



NDIS update

Two important articles about the National Disability insurance Scheme.

The first is about a new report that gives insights into the experiences of NDIS participants with hearing impairment, visual impairment or other sensory/speech impairment.

The second article explains the changes planned for the NDIS that have enraged advocates.

News from Deafness Forum

Read about:

- our submission in response to a raft of recommended changes to the Government's Hearing Services Program
- a Tinnitus research project with Macquarie University
- a survey in partnership with our opposite number in the United States of people living with hearing loss and their care-givers

You want the child to understand the world

Many deaf children experience an "illusion of inclusion": they may be in a classroom with other students but they're not accessing what other children are accessing because of a lack of communication skills. They don't fit in anywhere.

Census 2021

For the first time, a question will be asked about whether Auslan is a language used in your home.

You want the child to understand the world

Macquarie University linguistics lecturer Della Goswell — an Auslan/English interpreter and educator — believes that the lack of access to a first language for some deaf children had created "a generation of deaf adults who are frustrated and angry they didn't get the education and socialisation they deserved from the start".

She said many deaf children experience an "illusion of inclusion": they may be in a classroom with other students but they're not accessing what other children are accessing because of a lack of communication skills.

"If your hearing is good enough with cochlear implants and you can keep up with the class that's one thing, but the deaf kids who don't have enough hearing to do that or have unsuccessful implants are in a little world of their own without access to what's going on. They don't fit in anywhere."



"Deaf adults who are language deprived can have huge holes in their world knowledge and relational skills. Mental health is a significant issue for deaf people because of the struggle to be understood and to belong somewhere. Solitary confinement is what I've heard some deaf people call what they have gone through."

Chelle Destefano was born profoundly deaf. She was given a cochlear implant aged 13 and said she was led to believe she would be able to hear clearly, but it never happened.

Ms Destafano can only make out different sounds like birds, cars or a phone ringing, but individual words are extremely difficult to decipher.



She learnt Auslan when she was 14 with the help of friends, but she said there were gaps in her knowledge of the language because she missed out on learning it from a young age.

"When I first learnt, I felt excited, amazed, freeing, and felt like I belonged somewhat. It got me in touch with the deaf community, but that took years," she said.

Months of not seeing the grandchildren are coming to an end

Gael Hannan writes for [Hearing Health Matters](#)

There were guidelines on physical interaction to be followed, but at least we were going to be with them. And talk with them!

Umm, that last activity actually works best if you're a *hearing* person, like a Hearing Grandad, but not so well if you're my kind of grandmother – one with hearing loss and tinnitus and sensitivity to noise, a bit of an acoustic mess.

I cope well with my communication challenges, but one nut I haven't been able to crack is understanding little people and their small voices. Specifically, I'm talking about the ones I care most about, the grandchildren. If I can't understand some random child, I just smile and nod at them and then move on or hope that they shift their attention elsewhere.

Grandchildren are the best reward of having children in the first place – especially adorable when they're small and oozing with love and energy. The downside is that this energy keeps them moving in all directions at once, with an accompanying narrative that I can *see* and *hear* them making but can't understand what most of it *means*.

The only way that is going to happen is if they can be persuaded to stand still, face me, and clearly repeat themselves. The problem? Small children aren't yet wired for the clear communication that people with hearing loss need. They squirm and don't maintain eye contact. And if they're asked to repeat themselves, they may not want to, thinking they may have done something wrong, or because the discussion has simply lost interest for them.

This weekend, we spent some blissful time with Madison, 4-almost-5 years old, and Grayson, just-turned-3. Madison is a kinetic being, so her face is hard to keep in my frame of view, making speechreading a challenge. Grayson is a sturdy little Mack truck, also in constant motion, but he has a voice like a small foghorn and his sentences are short and digestible, whereas Madison has a stream-of-consciousness style of communication.



