

## INQUIRY INTO HEARING HEALTH IN AUSTRALIA

Dear Senators,

Thank you for your inquiry, it is most welcome.

I have a severe hearing impairment and have worn hearing aids for about 30 years. I am a founding member of Deafness Forum, and a long time member of Better Hearing Australia, SHHH and Deaf Australia. I am an electrical engineer and musician.

Hearing Health in Australia is a disgrace. It is characterised by a lack of representation for consumers, a lack of regulation to protect consumers, and a lack of concern. Because discrimination against the vulnerable deafness community is rife, exploitation is systemic and entrenched. Hearing impaired people are generally perceived as elderly, and as such, of little value to society and even a burden. Hope of improvement is corrupted by our closeness to profit driven corporations with vested interests in our exploitation. Many Australians are hearing impaired and disabled unnecessarily because they cannot afford proper care.

### THE INQUIRY

Whilst I am very grateful for this inquiry, I think it is a pity that it has not been publicised more fully. The most important people – the consumers of hearing services – will not be making contributions because they will be unaware of the inquiry. I am a very involved member of the deafness community, and yet my only knowledge of the inquiry is through Deafness Forum, which has only 100 individual members. No associated organisations have advised me. I would like you to extend the period for submissions while you promote and advertise the inquiry more thoroughly and widely. Unless you talk directly to consumers you will see the wrong view.

### REPRESENTATION

There are 4 million of us who identify as being deaf or having a hearing impairment. Deaf people are represented by Deaf Australia. Hearing impaired people do not have representation. Deafness Forum is widely regarded as the peak body representing the deafness community in Australia but it is not. It comprises only 100 individual members and about 100 association members, most of which are, profit driven corporations, government organisations or deafness associations with close ties to provider industries.

Soon after Deafness Forum was established, consumer members attempted to re-build our constitution to ensure that we were a consumer based organisation, but it was too late. Service providers were already members and we lost the vote. Now, service providers, corporations and government can have more influence than consumer members. This is not in the interests of hearing impaired people. Our advocacy role is severely

limited when those we seek to influence are members or are too close. We tend to steer away from pressuring allied industries and government. An example is audio loop technology. We push for the building industry to provide audio loops while allowing the hearing aid and telecommunications industries to wind back the same technology. There is never any critical analysis of service provider industries. It is argued that corporations provide us with valuable information, but they can also have massive vested interests opposed to our interests. We are also reluctant to lobby the Government for changes when we are so reliant on its funding.

Deafness Forum is a misnomer. It is not a forum. We don't encourage dialogue or information sharing within our community. There is no exchange or canvassing of ideas, no interaction, polling or surveying of consumers. The community has very little influence on policy. Our journal does not even have letters to the editor. A true forum should be easy today when communication is now so cheap.

Better Hearing Australia is Australia's largest consumer based organisation for people with hearing loss with about 3000 members. BH mainly caters for an older demographic and is more concerned with social networking and coping with the status quo than advocacy or lobbying. BH has a very unhealthy relationship with hearing aid and telecommunications industries – actively promoting their services. Advertising content of the club journal often gets to 50%. Comment on service industries is always positive.

If 4 million hearing impaired people were offered free membership of Deafness Forum, and service providers were excluded, we would have a whole different outlook. Deafness Forum would be representative and more effective. The increased workload could be offset by the additional human resource, and the cost more than covered by access to a major source of unconditional funding.

## HEARING AID INDUSTRY

I am severely hearing impaired.

And yet, thanks to my hearing aids, I lead a normal active fulfilled life. I have family and we party, throw barbies and gatherings and I like quiet conversation. I go to shows, movies, theatre and watch tele. We travel.

I work for a large corporation and attend meetings, make presentations, communicate in large groups.

I am a muso and I love live music.

The hearing aids I wear are 10 years old and sourced from an antique shop on ebay for \$100. They provide me with very good hearing. With a slight touch of a lapel remote I can turn them on and off, use my telecoil, change directional microphones, and adjust volume and tone to suit my needs and environment. I can easily switch them off for use as earplugs, and the compression function protects me from loud noise. Most importantly they function in all sound situations from quiet conversation to live music gigs. I am very happy with them.

The problem is that I will need to replace them soon and supplies are running out.

