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deafness forum of australia

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## Budget 2021

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## One baby is born with a CMV-related disability every day

It is the rarely discussed but common virus that causes more birth defects including deafness than any other viral infection in infants.

## Classical musician and Audiologist combines passions for people with hearing loss

*Rediscovering Music* is definitely where my two professional worlds meet. It has been my absolute pleasure to be able to design and implement this program, which is a unique, rehabilitative approach for people with hearing loss to begin to enjoy music again.

## Falling off 'magical cliff': Call for review of NDIS age 'discrimination'

"If a person loses their legs in a motorbike accident and they are 64, they're entitled to NDIS benefits. If they do so when they're 65, they're not. There is this magical cliff here, and I say 'Well hang on, this is age discrimination and it should be reviewed'."

## Sam's bold life choices

"Being our true authentic selves is one of the boldest choices we can make and it's one I strive to achieve for every day."

## Nothing funny about hearing loss

The older man has grey hair and is a bit doddery. "Better get your hearing tested!" the TV commercial's voice-over says light-heartedly. It's hilarious! Please excuse the sarcasm.

# Federal Budget 2020-2021

There's nothing new for ear care and hearing health to get excited about in last night's Federal Government budget announcement. What's there is welcomed but opportunities were missed.

A \$5million hearing loss prevention public campaign is scheduled for late 2021. It will try to destigmatise hearing loss, and encourage people to seek treatment.

The interface for audiology clinics with the Hearing Services Program – called the Online Portal – gets a necessary cash injection to enable a technical upgrade. The old system is in dire need of replacing. There is not a direct benefit to people who are customers of audiology clinics, but any improvement to the way businesses access the Hearing Services Program – and the resulting data that can be collected – will ultimately improve the service customers receive.

Funding continues for certain activities under [Roadmap for Hearing Health](#).

## Hearing Services Program

The Department of Health is responsible for managing and administering the Australian Government Hearing Services Program, aimed at reducing the incidence and consequences of avoidable hearing loss in the Australian community by providing access to high quality hearing services and devices.

The Budget papers specified the amount of spending in coming years (aka, Forward Estimates). We can see that there is a sharp decrease scheduled from 1 July 2021 that compounds to a significant cut to current spending of around \$153million over 3 years. We will find out what is behind this budget reduction, noting that the Budget papers project an increase in Program clients from 820,000 to 911,000 in the next 3 years.

### Hearing Services Program budget allocations

2019/20: \$533,207million

2020/21: \$599,031

1 July 2021 - 30 June 2022: \$519,287

1 July 2022 - 30 June 2023: \$533,950

1 July 2023 - 30 June 2024: \$592,752

### Performance Criteria

Number of eligible Australian clients provided with a range of hearing devices and services to manage their hearing loss and improve their engagement with the community.

2019-20 Target	2020-21 Target	2021-22 Target	2022-23 Target	2023-24 Target
855,000 clients	871,000 clients	881,000 clients	907,000 clients	911,000 clients
2019-20 Result				
821,731 clients				

# **Missed opportunities**

There are at least three missed opportunities in this Budget. We are disappointed that it did not invest in services to (1) frail elderly people in residential aged care facilities, (2) prison inmates and (3) peer support (self-help) groups in the community.

## **1. Services to frail elderly clients in residential aged care facilities**

The Royal Commission into Aged Care has shown that the aged care system is in crisis so it is critical that any changes to hearing service delivery lead to improvements for people and do not add to existing issues within the aged care system. Providing hearing services to all frail elderly residents regardless of their income through a targeted, national Government program would allow services to be introduced quickly, seamlessly and in a cost-effective way and would provide the protections that are required for this highly vulnerable population.

## **2. Services to prisoners**

Provision of hearing services to prisoners is a state and territory responsibility. But the lack of progress in services to this group has been raised as an issue through various government inquiries for the last 10 years at least. The situation is now at a point where the prison facilities need an innovative, population-based, end to end service delivery model to be developed and implemented so that systems are established to identify and manage the high level of hearing loss in the prison population in the longer term.

## **3. Peer support groups**

Peer support groups have an important role to play to support individuals, and families and carers along the journey and to help them to achieve the best outcomes possible from their hearing rehabilitation program. Many of these groups – many of them are members of Deafness Forum - lost most of their government funding streams in recent years or have been receiving funding that has not been adjusted to meet the increased demand for services particularly since the NDIS was introduced. It is vital that the critical role that they play is formally recognised and appropriately funded especially if the outcome of the review indicates these groups should play a more significant role in supporting the client's rehabilitation program.

