

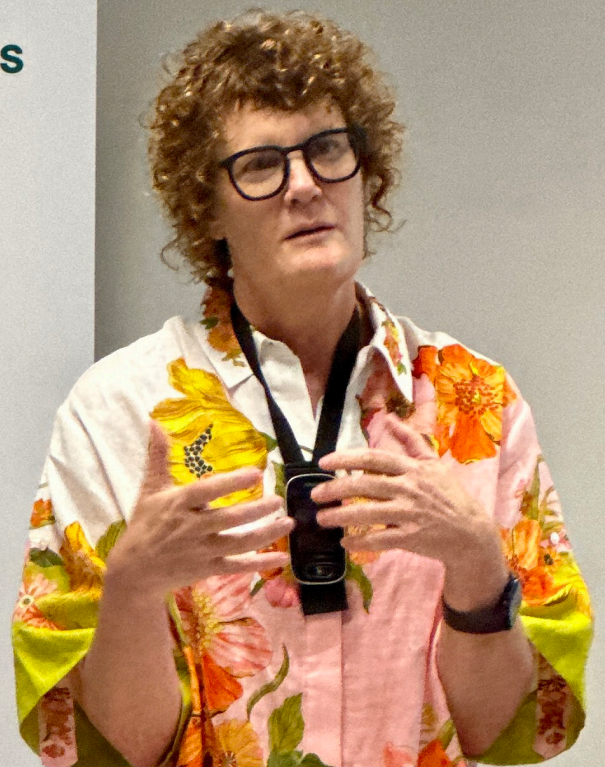


**HEARING MATTERS AUSTRALIA**

Support from real life experience

Australia's go-to destination for people with hearing loss

national support organisation



## Libby Harricks Achievement Award 2023

By **Katie Neal** at HMA AGM on 21 October 2023

**just wanted to start by saying thank you. I feel very undeserving of such an honour and award.**

I have always attended the Libby Harricks orations, which have been a great source of inspiration. Thank you to Aleisha Davis, Joanna McAdam, and Pia Watkins for quietly nominating me. Thank you also to the board for selecting me from among other deserving candidates and to Simone Punch, who has been a supportive presence throughout this process.



This is a good image to describe me at work: a bit chaotic, much like my mind. There's always a

lot going on. Pia, who is on my team, can relate to this photo. Work is constantly an experiment—sometimes successful, other times not quite. It's a mix of laughter, frustration, and sometimes sadness, but it's also a space to explore and think about what happens if we turn things upside down and connect things differently. It's a shared space with lots of clever and passionate people.

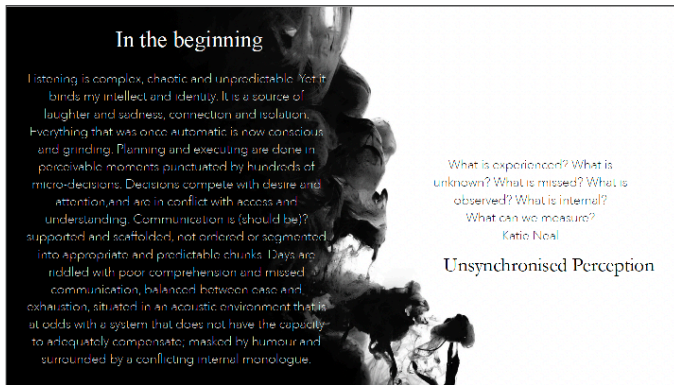
I thought I'd share with you today a little bit about my story and what it means to me now as an adult with profound hearing loss and cochlear implants to be working in this field and what I hope we can change. You've heard a bit about what I do for work, but the story of how I lost my hearing is maybe unusual. It started at the World Audiology Conference in Brisbane. First, I lost hearing in one ear, and then, three months later, in the other. So, I had a profound and sudden experience of hearing loss in a short period. I will say from that perspective that Chris, my beautiful husband, who has never heard me speak about my experience in public before, will know that my hearing wasn't just about me but very much about my family and

Images: Supplied.

my friends and how they experienced me and how I changed for them.

