear to be a backward step compared to the current OHS program and akin to requirements many years ago of prospective Office of Hearing Services clients needing to complete paper application forms and awaiting the issue of a Hearing Services Voucher. For people living remotely, although the intent to discuss their needs with an NDIS planner is reasonable, this needs closer scrutiny that systemic barriers to timely service do not emerge and opportunities for service are not missed.

The current benefits of a national provider (with a presence in remote locations) and access to a comprehensive national database cannot be under-stated with respect to those whose needs are highlighted in the following recent cases:

- A family moved from interstate to live and work in a remote NT community. They returned to their original interstate city for the birth of their baby who was then diagnosed with moderate sensorineural hearing loss following newborn hearing screening. Having stayed longer interstate than originally planned until the diagnosis and initial interventions including appropriate amplification had taken place, the family returned to the NT remote community. The family was aware Australian Hearing provided services across NT so they phoned Australian Hearing to enquire when and how they may next access an appropriate appointment. Australian Hearing visits this remote community four times/year. By chance, Australian Hearing was in the community that very day and within hours the family presented for an appointment to see myself as the audiologist. Given good access to remote internet connectivity and an accessible in-house national database and client management system, I was able to have read the original Australian Hearing results and clinical notes from interstate appointments prior that afternoon's appointment and to discuss the child and family's ongoing needs and management plan. The family continue to receive services regularly at the remote NT site as well as accessing services if travelling back to their original interstate city for other reasons.

- A young teenager living outside NT with a moderate hearing loss is travelling with her family on a cruise around Australia and nearby seas. After some water-based activities at one port, her hearing aids became wet and no longer working reliably which severely restricted her auditory capacity and communication. As soon as the cruise ship docked into Darwin for a day, the family sought out Australian Hearing and appropriate repairs and maintenance were performed. The teenager and her family then rushed back to the cruise ship, holiday activity and onward journey.
- A man in his early 30s self-presented while Australian Hearing visiting a remote clinic in the NT community where he now lives. He had obvious hearing impairment and communication difficulty and complications from otitis media and a cholesteatoma (ear disease) were becoming apparent. His family accompanied him such was the level of concern with his communication and listening skills. The man had no current hearing assistance but indicated that he had previously worn a hearing device for a short period many years ago during his late school years when living in another state. Possible ear surgery was also discussed with an ENT when younger. An initial search of the Australian Hearing database yielded nothing. The man then clarified that information may be under his old name – an additional search of an older database identified his original service history and helped inform the remainder of the consultation and discussion of clinical plan. Subsequently his interstate Australian Hearing paper records were transferred to Darwin, enabling more detailed information on his earlier ear health history, hearing loss, ENT reports and audiological program from that time.

Such cases of mobility and movement (temporarily or longer term) across states are not unusual. I would wonder how such case scenarios may be managed seamlessly and how timely when NDIS is at full roll out. I would anticipate (subject to the type and geographical or on-line footprint of future NDIS providers) there may well be the need to contact NDIS, an NDIS planner or other hearing providers for information and appropriate approvals to proceed. This again highlights a real risk of delays compared to current remote hearing service arrangements and what safeguards NDIS could have in place so that remote clients are not worse off.

Unfortunately, children with severe to profound deafness in remote locations do not consistently receive the same intensity and frequency of specialised intervention, habilitation and therapy sessions as their urban counterparts. Although there may be some exceptions to this and the use of video-conferencing and on-line communications has improved access for some, the level of family support and engagement, participation by family in sessions to support their child's goals, consistent attendance at school, capacity for families to travel and capacity for families to navigate 'the system'and advocate their child's needs are all factors leading to relatively successful outcomes in language development, communication and development of literacy. The Deaf and hearing impaired children living remotely who have managed to achieve remarkable outcomes despite their challenges and barriers are a credit to their own resilience, and the support, determination and advocacy of their family, educators and other professionals working with that child.

For remote deaf children, collaborative and team approaches to meet a range of their needs may be required by providers with different expertise. I understand NDIA and planners could work with families

to help foster and co-ordinate such collaborative efforts – it will however, be important to recognise early when any barriers to success need to be addressed or funded appropriately, particularly during the critical early learning years when delays in service provision could compromise longer-term outcomes.

(c) The adequacy of funding for hearing services under the NDIS

I would expect the Committee and NDIA would be already mindful of the costs of service provision in remote Australia. To reiterate, it is more expensive than delivering service in urban areas.

To highlight some examples of additional costs that need to be recognised and accounted for in remote service provision – remote travel (commercial flights, charter flights, 4wd and maintenance, 4wd safety and retrieval gear, vehicle hire, accommodation), the additional costs of excess baggage on commercial flights when transporting clinical equipment and supplies and any food provisions, rent of any clinical premises if required.

