

SOUNDFAIR

SUBMISSION TO THE



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



Soundfair thanks the following contributors to this submission, many of whom wished to remain anonymous:

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ACKNOWLEDGEMENT OF PEOPLE WITH LIVING WITH HEARING CONDITIONS

We would like to acknowledge and pay respect to those living with hearing conditions who have fought hard for their right to be heard. Your strength and resilience are invaluable to Soundfair, and the general community. We would like to acknowledge and thank the Rankin and Gunning families for their generous bequest donations. We are beyond grateful for these respective investments. These types of donations allow us to deliver person-centred care for our clients, supporting them to live connected lives and overcome the emotional and social impacts caused by hearing conditions.

ACKNOWLEDGEMENT OF COUNTRY

Soundfair would like to acknowledge and pay respect to the traditional custodians of the land in which we conduct our business on. We would like to thank Elders past, present and emerging.



SOUNDFAIR

INTRODUCTION

When we are talking about physical accessibility, putting a ramp into a building is something that people get. They understand that if there is one step, the person in the wheelchair will not be able to get in. But where is the consideration in terms of communication access?

– Sarah

According to the World Health Organisation's World Report of Disability, employment rates for people with disabilities are lower than those of the overall population (12.1% lower for men and 10.3% lower for women).¹ The impact of these rates is considerable given that there are close to four million people with hearing loss in Australia² (approximately around 1 in 6 people) of which more than 11,000 use Auslan as their primary communication mode.³ The daily impacts of hearing loss are predominantly psychosocial. That is, hearing loss impacts communication, relationships and intimacy; workplace performance and progression; and confidence, self-worth and agency. Hearing loss can ultimately lead to degrees of social isolation and experiencing loneliness, alongside increased risk of depression and anxiety and, if not acted upon, is a risk factor for dementia symptoms.

To understand the causes of such inequities, we must first understand the framing of disability in our society. There are two prevalent ways to view disability: the medical model and the social model.

The medical approach understands disability as a physiological problem to be solved by physical health interventions. In the case of hearing loss, for instance, a medical model's solution is adopting the use of hearing aids to overcome the loss of sound audibility. While hearing devices are critical for many people living well with hearing loss, a myopic focus on technology as a solution to what is a complex psychosocial condition leaves most people with hearing loss experiencing significant residual activity limitations and participation restrictions.^{4,5,6,7,8}

Moreover, by providing a 'solution' to the individual, the sole responsibility for overcoming a disabling world is placed on the individual, whereas those around the person with hearing loss, and social, educational and vocational environments, incur no responsibility to be accessible and inclusive. A medical (and, for hearing loss, a device-centric) model can become a form of "victim-blaming" as the person constantly bumps into a glass ceiling that they have no agency or power to change.

Since the late 1960s, a second conceptualisation of disability has emerged: the social model of disability

captures the political experiences of people with disability; shifting the analytical gaze from the individual alone to including society and focusing on how social environments, such as workplaces, educational institutions and the structure of social activities, can limit and/or exclude certain groups of people.⁹

From the social model of disability emerged the term "disablism", which refers to "a form of social oppression involving the social imposition of restrictions on the activity of people with impairments and the socially engendered undermining of their psycho-emotional well-being".¹⁰ In essence, disablism states that people with hearing loss, for instance, are not disabled by their hearing conditions. Rather, it is the discriminatory societal structures that exclude them from communication access that are disabling.

Disablism can take many forms. Able-bodied norms, for instance, can exclude people with disabilities from the workforce, effectively disabling them.¹¹ In addition, formal policies targeting employees with disabilities can become tokenistic or further alienate people with disabilities by making them "special" and an "exception".¹² Disablism can also lead to stereotyping and stigmatising practices among colleagues and managers that are detrimental to the disabled person's confidence and wellbeing, leaving them at a disadvantage. Finally, it is important to note that the effects of disablism can spill over into other areas of people's lives. What happens in the workplace can have a long-lasting impact on personal lives and relationships, even if not directly correlated.

