## LET US HEAR

Campaign Committee of Deafness Council of NSW Inc *for* Equity & Continued Access to Australian Hearing Services for Deaf Adults

# INQUIRY INTO HEARING HEALTH IN AUSTRALIA October 2009

"Let Us Hear" is an organization known throughout Australia representing deaf people between 21 and 65 years, who are former child clients of Australian Hearing (AH).

It was started in 1997 by a small group of parents who realized the need of many hearing impaired and deaf young adults who were unable to access affordable hearing aids and services in the private sector.

"Let Us Hear" recommends:-

## Option 1

That the Australian Government allows former child clients of AH over the age of 21 be included on the Eligibility List of AH. We understand that this could be through the voucher scheme.

or

## Option 2

That the Australian Government allow for all former child clients of AH over the age of 21 be permitted to continue to be serviced on an affordable co-payment basis with appropriate subsidies for low income earners.

#### INTRODUCTION

From the beginning of time deaf people have always been a very isolated part of society. Over the years technology has brought an improved quality of life to deaf people giving them the opportunity to work and socialise in a hearing world. Sixty years ago there was some help for severe/profound deaf people who wore primitive hearing aids and were mostly taught sign language and called deaf and dumb. The situation for the partial to moderately deaf children was slightly different because once fitted with hearing aids many went to their local school.

In the 1950s a few educators saw that it could be possible to teach profoundly deaf people to listen, lipread and speak using their hearing aids. As soon as a baby was diagnosed parents were given a choice to have their baby taught signing or oral communication. The training for oral communication involved very intense training for the child under the guidance of a Preschool Teacher of the Deaf with a 24/7 follow up by the parents. This method brought very good results for many profoundly deaf children.

Annette Shepherd had the foresight to see there was a need for preschool centres to concentrate on this training and the Shepherd Centre was started at Sydney University in 1973. The OD (Opportunity Deaf) classes were set up in NSW schools to give children

the opportunity to have their deaf needs met while having the opportunity to mix with hearing children. Visiting Teachers of the Deaf visited integrated deaf children in their local primary or high school several times a week, giving them individual tuition. While these giant steps were being taken with education, audiological technology was also making progress with NAL (National Acoustic Laboratories) being recognized as a world leader in research.

Currently we have the situation that the Federal Government finances the audiological needs of deaf children, which supports their education, up to the age of 21. Also with the continuing improvement with hearing devices, which today includes hearing aids and cochlear implants, many of these people have reached great outcomes by the age of 21. Unfortunately the Governments' interest in these people has not kept up with the vast audiological and educational improvements we now see in the average 21 year old today, compared to 60 years ago. The Policy made in 1948 has never been changed and the need for a lifetime use of hearing aids has been ignored. In the 12 years of our campaign we have met with successive Ministers. Although some of these Ministers have shown a real interest in this oral group, nothing concrete has happened to improve the situation. **Oral deaf people are the hidden disadvantaged who have not been identified or understood by the Government.** 

By the time they reach 21 they are completing their tertiary education and/or seeking employment and there is no further audiological support available from AH or the audiologists who they have relied on since diagnosis. They must finance all this themselves. It is a travesty of justice that they should work as hard as they have to fit into society only to have their access to AH denied. It is also difficult to understand the Government's rationale for spending so much money on audiological services and technology only to allow the benefits they bring, to fall away during the productive years.

#### THE EXTENT AND CAUSES OF HEARING IMPAIRMENT

It was stated at Hearing Awareness Week 2009 by Hon Justine Elliot, Minister for Ageing (and Hearing Services) that one in six Australians suffers from a hearing loss and it is a growing problem mainly due to the increase in the ageing population and the impact of high volume ipods on young people's hearing.

There is a wide misconception amongst the community that the word "deaf" means using sign language. The deaf world appears to be factionalised between:-

Oral deaf

 Iistening, talking and lipreading with the use of hearing devices

 Auslan

 listening, talking and lipreading with the use of hearing devices

 oral deaf

 sign language used by deaf people, some of whom choose not to wear hearing devices

• Acquired deaf deafness developed after language has been established.

However the nature of the Let Us Hear Submission is to consider the congenitally oral deaf and those who are diagnosed deaf during their childhood years and have been child clients of AH. Childhood deafness has many causes including genetic, infection, medication, and adventitious reasons

The NSW Statewide Infant Screening/Hearing programme has been operating for some years and is a very worthwhile initiative. So much so that the Rudd Government has

recently announced that by 2011 all babies born in Australia will be tested for hearing loss at birth. The reason that this is considered to be so important is that it gives babies the earliest opportunity for the fitting of hearing devices and the commencement of training enabling them to have the best chance of acquiring language, cognition, auditory skills and speech, along with their hearing peers. This also gives them every opportunity to be part of the hearing world. It is accomplished by a great deal of hard work from parents, professionals, friends and most of all, the child. The need for the fitting of hearing devices at birth should highlight the fact that this should be a lifelong commitment by the Government to maintain auditory support for the oral deaf through their productive years.

#### THE COSTS OF HEARING IMPAIRMENT

After the age of 21 when they are unable to continue to access the services of AH and are unable to afford the high costs of repairs or replacement of hearing aids they often develop high levels of anxiety. Without hearing devices there are great problems with communication affecting relationships within the family and community, **causing isolation, social disadvantage and mental health problems.** Few hearing people can appreciate the impact of this exclusion and profound isolation which is totally against the **Government's new Social Inclusion Agenda.** The fact that the Government has ratified the **United Nations Convention for the Rights of Persons with Disabilities** which "calls on governments to take appropriate measures to ensure that assistive technologies are available and affordable," gives it a responsibility towards former child clients of AH.

