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Committee Secretary
Senate Community Affairs Reference Committee
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Canberra ACT 2600

Submission to:
Senate Community Affairs Reference Committee
**Inquiry into Hearing Health in Australia**

In relation to the above Inquiry I wish to offer this submission with particular discussion of the following Terms of Reference:
b) the implications of hearing impairment for individuals and the community; and
c) the adequacy of access to hearing services, including assessment and support services, and hearing technologies.

I write this submission because it saddens me to know that the struggles, disadvantage and discrimination I have experienced throughout my life are still happening today. I acquired a hearing loss sixty years ago and the difficulties I have faced have been mostly due to the attitude of the community, hearing professionals and governments — not my deafness. I'd like to think that it is still possible for changes to be made, for the better, within my lifetime. I am relating some of my personal story to demonstrate the numerous issues I, and other hearing impaired people, have experienced.

When I was around six years old my ears became a significant part of my life. They were often itchy and sore so I was taken to the family doctor to have them syringed to remove a build up of wax. This was a very distressing experience for me. The force of the water rushing into my ears was painful and it caused my head to spin and my ears to ring. The adults ignored my tears. After the syringing my ears would ache for days. This was a regular occurrence over approximately five years. No one knew the long-term consequences of those episodes.

Twenty years later I visited my doctor as my ears were causing me some concern again. When he suggested syringing as the remedy I became very nervous. He thought I was being silly and as he came closer with the syringe in his hand I almost fainted with the fear of what was to come. When he saw my genuine distress the doctor immediately took a closer look into my right ear and discovered that I had a large perforation in the eardrum and the ear was infected. The left ear also had a perforation. The doctor was profoundly apologetic and referred me to an Ear Nose and Throat Specialist.

At the consultation with the ENT I learnt that the syringing of my ears when I was a child had perforated my eardrums — hence the pain. The almost constant ear-aches were caused by infections. Those chronic ear infections had damaged the hearing bones in both ears, which meant that I had a moderate to severe hearing loss. I also had the constant sound of cicadas in my head — tinnitus. The other surprising news was that I had developed, and been using, lipreading skills without even knowing it.

With this information I at last had some answers to the many unknowns of my childhood. Especially those of my school years. In the classroom when the teacher would ask questions I was always the last one to respond. I can remember thinking many times,"I know there is nothing wrong with my brain so why am I so much slower than the other kids?" My reading and writing skills were average but I found arithmetic very difficult and as I got older and the maths became more complicated I really started to struggle. Maths was a language I did not understand. I was categorised as a slow learner.

Being quiet and timid I found it difficult to make the first move towards friendship. After a while it became clear that most of the time I was quite content to be on my own. This, of course, set me apart and many a time I was the brunt of ridicule from the other children. When this happened I would usually make an effort to find a friend but somehow it never lasted for long. If a group gathered I would withdraw. I was always mystified as to why this was so.

I left school with a deep feeling of being lost within a community I didn't understand. I tried to hold down shop assistant work, without success. I decided I needed a job where I didn't have to serve people and eventually got a job in a clothing factory.

After the hearing loss diagnosis I had skin grafts on my eardrums to cover the large perforations. A bit later I had a stapedectomy which only lasted a few months before the hearing bones in both ears disintegrated, my hearing loss was now severe. I was surrounded by people who either felt sorry for me or ignored my predicament. The only answer was hearing aids I was told. With high expectations I went to see an audiometrist and was fitted with two hearing aids but the result was devastating. I was suddenly surrounded by loud noises that I didn't recognise and I couldn't understand people when they spoke. I had been convinced that hearing would be the answer to my communication difficulties. But the extra sound only made things worse.

