SUBMISSION TO THE AUSTRALIAN SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

INQUIRY INTO HEARING HEALTH IN AUSTRALIA

GOVERNMENT OF SOUTH AUSTRALIA

October 2009

Terms of Reference

The Inquiry examines Hearing Health in Australia with particular reference to:

1. the extent, causes and costs of hearing impairment in Australia;
2. the implications of hearing impairment for individuals and the community;
3. the adequacy of access to hearing services, including assessment and support services, and hearing technologies;
4. the adequacy of current hearing health and research programs, including education and awareness programs; and
5. specific issues affecting Indigenous communities.

Key Messages

The key messages that the Government of South Australia would like the Senate Community Affairs References Committee to note are:

- The implications of hearing impairment for individuals exceed the basic cost of screening and treating the medical condition. Hearing impairment impedes learning and language development. If children are unable to hear properly the premise of education is undermined, resulting in significant long term social costs.
- The South Australian Government is committed to improving the hearing health of all South Australians through:
    - Universal access to a hearing screening program for newborn children.
    - Early intervention, treatment and support for South Australians diagnosed with hearing impairment.
    - Acoustic modification and amplification of classrooms for students with hearing impairment.
    - The provision of Cochlear implants.
- The incidence of hearing impairment among South Australian Aboriginals is unacceptably high.
- While the South Australian Government provides several extensive programs to improve the hearing health of Aboriginal people, more needs to be done.
- A coordinated approach that facilitates the Australian and South Australian Governments, Aboriginal Community Controlled Health Services and others working together is needed to provide services to Aboriginal people in rural and remote locations.

Introduction

The Government of South Australia welcomes the opportunity to make the following submission to the Inquiry into Hearing Health in Australia.

Having a hearing loss (impairment) means that a person has lost some hearing in one or both ears. Hearing impairments are described according to how much hearing has been lost. Loss is usually explained as mild, moderate, moderate to severe, severe or profound[1]. Profound hearing loss is when no sounds can be heard without the help of a hearing aid. In some cases, a cochlear implant will be used to increase the amount of sound a person can hear.

Hearing is at its most acute at birth. Young children are immature listeners and need a signal to noise ratio (S/N) of +15dB in order to receive intelligible speech, meaning children require speech signals to be 15dB higher than the ambient background noise. Mature adult listeners can manage with a S/N of -5dB, meaning adults can comprehend speech even when the signal is below the background noise.

There are three common types of hearing loss:

- *Conductive hearing loss* happens when there is some block to the transfer of sound from the outer ear to the inner ear (cochlea). In some types of conductive loss, hearing levels may change gradually over time or they may change from day to day. Middle ear infections are the most common cause of conductive hearing loss.
- *Sensorineural hearing loss* happens when there is damage to the inner ear (cochlea) or to the auditory (hearing) nerve. This type of hearing impairment may affect how loud the sound seems or how clear it seems.
- *Combined conductive and sensorineural hearing loss* (sometimes called *mixed loss*) happens when sound is not transferred from the outer to the inner ear (cochlea) and there is also damage to the inner ear or auditory (hearing) nerve.

The Government of South Australia provides a range of screening, treatment and support services to people with hearing impairment.

The South Australian Department of Education and Children's Services (DECS)
DECS provides services for children and students with hearing impairment from birth to school leaving age. These services are available to all children with any level of hearing impairment.

[1] Parenting and Child Health, Children, Youth and Women's Health Service (http://www.cyh.com/HealthTopics/HealthTopicDetails.aspx?p=114&np=306&id=1878)

SA Health

The Children, Youth and Women's Health Service manages the South Australian Universal Neonatal Hearing Screening Program (UNHS), the Hearing Assessment Centre (HAC) and the paediatric Cochlear implant program. The Southern Adelaide Health Service, through the Flinders Medical Centre, provides adult Cochlear implants.