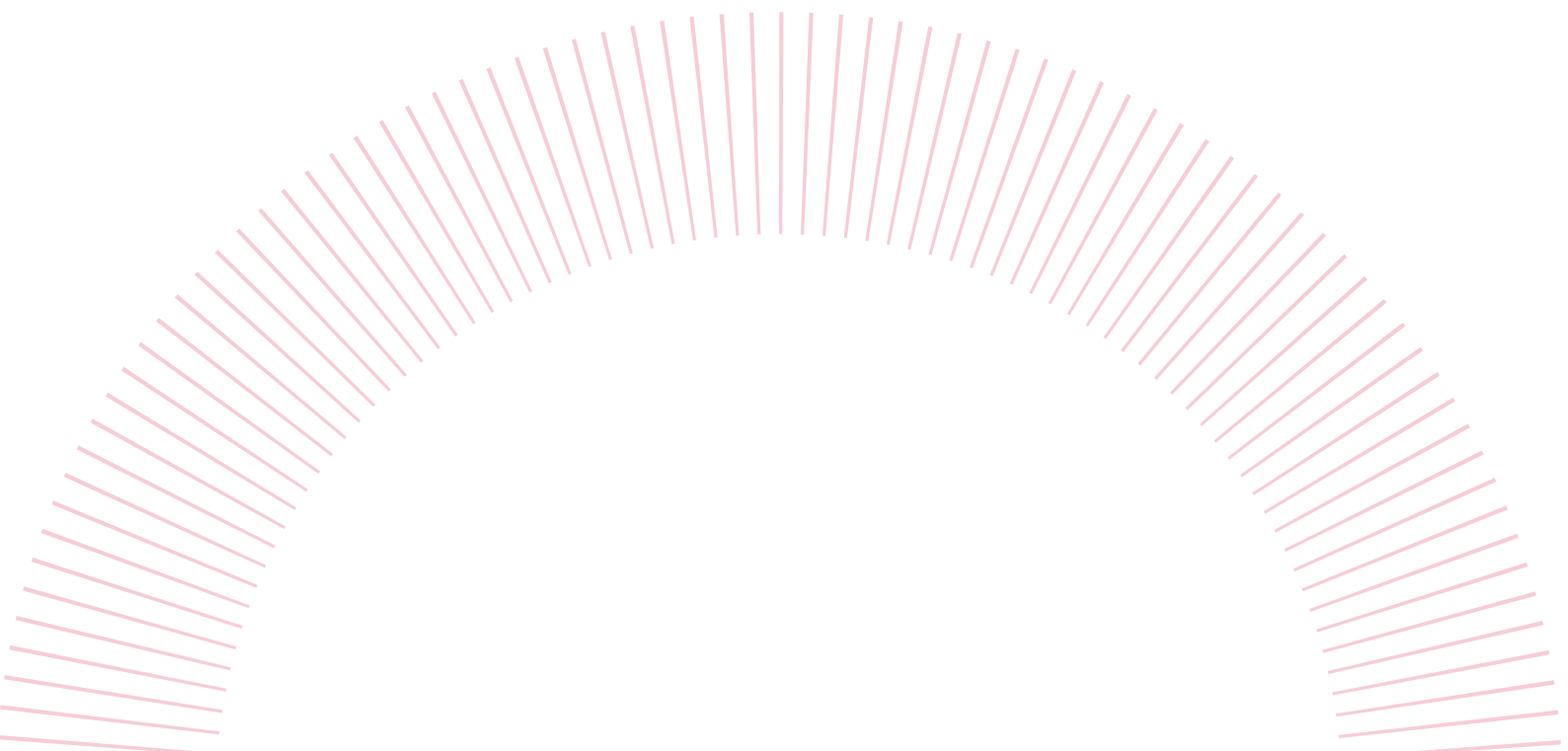
The collected stories in this submission shed light on the impacts of disablism at the workplace. They recount lived experiences of violence, abuse, neglect and exploitation that people with hearing loss face on a day-to-day basis with the hopes that they allow the Royal Commission on Disability to identify key themes and, thus, identify the necessary steps to pave the way for a more inclusive society.

In September 2020, Soundfair collated lived experiences of abuse and discrimination from people living with hearing loss. From these stories, the following key issues emerged.

KEY ISSUES

1. Workplaces are often inaccessible, lacking the basic necessary conditions that would allow people with hearing loss to perform comparable to their peers without hearing loss.
2. Because the medical model of treating hearing loss with devices has predominated, there is a lack of willingness and/or or interest from individuals and/or organisations to (1) educate themselves and (2) make accessible for and include people with hearing loss, thus leaving the current problems and limitations unsolved.
3. Stigmatising attitudes permeate work culture and the broader society, perpetuating low confidence in people with hearing loss, negatively impacting their self-esteem, and increasing the likelihood for them to leave the workplace and socially isolate.

In line with the above, our submission comprises of three parts: In the first section, we highlight individuals' experiences with discrimination in the workplace. In the second, we analyse the effect these experiences had on their vocational confidence, success and career progression to better understand the impact discrimination has had on people's lives; and, in the third and last section, we share recommendations from the people who shared their stories on how to build a more inclusive society for people with hearing loss.



EXPERIENCES OF DISCRIMINATION IN THE WORKPLACE

I was working as an administrator at a local high school when we got a new boss. She was supposed to be an expert in supporting kids with special needs, however, she would never look at me when speaking, would eat at her desk and talk with her mouth full. One year later she changed the office to open plan and I just couldn't hear anything.

I decided to go to my HR Manager to voice my concerns. He simply said there was nothing they could do; that I was 'not going to change people' no matter what I did. I tried to be proactive and suggested that I could run some workshops on how to communicate with people with hearing loss. He declined, said I was not qualified. He suggested that I print out a sign that said I had a hearing loss and put it in my desk for others to see instead.

I decided not to give up and take the matters higher. I went to my union. That did not go well either. I was advised to get government funding to get some equipment that could help me with my hearing. The woman that came to assess me had no experience with hearing loss and didn't know how to read an audiogram...I ended up with a massive pile of equipment in my desk that wasn't compatible with my hearing aid and that I didn't know how to operate. By then my boss was very angry at me. She started taking tasks like reception and organising meetings off me. She stopped including me in meetings. I decided to resign. – Courtney

A person's professional career is a journey comprised of several transition points. It starts when transitioning from educational institutions to the workforce, shifts and grows every time a new job and/or position is sought out and finishes with retirement. At each of these stages, people with hearing loss face additional challenges that can place them in an uneven field or exclude them from participating in the workforce outright.

GETTING A JOB

When finding work, the stories we collected reveal that most people with hearing loss decide not to disclose their hearing loss at job interviews for fear they will be disqualified before being given a chance to prove their skills.

"The idea of having the conversation about reasonable adjustments with an employer requires a level of self-advocacy. It requires me to be vulnerable or, at least, makes me feel vulnerable, and some days I just don't want to go there." – Sarah

Most people adopted this strategy after having a negative experience that deterred them from disclosing this information in future occasions.

"I knew that I could do this job, but I also knew that people who don't understand hearing loss have low expectations of what people can achieve and do. One time, for instance, I applied for a job that entailed helping offenders go back into the workforce. I decided to tell my interviewer that I had hearing loss and she immediately said: 'you're not suitable for this position. Commonwealth Bank hires people with disabilities – maybe that would be a better fit?' After that, I decided to get the job first, prove my ability and then tell them about my hearing loss." – Courtney

"I recall applying for a job as an Early Childhood Educator only to be rejected due to the staff members being concerned about the 'supervision and the safety of such young children in the play areas' if I was unable to hear. I also tried to work in community development and primary health care but I was constantly made to feel that if I missed someone's name or a specific detail I was the one at fault and it was up to me to listen better and pay more attention." – Christine

While getting a job is hard for people with hearing loss, losing one is often easy.

