

29 September 2021



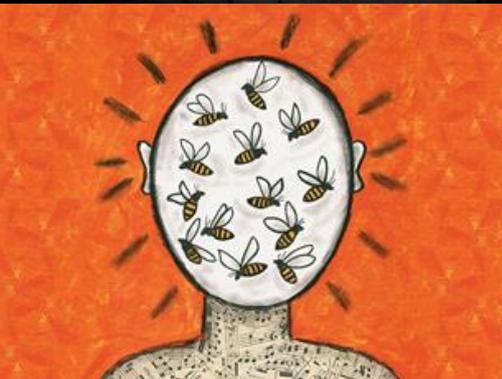
Deaf twins challenging stereotypes

When we started studying fashion, we were suddenly thrown into the hearing world. We felt people often looked down on us because they didn't have any awareness of what deafness meant, and that really affected our confidence.



Screening for leading infectious cause of infant hearing loss

Research led by the Murdoch Children's Research Institute could pave the way for testing of congenital cytomegalovirus (cCMV) to be added to infant hearing screening programs across Australia.



Explainer: proposed changes to NDIS

There appear to be a number of good aspects to the changes being proposed to the law that governs the National Disability Insurance Agency. But there are four significant changes which participants and advocates should consider in more detail.



Tinnitus

If we are in a silent enough environment and we are really listening hard, we will all hear something, some sort of sound that the body makes. A small proportion of people find that very difficult and they can become quite distressed by it.

Locked out of education support funding

Emily is a student with hearing loss and an auditory processing disorder. The grade seven student needs minor classroom adjustments to help her with her learning, but confusion around a new disability funding model means she is not receiving the support she needs.

Currently **one in six** Australians suffer from some form of hearing loss. This may increase to one in four by 2050. *Access Economics 2006*

Deafness Forum of Australia is the peak national body representing the views and interests of all Australians who live with hearing loss, people who have an ear or balance disorders, and the families that support them. Our mission is to make hearing health & wellbeing a national priority in Australia.

Two women are changing the perceptions around deafness

"We see being deaf as an advantage" by [Alex Davies](#) for [Australian Women's Health](#)



Hermon and Heroda are content creators and disability advocates [via their blog](#) and [Instagram](#). The deaf twins are all about fierce fashion, clearing up stereotypes and changing perceptions.

"When we started studying fashion, we were suddenly thrown into the hearing world. We felt people often looked down on us because they didn't have any awareness of what deafness meant, and that really affected our confidence. But, the doubters gave us determination to fulfil our dreams.

"Being deaf is not the problem; it's the perception and barriers we face every day that are the problem. We want to encourage all women to gain confidence and learn that anything is possible. We also want to promote awareness and highlight discrimination, especially ableism and audism.

"We see being deaf as an advantage. With our hearing diminished, our other senses become heightened, so our touch, taste and vision can appreciate aspects that a hearing person maybe wouldn't. There are lots of misconceptions, like deaf people can't do the same things as hearing people. Yes, they can! They can drive, dance, appreciate music. They can do everything except hear; that's it.

"It's very important to celebrate disability because knowledge is power. Education and awareness are key to making our society more accessible for all. There are 466 million people in the world who are deaf or hard of hearing. It's so important to educate about the communication issues they struggle with every day... and improve their lives by removing those barriers.

"Be aware, always ask, unlearn stereotypes, use your privilege and be an ally. Respect the experiences of people with disabilities and hire or promote them. Consider how your words or actions can affect others. Show compassion and understanding. With encouragement, people of any identity or community will excel."

Saliva test to screen for leading infectious cause of infant hearing loss

By [Emily Henderson, B.Sc.](#)



A saliva test taken by parents to screen for the leading infectious cause of hearing loss in babies was feasible and well-received, according to a new study.

The research led by the Murdoch Children's Research Institute (MCRI) and published in the Journal of Paediatrics and Child Health, could pave the way for testing of congenital cytomegalovirus (cCMV) to be added to infant hearing screening programs across Australia.

cCMV can be harmless, but in some babies it leads to hearing loss and neurodevelopmental disorders such as cerebral palsy or vision loss. About 1 in every 200 babies is born with cCMV.

MCRI researcher Emma Webb said this was the first study to show that saliva swabs taken by parents to check for cCMV in their babies was achievable and acceptable to Australian families, even when the swabs were taken at home after discharge from hospital.

