

Disability Excellence: Big Dreams, Limitless Futures

A paper by Mark Robinson SC to the University of Sydney's
Disability at Work Network (DAWN)
given on campus on 13 September 2022 at the Chau Chak Wing Museum

I have been invited to speak today by the Disability at Work Network (DAWN) which was created in 2014. It is for university staff with lived experience of disability and those who want to help create a disability-inclusive university. It connects staff and provides a supportive environment to allow shared experiences. It is useful in other areas connected with university life especially when changes are proposed or barriers are identified.

For myself, I have a hearing impairment in both ears.

I am often told that I am just not listening. I am sometimes told I am stupid.

Most times, only one of those things is correct.

In truth, I always hear what I can (when I can) and, in my experience, stupidity is no bar to a fulfilling career in the law.

In June 2005, I was privileged to be asked by the NSW Bar Association's Equal Opportunity Committee to chair a major seminar on disability discrimination. I chose that event to publicly speak for the first time about my hearing loss. In November 2010, the NSW Law Society's Young Lawyers Section asked me to speak on the topic "How Accessible is Your Daily Life". That was the second occasion. My talk today is the third occasion that I speak about my deafness.

At that seminar in June 2005, I gave a blow by blow description to about 100 barristers of just how difficult it was in practical terms for me to conduct a case before a judge and/or jury while being deaf at the same time.

I am still paying a price for coming out as it were in a number of ways. For example, for years, a senior counsel and colleague came up to me (in the street or in the lift) and said loudly, "*Can you hear me, Robinson? Are you well? Are you sure you can hear what I'm saying?*".

The word has spread wider as well. Judges sometimes lean close into the microphone at the commencement of hearings and say (sometimes loudly) "*Is everything alright, Mr Robinson? Is the hearing equipment all working?*".

These are only some of the challenges.

I have congenital deafness in both ears described as *sensorineural hearing loss*.

It used to be described as “*nerve deafness*”. I was born with a mild to moderate loss. It has progressed with age. It is now in the severe range. Recently, an audiologist told me I was now 70% deaf (whatever that means). I am not looking forward to being profoundly deaf (in the next 20 years or so).

I was one of 7 children growing up in Sydney (my Borg designation was 5 of 7). My parents did not pick up my hearing loss until I was 7 years old, in my second year at primary school in Sydney. This was surprising in the circumstances, as my father was deaf (and four out of six of his siblings were deaf), and three out of four of my older siblings were deaf. I turned out to be the least deaf of all of them. I remember clearly about then, an audiologist came to my primary school and conducted hearing tests on all the children. When it was my turn, we were talking for a while and he then conducted the test on me. He held a large alarm clock about 6 inches from my ear and said “Tell me when you hear the ticking.” It was only when he brought it in closer and closer, and, finally, when he pressed it firmly against my ears that I could hear the ticking sound. He said “*You have a significant hearing impairment. I am astonished that you are able to speak at all, let alone speak clearly and well*”. I said we have a deaf family at home and we turn up the television and speak very loudly to each other!

I was to hear similar remarks from different audiologists all of my life.

The then National Acoustic Laboratory (now Hearing Australia) looked after me and fitted me with hearing aids (the currently correct description is “*hearing instruments*”) in my second year of school. After University, I was looked after by Audio Clinic in Sydney and now, Value Hearing. I have worn hearing aids since I was 7 years old. There are many hearing assistive devices or assistive listening devices available as well.

My problem is hereditary.

I carry a dominant mutation gene, which has not yet been identified. I got it from my father. It is likely a single gene. It affects both men and women. If you have the gene, there is a 50% chance you will pass on the deafness to your child (and that person will have a 50% chance of passing it on again). It stops with the person who does not receive the gene and it cannot then be passed on. It has been in my family for five generations. I passed it on to one of my

children (two have perfect hearing) and I have quite a number of deaf nephews and nieces.

As to the mechanics of the problem, the cochlea (the inner ear) is a snail shaped shell filled with fluid and which contains many microscopic components, all of which behave much like a microphone.

When the liquid inside the cochlea is set into movement by sound, it then sets the membrane and hair cells into vibration. Different hair cells correspond to different sounds. The high frequency cells are mainly positioned on the end of the "*tube*" where they will be the first "in the line of fire" as it were, as all the sounds will reach those cells first. That is why, in a typical hearing loss situation, the high frequencies are affected more than the low frequencies. Low frequency cells are positioned at the top of cochlea so they are not so much exposed to loud noise.