I found the continuing visits to the audiometrist distressing. I failed the hearing tests. My concerns of the loud noises were ignored. "Just persevere," I was told. When I had sore ears because of badly fitting moulds I was told I wasn't putting them in my ear correctly. At family gatherings I was told to, "Turn your hearing aids up," or ",concentrate harder," if I wanted something repeated. Years went by and emotionally I was struggling, as my feeling of helplessness grew. I was withdrawing from conversation where ever possible. As hard as I tried I was not living up to everyone's expectations. My confidence in my ability to communicate successfully had plummeted and I didn't know who I was or what was to become of me.

I eventually agreed to have a full reconstruction of my left ear but from my point of view it was a disaster. I thought I would go insane as every sound was piercingly loud and unrecognisable and unlike a hearing aid I could not turn it off. Fortunately after several months the effects of the operation waned and my hearing returned to much the same level as before. After much thought I made some important decisions that would shape the rest of my life.

I decided there would be no more ear operations. I was going to attend lipreading classes to see if I could reignite my previous skills and I stopped wearing my hearing aids.

My first lipreading class was an amazing experience. I quickly discovered I still had my lipreading skills which boosted my confidence considerably. Within weeks I was training to be a lipreading teacher. I devised ways to improve my language skills, broaden my vocabulary and improve my speech. I had come out of the depths of despair with a determination to take charge of my life and find my rightful place in a hearing world.

As a teacher I was in a position to both, share my skills, and learn from the members of the class. I listened with interest to their individual stories about difficulties communicating with family and friends. How they had stopped attending church services and participating in community gatherings and activities. Some wore their hearing aids successfully, others did not. The camaraderie between the class members was all that was needed for some to improve their feeling of self-worth. The class members were learning new ways to improve their communication in a safe and supportive environment. A shared experience that allowed them to feel less alone. However there were many people I met over the years whose needs were greater.

One example was Neil. With severe industrial deafness, poor word discrimination and tinnitus, Neil was a quiet, shy man who was embarrassed by his limited communication skills. He was having difficulties at work because of communication breakdowns with his work mates. This was affecting his ability to do his job. Neil's concerns that his hearing could be the problem were ignored. He decided to take early retirement. Neil was also having difficulties at home. His relationship with his wife was rapidly deteriorating because of misunderstandings and unrealistic expectations. He was assessed for hearing aids and a cochlear implant but neither was suitable. This news was devastating for both Neil and his wife. He was in a state of despair. His wife was angry. I met with Neil weekly over a number of years, his wife rarely attended with him despite our encouragement. Neil and I would talk about different strategies that he may find useful both for himself, and his family and friends. The main benefit for Neil though, was to have a successful conversation, without the blame and expectations loaded upon him by everyone else, even if only for one hour a week. He regained some confidence and his communication skills improved. His wife never came to terms with the fact that her husband was deaf so there were no changes in her attitude or behaviour to accommodate his communication needs.

Another example was Bill. He had a profound hearing loss acquired later in life and wore a high-powered hearing aid which gave him little benefit. He came with his wife to a lipreading class but it was obvious that it was not the best situation for him. His wife was writing everything said on a note pad for him to read. I was writing information on the board but it was not enough to keep him up with what was going on around him. He had become so reliant on his wife and family for the written information that he had no lipreading skills. However he did have language. So through the course of that first lesson I began to use gestures and at times act things out. This was enjoyed by all the class including Bill. That same week I joined the Deaf community where I was welcomed enthusiastically and over time learnt to sign. I was seeing Bill and his wife on a weekly basis and was incorporating what signs I had learnt into our conversations about lipreading and strategies that would help with his rehabilitation. The results were amazing. Bill became more observant and because we were having a conversation, even though somewhat limited at times, his communication skills improved along with his confidence. So much so that he would politely wave his wife away if she began to write something down. His wife was also learning the signs and Bill was teaching his family, including his grandchildren. What remarkable progress this man had made over a period of three months! He and his wife rejoined the lipreading class much to everyone's delight and the whole class were learning a few basic signs each week. This demonstrated what could be achieved by a willingness to try new things to achieve better outcomes.