## **Amber Schultz writing for [CRIKEY](#) says: Government giveth and taketh away, with a boost to mental health and cuts to social services.**

While the government has shelled out extra money for mental health services, there are cuts to the Department of Social Services.

The **National Disability Insurance Scheme** (NDIS) is set to get a little more cash than planned but will also need to support more people than expected; while its watchdog, the already overwhelmed NDIS Quality and Safeguards Commission, will see funding and staff cuts.

Despite the number of Australians on the NDIS and the growing number of complaints received by the Quality and Safeguards Commission, the commission is set to have its staffing levels and funding slashed.

## Common but unknown virus causing more birth defects in infants than other viral infections

Parents around Australia are hoping to raise awareness about a rarely discussed but common virus that causes more birth defects than any other viral infection in infants.

Shanie James' son Knox was diagnosed with profound hearing loss at just eight-days old but was baffled as she had no family history of deafness.

The 27-year-old mum wants more people to know about the danger of the common [virus](#) that caused it.



Doctors told the 27-year-old-mum the cause was a common infection – [Cytomegalovirus \(CMV\)](#).

"It makes me feel sick just thinking about it, but the list of things that can come from CMV like cerebral palsy, the hearing loss which he's got ... I still don't know what's going to come from this," Ms James said.

In healthy people, CMV infection causes a minor flu-like illness.

But in pregnant women, it can be transmitted to their unborn child and cause a range of birth defects, including deafness.

Virologist Professor William Rawlinson from UNSW says one baby is born with a CMV-related disability every day.

"There are more CMV babies born in Australia than are born with [Down's Syndrome](#)," Professor Rawlinson said.

It's estimated around half of adults carry the virus – and young children can be spreaders.

"It's typically through acquisition from young children, often their own toddler who gets it from childcare ... perfectly healthy, might have a sniffle, might have a bit of a fever ... but really gets better in a day or two," Professor Rawlinson said.

Ms James, already a mum of two boys before Knox came along, was also working in childcare during her pregnancy.

She and her husband - like most parents – had no idea about danger posed by CMV.

"If I knew about it maybe I wouldn't have kept changing nappies at work or maybe I wouldn't have shared my children's drink bottles or kissed them on the lips for the nine months that I was pregnant," she said.

To reduce the risk of (CMV) infection pregnant women should avoid sharing food and drinks with young children.

Do not put a young child's dummy in your mouth and always wash hands after nappy changes.



At the moment there is no pre-delivery screening program for CMV or vaccine to prevent the virus, but medical researchers are working on both.

"I think in the future it's very likely that we'll be considering screening pregnant women," Professor Rawlinson said.

Ms James said she hopes by talking about the infection, less families will be impacted by CMV.

"I hope in sharing this, women can make that decision to try and prevent it from happening."

From [9 News](#)



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# **Sam Martin shares the bold choices he has made in his life**

## **Interviewed by Nicole Bagatsing**

*Tell me about your show from SAM I AM.*

“Sam I Am” is an autobiographical inspired one-person show, that one person being me! I am the writer and performer of the show and Dan Graham is the director. Focusing on the universal experience of discovering identity, the show draws on my experiences of navigating the world as a young adult discovering not one but two identities. Intersectionality and complexity with identity combined with the formative experiences that define who we are is at the forefront of this show. The show had its debut in Sydney at Brand X Theatre and will soon have its Melbourne premiere with Antipodes Theatre. Both shows are very different from each other. It was only natural that since the first performance, a show about my life would change when performed next. “Sam I Am” is an ever changing and developing work just like the journeys we embark on our lives with discovering who we are.



*What bold choices have you had to make towards the production of SAM I AM?*

Apart from identity and its complexities, “Sam I Am” is putting a disabled Queer actor at the front and centre of a production. Having a Deaf, Queer performer on stage is automatically a bold choice through the uniqueness and rarity. I identify as Hard of Hearing/Deaf and Gay/Queer and rarely if not ever have I seen myself reflected in the art world. The director Dan Graham also identifies as being Queer and having a disability. This project for us is about showcasing authentic representation and stories front and centre.

*What did you most enjoy about your show?*

What I enjoyed most about the show in Sydney and about the current production developing in Melbourne is collaboration. “Sam I Am” has expanded my network of people and led to me collaborating with Queer, Disabled, Queer and disabled and PoC theatre practitioners. I strongly believe that having a diverse collaborative network has contributed so much to this project in such a unique way. By far, this has and still is the most enjoyable aspect of the show.