The vibration converts sound waves into a message that travels to the brain via the auditory nerve. There are about 250,000 hair cells inside the cochlea and they start deteriorating from the moment we are born. That is why almost all aged people have some noticeable hearing loss.

I just got a head start on the deterioration of the hair follicle side of things.

My kind of hearing loss has other practical deficits as well.

There are things that I simply cannot hear at all, no matter what the situation.

In speech, when I do hear what is said, the vowel sounds can be heard okay, but the consonants are often heard wrong. This is because the vowels sound on the lower frequencies and the consonants are in the higher frequencies. This means, in practice, that I often hear wrong. It never ceases to amaze me some of the silly things that are said to me (because I have heard them wrong). Because of this, I need to lip-read all the time or rely on captions if available.

I need to ensure that what I am hearing is in fact what was said.

Hearing aids only amplify this understanding problem. I still need to lip-read while wearing them.

Often, it takes a few seconds after I have heard something for me to work out what was in fact said. I go through a constellation of possibilities to ascertain the likely correct word.

Sometimes this is done in less than a second. There's probably a confused or blank look on my face while I do this, which is itself sometimes confusing to the person speaking. I am also trying to work out if I can safely just respond with "okay" to whatever was said and get away with it (this time, and yet again).

One other problem with hearing aids is that they destroy the ear's natural capacity to collect sounds and inform the listener from where the direction of that the sound is coming.

With hearing aids, I have almost no sense of direction. I have never had it.

Also, many hearing aid wearers, including me, suffer from tinnitus. It is a particularly cruel side effect for some to have silence replaced by constant noise, even when you take out your hearing aids.

I wore two analogue hearing aids for most of my life. They were made up of a microphone, and amplifier and a speaker. Basically, they were a miniature home stereo system that sat in or behind your ears.

They were loud and the sound was harsh and never comfortable. When I received my very first pair, I wore them to primary school. My teacher asked me to take them out and pass them around the class, so that the other students could see them close up and understand what I was wearing from now on. I complied, but I was a little uncomfortable about it. Looking back now, it was a horrible thing for my teacher to ask.

When I studied economics at Sydney University in the late 1970's, there was almost no hearing assistance that I could tap into. I sat in economics lectures in the Merewether Building with 500 other students and listened for an hour while the lecturer (Professor Bruce Ross, Economist) read out a prepared text every lecture and everyone was head down writing it down word for word. My difficulty was, as you can imagine, I could listen and lip-read and understand the lecture or I could attempt to write it down and lose some of the lesson and therefore often lose the gist of the entire topic! After a few weeks of this same pattern, I approached the lecturer in person and explained my problem. He said "No Worries" and dipped his hand into his bag and handed me a full typed set of the entire semester's lectures. I was ecstatic. It restored my faith in humanity.

I had the same problems in lectures in the Carslaw Lecture Theatre. It was always packed with hundreds of other students and the acoustics of the room was terrible.

When I switched to Law at Macquarie University, the subject was taught in tutorials only and no larger classes than 25 students. We were always seated in a circle, so I was able to see and lip-read everyone.

When I started work as a legal researcher in the NSW Law Reform Commission, all I really needed was a special volume controlled telephone. Once installed, I was able to function properly.

I have never been able to use a telephone like normal people.

I simply do not hear sufficient sound through the earpiece. There are some phones available that have increased volume or loop coils (that work with the hearing aid's T-switch) or good speaker functions with a volume control. It is hard to find the right one. They are usually made and tested and calibrated by hearing people. I found one that worked well and I took it from workplace to workplace for many years. I used it at the High Court of Australia for 2 years when I worked as a senior legal research officer.

When I became a solicitor and it came time for me to appear in court, I was still wearing analogue hearing aids. I would turn them up full volume at times in order to ensure I did not miss anything. Often, I wore them at full volume for many hours at a time, just to get through a full day's hearing. I wore them so loud that I often tested my pain threshold and the mere rustling of paper in court would physically hurt me. It gave me headaches.

My first appearance in court as a solicitor was in the ACT Supreme Court in 1987. I worked for the law firm Mallesons Stephen Jacques. I was in the litigation section. My supervising partner pointed to a 60 cm pile of folders sitting on my desk and said you are in the Supreme Court at 10am for a call over for these 20 matters. The instructions for each matter are contained in the files. I said "What is a callover?" He said "You are in a list of matters. Just do what the others will be doing." It was 9am when he said this. I went to the court (my first time there) and sat down. I very quickly realised that I could not hear the judge and I could not hear the advocates appearing (solicitors and barristers) and I did not have a copy of the court list with me and I did not even know when my matters would be call on for hearing. It was a long morning and I was so traumatised by it, I vowed that it would never happen again. I would strategize, prepare better and use assistive listening devices where I could. And I did for the next 30 years.

