



7 FEB 2024

Working Line to fix the NDIS.

Tinnitus Awareness Week.

Deaf Children have Hearing Restored by Gene Therapy.

Communicating above the din.

To Get a Fair Hearing: High Proportion of Indigenous Canberrans in Prison.

Nearly a third of Canberra's average prison population is Indigenous, despite Indigenous Canberrans constituting only 2% of the ACT population.

This is according to national data released by the Productivity Commission, the Australian Government's independent research and advisory body on various economic, social and environmental issues.

The Australian Capital Territory is currently facing a significant challenge, with the highest rate of incarceration rates for Indigenous people in the nation compared to non-Indigenous residents.

Key Points:

Disproportionate Incarceration

Rates: Productivity Commission figures reveal that 27% of Canberra's average prison population is Indigenous, despite Indigenous Canberrans constituting only 2% of the ACT population, according to the 2021 census. Indigenous Canberrans are 24.6 times more likely to be incarcerated than their non-Indigenous counterparts, a disparity significantly higher than the national average of 17.4. **Government Response:** ACT Attorney-General Shane Rattenbury has acknowledged the unacceptable rates of Indigenous incarceration and the need for improvement. The Government has committed to reducing the incarceration of Indigenous people to match non-Indigenous incarceration rates by 2031.

Review Structure: A review commissioned by the ACT Government and run by the Jumbunna Institute at the University of Technology Sydney will produce two reports. The first, expected in May, will evaluate the ACT's implementation of the Australian Law Reform Commission's recommendations from the 2018 Pathways to Justice Report. The second report, due later in the year, will propose additional practical measures to decrease Indigenous incarceration rates.

Community Engagement: The review emphasised collaboration with Indigenous people with personal experience in the justice system and Indigenous organisations. ACT Attorney-General Shane Rattenbury said the review team would engage with Indigenous people who have lived experience of the ACT justice system and local Indigenous organisations, including Yeddung Mura and Winnunga Nimmityjah. Professor Lindon Coombes, leading the review by the Jumbunna Institute, expressed confidence in developing practical recommendations through close work with the ACT Indigenous community.



Calls for Effective Action: Julie Tongs, CEO of Winnunga Nimmityjah Aboriginal Health and Community Services, highlighted the absence of support programs for integrating offenders into the community and called for alternatives to incarceration and investment in justice reinvestment programs.

Addressing Undiagnosed Hearing Loss among First Nation Australians in Incarceration: A Crucial Step in Reducing Disparities.

Deafness Forum Australia and its members have been involved in various reports to the Australian Government highlighting the high rates of hearing loss amongst First Nations people. We have been advocating for improved funding, resources, and programs to address these health disparities.

A critical yet often overlooked aspect of the plight of First Nation Australians in incarceration warrants attention: undiagnosed and untreated hearing loss.

While the ACT Government review being undertaken by Jumbunna Institute promises to shed light on systemic issues contributing to Indigenous overrepresentation in prisons, it is imperative to acknowledge the multifaceted health challenges faced by incarcerated Indigenous individuals. Among these challenges, undiagnosed hearing loss is a significant yet under-recognised issue that demands immediate action and intervention.

Recent studies have highlighted the disproportionately high prevalence of hearing loss among Indigenous Australians, attributed to a myriad of factors, including historical trauma, intergenerational disadvantage, limited access to healthcare services, and socioeconomic disparities. Unfortunately, within the context of incarceration, the problem is often exacerbated due to inadequate screening protocols and a lack of culturally sensitive healthcare provision within correctional facilities.

The consequences of untreated hearing loss in prison settings are far-reaching and profound. Communication barriers exacerbate social isolation, impede access to educational and vocational programs, hinder rehabilitation efforts, and heighten the risk of conflict and misunderstanding between inmates and correctional staff. Moreover, undiagnosed hearing loss can perpetuate cycles of recidivism as individuals struggle to reintegrate into society upon release due to unaddressed communication deficits.

Addressing the issue of undiagnosed and untreated hearing loss among First Nation Australians in incarceration demands a multifaceted approach that prioritises culturally competent healthcare provision, comprehensive screening protocols, and targeted interventions tailored to the unique needs of Indigenous inmates. Collaboration between healthcare providers, correctional authorities, Indigenous community leaders, and advocacy organisations is essential to develop and implement sustainable solutions that promote equitable access to healthcare services and address the underlying social determinants driving disparities in hearing health outcomes.