I have looked at new aids. They were billed as miracles of technology, with promos that would put Dolce and Gabbana to shame. With promises of 'better than normal hearing', 'uber space age', 'hear with your mind', 'sounds like silk', and 'miniaturisation' to the point of 'virtually invisible', it seemed like aids had improved beyond imagination. The prospect of experiencing 'Zen Harmonic' and 'Life Is On' was irresistible and exciting.

So, I was fairly startled to find that the hype was pretty much the inverse ratio of reality. Not only could I not find a better aid but none were as good as my museum pieces. Audiologists said that I was wrong and that my attitude was common among existing aid wearers as we are resistant to change. I think it is us who can recognise the swindle. I had no budget constraints and yet I could not find a better aid. The first surprise was that there was no change in the size of aids. Then there was the lack of remote on/off switch, manual controls, and no fullness of loud and clear sound. But the most astonishing aspect was that it was not possible to obtain aids for listening to both conversation and music. My audiologist advised that I would no longer be able to obtain an aid that can handle both music and speech successfully, because digital aids could only input quiet sounds.

However, I was keen to trial them, so I chose the best aids recommended for my condition at a cost of \$14,000. The aids were packed with automatic features – anti feedback, noise suppression, limiters, directional microphones, etc. I tested them thoroughly in many various situations over six weeks. The automatic experience was hideous. Generally, loud sounds were softened and soft sounds were increased. A vehicle moving away would sound like it was approaching, and vice versa. The automatic response was too slow. Painfully loud noises were not cancelled immediately and soft voices went unrecognised. The audiologist was right about music. There was no way of listening to live music. I tried playing a quiet little song with my guitar. When I sang, the aid recognised voice and so it suppressed the guitar, when I played melody it recognised music and dropped out the bottom end, when I played chords it recognised noise and turned all sound off. The quality and strength of the sound did not improve. I was fairly bewildered until one day I visited mum in a nursing home. The aids worked perfectly and the penny dropped. I had found the target market, with no active life, no music, no parties, and no need to worry about which way the traffic flowed, all mum needed was an aid that she could pop in and leave, no fiddling, no feedback and fully automatic. Apparently hearing aids are now automatic to mimic our natural ears. Automatic ears ??

I returned the aids and was abused.

The hearing aid industry claims that most of their 100,000 clients per year are satisfied, but no-one is checking. You only need to talk to consumers or search the various hearing aid forums on the net, to see that many people are disappointed. Most are unaware of how poorly they are treated. We have the technology to produce much better hearing aids, but it is not used. Instead the hearing aid industry uses modern technology to reduce the cost of manufacture while increasing prices, and limiting choices. Prices of hearing aids continue to increase while other more sophisticated electronic devices like mobile phones, computers and televisions, some with

lower market volume, routinely decrease. Hearing aids are claimed to be state of the art but in fact are many years behind these common domestic appliances.

In Australia no qualification or registration is required to sell hearing aids. Sellers enter into dodgy commission arrangements with the manufacturers. Sales ethics are not overseen. While this industry remains unregulated there will be no change. Aids will be inferior, claims will be more outrageous and advertisements will look sillier.

The Hearing Aid industry is not a caring service provider to the hearing impaired community. Deafness Forum and Better Hearing should cease supporting this industry and instead actively campaign for a better deal. If aids were a better quality and priced correctly, few of us would be disabled and there may be less need for government funding.

#### TELECOMMUNICATIONS (Telstra)

Although I have a severe hearing impairment, I was not disabled because I had 2 good hearing aids and a great CDMA mobile phone for telecommunications. However since Telstra closed the CDMA network I have not been able to find a suitable Next G handset. I have been effectively disconnected from the telecommunications network since November 2007.

Now I am disabled. Telstra has made me disabled, and there is nothing I can do about it.

My mobile phone was my Telecommunications Central. It suited my situation well because it featured a good telecoil, which provided a strong signal for my hearing aids. I had my other less suitable phones diverted to my mobile so I was always connected. I relied on my mobile for home, work, leisure, safety, security, organising and family contact.

Now, my life is severely disrupted. My job is in jeopardy. A mobile is vital in my current role. An important link to my family is broken. The enjoyment of spontaneous communication with my wife and children is gone. Today's world is increasingly mobile and I am a part of that world. My ability to participate in modern technological communication is greatly diminished.

I sought assistance.

