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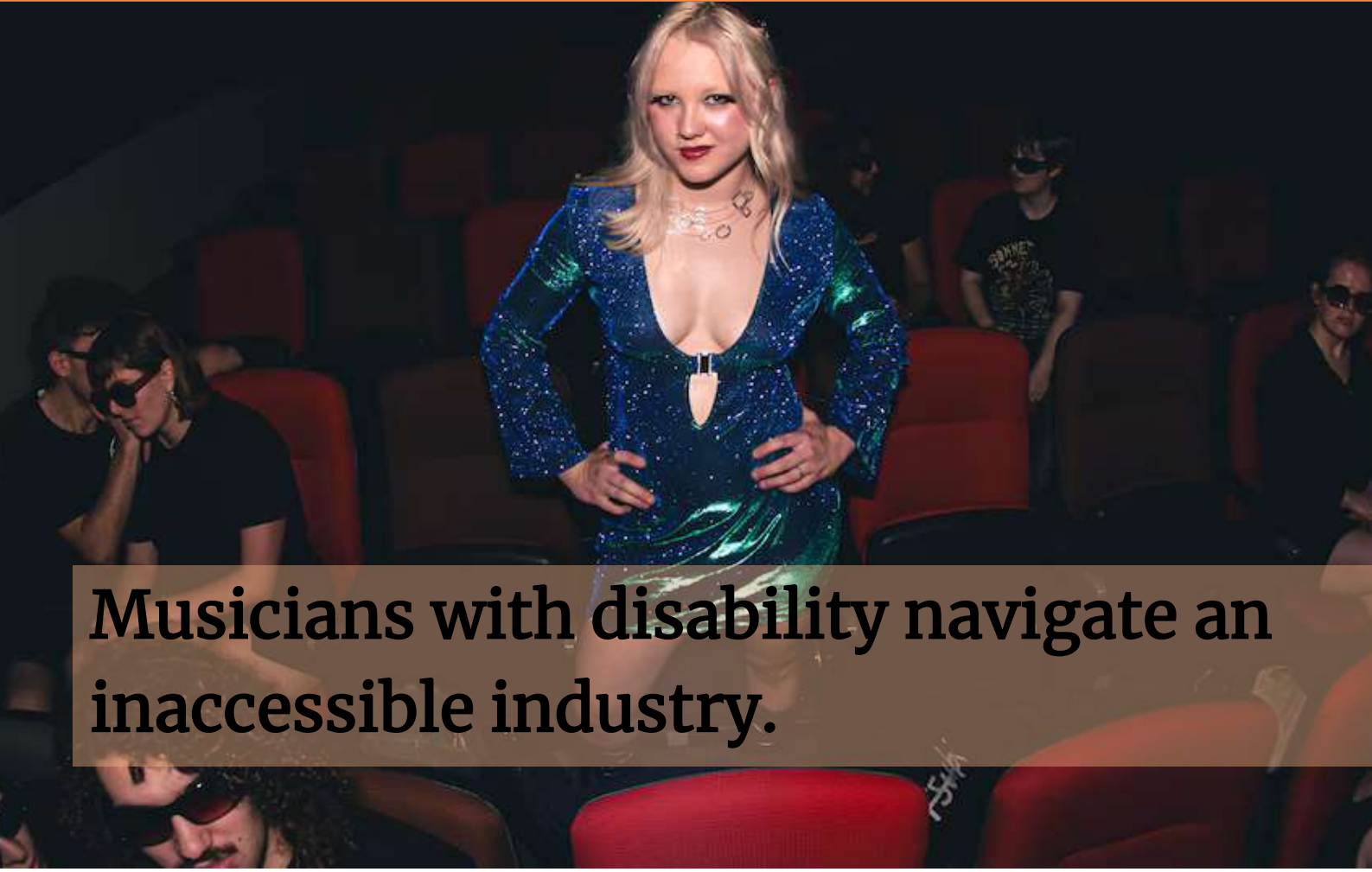
9 DEC 2024

Health Literacy Empowers Young Adults with Hearing Challenges

Meet the new Board of Deafness Forum Australia

Blueprint for Equity: Advancing Foundational Supports in Disability Services



Musicians with disability navigate an inaccessible industry.

For Sonnet Cure, performing and singing is an out-of-body experience.

Sonnet was born with a deformed cochlea, which means she's deaf in one ear. The cochlea is a spiral-shaped part of the inner ear that converts sound vibrations into nerve impulses that the brain can interpret as sound.

But Sonnet says when she sings, it doesn't have much to do with her hearing.

"The good news is it's very much about the internal, like, how it feels inside of you, and the muscles that are at play and feeling it throughout your whole body," she says.

"You know when you hit a tuning fork? And it's so warm, full and it feels very physical and bigger than just this tiny little like fork? That's what [singing] feels like within your body."

"Music is so human and important to us, to our growth and our emotions to express ourselves this way."

Sonnet is featured in the new ABC series Headliners.

Turning Down the Volume on Workers' Rights

Dramatic cuts are being proposed to compensation for hearing loss in NSW workplaces.

The body which manages workers' compensation in NSW, the State Insurance Regulatory Authority, conducted a limited consultation in October among select hearing health sector stakeholders to get feedback on its proposed changes to the fees it would pay providers in 2025. These changes include slashing the hearing aid cap from $2500 to $1750 and hearing rehabilitation from $686.90 to $85.80 and entirely removing the handling fee.

