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deafness forum of australia

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Triumph of commonsense

The Government has announced its arrangements for NDIS funded hearing services to commence on 1 July 2020. And the decisions are framed for the benefit of consumers.

Government plan to protect people with disability in the COVID-19 crisis

Good communication is of great importance in an emergency. We are concerned that public communications and consultations with representatives of people with disability are at the bottom of the list in the Government's Plan.

A deaf lipreader in the health mask era

Never have I felt more deaf. I'm an excellent lipreader, but I lack Superman's x-ray vision. My biggest fear is ending up hospitalised. I have deaf friends who lie awake at night scared to death about this possibility.

Disability Royal Commission

For now, the Royal Commission has suspended (only) its public hearings and face to face private sessions due to concerns about the spread of COVID-19 coronavirus. But it continues to accept submissions from people who want to share their experiences of violence, neglect, abuse or exploitation.

I thought I was a loser

The rise and rise of Attention Deficit Hyperactivity Disorder (ADHD) in adults. Undiagnosed adults can struggle to finish school, hold down jobs and manage day-to-day tasks – which can lead to at increased risk of relationship troubles, other mental health problems, alcoholism, drug dependence, car crashes and criminality.

Announcement: future of Hearing Services

The Government has announced its arrangements for NDIS funded hearing services to commence on 1 July 2020. Before this announcement, advocates were concerned that consumers would not be given adequate time to prepare for changes, should they be introduced. A Government taskforce announced these arrangements after consultations with Deafness Forum and its members, and other organisations.

CHILDREN 0-26 YEARS

There is to be <u>no change</u> to the way that infants, children and young adults aged 0 to 26 years access their hearing services. Hearing and communication programs including device fitting and maintenance will be provided through the Community Service Obligations component of the Australian Government Hearing Services Program with Hearing Australia as the sole provider.

Children will also be able to register as NDIS participants where they can access additional supports such as early intervention services, Auslan language development, and technology that is not provided under the Hearing Services Program. The child's NDIS plan will include funding for these additional supports but it will not include funding for the services provided under the Hearing Services Program.

ADULTS 26-65 YEARS

Adults who are eligible for the Australian Government Hearing Services Program will continue to receive their hearing and communication programs including device fitting and maintenance under that Program. If they meet the access requirements for the NDIS they can access additional supports such as technology that is not provided under the Hearing Services Program through NDIS funding.

Adults aged 26-65 years with hearing loss who are not eligible for the Hearing Services Program can test their access to the NDIS. If they meet the access requirements then their NDIS plan will include funding for all of the supports assessed as reasonable and necessary including audiological services, devices and maintenance.

If a person does not meet the criteria for the Hearing Services Program or the NDIS, the options for accessing hearing services include the Job Access Program, hearing aid banks or self-funding their hearing services.

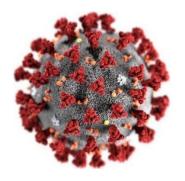
ADULTS 65 YEARS AND OVER

Adults 65 years and over who are eligible for the Australian Government Hearing Services Program will continue to receive their hearing and communication programs including device fitting and maintenance under that Program.

Adults aged 65 years and over are not eligible to <u>join</u> the NDIS. But if the person was a NDIS participant prior to the age of 65 years they can continue to receive services as a participant after turning 65.

If a person does not meet the criteria for the Hearing Services Program and they were not previously an NDIS participant before turning 65 years, then options for accessing hearing services include the Job Access Program if they are still working, hearing aid banks or self-funding their hearing services.





Australian Government's plan to protect people with disability in this COVID-19 crisis

The Australian Government has created a Plan to deal with the impact of the health pandemic on people with disability.

It was written by the Department of Health in a few weeks so it cannot be complete. However, suggestions can be made to improve it.

Deafness Forum's members offered their thoughts and two common points were made:

COMMUNICATION IN A CRSIS

In an emergency good communication is of great importance. Lots of announcements are being made but not a lot is communications accessible.

We are concerned that *Public Communication* and *consultations with representatives of people with disability* were in Phase 3, but they really should be up front.