The study involved 96 families across four maternity hospitals in Melbourne whose babies did not pass their second Victorian Infant Hearing Screening Program (VIHSP) tests. Accurate diagnosis of cCMV requires a saliva test from an infant in the first 21 days after birth, with antiviral treatment recommended, if clinically indicated, within the first month of life.

During the study, 26 per cent of parents did the saliva test at home, 60 per cent at the hospital and 10 per cent as outpatients. The research found a high uptake by parents with 76 per cent agreeing to do the screen and 100 per cent of infant saliva swabs taken within the required timeframe. One baby was found to have cCMV and was immediately treated. The findings also showed more than 90 per cent of parents thought the screening was easy to do, was a good idea, and were glad their baby had the test.

Ms Webb said CMV was present in 80 per cent of Australian adults and while it's mostly harmless, it could affect a developing fetus.

"Once a person becomes infected, the virus remains present but usually dormant for life. Infection or reactivation can occur during pregnancy, with the small risk that the unborn baby may contract the virus."

International guidelines recommend targeted cCMV screening of newborns who do not pass their hearing checks.

MCRI Associate Professor Valerie Sung said because cCMV was not routinely screened for in Australia, detecting affected infants in time to offer potential antiviral treatment was less likely.

"Given this test allows for an early and accurate cCMV diagnosis, could reduce unnecessary parental guilt, and help prevent lifelong disabilities it should be rolled out nation-wide through newborn hearing screening programs," she said.

Associate Professor Sung said timely screening for cCMV became more difficult after women and babies were discharged.

"Early discharge, as we're seeing more now of during COVID-19, can be a big problem because it means we might miss cases of cCMV," she said. "But our study has shown parents can do the swab themselves even at home after leaving the hospital."

Associate Professor Sung said training of hearing screeners, midwives and nurses to complete swabs in hospital would likely reduce false positive rates and further improve the uptake and turnaround time for results.



Victoria Cottrell, whose son Teddy was the only one to test positive for cCMV in the trial, said the test was quick and simple and taking part was the best decision she had ever made.

"I had never heard of cCMV before and thought the cause of the hearing loss most likely was genetic," she said. "During my pregnancy check-ups many infant conditions and foods to steer clear from were mentioned but cCMV was never talked about. The diagnosis came as a shock and was a lot for our family to process."

Profoundly deaf, Teddy, now aged 2 and wears cochlear implants, underwent six months of antiviral treatments and currently has physiotherapy to help with walking.

"If his cCMV diagnosis wasn't picked up so soon he would be further behind in his gross motor skills. Having the awareness early we have received support quickly and our specialists have been on top everything. If the trial hadn't happened, we would never have known Teddy had cCMV," she said. "I'm just so thankful and relieved that this trial existed to get the best outcomes for Teddy."

From [News Medical Life Sciences](#)

Hearing Services Program

The Australian Government is considering a suite of recommendations about important changes to its Hearing Services Program (HSP).

The HSP affects 100,000 of our constituents. The HSP aims to reduce the impact of hearing loss by providing free hearing devices and rehabilitation services to groups of people who are vulnerable and in need of assistance.

A review of the HSP has been done by an Expert Panel. This Expert Panel wrote a report that was recently presented to the federal minister responsible for hearing, Dr David Gillespie MP.

But the report had not been made available publicly so that we and others could examine it.

However, the Health Department told Deafness Forum this week that the Report would be made public on Thursday 30 September. The Report will be available on the Health Department website, but you can contact Deafness Forum and we can send you a copy.

Its release is good timing because Deafness Forum and its advisers will meet on Friday with the Minister responsible for Hearing, Dr David Gillespie. Our advisers are the Deafness Council Western Australia, Hearing Matters Australia, Parents of Deaf Children, UsherKids Australia, Hear For You, and Aussie Deaf Kids.

It is this coalition of advocates that successfully persuaded the Government to halt plans to sell the tax-payer owned Hearing Australia to private interests. Later, it created the Hearing Stream adopted by the National Disability Insurance Scheme; and was instrumental in delaying a rush to transfer some clients of the Hearing Services Program to the NDIS when the system and providers were not ready for such a change.

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Research at Macquarie University



The Department of Health has committed to continuing support for the ongoing Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) for the next five years. The [LOCHI project](#) is a population-based longitudinal study that prospectively evaluates the development of a group of Australian children with hearing loss as they grow up.

Director of National Acoustics Laboratories (also known as NAL), Brent Edwards said the additional financial support will help to fund the creation of a longitudinal study on the impact of otitis media on Aboriginal and Torres Strait Islander children: the beginning of a First Nations LOCHI study.