Because we haven't been able to see each other much during the pandemic, I needed to reacquaint myself with their speech patterns and they had to become more comfortable again with my hearing loss. Because I'm their Gigi and not their mom, good communication with me is less important to them, but when my son was their age, it was crucial that we understood each other. Luckily for both of us, Joel had a strong voice and clear speaking style, due in large part, I think, to my hearing loss. He learned early that to get what he wanted, he needed my attention and to speak with me eyeball to eyeball.

So, how *do* we hear those high kiddie voices? Well, any which way we can – and good luck to you. With the grandkids, my constant fallback strategy is to turn to a parent and ask, "What did she say?" This is an accepted part of our communication playlist. Also helpful has been my cochlear implant which has given me more of the sibilant sounds of child-speech – I can hear 'Gigi' being called from a distance, although they still need to come to me, or I to them, if I want to understand the words that follow.

In time it will get easier; the children will feel more comfortable with you, especially after you explain what that weird looking technology is in your ear or on the side of your head. You just have to *train* them, like you teach kids to do anything, from sharing their toys to using the potty. They will learn to get your attention, face you when speaking, speak as clearly as possible, speak up if necessary, and repeat themselves upon request. But don't forget to ask for all this with a smile; that hearing loss frown of concentration can be pretty scary to a small child.

The payoff – hugs, smiles and the delicious things they say – is huge. And as for how to hear *other* people's kids, it's hit and miss. A smile may be your best offering.

Photo: Grayson on a rock trying to tell Gigi something. I joined him on the rock and asked him what he was saying. He pointed to some tiny crabs.



Miss a hearing? You can watch them on the Royal Commission [website](#). Go to the Public hearing page, look under **Documents**, then click on **Video/Auslan**. Each video has captions and Auslan interpreters.





Dear members & friends,

The Australian Government is taking a close look at its **Hearing Services Program** (HSP).

This is important because the HSP affects 100,000 of our constituents. The HSP has been around for decades - it 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.

This review has resulted in a report that sets out recommendations for potential changes to the HSP.

Deafness Forum worked with its member organisations with authority on the topic to write a response on behalf of consumers to the Government's recommended changes. These members were the UsherKids Australia, Deafness Council Western Australia, Hearing Matters Australia, Parents of Deaf Children, Hear For You, and Aussie Deaf Kids.

What do we think about the recommended changes to the HSP?

There are some positive changes recommended.

But there were missed opportunities in the recommendations to improve the lives of residents in aged care facilities, people living on low incomes, and people in the criminal justice system.

We do not support the recommendation to remove eligible adults with complex hearing needs from the Community Service Obligation Program. Removing this safety net would create an unacceptable risk that the most vulnerable people could fall through the gaps and not receive the services and supports they need.

The need for hearing services for children who are long term temporary residents or refugees has not been addressed in the recommendations.

There's more to say and you can read about our opinions in the submission that we made to the Government. [Click this link](#) to open the document.

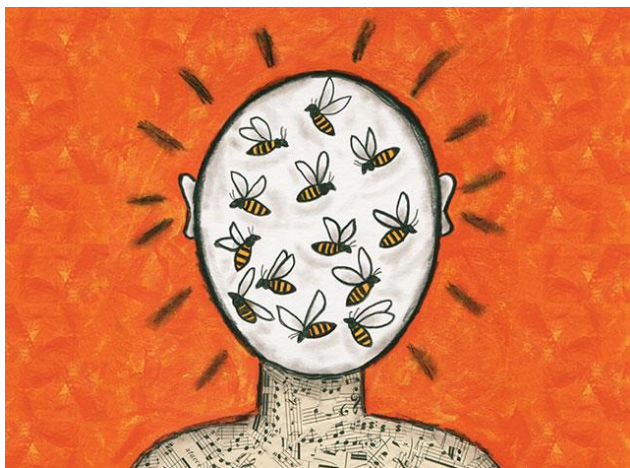
To our member organisations, it would be v helpful if you could promote the consumer perspective explained in this document via your channels. If you would like me to write a short version for your social media/website/newsletter, you have only to ask.