"I enjoyed working in sales, but I had hearing loss and didn't know it. At times, my manager had to take over because I couldn't hear clients properly, so I couldn't sell to them. This made me look incompetent and unconfident. I was told it would be a good idea to look for a career change. In the end, that's what I did." - Jane

"I often got jobs in sales and telemarketing where I couldn't hear, so I would get the sack. Once I was doing some training in a telemarketing company. We were sitting in a semicircle, our backs towards the trainer, who was in the centre of the circle. When I said I couldn't hear her very well, she simply said 'well, if you can't hear me you can't do the job'. I was sacked within two hours. I probably got sacked from 20 jobs overall." - Jane

THE GOOD, THE BAD AND THE UGLY: NAVIGATING WORK WITH ASSISTIVE DEVICES

"I find frustrating reaching out to government services because you have to ring them all the time and, as a deaf person, that's impossible." - Frank

Once in the workplace, the main barriers people with hearing loss face are around having effective communication with their peers. Businesses rely heavily on the phone to communicate, which is a particular struggle for people with hearing loss due to: a) the lack of visual cues to complement distorted or reduced audibility and b) most telephone signals do not transmit above 3kHz (important frequencies for speech understanding, especially if you are needing to hear as much content as possible due to your hearing loss).

"In business, people typically use phones when they need a quick response or are discussing a sensitive matter. A phone remains a standard everyday tool for communication, even with all the other modes of communication available, because not all tools are comparable or used for the same purpose. When my clients and peers (with or without hearing) rely on being able to contact me by phone, I need to be enabled to be contactable by phone to perform my job. Removing me from jobs that don't require a phone is career limiting and disempowering. All people need access to functional devices that enable people to effectively communicate by phone." - Gillian

Before 2020, the CapTel phone (a proprietary handset phone, with captions provided onscreen by relay officers) proved to be a suitable tool to overcome this barrier when it comes to telephone communication: by simply pushing a button when using the phone, people with hearing loss could read accurate captions while listening to the person on call and voice their responses effectively without having to disclose their condition to anyone.

"I cried with joy the first time I was introduced to my CapTel Captioned Phone because it was the first time in my life that I could converse over the phone

with discreet dignity and on an equal level. I was devastated to learn that the Federal government was axeing the CapTel due to changes to the National Relay Service and transitioning the hard of hearing backwards to outmoded complex technology."

- Christine

None of the National Relay Service (NRS) current services have :

1. been demonstrated to provide comparable access to a standard telephone service on terms, and in circumstances, that are comparable to those on which other Australians without hearing loss have access to a standard telephone service.
2. meet key standard telephony features and requirements that other Australians without hearing loss enjoy in the workplace, including:
 - to receive direct incoming calls, including calls transferred in-house (i.e. how does a known or unknown caller know who they need to call via the NRS?)
 - callers can leave phone messages that can be accessed with audio and captioning
 - the choice not to disclose disability / impairment

People with hearing loss are often made to feel as if it is their responsibility to adapt to an inaccessible world instead of being offered tools, such as CapTel devices, with which to mitigate inclusion barriers.

"My daughter had a front office position and was chastised every time she failed to take down the caller's name and correct message details. When she asked for workplace modifications and support, she overheard a colleague say they 'never would have granted the traineeship if we knew she came with a Disability Employment Support person'. We both have submitted complaints of discrimination to the relevant commissions (EO and Human Rights) but during conciliation meetings it always comes down to 'we can't possibly afford to accommodate interpreters/note takers/scribes or live captioning as needed.'" - Christine

EXCLUSION ZONES: HIDING IN PLAIN SIGHT

Other than phone-call and technological challenges, in terms of daily work life, open-plan offices are especially detrimental to people with hearing loss: the constant background noise makes it harder for people to hear others and the walls between desks makes it impossible for them to see other people's faces when communicating.

"I had a boss when I was working in local government that would come to me twice a day, whispering in an open-plan office. For ages I just nodded and said yes. At some point I told her I couldn't hear her and asked if we could go to another room to talk. When we did, she still mumbled and covered her mouth when she talked. She just couldn't change her habits." - Jack

"I reported to a Director at the NDIS that had no concept of how to work with a person with disability.

My hearing loss started after my ears burst in a flight. After getting treated, I went back to work. I was working at a local council, facilitating community groups. However, as I was going into that room, where I had facilitated countless workshops, I had waves of anxiety flood over me. I felt nauseous, realising I did not think I had the ability to pull it off now.

I decided to ask the organisation if I could have an additional team member with me and was questioned about why I needed this. The thing is, I couldn't articulate why. I couldn't articulate my hearing loss well because I didn't understand it. I knew something was wrong. I knew something was missing. I knew I needed help. But I felt guilty about it. I was afraid of my hearing loss being interpreted as a limitation. So, I just started thinking 'maybe I can't do this anymore'. 'Maybe this work is beyond me now.'

I did not feel like I could put myself up for leadership positions because I didn't feel like I was able to communicate as subtly and as well as I once could in corporate environments.

- Jack

He sat on the other side of a divided desk and would yell out instructions. Most of the time I had no idea what he was talking about. Because of this, he and my other colleague developed a shorthand relationship that excluded me. Following repeated and unsuccessful attempts to improve the situation, one day I reached the point where I couldn't take it anymore, I walked out of the office and stayed home for three days until another manager who had understood what was going on, called me and invited me to work in another team." - Sarah

As briefly stated by Sarah, people with hearing loss are often excluded and even bullied at the workplace.