ADDRESSING THE TERMS OF REFERENCE:

1. The extent, causes and costs of hearing impairment in Australia

1.1 Extent

The extent of newborn hearing impairment

Bilateral moderate or greater congenital hearing loss occurs in about 1-2 of every 1000 births and at least as many more infants are born with milder or unilateral losses, of lesser but not negligible impact. A child with moderate hearing loss cannot hear all the sounds of conversation-level speech and therefore suffers significantly reduced speech and language experience if left untreated.

The SA Health Universal Neonatal Hearing Screening Program screens 96% of live births in South Australia per annum. Of these births 16% progress to level 2 screening, 4% progress to level 3 screening, and 1.5% require a definitive audiology assessment. These 1.5% of births equalled 269 newborn children in 2007 and 249 in 2008 in South Australia and the results of their Audiological Definitive Assessment Summaries are provided in the below tables[2].

2007 Results	Number of cases
Normal	164
Conductive 1	49
Conductive 2	20
Unilateral Sensorineural Hearing Loss	14
Mild Bilateral Sensorineural Hearing Loss	10
Mod Bilateral Sensorineural Hearing Loss	7
Severe Bilateral Sensorineural Hearing Loss	3
Profound Bilateral Sensorineural Hearing Loss	2

2008 Results	Number of cases
Normal	137
Conductive 1	46
Conductive 2	32
Unilateral Sensorineural Hearing Loss	13
Mild Bilateral Sensorineural Hearing Loss	2
Mod Bilateral Sensorineural Hearing Loss	7
Severe Bilateral Sensorineural Hearing Loss	4
Profound Bilateral Sensorineural Hearing Loss	8

[2] Universal Neonatal Hearing Screening Program, Children, Youth and Women's Health Service

Permanent childhood hearing impairment of later onset

Extensive research in the UK[3] has determined that compared with the prevalence of congenital hearing loss 50 to 90% more children will have acquired significant permanent bilateral hearing loss of later onset (i.e. after the perinatal period) by the age of nine years.

Non-permanent middle ear conditions with hearing loss

Otitis media with effusion, a form of middle ear infection, is exceedingly common in children under 4 years, with one source quoting an incidence of 60% of children by age 2 years[4]. Most often it is associated only with mild transient hearing loss of minor medical impact. This condition may be considered of greater potential significance in children already affected by longer-term developmental, sensory or learning disabilities. Five to ten percent of episodes may persist for a year or longer[5], and in a smaller group of these chronically affected children, structural middle ear changes may be seen, or middle ear effusion may cause moderate, persisting hearing loss sufficient to affect speech and language development significantly. The prevalence of this condition in Aboriginal children is much greater, as described in Section 5.1. The challenge is for family practitioners to acquire the skills firstly to recognise the subtler clinical signs characteristic of the persisting form of otitis media with effusion, and secondly to discern when it poses a significant risk to longer term ear health and development.

Chronic supportive obits media in Indigenous and Refugee children

Some children suffer chronic supportive obits media, with recurrent and persisting ear discharge, destruction of the tympanic membrane and potentially other middle ear structures. This condition is more difficult and costly to halt and correct, and some continuing hearing impairment is likely. It is rare in Australian children of European origin, more common in immigrant children from impoverished or refugee settings in African countries or Afghanistan, and is very common in Australian Aboriginal children.

Cochlear Implant Services

Ten Cochlear implants are provided to adult South Australians and 15 to 18 Cochlear implants are provided for children under 18 years of age per year.

Increased noise in education environments

Methodology shifts in the past decades mean more learning is done in the presence of background noise. Students are increasingly expected to be active learners, interacting with those around them. Schools are increasingly noisy environments subject to intrusive noise from surroundings, and noise generated within the school by air conditioners, computers and surrounding classes.

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[3] Fortnum HM et al. (BMJ 2001; 323:536)

[4] Clinical Practice Guideline: Otitis Media with Effusion, issued by the American Academy of Family Physicians, May 2004

[5] Fortnum HM et al. (BMJ 2001; 323:536)

A New Zealand study shows only 12% of average classroom time is spent in a didactic mode i.e. where one person is speaking and background noise is reduced[6].