- The Deafness Forum (DF) and Better Hearing Australia (BHA) had already been visited by Telstra and because of their very close relationships, and the commitments Telstra had made regarding the quality of the new service, DF and BHA accepted Telstra's hype without challenge. DF and BHA commenced promoting the NextG network. Any queries on the new phones were responded to directly from Telstra's media release. BHA even rolled out a roadshow to promote NextG. My request for assistance came too late. It was impossible for the associations to backtrack, suffice to providing me with a note confirming that the above was true, and to advise me that they had never endorsed the new phones. However,

Telstra had misconstrued the willingness of the DF and BHA to promote NextG as indeed an endorsement of its product. This then became part of its spin and was circulated to whoever needed convincing of its sincerity – including the Minister for Broadband and the Australian Communications and Media Authority (ACMA).

- ACMA acknowledged to me “that Telstra’s decision to close its CDMA network has left you in an unsatisfactory position, and while ACMA does not doubt that you have been unable to identify a Next G handset which fully meets your needs, it is of the opinion that Telstra has responded to your concerns in an appropriate manner.”
- I requested help from The Telecommunications Industry Ombudsman, but did not receive a response.
- The Minister for Broadband provided the most Kafkaesque response. After I had advised him that I did not have a phone, he advised me that I did have a phone.
- The National Acoustics Laboratories (NAL) supported Telstra’s contention that I should be able to find a suitable mobile phone.

Only the Telecommunications and Disability Consumer Representation (TEDICORE) provided me with support. It already understood that there were problems with the telecommunication system.

Telstra is involved in many disability and senior’s programmes. It provides training and information sessions for deafness groups. It assists the Victorian Government, by not only sponsoring the Victorian Seniors Festival but also, in determining the content of the seminars. “Telstra Connected Seniors” is a recent programme to help the elderly stay connected. Only last week Bill Shorten congratulated Telstra on its disability initiative, the Telstra-TJA Prize for Telecommunications and Disability. All of which seems very honourable, but a quick scan soon reveals that these initiatives are little more than a front for flogging its products and fleecing the vulnerable.

If Telstra is serious about contributing to the Hearing Impaired community and making its mobile network service accessible to people wearing hearing aids:

- It would ensure that there were processes in place to ensure its phones are satisfactory and that they have suitable telecoil signal strength. It would request handset manufacturers to provide magnetic signal strength information and units with a useable signal. It would have handsets undergo thorough and ongoing independent scientific testing, and have the test results made freely available. Telstra would accept responsibility, as the service provider, for the setting of specifications, standards and ensure the usability of mobile handsets. It would ensure that all who can benefit from telecoil technology have access to it by retaining a simple and cheap telecoil device in mobile phones.
- It would cease opposing the proposal made by the Telecommunications and Disability Consumer Representation (TEDICORE) for a revision of the AS/ACIF Standard S040:2001 Requirements for Customer Equipment for use with the Standard Telephone Service – Hearing Aid Coupling; which currently specifically excludes mobile phones from complying with a standard magnetic field strength.

- It would have Telstra's Mobile Device Integration team to add telecoil capability and magnetic field strength to mobile device requirement specifications.
- Handsets would be tested by the NAL with a view to rating them for Hearing Aid Compatibility as per America's FCC requirements, where 50% of mobile phones are mandated to be hearing aid compatible and to ensure mobile phones have satisfactory telecoil signal strength.
- Telstra would accept that it could play an important role in improving the life of hearing impaired people. It would work with deafness advocacy groups to encourage, listen to, and act on feedback to formulate a policy of co-operation and inclusion. It would cease peddling marketing spin and ripping off the vulnerable.
- Telstra would accept that there is a telecommunications problem, and that thousands of hearing impaired people need not be disabled, and their quality of life could be improved dramatically if only it acted responsibly.

Meanwhile, I still don't have a phone. Many others share my experience, but are they know it is pointless to complain.

Telstra is not a benevolent benefactor of the hearing impaired community. It is a profit driven corporation intent on exploiting us to build its brand and also to sell its products. We should loosen our close ties with Telstra and actively lobby for its reform. If it was a better corporate citizen many of us would not be disabled.

#### AUSTRALIAN HEARING – NAL

The National Acoustic Laboratories is the research division of Australian Hearing, a Commonwealth Government Authority under the Department of Human Services. To most people the NAL is a well-respected scientific organisation dedicated to interests of the Deaf and hearing impaired communities the service of hearing impaired people. But, the NAL also provides assistance to organisations that do not have the interests of deafness community at heart.