We had some helpful things to say in our submission to the Government about:

- Face masks block more than germs a reference to the challenge for lip-readers when they interact with health professionals wearing protective face gear
- Information on television and in social media must be captioned and have an interpreter insert captions must be accurate and legible; and the interpreter can't be a tiny figure in the background
- Service providers must provide accessible communications

EMPLOYMENT OF PEOPLE WITH DISABILITY

This health crisis poses a serious setback to the medium- and long-term employment opportunities for people with disability.

The pre-pandemic employment ratio was pretty uninspiring, but it could get far worse.

There's a need for an independent body to take on a watching role.

If you have a suggestion to improve the Government's Plan for People with Disability in this health pandemic, send it directly to COVID-19Disability@health.gov.au

You can read and download the Government's Response Plan on our website at https://www.deafnessforum.org.au/news-and-issues/coronavirus/



Teachers help deaf and hard of hearing students navigate through distance learning

MCALLEN, Texas - As schools move online, students who are deaf or hard of hearing are among those facing challenges.

Distance learning is becoming the new normal for schools around the country. Celina Maya and Linda Gomez Ochoa are 2nd-grade teachers for both deaf and hearing students.

"Teaching 7-year-olds has to be a visual experience for our kids, it has to be very language-rich for both our deaf and our hearing students," said Maya. "Even our hearing kids are learning a lot of sign in this environment."

While distance learning was a sudden change in lesson plans for both teachers and students, they all remain optimistic about the experience.

"There's always a silver lining to everything and right now I think we are becoming more aware of all the technology that is out there and for sure we will implement some of what we've learned so far," said Gomez Ochoa.

https://www.valleycentral.com/news/teachers-help-deaf-and-hard-of-hearing-students-navigate-through-distance-learning/



Together to build a stronger Usher community

UsherKids Australia will host a virtual coffee catch-up on Tuesday 5 May, 10:45am (Melbourne time). To join the coffee catch-up, inquire at https://www.usherkidsaustralia.com/contact-us/

If you are struggling, now is the time to ask for help!

If you have the capacity to give, now is the time to give! To donate the cost of a coffee to this special cause go to https://www.givenow.com.au/usherkidsgivingtuesday



A deaf lipreader in the mask era

Never have I felt more deaf. I'm an excellent lipreader, but I lack Superman's x-ray vision.



Lisa Goldstein writes: my biggest fear is ending up hospitalised. I have deaf friends who lie awake at night scared to death about this possibility.

I attended a captioned webinar recently hosted by Dr. Chad Ruffin, an ENT who has cochlear implants, and Tina Childress, an educational audiologist and late-deafened adult who is fluent in ASL and has bilateral cochlear implants. As Dr. Ruffin explained, patients with COVID-19 are kept separate from the rest of the hospital. Healthcare providers are all, justifiably, masked. Because of increased visitor restrictions, I would probably be on my own. Accommodations (captioning, interpreter, etc.) will take some time to set up.

Yes, I've seen the article about Ashley Lawrence, the college student who's making clear face masks. Everyone and their brother sent it to me. I applaud her endeavour, but clear masks that are FDA-approved already exist. And the people who really need to wear them – the healthcare providers – likely won't, because there isn't one that's both N95 and FDA-approved.

Don't get me wrong. I wholeheartedly support social distancing, universal masking, and doing whatever possible to flatten the curve and end this pandemic. Everyone is experiencing difficulty in one way or another. But being deaf during COVID-19 presents a unique set of challenges.

Some background: I was born profoundly deaf but wasn't diagnosed until 14 months of age. I was immediately outfitted with hearing aids and began daily speech therapy that didn't end until I graduated from high school. I received a cochlear implant as an adult and wear a digital hearing aid in my other ear. As much as I benefit from these hearing technologies, however, I still rely almost exclusively on lipreading.

The first week of sheltering in place – and before face masks were mandatory – I did a grocery run for our family of four. My hearing husband has since taken over any errands that involve leaving the house. As an engineer, he's already trained to be careful – more so than the rest of us. And if the same person within the family exposes themselves, that limits the risk. As it now turns out, this also means I don't have to worry about feeling like an alien adrift in a sea of masked faces.