Best wishes

Steve

Steve Williamson
Chief Executive
DEAFNESS FORUM of AUSTRALIA

Representing Australia's consumers in the World Hearing Forum, a program of the World Health Organization



Researchers at Sydney's Macquarie University have partnered with Deafness Forum of Australia for a new study into Tinnitus

Tinnitus is very common throughout the world. It causes people to hear constant sounds in one ear, both ears or in their head. It can cause stress and anxiety.

Helen Bishop and John Newall from Macquarie University are investigating tinnitus smartphone applications: Tinnibot and Woebot as part of Helen's master thesis.

If you are in Australia (sorry to our overseas readers) and suffer from tinnitus or know anyone that could fit that description, please take the survey to participate here - <https://lnkd.in/gmEw8bZ>



Deafness Forum Australia is assisting its opposite number in the United States with a survey of people living with hearing loss and their care givers. The information from our Australian survey will contribute to information gathered from throughout the world to help improve advice to governments both here in Australia and overseas. We are asking you 4 questions:

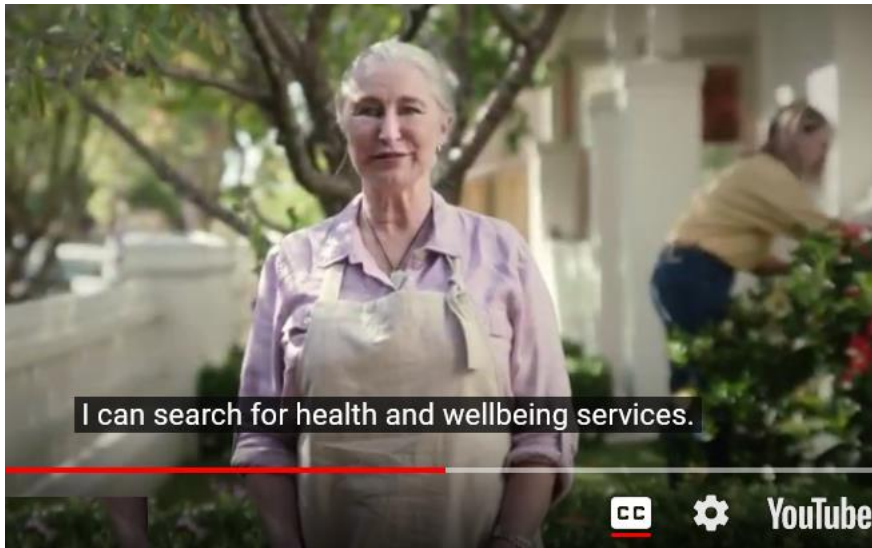
1. Of all the things that you experience (or your loved one experiences) because of hearing loss, what are the 1-3 things that have the most significant impact on quality of life?
2. How do these things impact specific activities that are important to you?
3. What are you doing (or what is your loved one doing) to help address hearing loss, and how well is this working?
4. What are the downsides to the way you are addressing it?

We will also ask you a little about yourself: whether you are a person living with hearing loss, someone who cares for a person with hearing loss, or both.

[Follow this link to take the survey](https://lnkd.in/gmEw8bZ)

Disability Gateway

The Disability Gateway is an Australian Government initiative. It is for all people with disability, their families and carers to help them find information and services.



Watch the [TV advertisement](#) and [read about](#) the Disability Gateway Service.

Census to ask about Auslan

Australia's next national Census will be held on Tuesday 10 August.

The Census is a snapshot of who we are and tells the story of how we are changing. The Census provides data on important topics such as populations, rents, mortgages, incomes, religion, languages, housing and more. It helps governments, businesses, researchers, not for profit and community organisations make informed decisions about transport, schools, health care, infrastructure and business. It helps plan local services for individuals, families and communities.

For the first time, a question will be asked about whether Auslan is a language used in your home.

See this [video in Auslan](#) for more information.



NDIS: new report on people with communication difficulties

The National Disability Insurance Scheme (NDIS) provides funding to people with a permanent and significant disability to access the supports and services they need.