*What bold choices have you had to make in life?*

Being open personally and publicly as a Queer disabled person I believe is a bold life choice. Coming out is also one of the boldest choices I’ve made. Defying the expectation of what sexuality should

be, going through the experiences of accepting myself and then telling those closest to me that I love the most, was painfully difficult but ever so rewarding. Being our true authentic selves in today's society is one of the boldest choices we can make and it's one I strive to achieve for every day.

*What advice would you give to young people?*

There is a quote from Oscar Wilde that I have always loved, "*Be yourself; everyone else is taken*".

I feel this message more than ever is so important especially for the world we live in now. Our society more often than not encourages us either intentionally or subconsciously to be something we're not such as a beauty standard or a personality. My advice for young people would be to build an environment where they can grow and be who they are. This environment could be created by being with a supportive network of people, friends and role models.

Identity is no longer one or the other, it's now a spectrum that is measured and determined by us individually. In addition to this, I would tell young people to embrace the intersectionality of their identity. Being aware of our identity/ies helps us understand who we are and our place within the world. Most importantly though, remember this journey may be life long to some and change as you grow, and that is perfectly okay.

Follow Sam now on his Instagram, [@s.f.martin](https://www.instagram.com/@s.f.martin), and check out [his website](http://his website)

By Nicole Bagatsing for [Loud Youth](http://Loud Youth)



**Loud Youth** is a nonprofit e-magazine that seeks to empower your voice and your story through the platform of creative media.

For its summer June 2021 quarter, the theme is: "**We Proudly Stand**" in honour of Pride month! This is a special edition to celebrate the youth leaders and artists of the LGBTQIA+\* community. We want to hear from our young people why they stand, why they are proud, and why we are in this together. Check out our previous articles for inspiration!

Deadline is 1 June 2021. [Learn more here](http://Learn more here)

## Nothing funny about hearing loss - as my child knows

The older man has grey hair, and is a bit doddery. He's mishearing his wife, repeatedly. "Better get your hearing tested!" the TV commercial's voice-over says light-heartedly.

It's hilarious! Please excuse the sarcasm. The truth is, it's not at all funny. Hearing loss is a serious challenge that brings with it many frustrations for a diverse range of people.

I discovered this last year when my daughter, aged eleven, experienced sudden sensorineural hearing loss: she went to bed one night with normal hearing, and woke the next morning with profound, permanent hearing loss in one ear. This affects her life every single day.

It means a teacher forgetting, telling her off for not concentrating when she asks them to repeat something. It's the exclusion when her friends say, "It doesn't matter" when she doesn't hear them. It's a constant ringing in her ear (tinnitus) as she tries to fall asleep. The assumptions that using a hearing aid should give her perfect hearing. When she forgot her hearing aid one day, she came home from school barely able to function, so extreme was the exhaustion of simply trying to hear.

This is not a comedy routine; this is real life. Mishearing people, or not hearing them, isn't funny.



On morning TV, David Campbell received the news of his hearing loss. Co-host Belinda Russell made a joke: "Earlier this morning the floor manager said, 'Camera three', and next minute you're going into the next studio because you thought he said, 'Come in here'." The pair laughed.

Hearing loss is grossly misrepresented: we are shown, almost exclusively, older people. This demographic is vulnerable to hearing loss, however the perception is that they're the only ones.

My daughter and I visit hearing centres regularly, where she's surrounded by images of the elderly. She's almost a teenager, placed into a box titled 'The problems with ageing'. This image is created by those who should know better.

Hearing loss is a diverse experience – affecting babies, children and grown-ups of any age – yet it's presented with a lack of diversity that, perhaps, makes us feel OK about fueling the comedy.

When my daughter hears people laughing about it, she asks why her challenges are comedic.

I say that people don't know better, they don't think hearing loss through with empathy. Not yet. I suggest that people will learn when those who don't fit the stereotype speak up.

So, here we are, telling those in a position to publicly portray hearing loss: you must do better.

This article is from [The Sydney Morning Herald](#). Its author, Megan Blandford is a freelance writer.

# Australian Government Hearing Services Program news



## Changes

There are several changes to the Hearing Services Program coming into effect on 1 July 2021. A reminder of what will be changing is on the [Program Changes webpage](#).

Some common issues have been found with service providers' claims. You can find tips for improving claiming [here](#).