Without hearing devices, gaining or maintaining employment is jeopardized and this has a profound effect on productivity. We are aware of the "Workplace Modification Scheme" which is useful, but only provides assistance on a short term basis "Let Us Hear' is advocating long term affordable audiological support for deaf people over 21. The last figures we received from the Bureau of Statistics regarding **deaf unemployment were profoundly deaf 68% and hearing impaired 53%.** We must not forget that a large number of employed deaf people are working poor who also cannot afford to support their hearing needs.

The current expenses for hearing services charged by private providers are as follows:-**Hearing aids** \$2000 - \$4000 per aid with most people needing 2. The life of a hearing aid is approximately 5 years.

- **Batteries** \$250 \$300 per year
- **Ear moulds** \$200 \$350 per year
- Other accessories are:

TTY (Typing telephone) \$817 - \$1172. Telstra customers can rent these for \$18 initial payment and then pay \$2.72 monthly Shake Awake vibrating alarm clock \$70 Front door bell detector transmitting to a flashing light or vibrator \$306

**Baby Observer** \$305, transmitting to a flashing light or vibrator \$306.

## **Cochlear Implant**

- Flat rate for any **minor repair** \$396
- \$8000 for any **major repair** (upgrade for processor) can be claimed on private health cover. If not insured this is a personal expense.
- Batteries \$365 per year

The cost to Australia of numbers of oral deaf people, brought up to use audition as their main form of communication, and now cannot afford replacements of hearing devices, is part of the increased numbers of people on welfare payments, be it on a Disability Support Pension (DSP) because of mental health problems or other disabilities, or Newstart because of unemployment.

On 14 September 2009 the Government released a **National Health and Disability Employment Strategy** which said "We need to ensure that we remove the barriers and negative attitudes facing people with disability who want to work, and recognize their potential rather than their impairments."

To our great disappointment the needs of the oral deaf have not been included in this Strategy although consideration was given to interpreters for the Auslan signing deaf. It was also noted under the heading "Additional Support for Student's with Disability", payment for alternative format materials such as Braille and audio tapes for student's with vision impairment, but did not mention captions on educational video tapes for the hearing impaired.

## THE ADEQUACY OF ACCESS TO HEARING SERVICES

In 2008, 1,852 children nationally were first fitted by AH. Those fitted with hearing aids will remain under the care of AH until they turn 21. Those whose parents choose cochlear implants will have access to AH for batteries and repairs for their devices but this also cuts out at 21. Approximately 700 children lose eligibility at the age of 21 each year even though they wish to continue using the services of AH

The only former child clients of AH who can continue to access all services of AH are those on a DSP. Those fitted with cochlear implants who are on a DSP are entitled to access AH for batteries and minor repairs. There is no provision for major repairs in the form of upgrades to their processor, these must be obtained by the person concerned. From 1948 NAL (later to become AH) has provided a very professional and caring service, always providing their clients with optimum hearing aids to meet even the most complex cases, and treated by audiologists who specialize in pediatric audiology. Because of this complexity they greatly need the continuity of a recognized and trusted provider who understands their requirements **and this is where the problems begin.** Many have not been able to access a satisfactory service from the private sector because they have not been able to find the expertise they have been used to, from pediatric audiologists at AH. There are probably many suitable audiology clinics to choose from but very difficult for the uninitiated 21 year olds to find. There are now many AH trained audiologists working in the private industry who know the intricacies of dealing with complex, congenitally deaf cases.

We suggest that information be given to these clients from AH, as the time approaches for these services of to cease. They need to know how to look after their own hearing needs. They need to understand about aided and unaided audiograms, the workings of a hearing aid and the available options. Many of the options are not beneficial to all hearing losses and they sometimes spend their money unwisely. They don't know what questions they need to ask of audiologists or audiometrists to enable them to assess which is the right clinic for them. This, of course, will only be helpful for those deaf people able to finance private audiological services

Clients should not have to pay for ill fitting, unusable moulds as is the practice at some audiology clinics.

The Macquarie University Audiology Clinic runs a hearing aid bank providing second hand hearing aids for sale. We feel this is a third world solution because the aids cannot be tailored to the individual hearing loss.

### INDIGENOUS DEAFNESS

The main reason for deafness amongst the indigenous people is high levels of Otitis Media. This is a result of poverty conditions in Aboriginal communities which stems from poor hygiene, poor nutrition and a lack of health education. There is not a consistent response to keeping up medical treatment to control this bacterial infection and it rapidly spreads to all in the communities from the age of 1 month. Without constant treatment the infection eats away the whole of the middle ear including the ear drum resulting in permanent moderate hearing loss. Until there is control of this infection many children will not hear properly at school, causing high levels of truancy and anti social behavior. Indigenous people also lose the services of AH at 21.

## CONCLUSION

- We advocate that the Government permit all former child clients over the age of 21 continue to be serviced by AH on an affordable co-payment basis, with appropriate subsidies for low income earners or that these former child clients are on the eligibility list of AH. We understand this could be through the voucher scheme.
- Because deafness in the community is a growing problem we request discussion about the suitability of Hearing Services being moved from the portfolio of Ageing to a stand alone portfolio under Health.

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