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Final edition for 2023

Festive socialising with tinnitus.

When you have tinnitus, socialising in noisy places may be the last thing you want to do. During the festive period, the pressure to join in and have a good time can be overwhelming. Office drinks, family parties and children's concerts can all bring a level of stress about how you'll cope with the noise.

By Lucy Straker for Tinnitus UK.

Your family or work mates have organised a Christmas meal out. Your heart says "go", but you worry that the venue will be noisy. You know you'll have to concentrate to hear and will sit back, smiling and nodding vaguely. You'll feel excluded and more alone than if you'd said no to the invitation. Then by the end of the night, you'll have a headache from all the effort, and your tinnitus will be screaming. So you say, "no thanks" and make an excuse.

If that sounds familiar, you're not alone. Our recent survey discovered that 4 in 10 people with tinnitus have changed their social lives because of the condition. It can be very easy to become isolated and withdrawn.

But it doesn't have to be like this. Here are some ideas about how to reclaim your social life over Christmas and New Year. Your social life doesn't need to stop if you develop tinnitus. With planning and some coping strategies, you can return to the activities that add colour to life.

Be honest.

Tinnitus is often an invisible condition. People around you might not realise or remember that you have it. Be honest with those around you. Most people are understanding once they know. If someone is curious and wants to know more about what tinnitus can be like, you could share this video of people's stories with them.

In a restaurant.

The acoustics in a restaurant can make a big difference to the experience of someone with hearing loss, tinnitus or other sound sensitivity disorders. Restaurants with upholstered chairs, low ceilings, carpets and generous curtains will be easier on the ear than places with stark benches and tiled floors and walls. Soft furnishings absorb sound. Could you suggest that your event happens at a venue with good acoustics? It may be a more pleasant experience for others too.

You could also:

- ask to be seated in a booth or the quietest area away from the bar, sound speakers or open kitchen.
- ask staff to turn down the music if it is overpowering.
- switch places with someone to get the best possible spot for your hearing – if your tinnitus is one-sided, have the 'good' ear nearest to people.
- consider making a booking outside of peak times so the restaurant is quieter. Service is often better then, too.

At a party

Parties can be hard work if you have tinnitus or a hearing problem. There's often loud music, and with everyone talking, it creates a confusing wall of sound.

The same tips about acoustics and reducing the distance from loud sounds apply. You might also want to move outside or to a quieter room if you can. If the party is very noisy with loud music, wearing ear plugs can help to protect your ears.

Try to focus on one person at a time instead of lots of people in a group. Get as close to the person talking as personal space (and your comfort level) allows.

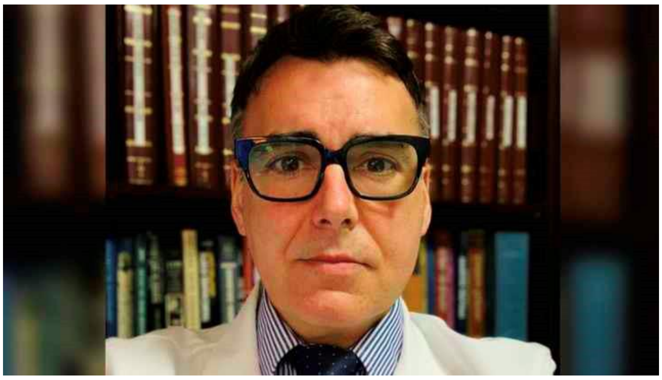
Walk into the party knowing you won't hear everything. Give yourself some leeway, relax and let some conversations go by.

New research on tinnitus.

Research at Mass Eye and Ear shows that people who report tinnitus - present as a ringing in the ears in more than one out of ten adults worldwide - are experiencing auditory nerve loss that is not picked up by hearing tests.

"We won't be able to cure tinnitus until we fully understand the underlying mechanisms. This work is a first step toward our ultimate goal of silencing tinnitus," said Stéphane F. Maison.

Many individuals with hearing loss report a buzzing, humming, ringing or even roaring sound in their ears. It's been a longstanding idea that these symptoms, known as tinnitus, arise because of the brain trying to compensate for the loss of hearing by increasing its activity, resulting in the perception of a phantom sound, tinnitus. Until recently though, this idea was disputed as some tinnitus sufferers have normal hearing tests.



Stéphane F. Maison, PhD, an investigator at Mass Eye and Ear's Eaton-Peabody Laboratories, U.S.

Subsequent research found that people with a normal hearing test can have a significant loss to the auditory nerve. Maison and his team sought to determine if such hidden damage could be associated with tinnitus symptoms. They found that chronic tinnitus was not only associated with a loss of auditory nerve but that participants showed hyperactivity in the brainstem.

"Our work reconciles the idea that tinnitus may be triggered by a loss of auditory nerve, including in people with normal hearing."

"The idea that, one day, researchers might be able to bring back the missing sound to the brain and, perhaps, reduce its hyperactivity in conjunction with retraining, definitely brings the hope of a cure closer to reality," Maison added.

The results from this study provide a better understanding on the origins of tinnitus and are published in *Scientific Reports*.

More inclusive work environments.

Discrimination, a lack of accessibility and isolation still prevent people with hearing loss from experiencing equity and inclusion at work.

Hearing loss is a critical diversity, equity and inclusion issue for managers and employers. People with hearing loss are a growing population around the world.

Discrimination, a lack of accessibility and isolation still prevent equity and inclusion at work. Persons with hearing loss also experience higher levels of stress and fatigue and earn lower incomes.

Knowledge of disability, reasonable workplace accommodations, effective communication skills and support from mentors and peer networks all contribute to positive career outcomes.

How do persons with hearing loss cope with isolation at work?

