9 October 2009

SENATE INQUIRY INTO HEARING HEALTH IN AUSTRALIA

Thank you for the opportunity in allowing me to address a number of issues stated in your terms of reference outlined in the above Senate Inquiry:

Firstly I would like to provide some background: I am the mother of three adult children. My youngest child, a daughter was born profoundly deaf. She is now 23 years old. My husband and I decided that she should learn spoken English in the first instance, as she was born into a family whose first language is spoken English, as opposed to signed English or Auslan.

My daughter, Adelaide was 9 months old when she was fitted with hearing aids provided by the Federal Government through the National Acoustics Laboratory (NAL). She attended early intervention programs with the Shepherd Centre and St Gabriel's in NSW who taught oral English. She also was taught on a weekly basis by a wonderful teacher by the name of Margaret Colebrook who was attached to the Department of Education in the NAL's Chatswood rooms.

My husband and I decided to put all our best efforts into her attaining language. I stayed home to look after my three children, as opposed to going back to work, as the stakes were extremely high, and we wanted our youngest child to have the same opportunities available to her that were available to her sister and brother who are now 27 and 26 years old.

When it was time for Adelaide to go to school, my husband and I made a conscious decision to move away from the 'Special school' that was attached to Chatswood Public School, which is where we lived at the time. This was because, after spending some time observing the children who attended this school, it was clear to me that they were not integrated for any great period of time into the mainstream. We believed that for Adelaide to succeed in the hearing world in which she was born, she had to function in it. We moved ourselves to the small village of Mt. Victoria, which had a public school which was prepared to accept Adelaide as a student and who would provide the necessary support that was needed to help her to integrate into her local community school and to continue to assist her in the acquisition of language. The added benefit was that the classes were small, and the school population was only 88 children.

By the end of kindergarten, it was clear that Adelaide was not acquiring language quickly enough for her to keep up with her peers. My husband and I decided that we had to do whatever it takes for her to acquire language, whether it be sign or spoken English. As she was an oral child, and because the Cochlear implant was proving to be a great success with some of her peers in the Shepherd Centre, we decided to take that option first. To say that the Cochlear Implant was a resounding success, is an understatement. She made vast improvements in her spoken language (expressive), but I add, this could only have been possible because she had also internalised much of the language that was taught to her by my husband and myself over the previous 6 years.

The Cochlear implant did not cure her deafness. Even now, it brings her to a level of communicating as a 'severely' deaf person, as opposed to a 'profoundly' deaf person. Adelaide does not refer to herself as deaf, but as 'hearing impaired'.

She manages extremely well, but she also misses out (as many deaf and hearing impaired people also miss) on many of the subtle cues that language holds. She finds it difficult to communicate effectively with groups of people as opposed to one to one situations. This was always difficult for her in the class room, whether it be at School or now at university, where she is studying Law part time. Adelaide has worked full time since completing her Higher School Certificate at the age of 17 years old. She was always fully integrated into mainstream school. This would not have been possible but for the invention of the cochlear implant and the massive amount of time and effort put into her developing spoken language by herself, her teachers, and her family.

I would like to address a number of points:

(a) <u>The extent, causes and costs of hearing impairment in Australia</u>

When my husband and I were advocating for services for Adelaide, we would always argue to the Department of Education that if you put the resources into our daughter now, as a baby and as a young person, then it will pay off in the future and you will not be paying for her as an adult through welfare. This argument was used constantly by us when she was at school and needed to have resources in the way of a teacher's aid and a specialist teacher of the deaf allocated to her on an annual basis.

Costs can be contained in the long run for governments , if resources are given to schools and to the child and the child's family to provide the necessary resources in the early years. Our daughter decided not to claim any benefits from Centrelink and instead chose to work. It was difficult for her at first, as her speech is not as clear as other young people of her age, but she had an education and she was incredibly motivated. She managed to get employment with legal firms from the time she was 17 years old. This positive situation was due in part to the resources put into educating her. My hope was for her to complete school, given the knowledge that I had of the poor literacy rates for deaf and hearing impaired people. However, I never would have dreamed as a young mother, that she would have been accepted into UTS to study law and worked full time as in a well established legal firm. So if anything is to be learnt - put the resources into schools and families to bring these children up to par with their hearing peers.