I was fitted with new digital hearing aids in about 1998.

They significantly improved my ability to hear and understand in court. They had the same basic components as the old analogue aids – microphone amplifier and speaker, but some significant computer power in between.

They were a radical change in hearing. I heard moving water and rain for the first time. I heard the rustle of clothing on people's bodies for the first time. I heard breathing for the first time. I sat in the car and I said "What is that ticking sound" only to be told it was my indicator which always made that sound. While it was all wondrous, I also thought "How can you hearing people stand to hear all this noise all the time?"

I have had about 6 or 7 pairs of digital hearing aids since then.

Each time, the technology has improved and I am hearing new and different things. But I still need to lip-read.

The digital aids came with a "streamer" device which hooks on your clothes and plays music and allows you to receive, talk and end mobile phone calls. That was very handy. It works by wireless or, nowadays, Bluetooth. It also plays the phone's music or audiobooks directly into your hearing aids.

The digital instruments I now wear are state of the art behind-the-ear style hearing aids called "*Oticon More I*" made by Oticon, which are 100% digital and fully automatic.

Digital hearing aids generally have two microprocessors in them and they convert analogue sound to a digital signal and split the sound into two streams. The first processor increases the consonant sounds and the second decreases the vowel sounds and it is converted back to analogue sound, amplified and the gain is adjusted depending on the volume level in the area 1,000 times per second.

The new model I now wear has the ability to actually search for and focus in on human speech and further reduce background noise. The technology is improving every year.

I now walk down the street and I can hear what people are saying all around me for the first time in my life. It's a little unnerving, frankly. Who wants to hear all that?

The Oticon More hearing aids herald a new hearing aid technology called the Deep Neural Network (DNN) – it is said it mimics the way the brain functions. It is a fundamentally new approach to sound processing. The computational processing power and speed has increased

significantly as well. The sound is fantastic.

Until 2005, I positively resisted mentioning my hearing loss to anyone unless I had no choice.

When appearing in court, for example, from 2005, I commenced routinely contacting the judge's associate just before a hearing to ask them to inform (or remind) the judge hearing the matter that I am deaf and that I simply want the judge to be aware of that fact (and to do nothing about it). I was prompted to do this when I read in the newspaper that a District Court judge had declared a mistrial in a criminal matter upon him believing that one of the counsel appearing before him could not hear (it was not me). From then, I erred on the side of caution.

I did not normally mention the fact to my opposing counsel and, in Court, only the judge was aware of my disability.

I had to explain it all to any junior barrister appearing in court with me. They had to write notes to me during the proceedings instead of leaning over and whispering (which I could not hear). The upside is that I do not hear my opponent at the other end of the Bar table griping or whining about what I am submitting to the court. There are no distractions.

For many years, I have utilised the fantastic infra-red and FM systems available to all provided by the NSW Attorney-General's Department (in State Courts and Tribunals) and access the hearing loops installed in many courts by the Federal Court. When I am in court now, it may be a little obvious to all that I must have some disability because of the additional and noticeable equipment I must wear. Then again, there are so many gadgets around, perhaps they think I am linked to my computer by a wireless connection and I am taking my emails in court.

As a result of this new equipment, in court, I no longer depend in part on lip-reading and I can take better notes of the proceedings and the evidence for the first time. I am significantly less stressed at the end of each hearing day. As a backup, I also have a small portable battery operated Sennheiser FM system which I can set up myself anywhere quickly. It is 40 years old and it is very reliable. I call this "*Plan B*".

I personally lobbied the State and Federal courts and tribunals for many years to have them install hearing assistive devices. There was some significant resistance in some quarters. Sometimes, the wrong system was installed and I had to resort to Plan B in court or in a

tribunal. The main problems include, not testing the equipment, or batteries left to run dry or the wrong cabling or no cables at all. When it is all present and working, the sound level is not turned up sufficiently or calibrated properly. Sometimes it just cuts out. Sometimes the sound comes in and out and in again. Often it just stops.

Just on Monday last, I appeared in a tribunal. The infra-red system worked for 5 minutes, and then it failed. I resorted to Plan B and my own batteries failed. Fortunately, I was able to move to Plan C – my own new hearing aids and I was able to hear the proceedings sufficiently to go on.