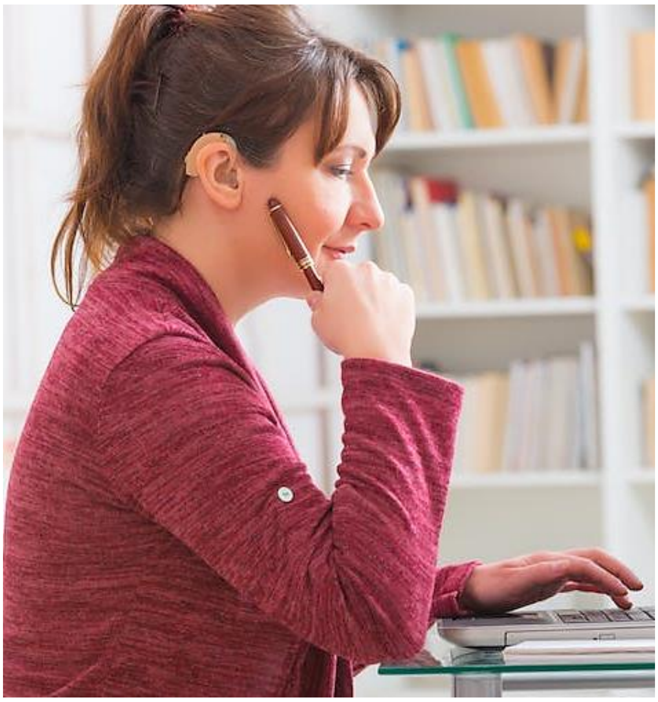
A new study examines how employees with hearing loss cope with feeling isolated at work. It found that how employees cope depends on both the severity of hearing loss and the quality of their relationship with their supervisors.

Specifically, the results suggest the severity of an employee's hearing loss influences the degree to which they rely on professional connections for their sense of self. This, in turn, has consequences for their career outcomes, especially for those with less supportive supervisors.

Surprisingly, the research found that employees with more severe hearing loss tend to fare better in terms of the impact of isolation on career outcomes. This is because employees with more severe hearing loss were more likely to experience awkward, anxious and frustrating interactions with co-workers and have a harder time building and maintaining professional connections. As a result, employees with more severe hearing loss usually placed less importance on professional connections and more importance on connections with other persons with hearing loss, making them less sensitive to isolation from professional connections.

What can people with hearing loss do to support themselves?

The research found that they use a number of strategies to help themselves in their careers. One thing is accepting and embracing hearing loss as part of their identity. This positively changes how they view themselves and their relationship to work.



Many also redefine their personal definitions of career success. They shift from material achievements to social contributions, personal growth and wellbeing. Some end up moving to new roles or occupations that better match their changing skills, interests and values.

Some even turn their hearing loss into an asset. For instance, attorneys, doctors or therapists with hearing loss can focus on serving clients and patients who share their condition.

What can co-workers and supervisors do to help make workplaces more inclusive?

There are a number of practices supervisors can adopt, including avoid assuming an employee with disability is less able, ask them about their preferred communication methods and provide reasonable accommodations for them, such as captioning, assistive devices, interpreters, and flexible work arrangements.

The Australian Government [Employment Access Fund] gives financial help to eligible people with disability and mental health conditions and employers to buy work related modifications, equipment, Auslan services and workplace assistance and support services. The EAF is available to eligible people with disability who are about to start a job, are self-employed or who are currently working.

Regular check-ins with employees to see how things are going, what challenges they are facing and if they need any support are also essential. Supervisors and co-workers should raise awareness, educate others, challenge stereotypes and promote accessibility at work. They should advocate for a more inclusive and respectful work environment for all employees, including those with hearing loss.

From [The Conversation].

Inaugural cCMV symposium.

Congenital Cytomegalovirus (cCMV) is a viral infection that occurs when a pregnant woman is exposed to the cytomegalovirus.

If the virus is transmitted to the fetus during pregnancy, it can lead to various health issues in newborns.

The recent inaugural cCMV Symposium in Melbourne marked a milestone in the collective efforts to combat this pervasive viral infection.

The symposium heard from maternal fetal medicine specialists, paediatricians, infectious diseases specialists, audiologists, midwives, general practitioners, public health researchers, early intervention specialists, and hearing screening professionals.

Presentations delved into ongoing initiatives across Australia, encompassing cCMV awareness and education, screening protocols for both expectant mothers and newborns, breakthroughs in treatments and vaccine development, advancements in models for prevention and treatment modalities, and the establishment of a national register.

One of the symposium's highlights was the sharing of compelling narratives by families who have directly experienced the impact of cCMV.

The event received generous support from Mercy Perinatal and the MCRI Infection Immunity Theme.

For healthcare professionals interested in enhancing their knowledge, a free online module on CMV and syphilis during pregnancy is [available here].

A comprehensive set of resources, including posters, flyers, and educational videos, designed to aid healthcare practices in raising awareness about cCMV, can be [accessed here].

Nursery rhymes and singing may help babies learn language.

Parents should speak to their babies using sing-song speech, like nursery rhymes, as soon as possible, say researchers. That's because babies learn languages from rhythmic information, not phonetic information, in their first months.

Phonetic information – the smallest sound elements of speech, typically represented by the alphabet – is considered by many linguists to be the foundation of language. Infants are thought to learn these small sound elements and add them together to make words. But a new study suggests that phonetic information is learnt too late and slowly for this to be the case.

Instead, rhythmic speech helps babies learn language by emphasising the boundaries of individual words and is effective even in the first months of life.

Researchers from the University of Cambridge and Trinity College Dublin investigated babies' ability to process phonetic information during their first year.

Their study, published today in the journal *Nature Communications*, found that phonetic information wasn't successfully encoded until seven months old, and was still sparse at 11 months old when babies began to say their first words.

"Our research shows that the individual sounds of speech are not processed reliably until around seven months, even though most infants can recognise familiar words like 'bottle' by this point," said Cambridge neuroscientist, Professor Usha Goswami. "From then individual speech sounds are still added in very slowly – too slowly to form the basis of language."

The researchers recorded patterns of electrical brain activity in 50 infants at four, seven and eleven months old as they watched a video of a primary school teacher singing 18 nursery rhymes to an infant. Low frequency bands of brainwaves were fed through a special algorithm, which produced a 'read out' of the phonological information that was being encoded.

