Dear Sir/Madam,

I apologise for the lateness and brevity of my comments but hope that you might still be willing to add them to the list of submissions for the Senate Enquiry into Hearing Health in Australia. I have only just learned of the Senate Enquiry today, having arrived back in Australia earlier today from a month overseas.

My interest in making comments to the Enquiry is because my husband and two teenage children all have a progressive bilateral hearing loss. My husband's hearing loss is now a severe-profound hearing loss and my two children now have moderate hearing losses. All were first diagnosed with mild-moderate hearing losses in childhood and use oral speech rather than being members of the Deaf community. They all rely heavily on and wear their hearing aids every day - our childrens' hearing aids are from Australian Hearing Services and my husband's hearing aids have had to be purchased through private audiology practices. Whilst I have normal hearing, I live with the personal, social and financial consequences of hearing loss on a daily basis and I would like to emphasise that these are significant costs for each member of the family.

<u>Access to hearing aids</u>
The cost of purchasing hearing aids through private audiologists since my husband turned 21 and was no longer eligible for services from AHS has had a significant financial impact on us as a family. He needs 2 hearing aids, therefore the MINIMUM cost to us is approximately $6000 each time he replaces his hearing aids. In fact, the real cost is much higher because the "base" level hearing aids do not meet his particular needs, therefore we have usually had to pay more than $3000 per hearing aid. The cost of hearing aids is not able to be recovered through the taxation system, therefore replacing hearing aids is an AFTER-TAX cost to us. The rebate which we obtain from private health insurance is minimal and most private health insurers will only provide a rebate for one hearing aid OR will double the time period which he must wait before qualifying for rebates again. The cost and limited rebates available means that he has delayed replacing his hearing aids well beyond the "life expectancy" of his hearing aids and to the point where he was struggling to hear because his hearing aids no longer met his audiological needs (which has had a high personal cost within our family), especially when we were living on one income or 1 1/2 incomes whilst our children were small. In addition, he has always compromised on the hearing aids which he has purchased because of the cost - he has purchased hearing aids which were "adequate" (at the time) rather than those which best met his needs (which were much more expensive). We have also had to compromise in many other areas of our lives in order to meet the ongoing expense of replacing and repairing hearing aids.

I understand that it is recommended that hearing aids are replaced every 2-3 years because of the changing audiological needs of the hearing impaired person and also to enable access to improved technology, but this would have been impossible for us to achieve financially as a family especially when our children also have had additional expenses/needs relating to their own hearing losses.

The high cost of replacing hearing aids places a significant financial burden on individuals with congenital hearing losses throughout their adult lives AND on their families.

<u>Access to impartial audiology services</u>
Compounding the cost and challenges of replacing hearing aids is the difficulty of accessing impartial audiology services after the age of 21 years when the individual is no longer eligible for services from AHS. In my husband's experience, most private audiology practices are aligned with a particular brand (or brands) of hearing aids and therefore their advice is heavily influenced by the need to promote and sell those particular products. That means that the client is rarely receiving advice which is in his/her best interests or which best meets his/her needs, but rather even with the best will or intent of the audiologist, reflects the audiology practice's product lines. Furthermore, most private audiology practices are well versed in the needs of older people with acquired hearing loss but are unfamiliar with the different needs and challenges of people with congenital hearing losses. My husband has had to repeatedly argue with audiologists who "knew best" in order to have his hearing aids set at levels which met <u>his</u> needs rather than reflecting the preferences and needs of people with acquired hearing losses (who are often less successful users of hearing aids and who prefer dampening of certain frequencies which my husband needs to hear). Lastly, the private audiology practice owns any records relating to their clients and therefore it is almost impossible for the individual to maintain a comprehensive record of his/her changing audiological needs over time, especially when private practices are sold or if the individual moves interstate.

Access to impartial, best practice professional audiology services is almost impossible for people with congenital hearing losses who are over the age of 21 years and who are ineligible for services from Australian Hearing Services.

Cost of other equipment for daily living

The cost of other equipment which would be beneficial for us as a family where 3 members of the family have a significant hearing loss, is also significant. We are not eligible for any subsidies on equipment, and accessing advice about what equipment is available is also extremely difficult because we are not eligible for formal services (because we are not in receipt of disability pensions) where we might obtain that advice. For example, under South Australian law when we bought our house we were required to install mains-powered smoke detectors in the house however the cost of installing smoke detectors which could be heard/experienced by my husband was prohibitively expensive. I was quoted more than $1000 per alarm (and we needed 3 such alarms for each hearing impaired family member) compared to $180 for a "normal" smoke detector installed by an electrician. Those alarms were an additional expense which could not be claimed through any kind of insurance or the taxation system. Needless to say, after meeting all of the expenses of purchasing a house, our house is fully fitted with standard smoke detectors required under SA law, but in the event of a fire and if I am not at home, it is arguable that the other members of the family would not be aware of a fire until it was too late for them to escape the house.