"Once I told my boss that I had a hearing loss, so they relocated me to the far corner of the call-centre by myself. I felt very isolated." - Jane

When people with hearing loss mishear, they are often faced with snickering from others, which creates feelings of shame and isolation.

"Gaslighting you with jokes when you mishear something is the worst thing. The footy club room is just not cool. I think that's why people are ashamed of admitting they have a hearing loss." - Courtney

Often these behaviours start well before the workplace. People with hearing loss who faced segregation and exclusion as children often decided at a young age not to wear hearing aids or admit to their hearing loss until well into their adulthood out of fear of facing that exclusion again.

"I was a very tall kid, so I always sat in the back row at school. When I was diagnosed with a hearing loss in year 2, I remember that I wore hearing aids to school and the teacher decided that I needed

to sit in the front row. This was the worst thing the teacher could've done because the other kids gave me grief because they couldn't see around me or over me. As a result of the abuse and bullying, I took out my hearing aids and didn't wear them again until I turned thirty and had a particular incident at work that made me realise the hearing aids and access to accurate communication was critical for other people's sake not just my own." - Sarah

"In primary school I experienced a lot of bullying and exclusion because I had a hearing aid. This made me determined not to let anyone know about my hearing loss. It wasn't until six or seven years ago that I got myself a hearing aid again. And this came about because I had a stalking incident from an ex-partner who happened to be a police officer and installed hearing devices in my house. He installed them while I was in the shower and couldn't hear him. Now, I am terrified. I hope the hearing aid can help me feel safe." - Courtney

HEARING LOSS: A CAREER-LIMITING EXPERIENCE

Because of the barriers that they find in the workplace, people with hearing loss often find they cannot progress in their career at the pace hearing people normally would, which they find demoralising.

"We operate in a society, and workplaces, designed for people who hear. Take fire alarms, for instance. If alarms are audio only and not accompanied by visual alerts, you may be dependent on other people to evacuate safely. During typical business hours, this loss of independence may be a compromise. However, this is raised as a work health and safety issue that limits one's ability to access flexible working hours in the absence of trained peers being on hand to relay the evacuation tones." - Gillian

“By this point in my career I would’ve had a good salary and been able to afford a place on my own. But for the last ten years I have had a very small, casual income. It can be frustrating when I think about it.” - Jane

“Many times, I would secretly retreat and sit alone in tears. In the end I gave up Children’s Services, which had a severe impact in my mental health. Day after day, I meet and look at people on the other side of the desk and think: I could have had your career and prestige if only I were given the needed tools and support.” - Christine

THE EMOTIONAL AND PSYCHOLOGICAL IMPACTS OF WORKPLACE DISCRIMINATION

The key issues highlighted above have a negative impact on the wellbeing of people with hearing loss. Workplace segregation, exclusion and fears around career development and ability to perform often lead to health deficits such as depression and anxiety.

In addition, the added effort necessary to perform day-to-day tasks leaves people with hearing loss feeling exhausted, which leads to social isolation, chronic fatigue, and risk of burnout. Jack mentioned that a day with “three or four meetings or a two-hour workshop” will exhaust him. And Sarah said that by the time she gets home from work she’s “shattered from the effort used in communications, so going out and socialising is off the cards”. This can, in turn, generate social isolation and mental health problems that further exacerbate the situation.

“As an extrovert, my tinnitus has deeply affected my social life. People that have lived in lockdown will now understand; you want to go out, but you can’t. I started being really angry. I broke up with old friends and haven’t seen them again for 15 years.” - Jane

“I miss the sticky floor of a live gig. But I probably miss out on 60% of a conversation when catching up with people in noisy venues or having conversations with more than three or four people. I end up feeling like I can’t contribute, so I decide not to go.” - Jack

People with hearing loss often take on the burden of “strategising” their social encounters to make the communication more effective.

“It’s not as simple as accepting an invitation. If I was invited to a noisy venue, I’d have to assess: is it worth it, knowing I won’t be able to talk to anybody? How bad will the tinnitus be afterwards? How long would I cope staying? It seemed that everything that I did in a public space I had to strategize around. I would accept the invitations, because I didn’t want to become socially isolated, but my anxiety levels would build between then and when I went.” - Maxine

It is evident there is a tendency for government, businesses and advocacy groups to take the medical approach to disability and think that technological tools, such as hearing aids and NRS equipment, solve communication problems for people with hearing loss – placing the expectation for mitigation with the individual. To avoid discriminatory practices from emerging, stakeholders must be willing to contextualise communication barriers as a social inclusion issue and address them as such.

“My two daughters also have hearing loss. I was determined that they would not suffer the same discriminatory attitudes at school and in their chosen workplace so I advocated for them. But the attitude was always about fixing the hearing loss instead of accommodating communication difficulty.” - Christine

In addition, it puts individuals at considerable risk. Experiencing hearing loss is an important stressor that might push people to strive to find quick solutions to their problem. Without guidance, people with hearing loss are easy prey for scams and fraud from device manufacturers.

“I have found that the hearing aid industry as such often rips older people off with prices at shopping malls. They double the prices of a reputable dealer and/or con people into buying bad equipment. They take advantage that it takes us a week to ten days to get used to the hearing aids. That’s got to stop. We don’t have the luxury of having many shops to choose from and it’s stressful enough as it is.” - Frank

PATHWAYS MOVING FORWARD

Positioning myself as a business owner within the disability sector has allowed me to pour my lived experience into my workplace role, and thus, for relatability and advocacy. Being an owner/operator also allows me flexibility on suitable projects and environments to ensure they suit my individual needs as a person with hearing loss.