“This strong commitment demonstrates the value that LOCHI insights bring to paediatric hearing health care policy. NAL looks forward to continuing to improve the lives of children with hearing loss in Australia and around the world with insights from its LOCHI program.”



Professor David McAlpine, the Academic Director for Macquarie University Hearing, has been awarded a prestigious [Einstein Fellowship](#), worth €450,000 over three years.

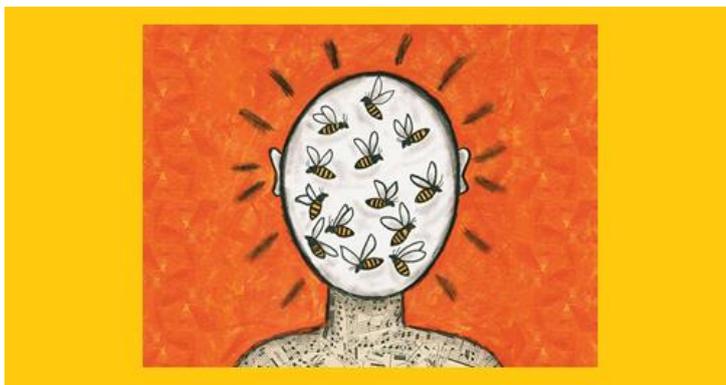
The project entitled ‘Listen and learn - subcortical-cortical interactions in the emergence of statistical learning’ will explore how auditory memories are formed in the listening brain.

Professor Catherine McMahon and her team have been selected as Highly Commended finalists in the Macquarie University 2021 Research Excellence Awards.

Dr Kylie Gwynne (Dept of Health Systems and Populations), Dr Leanne Holt (Pro Vice – Chancellor, Indigenous Strategy) and Professor Liz Pelicano (Macquarie School of Education), together with Professor Catherine McMahon (Head, Dept of Linguistics, and Director of HEAR Centre) have been Highly Commended due their body of research into improving hearing health for Aboriginal children with otitis media.

From the [Australian Hearing Hub newsletter](#)





What causes tinnitus and what can be done about it?

By Tegan Taylor reporting for ABC Health Report with Dr Norman Swan

Tegan Taylor: What is tinnitus, what causes it, and why are so many people living with this noise in their heads told there's nothing that can be done to help it? About seven years ago, something weird started happening in Victoria Didenko's head.

Victoria Didenko: I don't listen to loud music, I'm very sensitive to sound. I did have a fall with my dog, when I think back, it could be a head and neck injury, it could be all of the above or none of the above. A ringing in my years, a buzz in my head. It was just this noise, like a static noise, a whistling kettle, and it actually hurt. And it just seemed to really intensify as the days went on.

Tegan: It's a symptom which occurs in most people, but for a chunk of the population it can cause problems. Myriam Westcott, an audiologist who specialises in treating tinnitus.

Myriam Westcott: If we are in a silent enough environment and we are really listening hard, we will all hear something, some sort of sound that the body makes, and about 15% to 20% of people will become aware or will report constant tinnitus, so it's pretty common. Most people who develop tinnitus will over time, if not straight away, habituate to it. A smaller proportion of people do find that very difficult and they can become quite distressed by it.

Tegan: Victoria Didenko was one of the people who found the phantom sounds very distressing.

Victoria Didenko: I just segued into panic attacks, depression. The sound was in my head, I couldn't get away from it. I was despairing, I went to the doctor for help, and they couldn't offer it and they said I would cope in time. But I was not told how to cope.

Tegan: Tinnitus is challenging to treat, but it is treatable, despite what many people are told by medical professionals when they start seeking help. But what is tinnitus exactly? When you are hearing sound normally, your middle ear picks up sound waves and your inner ear turns these into electrical impulses that are translated by your brain. But damage to your ears or the neurons involved in hearing can change the way your body processes sound.

Tinnitus is usually associated with hearing loss, partly because your brain is a statistical machine. In the interests of efficiency, along with translating sounds it's receiving, your brain is sometimes also predicting what it thinks it is going to hear. This is normally useful but can become a problem when you have a change to your hearing. Here's Dirk de Ridder, a tinnitus researcher from the University of Otago.

Dirk de Ridder: My brain predicts these frequencies should arrive, and because they do not arrive, the brain says 'well, better safe than sorry', and therefore it will generate the sound itself, pulling that sound from memory based on what it expects to hear, and that is the tinnitus that we hear.