There is no apparent clinical justification offered for these cost cutting measures by the State Insurance Regulatory Authority, contradicting the Authority's published research on the complexity of occupational noise induced hearing loss.

The Hearing Care Industry Association, representing hearing healthcare providers in Australia, said that clinicians and consumers should be very concerned about these proposed changes and how they will degrade outcomes for injured workers. While the consultation is now closed, concerned parties can email the State Insurance Regulatory Authority to get a copy of the paper and provide feedback.

The complexity of work-related noise-induced hearing loss compared to general age-related hearing loss is significant and requires significantly more investment by clinicians, consumers and insurers, according to the Hearing Care Industry Association. These workers experience greater difficulty performing job-specific tasks than those with age-related hearing loss, necessitating more robust support systems.

Work-related hearing loss is often associated with more severe functional and communication challenges, necessitating rehabilitation plans beyond standard age-related interventions, requiring longer sessions, multiple follow-ups and tailored counselling that address the specific demands of occupational settings. Work-related hearing loss is also tied to higher rates of emotional and psychological distress.

Workers' compensation patients often present with complex hearing issues, such as tinnitus and steeply sloping hearing losses. These cases require more effective background noise reduction and more in-depth rehabilitation.

The injured workers that get support are generally relatively young (50 onwards) and in the workforce. Their active lifestyles demand further considerations, such as outdoor support and wind noise reduction.

The Hearing Care Industry Association said proposed cuts will leave patients with suboptimal hearing solutions that do not meet their needs, leading to continued difficulties in communication and a slower, less effective rehabilitation process.

In the absence of clinical considerations, the proposed changes show cost-cutting measures heavily reliant on an unknown – and arguably irrelevant – need for fee harmonisation across different state jurisdictions – each with different premiums, benefits, employers and rules – in what appears to be a "race to the bottom".

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Hearing care for vulnerable Australians

Hearing Australia has been working closely in 2024 with the Salvation Army to provide regular hearing services to some of the most vulnerable people in Melbourne.

The Sallies' Magpie Nest Café provides free meals, crisis intervention and support to people in need, including people who may be homeless or have drug and alcohol addiction or mental health and general health issues.

Hearing Australia's partnership with the Salvation Army, launched in October 2023 by the Minister for the NDIS and Government Services Bill Shorten, has improved access to hearing care for Australians who are doing it tough.

Major Brendan Nottle, Commanding Officer of the Salvation Army, says the partnership is helping to provide the support people need to reconnect with the community again.

Tarnia at the Hearing Australia Richmond Centre says, "Through our fortnightly visits to the Magpie Nest Café, we've been able to connect with people who don't commonly interact with mainstream services and who have been living with hearing loss."

Audiologist Jess said that being able to help the Magpie Nest community provided some truly unforgettable moments.

"I saw a client who lives in social housing with her daughter, and she was struggling to hear her. Her hearing loss also affected her anxiety and self-confidence. She was grateful when we helped her with hearing aids and became very emotional when they were fitted."

Kim Terrell, Managing Director of Hearing Australia said that just like the Salvation Army, Hearing Australia is committed to improving the lives of others, regardless of their age, location or background.

"We're continuing to work with many partners to improve the hearing health of the nation.

"Thank you to all those who work alongside us to transform the lives of people with hearing loss," Mr Terrell said.

Health Literacy can Empower Young Adults with Hearing Challenges.

Digital tools, like smartphone apps, are becoming essential in our daily lives. They can potentially improve health awareness and preventive behaviours, especially among young adults.

Young adulthood is a pivotal time for establishing health behaviours that impact long-term wellbeing. Good health literacy allows young adults to make informed decisions and adopt healthier lifestyles, leading to better mental health and quality of life.

However, studies reveal that many in this age group have low to moderate health literacy, underscoring the need for effective educational interventions. Targeted strategies like school and web-based programs, social media outreach, and peer-led education are essential for improving health literacy among young adults.

A Zurich University of Applied Sciences study has focussed on the health challenges of young adults aged 18–28 with hearing loss. The goal was to understand their needs to develop a chatbot - a digital assistant meant to help manage health issues without replacing human professional support.

The study highlights the crucial role of health literacy in improving these young adults' mental and social wellbeing. With many in this age group owning smartphones, there's a good opportunity for health apps to improve communication and information access. While digital media has great potential to help those with hearing issues, there are still hurdles to clear, particularly in breaking down communication barriers and making content easy to access.

The research suggests that customised digital tools to meet these young adults' specific needs and challenges can significantly improve their quality of life. These tools should focus on helping them feel connected and healthy despite their challenges.

Developers must make them accessible, intuitive, and straightforward to install, allowing for easy integration into their daily routines.

Creating tailored, accessible digital tools like chatbots can play a crucial role in boosting health literacy among young adults with hearing loss, but it requires ongoing research and development to ensure these tools are effective and sensitive to the unique challenges they may face.

From Health issues of young adults with hearing loss or deafness: A basis for the development of a chatbot.

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Strengthening Trust and Safety

Australia's State and Territory Health Ministers are considering options for regulating the audiology profession.

Health Ministers commissioned an investigation to assess future options for regulating the audiology profession.

Targeted consultations (Dec and Jan) are underway to inform research and analysis.