The researchers found that phonetic encoding in babies emerged gradually over the first year of life, beginning with labial sounds (e.g. d for "daddy") and nasal sounds (e.g. m for "mummy"), with the 'read out' progressively looking more like that of adults.

This is the first evidence of how brain activity relates to phonetic information changes over time in response to continuous speech.

Goswami believes that it is rhythmic information – the stress or emphasis on different syllables of words and the rise and fall of tone – that is the key to spoken language learning.

"We believe that speech rhythm information is the hidden glue underpinning the development of a well-functioning language system," said Goswami. "Infants can use rhythmic information like a scaffold or skeleton to add phonetic information on to. For example, they might learn that the rhythm pattern of English words is typically strong-weak, as in 'daddy' or 'mummy', with the stress on the first syllable. They can use this rhythm pattern to guess where one word ends and another begins."

"Parents should talk and sing to their babies as much as possible or use infant directed speech like nursery rhymes because it will make a difference to language outcome," she added.

Goswami explained that rhythm is a universal aspect of every language all over the world. "In all language that babies are exposed to there is a strong beat structure with a strong syllable twice a second. We're biologically programmed to emphasise this when speaking to babies."

From University of Cambridge.

Dear One in Six

Sally from Sally, Rockhampton QLD writes:

As a Teacher who is mildly to severely deaf (and subscriber to your magazine), I really connected with the recent article called Pardon (Ed: By Gael Hannan, published in One in Six, 29 Nov.), so I thought I'd let you know how much it meant to me, and that I feel more educators need to know about it.

I feel Gael really hit the nail on the head over and over in this article. I still trying to share this message with my family, after suffering significant hearing loss in 2017. Despite my efforts, many friends, family and colleagues alike, don't understand that hearing, is difficult in the best of environments, and to then have to interrupt the flow of a discussion, to request someone to repeat what they said, makes things more problematic.

I find that many people, including those who are aware of my difficulties, are often offended, dismissive, and in some cases frustrated that I would suggest that they need to repeat something.

This difficulty occurs extremely often in social, professional and educational settings. When you consider that some people don't repeat what they said, for whatever reason, it can exclude the deaf or hard of hearing person from following the rest of the conversation. Thus, this issue may be seen as the beginning of discrimination.

As I consider my feelings as an adult, which Gael was able to explain, and then consider the child, the problems this issue must bring would multiply exponentially.

This particular difficulty is not often spoken of in terms of the needs of hard of hearing students, so I thank you for sharing it and hope you can thank Gael for her contribution.

My major problem is the prevalence of piped music *everywhere* that drowns out the speech of even the person next to me in my hearing aids.

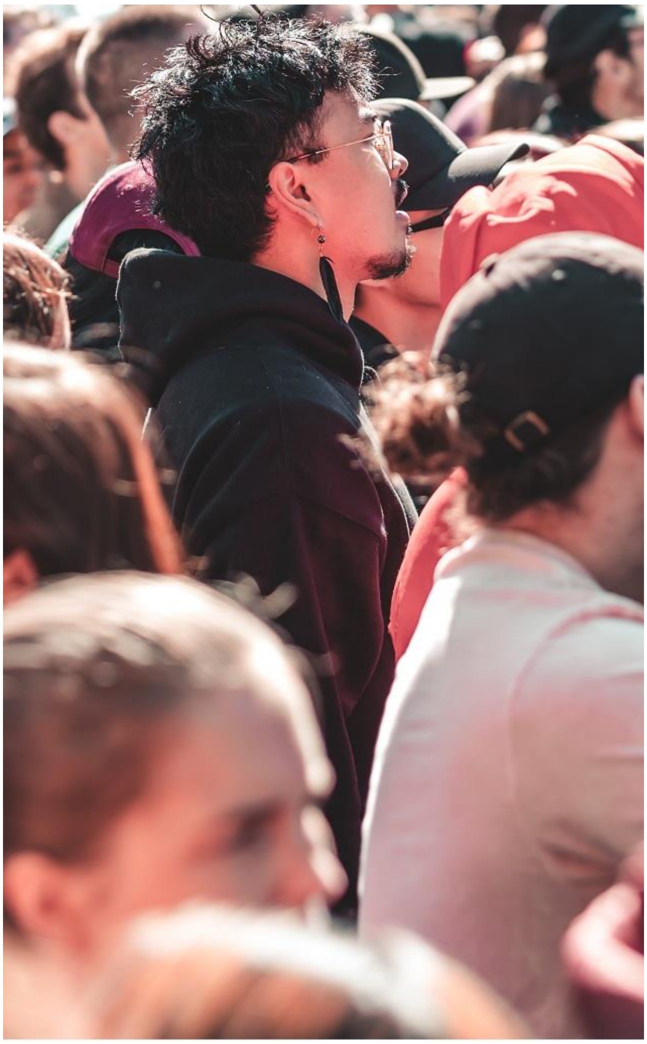
I've complained to my local shopping malls about this and they say it's not their problem it's a separate provider. Nobody does anything. And on the rare occasion when they make an announcement broadcast it's completely unintelligible. I can't make a phone call anywhere in the malls, often the busy street outside is quieter than inside the mall.

Doesn't bother my (hearing) wife at all who doesn't even notice it. But my hearing aids zoom in on it every time, cutting off the person next to me, and I've had to get the supplier to turn off the hearing aids automatic program switching to stop that from happening.

Thanks for listening.

Paul, Senior Member IEEE.

Improving hearing in an increasingly noisy world.



Meeting a few friends in a noisy café can mean straining to hear all the conversation. It can be more of a struggle, with age, to make out what a companion is saying in a busy pub or restaurant. Whatever else may improve with time, a person's hearing does not.

Yet when people complain of poor hearing, they might go for a test only to be told that nothing is wrong.

'The doctor says your audiogram is normal - you don't have a clinical hearing problem,' said Sarah Verhulst, a professor of hearing technology at Ghent University in Belgium.

That doesn't mean the people were imagining their difficulties, however. The hearing trouble may lie elsewhere.

Ageing and loud noise cause wear and tear on the hairs or nerve cells in the inner ear. This damage is what most tests are designed to detect.