Tegan: Rarely, tinnitus can be a symptom of another medical problem, especially if it's just in one year or it has a pulsing quality. For example, Meniere's disease where people have hearing loss that fluctuates, can also produce fluctuating tinnitus. There are even some medications that can cause it, although this is rare.

About half the people who seek help for tinnitus develop hyperacusis or reduced tolerance to noise. Around the same proportion can develop something called tonic tensor tympani syndrome or TTTS, where a tiny muscle in the ear called the tensor tympani goes into spasm.

A key difficulty with hyperacusis, TTTS and tinnitus more generally is that they are exacerbated by anxiety, which hasn't exactly been in short supply this past year and a half.

Myriam Westcott: Since the pandemic, the numbers seeking help from us have just about trebled. If the part of the brain that is responsible for dealing with fear and threat is all stirred up, then something like tinnitus can become perceived as more sinister.

People tend to monitor their tinnitus a great deal, and we try and discourage that, monitoring it will keep it prominent and will reinforce to the subconscious brain that it's an important sound. If the tinnitus is going to be there, we want the subconscious brain to evaluate it as an unimportant sound.

Tegan: Part of the reason people with tinnitus are often told there's not much that can be done to help them is because that was true as little as a decade or two ago.

Dirk de Ridder trained as a neurosurgeon and has been chipping away at the tinnitus puzzle for some 20 years.

Dirk de Ridder: Every time we think, 'well, we've solved it' and when we then try to apply that in research and in the clinic, we unfortunately see that that does not work. It works for about 20%, 30% of the patients but not to everybody. We are certainly getting closer. If not, I don't think anybody would still be doing research if we would just have the feeling that we got further away.

Tegan: His most recent work is looking at disrupting tinnitus with a combination of electrical stimulation and psychedelic drugs like ketamine. It sounds full-on, but it's actually like treatments for people with post-traumatic stress disorder, and it's working on similar principles.

Dirk de Ridder: Oh, I hope that I have always been a very optimistic person, and in 10 to 15 years we will be able to treat at least 80% to 90% of people with tinnitus with one of the techniques that have been developed, whether it's by us or by somebody else, it doesn't matter.

Tegan: As for Victoria Didenko, it hasn't taken fancy tech. Working with a tinnitus counsellor, she has reached a place where she is now able to live with her tinnitus.

Victoria Didenko: So, I can still hear it but it's not triggering those panic attacks, the anxiety, and I'm not going into a depressed state with it. I accept it, it's there, I'm living with it, I'm embracing it. But gosh, it took a long time to get there, too long.

Listen to, and read a transcript of the full interview at [Radio National](#)

Week to celebrate Deaf people



Posted to [Disability Support Guide](#)

The International Week of Deaf People and the Day of Sign Languages happened in September.

“Traditionally, we take this opportunity to promote awareness of Deaf people and our communities through a social and rights-based model as an opportunity to get the wider hearing community to see us, our community, language and culture as something to be celebrated and not as a medical or charity-oriented disability group,” said Deaf Australia’s Jen Blyth.

For people who are Deaf, Deafblind or hard of hearing, Jen Blyth said the Week is “no different to Latin music festivals or Chinese New Year” and gives them an opportunity to “go home” to their community by being involved in celebrating and sharing experiences together.

The week began with the online [Flow Festival](#) of Auslan storytelling, Deaf Slam Poetry, dance, theatre, short films, children’s art activities, workshops, artist talks, Deaf Indigenous storytelling and art workshops, Queer Arts and Deafblind Arts.

“Hearing people or deaf, deafblind and hard of hearing people are invited to learn and celebrate with us. Most of all, listen to us when we celebrate our language, community and culture. We are a very proud bunch.”

The International Day of Sign Languages is also important to integrate into the week of celebrations: Auslan (Australian Sign Language) is an integral part of culture.

“Auslan is at the very heart of our community and culture; and is a unifying characteristic. We identify more as a Cultural and Linguistically Diverse (CALD) group than a disability cohort.

“When you are Deaf, you see the world in a different way. You communicate differently. You seek out others who are Deaf because they understand you.

“You don’t believe you have a disability and you don’t want to be fixed.”

Deafness Forum of Australia acknowledged the contributions of Deaf community leaders past, present, and emerging.

Chair David Brady said, “Let’s give special recognition to the people who go about their advocacy in a selfless and meaningful way in their everyday lives. They don’t get publicity but they are heroes in our community.”

What are the Government's planned changes to the NDIS?