The cost of interpreters needs to be adequately funded and available through NDIS funding – professional Aboriginal interpreters and Auslan interpreters. Interpreters in remote areas may have their own travel costs built into fee structures. Fortunately video-conferencing or on-line technology are emerging with interpreter services. Remote access for these however may be hampered by factors such as internet access, weather affecting satellite communications, appropriate facilities and technical support to facilitate video-conferencing sessions.

Time spent travelling (or preparing clinical equipment and supplies for an outreach trip) means less direct time spent clinically with clients and delivering services which would be funded. Unexpected and unforeseen events can impact and cause an additional impost on the best made plans or loss of productivity for remote service delivery. Adverse weather events, small plane and 4wd vehicle breakdowns or maintenance, road conditions, cultural events, power outages are familiar remote issues.

Appropriate staff training for people working in remote locations which may be additional to requirements in urban areas may be 4wd driver training, emergency first aid and remote workplace safety, cultural competency training for remote Aboriginal communities, training in the use and interface with different community health clinical databases. (To understand a remote Aboriginal person's hearing loss, it is important to understand their ear health history and management plan so access to clinic databases is required for shared communication between professionals).

In addition, scopes of practice are a consideration in remote hearing service provision. The rates of otitis media are unacceptably high in Aboriginal communities. Audiologists generally are not trained in the clinical management of ear health conditions. However, when working remotely they have a unique opportunity to contribute to improvements in the diagnosis, treatment and follow-up of otitis media for individuals they encounter in the course of their main work activity ('the right person in the right place at the right time'). They could help train other remote health workers in ear health conditions to improve skills and knowledge. I would advise any audiologist working in remote Aboriginal communities to extend their scope of practice with appropriate training and practice to become more familiar with otitis media, diagnosing ear health conditions and local clearly defined treatment guidelines. Although these aspects of primary ear health care may not be regarded as a core function if delivering tertiary

hearing services, the remote audiologist needs these skills to manage such clinical presentations as they arise, more so in communities where nurses or Aboriginal Health Practitioners are not available or limited in resources. Flexible funding models need to be available for occasions when audiologists may perform such primary ear health activity.

The loss of hearing devices in remote communities can be a challenge. Some families have difficulty keeping personal items safe when living in over-crowded housing, with limited private and secure space. Anecdotally 'little kids' are often identified as the reason why hearing devices go astray or broken. The prompt repair and replacement of hearing devices is an important consideration for funding services and quality safeguards.

Remote clients need options to choose robust and easy to maintain hearing devices that may not require frequent maintenance or to be sent away for repairs. Mail service between remote communities and urban centres for repairs adds to the delay of not being able to listen or communicate during these times and would be frustrating. Funding provisions should include capacity for back-up or spare devices in some circumstances.

Specialist medical and allied health service provision in remote locations is generally not as readily available as urban areas so delays between visits are common. Telehealth models are further evolving to improve this access. Currently, when a person is identified remotely with hearing impairment, in some circumstances, devices may occasionally be fitted the same day but generally an appropriate appointment is planned for the next visit. Priority for a more urgent appointment is recognised so appropriate alternate arrangements can be offered and successfully made. Unfortunately, currently in the NT, the Patient Assistance Travel Scheme (PATS) for allied health services is only approved in very limited circumstances if associated with intensive medical or surgical treatment and is subject to a rigorous approval process. If a provider deems the urgency to visit a remote location before their next scheduled visit, would the provider wear the cost of this intervening travel or would NDIS have provision for such circumstances if no alternative arrangement was available?

In my Outreach work, I am based at both clinics and schools. A significant portion of time can be spent directly liaising with families after school and with school staff or early intervention staff or other professionals discussing particular children. This is additional to direct client contact and clinical activity. Liaison and clinical reporting functions need to be factored into funding arrangements. Similarly, funding needs to factor time spent such as training and providing in-services for school and clinic staff for the benefit of NDIS clients and their needs.

(d) Accessibility of hearing services, including in rural and remote areas.

Factors to consider for access in remote areas have been mentioned in other sections.

(e) The principle of choice of hearing service provider.

The principle of choice of provider is valid and regarded as beneficial for clients. Clients (and their families) should have the capacity to choose an alternate provider if they wish. However, I am concerned there is a potential significant downside for the needs of paediatric clients and those with complex needs with a yet-to-be-determined future for Australian Hearing and its current expertise.