But the auditory nerve itself can get impaired, reducing the number and quality of points of connection to brain cells. These junctions are known as synapses. The human skull has twelve pairs of nerves connected to the brain. One of them, responsible for balance and hearing, is the auditory nerve.

'This is a new kind of hearing impairment where the synapses attached to hair cells that transmit the sound to the brain are damaged,' said Verhulst.

This synapse harm can be missed in standard hearing tests.

Amplifying sounds using a hearing aid can compensate for fewer hair cells but is less effective in cases of injury to the nerve and its connecting synapses.

Nerve numbers.

In healthy hearing, each hair cell has about 15 nerve connections that transmit to the brain, according to Verhulst.

While only one synapse is needed for sound detection, having multiple transmission routes becomes important when trying to tune into specific sounds in an environment with many of them, such as a crowded bar with the music turned up.

Disability Employment Centre of Excellence.

Deafness Forum Australia provided its ideas to the creation of a national Disability Employment Centre of Excellence.

This Centre, to be established by the Australian Government, aims to significantly improve employment opportunities for individuals with disabilities, addressing the persistent employment gap across Australia.

The Importance of Employment.

Employment plays a crucial role in the lives of people with disability. It offers financial independence and boosts mental health, self-confidence, and social inclusion. Despite their eagerness and ability to work, people who are deaf or hard of hearing face higher unemployment rates than people without disability and can experience numerous employment barriers, including attitudinal, environmental, and systemic challenges.

Our Vision for the Disability Employment Centre of Excellence.

The proposed Centre should be a disability-led initiative and operate independently from Government to maintain impartiality and public trust. We've proposed that the Centre's goals should include:

- Raising awareness of employment inequities.
- Offering practical solutions.
- Providing targeted training and information to various stakeholders.

Our Recommendations for the Centre.

1. **Translating Research into Practice:** Convert academic research into accessible, practical resources for employment service providers, employers, and people with disability.
2. **Disability Inclusion Training:** Develop a nationally recognised disability accreditation program, co-designed with people with disabilities, to train employers and employment service providers.
3. **Support the development of Disability Action Plans:** Promote organisations creating and implementing Disability Action Plans that outline clear, measurable strategies for reducing disability discrimination.
4. **Encouraging Collaborative Communities:** Foster cooperation across different sectors to address disability workforce inclusion as a society-wide issue.
5. **Employer of Choice Recognition Program:** Implement a program acknowledging organisations committed to disability inclusivity aligned with the Disability Discrimination Act.
6. **Data Collection and Analysis:** Gather and publish data to monitor progress and hold employers and service providers accountable.

Establishing a Disability Employment Centre of Excellence represents a critical step towards bridging the employment gap for people with disability in Australia.

By addressing societal misconceptions, providing practical tools and training, and fostering a collaborative environment, this Centre can significantly contribute to the empowerment and inclusion of people with disability in the workforce.

Deafness Forum Australia's recommendations lay a solid foundation for creating a more equitable and inclusive employment landscape.

With 15 independent channels to transmit the same sound from the inner hair cell to the brain, a person can average this signal and tune out the background acoustic noise. In a noisy environment, someone with fewer synapses will struggle to distinguish sounds.

Auditory difficulty increases with age and can't be solved with hearing aids. The key might be in tweaking sound in a way that is helpful to the remaining nerve connections, for example by enhancing silent periods and sharpening peaks in sound.

Modern-day machines, traffic and entertainment all mean that people are more exposed to loud sounds than their ancestors.

“This sort of synapse damage is normal in the new generations who are constantly exposed to noise, such as listening to headphones,” said Verhulst. “People are going to be hearing impaired at a younger age than for our previous generations.”

But those who are deaf or severely hard of hearing can benefit from a cochlear implant. This small device bypasses damaged parts of the ear and stimulates the auditory nerves.

By Anthony King, Horizon: The EU Research & Innovation Magazine

The sounds we hear are not just about pitch and volume.

A recent study from Switzerland found that the direction sounds come from affects how we feel about them.

Generally, we find sounds that come towards us more unpleasant, powerful, and intense compared to sounds that move away, especially if they come from behind us. This may be because our ancestors in the African savannah would have seen sounds from behind as a sign of a predator sneaking up on them.

The researchers also discovered that the direction of sounds has an impact on our emotional response to positive human sounds, like laughter or pleasant voices. When these sounds come from our left side, they have a stronger effect on us compared to when they come from the front or right side.

The study used brain imaging to measure how people's brains respond to different sounds. Participants listened to sounds coming from the left, front, or right side while their brain activity was recorded. By comparing how the brain reacted to different sounds, the researchers wanted to understand how direction and emotional meaning affect the brain.

The results showed that both sides of the brain's hearing areas were most active when people heard positive human sounds from the left side.

But when the sounds came from the front or right side, or when they were neutral or negative, the brain's response was lower. This suggests that the brain's hearing areas are particularly sensitive to positive human sounds from the left, while other types of sounds don't have the same effect.

It's still not clear why our brains prefer positive human sounds from the left side.

The researchers suggest that more research is needed to understand when this preference develops and if it's unique to humans. It could be connected to things like hand preference or the way our internal organs are organised.

The direction sounds come from influences how we feel about them. Positive human sounds have a stronger impact on us when they come from our left side, according to brain imaging studies. This research helps us understand how we perceive sounds, our emotions, and the way we interpret where they come from.

From Frontiers in Neuroscience

Working together to fix the NDIS.

The Government’s review of the National Disability Insurance Scheme was published this month.

In the Working together to deliver the NDIS report, there are 26 recommendations with 139 actions to improve the scheme over the next five years.

The NDIS is jointly funded by the Australian, state and territory governments. The NDIS was established in 2013 to provide funding for reasonable and necessary supports for eligible people with disability. Funding for each NDIA participant is determined through the development of a participant plan, which sets out the participant’s goals and aspirations, the reasonable and necessary supports that they require and will be funded, and how that funding will be managed.