There has not been a corresponding change in the construction of learning facilities that reflects the understanding of the effect of background noise and poor acoustics upon neurological development and learning. Children are at risk of developing limited speech discrimination and listening skills in poor listening conditions[7].

1.2 Causes

Congenital permanent loss

More than half of congenital hearing losses are of genetic origin; other important causes are severe prematurity, perinatal difficulties and infections, and intra-uterine viral infection, most importantly cytomegalovirus (CMV).

Permanent childhood hearing impairment of later onset

Important causes are meningitis, intra-uterine CMV, enlarged vestibular aqueduct syndrome and familial conditions.

Progressive hearing loss in the Elderly and those exposed to excessive noise

Elderly people suffer gradual loss of "outer hair cell" function in the cochlea, or inner ear, which diminishes their ability to distinguish similar speech sounds, or sounds heard simultaneously, such as speech in a noisy setting. This condition is not initially detectable by standard hearing tests in its early stages but results in measurable, high-frequency hearing losses as it progresses. Their discomfort may be compounded by tinnitus, a recurrent or persisting sensation of sound in the ears or head, independent of external stimulus.

Exposure to excessive levels of loud noise produces destruction of outer hair cells, very similar in its effect to premature ageing of the hearing organs. It has been associated with military service (gunfire and explosives) and employment in a wide range of mechanised industries, but these sources of noise exposure have been subjected to controls for some years now.

Much less subject to controls has been exposure to leisure noise, of which the most important source in terms of numbers of young people exposed has been nightclubs and

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[6] Valentine J, 3 August 2000, *"Classroom Acoustics: A New Zealand Perspective",* Conference presentation at the New Zealand Acoustical Society Conference – August 2000, published in New Zealand Acoustics, Valentine J, Wilson O, Dodd G, McGunnigle K, Hellier A & Wood J, (2000).

[7] Chermak GD, Musiek FE. *Central auditory processing disorders: New perspectives*. San Diego, CA: Singular Publishing Group; 1997.

similar venues characterised by heavily amplified music[8]. Some schools, including primary schools, have provided this sort of activity for their students. A smaller number of secondary school students will have exposure to amplified music of greater intensity and duration through their active participation in music bands using amplified instruments as a school activity. All students should be supervised in ear protection use, and sound output should be limited. Students should receive thorough instruction in the hearing health risks of amplified music activity and school management should consider its liability for hearing injury sustained by these students.

1.3 Costs

Universal Neonatal Hearing Screening Program and Hearing Assessment Centre

SA Health provides $522,865 per annum to the Universal Newborn Hearing Screening Service to provide the equipment, training for midwives, audiological review and the administrative processes for hearing screening of newborn babies soon after birth at most hospitals. Follow-up hearing screening occurs through the Universal Home Visiting service by infant health nurses from Child and Family Health Services which is part of Children, Youth and Women's Health Service (CYWHS).

SA Health provides $316,350 per annum to the Hearing Assessment Centre to provide hearing testing of children who are identified with possible hearing loss by parents, maternal health nurses, general practitioners and other professionals.

The South Australian Department of Education and Children's Services

DECS provides the following services at an annual estimated cost of $5,570,600:

- Early Intervention Service – Hearing Impairment
- Regional Hearing Services Coordinators
- Centres for Hearing Impaired
- Guidance Officer: Hearing Impairment
- Kilparrin Teaching and Assessment School
- Direct funding support for students in mainstream classes.

DECS provides acoustic modifications for teaching spaces accommodating children and students with impaired hearing, averaging 30 upgrades per annum with an approximate cost of $25,000 per upgrade, at a total cost of $750,000 annually.

DECS provides soundfield systems in teaching spaces accommodating children and students with impaired hearing (55 units at average cost of $3,900) with total cost of $214,500 annually.