Similarly, we must purchase any other equipment needed by family members at our own expense. Ideally these would include a loop system to enable family members to watch TV more easily, flashing door and telephone alarms, a "loop" system for my husband's mobile phone (he is required to be "on call" 1 week in 3 for his work and a loop system would enable him to use his mobile phone much more easily than he can currently manage), as well as a second Micro-link for each child on their AHS-supplied FM systems (used at school). It would be great to be able to purchase supporting technology such as Ipod loops for our kids so that they can access the same devices as their peers. Most of these items are available at a relatively high cost, presumably because of the low volume of sales here in Australia and the technology involved in producing the products, although they are not always available from local suppliers which means trying to buy products unseen from interstate suppliers (and trying to judge through the inter-state telephone sales pitch whether or not the product will actually meet our needs).

The recent advent of digital decoders has meant that we can now access sub-titles on many television programs which has been a real boon to the whole family - previously I found it extremely stressful to be in the same room as the rest of the family when they were watching TV because the television volume was too loud for my comfort if they were to be able to hear and understand. Sub-titles mean that we can now enjoy watching movies or television together as a family although live-to-air subtitles for news services are truly abysmal (poorly spelt, often completely inaccurate and generally at least 1/2 a story behind what is currently being said so that it is impossible to lip read and check the subtitles simultaneously because they don't make sense).

Accessing volume control telephone equipment is also problematic. Telstra only supplies such equipment to its own customers therefore, in order to be able to access that equipment, our choice of telecommunications providers is restricted to one supplier or we must try to find our own solution (with limited success).

The cost of batteries is also a significant ongoing cost for the household budget. Whilst the batteries needed for our children's hearing aids are supplied through AHS, my husband must buy his through pharmacies. Sometimes it is difficult to find a pharmacy with the right size batteries in stock, and once again, the purchase is not cheap. He would replace both batteries in his hearing aids approximately every 7-10 days therefore buying hearing aid batteries has to be factored into our weekly household budget.

Access to supporting technology in the workplace

Whilst it is illegal to overtly discriminate against someone on the basis of a disability, in reality subtle (and perhaps unintentional) discrimination for people with congenital hearing loss continues in the workplace on a daily basis through the difficulty of accessing supporting technology. It is understandable that employers are reluctant to purchase (high cost) technology which can only be used by one person, but their unwillingness to provide such support limits the individual's capacity to contribute and to meet his/her full potential in the work place. This in turn impacts on the individual's employment prospects including the opportunity for career advancement (regardless of his/her real potential). In my husband's case, he is required to participate in lengthy teleconferences up to 5 times each week where he has to try to listen and decipher what each person is saying regardless of the quality of the telephone connection, accents, mumbling or any other possible difficulty. He is usually exhausted after the longer teleconferences and admits that he spends so much time working out what is being said that the conversation has usually moved on before he is able to contribute his own expertise and advice. He would benefit enormously from newer technology which can translate spoken word into text in real time but such technology is expensive and the organisation must be willing to recognise the possible benefits to them of purchasing the equipment. Even if we were personally able to afford such equipment, his organisation must be willing to integrate the technology into their own ICT systems and this is also not always feasible.

People with hearing losses face ongoing additional costs in order to be able to live independently and work productively in the community.

Access to Child Disability Allowance and government-funded employment services
Because both of my children have degenerative hearing losses, we were not aware that we might have been able to access the Child Disability/Carer's Allowance until shortly before my son's 16th birthday, therefore he was ineligible for the allowance after that date. We do currently receive the Child Disability Allowance for our daughter, however she will also cease to be eligible after September 2010. It would be great if eligibility for this allowance included recognition of carers who are juggling the needs of mul.tiple children and adults with a disability in the same household even if individually none of those individuals was eligible for ongoing income support - meeting the needs of 3 people with hearing impairment can be quite demanding and stressful, even if on a one-on-one basis it does not seem so to the outside observer.

Receiving the Child Disability Allowance has enabled us to purchase goods and services which would otherwise be unaffordable for us, including purchasing tutoring services for our son who is currently in his final year of schooling and who has some learning/language difficulties experienced by many children with hearing impairment. Because our children both speak well (after early intervention and ongoing effort and support), neither have received much support at school academically. Their needs, in particular the needs of our son, have not been recognised despite our efforts to negotiate and lobby for additional assistance for him and therefore we have have had to seek private tutoring for him at our own expense. It strikes me as ironic that at a time when we are desperately trying to support our son to achieve tertiary entrance (of which he is intellectually quite capable of achieving), the financial resources to assist us with that support have been withdrawn because of his age. We are not keen to pursue an adult disability allowance for him because we want him to realise that he needs to be responsible for his own way in life (and in any case it is questionable whether or not he would be seen to be eligible for the allowance) but it would most certainly have been very helpful if he had continued to be eligible for Child Disability Allowance until he had finished his formal schooling.