In 2022, the Government started an independent review to put people with disability back at the centre of the NDIS. The purpose was to restore trust, confidence and pride in the scheme. The review looked at the scheme’s design, operations and sustainability; and how to build a more responsive, supportive and sustainable market and workforce.

Shadow Minister for NDIS Michael Sukkar said the review left many questions unanswered.

"The government will now have to outline which changes they support and how they plan to transform these recommendations into tangible action."

"There is still very little detail on how the Scheme's 8 per cent growth cap will be met.

Minister for Disabilities Bill Shorten addressed the National Press Club this month and issued the NDIS Review Report.

Nothing will change right away.

The Federal Government's full response to this review will be released next year. After that, a final recommendation in the Review report will come into effect – “The Department of Social Services should review the recommendations from this Review and develop a proposed package of legislative reforms.” So, the key question is, will the Government’s response and the Department of Social Services review (of the review) reflect the detail and intent of the changes recommended in this ‘Working together to deliver the NDIS’ report?

The interfaces with mainstream sectors are critical to the success of the NDIS, given the Scheme’s defined goal of supporting inclusion and participation of people with disability in all areas of the community. Mainstream services like health, education, and transport, etc. work together with the NDIS but it will take champions in every government department and agency to raise all boats.

Green's senator Jordan Steele-John says it is going to take years for these services to work for Australians with disability.

"Everyone agrees there must be strong services available to disabled people in the community and through the NDIS. However, we know that right now our education, health, housing systems are drenched in ableism. It's going to take years for these services to be operational and work for disabled people. We will not accept NDIS supports being removed with nowhere for people to turn to.

"Today, our community's message to the government is clear — we will not be your political football and we will not accept any changes that will make life worse for anyone in our community."

Addressing the accessibility and affordability gap.

The National Disability Insurance Scheme was created to provide individualised support to approximately one-in-fifty Australians, leaving the vast majority of the one-in-five Australians living with disability to rely on community-based foundational supports and mainstream services. The NDIS was intended to be a component of a larger ecosystem of support, fostering inclusivity and accessibility for all Australians with disability.

A recent study by the Melbourne Disability Institute revealed that 90 percent of people with disability, along with their families and caregivers, believe that existing supports and services outside the NDIS are inadequate in addressing the needs of people with disability. This disparity between those inside and outside the NDIS is inherently unjust. Those eligible for the NDIS have access to a wide array of tailored supports, while those ineligible struggle to find appropriate support to fulfill their needs.

The over-reliance on the NDIS can be attributed to decisions made during its initial rollout. The urgency to transition individuals into the scheme quickly overshadowed the needs of disability support systems outside the NDIS that all people with disability depend on for essential services.

It is true that throughout the past decade, governments substantially increased funding for disability services. But the bulk of this funding was directed towards their share of the costs of the NDIS, accounting for over 93 percent of all disability funding in 2021-22. Regrettably, these investments left people who are not eligible for the NDIS without the support they need.

It is imperative that individuals with disability not only have equal access to mainstream services and support but also affordable Foundational Supports tailored to meet their disability-related needs.

The first of the NDIS review’s 26 recommendations is a group of disability services, called Foundational Supports, outside the scheme and accessible to many more people with disability.

An article in The Conversation explains that establishing “...Foundational Supports outside the scheme is the end of a long battle - the states have cried poor, while the Commonwealth has insisted the NDIS cannot be the only source of services to people with disability. (Foundational supports could also include help with shopping and cleaning, or assistance navigating the system.) Many supports which have been sucked into the NDIS could be removed from the scheme and funded on a more sustainable basis.

“For example, providing services through schools and early childhood centres means more children get early intervention. These children might not need a NDIS plan but rather the reasonable adjustments these settings are already obligated to provide.”

Bruce Bonyhady, one of the co-chairs of the NDIS review was on the ABC's Afternoon Briefing program:

"[This would] ensure that all children receive the supports they need is early in life as they need them. It means that developmental concerns are going to get picked up much earlier in maternal child centres.

"This is about making sure that all children, whether they are in the NDIS and receive an individual package, or they are outside and don't receive an individualised package, get the support they need to get the best start in life."

Foundational supports would be jointly funded by the states and Commonwealth, and delivered via the health sector, early-childhood education and schools. National cabinet agreed they would be rolled out in 2024. Making mainstream services available should curb escalating demand for the professional diagnoses and reports currently needed to get into the NDIS.

“More foundational supports will help the NDIS budget, too. If more disability services are available to people outside the NDIS, fewer people with disability will have to join the scheme to get what they need. It should mean people with higher intensity needs will be directed into the NDIS where they can get specialised services.”

Integrating GPs into the NDIS improvement process.

The Royal Australian College of GPs is concerned that the report falls short in its exploration of healthcare for individuals with disability, specifically in the context of general practice care.

One significant barrier is the absence of a Medicare patient rebate for NDIS paperwork. This places a substantial burden on patients, necessitating them to attend a consultation solely for administrative purposes. This issue becomes even more challenging for Aboriginal and Torres Strait Islander patients, who require additional paperwork to support their NDIS applications.

The Royal Australian College of GPs points out that better utilisation of GPs can enhance the efficiency of the NDIS. GPs possess in-depth knowledge of their patients and their unique circumstances. By enabling GPs to directly liaise with NDIS service providers, the right type of support can be ensured, and duplicated services can be avoided.

The Royal Australian College of GPs stresses the importance of strengthening connections between mainstream services and the NDIS. Greater collaboration between GPs, other healthcare professionals, and the disability sector is essential to prevent fragmentation of care.

Simplifying the NDIS application process is crucial, as GPs often spend significant time navigating red tape to help patients access the scheme. Integrating NDIS forms with general practice clinical information systems can streamline this process.

The report's recommendation for improved access for Aboriginal and Torres Strait Islander patients is also endorsed by the Royal Australian College of GPs. This has been a consistent call, particularly since these individuals face unique barriers in accessing support services. Culturally safe disability services and supports are essential to address their specific needs.

Better systems navigation for people inside and outside the NDIS.