In preparation for the introduction of its NextG mobile phone network Telstra requested the NAL to collaborate in an investigation into the potential for the new phones to cause interference in hearing aids. Test subjects were recruited from Telstra. The handsets were only tested for interference, and not for other aspects of Hearing Aid Compatibility. On the basis of that limited report Telstra launched into a campaign to win over the deaf community to the new network.

Last year I lodged a complaint with the Human Rights and Equal Opportunity Commission against Telstra on the grounds of discrimination, because at the introduction of the NextG network it had taken away my access to a mobile phone. During the period of my case Telstra commissioned another report from NAL. This time to discredit me.

The resulting 42 page report, "Next G Compatibility with Hearing Aids in Telecoil and Microphone Setting" looks impressive. Actually, it is scientific fraud. It is based on questionable methodology and amounts to a clear indictment of the NAL. The study was not independent. Telstra part funded the study, set the criteria, parameters and target dates, etc. The tests were not objective with the participants giving their subjective opinions. 50% of the 2 participants who completed the study were employed by Telstra. The subjects of the experiments had perfect hearing and so the results can no way be extrapolated to the deaf community. Although the report doesn't conclude that the results are applicable to all people who wear hearing aids, for all levels and types of hearing impairment, it does not clarify its limits either. NAL would have just a little bit of trouble having it published in a science journal I would think.

I contacted the NAL for clarification of the limits of this report. Its comments were even more disturbing. The NAL supported Telstra and provided me with some alternative solutions, which were alarming and quite wrong, and not in the interests of hearing impaired people.

Telstra presented the report to the Human Rights and Equal Opportunity Commission during my case as an independent study, with the assertion that it was evidence that the hearing impaired community should be able to use Next G phones with confidence.

The National Acoustic Laboratories is the research division of Australian Hearing, a Commonwealth Government Authority under the Department of Human Services. Contrary to its mission, it is not dedicated to interests of the Deaf and hearing impaired communities and the service of hearing impaired people. It also works for the highest bidder, which may be contrary to our interest. By allowing Telstra to use the NAL the Australian government is complicit in our oppression, and it compromises NAL's scientific credentials.

We should look closely at the operations of NAL, seriously question its scientific work, and be prepared to confidently challenge its advice and findings. We can also occasionally remind Australian Hearing, the Department of Human Services, and the Government of our priorities.

## DISCRIMINATION

We have an Act that makes disability discrimination unlawful and aims to promote equal opportunity and access for people with disabilities – but we do not have the right to enforce that act. Last year I lodged a complaint with the Human Rights and Equal Opportunity Commission (now Australian Human Rights Commission) against Telstra on the grounds of discrimination. HREOC investigated my complaint and found that my case had merit. However, it advised that its role was impartial and that it cannot make any findings of unlawful discrimination. If Telstra wished to ignore my complaint it could, which of course it did.

HREOC gave me the opportunity to take legal action against Telstra. My lawyer advised me not to. As well as \$14000 for a barrister there would be major costs for witnesses, time off work, and effort in preparation, and much more if I lost. Even if I had the support of Deafness Forum Telstra would crush me anyway and create a legal precedent to enshrine discrimination. My lawyer also advised me not to criticize Telstra out of court. I am very disappointed with the Human Rights and Equal Opportunity Commission. Its ability to prevent discrimination is very limited. Its role seems to be to mediate voluntary compromise deals between disagreeing parties. Not to prosecute discrimination. The perpetrator of discrimination can even refuse to be involved, without penalty. HREOC gives the impression that we have rights. We don't. Without a guarantee of rights we will continue to be crushed.

## CONCLUSION

With will and determination Hearing Health in Australia can be greatly improved. With proper management, hearing services in Australia can operate more efficiently and effectively. If consumers were better organised with true representation, their advocacy role would be strengthened and better outcomes would follow. Cosy links with predatory profit driven corporations only undermine our position and must be broken. Our governments should give us more consideration and support, fund us fairly, regulate the hearing aid industry, and enact proper anti-discrimination laws.

I have limited my contribution to a small sample of Hearing Health issues from my perspective. There are many other aspects requiring attention. Most of my assertions can be substantiated and I can provide further details.

I wish you well with the inquiry and hope you can have a nice break over the festive season.

Thanks