[8] Mansfield JD et al Br J Audio 1999 Aug 33(4):211-22

Cochlear Implants

The average cost of the Cochlear Implant and speech processor is approximately $25,000. The South Australian Government provides funding to Southern Adelaide Health Service (SAHS) and CYWHS to enable the provision of implants to adults and children. SAHS also receives funding for a full time audiology position.

Patients are provided with the surgery, implant and the initial speech processor at no cost. The speech processor is a device that is worn externally, similar to a hearing aid. The implant itself is useless without the external speech processor. Unlike the implant, which is expected to last a lifetime, the speech processor has a limited lifespan. Even with the best of care, speech processors will need to be replaced as maximum expected use is 10-12 years. Additionally, speech processors are eventually made obsolete by the manufacturer and cannot be repaired. A replacement speech processor costs over $8000 and the patient is responsible for the replacement costs.

Patients are also responsible for repairs outside of the 3 year warranty period (approximately $350) and for the cost of batteries (2-3 packs/week), unless they are eligible for services under the Australian Government Office of Hearing Services (OHS) scheme. If patients are OHS eligible, batteries and repairs are covered through Australian Hearing complex adult funding. Patients are also encouraged to consider loss/damage insurance cover for their speech processor to cover loss or accidental damage beyond repair.

2. The implications of hearing impairment for individuals and the community

The effect of hearing impairment on learning and development

Hearing is a complex process and not fully understood. The identification of the impact of otitis media and conductive hearing loss upon language acquisition and learning has only occurred within the past few decades.

For children with 'normal' hearing, the great majority of learning is through hearing – and in addition to the acquisition of language, this learning includes social rules, culture and identity. It is estimated that students are required to listen for 70% of the school day.

Hearing impairment causes delayed language development in babies and children and the consequent poor development of reading skills. If children and students are unable to hear clearly, their opportunity to participate in and benefit from the education system is under threat.

Hearing is the most efficient sense for learning – it is a distance sense (like vision), it never sleeps (unlike vision), it scans 360° of the environment (unlike vision), it operates in all situations (unlike vision).

As an "invisible handicap", the effects of hearing impairment are often unidentified and underestimated especially the long term impact upon development of language, including the 'internal language' used in cognition, identity and social interaction. A high percentage of children with unilateral losses are required to repeat a school year[9].

Identification of an existing hearing impairment at five years of age is too late to prevent language delays.

An Australian National Acoustics Laboratory 2004 survey[10] of the speech perception abilities of over 15,000 students with hearing aids showed that those with "minimal" hearing impairment (under 30 dB) comprehended only 37% of speech in the classroom.

[9] Bess F, Tharpe A. Case history data on unilaterally hearing impaired children. Ear Hear. 1986. 7(1): pages 14-9.

[10] Massie R, (2004), *Soundfield Amplification: An assistive device to enhance listening in the classroom,* paper presented at "The Whole Child" Parent Council for Deaf Education conference and expo, Sydney. PowerPoint available at http://www.nal.gov.au/ (accessed May 2006)

Psychosocial effects of hearing impairment

There is a significant emotional / psychosocial cost of hearing impairment, pertaining to social inclusion and acceptance into society.

The psychosocial effects on the individual diagnosed with a hearing impairment include:

- Increased levels of depression.
- Increased levels of low self esteem.
- Increased risk of psychological distress.
- Increased levels of anger when attempting to communicate.
- Increase levels of isolation, resulting in reduced interaction and involvement in mainstream society.
- Reduced literacy.
- Reduced opportunity for employment and self-sufficiency.
- Reduced access to those community events and entertainments mediated principally by speech or music.

Longer term social effects of hearing impairment

If it is not detected, research shows that people with hearing impairment will steadily fall behind their hearing peers in language, cognitive performance, social skills, literacy, and academic skills with increasing age, resulting in:

- Lower potential employment levels as adults.
- Loss of life-long productivity.
- Increased costs required of the community in supports and services.
- Increased risk of failure to complete secondary school.
- Increased risk of engagement with the justice system.
- Increased risk of mental health concerns.