A consultation paper was created to guide and inform this stakeholder consultation. Here is the paper: Queensland Health | Consultation Paper 2 | Audiology Decision RIS

Deafness Forum supports the most comprehensive and safest model option, national registration under the National Registration and Accreditation Scheme administered by the Australian Health Practitioner Regulation Agency. If you have views that support our position to include in our submission, contact Hayley Stone, our Policy Team, for a confidential chat - hayley.stone@deafnessforum.org.au

Protecting the Public from Unsafe Practice is our Priority

Comprehensive knowledge and expertise in managing the complex nature of deafness and hearing loss is critical across all hearing health practitioners. The public is at risk if other vulnerabilities are not recognised and addressed as part of hearing health services.

Hearing loss and deafness are often identified at vulnerable points in life, such as when a child is newly born or during advanced age, when cognitive decline may be present. Hearing loss is often a symptom of a broader health condition and can coexist with other disabilities.

We believe that registration would enable the public to trust that they will receive services from suitably qualified professionals, registered with a national body and to have a transparent and simplified complaints pathway when they do not.

Benefits All Australians

Protecting the public from unprofessional practice is a priority for Deafness Forum Australia.

We want consumers to trust audiology and audiometry services in the same way they trust others who provide their healthcare, such as general practitioners, nurses, or optometrists.

Mandatory professional registration would mean that the public could trust the titles audiologist and audiometrist.

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Improving Hearing Aid Use with a Focus on Positivity.

Some people don't use hearing aids because they believe these devices don't help them enough. Improving the perceived benefit of hearing aids could lead to better user outcomes.

Research shows that psychological factors, such as "positive framing," can greatly influence how effective people perceive their hearing aids to be. For example, one study found that when hearing aids were described as "digital" technology, users reported more benefits than when the same devices were called "analog." In this study, participants used the same digital hearing aids for two months. Still, they were told they were using different devices each month. Similarly, other studies showed that hearing aids labelled as "new" were preferred over those labelled as "conventional," even though both devices were identical in performance.

Another study in 2022 found that telling users a positive story about hearing aids before fitting them led to better performance in hearing tests than when users were given a neutral or negative story. These studies suggest that using positive language and framing during the fitting process can improve short-term outcomes for hearing aid users.

More recently, researchers explored the benefits of focusing on positive listening experiences, known as the "positive focus" approach, for experienced hearing aid users. Unlike previous studies that relied on external narratives, this approach encourages users to reflect on their own positive experiences with their hearing aids. The goal is to counteract the tendency to focus on negative experiences, a common psychological bias. Studies have shown that maintaining a focus on positive experiences can improve cognitive and emotional well-being, as well as overall happiness.

One study found that when users focused on and shared their positive listening experiences for two weeks after getting their hearing aids, they reported greater satisfaction and better hearing performance. Given how simple and effective the "positive focus" approach is, it could be a valuable tool in clinical settings to enhance the effectiveness of hearing aids and encourage more people to use them. However, the long-term effects of this approach or its impact on first-time hearing aid users still need further investigation.

From Focusing on positive listening experiences improves hearing aid outcomes in first-time hearing aid users: a randomised controlled trial.

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Blueprint for Equity: Foundational Supports in Disability Services.

Federal, State, and Territory governments are jointly and individually developing what aims to be a unified system of supports for all people with disability. This new framework is called 'Foundational Supports'.

If done well, the new Foundational Supports framework could finally address the dearth of available support for the one in six Australians with hearing loss, deafness, or other auditory conditions who don't qualify for government programs like the National Disability Insurance Scheme.

The framework could address the arbitrary delineation created by the introduction of the National Disability Insurance Scheme, as to who is 'disabled enough' to deserve the necessary supports to participate as individual citizens and members of the community; and allow Australia to demonstrate a comprehensive commitment to meeting its international and domestic commitment to upholding the fundamental rights of all Australian citizens with disability. These Foundational Supports will replace supports that have until recently been funded by the Federal Government's Information, Linkages, and Capacity Building program.

Deafness Forum Australia has high aspirations for the Foundational Supports framework.

The challenges will be ensuring that governments commit the necessary time and effort to get this rare opportunity right and that the interests of people who are Deaf, those with hearing loss, and people living with other conditions like Tinnitus and Meniere's are prioritised across the reform process.

Progress towards developing the framework is in its early stages, and work is flagged to continue across the whole of 2025.

Over the last couple of months, Deafness Forum has been talking to our member organisations, people with lived experience and their families (including Deafness Forum's Lived Experience Advisory Group members), as well as providers, to scope where the support gaps are, and what people want to address these gaps.

More broadly, we've been working with other disability representative organisations to increase the visibility of people who are Deaf, hard-of-hearing, or have other auditory conditions as priority stakeholders in this reform.

It's an exciting period in disability reform, but there's a lot at stake. If poorly executed, the Foundational Supports could end up being little more than lip-service, falling short in realising

the ecosystem of interconnected supports envisioned in the final report by the NDIS Independent Review.

We could see ourselves confined to yet another strategy that talks up the rights of people with disability but does little to address real needs, while access to the National Disability Insurance Agency is tightened.

Figuring out how to move forward is complex

There are established organisations that have been providing high-quality, meaningful supports to people who are Deaf, hard-of-hearing or have other auditory conditions, for many years. Several highly respected organisations have closed in the last two years.