Australian Federation of Disability Organisations was happy to see the review report recommend the creation of a way for all people with disability to navigate mainstream, foundational and NDIS service systems. The intended purpose of the 'Navigator' arrangement is to support people with disability under the age of 65 who are not eligible for the NDIS, as well as NDIS participants and their families.

"(However,) It is imperative that equivalent navigation services are also available to people with disability over the age of 65 to ensure equality of opportunity."

Lack of attention to systemic advocacy.

Australian Federation of Disability Organisations believes it is imperative that systemic advocacy is adequately funded into the future.

"While the report itself does include a few passing references to aspects of the intended reforms being informed through “co-design”, the term is not used anywhere in the list of recommendations and supporting actions. While some of the supporting actions do refer to “consultation”, there is no reference to the need to consult with disability representative organisations and disabled persons’ organisations. This goes against the aspirations of the Convention on the Rights of Persons with Disabilities."

Urgent attention needed for workforce challenges.

The disability sector is currently facing significant financial challenges, compounded by chronic workforce shortages. The successful implementation of reforms relies on the existence of a viable disability sector. Unfortunately, the latest figures indicate that this is not the reality, as many providers grapple with financial sustainability challenges.

There is a call for the establishment of a NDIS Reform Implementation Taskforce and recommendations for the creation of an NDIS Review Implementation Advisory Committee. This advisory body, led by individuals with disability, their representatives, providers, and critical stakeholders, along with government funding, is essential to ensure a co-designed, safe, and practical implementation of the proposed reforms.

The announcement of an independent pricing mechanism is also welcomed. Claims of price gouging by some providers damage public confidence in the scheme.

Exclusion of people who acquire a permanent life-altering disability after 65.

If you acquire a disability after the age of 65, the National Disability Insurance Scheme will not fund you. And that’s not about to change.

NDIS recipients receive more in support on average than My Aged Care recipients. It is vital that the NDIS eligibility criteria be reviewed so that it is targeted to the broader ageing population.

“There are people in the community who say that the quality of disability care after the age of 65 is inferior to the quality of disability care before 65,” NDIS Minister Bill Shorten told reporters early this year. “I think they have a point.”

“[The] NDIS, despite all of its challenges, is still a scheme that looks better for people in aged care than what they have.”

“There is a challenge for disability care for over 65, whether or not the solution’s an NDIS – which is very expensive – or an improvement in the quality of disability care and aged care. That will be a matter for the whole of the government.”

Real carers, real stories.

“Keeping a good work, life, care balance is essential if I am to continue providing proper care and support, and Carer Gateway was able to help me do this.”

“I would highly encourage carers to browse through the website, there’s something for everyone.”

Aakriti is one of ten carers who have shared their story about caring through [Real Carers, Real Stories – In Their Own Words](), a digital photographic exhibition. The exhibition features photographs, videos and stories available in a selection of languages.

Visit the [online exhibition](). Visit [Carer Gateway]() to discover resources in 30 languages.

Special Edition: Aboriginal Women in Advocacy and Hearing Healthcare.

We invite you to contribute to a special edition in early 2024 of the One in Six newsletter highlighting Aboriginal Women in Advocacy and in Hearing Healthcare.

In coming months, we hope to gather diverse, compelling stories that reflect the impact and contributions of remarkable women.

You may be able to suggest potential profiles of Aboriginal women whose work has been influential.

By featuring these profiles in our newsletter, we aim to amplify their voices and achievements to a broad audience, enhancing the visibility and impact of their work.

Please get in touch with us with any questions or suggestions: info@deafnessfrum.org.au

Empowering aged care volunteers.

A new webpage has been launched containing valuable resources aimed at strengthening the national consistency of volunteer training, support, management, and promotion within the aged care sector.

In early 2023, the Commonwealth Department of Health and Aged Care conducted the "Volunteers in Aged Care Survey." The survey's primary objective was to gain insights into the pivotal role volunteers play in providing person-centred aged care. The survey collected responses from volunteers, managers, and providers across the nation. The findings informed the creation of these new resources.

Introducing the new webpage and resources.

These new resources are now available for you to access and use.

You can find them at health.gov.au/topics/aged-care/volunteers.

These comprehensive resources are geared towards addressing various aspects of aged care volunteering, and they encompass:

- The Importance of Engaging Volunteers: Understand why volunteers are vital to delivering person-centred aged care.
- Volunteering in Aged Care: Get insights into what it involves and how it contributes to the well-being of our elderly citizens.
- Becoming an Aged Care Volunteer: Step-by-step guidance on how to embark on a fulfilling journey as an aged care volunteer.
- Guidance for Aged Care Providers and Managers: Resources that empower providers and managers to optimise volunteer support and management.
- Training and Resources: Access valuable training materials and resources tailored specifically for aged care volunteers.