It is incumbent upon policymakers, healthcare professionals, and stakeholders to recognise the intersecting dimensions of Indigenous health inequities within the criminal justice system and prioritise strategies that foster holistic wellbeing and rehabilitation for incarcerated First Nation Australians. By acknowledging and addressing the prevalence of undiagnosed hearing loss, we can take a significant step towards dismantling systemic barriers and advancing the cause of justice, equity, and reconciliation for Indigenous peoples in Australia.

You can <u>read the full report and</u> <u>recommendations from Deafness Forum</u> <u>Australia.</u>



It's Tinnitus Awareness Week

Tinnitus Awareness Week is observed throughout the world in the first full week of February and the purpose of it is to educate the public about the symptoms of tinnitus and how it affects people.

Tinnitus is a condition where you hear noises like ringing in your ears, which aren't caused by sounds around you. There are two types:

- Subjective tinnitus: Only you can hear these sounds. This is the most common.
- Objective tinnitus: Your doctor can hear these sounds during an examination.

About 1 in 5 people experience tinnitus at some point, especially older adults. Tinnitus can be constant or come and go. Some find it manageable, while others find it very distressing. Besides ringing, tinnitus can sound like humming, hissing, whistling, clicking, roaring, whooshing, or buzzing. It can happen in one or both ears and may feel like it's inside your head. Some people with tinnitus also suffer from hearing loss or vertigo. Pulsatile tinnitus sounds like regular pulsations.

Causes of tinnitus include hearing loss, ear wax buildup, loud noise exposure, ear infections, Ménière's disease, tumours, inner ear problems, certain medicines, and head injuries. The exact cause isn't always clear. If you have tinnitus, see a doctor. Treatment depends on the cause and severity. Options include self-care measures like stress reduction, avoiding loud noises, and checking medications with your doctor. Hearing aids can help, especially if there's hearing loss. Sound therapy and psychological therapies like cognitive behavioural therapy are also options.

The sounds you hear can help your doctor identify a possible underlying cause.

- Clicking suggests muscle contractions in and around your ear might be the cause of your tinnitus.
- Pulsing, rushing or humming sounds can stem from blood vessel causes, such as high blood pressure, noticeable when you exercise or change positions.
- Low-pitched ringing may point to ear canal blockages or Meniere's disease.
- High-pitched ringing is the most commonly heard tinnitus sound. Likely causes include loud noise exposure, hearing loss or medications.

Tinnitus caused by certain medicines can be prevented, but not all types can be. Tinnitus can lead to anxiety and depression if it's distressing. If you're struggling, seek support from your doctor or organisations like <u>Beyond Blue</u> and <u>Tinnitus Australia</u>. <u>Tinnitus U.K.</u> has <u>free</u> <u>webinars</u> and other <u>videos can be purchased</u> (the cost is under 3 pounds in English currency).

Five Deaf Children have Hearing Restored by Gene Therapy.



A new study reported findings of a clinical trial showing hearing recovery and improvements in speech recognition in five out of six children treated with a gene therapy for hearing loss.

The trial began in December 2022 and was conducted in China in collaboration with Mass Eye and Ear, a teaching hospital in the United States. This trial was the first to administer a gene therapy to a child with the inherited deafness, DFNB9. This research represents the first human clinical trial to administer gene therapy for treating this condition.

<u>Akouos</u>, describing itself as a genetic medicine company focused on developing gene therapies with the potential to restore, improve, and preserve high-acuity physiologic hearing for people worldwide who live with disabling hearing loss, announced positive initial clinical results from its <u>gene therapy study</u>. The first participant to receive the gene therapy, an 11year-old with profound hearing loss from birth, experienced restored hearing within 30 days.

"The results from this study are truly remarkable. We saw the hearing ability of children improve dramatically week by week, as well as the regaining of their speech," said Zheng-Yi Chen, associate scientist in the Eaton-Peabody Laboratories at Mass Eye and Ear.

For hearing loss in children, more than 60% stems from genetic reasons. DFNB9 is a hereditary disease caused by mutations of a particular gene (OTOF) and a failure to produce a functioning protein which is necessary for the transmission of the sound signals from the ear to the brain.

All six children in the study had total deafness, as indicated by an average auditory brainstem response threshold of over 95 decibels. After 26 weeks, five children demonstrated hearing recovery, dramatic improvements in speech perception, and the restored ability to conduct normal conversation. In follow-ups, 48 adverse events were observed, with a significant majority (96%) being low grade, and the rest being transitory with no long-term impact.

"I am truly excited about our future work on other forms of genetic hearing loss to bring treatments to more people," said Yilai Shu of the Eye & ENT Hospital of Fudan University, China.