– Maxine

People with hearing loss face systemic barriers that result in discrimination and an uneven playing field when it comes to inaccessible professional development and training and ability to perform to potential at work. This has far-reaching impacts that affect people's personal lives, relationships, psychological and emotional wellbeing, social participation and overall health. There are several areas that can be modified to ensure a more inclusive and fair workplaces and across society more broadly. Recommendations are summarised on page 11.

Previous research has found that one of the most notable negative impacts of discriminatory practices is the negative effect it has on people's self-efficacy; understanding self-efficacy as their belief in their own ability to succeed.¹³ As seen in these stories, when people with hearing loss are unable to perform on par with their colleagues (often because the structures in place are limiting and not tailored to their needs), they often interiorise this and start believing it is they who are incapable of doing the task at hand, belittling and secluding themselves in shame and resignation.

In order to avoid this, evidence suggests organisations must foster social inclusion through enactive mastery experiences, vicarious learning opportunities, verbal persuasion (positive feedback and encouragement from authoritative figures and peers), and acceptance of their diverse physiological and psycho-emotional states (versus judgement and undermining attitudes).¹⁴

Firstly, and to allow for enactive mastery, workplaces should improve accessibility by providing appropriate communication channels with which people with hearing loss can thrive. In this regard, captioning in all audio-visual materials (including videoconferencing, educational resources, and even cinemas and broadcasts), mandates on safe noise levels, noise reduction measures (e.g. noise-cancelling meeting booths, keeping noisy areas like kitchens away from workplace areas, etc.), having signage, and ensuring people can see other people's faces when working together should be considered.

"There needs to be captions in videoconferences

and in any audio-visual material and written announcements in public places. Just navigating public transport is often a nightmare. There's screens everywhere and you can't hear platform changes and you see everyone moving and trying to figure out what's happening." – Courtney

"The wider acceptance and availability of FM systems would go a long way to ensuring communications were accessible in noisy places. One of the best examples is an FM system available at the ferry booking office at Circular Quay. With all of the background noises of trains and people having conversations and walking past etc. it's such a relief to be able to turn my hearing aid to FM and be able to converse with the person selling tickets. Why can't we have more of those kinds of well-placed FM systems to ensure accessible communications?" – Sarah

Secondly, there is not only a need for emotional and social support opportunities for people with hearing loss to be better equipped to navigate their journey, but also more education for government officials, managers, and hearing people in general about the different types of hearing loss and what each of these entail – drawing on the social conception of disability.

"It really comes down to education. It comes down to having people with lived experience training managers." – Courtney

"While we're getting some messages out there, we're not getting the complete message out there as to what it means to have hearing loss. It's not just 'whack in the hearing aid and you can hear perfectly'. And yet, I often get asked 'why can't you hear if you have hearing aids?' People don't realise that hearing aids don't make you hear perfectly." – Jane

"Hearing people believe we cannot be THAT deaf or else we would use Auslan." – Christine

It is important that all people are aware of what accessible communication looks like. For instance, that individuals know to make sure their face can be seen to allow for lip-reading, speak clearly and at a regular pace, limit the use of jargon, and ensure one person speaks at a time during meetings. Workplaces should train their staff in these simple

practices as common knowledge and a matter of business etiquette.

Finally, there is a need to attend the psycho-emotional aspects that living hearing loss entails. It took Jane ten years to come to terms with her hearing loss. It took Jack twenty. This timeframe is unacceptable, with too high a price paid not only by people with hearing loss, but also their families and our society. A holistic, person-centred approach to hearing loss together with a society-wide approach to mitigating disability is the only way to do this.

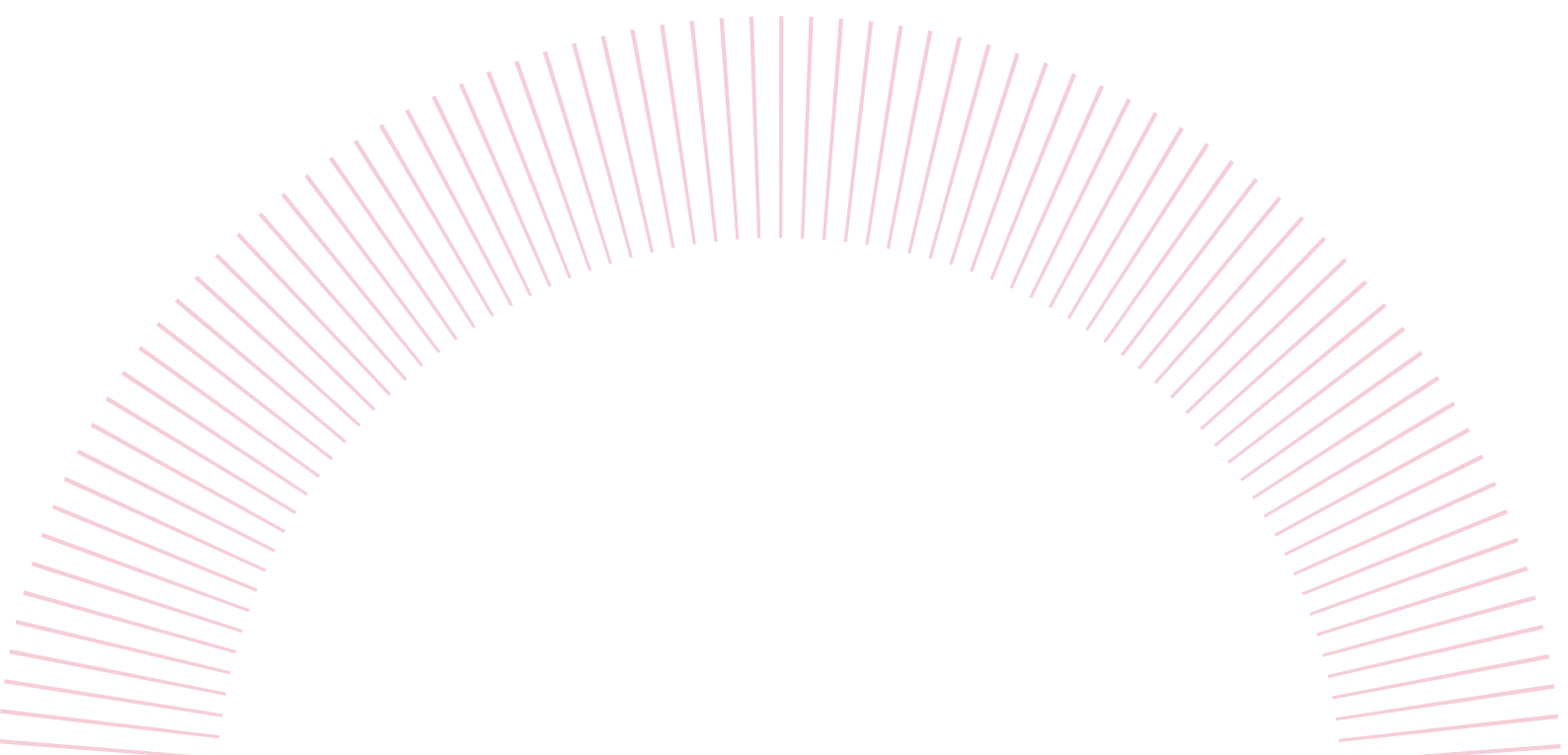
“When I first had my hearing loss diagnosed, the whole process was very mechanical - I was diagnosed with a mechanical issue that needed a mechanical solution. Having a discussion twenty years ago about the fact that this was something I was going to live with for the rest of my life and the impacts it would have around communication and self-image would’ve changed my life. If I would’ve known that early on, I would’ve been better prepared.” - Jack

