This submission is being made following initial contact with Senator Rachel Siewert. My wife Theresa and I have had a connection with the hearing impaired world for over 23 years via our son Alex who was born profoundly deaf. We have attached a copy of a document we supplied to Steven Grundy the CEO at Australian Hearing which briefly outlines our journey. The main issues we would specifically bring to the attention of the enquiry are:

- With the assistance of hearing and habilitation professionals, including itinerant inclassroom services of various agencies, Alex has been able to navigate his way through a mainstream education and into employment and society. His opportunity to lead a rich and fruitful life has thus been optimised. We are very grateful for the efforts of government and community agencies for this. This has been achieved with much less cost and commitment from the community than if he had received education in a non-mainstream environment. The commitment to maintain and keep up to date a system supporting deaf children who are attempting to remain integrated into the mainstream hearing community should be continued and enhanced. Agencies providing non mainstream education of course remain vital and funds should not be diverted from them.
- As a hearing impaired young adult Alex still faces everyday challenges and discrimination particularly in the employment arena where so many jobs required good verbal communication and telephone skills. We have observed with Alex and other hearing impaired young adults that this often results in underemployment and employment in lower paid positions with reduced opportunities for advancement. To this is added the significant financial burden of self funding the functioning, maintenance and upgrade of his cochlear implant which, as with any high tech device is very expensive to repair and maintain and in Alex' case, has a voracious appetite for specialized batteries. For Alex this can amount to thousands of dollars a year. Young adults at the very least should be given some assistance during this financially stressful time of their early employment and perhaps this financial support should continue until a level of financial security is achieved. This commitment is required regardless of the brand or type of the device or hearing aid and extends to ancillary equipment such as specialized alarm clocks, door bells, smoke detectors etc. Hearing aids, batteries and ancillary equipment are not even tax deductible for those lucky enough to be paying tax! Young hearing impaired adults have been known to forgo using their hearing aids or cochlear implants altogether due to financial pressures -- this cannot be allowed to occur!
- There is also the need to ensure that, not only is there adequate research and development into updates and improvements, but also a commitment to the maintenance of the earlier models of the devices. Failure to ensure support and maintenance of older models which have been proven to best suit individual users will allow commercial imperatives to decide when an old model is no longer supported in much the same manner as Microsoft withdraws support of older versions of Windows or a car manufacturer stops making parts for an old model.

These young adults deserve full community support not only for their own benefit but also to reduce the financial and other impacts on society generally.

We welcome and fully support the work of this committee and are available for further enquiry at any time.

Chris and Theresa Spraggon

# **Our Journey with Australian Hearing**

### Our first contact with Australian Hearing

We had never heard of Australian Hearing until we walked into the Chatswood Hearing Centre with our seven week old son. Even at his early age a hearing loss was suspected so audiologist Sue Cotton organised for electrophysiological testing at the Children's Hospital in Camperdown. At the hospital we were informed our tiny baby "was pretty close to stone deaf." That afternoon our son had his first ear moulds taken.

Over the ensuing days, weeks and months we were carefully drip fed information and counselling to help us come to grips with the needs of our son, the way we could help and the support and options available to us. We had many questions and would have found the experience completely overwhelming if not for the empathic and professional guidance received from Australian Hearing.

### Deciding the strategy to move forward

Given the profound nature of Alex' hearing loss (left hand corner audiogram with an average loss of 110dB) we examined closely the options available ie Cued Speech, Total Communication or Aural/Oral speech.

Despite choosing the most difficult mode of communication for such a hearing loss Australian Hearing was fully supportive of our decision to use audition to help our son learn to speak and become part of with the hearing world.

To achieve our goal it was absolutely essential that Alex was hearing optimally at all times. This was supported by having regular testing, good fitting ear moulds, optimally operating hearing aids and spare parts always on hand.

Amongst others we sought support from Margaret Colebrook, a Department of Education early intervention teacher who was conveniently located on site at the Chatswood Hearing Centre.

Over the ensuing years we were frequent visitors to the Chatswood Hearing Centre and valued enormously the relationships forged with audiologists and technicians. These professionals were obviously well trained and empowered to understand and deliver the very best of services needed by a family like ours.

## **Cochlear implant**

Although Alex progress was excellent given his hearing loss it became obvious that we needed to consider the cochlear implant which was just starting to emerge as a possible option. We sought advice from various professionals on the suitability of this device for our son. The audiologists from Australian Hearing provided us with excellent, measured and well informed information which allowed us the confidence to go ahead.

## Australian Hearing's role in supporting services

After receiving his cochlear implant Australian Hearing continued to play an important role in supporting our family in a number of ways. Australian Hearing supplied audiograms, provided maintenance and spare parts to both the remaining hearing aid and cochlear implant speech processor. Whilst the role of supporting Alex' hearing was now shared amongst others it was important and comforting to understand that Australian Hearing was always actively monitoring and regulating the delivery of product and services. Australian Hearing's role in providing upgrades of approved hearing devices was imperative in making sure Alex could take advantage of technological upgrades and could access the very best hearing.

## Moving into adulthood

Our journey through our son's school years consumed much of our energy and having Australian Hearing and others as partners enabled us to focus on his education. This service also assisted him through his tertiary education.

Once Alex had passed 21 he soon became burdened with the cost of spare parts, batteries and service of his speech processor.

A considerable cost to any young person especially to someone who already faces discrimination and is at a disadvantage amongst others in the workforce.

Alex works hard as a hearing impaired person who is fully integrated with all aspects of daily life. Although Alex has assumed responsibility for his own life, as parents we remain concerned that he and others in the Deaf and hearing impaired community continue to receive the support of the Australian community spearheaded by Australian Hearing who played such a large part in getting him where he is today.

We have been proud to support Australian Hearing and its objectives with our personal involvement in research projects, the production of videos to parents, participating on panels to help audiologists understand a parent's dilemma's and actively involved as a member of Australian Hearing's Consultative Group for Cochlear Implants. We continue to support Australian Hearing in its role of supporting not only Deaf and hearing impaired children but also their transition to young adulthood and beyond.

Chris and Theresa Spraggon July 2009