A new report released by the NDIS ([download it here](#)) provides insights into the experiences of NDIS participants with hearing impairment, visual impairment or other sensory/speech impairment. The report is divided into four sections and covers participant characteristics, participant experience of the NDIS, plan supports and payments for supports, as well as participant goals, outcomes and satisfaction. Some key findings:

- At 31 March 2021, there were 450,000 active NDIS participants with an approved plan. Of these 33,500 had a primary sensory disability:
 - 21,700 (4.8%) had a primary disability of hearing impairment
 - 8,897 (2.0%) had a primary disability of visual impairment
 - 2,903 (0.6%) had a primary disability of other sensory/speech impairment.
- A higher proportion of people who apply to the NDIS with hearing impairment or visual impairment meet the access criteria compared to individuals with other disabilities. The opposite is true for people with other sensory/speech impairment, with a significantly lower amount of these people meeting the NDIS access criteria.

What changes to look out for in the NDIS Amendment Bill

You may have read or heard that disability advocates throughout Australia are engaged in a battle with the NDIS over changes that are being proposed this month.

Some advocates say that the changes, if they go ahead will fundamentally alter the original intent of the NDIS to provide necessary and reasonable supports for people with permanent and significant disability.

This article by the Public Interest Advocacy Centre provides One in Six readers with a straightforward and complete summary of the main issues that have caused concern.

The Government is proposing reforms to the National Disability Insurance Scheme. These reforms are set to be the most significant changes to the NDIS since it was introduced.

The Public Interest Advocacy Centre (PIAC) has written about its concerns [here](#). Its detailed submission to the Parliamentary Joint Standing Committee on the NDIS' inquiry into independent assessments is available [here](#).

The Minister for the NDIS has indicated that Disability Ministers from the Commonwealth, States and Territories will meet this month to discuss the proposed reforms. We anticipate a draft of the Amendment Bill to be published in the weeks following that meeting.

This article by the Public Interest Advocacy Centre sets out five key issues to be on the lookout for when the draft is released. It is prepared based on public statements made by the Minister for the NDIS and the NDIA CEO, and the draft amendments which were leaked in March 2021.

1. Introduction of mandatory independent assessments

The Minister has made clear that independent assessments will be introduced in some form, and that these assessments will be mandatory for all NDIS participants and new applicants to the Scheme. The question is what form these assessments will take. There are three key things to look for in the draft Bill in relation to independent assessments.

First, does the Bill provide any detail into how independent assessments will work? In the March 2021 draft, the words 'independent assessment' or 'functional assessment' were not used. No details were provided on the use of independent assessments. Instead, very broad wording was used to allow for 'assessment or examination' by a 'person included in a class of persons made known to the prospective participant'. Some details that we would want to be addressed in the Bill include:

- Can participants submit their own evidence, alongside the independent assessment?
- If so, what weight will that evidence be given?
- What is the 'scoring' process to determine level of 'functional capacity'?

The less detail there is in the Bill, the more scope and power the NDIA and Minister have to change the independent assessments process as it is introduced. This would result in less transparency and accountability in the implementation of independent assessments.

Second, when is a person exempted from undertaking an independent assessment? The March 2021 draft did not include a provision for this. Available exemptions should be included in the legislation, otherwise the NDIA will be able to change the exemptions at any time. The legislation should also clearly set out the criteria for receiving an exemption to ensure consistent decisions are made.

Third, are independent assessments and exemption decisions subject to review? The NDIA's initial position was that assessments themselves and exemption decisions would not be reviewable. Only decisions made by the NDIA *based on* the assessments could be reviewed (for instance, decisions about access or plans). This is contrary to what was recommended in the Tune Review. Because independent assessments will be fundamental to ensuring the rights of a person to access and receive funding under the NDIS, it is important that there is a review process available to challenge incorrect or inadequate assessments.