“I was in my forties when I was diagnosed with hearing loss. The majority of people my age don’t have that, so there was no one I could talk to. I felt like I was in nowhere land. I couldn’t see the light at the end of the tunnel. I would’ve liked having support from a psychologist that could tell me ‘this is what it

could mean and let’s make sure you’re prepared for that’. To have had resources. To have had someone who specialised in this field to pat me on the back and tell me that things were going to be OK, instead of me trying to find things on my own.

“A holistic lens is a major thing I missed out on. My journey was lived through the physical lens alone and I missed out on the emotional and psychological lens. I had no idea how much this was going to impact on my life. I wish I had had an opportunity to talk with an audiologist that could’ve given me information about strategies. Six months after surgery I tried some hearing aids and they made little difference, so I took them back. The thing is, nobody talked me through what the hearing aids would and wouldn’t do. Nobody explained that I wouldn’t be able to determine where sounds were coming from. I nearly got run over more than once because of this. It’s about the little safety measures like this that nobody thinks important to say and that I hadn’t had to think about before. I would’ve arrived at acceptance a lot earlier had I been better prepared.” - Maxine

People with hearing loss often navigate their journey on their own - learning about the impacts of their hearing loss and finding ways to adapt as they go. To address this, there is a need to incorporate mental health plans and co-create strategies with people when they are diagnosed with a hearing loss.



RECOMMENDATIONS

Soundfair and the individuals who contributed their experiences to this submission strongly advise the following:

1. Foster enactive mastery experiences in the workplace by improving communication accessibility.
 - a. Embrace and enable access to proven solutions and tools, such as real-time captioning, that best provide people with hearing loss the ability to participate more equitably in society
 - b. Have diverse communication channels available so that people have choice and control
 - c. Set mandates on safe volume levels
 - d. Use signage in public venues, instead of relying solely on voiced announcements
2. Include vicarious learning opportunities for both people with hearing loss and hearing people
 - a. Mandate D/deaf cultural and communication awareness training in workplaces
 - b. Set up peer-support groups and mentoring frameworks for people with hearing loss and the Deaf community
 - c. Improve communication pathways between community, advocacy groups, and government that allow for evidence-based decision-making.
3. Adopt a whole-person and biopsychosocial approach to disability to ensure that the psychosocial impacts that living with hearing loss are addressed alongside the physical. This should include:
 - a. Mental health and social health plans and access to peer support groups as part of strategic health plans (eg., social prescribing)
 - b. Build accessible health pathways that consider diversity in communication mode and preferences (e.g., telehealth over the phone is not accessible to many people with hearing loss)
 - c. Increase provision and access to trusted and quality information for consumers and the public about hearing loss, its' impacts and evidenced treatment and management techniques and technology to minimise commercial motivations negatively impacting choice and control for people with hearing loss.

CONCLUSION

I want to be able to set up the best possible situation for me, not have you take some sort of hatchet job with a band aid approach to my communication requirements. It is not just about having captions available and looking at the person when talking. It is about having multiple communication channels available so that people have a choice.

Don't make me a 'special' person in the worst possible way and then applaud yourself based on how you are accommodating me. It is not about providing accessible communication as an exception – it is about making accessible communications the accepted baseline standard.

– Sarah

People with hearing loss often face systemic barriers to participation in the workplace and ableist attitudes that have a negative impact on their professional development and psychological and emotional well-being. What becomes clear from the stories collected for this submission is that society with its emphasis on the medical model of disability is not set up to be inclusive to people with hearing loss, often putting the onus on them to ask for adjustments that suit their needs.