We know of other organisations that are in a precarious financial situation because of the Federal Government's decision to discontinue the Information, Linkages, and Capacity Building grant program.

We are acutely aware that once good organisations close, we lose vital knowledge and expertise as a community, which may never be regained.

We also need to make sure there is a place for peer support in the new Foundational Supports Framework in recognition of the vital role peer support groups play, particularly in areas where government services are not readily available. We know peer support groups not only provide information and capacity-building skills, but also offer an avenue for people to engage in their communities, connect with peers, and build a sense of cultural identity.

We have made eleven recommendations

which we believe will be critical to achieving a comprehensive and inclusive Foundational Supports system. These recommendations come from our consultations with people with lived experience, parents, and community organisations.

1. **Conduct Comprehensive Audits and Consultations**

   Federal, State, and Territory governments should audit existing supports and services and consult with a diverse range of disability cohorts, support providers, and advocacy organisations to ensure a targeted approach in building Foundational Supports that effectively address gaps.

2. **Prioritise Supports for NDIS-Ineligible Individuals**

   Develop meaningful supports specifically addressing the needs of individuals aged 26 years and older who are ineligible for the NDIS, focusing on these individuals as a priority.

3. **Ensure Equitable Access to Foundational Supports**

   Guarantee that all individuals have equitable access to a core range of culturally safe Foundational Supports provided by culturally competent providers. These supports should be available irrespective of age or locality.

4. **Support Established Organisations**

   Ensure that established organisations connected to communities of people who are Deaf, have hearing loss or have other auditory conditions, are supported with Government funding to continue providing services while Foundational Supports become established. This should include organisations that offer specialised support to under-serviced, and vulnerable cohorts, such as those with Usher Syndrome or who are Deafblind.

5. **Preserve Peer Support**

   Peer-led community groups should be funded to continue and expand under the Foundational Supports strategy, particularly where government services are not readily

available, for instance, in regional, and remote locations. Access to peer support builds resilience, promotes knowledge sharing, and builds cultural identity.

6. **Enhance Information Accessibility**

   Provide clear and comprehensive information in various accessible formats to explain what Foundational Supports are, the supports available locally, and how these supports can be accessed. This can include investing in high-speed internet connections, for instance, Starlink connectivity for people in remote and regional areas to access online information and support.

7. **Commit to Co-design**

   Maintain an ongoing commitment to genuine co-design with the disability community, disability support organisations, and representative organisations throughout the reform process, including involvement through both the National Disability Insurance Agency and the Department of Social Services.

8. **Extend Supports to Carers and Family Members**

   Expand Foundational Supports to include resources for carers and family members, such as providing Auslan courses, to equip them with tools to support their loved ones effectively. Supports should be provided in accessible formats.

9. **Educational Resources for Wider Inclusion**

   Embed educational resources in Foundational Supports to enhance disability awareness and inclusion, acknowledging that promoting disability awareness and inclusion is a whole-of-society responsibility.

8. **Implement an Open Tender Process for Contracts**

   Award contracts to administer Foundational Supports through an open tender process, offering funding terms of 3+ years to give organisations a better opportunity to attract and retain staff, and to effectively evaluate and refine support projects.

9. **Ensure Adequate Funding for Service Providers**

   Ensure that funding for service providers, especially community peer support groups, is sufficient to cover all reasonable costs and provides decent remuneration for staff, addressing the increased demand expected due to tighter NDIS eligibility rules.

The recent Independent Review of the National Disability Insurance Scheme calls on governments to *bring fairness, balance, and sustainability to the ecosystem supporting all people with disability.* We hope governments will act in the spirit in which the recommendation was made.

Governments can ensure this is attained by engaging in genuine co-design with people with disability, their families, and supporters and in guaranteeing that no person with disability will be worse off under the new Foundational Supports strategy.

Deafness Forum Australia is committed to supporting all levels of government throughout this process to represent the interests of people who are Deaf, have hearing loss, or have other auditory conditions and will flag opportunities for community members, families, supporters, and provider organisations, to support our work across the new year.

By Hayley Stone, Deafness Forum Australia's National Director of Policy and Advocacy.

Canadian Comedian (there is such a thing!) Avoids the 'Hearing Aid Guy' Label

Stand-up comedian D.J. Demers, who is hard of hearing, aims not to be pigeonholed simply as "the hearing aid guy".

Demers, known for appearing on shows like Conan and America's Got Talent, leverages his unique perspective to connect with audiences through humour about his experiences.

Demers was diagnosed with hearing loss at age four and has always considered it a unique angle for his comedy. "My hearing aids aren't waterproof, which is ridiculous. So I have to take them out when I'm taking a shower or when I go swimming. So, you know, pool parties are a nightmare," Demers jokes, illustrating the everyday challenges that have resonated with diverse audiences. Despite his humorous take on life with hearing aids, Demers revealed that as a child, he would hide them to avoid drawing attention.

His comedy career, which began in mainstream venues, evolved to include performances accessible to deaf and hard-of-hearing audiences, highlighted by his hiring of sign-language interpreters for his shows. The first interpreter he hired, Jennifer Lees, noted a gap in entertainment for people who rely on sign language, particularly in comedy. Demers's initiative has helped bridge this gap, bringing laughter to a broader audience that can relate deeply to his experiences.