### Where I started?

*“My hearing was part of me. It was the part that facilitated my humour, that often enabled my empathy and connected me to the humans around me. It was tied to my intellect and how I navigated the world.”*



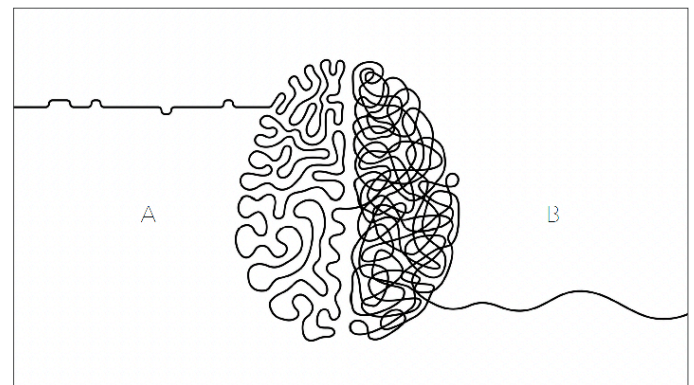
What I learnt when I lost my hearing was how integral my hearing had been to me as a person, how it defined my intellect and humour, my source of empathy and communication to the people that I loved and it really connected me and I didn't understand that before I lost it. That experience initially was a really emotional one for me. It was emotional because I had a 14 year old son who was becoming an emerging teenager with this beautiful complex mind, fast speech, rapid ideas, and we always had this very strong bond and I lost it really quickly. I couldn't understand him easily and he didn't know how to adapt. That for me was very heartbreaking.

I will say that as Chris is here, he has been the most intuitive communication partner that anyone could ask for and scaffolded me the whole time, so I just wanted to say thank you to him and to say that my story is also one being surrounded by people who have held me through this process. That's where I started and was what I understood.

What happened next when I lost my hearing was really about me just having this concept of unsynchronised perception, that what I understood and what I experienced didn't match. I read a beautiful story about TS Elliot being in love with someone but the timing was always off. This was how it felt for me: my timing was off. When I understood something, it was five minutes after someone said it. I had to try and put bits of

information together in real time, like a constant game of Scrabble trying to make sensible words that would fit into the conversation. There were so many things that I felt were really difficult and I didn't have a way to centre them in my world, especially where I worked, when I'd been an expert in that space. Probably not the expert I thought I was until I lost my hearing, I will say, but I was also just trying to navigate and understand not only for myself but for my family at the same time.

So, what it led me to think about was the measures we use with hearing loss being unrelated to the experience. They don't tell us about the experience of adults or children and the way that they navigate and communicate in life. So, this is a quote from the beginning of my thesis – about how I perceived my communication and what it felt like for me.

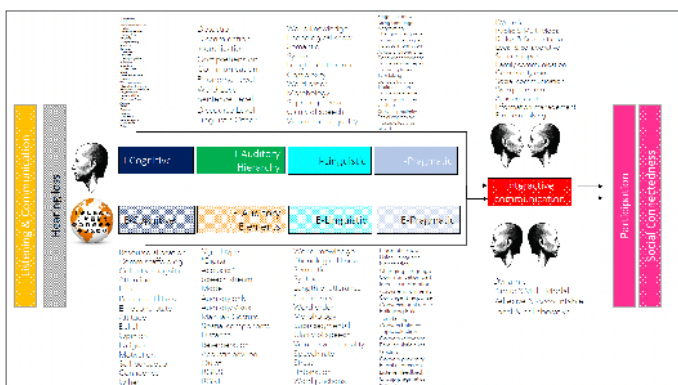


This formed the foundation of my research and work initially: really understanding how I go from A to B, how do I go from what I'm hearing and understand now as a bilateral cochlear implant user to communicating and navigating the world. The other thing that I explored in my own journey was just trying to understand what my identity was at that stage, because I wasn't hearing any more. It felt fraudulent to say that I was deaf because I'd worked with congenital infants for a long time and I didn't have the same experience as them, they grow and learn with their hearing as part of who they are. So I didn't really have a place to respond or answer the questions that people had about who I was, and I think I was still learning at the time about who I was, and so for me, there was lots going on and it really drove the research that I did and what I explored.