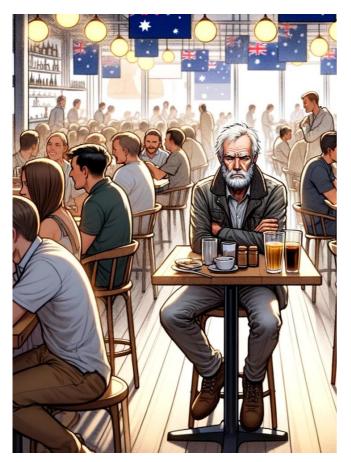
The researchers plan to expand the trial to a larger sample size as well as track their outcomes over a longer timeline.

"Not since cochlear implants were invented 60 years ago, has there been an effective treatment for deafness," said Chen.

The work is published in *The Lancet* as <u>AAV1–</u> <u>hOTOF gene therapy for autosomal recessive</u> <u>deafness 9: a single–arm trial.</u>



Communicating above the din.



By <u>Damien Howard</u> B.A, Dip Ed, Grad Dip App Psych, PhD, MAPS: Consulting Psychologist, Nightcliff NT.

Today, in the new year, I had lunch with friends at a very noisy café. As someone interested in communication challenges, this setting provided a unique opportunity to explore different methods of connection. My partner, who is profoundly deaf and Vietnamese, and I usually communicate using Vietnamese Sign Language. However, my limited proficiency sometimes makes it difficult to fully convey the context of our discussions.

I have found using AI to translate text Vietnamese effective. It helps to describe context that would be hard to do solely through my limited Vietnamese sign. For instance, I used an AI translator to explain to her we were discussing various uses of AI, like drawing pictures and writing articles. In the past, without such tools, establishing context, especially for topics not immediately visible or recently discussed, was often a struggle.

I've found that speaking into a speech-to-text application and having the AI organise what I am trying to say first and then translate the text into Vietnamese yields far better results. My partner finds this organised then translated text much easier to understand and follow.

Another friend at the café, who recently suffered hearing loss in one ear, found the background noise particularly challenging. I used my iPad with an NAL scribe app, which effectively provided real-time subtitles for our conversation. Additionally, her noise-cancelling earbuds connected to her also phone helped hear what was said more effectively.

During our lunch, another a tech-savvy friend shared an interesting development in AI – the creation of visual recognition software capable of translating sign language into written or spoken language. This technology, currently being developed for American Sign Language, holds immense potential for multi-language translation, especially for First Nations communities in Australia. Many in these communities don't use Auslan and use other unique sign languages linked to their local culture. An app capable of learning and translating these local sign languages could significantly reduce the isolation experienced by many, especially those living away from their communities in urban areas where few if any know their sign language.

For First Nations people, learning English or Auslan is often an arduous task, compounded by cognitive disabilities in some cases. A device that can bridge this communication gap could be lifechanging, akin to a universal translator from Star Trek. The future of AI in facilitating communication, as I saw first-hand today, is not just promising; it's unfolding right before our eyes.







ENDORSED BY Parliamentary Friends of Hearing Health

Professor Kelvin Kong AM will give the 25th Libby Harricks Memorial Oration at Parliament House Canberra on the evening of Monday 25 March 2024.

Kelvin Kong is Australia's first indigenous surgeon, a Worimi man, and an ardent advocate for hearing health. He was honoured as the NAIDOC Person of the Year in 2023 and received the Medal of the Order of Australia (AM) in 2024 for his work with Indigenous children at risk of hearing loss.

"It is disheartening discussing my mob on an international scale because of the dichotomy that exists with ear disease here."



From the video,

"I ask the Prime Minister, what if it was your child and they weren't hearing that well? What would you do to make sure they heard well and got the correct education they required?"

Come to Canberra in March: join us to be part of an enlightening journey led by Prof Kelvin Kong that promises to:

- Spark a new awareness about the significance of ears and hearing in our everyday lives.
- Offer fresh, engaging perspectives even • to experts in the field.
- Equip ear and hearing advocates with information and renewed enthusiasm to champion change.

This event is hosted by Deafness Forum Australia, the national peak body for the 4 million Australians living with hearing loss.

The venue will be the Parliament House Canberra, 6pm Monday 25 March 2024. All are welcome but places will be limited.

For more information, info@deafnessforum.org.au



Since the first Libby Harricks Memorial Oration in 1999, the series has featured renowned speakers worldwide. The series honours the memory of the late Libby Harricks who was made a Member of the Order of Australia in 1990 for her work on behalf of deaf and hard-ofhearing people.





Working together to fix the NDIS

Throughout January, Deafness Forum Australia analysed the Independent Review of the National Disability Insurance Scheme's Final Report, examining and contemplating its extensive findings and recommendations.