The pandemic posed additional challenges for Demers, as masks and barriers at places like banks made lip-reading nearly impossible, a situation he turned into comedic material. His observations about communication barriers have offered insights into people's everyday experiences with hearing loss. "I get really worried in a sketchy hotel because I wear hearing aids. I take them out to sleep. I'm very easy to murder," he quipped, bringing a light-hearted approach to his real concerns.

"And I have a kid now, and now he's got a hard-of-hearing father, so I'm watching how he perceives me when I can't hear him well. And so that's shifting my own perspective," Demers reflects on how fatherhood has altered his view of his disability, adding a personal and evolving layer to his stand-up material.
From Comic D.J. Demers jokes a lot about hearing loss

DEAFNESS FORUM AUSTRALIA

Meet our Board

The board of Deafness Forum Australia sets the direction and policy on key issues.

It is elected by and represents our national membership of individuals and organisations.

The composition of the Board reflects the broad nature of the deafness sector. The directors' various life experiences and professional expertise, coupled with the Deafness Forum's activities and consultative processes, ensure the organisation has the authority to respond to key issues common to the entire deafness sector.

The board ensures that Deafness Forum is focused on its purpose and strategic objectives and manages its resources efficiently and effectively for the future.

Last month, David Brady retired after nearly 13 years at the helm of Deafness Forum Australia. David's retirement as Chair was a significant moment in our organisation's history. His visionary leadership and dedication steered our organisation through pivotal changes and remarkable achievements. While we will greatly miss his guidance, we are grateful for the strong foundation he has built.

Raelene Walker, Chair

Perth, WA

Rae first joined the Deafness Forum Australia board in 2018, equipped with a wealth of experience as an educator, access and inclusion advocate, and community leader. With a career spanning various educational settings in Western Australia, Rae has contributed significantly as a Teacher of the Deaf, utilising both Auslan and English to support Deaf and Hard of Hearing students, fostering both academic and personal growth.

Having become profoundly Deaf as an adult, she navigates severe tinnitus and vertigo, enriching her understanding of the challenges faced by those with similar conditions. Her advocacy extends to her role on the board of Deafness Council WA and volunteer work at St Patrick's Community Support Centre.

As a Director of Deafness Forum Australia, Rae's unique insights and personal experiences significantly shape the organisation's initiatives, focusing on inclusive education, hearing health services, and mental health support in remote areas. Her leadership is pivotal in driving systemic change and enhancing the quality of life for the Deaf and hard of hearing.

Christopher Blackham-Davison, director

Darwin, NT

Christopher was nominated by Australian Lions Hearing Dogs and joined the board of Deafness Forum Australia in 2024.

He was born with hearing loss and is a recipient of bilateral cochlear implants. Fluent in Auslan and supported by his hearing dog, Frodo, he has a Bachelor of Teaching in Special Education from Griffith University and has taught in various NT locations, including remote areas. Currently, he teaches Auslan to primary students in Darwin.

From 2020 to 2023, he chaired the NT Disability Advisory Committee and received the NT Disability Service Award for Excellence in 2017. He has been a judge for the NT Disability Service Awards since 2021 and participated in national forums, contributing to the NT Disability Strategy 2022-2032.

Christopher is committed to advocating for disability rights and improving lives within the hearing-impaired community. He has been involved with Lions International for 20 years, holding various leadership roles. He believes significant advances like increased access to Auslan and real-time captioning have positively changed the Deaf community and is eager to drive further progress.

Rhonda Locke, director

Coffs Harbour, NSW

Rhonda was first nominated by Better Hearing Australia in 2022.

For more than 20 years, Rhonda worked in senior marketing roles in the public and private sectors. She holds a Bachelor of Business and a Graduate Certificate of Business. Her career spans various industries, including media, transportation, health, not-for-profit, employment and training, technology, and events. She was the Head of Melbourne for a highly successful marketing agency. Today, she owns and manages a successful business in regional NSW.

In 2022-23, she led a project to rebrand Deafness Forum Australia, depicted by a Dragonfly Logo.

Rhonda lives with Meniere's disease, which has significantly affected her life. She suffers from severe and constant tinnitus and has lost hearing in one ear. She also experiences 'dizziness' and has learned to recognise the symptoms before an episode, although it can still occur unexpectedly.

Understanding the impact of this condition on an individual's career, family, and everyday life, she aspires to assist those with similar situations and ensure their needs are considered when creating policies and opportunities. She is actively contributing to the health and welfare of the many people with vestibular conditions.

Barry MacKinnon AM, director

Perth, WA

Barry was first nominated by Deafness Council WA and joined the Board in 2022.

He spent six years as leader of the WA Liberal Party and leader of the Opposition between 1986 and 1992.

Barry is the parent of a son who has hearing loss. He has extensive experience in community service, politics, and the corporate and disability sectors. Barry was involved with many organisations in the disability sector, including the Disability Services Commission, Commonwealth Hearing Services Consultative Committee, Telethon Speech and Hearing, Amanda Young Foundation, Mental Health Advisory Council, Hearing Research and Support Foundation, and Deafness Council WA. He was a board member of Telethon Speech and Hearing from 1983 to 1986, during which time he was also chair until he became leader of the state Liberal Party. He was a key figure in the establishment of an organisation called PUSH, the Parents United to Support Hearing Impaired Children.