This is a quote that came out of my thesis: that people rarely experience listening or communication in the context of which it's measured. It's linked to the work of Richard

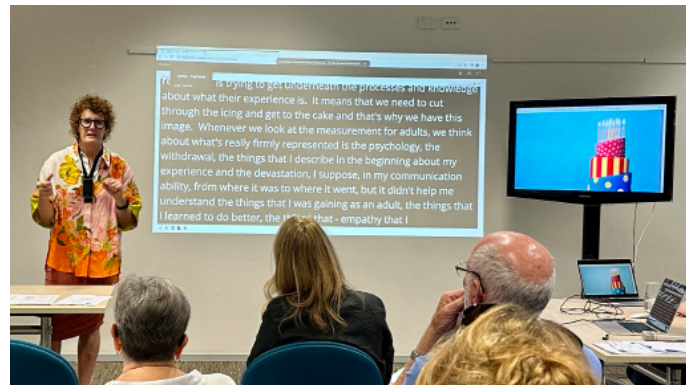
Dowell and his team about the importance of early cochlear implantation. Their work looks at the value of loss for adults when we don't support them to access communication in a full and rich way at the point when they need it. This was the beginning of my thesis work.

I did something a bit ridiculous for my thesis. I looked at 16,000 articles to understand how we really measure hearing loss and communication, using research publications as a proxy for this. From these, we extracted relevant measures to look at what are we really doing. Have we changed what we're doing across time? There's lots of information and evidence that tells us about cognitive hearing and impacts of hearing loss but we haven't shifted the experience of people. This work aimed to explore that in a more complex way and to understand: Are we changing with the times? Are we honouring the stories of the narrative of the people that we work with? And the answer was, no. I think I knew that before I started, from the work of many researchers and the previous evidence from Grandberg et al that categorised measurement for the ICF, but now it was laid out in numbers and across time, evidence that suggests that's the case. So you can see that even in 2021 when I finished the analysis, we still really focused on narrow concepts for adults. Infants often have more complex and complete pathways, and in adults, we concentrate on hearing levels, speech reception, passive communication pathways, possibly, depending on where you are.



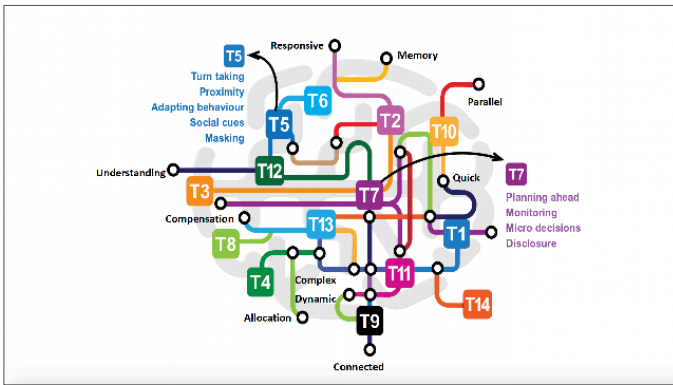
This is a model of what communication might look like for us as adults, the complexity that it contains and explores how we move through this process and understand this in a more complex and experienced based way. Simone Punch was part of my work and she gave me some beautiful insights into the different things that we do about

the internal nature and experience of hearing loss and the external representation of it as a communication partner or a communicator. So, this is just looking at this model, you can see how rich nuanced and complex it is if we just list things that we know from a very theory based perspective, and you can see how that contrasts those two very small measures that were represented before. It might also tell us that we need to support adults to understand how communication and hearing are linked, because for most adults that connection is missing.