By Hayley Stone, Director of National Disability Policy and Advocacy for Deafness Forum Australia.

The NDIS was established in 2013 as a collaborative funding effort by the Federal Government and state and territory governments. Its primary objective is to provide necessary and reasonable supports for eligible individuals with disability.

In 2022, the Government initiated an independent review with the express aim of realigning the NDIS with its core mission: placing individuals with disability at the forefront. The review aimed to rebuild trust, confidence, and pride in the NDIS.

The review's final report was published in the weeks before Christmas. Titled "Working together to deliver the NDIS," the report outlined 26 key recommendations and 139 specific actions to enhance the scheme over the next halfdecade.

Like many organisations in the disability advocacy sector, Deafness Forum Australia was concerned about what the report might mean for the future of the NDIS and its participants – especially given ongoing public concerns around higher-than-predicted participants and the increasing costs associated with the Scheme.

While the review calls for significant readjustment to how the NDIS operates, there were no obvious red flags. The review's 26 recommendations and 139 integrated actions provide a detailed blueprint for reducing cost projections, addressing many pain points of the Scheme while also expanding supports to cover people under 65 who currently fall through the cracks.

The recommendations go beyond the NDIS, calling for a well-coordinated, national effort towards designing, operating, and governing a new disability support ecosystem, and call for a massive investment in resources and services over the next five years, in addition to a shifting of responsibilities back to States and Territories for a new category of supports.

But nothing has been decided yet.

While states and territories have expressed commitment, in principle, to the reforms, we

anticipate some pushback once planning gets underway. At the same time, the proposed fiveyear rollout would extend into the tenure of a new government, so it's vitally important to have the solid commitment of the Opposition.



We've put together a summary of the review's significant recommendations, with our initial thoughts.

1. A new model for disability support.

The report has recommended replacing Tier 1 and 2 supports with an expanded range of foundational supports that would be available to people with disability under 65, irrespective of whether they are participants of the NDIS or not.

Targeted foundational supports would be for people with specific, but less intense, disability support needs, and would include things like aids and equipment, and home maintenance services.

General foundational supports would include services like peer support, information, and advice, as well as disability employment services.

What's good about this model is that it will potentially expand the supports available to people with disability who are ineligible for the NDIS, but there's limited information on precisely what supports would fit under the 'foundational' umbrella or whether this will mean that participants of the NDIS will have

their supports split across foundational supports and their individualised plans, which could be challenging to navigate.

We also don't know whether NDIS participants might be expected to transition off the Scheme if the supports they need can be accessed as foundational supports. It also doesn't appear that foundational supports will be available for people aged 65 years and older – a missed opportunity for the review to address the inequity between the NDIS and Aged Care.

Another issue is that the proposed model transfers significant responsibility back onto states and territories to administer and provide funding for foundational supports. While this isn't a new idea, we know that many statefunded services have been eroded over the past decade. Significant work will be required to rebuild those services to achieve the interconnected disability support ecosystem necessary for this recommendation to work in practice.

2. The introduction of systems navigators.

Another recommendation is the introduction of navigators to support all people with disability under 65 years of age to access the support and services they need. The expectation is that navigators will have consistent training and national oversight but will be locally based to ensure they understand local communities. Systems navigators would be available to all people with disability under 65 years of age.

If a person with disability wanted to apply for the NDIS, the navigator would assist them in understanding the scheme and support them through the application process. Once a budget and plan have been set, the navigator could support the participant in accessing services in their local communities.

As we all know, the complexity of the disability support landscape is a significant barrier to people with disability getting access to the supports they need when they need them.





Navigators are used effectively in several other public service contexts, including healthcare and could significantly improve the experience of people with disability interacting across various elements of both the NDIS and the broader disability support 'ecosystem', but we need the right people for this vital role.

Navigators need to be unbiased and impartial. Service providers or entities affiliated with service providers should be excluded from providing navigation services to ensure that people with disability are appropriately referred, based on their preferences and requirements. We've also recommended that any navigator scheme be extended to support people with disability aged 65 years and older.

3. A new system for determining NDIS eligibility, funding and supports.

The review has proposed that the NDIS place less emphasis on diagnosis and functional capacity as the mechanisms for determining eligibility, funding and supports.

The recommendations propose scrapping the Access List in preference of a uniform assessment process to determine eligibility based on applicants' needs. The assessment would be based on self-reporting and strengthbased interviews. The same assessor who conducts the assessment would support a successful applicant to plan their budget and supports.

It's clear that the proposed assessment model is not a rebranding of the independent assessment model that was fiercely opposed in 2021. The proposed model doesn't work to an algorithm, it doesn't use the same diagnostic tools and looks to have scope for assessors to seek supporting information from an applicant's treating professionals.