Captions have been very important to the deaf community for the last 20 years or so.

Sometimes in court, captions are offered in an audio visual hearing, sometimes in WebEx or Microsoft Teams or in Zoom. You usually have to ask the host that captions be enabled. Unfortunately, there is no human being doing the typing. They are automatically generated, but they are better than nothing.

Captioning of movies and TV shows is also essential. It never ceases to amaze me the number of such shows that are not captioned in Australia. I have had to write a few letters of complaint in the past, seeking to have captions enabled on news related programs.

How to Speak to a Person who is Hearing Impaired

This is my own short list of how to speak to a person whose hearing is impaired.

First and foremost, be alive to or aware of that person's hearing loss – its nature and its extent.

Face the hearing-impaired person directly.

Before you commence to speak, gain their attention (this is critical, as well as being common courtesy).

Do not speak while in front of a window or bright light (lip-reading is very difficult).

Do not rush things, speak at a measured pace and in your normal voice and at your normal volume. Do not speak louder (as this distorts your voice and your mouth).

Do not repeat things. If what you are saying is not understood then say it in a different way.

Be patient (at all times) do not get frustrated.

Be alive to any background noise present. It can interfere. Shut the door if necessary.

Do not speak from another room. Ever.

Do not place your hands in front of your mouth or anywhere near your mouth. Not even for a second.

If it helps you, think of the person who is hearing impaired as someone for whom English is a second language. Often, when speaking to such a person, you speak clearly and you have patience and you look for signs that you are being understood.

Disability Council of NSW

On 14 December 2021, I was appointed by the Governor of NSW as a member of the NSW Disability Council. It was on the recommendation of the Minister for Families, Communities and Disability Services.

The Disability Council NSW provides independent advice to the NSW Government on policies that advance the equality, inclusion and interest of people with disability.

The Council's main responsibilities under the *Disability Inclusion Amendment Act 2022* (NSW) are to:

- Monitor the implementation of government policy
- Advise the NSW Minister for Disability Services on emerging issues relating to people with disability, and about the content and implementation of the NSW Disability Inclusion Plan and Disability Inclusion Action Plans (DIAPs)
- Advise public authorities about the content and implementation of Disability Inclusion Action Plans
- Promote the inclusion of people with disability in the community and promote community awareness of matters concerning the interests of people with disability and their families
- Consult with similar councils and bodies, and people with disability
- Conduct research about matters relating to people with disability.

We are currently formulating our own plan for 2022 – 2024. Our “five pillars” of activity in

that time may be:

- Accessible communities
- Ensuring the voice of people with disability is heard
- Employment
- Justice and rights
- Housing.

I have responsibility for Justice and Rights (with one other member).

We accept that people with disability face multiple barriers in accessing justice, including courts and tribunals. Some barriers are practical (such as physical barriers in old buildings; no hearing loops) while some relate to the quality of support provided to people with disability in the justice system. This leads to people with disability, in particular people with intellectual disability, being over-represented in prisons. This is in part a symptom of a broader failure to ensure the legal rights and human rights of all people, including people with disability. These barriers exist not just in accessing justice, but they travel along the justice pathway. People with disability in prisons, on remand and those subject to control or supervision orders have particular needs that are not always identified or properly accommodated.

The Council will likely commit to:

- Work with DCJ on courtroom and tribunal physical and hearing assistive devices
- Review the DCJ Disability Inclusion Access Plan to identify gaps/opportunities to promote access to justice and the rights of people with disability
- Meet with the Secretary, DCJ and relevant Executive to discuss findings
- Advocate for policy and legislative changes so as to ensure full access to the justice system for people with complex communication needs.

It is early days for me, but I look forward to engaging with the disability community and its very many organisations and representative groups on this important topic.

Being a person who is deaf, I am pleased I have been able to have a satisfying and relatively successful life and career so far.

My other family members have also fared well.

My father taught in a school for decades. He struggled with his deafness in the last few years of teaching. My eldest brother was also a school teacher for decades. The next eldest brother worked for IBM Australia and became the Manager of National Product Standards and Compliance Engineering in Australia and he sat on many international standards committees meeting in countries all over the world representing IBM and Standards Australia. The committees deal with electrotechnology, cabling, television transmitters, regulatory compliance and the safety of electronic equipment.

The only limits that a person who is deaf must live by are those we set for ourselves.

Thank You.