The Government recently released details on its proposed changes to the National Disability Insurance Agency Act (the law that governs the NDIS).

An analysis of some of the major changes was prepared by the [Public Interest Advocacy Centre](#). This article is an edited summary of the complete article.

Positive changes

There appear to be a number of good aspects to the changes being proposed.

As promised, the Government has abandoned proposed changes relating to independent assessments.

There are no changes to 'reasonable and necessary supports'.

There are no new debt recovery powers.

Future changes to the NDIS assessments and funding model will be co-designed with disability representatives.

There are a number of changes that should improve how the system works. These include:

- inserting timeframes around access, participant plans and internal reviews.
- annual reporting by the Commonwealth Ombudsman to review the NDIA's performance against the Participant Service Guarantee (a promise of service standards to participants).
- clarifying the language around the different types of 'reviews' which was causing confusion.
- fixing the Administrative Appeals Tribunal's jurisdiction when it comes to reviewing plans which have been varied or replaced by new plans over the course of the appeal.
- improvements to the NDIS principles, including adding co-design with people with disability.

Concerns and areas for improvement

There are four significant changes which participants and advocates should consider in more detail. Some of these changes were not mentioned in the Tune Review, while others have adopted approaches which we think do not directly implement the Tune recommendations.

1. Plan variation without consultation

A proposed change would allow participant plans to be varied without a 'reassessment'. This may be a positive change in as far as it allows plans to be amended or fixed where the amendments are not significant and when requested by the participant. However, it also allows plans to be varied on the CEO's own initiative, without request, consultation, or consent from the participant.

2. Changes to the 'Becoming a Participant' Rules

Changes to the Becoming a Participant Rules include new requirements for determining whether a person has a 'permanent' impairment or 'substantially reduced functional capacity' for the purposes of accessing the NDIS.

3. Changes to Plan Management and Payment of Supports

The change to plan management essentially imposes a risk management process for participants who request to have their funding plan managed.

There are also proposed changes to the way in which supports are paid by the NDIA, intended to make it easier for self-managing participants to

make claims, by using a 'tap and go' system on a smartphone app with their service provider, rather than paying out of pocket first and seeking a reimbursement. Some people may be concerned by the inability for self-managed participants to opt out of this system and pay for their own supports first, or to mix-and-match their preferred payment method.

4. Reasons for decisions

Proposed changes would allow participants to request reasons for decisions made by the NDIA, prior to any internal review application. This is a welcome change, as it can empower individuals to understand decisions made about them at the initial stage – for example, initial decisions about access or participant plans.

However, the provision of reasons should be given automatically, as a matter of course, for all participants when a decision is made about them.

Missed opportunities

There is a missed opportunity to fix a technical issue currently clogging up the Administrative Appeals Tribunal. The issue concerns the AAT's jurisdiction to consider additional supports requested by the applicant during the AAT process, but which were not initially raised at the internal review stage. It ties up everyone involved in costly jurisdictional disputes that leave participants worse off.

There is also a missed opportunity to simplify the NDIS framework. While attempts have been made to improve some of the rules, the NDIS framework remains extremely complex, and this package of changes only adds to the complexity, with new rules and principles in disparate locations.

While the use of rules allows more flexibility and responsiveness as changes are required, it also gives the Minister and the NDIA more capacity to define and redefine the scope of its own power.

Participating in the consultation

Participants and advocates may tell the Government how these changes impact you. The deadline for submissions is 7 October 2021, and details on making a submission are [here](#).

Deafness Forum and other peak groups had asked the Minister who is responsible for the NDIS to allow more time for this current public consultation.

The Minister, Linda Reynolds said in response that there was a window of opportunity to pass legislation in 2021, "...an opportunity we may not get for some time if we wait any longer."

Linda Reynolds said, "I believe the Bill proposes changes that will improve the Scheme for participants, and so I am keen, subject to the outcomes of the current consultations, to see it progress to become law this year. To ensure all submissions are given thorough consideration, while also allowing for the necessary documents to be prepared for the parliamentary process, an extension to this latest round of consultation is not possible."

Translating and Interpreting - Case for Change

The Government plans to update the Diploma and Advanced Diploma qualifications in Translating and Interpreting.

The Diploma and the Advanced Diploma of Translating and Interpreting are fundamental qualifications used to ensure professionals are equipped with the right skills and knowledge to gain accreditation.