Australia is at risk of being worse off if paediatric hearing services (as currently provided through a national agency such as Australian Hearing) become too fragmented or too regionalized within separate States across a larger number of providers. A divide in access to and quality of service is highly likely to emerge if urban based and well-resourced providers do not extend their presence, high standards of service and capacity for innovation to rural and remote areas and locations where it is difficult to attract and retain appropriate trained staff and expertise. The additional impost of delivering sustainable and long-term remote and rural services with reliable access for clients in a vast regional or remote area may not be attractive to every private entity's business model. It would be a challenge to make a profit and for this reason government funded community service obligations have been required up to now. Although there are exceptions and some private providers already have a presence in rural and some remote areas or have become innovative in their business model to address rural/remote needs, it is not consistently replicated or taken up in all parts of Australia.

A strong advantage of Australian Hearing currently is that an Australian Hearing paediatric audiologist could walk into any Australian Hearing centre across the country tomorrow (or provide an Outreach service from that location) and be able to deliver services with the same consistent clinical knowledge and expertise and access to the same range of devices for clients regardless of location.

Schools and early intervention agencies would also be at risk of having to manage an array of different personal amplification and wireless technology devices if there are various providers in a particular school catchment area. This may potentially be overwhelming for new staff managing a larger group of hearing impaired students (for example in a specialist Deaf/hearing impaired unit or school) rather than becoming familiar and confident with a smaller or more consistent pool of devices amongst students.

I have valued Australian Hearing's collective expertise, knowledge and experience. I have valued its national database and systems to manage clients. Australian Hearing has enormously benefited the needs and outcomes of the paediatric hearing impaired population and the development of my (and countless other audiologists) skills and knowledge. Australian Hearing has been an asset for me to easily network, share experience and gain valuable advice for more complex cases or issues, particularly when working in very remote parts of the country. This in turn benefits the Australian Hearing clients from those locations.

(f) Investment in research and innovation in hearing services.

Research and evidence are important to drive future improvements in service delivery models, clinical practice, clinical pathways and outcomes, technology (clinical equipment, hearing technology and communication/systems/databases) to support services.

Innovations in service models, products and technology are important to benefit Deaf and hearing impaired clients, support service delivery and allow Australia to continue to be a world leader in audiological research and services.

(g) Other related matters

The rates of moderate hearing loss in adults arising from childhood or ongoing otitis media is generally known to be high in Aboriginal communities. My observation is the rates in some NT communities

appear higher than in other NT communities - but this observation of course would be shaded by the willingness of these adults to present for referral, assessment and to participate in a hearing rehabilitation program.

The stigma of wearing hearing devices seems to vary in different communities. There are a few communities where the 'tipping point' of community acceptance for adults using hearing devices has been crossed and proportionally more adults are more motivated to actively seek out follow-up hearing aid maintenance services, batteries and device replacement when lost. In contrast, other communities appear to have more widespread reticence to actively engage with hearing services, use hearing devices outside of the home or perhaps use only at night-time (when lipreading and community signing or 'hand talk' over a distance is much harder). Hopefully with time and community education and further guidance to tackle this issue from local health workers, this stigma will diminish and more people actively seek service.

I would trust that NDIA have accounted for the expected numbers who could be seeking future service.

The acceptance of hearing loss and hearing devices in teenagers and young adults living remotely is also a challenge. Without strong family and community support or strong self- motivation and resilience, some choose not to continue use of their hearing aids or participate in ongoing audiological support. This highlights psycho-social needs and the need for access to appropriate counselling and support given the functional impact of attitudes/beliefs, mood/affect and thought form/content of young hearing impaired teenagers and adults during these times. Initiatives through the NT Department of Education (and Deaf Children Australia) such as an annual Talking Hands Camp in Darwin has been highly regarded as one example to help build self-esteem, confidence, social skills and friendship networks.

I am aware of adults working and living remotely with significant hearing losses but not eligible for hearing services - listening and participating at work and home can be a challenge. The cost of hearing devices and cost of travel to a private provider can be prohibitive. Although there may be more economical options (eg basic personal amplifiers used with headphones or earbuds, they may not always be practical or suitable for their needs). As NDIS rolls out, it will be interesting to see how and when such people access any available NDIS service.

In my travels across remote NT, I have mentioned NDIS to some clients, their families and also some health professionals. The level of awareness is very low but I understand NDIA will address this as the roll out continues.

The delivery and approach to remote services does vary between different remote Aboriginal communities. Challenges for NDIS remote service delivery will be inevitable. Relationship building (with individuals, communities and between other professionals and agencies), consultation and continuity of support will be important for all involved. Empowering family members and carers to support an individual with hearing loss is often best done face-to-face within the community. Key people may only come to light by being in the community.

Yours sincerely,

Paul Hickey (Audiologist)