"I feel like there is a lot of responsibility on the individual to solve the problems of inaccessible and non-inclusive design to meet the needs of people with hearing loss as readily as it meets the needs of people without hearing loss. Communication is a two-way street. I have control over one side of the conversation (mine) and the biases and assumptions I assume my audience has in receiving and processing information. We're employed to do the job we're hired to do. But I'm amazed at the amount of time I spend advocating and educating to gain access to the same information that is readily provided to everyone else. People need access to the right tools from the get go to do the job we hired them to do, not be moved

into other jobs because we couldn't find enabling and empowering solutions." – Gillian

Given that people with hearing loss often have to navigate their journey on their own, having been given an overly simplified diagnostic that only focuses on the physiological impact of their hearing loss without regard for broader emotional, psychological or communication impacts, it is hard for people with hearing loss to advocate for their needs – especially if they are not familiar with what those needs are and/or with the options at hand that would make it easier for them to communicate. This results in a loss of confidence and negative self-image that is detrimental to their performance, hinders their career prospects and leaves them excluded from the workplace and, more broadly, feeling socially isolated, inadequate, and alone. Thus, further hindering their ability to self-advocate.

If we are to change this, workplaces need to become educated on what living with hearing loss entails to better design spaces and practices that are inclusive of all.

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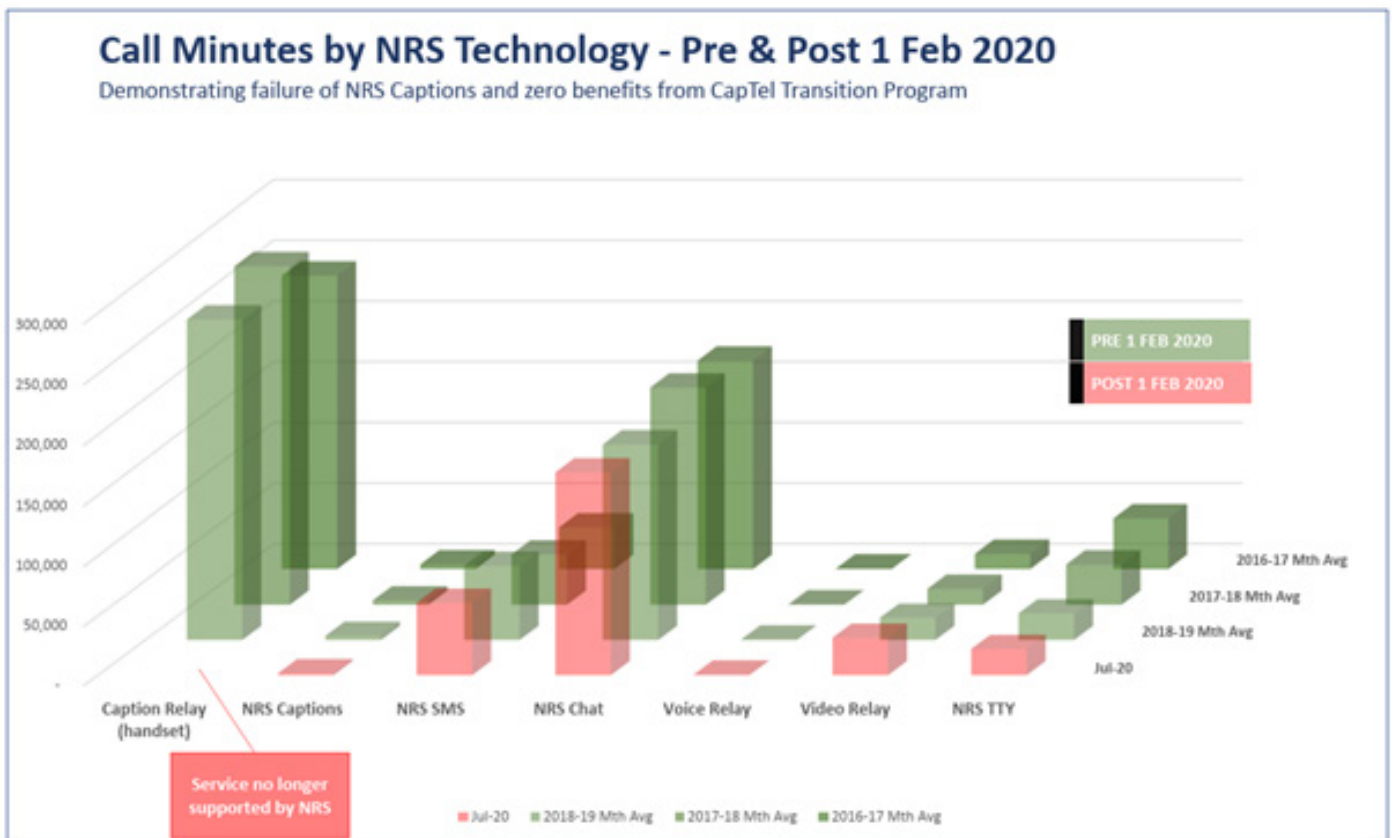
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APPENDIX – CAPTEL

The National Relay Service (NRS) was established in 1995, to provide adequate telecommunication options for people with hearing loss, namely, real-time captioned relay transcription for telephone calls assisted by relay operators. NRS services are managed under contract by the Australian Government, with funding coming from the Telecommunications Industry Levy. In June 2019, Concentrix Inc, a US corporation with a local subsidiary, replaced the Australian Communication Exchange (ACE) as the National Relay Service (NRS) service-provider. This new arrangement removed the integrated relay captioned telephone handset (CapTel) as a service and replaced it with TTY (Uniphone 1150), an inadequate alternative.

