Deafness Foundation

9 October 2009

Committee Secretary
Senate Community Affairs References Committee
community.affairs.sen@aph.gov.au

Dear Sir / Madam

Re: Inquiry into Hearing Health in Australia

Deafness Foundation wholeheartedly supports the ongoing consideration of issues relevant to Hearing Health in Australia but, at the same time, we also believe that a comparable focus should be directed to Deaf Health and all relevant issues that affect the lives of those who are Deaf.

Deafness Foundation is a not for profit organisation located in Victoria which was founded in 1973 by the Hon. Peter Howson to act as an umbrella organisation, forum and information exchange and hopefully speak with a united voice for the Deaf and hearing impaired in the community.

The Foundation provides support to the Deaf and hearing impaired through a variety of ways including a financial grants scheme that supports projects Australia wide associated with research, prevention of deafness, early detection of deafness, education and technology.

The services of the Foundation are made possible through the success of fundraising initiatives including a Butterfly Badge Appeal. The Foundation receives a government grant, which supports the position of a Rubella Education Officer who conducts the Rubella Education Program in Victoria. The Foundation has conducted this program since 1974 and believes that rubella education and prevention is another critical aspect of Hearing Health. A separate report is attached that addresses Congenital Rubella and Hearing Health for your consideration and information.

We are pleased to provide the following in response to the issues referred to the Community Affairs References Committee:

a) The extent, causes and costs of hearing impairment in Australia

The extent of hearing impairment in Australia is covered in the Access Economics (2006) *Listen Hear* Report. The findings from this report reveal that one in six Australians is affected by hearing loss with a projected increase to one in every four Australians by the year 2050.

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The causes of hearing loss generally stem from one of two causes, conductive hearing loss or sensorineural loss. These can occur through pre and post natal conditions, illnesses, accidents and injuries, workplace noise and recreational activities (eg personal use of iPods, MP3 players, the use of noisy machinery, recreational pursuits including shooting and motor sports).

The costs of hearing loss in Australia are documented in the Access Economics (2006) *Listen Hear* Report and noted as $11.75 billion per annum. The report identifies the previously hidden impact of hearing loss on Australia, noting that productivity loss related directly to hearing impairment accounts for more than 57% of the total financial costs – or some $6.7 billion a year. The time of onset of hearing loss is relative to the overall costs involved with reference to the interventions and support services required.

b) The implications of hearing impairment for individuals and the community

Individual implications
These are of course very dependent on an individual's circumstances and stage of life at which hearing loss develops or presents as an issue that makes it very difficult for an individual to continue to live his/her life in the accustomed manner.

One of the major implications for an individual with hearing impairment is a reduced capacity to communicate easily. The timing of the onset has a direct impact on an individual's ability to develop or maintain language skills. Implications can include isolation, lack of family and community support, reduced capacity to continue with education and tertiary training and work opportunities, loss of financial independence, increased personal costs including the cost of hearing aids and their maintenance should a person be ineligible to participate in the Government funded hearing services program.

The implications are enormous in terms of social and community connection, the costs involved for an individual in accessing not only hearing aids, but assistive technological devices, medical care and support services.

Community implications
Due to a reduced capacity for people with hearing impairment to communicate easily and the resulting isolation, this can create issues around family relationships, mental health issues, unemployment, lack of educational opportunities, financial stresses and so much more.

The issue of dealing with hearing loss within migrant communities is an area that needs some investigation and follow up.

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

The access to hearing services for individuals who fall outside of the Australian Government Hearing Services Program is a very costly exercise. Those who can afford to pay for such services do so and those who cannot afford the costs of hearing aids and technology are very disadvantaged and often find themselves withdrawing from society and becoming very isolated.

Assessment services need to be readily available and conducted as part of a regular health screening process. This needs to include newborn hearing screening, toddler screening, school age hearing screening and screening undertaken as part of a general medical assessment. There needs to be available and affordable interventions and support services for those individuals for whom screening reveals a hearing loss.

Support services need to be readily available and affordable and include access to hearing aids and training, social support and so much more.

Hearing technologies include personal aids and assistive devices that support Deaf and hearing impaired to participate inclusively in the community. Access to and affordability of these technologies is vital.

These may include a hearing aid, a personal communication device, a specialised piece of equipment eg a telephone, an alarm clock, etc or a form of support provided to ensure inclusion for all such as captioning on TV, DVD's, at the movies, audio-loops at vital community gatherings and access to Auslan interpreters etc.

One of the major factors with hearing technologies is the lack of financial support for such devices. They are not considered under the Government's Victorian Aids and Equipment Program nor are they covered in most cases by Medicare or as a Medical Expense Tax rebate. These are issues that need addressing.

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

The current hearing health and research programs - there are currently inadequate resources for the establishment of language in deaf children. There is no system for providing free hearing aids for adults with acquired sudden deafness so they may be appropriately re-educated.

Whether deafness is congenital or acquired, sudden or progressive, affecting one or both ears there should be a protocol that recognises the health and education implications for the individual's communication skills.

Education and awareness programs need to focus on introducing systematic prevention, coordinated health and education agendas to improve management and a change to community attitudes to those who do not hear well.

There is great need to put resources into developing a national program which raises awareness of noise injury and focuses on the prevention of hearing loss through noise.