In 1997, Barry was made a member of the Order of Australia for services to people with hearing impairments. He also received a centenary medal in 2001.

Hannah McPierzie

Perth, WA

Hannah was nominated by DeafBlind West Australians – she is its current President - in 2024.

Hannah is a community leader with a firm belief in equity and fairness. Using her lived experience perspective to speak up for those without a voice, she passionately believes in identifying and removing barriers to enable everyone to participate fully in life and society. She worked as a teacher of students with disabilities within the WA public education system for 15 years, finishing in 2024 to work as an educator in the broader community.

Hannah has a rare disease, Neurofibromatosis Type 2 (NF2). Life-saving brain surgeries resulted in her profound deafness in 2021. NF2 also impacts her vision and balance system. She has bilateral auditory brainstem implants, which she uses to access sound. She uses a range of strategies to communicate with the world: voice-to-text programs, lipreading, Auslan, and speech.

In her consultancy role, she has recently begun running lectures at the University of Melbourne's School of Audiology, teaching the students how to communicate effectively with their patients.

Jason Krstanoski, director

Sydney, NSW

Jason brings a deeply personal connection to his role at Deafness Forum Australia. His journey into the world of hearing health began with his daughter's diagnosis, revealing her inability to hear low tones, including adult male voices like his own. The discovery reshaped their family dynamics and schooling experiences, sparking Jason's commitment to learning Auslan and engaging with the Deaf community.

Professionally, Jason is an executive in the power industry, currently overseeing safe operations as part of Transgrid's leadership, managing 350 staff across NSW. His career includes significant roles such as Head of Procurement at Ausgrid. His expertise extends to engaging with various stakeholders in the government and private sectors.

Jason's active search for a meaningful volunteer role led him to Deafness Forum Australia, where he can align his professional skills with his values and experiences. His family's involvement with disability and the NDIS, enriches his perspective, enhancing his contributions to the board and the broader disability sector. Jason is passionate about driving positive change and fostering inclusivity through his role at Deafness Forum Australia.

Dwin Tucker AM, director & treasurer

Sydney, NSW

Dwin joined the board of Deafness Forum Australia in 2020. With a history of leadership as CEO in eight different organisations, ranging from large corporations to smaller enterprises, Dwin has demonstrated his expertise in financial management, strategic planning, and technological innovation. His leadership skills extend beyond executive roles, as evidenced by his current position as Vice President of Médecins Sans Frontières Australia, where he contributes to global medical humanitarian efforts.

In addition to his professional accomplishments, Dwin is deeply committed to supporting education and research in hearing impairment. He funds two annual prizes: one for the best HSC student in NSW with hearing challenges and another for the best tertiary paper in hearing research.

Dwin holds a Bachelor of Science, a Bachelor of Commerce, and a Master of Business and is a Fellow of the Australian Institute of Company Directors. His educational background and professional training have equipped him with the tools to guide and influence the organisations he serves effectively.

Dwin was awarded the Order of Australia in 2023.

Improving Care for Children with Usher Syndrome

Research by UsherKids Australia and the University of Melbourne found how much healthcare clinicians like audiologists, optometrists, and orthoptists, know about Usher syndrome.

The outcome of the investigation will improve the care received by families of children with Usher syndrome by guiding the development of new, targeted professional development programs for health care workers.

Usher syndrome is a rare genetic condition that causes deaf-blindness, affecting approximately 1 in 6,000 people worldwide. The condition involves hearing loss, progressive vision progressive vision deterioration, and sometimes problems with balance. To ensure the best care possible, a team of different healthcare professionals is needed.

In this study, researchers asked clinicians working in Australian university-affiliated clinics what they knew about Usher syndrome and its symptoms, and which healthcare professionals were essential for managing the condition.

Researchers found that most clinicians surveyed knew that Usher syndrome was a genetic condition and that it affected hearing and vision. However, their awareness of the balance problems sometimes associated with Usher syndrome was not as good. They also didn't fully recognise the importance of the role played by the relevant healthcare professionals in managing the condition. Many didn't know about the critical roles of speech pathologists, geneticists, and genetic counsellors. And they were not entirely aware of specific care aspects related to their own discipline.

The research findings highlight that healthcare clinicians need more education about Usher syndrome to provide better care. Improving their understanding of the balance issues and vision loss experienced by those with Usher syndrome is crucial. It is also essential to help them recognise the valuable roles of different healthcare professionals in multidisciplinary care. By increasing awareness and knowledge, healthcare clinicians can support individuals with Usher syndrome and their families more effectively.

Future research should focus on developing effective educational tools to enhance awareness among healthcare professionals and improve the quality of care for those living with Usher syndrome.

Read the full publication here.

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Letter to the Editor

My mother is in residential aged, she is profoundly deaf, her hearing aid and cochlea help a little but like many hearing impaired people, her processing time is slow, although her thinking capacity is still relatively good.

I'd assumed that going into a residential facility would offer support and reduce her isolation. If anything, it has made it worse.

People of her generation grew up with migrants with European accents and people interacted face to face.

Most of those employed in Aged Care facilities are young. They are used to communication with text, or on devices rather than in person, and have poor communication skills and little empathy with those needing support to understand.

They speak to my mother too fast for her to follow, often shout in her ear with a strong accent (sounds like a radio station with the volume too high and not tuned) or are busy attending to something else while they are speaking.