There were many more people I met during my career who didn't find a technological solution to their communication needs. The expectation that hearing aids could replace hearing were destructively misplaced in a lot of situations.  There was no support service in place within the hearing health system to accommodate the needs of these people, or their family and friends.

My time spent with the Deaf community learning a second language was such a valuable experience. It gave me a broader view of the diversity of needs amongst people with hearing impairment.  I also became aware of the divisions which existed between the Deaf community and hearing people at that time.

With new-found confidence I applied and was accepted as a trainee Audiometrist within the hearing aid industry.  I completed the Audiometry course at night while working during the day.  Having empathy for the clients' needs meant I was very successful. I was seen as an enigma by my colleagues with comments, "What would a deaf woman know about hearing aids?" Even though I spoke at conferences with suggestions on how to improve the service provided to clients, I was largely ignored. One thing I did achieve was that clients were given the option of trying a hearing aid before they purchased it. I enjoyed working with the clients, however after a few years I became disillusioned with the hearing aid industry in general. The emphasis on selling hearing aids without improving the level of service to the clients eventually became intolerable and so I resigned.

My next job was working for the Education Department as a teachers' aide for deaf students at a high school.  This was at the time when Signed English was introduced to deaf education but some of the students had never signed before.  At the same age I had thought my language skills were poor but some of these bright, enthusiastic students didn't know the names of basic food items, they couldn't tell me the names of relatives or where they lived, yet were expected to progress through the regular curriculum. They knew they would struggle and ultimately fail so their willingness to try was decreasing all the time.  The emphasis from teachers was on the students 'hearing' instead of desperately- needed language development.

As time passed I worked at different primary schools but the situation for hearing impaired students was very similar. Integration into mainstream schooling was the focus yet they were still not achieving outcomes equal to their hearing peers. Some students had teachers' aides for support, but their hours were limited.  For most of the school week the student was expected to cope on their own.  The class teachers had a difficult task. They had little or no experience with hearing impaired students, and usually had several other students with special needs as well. In the playground the hearing impaired students were isolated without the communication skills to make friends. Educational resources were not captioned, and educational programs were inappropriate to meet the hearing impaired student's needs. With this situation hearing impaired students were unlikely to achieve their full potential. The emphasis being on the students 'hearing' not language development. I realised I had been fortunate to be born into a family where I was immersed in language both before and after the onset of my deafness. That input of language had been vital for me to survive in a hearing environment. The education system was also letting parents down because of limited information about all the options for their child's education.

Equal access for people with a disability became a talking point within the community, especially after the introduction of the Disability Discrimination Act. This was long overdue, however for most people, physical disability was the main focus. Technology such as audio loops and captioning was slow to be introduced. This was an unfair situation and so I decided to join the disability access committee of my local council to broaden my knowledge of the situation. I also attended a couple of council meetings and discovered that not only did the room lack an audio loop but it did not even have a PA system. I could not participate in the meetings. Council was notified of this situation but declined to rectify it. This was a discrimination issue so I contacted HREOC for information on the appropriate action to take. I decided to make a discrimination claim against the Council. This was very much a David and Goliath battle, made all the more difficult because of intimidating tactics used by Council to have me drop the complaint. I won the case after conciliation. This meant that the Council was obliged to install a PA/audio system.

A few months after my case, I appeared at the Productivity Commission's inquiry into how the DDA was working since its introduction. My concern was that the onus was placed on the disabled person to prove the discrimination rather than the perpetrator proving they were not discriminating.

Recently I was subjected yet again to discrimination at a cinema so decided to visit the Human Rights Commission to see if there were any changes to the complaint process. Unfortunately not, as I was informed that I am required to fill out a form for each act of discrimination I experience, one by one. In my case that would be at least a weekly occurrence. I was left wondering how this outdated procedure can be justified after seventeen years since the Disability Discrimination Act was introduced.