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

3.1 Current access to hearing services and programs in South Australia

The development of newborn hearing screening services in South Australia

Evidence regarding the importance of detection and early enrolment in early intervention to improve the outcomes of children with Permanent Childhood Hearing Impairment (PCHI) began to accumulate in the 1990s, after research from the USA Joint Committee on Infant Hearing reported that children with PCHI who received intervention services before 6 months of age had language scores comparable to those of hearing children at 3 years of age. This research lead to the publication of the USA Joint Committee on Infant Hearing Year 2000 Position Statement Principals and Guidelines for Early Hearing Detection and Intervention Programs[11]. This Position Statement was used globally as the benchmark for developing newborn hearing screening programs and was updated in 2007.

As a result of this publication, a Consensus Statement was agreed upon at the "Universal Neonatal Hearing Screening in Australia: a National Forum for Consensus and Implementation", held on 24 March 2001, at the Women's and Children's Hospital in Adelaide. There were over 110 participants from all States and Territories of Australia including audiologists, teachers of the hearing impaired, neonatologists, paediatricians, ENT surgeons, nurses, epidemiologists, and parents of children with hearing impairment.

There has been a rapid introduction of newborn hearing screening programs in most states in the past few years. The rollout of whole of population hearing screening programs has been completed in NSW, ACT, Queensland, Tasmania and South Australia.

Upon the introduction of newborn hearing screening as a statewide initiative by SA Health in 2005, the Minister for Education determined that each family would be provided advice on the value of early intervention and with support to engage with one of the services as a means of minimising delays in language and speech acquisition prior to school enrolment. South Australia is the only state with a formal process to ensure that families whose babies are diagnosed with impaired hearing by health services engage with an early intervention service.

[11] Principals and Guidelines for Early Hearing Detection and Intervention Programs, Joint Committee on Infant Hearing, http://www.jcih.org/jcih2000.pdf

In 2008, the Screening Subcommittee of the Australian Population Health Development Principal Committee, which reports to the Australian Health Ministers' Advisory Committee, agreed to take a lead role in the issue of neonatal hearing screening and established the Neonatal Hearing Screening Working Group. The Working Group consists of Commonwealth, State, Territory and New Zealand government representatives and specialists in the field of paediatric hearing.

The aim of the Working Group is to develop a screening pathway to support improved population coverage for neonatal hearing screening, develop minimum National Standards for screening and post screening services, establish a national quality and reporting framework and develop a national approach to data collection and management. At the request of the Prime Minister, Premiers agreed to fast track the introduction of newborn hearing screening for all Australian newborns at the Council of Australian Governments (COAG) meeting on 2 July 2009. The timeframe for delivery of the national approach to newborn hearing screening for all Australian newborns is by the end of December 2010.

CYWHS and DECS were the primary sponsors of the national 2009 Newborn Hearing Screening conference in Adelaide where national standards were a key focus. Following the conference, DECS drafted the *Standards for Early Intervention, Management and Long-term Outcomes* which are now under consideration by the Commonwealth Department of Health and Ageing (DOHA).

Access to newborn hearing screening programs in South Australia

South Australia has reliable data on the numbers of babies diagnosed, their engagement with early intervention services, and the predicted date of school enrolment. In South Australia 96% of all live births participate in the UNHS. This is the second highest rate in Australia, as shown below[12].

	SA	WA	NT	Tas	Vic	ACT	NSW	Qld
Percentage live births screened	***96%***	***46%***	***15%***	***90%***	***57%***	***95%***	***95%***	***98%***
Identification rate per 1000	***0.8***	***0.9***	***N/A***	***2.0***	***1.25***	***1.4***	***0.9***	***1.34***

The rate of engagement with early intervention services in South Australia is over 95%.