## Telehealth in the Program

The [Schedule of Services Items](#) is being reviewed to ensure clarity of program requirements for service delivery and incorporates the Hearing Rehabilitation Outcomes into one document. In response to the feedback received about the allowance for telehealth because of COVID-19, extra provisions for telehealth have been included in the schedule. The final version will be available to stakeholders this month. A [Provider Factsheet - Telehealth in the Program](#) is now available and outlines which service items may be performed through telehealth from 1 July 2021.

## Roadmap for Hearing Health Aged Care Workforce Initiative

The [Roadmap for Hearing Health](#) aims to improve use of high quality hearing services for vulnerable Australians. Roadmap activities supported through the 2020 Federal Budget includes \$2 million to develop and test training programs for residential aged care workers. This will help support residents with hearing loss. The Aged Care Workforce branch is running this project, which has two phases:

- A gap analysis of the training needs of the residential aged care workforce
- Develop and testing of the training modules

Australian Healthcare Associates has been contracted to run Phase One: the gap analysis. About 60 stakeholders including Deafness Forum of Australia are participating in the consultation.

## Falling off ‘magical cliff’: Call for review of NDIS age ‘discrimination’

As a senior executive of the “millionaire’s factory”, Macquarie Bank, Bill Moss AO was a giant of Australian business. He made tens of millions of dollars a year and had politicians on speed dial.

Now, he says, “I can’t roll over in bed. I can only eat with my left hand ... I have trouble swallowing. I get a lot of pain. Most of my joints, most of the time, are dislocated.”



Bill Moss would like to see the government remove the age cap on the NDIS. *Credit:Kate Geraghty*

Mr Moss has facioscapulohumeral dystrophy (FSHD), a form of the muscle-wasting muscular dystrophy. But he still considers himself lucky because he can afford his own care, and he is still up for a fight. He founded the FSHD Foundation in 2007 and remains its patron, committing \$8.3 million to fund 40 ongoing medical research grants in nine countries.

And now he is taking on the federal government over a feature of the National Disability Insurance Scheme that means people with a disability who do not register before the age of 65 are barred from funding under the scheme. Instead, they are at the mercy of the aged-care system.

“If a person loses their legs in a motorbike accident and they are 64, they’re entitled to NDIS benefits. If they do when they’re 65, they’re not,” Mr Moss told *The Age and the Herald*. “There is this magical cliff here, and I look at it and I say ‘Well hang on, this is age discrimination and it should be reviewed.’”

He has written to the federal government asking them to remove the age cut-off and make all people with a disability eligible for the NDIS. The cut-off only applies to new participants – someone already receiving support from the NDIS can continue to do so after turning 65.

“People with disability aged 65 or over who are not NDIS participants can receive care and support from the Commonwealth aged care system through My Aged Care,” said a spokesperson for the Minister for the NDIS Senator Linda Reynolds. But Mr Moss says the scope of services available under the federal government’s My Aged Care program were “minute” compared to the NDIS. “It’s chalk and cheese”.

By [Jewel Topsfield](#) writing for [The Sydney Morning Herald](#) Photo by Kate Geraghty

# Classical musician and Audiologist combines passions for people with hearing loss



Kristen Sutcliffe has been both a specialist audiologist with Hearing Australia and a bassoonist with the Canberra Symphony Orchestra (CSO) for over 10 years.

She is passionate about the intersection of music and healthcare. She plays a central role in CSO community engagement and has curated and presented CSO's *Rediscovering Music* program.

## Where did your musical journey begin?

"Inspired by my Mum's collection of tapes and LPs, I announced to her at the grand old age of four that I would like to learn the piano or the violin. She asked me to decide between them—after much thought, I chose the violin.

"I completed up to Grade 8 on the instrument before I found a better fit for me: the bassoon. I enjoyed playing my own part in orchestra and not sharing with others!"

## How do music and audiology intersect in your life?

*Rediscovering Music* is definitely where my two professional worlds meet. Over the last nine years, it has been my absolute pleasure to be able to design and implement this program, which is a unique, live, rehabilitative approach for people with hearing loss to begin to enjoy music again.

"I also help out with tricky musical needs of our Hearing Australia clients; it's not unusual to get emails from around the country asking for musical advice for both our adult and paediatric clients."

"Being able to bring enjoyable music to people who are hard of hearing or Deaf—through *Rediscovering Music*—and being there with them for the journey over many years continues to be a privilege."