In an attempt to mitigate some of these discriminatory issues, some years ago I attended an Australian Hearing Centre for a hearing assessment. I wanted a hearing aid so that I could use the audio loops that were installed in some cinemas and public facilities. I informed the audiologist prior to the hearing test of the sensitivity of my left ear to certain noises yet I was subjected to loud tones during the test that were so painful I had to remove the head phones. At no time during the assessment were my communication needs met — from the time I arrived at reception to the conclusion of the consultation. My previous experience both as a hearing aid wearer and an audiometrist was ignored. I was categorised as a difficult client and it was written on my assessment record. This was a very distressing experience that no one should have to endure. Unfortunately I knew I was not alone in receiving unsatisfactory service from the hearing aid sector.

No further evidence is needed regarding the quality of hearing health services in Australia than to look at what is happening in aged care. For approximately two years I have been volunteering at a local aged care facility. I have been visiting hearing impaired residents to give them practice in enjoyable, successful conversation. I also carry out basic hearing aid maintenance on residents' hearing aids which helps reduce their frustration at being left with hearing aids not working. Residents sometimes wait months for hearing assessments, and then weeks before the hearing aids are fitted. Often there are no follow-up appointments for new hearing aid wearers. Residents are then left without much-needed information in regard to taking, at least some, responsibility for the care of their hearing aids. Modern hearing aids are smaller and the new sophisticated technology makes them more desirable for some clients. However many hearing aid wearers are not satisfied that a volume control and T switch have been omitted from their hearing aids. These changes can limit the benefits gained from their hearing aids and also prevents them from accessing information from audio loops. Hearing aid repairs take weeks for the simplest of problems. New moulds for hearing aids are delivered to clients by post where there is, almost certainly, no one qualified to fit them. Staff at the aged-care facility have little or no knowledge of hearing aids which means that residents can be left without working hearing aids for days because of simple problems like flat batteries. Staff do not have basic communication skills for successful interactions with residents. Residents are left isolated with no opportunities to practice their language skills or enjoy successful conversation. A resident's hearing loss is never considered when organising activities. Residents complain they are unable to understand staff but those complaints are ignored. Residents are having their ears syringed to remove wax, when there is a less invasive and safer procedure available.

I have written about some of these experiences from my life to illustrate the myriad issues faced by hearing impaired people daily. The lives of hearing impaired people could be greatly improved if changes were made to the ways we, as a community, deal with hearing impairment.

Below are issues I would like to see addressed as part of the Senate Inquiry:

- the practice of syringing ears be discontinued
- hearing augmentation, adequate signage and captioning on information videos be mandatory for all public facilities, including government agencies, Councils, cinemas, theatres, and public transport
- standards be implemented for a level of care and service in the hearing aid industry
- all educational recourses captioned
- improvement to university training for teachers of the deaf
- more support, including unbiased information about educational options, be provided to parents of hearing impaired children
- improved standard of education programs for hearing impaired students
- a change in the Disability Discrimination Act to make it more equitable and accessible
- the provision of independent advice about technology, including telephones, assistive listening devices and hearing aids, such as that available to people with a vision impairment
- that deaf and hearing impaired people have the opportunity to participate in this hearing health inquiry

More broadly, perhaps our most powerful achievement would be the development of a quality community awareness campaign. We have seen the potential of these campaigns, and their ability to bring about changes in attitude, in areas such as depression and mental health. Hearing impairment is still a hidden disability which is only talked about as a medical or technological issue and as a problem for the hearing impaired person to solve. Considering the aging population a more wholistic approach to hearing health is required before hearing impaired people will have a quality of life that is taken for granted by the broader community. With change comes benefit for the entire community. Imagine the potential effect on literacy and language learning of universal captioning. Better signage means improved productivity. More effective communication brings informed and contented citizens and a better quality of life.

I thank the Committee for the opportunity to raise these issues and look forward to their discussion, along with the more equitable society which will be created as a result.

Yours Sincerely

Yvonne Batterham