Dr. Ruffin's webinar provided some useful tips for what to do if hospitalised as well as how to communicate effectively. One suggestion was to develop a communication strategy for expected



scenarios by talking to family members about my needs before going to the hospital. They may have to advocate for me if I'm unable to speak for myself. Another valuable suggestion was to learn what time rounds occur in advance, so my advocate can phone in.

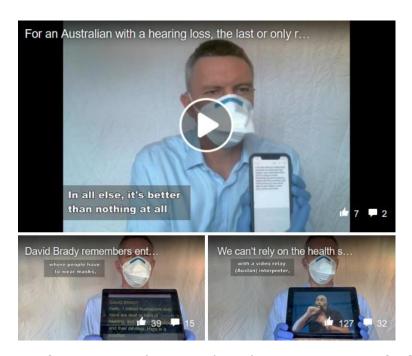
For now, my family and I are healthy. As the days blur into one another, I'm grateful for the technology that allows me to connect with my friends and family. But I'm learning that accessibility still has a way to go. If I was a student, I'd be struggling with online schooling, with videos that aren't captioned and presentations that are difficult to follow.

As it is, I've been participating in virtual meetings (including one with 25 people!) and viewing live videos or recorded ones. Unfortunately, the most popular video conferencing platform, Zoom, doesn't have captioning built in. If I won the lottery, I could pay for a third-party captioner. My deaf friends have been sharing and testing out some captioning apps or websites like webcaptioner.com. Though I have yet to try one, I will soon. More often than not, I either log out of the live stream or suffer along silently. Please, for the love of God, don't get creative with the virtual backgrounds. They make it more difficult to lipread. Make sure you have good video quality and sit close to the camera. And mute yourself when you're not speaking!

A friend pointed out that what we really need is equity in accessibility for apps that would help us communicate. Google Live Transcribe is supposed to be pretty accurate, yet I don't have an Android. I can only hope that with increased need, accessibility as a whole will improve.

Until then, I leave you with this thought to consider: If you're wearing a mask and think someone is ignoring you, maybe they are. Or maybe they have a hearing loss!

https://www.unabridgedpress.com/deafmasks/?fbclid=IwAR0_nMyp5wtl4Fo0C190R7m80xGWRmlLNiHqLBaK7ijUIoev6fXxQO7t0mM



Deafness Forum chair David Brady create a series of information videos about communicating with frontline health workers during this COVID-19 pandemic.

Find the videos on Deafness Forum's Facebook page, https://www.facebook.com/deafnessforum/



Disability Royal Commission

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability continues to accept submissions. A submission is the main way people and organisations can provide information to the Royal Commission about their experiences of violence, neglect, abuse or exploitation of people with disability.

Anybody can make a submission. Submissions can be made using the form available on the Royal Commission <u>Submissions page</u>. An Easy Read version of the form is also available.

For now, the Royal Commission has suspended only its <u>public hearings</u> and <u>face to face private</u> <u>sessions</u> due to concerns about the spread of COVID-19 coronavirus.

Deafness Forum's work on behalf of the Disability Royal Commission is supported in part by a financial grant from the Department of Social Services.

Your voice is important

A Tasmanian mother, Dr Rebecca Kelly described her experience of giving evidence to the Disability Royal Commission as empowering.

And she's encouraging others to share their story.

At a hearing into the provision of health care or services for people with cognitive disability, Dr Kelly detailed the treatment of her 8 year old son Ryan.



"I knew that there was every chance that speaking publicly could backfire and make Ryan's care worse, but I felt strongly that things have to change and that people who can speak up should tell their stories, so the country has to listen," Dr Kelly wrote.

Dr Kelly detailed how Royal Commission lawyers flew to her home in Tasmania to interview her and record her evidence.

Just prior to the hearing, Dr Kelly joined other witnesses in a familiarisation session.