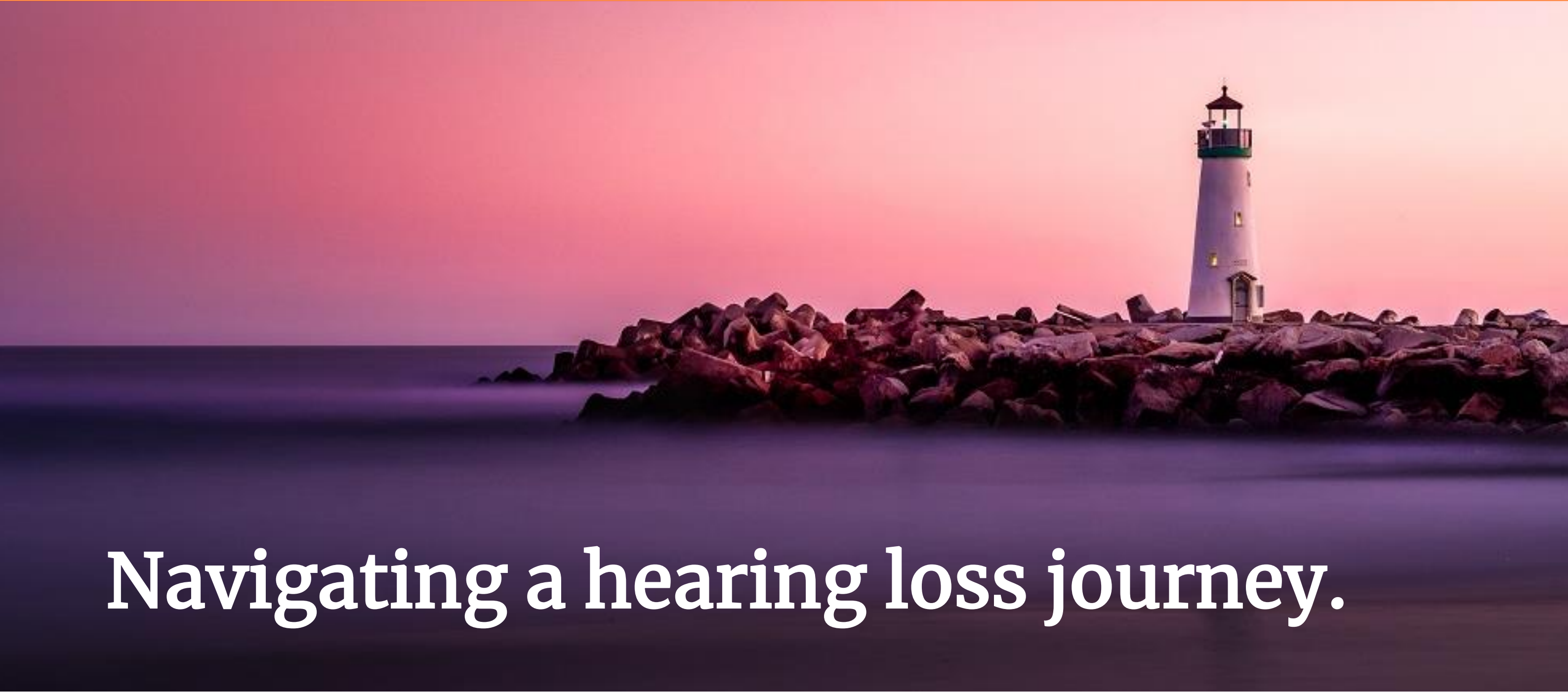
Call for Good News Stories.

Aged care volunteers and managers across Australia are doing remarkable work, often innovatively overcoming challenges to ensure the best care possible for our elderly population. We want to celebrate, recognise, and showcase these incredible stories of dedication and innovation.

We invite you, your colleagues, and anyone you know involved in aged care volunteering to share their inspiring stories. We are particularly interested in hearing about:

- Your personal experiences as a volunteer or stories from dedicated volunteers you know.
- The impact volunteers have on improving the quality of care for the elderly.
- Innovative solutions and approaches that have been used to overcome challenges.

These stories will be shared on the Department of Health website and social media. Submit your stories by getting in touch with the team at agedcarevolunteer@health.gov.au



Navigating a hearing loss journey.

When local doctors in Kenya informed Neetal Mardania that her 18-month-old daughter's hearing was "perfectly fine", she simply couldn't accept the diagnosis. Call it gut feel or mother's intuition, but Neetal was convinced that Nena's hearing was compromised.

"She wasn't responsive when we spoke to her and didn't react to loud noises," she explains. "I just knew, deep inside, that something was not right."

Neetal travelled almost 500 kilometres from the family home in Mombasa to the country's capital, Nairobi, to seek a second opinion. The outcome confirmed her worst fears – that Nena was profoundly deaf in both ears.

"At first I was in shock," says Neetal. "I didn't want to believe that it could be true; that I had a deaf child. I had so many questions but very few answers."

Around the same time, an armed gang forced their way into the hair salon that Nena's father Mehul owned in Mombasa. This, together with the relative lack of support for Nena they could expect to receive in Kenya prompted the family to make the brave decision to pack up their belongings and embark on a journey across the world. They ended up in Australia, where they settled in the northern suburbs of Perth in December of 2006.

"It was such an emotional journey, and it was so hard," explains Neetal. "We left all our family in Kenya. It took a long time to get settled in Australia and find the right supports for Nena. I was pregnant at the time, too, so Mehul was the only one working.

"While I was at home I did research on the best treatments for Nena, and I came across Telethon Speech & Hearing (TSH). I called them up and made contact with Wendy Tunbridge. TSH has been such a blessing in our lives. They introduced us to all the support systems that were available in Australia and we are so grateful for all their knowledge that they shared with us.

"They were not afraid to tell us some hard truths too," she says. "They told us that the journey would be very difficult, but not impossible, and they convinced us that Australia was the best place for Nena and our family. I'm so grateful that they did, because I look back now at how far we've come, how much we battled through the last 17 years, and I know that every struggle and every minute was worth it."

At the age of four, Nena received her first cochlear implant, something that would have been extremely unlikely back in Kenya, with the second coming at the age of six. Neetal recalls the moment the CI was switched on.

“It was an amazing moment, and it changed our whole world,” she says. “Her first word was ‘baba’. I looked over at my husband, who was in tears – happy tears - and I saw the smile on his face. I remember, at that point, being so grateful for all that God had given me on this earth.”

Although Nena was suddenly able to hear, she had a lot of catching up to do, as her hearing loss had left her with a severe language delay.

She began an intensive program at TSH and, after a while, TSH’s Josie Hawkins convinced the Mardanias that it was time for Nena to start attending school. She recommended that Nena join TSH’s Outpost program, so that she could benefit from mainstream schooling while enjoying the supports that TSH provides, including teachers of the deaf, note takers, speech therapists, occupational therapists and a psychologist.

Nena attended St Stephen’s School Carramar for her primary school years, where she received multi-disciplinary language support on a daily basis. At home, Neetal and Mehul continued the support work and Nena made slow, but steady, progress through her school years.

“Josie also introduced us to other parents who were undergoing a similar journey,” explains Neetal. “That was a real eye opener for us, seeing that other parents were going through the same thing.”

Last year Nena graduated from Servite College and, while she ponders what her future holds, she has begun working at her local KFC.