I ask her if she understood what they said, and she says "no".

I ask that they speak to her so that she can see what they are saying and confirm that she has understood.

Sometimes they do try, sometimes there is a sigh and a feeble attempt to do so, sometimes they cut her out and ask me the question, other times there may be an 'it doesn't matter' response as they walk away. There are a couple who will write her a note if necessary and I appreciate that.

We have multiple signs on the door and around her room from the Better Hearing Package - *I have a hearing disability, Face Me, Don't shout*.

I completely understand that this may be as frustrating for them, as it is isolating and distressing for the hearing impaired care recipient, but they are employed as care givers, the residents al have a right to appropriate care, whatever their needs. Having worked in Aged Care myself, this issue is endemic.

Training in appropriate communication needs to be provided as a distinct unit as part of the Level 3 Certificate. Not just how and what to say, but also an understanding of empathy by those who are young and unaffected. To not do so is enhancing neglect of a large part of the hearing impaired community in the Aged Care sector.

I am aware that there are units available, however it seems that they are not mandatory. A friend who works in Disability services has advised me that their Care Workers are obliged to be trained in communication.

I recently enquired at my mother's residential care home, about the availability of a T Loop in their activities areas. No one even knew what it was. Their best response was that they would ask their IT person. Our experience with their IT people was that they were unable/unwilling to assist with the installation of her Captel phone.

Sue, NSW

Comment

Addressing the hearing needs of people in aged care facilities is a complex and challenging problem. It is also financially unattractive to commercial audiology service providers.

Research shows that those in aged care have a much higher prevalence of hearing and communication impairment than those living in the community, contributing to further barriers to psychosocial wellbeing. They are also more likely to have more complex health conditions combined with hearing loss such as dementia, vision loss and physical impairments, requiring a program that can provide specialist care and support.

The hearing needs of people in aged care facilities should be managed through the Government's Community Service Obligation program. This would be a meaningful action in addressing the findings of the recent Royal Commission into Aged Care.

Two Professions. One Association.

While distinct, the professions of audiology and speech-language pathology are also integrally connected - and they're stronger together, under one umbrella.

Despite the differences in the services audiology and speech-language pathology provide, they share a common vision of making effective communication, a human right, accessible and achievable for all.

In her message to members of the American Speech-Language-Hearing Association, outgoing president Tena McNamara says: "This shared vision unites us and guides our efforts to improve the quality of life for people and their families that we serve."

"Having two professions under one association governance has advantages. Resources are combined, allowing for greater outreach in state and national advocacy for policies and funding to advance our professional practice and our patients, clients, and students. Furthermore, students can learn from each other and grow as professionals together, supporting interprofessional practice and collaboration.

United, Yet Unique

Although audiology and speech-language pathology share a general commonality, there are important differences. The types of services and how each profession practices can be strikingly different. Likewise, both involve more than just evaluating and treating communication difficulties. For example, speech-language pathologists are also experts in swallowing disorders, while audiologists may diagnose and care for individuals with balance disorders. Because of these distinctions, it is essential to consider the independent needs of each profession.

My experience at ASHA has shown that although we are one association, ASHA works to meet the unique needs of both professions. The staff and the Board of Directors weigh each issue on how it individually affects audiology and speech-language pathology. The outcomes are sometimes the same and, at other times, different. ASHA also advocates for specialised issues that are exclusive to each profession.

Stronger and Better

I feel incredibly fortunate to have served as your president this year. I have learned so much and have grown as a person in so many ways. One of the many things I have learned is that collaboration can be very motivating, and it is always better to work with a diverse group than with a group of people who all have the same ideology. Exposure to different perspectives makes us think more broadly, leading to better problem-solving and improved innovation.

I have also learned that interdisciplinary teams are more flexible, creating an environment where diverse viewpoints contribute to more timely identification and resolution of issues. As part of that learning, I've seen firsthand that having audiology and speech-language pathology together within the American Speech-Language-Hearing Association makes us stronger and better. This unification of two professions improves collaboration, advocacy, and professional development, ultimately benefiting both us as professionals, and the individuals we serve."

Article by Tena McNamara. Teena is a clinician in a private practice paediatric centre and is the coordinator of a cultural and informational hearing centre, in Illinois, U.S.

From an article in AshaWire.

A Unified Future in Australia?

This article raises an intriguing question for the professional bodies in Australia:

Could a unified organisational model be beneficial here as well?

Teana McNamara highlights how, despite their differences, audiology and speech-language pathology are intertwined, sharing a core mission to enhance communication accessibility.

While no formal proposals are on the table, it invites a valuable reflection for members of the relevant Australian bodies.

Thinking outside the box, as McNamara encourages, could open doors to new ways of enhancing service delivery and advocacy in these fields.

It's a perspective worth considering, even as a theoretical exercise, to explore how different structures might serve the evolving needs of both professions more effectively.

Share Your Views

Deafness Forum invites you to tell your story – in confidence - about your experiences receiving care from hearing care providers.

Service providers, your experience and views matter too. We invite you to share your perspective so that we can understand the issues from all perspectives.

There are two surveys.

To share your lived experience as a user of hearing services, please complete our online survey before 30 November 2024.

https://www.surveymonkey.com/r/R8ZX6CV

The survey is designed to find out more about your lived experience and opinion of regulation for audiologists and audiometrists.