2. Changes to reasonable and necessary supports and 'personalised budgets'

In the March 2021 draft, all reference to 'reasonable and necessary supports' was removed. The Minister has since stated that reasonable and necessary supports will remain, but the method for determining NDIS plans will change. The new method will involve matching participants' independent assessment results to one (or more) of 400 'profiles' built by the NDIA. Each of the profiles will come with a draft budget attached, and funding will be given to the participant based on that budget. In reality, this likely means that the right to reasonable and necessary 'supports' will instead be a right to a reasonable and necessary 'budget'. That is, most participants will be given a single numeric figure for the funding provided to them. This number will be based on their independent assessment and will reflect the expected costs of a participant in similar circumstances – someone with a similar level of functional capacity and environmental context. It will no longer be based on their individual goals and support needs.

By removing the requirement to consider a participant's individual needs, the Bill could allow the NDIA to give greater weight to internal considerations of 'financial sustainability' when it comes to determining the size of the participant's funding, without informing participants about what those financial sustainability considerations are. This will depend on how the Bill is drafted.

This would be a major change to the NDIS. Changes to watch for include:

- Will details about this new process, including the 400 'profiles', be included in the Bill? We anticipate they won't be. Instead, it's likely that the Minister will have the power to make rules about planning. This gives the Minister greater power to change the methodology. This is because rules don't need to be debated and passed in Parliament, unlike legislation. Rules also don't require consultation with people with disability or disability advocates. Allowing the Minister to make rules about key aspects of the NDIS process reduces transparency and accountability and makes it harder to scrutinise how the NDIA makes these decisions.
- Will the Bill specify the weight given to 'financial sustainability' considerations for allocating budgets? Without this detail in the Bill, the NDIA would have greater power to reduce budgets based on their internal assessment of 'sustainability' of the NDIS. This includes, for instance, if future governments decide to reduce the NDIS budget.
- Will there be reference to a participant's 'goals and aspirations' in the new process? The current NDIS Act requires goals and aspirations to be considered in determining reasonable and necessary supports. This is important as goals underlie the participant's social and economic participation – for example, choice and control over what the participant wants to study, or what activities they would like to partake in. The NDIA has not been clear about how the proposed new process will consider goals.
- Is there a process for finalising draft budgets? The NDIA's position on 'draft' personalised budgets appears to have softened recently, from their initial proposal to only allow changes to draft budgets in exceptional circumstances.
- What will 'reasonable and necessary supports' look like? By moving to a 'personalised budget' system, the NDIA says participants will no longer need to request supports on an individual basis and will have more flexibility in deciding what to spend their funds on. If that's so, keeping the criteria for reasonable and necessary supports may actually serve to *limit* This all depends on what purpose 'reasonable and necessary supports' serves in the new law. For example, if a participant is now allocated a budget, but can only use it to buy 'reasonable and necessary supports' after a discussion with their planner, this *adds* a hurdle for participants, limits autonomy and creates uncertainty.
- What are the avenues for review and appeal of a personalised budget? There are two things to look for here. First, has the existing right to review and appeal been changed? The NDIA has said that this will not change, and we expect that to be the case. Second, even if the right has not changed, what level of detail is provided about how personalised budgets are decided under the law? If there is limited or no detail in the Bill, including detail about the scoring process and weight given to the various factors, it makes it very difficult to seek review or appeal of those decisions. This is because if the Bill does not set out how decisions are required to be made, it is hard to challenge the legal correctness of the decision.

3. Power to decide what's in and what's out of the NDIS

Under section 46C of the March 2021 draft amendments, a new power was inserted for the Minister to ban particular goods and services from being funded under the NDIS, without agreement from States and Territories. This power is designed to get around existing Court and Tribunal decisions, about what can be funded on the NDIS. For example, the NDIA has had several legal battles with participants about funding for things like gym memberships, disability-related transports, assistance animals and air conditioners for people living with MS. If this power is included in the Bill, combined with the introduction of 'personalised budgets', this will *limit* choice and control for participants. It means decisions about what may be funded and what people with disability need will be made by the Minister and NDIA public servants, without consideration of individual people.