If the new assessment model is adopted and implemented well, we anticipate that it should address current inequities around evidence

requirements for people with different types of disabilities, while ensuring people continue to receive customised supports.

If the new assessment model is confirmed, we will need to be assured that the tools are evidence-based, that the assessors have the skills and training necessary to administer the assessments, and that people with disability have the time and supports necessary to fully articulate their needs.

4. A continuum of supports for children and young people with disabilities.

Addressing the needs of children and young people with disabilities and their families was a key priority in the review. The report recommends additional screening processes to identify children with disabilities and developmental delays as soon as possible through general community screening, and a continuum of supports for children and young people with disability, irrespective of whether they are NDIS participants or not, to the age of 21,

Changes would include expanding the early intervention program to age 9, new supports and services for children and young people aged 9-21 to prepare for key life transition points, including secondary school and employment, and targeted funding for a capacity-building program for parents and caregivers.

Children would be assessed via a whole-ofperson needs-based assessment and monitored to track how well supports were working.

While we welcome these changes in principle, we've requested more details. We want to know how the impacts of supports would be assessed in practice and whether there is scope to optimise the universally available child development check for screening. We also need to be confident that needs-based assessments are evidence-based. age-appropriate, and conducted by people with the right skills and expertise.





Any capacity building programs for parents and caregivers, must be developed in co-design with people with disability and be identity affirming. We'd also recommend the development of a national database to track lifetime progress against measured outcomes, with scope for interventions as needed, to ensure that all Australian children with disability can reach their full potential.

5. Enhanced access to assistive technology supports.

The review noted that access to assistive technology for people outside the NDIS is underfunded, fragmented, and complex, with an estimated 108 different schemes to access assistive technology outside the NDIS.

The review has called for the Department of Social Services, with States and Territories, to develop a nationally consistent approach for delivering aids and equipment outside the NDIS with a focus on improved planning and coordination of aids and equipment between the NDIS, Health, and Aged Care.

While we would welcome a centralised, national program to link people with disability to the aids and technology they need, further detail is necessary to understand how such a scheme would be funded and coordinated.

6. A digitalised market with increased quality and safeguarding mechanisms to protect consumers.

The report proposes significant changes across the market, including introducing a new pricing and payments framework, a complete transition to electronic payments, and developing a centralised online platform to help participants find service providers in their local area.

The review panel also recommends that the National Disability Supports Quality and Safeguards Commission actively monitor the market to identify and respond to poor service delivery and introduce a new graduated riskproportionate regulatory framework.

Under the proposed framework, all disability service providers must be enrolled or registered with the National Disability Supports Quality and Safeguards Commission. Providers would have graduated regulatory obligations increasing depending on the risk associated with the services the provider is delivering. There would be minimal 'red tape' for service providers who provide low-risk services.

These recommendations represent a good balance between providing regulatory safeguards for consumers and facilitating their choice and control by encouraging a robust, diverse marketplace. We can anticipate that these reforms would reduce fraud, price gouging, and over-servicing.

So, what comes next?

It's now a matter of wait and see how many recommendations are picked up and the response from the Australian Government, States, and Territories to the five-year implementation target. Until then, we've been told by the NDIA that participants should expect things to be business as usual.

Our key priorities across the implementation of the reforms will be making sure Governments and the NDIA commit to genuine co-design with people who require hearing and speech supports and people whose first language is Auslan. We're aiming to influence and and inform decisionmaking around the practical implementation of the changes and will continue to advocate for increased supports for those who are deaf or hard of hearing who are over 65 years of age.

We'll keep you informed as we learn more about changes and will be reaching out for your thoughts and input over the next few months once we know the plan for the NDIS moving forward. In the meantime, there are some resources on the recommendations, including fact sheets on key topics and an easy-read version of the final report, on the NDIS Review website.

Townsville Twins Share Milestone.

Townsville twins Marley and Sienna share a love of swimming and gaming. Now 10-years-old, both girls have great aspirations for their futures.

Marley wants to be a veterinarian and Sienna has her eye on both interior design and acting.

The sisters both have hearing loss. In 2022, Marley and Sienna shared the experience of having a cochlear implant turned on for the first time. Their journeys with hearing loss have looked different up until this point.

Sienna

"Sienna was diagnosed with mild to moderate hearing loss at birth which was picked up via the newborn screening test done at the hospital," said Hayley, the twins' mum.

"She was initially fitted with hearing aids however her hearing gradually deteriorated."

"In June 2020, Sienna received her first cochlear implant in her left ear. She was so excited for her switch on. I remember her saying she couldn't wait to be able to hear what the other kids hear.