*Rediscovering Music* returns in 2021 with three free, interactive concerts for people with hearing loss, supported by Better Hearing Australia (Canberra). Register via [cso.org.au/events](https://cso.org.au/events)

From [Her Canberra](#). Photography by Martin Ollman

# Impacts of COVID-19 on households in Australia in March 2021

This article presents results from the Household Impacts of COVID-19 Survey, a longitudinal survey of people aged 18 years and over living in private dwellings across Australia (excluding very remote areas). The survey, conducted by the Australian Bureau of Statistics, is designed to provide a quick snapshot of the changing social and economic situation for Australian households with particular focus on how they are faring in response to the COVID-19 pandemic.

## Emotional and mental wellbeing

The survey asked Australians about feelings that had an adverse impact on emotional and mental wellbeing. Around one in five (20%) Australians experienced high or very high levels of psychological distress in March, which was similar to psychological distress experienced in November.

- women were more likely than men to have experienced high or very high levels of psychological distress (22% compared with 17%)
- more (28%) younger Australians (aged 18 to 34 years) experienced high or very high levels of psychological distress than those aged 35 to 64 years (18%) or 65 years and over (9%).

## Precautions

Almost all Australians took one or more precautions in the previous week because of the spread of COVID-19. This was similar to January but has decreased by a small percentage compared to six months ago.

- women (54%) were more likely than men (42%) to disinfect surfaces before using them
- people aged 65 years and over (93%) were more likely than those aged 18 to 34 years (85%) and 35 to 64 years (89%) to wash their hands or use hand sanitiser regularly
- people in Victoria (94%) were more likely than those in NSW (58%), Queensland (17%), South Australia (19%), WA (13%) and the rest of Australia (16%) to wear a facemask
- people in Victoria (76%) were more likely than those in NSW (66%), QLD (64%), SA (59%), WA (51%) and the rest of Australia (66%) to keep a physical distance from others
- people living in family households without children (34%) were more likely than those in family households with children (27%) to stay at home due to COVID-19
- people with disability (39%) were more likely than those with no disability (29%) to stay at home due to COVID-19

## Information sources

The most commonly reported sources of information related to COVID-19:

- men (23%) were more likely than women (16%) to use international news sources
- people aged 18 to 34 years (46%) were more likely than those aged 35 to 64 years (30%) and 65 years and over (11%) to use social media
- people living in family households with children (41%) were more likely than those in family households without children (29%) and those living alone (21%) to use social media

- people with a job (60%) were more likely than those without a job (45%) to use government health information sources
- people with no disability (34%) were more likely than those with disability (23%) to use social media
- people without a long-term health condition (35%) were more likely than those with a long-term condition (26%) to use social media.

## **Public transport**

Prior to the beginning of COVID-19 restrictions in March 2020, over four in five Australians reported being comfortable or very comfortable using public transport (82%) and taxi or ride share services (83%). In March 2021, around three in five people reported still being comfortable or very comfortable with using public transport (60%) or taxi and ride share services (63%).

The main actions that would help people feel more comfortable to use public transport, taxi or ride share services were:

- people understanding, and visibly following, COVID-safe practices (such as wearing facemasks, social distancing and sanitising hands) (32%)
- widespread uptake of a vaccine (15%)
- having received a vaccine (10%).

## **Voluntary work and unpaid help**

One in five (21%) Australians did unpaid voluntary work for an organisation or group in the last 12 months, compared to one in four (26%) prior to 1 March 2020.

Australians who had volunteered for an organisation or group at some point (either before 1 March 2020 or in the last 12 months), but did not do so in the last four weeks, were asked their reasons for not volunteering.

The most common reasons for not volunteering were:

- could not fit in around paid work (31%)
- could not fit around family or caring commitments (22%)
- my previous volunteering group stopped or reduced their operation (16%)

The survey asked whether people provided unpaid help to someone living outside their household in the last four weeks, such as assisting with errands, childcare, or domestic work. Two in five (43%) provided unpaid help to a family member or other person living outside their household.

Of those who provided unpaid help in the last four weeks to someone living outside their household:

- women (72%) were more likely than men (54%) to provide unpaid help to a family member
- men (68%) were more likely than women (57%) to provide unpaid help to a non-family member.

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

Drop us a line: [hello@deafnessforum.org.au](mailto:hello@deafnessforum.org.au)



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Thanks very much!

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.

People with disability have and continue to be subjected to isolation, exploitation, violence, and abuse. We thank the Australian Parliament for its bipartisan support of a Royal Commission into the evil committed on some people with disability.

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