10 Dec 2009

Submission to Senate Enquiry into Hearing Health

I wish to make a submission to this enquiry from a personal perspective. I have a condition called Neurofibromatosis Type 2 (NF2). NF2 is a genetic condition that generally leads to deafness in later life. In my life I have experienced full hearing, hearing impairment with deteriorating hearing over a decade, and deafness. I have family who have similar experiences. Because of this background I will limit my comments to the following Terms of Reference:

B) The implications of hearing impairment for individuals and the community.

C) The adequacy of access to hearing services, including assessment and support services, and hearing technologies.

D) The adequacy of current hearing health and research programs, including education and awareness programs.

I will also comment upon deafness in relation to these TORs because, for me, hearing, hearing impairment and deafness have been part of a continuum.

Background.

Unexpectedly finding out, at age 33, that I had a large tumour on each of my hearing nerves, was a profound shock. I was told I would need two operations, one on each hearing nerve and that I would probably become deaf as a result. I was told that there was a chance of saving some hearing but, without surgery, I risked death.

At that time I was working full time as a librarian. I shared a common view of hearing impairment and deafness at that time, namely that I would be worth less, and may lose my career.

I had an operation that left me half deaf, with some facial palsy. Consequently it was decided that the second round of surgery would be postponed because I still had useful hearing in that ear, and a second operation posed a large risk to the other side of my face. It was hoped that the second tumour wouldn't grow and that I would therefore avoid total deafness.

I lived like this for a further decade. My remaining tumour and hearing were monitored. My hearing deteriorated slowly over that time and seven years ago, I had the second operation. I am now fully deaf.

I was lucky to receive the support I did during that time.

When I was initially diagnosed I was offered counselling, both through the university I attended and through the HEAR Service at Vicdeaf in Melbourne. I was given support, free equipment, and lip-reading classes.

At that time Vicdeaf was divided into two sections – one for the Deaf community who use Auslan as their main means of communication, and one for hearing impaired (HI) people or people who are deaf/HI but do not use Auslan. I was lucky enough to have contact with both perspectives, having mistakenly visited the Deaf community building when first attending for counselling. Once in contact with them I was offered Auslan classes, which I started but pulled out of as I found the idea of accepting my deafness, and starting to mix with deaf people, confronting. I also attended Deaf awareness sessions.

At that time there seemed to be two choices for a person in my position. One choice was to continue mixing in the hearing world and use technologies and lip-reading to assist me; the other was to move away from the familiar, learn Auslan and use it to join in with the Deaf community.   I believed that learning Auslan would separate me from my hearing world so I initially chose the technology/lip-reading option.

Being hearing impaired is limiting. Other HI people I met were often sad and isolated. I felt like an outsider myself. Socialising was tiring because of the concentration required to lipread or make meaning through my hearing aid if there was background noise.   I could also see in my workplace that my hearing loss was viewed as an inconvenience to others.

In contrast the people I saw signing seemed lively and looked to be enjoying themselves, so I was intrigued by the Deaf community, right down to the capital D they used to describe themselves with. However for the decade in which my hearing deteriorated, I mixed primarily in the hearing world and worked there.

When I was told I would need the second operation and it would leave me fully deaf, I was also offered new technology called an auditory brainstem implant. (ABI). This technology is available through the Royal Melbourne Hospital in Melbourne. I was told that I may be able to have up to 50% of my residual hearing saved. Initially it did seem to hold some promise but, over time, I noticed it was becoming harder to make sense out of the electronic beeps it allowed me to “hear”. It only worked in clinical conditions with no background noise and it was a large unsightly contraption that attached to the top of my skull drawing stares from passersby. I was later told that the ABI can reduce in efficiency as scar tissue forms post surgery. I also later read a research report that doubts were being raised about its effectiveness. It is, however, still being used. My two second cousins, both deaf, had ABIs implanted. One doesn’t work but the second one, implanted about 6 months ago, is still working.