"It was an uphill battle getting Sienna used to wearing her cochlear at first, with moments of her refusing as she was struggling to get used to 'the beeps' and that was hard.

Marley

"Marley was diagnosed at nine years old with severe hearing loss in her left ear and a moderate hearing loss in her right ear.

"In fact, Marley's testing on her left ear was inconclusive for a period of time. She completed two Auditory Brainstem Response testing sessions to diagnose her hearing loss.

The double switch on

"Recently, Sienna received her second cochlear (in her right ear) and Marley was fitted with her first cochlear implant on her left ear and she wears a hearing aid on her right."

The family moved to Townsville from Melbourne in 2021 and Sienna started speech therapy at Hear and Say, Queensland's specialised provider of audiology and speech pathology for people of all ages – from newborn babies, to toddlers, school age children and adults..

"I hope their futures are bright and happy. I want them to be able to have careers that they enjoy and that they are successful in whatever adventures they get into," said Hayley.

"I hope they get to experience travel to other countries and immerse themselves in different cultures and be able to spread awareness for hearing loss."

From <u>Hear and Say</u>.

Macquarie University Wins Grant for Hearing Health Initiative.

A project by Macquarie University Hearing to provide access to credible, consumer-friendly educational materials and resources is among projects to be funded by the Government's National Health and Medical Research Council grants scheme.

Macquarie University Deputy Vice-Chancellor (Research) Professor Sakkie Pretorius said, "It is always very gratifying to see the hard work and dedication of Macquarie researchers being recognised and rewarded with highly competitive grants."



The project is led by **Professor Bamini Gopinath** (pictured) from Macquarie University Hearing receives \$660,737 over three years. HearHealth will be an online support service empowering people with hearing loss.

HearHealth will provide access to consumerfriendly educational materials and resources, facilitate improved perspective of hearing health needs and hearing loss risk factors, and promote behaviour change via online self-assessment and tailored care plans. The co-design of HearHealth will be done in conjunction with Deafness Forum Australia (the peak body for people with hearing loss), Google, Partners in this project include Curtin University, University of Sydney and University of Wollongong.



Murdoch Children's Research Institute is conducting research into the creation of a national registry for deaf or hard of hearing children.

It will be informed by the views and experiences of parents, and children and young people who are deaf or hard of hearing.

Deafness Forum Australia strongly endorses this project. We invite you to take part in a focus group with other parents and carers, or with other children and young people. Or, you could do a one-on-one interview if you prefer.

You are eligible to take part if you are:

- a parent of a child or young person who is deaf or hard of hearing (under 26)
- a child or young person who is deaf or hard of hearing (8 to 26)

Here is where you can learn more.

Register your interest <u>here</u>.



Deaf Ear to Public Transport Needs.

The NSW Government's Transport for NSW Disability Inclusion Action Plan acknowledges the importance of access to public transport. But people with disability are facing many barriers to access, say advocacy organisations, and both transport systems and compliance mechanisms need reform.

In 2023, an international survey ranked Sydney's public transport system as among the best in the world. The survey claimed that "Sydney boasts a strong multimodal transport network, seamlessly connecting bus, train, and ferry," and the "fully automated metro system ... is one of the world's most innovative transit systems".

It must have been music to the ears of Transport NSW, especially in the face of controversy over its increasing privatisation of buses and trains. However, does the ranking ring true for the 1.37 million people in NSW (one in five of the state's population) who have a disability?

Without reliably accessible transport, people with disability face a significant barrier to attending their medical appointments and other health services, being able to evacuate safely during disasters, attending education facilities or jobs, accessing community supports and services, and engaging in social interaction as other members of the community are able to do.

The NSW Government claimed in a 2019 press release that privatisation of transport services would lift the standard of transport, "delivering better services to commuters. The Government had already begun privatising bus services in the inner-western suburbs of Sydney in 2018, and in 2020 it privatised buses in the remaining three inner-city regions while also contracting Sydney Metro to Metro Trains Sydney. But this privatisation was done without consultation or the co-design of people with disability in the process.

The NSW Government has made a \$300 million election commitment to upgrade stations by making them more accessible, safe and secure as well as improving their amenity and role in the community. However, bus, ferry, metro and light rail services are privately run.



Education, information, and stronger regulatory frameworks.

Christine Hunter is the Deafness Forum Australia representative on the Transport for NSW Accessible Transport Advisory Committee.

As Hunter points out, Opal data indicates "in June 2022, there were 20 million Opal card trips in the month. It is accepted that 1 in 6 people in the general population have some degree of hearing loss, suggesting that 3.33 million passengers per month have hearing loss."