"They allowed us to meet the barristers who would question us. The room itself was set up so as to be less intimidating. The adults with intellectual disabilities who gave evidence were also supported. Their evidence was really powerful and set the scene where people with intellectual disabilities were themselves at the heart of the hearing," Dr Kelly said.

"It was very healing to tell our story and not only be believed, but have all these people agree, that what we went through was neglectful and terrible. Giving evidence at the Royal Commission felt like getting my power back."

www.disability.royalcommission.gov.au

'I thought I was a loser, now I have the answer': rise in adult ADHD

Catherine Cook had a sudden moment of clarity the day her 10-year-old son was diagnosed with attention deficit hyperactivity disorder (ADHD).

"They told me it was hereditary, and I thought, 'Uh-oh, that's me."



Catherine Cook, 34 and her son Ashton, 10, have both been diagnosed with ADHD. Credit:Renee Nowytarger

Ms Cook, 34, has a vague memory of being told she had attention deficit disorder when she was seven or eight, "but my parents thought the paediatrician was just wacky so we didn't do anything about it".

She was the teenager who could never finish a task, rushed her assignments at the last minute and left school at the beginning of year 11.

"I just thought I was a loser. I'd try so hard at things and beat myself up when I couldn't concentrate," she said. "I fell down a deep hole of depression and now I look back and I had the answer."

Rising numbers of Australian adults are being diagnosed with ADHD, tearing at the fallacy that it's just something children outgrow.

Chairman of ADHD Australia Michael Kohn said there had been "exponential growth" in the number of adults seeking ADHD testing as the public was becoming more aware of the condition.

The organisation's helpline received one call a week about adult assessments five years ago. Now it receives three inquiries a day, Professor Kohn said.

"They'll have ADHD traits that weren't picked up in childhood or they were dismissed as the naughty kid," he said.

President of the Australian ADHD Professionals Association and cognitive neuroscientist Mark Bellgrove said ADHD was "almost certainly under-diagnosed and under-treated in adults" but the lack of national rates of diagnosis data of the true burden was difficult to quantify.

"There is a lot of unmet need," Professor Bellgrove said.

Adult ADHD by the numbers

Global estimates suggest between 1 and 3 per cent of adults could have ADHD.

Roughly 30 to 60 per cent of children with ADHD will carry it into adulthood. No single gene appears to be responsible for ADHD but it is highly heritable. A 2009 review suggested genetics accounted for 70 to 80 per cent of the risk of developing ADHD.

Getting diagnosed can be an immense relief.

"All their lives they may have struggled to cope ... now they know it wasn't their fault."

Undiagnosed adults can struggle to finish school, hold down jobs and manage day-to-day tasks – which can lead to socioeconomic disadvantage, Professor Bellgrove said. They were at increased risk of relationship troubles, other mental health problems, alcoholism, drug dependence, car crashes and criminality.

"But I wouldn't want to paint an overly negative picture. Many people living with ADHD lead very productive lives and thrive, but they have a whole host of challenges they have to overcome," he said.



Catherine Cook and her sons Ashton, 10, and Jack, 18 months, at their home in Glenmore Credit: Renee Nowytarger

There are a handful of assessment tools used to "test" adults for the disorder, but it's ultimately a clinical diagnosis made by a specialist based on a patient's symptoms, which can be very different from the telltale childhood traits.

Adults are less likely to be hyperactive. They can be easily distracted, and have problems focusing and regulating their emotions, Professor Kohn said.

He said women with ADHD were more prone to have been overlooked as children because their internalised traits (excessive daydreaming and inattention) were not the hyperactive "squeaky wheel" common in boys.

However, there is evidence suggesting the condition has been over-diagnosed in some children.

"It's very important to get a thorough and accurate assessment from a clinician trained in ADHD," Professor Bellgrove said.



Impairment was the key criterion, he said. Many people will have ADHD characteristics but live unimpeded and would not meet the threshold for a diagnosis.

The condition was still terribly stigmatized. Some doctors do not recognise adult ADHD as a legitimate diagnosis and others are reluctant to prescribe stimulant medication to people suspected of having a drug addiction. But the medication could be life-changing, Prof Kohn said.