The effect of me becoming fully deaf was profound. At the time of my surgery I had no ongoing work and have not been able to find work as a librarian since. I was also a solo mother when I became deaf and, for a while, could not communicate for a while with my seven year old son. He was traumatised by me becoming deaf as people suddenly started treating him as the adult and me as the child. For a while I felt a failure as a mother.

It was at this stage I decided to learn Auslan. I went to classes, then to a two year Auslan interpreting course at Kangan Batman TAFE in Melbourne. The effect on both my, and my son's life, was dramatic. The Deaf community taught my son how to sign for free as there were no classes that were suitable for him. Using Auslan opened my world back up as I was able to start communicating easily once more on an equal level with them, instead of relying on people to write notes for me.

I also used Auslan to re-enter the workforce. Initially I was still learning Auslan and had problems using it to decipher the complex information being discussed at meetings. I was provided with a note taker for meetings but note takers are not subject to the same professional standards as interpreters. Notes, by their very nature, summarise what has been decided. They do not appear quickly enough to enable participation in meetings. This was an issue in terms of being able to contribute. Vicdeaf helped me locate a real time captioner (RTC) who has worked with me intermittently ever since.

Real time captioning is a technology that allows the captioner to produce a transcript at almost the speed of speech. It therefore allows deaf and hearing impaired people who can read, to participate in meetings and follow complex information such as conference proceedings

Now I can sign, my employer pays for two hours of Auslan interpreting for me for each day I work. I can be involved in the life of the community because so many organisations in the disability sector will now offer interpreting. I have deaf friends and enjoy a good social life. I am doing a writing course at TAFE and also can go along to community classes and festivals; I feel confident again and connected to both the Deaf community and everyone else.

I have organised my comments on the Terms of reference into two segments – experiences that helped me regain high levels of satisfaction with life, and experiences that could be improved:

B**) The implications of hearing impairment for individuals and the community &**

D) **The adequacy of current hearing health and research programs, including education and awareness programs.**

Positive

- Mixing with other deaf and hearing impaired people. Nobody understands how all the exclusion feels unless they have experienced it themselves. These people are a resource in terms of understanding what needs to happen in order to succeed with hearing loss or deafness.

Suggestions for improvement:

- Community education in understanding deafness/HI is needed urgently. Perceptions about deaf/HI people include a view of deaf or HI people us as a time-consuming nuisance; stupid, and essentially “different “from them. They don’t realise we would also like to be doing what they are doing, or discussing what they are discussing. These attitudes are not good for the community either as they deprive them of us and all the things we have to offer as individuals and fellow workers.

- Language support for hearing children of late deafened adults is needed, so that families can be maintained and supported through a period of transition. At the moment it is offered for adults but for preliterate children, there is nothing to support them adapting communicationally to having a parent become deaf.

C) **The adequacy of access to hearing services, including assessment and support services, and hearing technologies.**

Positive

- My experience as a late deafened and hearing impaired adult was excellent. As a rehabilitation client I received a fire alarm, TTY phone, digital decoder, flashing doorbell and shake awake alarm clock and the services of audiologists and case managers.
- Real time captioning (RTC) enabled me to work at a professional level while I was acquiring Auslan.
- Auslan allows me to continue to work at a professional level, access other signing deaf people for advice , support and friendship, and access what is on offer in the mainstream community.

Suggestions for improvement:

- Accountability from the medical profession to ensure that informed consent is being obtained from patients when making choices about hearing technologies, especially experimental ones.
- A more holistic approach to making communicational choices so that hearing impaired people are offered technological and medical support but also encouraged to consider Auslan as an additional option.
- Professional standards introduced for notetakers, I was personally shocked that some notetakers are not fully literate in English, nor able to comprehend complex meetings. Despite this they continue to be assigned to hearing impaired and deaf people.attending meetings and lectures.
- Introduction of appropriately trained and assigned real time captioners to record meeting proceedings and course notes. At the moment most of them would be too expensive to employ as a support for HI or deaf people, Creation of affordable and available access to RTC would improve employment prospects for many.

Thank you for the opportunity to make this submission,

Karen McQuigg