She advised that operators should undertake disability awareness training, including how to improve real time communications with passengers.

"There is little consistency on how operators and staff treat people with disability.

"It can't be a one-size-fits-all approach to training. I think staff training needs to be embedded in staff induction programs with ongoing refreshers. It's worrying that many private operators don't have an inclusion plan."





"I feel that disability advocates need to be central to how education is designed. I've noticed an emphasis on education and design for those with mobility issues and vision, which are generally more visible. If you have a disability that is less obvious – intellectual or hearing loss for example – then help is harder to acquire."

Hunter also points out that, despite the Help Points located on trains and on railway stations, "these rely on an audio amplification system. They are operating in an environment of background noise, and messages may at times be given by members of staff with different voice pitches or accents, which are sometimes difficult for many people with hearing loss to understand. A person who has hearing loss and who may not have the use of hearing devices is unlikely to be able to communicate effectively using current Help Point technology, especially in circumstances of stress, confusion or disruption."



Christine Hunter is Deafness Forum Australia representative on Transport for NSW's Accessible Transport Advisory Committee.

The priorities are clear: education, information, and stronger regulatory frameworks and consequences for non-compliance that shifts the onus onto operators and providers rather than people with disability.

Story by Cat Woods for <u>LSJ Media</u>, home of content for Australia's legal professionals.

Tinnitus is Psychologically Damaging.



Everyone has tinnitus. For most people it is so slight that it goes unnoticed.

<u>A German study</u> showed a significant correlation between patients suffering from tinnitus and higher levels of depression, anxiety, and somatic disorders. Roughly 40 percent of tinnitus sufferers exhibited higher levels of depression and anxiety versus 27 percent of those not affected by tinnitus.

There are no known cures for tinnitus, although therapies exist – some of which, such as the use of cannabinoids, remain unproven. Other treatments cover the gamut from ear-wax removal, to white noise generators, to hearing aids, to cognitive behavioural therapy.

But there is new hope for palliation of tinnitus, if not for an outright cure. <u>A study</u> conducted by researchers at the University of Michigan found therapy that combined acoustic input and electrical stimulation showed promise of reducing the noise of tinnitus. The dual treatment has not yet been approved for general use.

From Psychology Today

Story by **George Michelsen Foy,** essayist and novelist. <u>George Michelsen Foy</u>, <u>Facebook</u>.





REDISCOVERING MUSIC

Find joy in listening to music with any degree of hearing loss through **FREE**, tailored, interactive concerts led by audiologist and CSO musician Kristen Sutcliffe.



MUSIC FOR MANAGING TINNITUS

Featuring guitarist Steve Allen

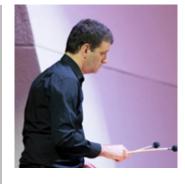
Wed 6 Mar, 5:30pm



DISCOVERING THE TUBA

Featuring CSO Principal Tuba Bjorn Pfeiffer

Tue 7 May, 2pm



DISCOVERING PERCUSSION

Led by audiologist and CSO percussionist John Dewhurst

In 2024, the CSO will offer

four instrumental music tuition scholarships for adults and children with hearing loss. Scan the QR code to find out more.

Tue 27 Aug, 2pm



Ainslie Football & Social Club

52 Wakefield Ave,

Ainslie ACT 2602

CHRISTMAS STRINGS

Featuring CSO String Players

Tue 3 Dec, 2pm



FREE REGISTRATION:

Visit cso.org.au/events, call (02) 6262 6772 (weekdays 10am-3pm) or scan the QR code.







Teleaudiology Guidelines for Australia.



Teleaudiology, providing audiological services through telecommunications technology, has become an increasingly vital tool in Australia. The country's vast geography often hampers access for many to traditional, inperson audiological care, a challenge further highlighted by the COVID-19 pandemic. This situation has accelerated the adoption of teleaudiology.

Despite its growth, teleaudiology still faces challenges. Some audiologists are hesitant to embrace these practices, preferring in-person interactions. This reluctance can be attributed to several barriers, including limited access to the necessary technology, a lack of training and support, and the absence of standardised guidelines for teleaudiology practices.

In response to these challenges, the Australian Government's Department of Health created comprehensive national teleaudiology guidelines. These guidelines are structured into three sections: general considerations for integrating teleradiology into consumer – and family-centred care, operational guidance for practices, and clinical guidance for delivering services. This structure aims to ensure that teleaudiology is implemented effectively and safely, enhancing service delivery across the sector.

A survey conducted by the Australian Department of Health revealed almost universal awareness of these guidelines among registered hearing service providers, with a substantial proportion already offering services via teleaudiology in alignment with the guidelines.