Ms Cook went to a psychiatrist for a thorough assessment soon after her son Ashton was diagnosed. She was put on a six-week stimulant medication trial.

"I have completely thrived," she said. "I have a clear mind instead of a billion things going on. I was suddenly able to go to work and complete mundane tasks ... I started a business course, my house is neat and tidy where it used to be chaotic."

She now embraces the condition as her "hidden superpower".

"You've got to use it to your advantage ... I'm really creative, I can think outside the square, I don't get caught up being over-analytical, I just go for it," she said.



By <u>Kate Aubusson</u>, Health Editor at The Sydney Morning Herald. https://www.smh.com.au/national/i-thought-i-was-a-loser-now-i-have-the-answer-rise-in-adult-adhd-20191101-p536kn.html



The Basic Ear and Hearing Care Resource is a publication by World Health Organization to serve as an information resource for community level workers as well as other interested members of the community.

The resource focuses on community involvement and raising awareness; and will provide useful information for preventing and addressing ear diseases and hearing loss.

https://www.deafnessforum.org.au/ear-and-hearing-care-resource/?fbclid=IwAR0v4XSQrnJI72OIPA TXd5S00Arq7RSNom dn2bjSwiie3BJBiVlbfNM7Y



Highlights in Deafness Forum's work in Jan-March 2020

Hearing services delivered by the Department of Health and the NDIS

Advice given to Government on the future of Community Service Obligation program and clients, with a focus on services for under 26 year old who will be transitioned from the Australian Government Hearing Services program to the NDIS.

NABS

Advice to Government that it does not proceed with planned transitioning of the National Auslan Booking Service to the NDIS until it is ensured that all current users will continue to access the service.

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Feedback to DRC Community Engagement on the efficacy of, and recommendations for improving communications accessibility, in relation to virtual engagement during this pandemic.

Button battery safety

Advice to the Australian Consumer and Competition Commission to help ensure that changes to consumer laws don't result in further impediments to the use of hearing devices.

National Disability Insurance Agency workforce

Contribute to the development of a national plan to build a capable and sustainable workforce needed to support NDIS participants.

Captions on Government announcements, including emergency announcements on TV and social media

Recommendations for changes to the Broadcast Act and signalling problems with social media captioning.

Australian Institute of Disaster Resilience

As a follow-up to the eastern states' bushfires, inputs were given to communications access considerations for the next update of the Government's Disasters Managers' Guide.

Australian Public Service Commission disability employment strategy

Inputs provided to a review of the current strategy to improve ratios of people with disability working in the Public Service.



Do you have a question about coronavirus (COVID-19)?



The Disability Information Helpline, funded by the Australian Government, can help families, carers, support workers and services. It's free, private and fact-checked.

You can contact the Helpline in the following ways:

- Phone (free call): 1800 643 787
- If you are deaf, or have a hearing or speech impairment, you can also call the National Relay Service on 133 677

The Helpline is available Monday to Friday 8am to 8pm (AEST) and Saturday and Sunday 9am to 7pm (AEST). It's not available on national public holidays.

Contact the Disability Information Helpline if something is worrying you. For example,

- your provider has stopped services
- it's hard for you to get food, groceries, medications or other essential items
- someone close to you has symptoms of coronavirus
- you are feeling upset
- anything else is worrying you.

Know someone who might like to get their own 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, and to elders past, present and future. We acknowledge the challenge of overcoming high levels of ear health issues among First Nation people and its role in Closing the Gap. We acknowledge the risk to indigenous sign languages of disappearing and the importance of Auslan.

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

Items in Deafness Forum communications may incorporate or summarise views, standards or recommendations of third parties, which is assembled in good faith but does not necessarily reflect the considered views of Deafness Forum or indicate commitment to a particular course of action. We make no representation or warranty about the accuracy, reliability, currency or completeness of any third party information. We want to be newsworthy and interesting and our aim is to be balanced and to represent views from throughout our community sector but this might not be reflected in particular editions or in a short time period. Content may be edited for style and length.