Similarly, the March 2021 draft proposed tightening the early intervention pathway into the NDIS. The proposed section 25(4) would allow the NDIA to refuse early intervention access to the NDIS if the NDIA thinks early intervention support should be provided by others, like State and Territory health systems, *even where that support does not exist*. If this is kept in the Bill, it could result in exclusions of people with particular disability types from the NDIS.

4. Debt recovery

The March 2021 draft proposed a new power to recover money spent by a participant in breach of section 46C. For example, if a participant spends their funding on a support person to assist with housework, but the Minister has determined that such services are not covered by the NDIS, they will owe a debt to the NDIA. This could include spending money on things that the NDIA says should be funded by State governments. The NDIA can then start legal proceedings to recover that debt.

This power would require participants to know when the rules are changed and when new bans on goods or services are added, to make sure they follow the rules. If they fail to keep updated, a debt could be raised against them even if they did not know about the rules. Any such power is likely to disproportionately affect people from marginalised communities, who may be less likely to understand and follow complex rule changes.

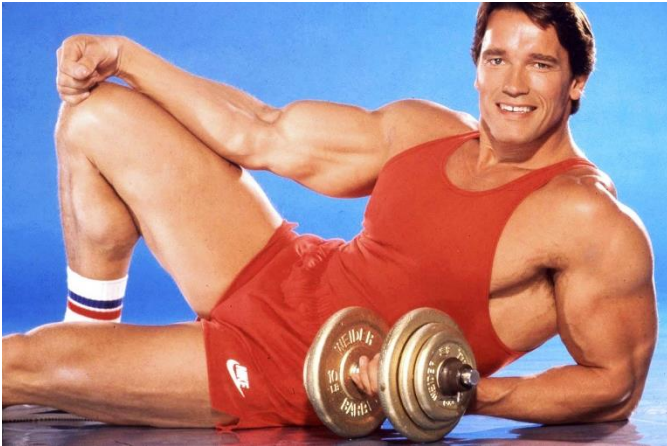
5. The Minister's powers

The NDIS Act allows the Minister to make rules about the administration of the NDIS. Rules dealing with key issues in the NDIS – like what can be purchased with funds – currently require unanimous or majority approval from States and Territories. They are rules that fall within 'Category A', 'Category B', or 'Category C'.

Some rules don't require agreement from any State or Territory - the Commonwealth Minister can make or change rules even if all State and Territories disagree. These are 'Category D' rules.

The March 2021 draft proposed that rules around how 'personalised budgets' are worked out and what goods or services are not funded by the NDIS (points 2 and 3 above) would be Category D rules. This would give the Minister power to change significant parts of the NDIS without having to go through either Parliament or even State and Territory Ministers. These powers could be damaging for the Scheme and are unnecessary.

Men with sensory loss are more likely to be obese



Men who suffer sensory loss, particularly hearing loss, are more likely to be physically inactive and obese than women, according to a new study published in the *European Journal of Public Health*.

Researchers found that inactive people with hearing loss were 1.7 times more likely to be obese compared to those who did not have any hearing loss.

Analysis showed a significant association between physical inactivity and obesity in men with vision or hearing loss, but not in women. Men with hearing loss were 2.3 times more likely to be obese than women who reported difficulty hearing.

Around 62% of adults in Spain are overweight, with 26% reporting as obese. In the UK, the figures are broadly similar at around 64% and 28% respectively.

Lead author Professor Shahina Pardhan, Director of the Vision and Eye Research Institute at Anglia Ruskin University, said: "Although women were overall less physically active than men, we found an association between physical inactivity and obesity in men, but not in women. This indicates that, especially in people with vision and hearing losses, exercise and being active has a very important role in preventing obesity for men.

"An effective strategy to increase the levels of physical activity in this population group would be targeted intervention programs based on health awareness on the importance of physical activity."

From [Science Daily](#)

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

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

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 of the disappearance of indigenous sign languages and the cultural loss it would cause.

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