This could create major public awareness that works towards reducing the expected increase in the numbers experiencing hearing loss to 1 in 4 by the year 2050.

There is also a need to consider the Deaf Community that use AUSLAN as their language and means of communication. This signing Deaf community and its trainers, offer's the wider community an opportunity to build bridges in communication strategies. This area has been unexplored and uninvolved, as teaching role models, for sustainable lifetime

experiences when confronted by hearing loss and the impacts upon family and community.

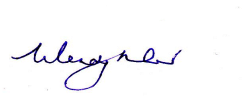
e) Specific issues affecting Indigenous communities

Hearing loss in the aboriginal community is very common with a very high rate of untreated hearing problems especially Otitis Media. At the last estimate in research completed through the Northern Territory Intervention 80% of people in every aboriginal community suffer a hearing loss from mild to severe at some time through the year. There are insufficient support services that are language and education specific, available to support the indigenous community, the education systems in place and the teachers in schools on location.

Services within the Northern Territory as a whole are inadequate to support those living with hearing loss let alone address the special needs of the indigenous community. The needs of the indigenous communities are well documented and extend beyond hearing health.

Thank you for the opportunity to provide comment on the above issues. We would welcome involvement in further discussion on Hearing Health in Australia.

Yours sincerely



Wendy Maher
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Deafness Foundation

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9 October 2009

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Deafness Foundation appreciates the opportunity to present information on **Congenital Rubella and Hearing Health** for your consideration**.**

Infection of the baby in utero in the first four months of pregnancy carries with it a significant risk of causing congenital deafness in the newborn. As well as this other major effects can occur – blindness, heart defects and intellectual disability. The earlier the infection occurs the greater the likelihood of infection in the baby and the greater are the effects on the baby such that infection in the first 2-3 months of pregnancy has an 80-90% chance of the baby being significantly affected. Australia has a link with the connection between rubella infection and fetal abnormalities as it was Sir Norman Gregg in Sydney in 1941, who first proposed the link between the two. The Deafness Foundation has had since its inception, a special interest in rubella prevention. (Downie 2006)

The significance of this condition as a cause of hearing impairment is not so much its numerical frequency but its major effects on the family of the child so affected and the cost to the community of the support for such children and adults. The condition is also readily preventable by the mother being vaccinated against the disease.

1.The incidence of Congenital Rubella Syndrome (CRS) in Australia in recent years has ranged from zero to 5 per annum (While this may seem a relatively small number it takes no account of any terminations of pregnancy for this condition and, regardless of the actual numbers, the potential impact of even one child born with CRS is huge.

2. The lifetime direct costs of a child born with CRS was calculated to be approximately $250,000 in 1982-83 (Owens et al 1983). This takes no account of the indirect costs (institutional care, special schooling etc) nor of the emotional cost of caring for such a child). In 2009 the equivalent cost would be of the order of $1,000,000.

3.Vaccination programs have been calculated as having a benefit/cost ratio of 12.85:1 (Owens et al 1983).

4.In recent years migrant and refugee communities especially from Asia and sub Saharan Africa have been identified as having a much greater susceptibility to rubella infection than those born in Australia or the developed world. (Francis et al 2003)

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5. Communities from these countries are largely unaware of the significance of rubella infection in pregnancy. Because they tend not to engage with the local communities and because of a lack of understanding of the benefits of vaccination in general, it is very difficult to conduct public health programs directed towards these communities.

6.We believe that a more proactive approach to vaccination for prospective migrants and refugees would be very cost effective. It is our experience that these communities generally accept vaccination once the benefits are explained to them. We believe that prospective migrants/refugees to Australia, should be given, as part of the premigration medical assessment information about relevant vaccine preventable diseases, offered vaccination and be required to either (1) undergo blood testing to ascertain their immunity to the diseases or (2) formally decline to be vaccinated without prior testing. We are not suggesting that vaccination be a condition of entry, merely that they be fully informed about the benefits of vaccination and be required to formally address the issue and make a decision as they feel appropriate. This is effectively the same situation as applies to local residents.

More can be done and should be done to help protect these communities and the Australian community at large. As noted above these programs are highly cost effective.

7.Ongoing surveillance is required to ensure that the community remains protected against rubella as immunity levels can decline with age especially when the immunity occurs as a result of vaccination.

8.Research is also required as to why some people do not respond to rubella vaccination, the effects of rubella reinfection and the risk to the fetus of reinfection in the mother during pregnancy.

References

1. Downie E ed. Hearing the Need: The Deafness Foundation 1974 to 2006. Deafness Foundation (Victoria) Nunawading, Victoria.

2. Australian Government. National Notifiable Disease Surveillance System 2009.

3.Owens H, Burrows C and Brown K. 1983. Prevention of congenital Rubella Syndrome. A Cost-Benefit Analysis. Economics and Health:1984. Proceedings of the 6th Australian Conference of Health Economists.

4. Francis BH, Thomas AK, McCarty CA. The impact of rubella immunisation on the serological status of women of child bearing age: A retrospective longitudinal study in Melbourne Australia. American Journal of Public Health. 93 (8) 2003 1274-6

I would welcome an opportunity to discuss this important issue further.

Dr Adrian Thomas
Chairman, Rubella Committee
Deafness Foundation