Captioning for TV is also something that improved our child's life by imparting a sense of belonging to the outside world. It is important for teenagers in particular to discuss their favourite TV shows and she was able to participate in those discussions with her school friends. So please encourage TV networks to continue to provide captioning for the deaf and hearing impaired. It benefits the community in the long run.

The personal financial costs incurred by our daughter for batteries for her cochlear implant and for upgrades is exceptionally high. She is on a clerk's salary and she has to pay for these items herself. As a matter of equity, it seems incredibly unfair that she has to pay for these very expensive items herself.

Assistance by the government for both working and non-working deaf/hearing impaired people who use devices such as hearing aids, cochlear implants and televisions that carry Teletext for captioning is vital for their inclusion into our global community. Please make some contribution to assist them to integrate into their communities by paying for their batteries and upgrades.

b. **The implications of hearing impairment for individuals and the community**

Loneliness and isolation is often the most difficult reality for deaf and hearing impaired people. Whilst I have not experienced this first hand, it is heart breaking to see my daughter being excluded from conversations unintentionally because it is so difficult to understand through noisy situations, and situations were groups gather. It is expensive for her to fund her batteries and upgrades. Other 23 year old people do not have to worry about such things. Not being able to use the phone to talk with friends is also very isolating. The advent of the mobile has been a great blessing as has been the Internet and the use of sites such as Face book. If the deaf and hearing impaired are included into society, then it benefits the whole of our community. Certainly the school communities which my daughter attended often gave the other students the benefit to understand deafness and become a more compassionate and less ignorant group.

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

It is self evident to me that the more resources you give young children to improve their educational standards of literacy and numeracy, then it will pay dividends in the end when they reach adulthood. The community at large will also benefit from functioning and well adjusted adults as will governments because they will not have to fund welfare payments to those deaf people who are illiterate and can't get employment.

School communities need to have not only deaf people, but all people with disabilities integrated into the classrooms. Hearing children will grow to be more aware of the difficulties if one of their class mates is deaf or hearing impaired. My daughter had a very happy upbringing in her local Blue Mountains community. She often finds it difficult now in adulthood adjusting to the ignorance of people in the work place and the public generally who know nothing of the hearing impairment disability. Work place awareness programs would be helpful, but education of the general community should start in our schools.

c. **Hearing Technologies**

Technology has been a friend to many of our hearing impaired people. High performing hearing aids and cochlear implants have helped both the elderly population who have become deafened and people who have been born deaf the opportunity to be fully integrated into their families, schools, friends, workplace, social events. Please encourage the funding of research to find more and more improvements in devices for the deaf.

e. **Specific issues affecting Indigenous communities**

I have been a solicitor for aboriginal people in remote communities in NW New South Wales and in North East Arnhem Land in the Northern Territory. It is noticeable the number of deaf or hearing impaired aboriginal peoples in these communities that I have worked in is far too high. Not because they were born deaf like my own daughter, but because they have become deafened because of poor health conditions. Surely if my white Australian daughter can receive a good education, it must be achievable that our indigenous people are afforded not only a decent education but also comparable health and educational services as their city brothers and sisters receive.

I only became aware of this Inquiry today, when my daughter, Adelaide told me that she was doing a submission. I felt that I needed to add to her story and the story of her family.

I believe that we have been very lucky. She has brought so much joy into our family. Her brother and sister have found life difficult on occasions when they have had to deal with ignorant and prejudiced people on her behalf, but they have become great advocates and very compassionate adults. as a result.

I hope this very small submission is able to offer some insight into the Inquiry and welcome any assistance that I may be able to offer. I know Adelaide would also welcome the opportunity to 'educate' those members of the committee who would like to learn more.

Thanking you,

Your sincerely,

Mary Ryan