The CapTel handset offered several unique benefits in comparison to the TTY Uniphone. Firstly, Uniphone uses 1970s TTY technology. It has a twin 6mm line scrolling display and requires users to interface either by typing or using walkie talkie type instructions. It also requires the use of two devices: PC/tablet for captions and mobile/phone for voice, resulting impractical and requiring users to be technologically-savvy. In comparison, the CapTel handset is a full size, integrated phone with large multiline, variable text height display. Secondly, Uniphone has no voice mail, or text-and-listen SMS relay capability, while CapTel does. Lastly, and most importantly, Uniphone requires in and outbound calls to be placed through the NRS to offer captions, thus obligating users to disclose their disability to callers. CapTel, on the other hand, allows users to connect to the captioning service provider directly through the internet, needing only to press a button to request captioning of a conversation. They can make and take calls directly from their device without the need to disclose their disability.

The low uptake of NRS services post 2019 is evidence of the unsuitability of the new options provided. Prior to 2019, 50% of all call minutes were done through CapTel. After 2019, these calls did not migrate to other NRS services, but disappeared altogether – negatively impacting between 2000 and 4000 users.



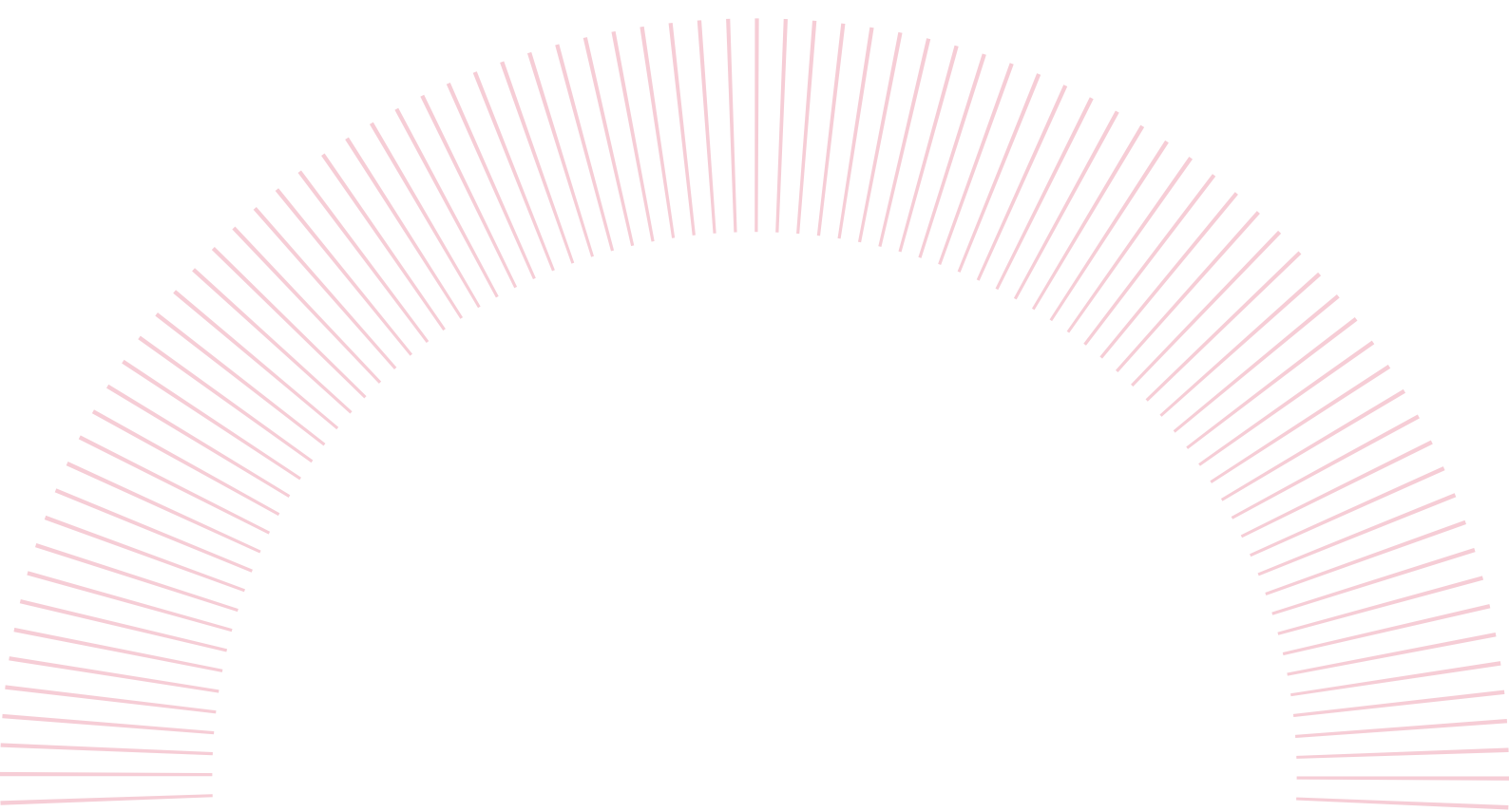
If the CapTel handset was such a key tool for people with hearing loss, why was it scrapped from NRS services? One possible answer is that Government failed to engage with user groups when deciding what NRS service-provider to choose, thus imposing a pre-determined outcome instead of seeking to understand the needs of people with hearing loss. Evidence provided in Senate Estimates reveals that CapTel users were not part of the consultation undertaken to issue a Request for Tender for the NRS service in 2018, which could explain why the service-provider failed to address the specific needs of these users.

Senator URQUHART: Prior to the tender outcome, did the department engage directly with users of CapTel services or their families for their feedback on actually removing the service?

Ms Sillari: No, we did not. One of the reasons was that we were in a procurement exercise. It's not appropriate to, I guess, speak about the outcomes or potential outcomes of procurement exercises until they are known.

Senator URQUHART: Did the department undertake any direct consultation with users of CapTel and their families over the course of the tender process?

Ms Sillari: No, we did not.





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