A number of key changes relating to workforce demand and the operating environment have meant that the training package products need to be urgently updated:

- Filling the current training gap in interpreting and translating to meet NAATI's minimum training requirement
 - NAATI is the national standards and certifying authority for translators and interpreters in Australia.
- Shortage of qualified trainers for low-volume languages
- Difficulties in recruitment mainly due to the short-term nature of casualised employment
- Current requirements of training package products being exclusionary of Deaf interpreter and Auslan/English interpreter students

The Case for Change is now available for public consultation until 8 October.

Please [click here](#) to visit the Project Page and to download a copy of the Case for Change. You will also find details of how to provide your feedback on the Case for Change on the Project Page.

For further information, please contact Devika Mudaliar at devika.mudaliar@skillsiq.com.au



Person who is deaf, or Deaf person? Research by Charles Sturt and Monash universities.

Should you be addressed as a person who is deaf or a deaf person? Do you think this varies depending on who is addressing you: friend, professional, media? Have your say! Tell us the most respectful way to refer to your health condition or disability.

[Click on this link](#) to complete a 15 minute survey.

Tasmanian families feel locked out of state's new model for educational support funding

By [Piia Wirsu](#) for [ABC News](#). Photos by ABC News: Craig Heerey



Emily is not getting a fair go as a student with hearing loss and an auditory processing disorder. The grade seven student from Tasmania's midlands needs minor classroom adjustments to help her with her learning, but confusion around a new disability funding model means she is not receiving the support she needs.

Her mother, Heather says Emily needs clear and concise communication that is preferably written, as her daughter struggles to hear in a classroom, but those basic adjustments are not being made.

When the Tasmanian government changed how it allocated disability funding and support to schools last year, Ms Harvey hoped her battle might be over.

"All I get out of them [the schools] is 'Oh, you're quite on the ball Heather, you can deal with Emily's needs. We'll get you to help us', but I can't help any more," she said.

The new Educational Adjustments Funding Model was designed to make support more equitable and accessible, but some parents and advocates query its effectiveness. Under the new model, funding is allocated based on a learning plan for individual children, which is meant to be a collaboration between parents and schools. But Ms Harvey said she had not had input into her daughter's learning plan.

"Where's the learning plan? Where's the funding?" she said. "Where is the government putting all this money into helping children? Emily's on the minor scale of it all, but there's children out there with major issues ... they can't even help with minor issues."

Ms Harvey worries about Emily's future.

"If anything happens to me and her father she's got to be able to fall on her feet, so she needs an education," she said.

Kristen Desmond, founder of the Tasmanian Disability Education Reform Lobby, said the system was not working as it should to support teachers and students and that the new funding model was being undermined.

"It's a system problem because [teachers] are not getting the right professional development, they don't have the right skills, or their workload is so high," Ms Desmond said.

She has concerns about its implementation and says Ms Harvey's experience is not isolated.



Kristen Desmond said some families are locked out of support because they don't have a formal diagnosis

"We've got too many parents going, 'My child doesn't get funding', when in reality they are but they just don't know how it's being spent," Ms Desmond said. "What we're seeing is often it's the school who is writing [the learning plan], a parent might get it emailed to them but they're not getting any real input."

Ms Desmond said some families were locked out of support because they did not have a formal diagnosis, which was often delayed due to a lack of diagnosing specialists.

"The department is telling us that they don't require a diagnosis, but schools are telling families that they do," she said. "We've got a whole cohort of kids out there who are waiting for a diagnosis who need adjustments now."

The state government says there are an additional 2,000 children receiving support under the new model, but Ms Desmond is concerned there are still another 2,000 who have not been able to get the help they need.

The government is planning to conduct an independent review, but not until at least 2023, saying the new model needs time to be bedded down. Ms Desmond said that meant any issues identified by a review would not be implemented until 2024–25.

"We need to understand that there is a delay [to changes being implemented], so any delay in review means it's just kicked down the road for another year and we can't afford to keep kicking it down the road," she said.

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

Drop us a line: hello@deafnessforum.org.au



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We acknowledge the traditional owners of country throughout Australia and their continuing connection to land, sea and community: we pay respect to them and their cultures, to elders past, present and future.

We want to be part of the effort to overcome the unacceptably high levels of ear health issues among First Nation people; and we understand that it is an essential component of Closing the Gap. We understand the risk to indigenous sign languages and the cultural loss it would cause.

We use Deaf (with a capital "D") to talk about culturally Deaf people, who were typically born deaf, and use a signed language, such as Auslan as their first or preferred language. In contrast, deaf (lowercase "d") refers to the condition of deafness.

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