Likewise, it appears from my enquiries to CentreLink that he can not access any employment support services because he is not currently in receipt of any CentreLink benefit. Like many of his hearing impaired peers, he has struggled to obtain the casual employment which so many teenagers take for granted and which provides them with the necessary experience and references to gain an entry into adult employment. He would benefit from being able to access employment support services (without being required to be in receipt of CentreLink benefits) because he is already disadvantaged in gaining employment, both now and in the future.

Extending eligibility for Child Disability Allowance to the end of formal schooling would ease the financial burden of supporting hearing impaired children for families.

Enabling hearing impaired teenagers to access employment support services would benefit them in gaining employment.

Access to Australian Hearing Services
Needless to say, I am extremely concerned that both of my children will cease to be eligible for support from Australian Hearing Services in their early adult years at a time when they will not have the financial resources to purchase expensive equipment nor the knowledge and confidence to be able to select appropriate service providers. This is the period in which they are likely to be entering the workforce and when they will rely heavily on the hearing aids which they have at that time. In my husband's case, one hearing aid broke shortly after he ceased to be eligible for AHS services and as he was living in his home (country) town at the time, he could not find anyone to repair his hearing

aid. He had to try to gain employment whilst relying on only one hearing aid and then to save over several years to be able to afford to replace the both the broken and functioning hearing aid because by then he had moved away from home for work and was trying to manage on a very limited income. As a young person, hearing aids are an unaffordable additional expense which must be fully born by the individual if they don't have private health insurance, at a time in life when earning potential is at its lowest and there are many other costs such as moving away from home, renting, paying HECS fees, buying a car, etc, etc.

It would be enormously beneficial if young people could continue to access services through Australian Hearing Services beyond the age of 21 years, even if they were to be required to make a partial contribution towards the cost of replacing their hearing aids or other audiological equipment (eg cochlear implant processors, batteries, FM systems, etc). Surely if it is not feasible to fully subsidise the cost of hearing aids, it would be feasible to have a partial payment or to develop a scheme whereby payment is based on income or is means tested and takes into account other expenses such as HECS fees or similar student loans? The audiologists at AHS are experienced in working with people with congenital hearing loss and have long-term records for individual clients which better equips them to recognise changes in the status and needs of hearing impaired individuals whereas purchasing private services is haphazard at best.

Enabling ongoing access to Australian Hearing Services for young people with congenital hearing loss or hearing loss acquired in childhood beyond the age of 21 is critical in enabling them to access the best possible advice and technology to meet their hearing needs.

Having a hearing loss impacts in every aspect of life - socially, at school, in the workplace, at home in the family, such that it is difficult to describe the enormity of the challenges and needs experienced by each individual with a hearing impairment, or the impact of hearing loss in families. I could go on at length about the challenges which we have faced as a family; in accessing early diagnostic services many years before universal newborn hearing screening, the frustration of being denied support at school because we have a deficit-based system which fails students by requiring them to be significantly delayed in developing skills and to be failing academically before services are implemented; the challenges of moving interstate between service systems which are inconsistent and almost impossible to negotiate without local knowledge; the challenges of growing awareness and coming to terms with being "different" for our teenagers as they try to find their places in the world; the fear and frustration of having to buy replacement hearing aids because of the financial burden which it imposes on the family and the compromises which must be made; the limitations in career pathways; or even in choices about where we live our lives because access to services in rural areas is so very difficult. Hearing impairment is in many ways an invisible disability, especially when the individual with hearing impairment speaks well and to all intents and purposes appears to function "normally" in their daily lives. The cost of hearing impairment is significant, both in terms of additional out of pocket costs which must be met by individuals or families, but also in terms of unfulfilled potential and lost opportunities.

As with any other parent, I want my children to be able to reach their full potential and to take their places in society in accordance with their skills, intellect and abilities. I want them to be valued for who they are and for what they can bring to the community rather than being pitied because of their hearing impairment. I want them to be able to access the services which will best enable them to reach their full potential and to be supported to reach that potential, rather than being disadvantaged through being unable to access the equipment and services which best meet their needs. I don't want them to be dependent on welfare. I don't want them to be forced into a position where they believe that the only option for accessing the services and equipment which they need is by being dependent on welfare. I hope and pray that the recommendations of this Senate Enquiry will recognise the very real challenges and costs to individuals and families, and will support us into the future.

Yours sincerely,
Eleanor Kennett-Smith