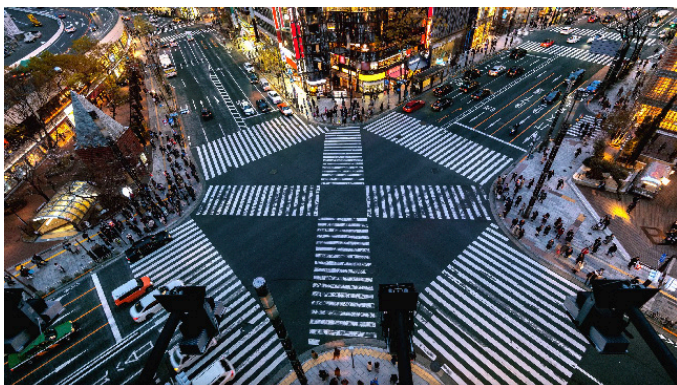


The other thing I learned was that if we really want to understand measurement, we also have to embrace the very pervasive and impactful perspective of the psychology of hearing loss for adults: what is really hard is trying to get underneath the processes and knowledge about what their experience is. Whenever we look at measurement for adults, we think about what's really firmly represented is the psychology, the withdrawal, the things that I describe in the beginning about my experience and the devastation, I suppose, in my communication ability, from where it was to where it went. But this representation and perspective didn't help me understand the things that I was gaining as an adult, the things that I learned to do better, the empathy that I regained in a different way, and that hearing wasn't the only thing that is beneficial to communication, so it really started to help me understand that there are lots of strengths that come with hearing loss. Working in paediatrics and with adolescents is a privilege and showed me that families know that the strengths are there. The system builds in a beautiful and dynamic way just as much as a hearing system does, and we need to honour that story from the very beginning and be honest about what the experience is like across the lifespan. That the experience of communication will be different and complex and that deafness will always be part of that experience.

Images: Supplied.



This is just some modelling (and it's much more complex than what is represented here) about what hearing might look like for an adult when they're just having a conversation: about all of the incredibly complex and sophisticated things that happen and what they do, about how they navigate communication and how that is represented in their mind and how clever they are. I think that's one of the things I'd love this work to represent, as well as conveying the responsibility that they carry as a communication partner. I'm in awe of the things we're doing just while we're having a conversation, just listening to each other.



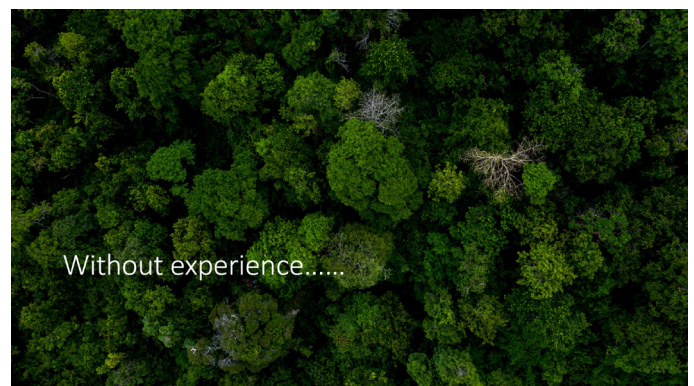
Aleisha will appreciate this picture which is something from the very beginning of this work. When we used to talk to parents about learning to listen, we said it was like when you first learnt to drive, it is driving in a car park, there is nothing around, you've got lots of space and you can practice with ease. But really communication is trying to cross this road, maybe without any traffic lights and without any crossings, and we need to build systems that can support people to do that in this way.

I think nine years post my hearing loss I'm happy to say that I'm a deaf adult. I'm really happy to embrace my deafness as a person. I'm not hearing any more and I miss it sometimes. I don't think I miss it actually any more. It has definitely shaped my family, my beautiful family who I say thank

you to again. It's shaped my perspective, given me insight and understanding and empathy that I didn't have before, and introduced me to some of the most remarkable people I know, the people who participate in this work, the generous researchers pushing boundaries, my colleagues at work and the hundreds of families that adults that we work with and listen too.

So, this is my unravelling, I suppose, over time. There are different sides of this discussion, and what I hope this research does, and it is very much the work of many beautiful minds and people, is start to change the narrative from the very beginning, that hearing loss isn't always about losing something, it can be about gaining something, and for children we can reframe it in a positive way. I think what hearing loss needs is a really good marketer, just so that we can change perspectives and change our understanding and inform people, and that's what I hope this work does, is really give them a sense of understanding of their experience and the tools to look at it slightly differently, with a slightly different lens rather than the one we may have represented it with originally.

I think without experience, without all of you, without all the people who have hearing loss, we really can't see the forest or the grass through the trees. It is important to build measures based on people's experience and not be afraid of the complexity that it brings.



So, thank you for having me and for listening to me. I really appreciate being awarded this. It is very humbling to me. Thank you.