This development represents an important step in promoting the effective and safe delivery of audiological services through telehealth. The guidelines address clinical and non-clinical factors, such as governance, ethics, and security, aiming to empower hearing service providers to integrate teleaudiology into their service delivery models. They facilitate patient and family choice and control over their hearing services, striving for consistent quality across Australia.

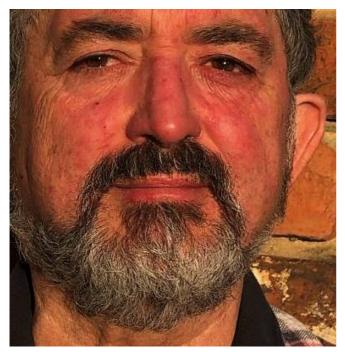
The guidelines were developed through extensive consultation, reflecting a collective effort to establish a robust framework for teleaudiology. They offer audiology professionals, other healthcare providers, and patients comprehensive, evidence-based guidance on the practical application of teleaudiology services.

The <u>Teleaudiology Guidelines</u> represent a significant advancement in ensuring Australians can access quality audiological services, irrespective of location.

DEAFNESS FORUM AUSTRALIA ONEINSIX

From The Hearing Journal.

Chris has Never Known Silence.



As far back as he can remember his life has been governed by the incessant background sound of tinnitus.

"Its intensity varied. I only noticed it when my day was quiet, when I stopped, or when someone mentioned it, and then it would take over my whole thoughts. I could not run from it. And even if I ran, exercise only replaced it with noisy breathing and a pounding pulse.

"Like many of my relatives, I started to lose hearing in one ear. The hearing in my other ear was normal. I was told it was nerve deafness and a hearing aid would not help.

"Later, I was offered a cochlear implant but I'd had so much surgery in other areas that I could not even bear the thought of having more.

"My hearing got worse. Suddenly, I realised I could no longer detect where a sound came from. I had lost directional hearing. 'I am here', they'd say. 'Thanks very much. Where's that?', I would reply. "Then the vertigo attacks came.... intermittently, then frequently until I had the trio of tinnitus, vertigo and deafness.

"I had to leave my job as I was getting an attack of vertigo every two days. I could not read for more than 60 minutes a day. It was torture.

"I sought help, as just being stoic was not enough. My doctors were kind but blunt. 'It's not a cancer, it's not a tumour, it's not Alzheimer's, although you're old enough for it.' Thank you', I said. But they said that they would do what they could for me. They could progressively use a series of treatments until I responded. After 18 months since the surgery, the vertigo stopped. The medication and time finally helped.

"I've got my life back now. The tinnitus is still there and I'm still deaf in one ear but I know the benefit of distraction, of background noise and the use of mindfulness.



Humans of the Australian Deaf Community is a new series of videos in Auslan.

These short video portraits will offer a window on the lives of Deaf people around Australia.

Watch the first episode of Humans of the Australian Deaf Community now on the SBS Australia YouTube channel, in Auslan with English subtitles.

https://www.sbs.com.au/audio/article/humansof-the-australian-deaf-community/czfrhof22

New episodes will be released monthly.



Madrid Taxis Equipped with Hearing Accessibility Technology.

In a significant advancement for accessibility, 3,000 taxis in Madrid, Spain, have been upgraded with hearing loops, a technology designed to aid those with hearing challenges. The legislation enacted in Spain mandates that all new taxis must be equipped with a loop system.

This has led to a collaborative effort in Madrid, spearheaded by the city's taxi industry association, Sociedad Cooperativa Madrileña del Autotaxi, and supported by Contacta Systems, a UK-based firm with a history of integrating hearing loops in vehicles since the 1990s.

The installation of these systems ensures that passengers with T-coil enabled hearing aids or cochlear implants can enjoy clear sound directly from the loop. The technology converts sound from a microphone near the driver into a magnetic signal transmitted through a loop of copper wire in the vehicle's ceiling. This signal is then converted back into sound by the T-coil in the user's hearing device, enabling clear communication while reducing background noise. Bespoke signage informs passengers of the availability of this service, enhancing the travel experience for those with hearing challenges. This project, requiring over a year of development and testing, addresses the unique challenges of vehicle environments, such as electromagnetic interference and ambient noise.

So far, about a fifth of the 15,000 taxis in Madrid are equipped with these loops, with installations ongoing at a rate of 150–200 systems per month. This initiative reflects a global trend towards more inclusive public services, providing a model that other cities, both within Spain and internationally, can emulate.

Know someone who deserves their own copy of One in Six?

Let us know at hello@deafnessforum.org.au

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