“Just getting out and working part time has been so good for Nena, She’s been cocooned in the safety net of her family for so long that she needs to get out of her comfort zone and mingle with new people.

“She has wonderful empathy, and her goal is to get into a career where she works with children. We are working to make that happen and I’m sure it will.”

From Telethon Speech & Hearing.

Become a research partner in the first Australian registry to improve the lives of deaf or hard of hearing children.

Dear Parent/Carer/Child/Young Person,

ANCHOR is short for Australian National Child Hearing Health Outcomes Registry. The registry is a way of collecting information about child hearing.

It is an important research project conducted by Murdoch Children's Research Institute to develop the foundations 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 about:

- your experiences
- what you want most for yourself and your future (or for your child and their future)
- what support you/your child may or may not have been offered.

This will help the research team learn what information and outcomes are most important to you and your child. An "outcome" is something that can be measured by service providers or researchers that can tell us how well children are progressing.

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. Alternatively, you could do a one-on-one interview if you prefer.

You will receive $50 for taking part in the focus group or interview.

Please register your interest here.

You are eligible to take part if you are:

- a parent of a child or young person who is deaf or hard of hearing (aged 0 to 26 years)
- a child or young person who is deaf or hard of hearing (aged between 8 to 26 years)

Here is where you can learn more: https://www.mcri.edu.au/research/projects/anchor | anchor@mcri.edu.au

murdoch children's research institute

DEAFNESS FORUM AUSTRALIA oneinsix

Advertisement.

We're back for 2024! Get ready to start, strengthen, or streamline your Audiology practice with Independent Audiologists Australia's intensive online **Business Bootcamp**!

This half-day program will feature vibrant local and international speakers offered across two concurrent streams: Start Strong and Level Up.

Start Strong is for new or prospective independents getting off the ground, and will include expert guidance on business planning, goal setting, assembling a team, confidently handling billing and reimbursement, and tackling the first steps on the journey to independent practice.

Level Up will serve established clinic owners, with a focus on business efficiencies and expansion, establishing and strengthening a cochlear implant program, fostering a culturally-safe workplace, and considerations when buying or selling a business.

All sessions will be recorded and attendees can register for one or both streams. Full program coming soon.

Open to all, with discounted registration for IAA members and subscribers. Join us and put your best foot forward for your Audiology business in 2024!

Click here for more details and to register.

Alcoa backs Earbus' vital work with Indigenous children.

A unique program that tackles ear health for Aboriginal and at-risk children will run locally for at least another three years in Western Australia, delivering much needed care.

By Giovanni Torre for National Indigenous Times.

Alcoa Foundation, the aluminium producer's global charity, will provide Earbus Foundation of Western Australia with $450,000 over three years, allowing Earbus to continue delivering ear health services in Kwinana, Peel and the Upper South West regions.

The commitment builds on the $330,000 in funding Alcoa has already provided in support of the innovative ear health service in this part of WA since 2018.

Ear infections occur among Aboriginal children at a significantly higher rate than non-Indigenous children and can have a serious, adverse effect on the ability to learn.

While Australia's overall population has one of the lowest rates of chronic ear disease in the world, the World Health Organisation (WHO) has a special listing for Australia's Indigenous people alongside its list of the five countries with the highest rates of middle-ear disease.

Earbus Foundation was established in 2013 to deliver world class ear care in regional and remote communities. It now services more than 100 sites across WA, deploying inter-disciplinary clinical teams and helping thousands of children who would otherwise not receive a service.

The "one stop shop" mobile clinic goes where the kids are, travelling to schools, daycares, kindergartens and early learning centres. The service is free to communities, removing cost and accessibility as barriers to Aboriginal and other at-risk children receiving the care they need.

Alcoa's support to date has enabled Earbus to conduct ear assessments for about 1,350 children across 33 schools, day care centres and early learning centres. That has included 3,046 ear screens, 1,647 hearing tests and 844 health checks.

Over the past three years, rates of middle ear disease in the areas served by the Alcoa Earbus Program have been reduced and rates of hearing loss have dropped from 11.6 per cent to 4.7 per cent.

The new partnership with Alcoa's global charity, the Alcoa Foundation was officially launched on 20 November at Harvey Primary School. This school regularly receives a service from the Earbus.

Attending the launch in November, Alcoa of Australia's Director of Corporate Affairs Jodie Read said "equitable access to education, especially for Indigenous and at-risk people, is a priority for the Foundation and one of the reasons why this partnership with Earbus Foundation is so important to us".

Deputy Principal of Harvey Primary School, Simon Philp, said "Having access to regular services pinpoints issues with hearing as well as learning difficulties, particularly in the younger years. This means we can get on top of the issues, support those students, get things sorted ... it's an essential service that we look forward to continuing in the future," he said.

Earbus Foundation of WA CEO and Co-founder Dr Lara Shur said the program was crucial for improving the lives of some of the most at-risk children in Western Australia.

"This renewed partnership with the Alcoa Foundation is an outstanding commitment to the health and wellbeing of children across this region. It will allow Earbus to continue to build on our award-winning program, taking the multi-disciplinary team of ear health screener, audiologist and nurse practitioner to where children are. It will enable us to continue to provide a high-quality screening, treatment and surveillance program," Dr Shur said.

Earbus works in partnership with a range of organisations, including South West Aboriginal Medical Services.

DEAFNESS FORUM AUSTRALIA

Office-bearers in 2024

Deafness Forum's office-bearers in 2024 have been announced.

- Chairperson, David Brady
- Vice chairpersons, Michelle Courts and Raelene Walker
- Treasurer, Dwin Tucker
- Chair of the Libby Harricks Memorial Oration Committee, David Harricks
- Accessible Transport Advisory Committee representative, Christine Hunter
- Australian Federation of Disability Organisations, Christine Hunter.
- Australasian Newborn Hearing Screening Committee, Emily Shepard.
- Aviation Access Forum, Emma Scanlan
- Standards Australia Committee FP002, Keith Shinn
- The CEO is the representative on all other committees.

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

Let us know at hello@deafnessforum.org.au