The second survey is for people in the profession

https://www.surveymonkey.com/r/RLVWL76

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Improving Hearing Health for Aboriginal and Torres Strait Islander Peoples

Living in remote areas of Australia predisposes Indigenous children to ear health issues, notably middle ear infections like otitis media, which are alarmingly prevalent. Aboriginal and Torres Strait Islander children suffer from these infections at one of the highest rates globally, particularly affecting those under two.

Persistent ear infections result in a rate of hearing loss approximately five times higher than the broader Australian population. The repercussions of these health issues extend beyond immediate impacts, profoundly affecting educational achievements and social integration and potentially leading to long-term problems such as underemployment and difficulties with the legal system.

The socio-political and behavioural determinants of health, such as housing, access to healthcare, nutrition, and hygiene, play critical roles in these health outcomes. Poor conditions that limit education, awareness of hearing health, and the ability to maintain hygienic environments are significant contributors to ear disease. Issues such as inadequate nutrition, insufficient running water, and exposure to tobacco smoke worsen the risk.

Government and Community Interventions

Recognising these challenges, it is crucial that interventions and strategies are codesigned with Aboriginal communities and led by culturally safe health services. This approach fosters trust and also ensures that interventions are respectful and effective. Health and housing agencies need to collaborate to enhance living conditions that support health, with increased housing stock and reliable access to essential health hardware. This integration is vital in preventing ear diseases and ensuring effective treatment and ongoing support are available.

Health services should prioritise early identification and appropriate medical interventions. In communities with a high risk of otitis media and conductive hearing loss, standard practice should include routine checks of ear and hearing health for all young children visiting clinics.

In the education sector, early detection and support can also play a transformative role. Early years centres and schools in high-risk communities should have systems in place to identify and support children with hearing impairments. This includes training for teachers to accommodate the learning needs of these students and improving classroom acoustics to aid their learning experience.

Role of Aboriginal-Led Media and Organisations

Deafness Forum Australia recognises its role in supporting these initiatives, acknowledging that it does not possess the cultural authority but can contribute by endorsing and promoting programs that embody true and effective partnerships between Aboriginal and Torres Strait Islander peoples and hearing health professionals. These programs must leverage existing successful ear health programs to avoid duplication and maximise resource use.

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Australian Government programs like the Hearing Services Program and its Community Service Obligation component, as well as outreach by not-for-profit organisations, must continue with bipartisan support. These initiatives are crucial in maintaining the momentum for change and ensuring that health services are equitable and effectively managed.

Deafness Forum Australia's contributions

1. Roundtable on First Nations Ear Health.

Back in March, Deafness Forum Australia hosted a national Roundtable meeting with a select group of influential Indigenous stakeholders and key organisations such as the National Aboriginal Community Controlled Health Organisation, Winnunga Nimmityjah (Strong Health) Aboriginal Health and Community Services, and Kalwun Development Corporation QLD.

This collective initiative aimed to address the ear care and hearing health disparities in First Nations communities.

Prof Kelvin Kong AM, an eminent ear, nose, and throat surgeon and ardent social advocate, facilitated the Roundtable in Canberra.

During our Roundtable, Indigenous representatives told us about pivotal healthcare access and delivery aspects, focusing on the challenges. Key actions and ideas emerged. An official communique was created: Meeting Communique – Addressing Aboriginal and Torres Strait Islander Hearing Healthcare MAR-2024

To augment the communique, we prepared a report that aligns the Roundtable outcomes with Closing The Gap Agreement priorities and the Roadmap for Hearing Health: Aligning Strategies with National Priorities – Roundtable Indigenous Hearing Healthcare MAR-2024.

We offer this authentic and authoritative consensus on healthcare access and delivery as a resource for every organisations that operates in this domain.

2. Addressing the hearing health of Aboriginal and Torres Strait Islander Peoples in the criminal justice system.

There is an urgent need to address the high rates of hearing loss among Aboriginal and Torres Strait Islander peoples in contact with the criminal justice system, with rates as high as 80-95% in some communities.

Our justice system remains ineffective in addressing this population's complex needs and vulnerabilities. As well as the enormous economic burden to society and particularly First Nations communities, Australia's commitments under the United Nations Convention on the Rights of Persons with Disabilities are currently being neglected, with Aboriginal and Torres Strait Islander peoples with hearing loss experiencing unlawful discrimination regularly.

Our report, first published in 2022 and updated in 2024, aims to provide evidence of the perpetual cycle that exists between childhood ear disease in Aboriginal and Torres Strait Islander peoples and how it impacts the disproportionally higher rates of incarceration for this population and makes recommendations accordingly.

Read our report, Hearing Health of Aboriginal and Torres Strait Islander Peoples in the criminal justice system APR 2024.

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Auslan Interpreting Service in Primary Care

This video provides a brief summary, in Auslan, of the Australian Governments review of Auslan interpreting service use in primary care. It includes information on the findings and recommendations to improve access to Auslan interpreting services in primary care in Australia.

The report discusses disability policy and services as key mechanisms through which Auslan interpreting services are accessed in primary care. We recognise that deafness is not widely accepted as a disability by the Deaf community, and we respect their identity as a culturally and linguistically diverse group.

Watch the Auslan video and read the transcript.

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Let us know at hello@deafnessforum.org.au

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Cover photo by Tom Williamson.