Universal Neonatal Hearing Screening Program

The UNHS, provided by SA Health through the Children, Youth and Women's Health Service, is a population based hearing screening service for infants aged 0- 6 months. The program provides best practice in newborn hearing screening through a specialised

[12] Presented by Prof Leigh, National Newborn Hearing Screening conference, Adelaide, May 2009

state-wide service, ensuring almost 90% of all infants with moderate or greater hearing loss are identified and actively involved in family focused intervention by 6 months of age. UNHS manages the screening program between hospital and community settings for optimal coverage and effectiveness, in public and private hospitals, metropolitan and rural areas and the Aboriginal population.

Unique to South Australia, a three stage screening model is implemented using Oto-acoustic Emission (OAE) machines and Automated Auditory Brainstem Response (AABR) machines. Midwives and designated Screeners are responsible for completing the first stage screening of all newborns before discharge from hospital. Second and third screens – or for those babies discharged early unscreened – are referred to the Child & Family Health nurse to complete within the community. Any subsequent confirmatory audiology assessment is further referred into UNHS to be seen by the mobile audiologist. Having a mobile audiologist provides a necessary service for families who can not travel large distances with young infants to major public hospitals. Upon confirmation of a hearing loss by an audiologist, infants are directly referred to Australian Hearing, a DECS Hearing Impaired Guidance Officer and an Ear, Nose and Throat (ENT) Specialist or Paediatric Consultant within 24 to 48 hours.

UNHS provides training and support services in implementing screening, provision and maintenance of equipment, governing the screening process, data base management, referral systems and contributes to a national approach to newborn hearing screening, the development of National Standards and a National Database.

The UNHS Program Initiatives are:

- To provide a sensitive and supportive service that is accessible and responsive to the needs of all families.
- To ensure that 95% of newborns complete the hearing screening process by the age of four weeks.
- To ensure that all infants identified receive appropriate definitive audiological assessment by eight weeks of age.
- To ensure that, by the age of three months, all children identified with significant Permanent Childhood Hearing Impairment (PCHI) have been seen by a registered medical specialist, DECS Hearing Impairment Services (HIS) Guidance Officer and Australian Hearing.
- To ensure that all infants with confirmed PCHI be actively involved in family focused intervention by six months of age.
- To work with service partners to maintain and improve service delivery.
- To provide education, training and ongoing development through expertise in the area of newborn hearing.
- To promote newborn hearing screening in the community.

- To be a leading centre of excellence in research, improving best practice in newborn hearing screening.

Hearing Assessment Centre

The Hearing Assessment Centre, provided by SA Health through the Children, Youth and Women's Health Service, is a state-wide service providing assessment of hearing and ear health in children and young people aged 0-18 years. Assessments are offered not only from the central city clinic but also in outer urban sites and major rural centres.

For example, assessment is offered weekly in the northern suburbs (alternately Salisbury, Elizabeth and Munno Para), and in the south at Noarlunga Hospital. The Hearing Assessment Centre visits Murray Bridge four times a year, and twice yearly at major rural centres – Mt Gambier, Naracoorte, Pt Augusta, Whyalla, Pt Lincoln, Pt Pirie and Berri. The Hearing Assessment Centre visits the Pika Wiya Health Service in Pt Augusta twice a year, and has visited other Aboriginal communities on several occasions in response to specific requests.

The program employs a Senior Medical Practitioner, an Audiologist and an Audiometrist. In November 2007, the Hearing Assessment service and UNHS program amalgamated to be managed as one unit.

The major aims of the Hearing Assessment service are consistent with a population health approach, including:

- Improving the effectiveness of hearing and the status of ear health of children and young people in SA;
- Promoting and supporting the earliest possible identification and intervention for children with significant hearing deficit; and
- Improving the hearing and ear health status of Aboriginal children and young people in South Australia.

The Hearing Assessment Centre responds to requests for assessments as a result of a number of identified areas of concern including:

- Speech, language or learning difficulties (49% of first assessments),
- Unsatisfactory response to a hearing screen in newborns (23%).
- Poor responsiveness to voice or other noise (16%).
- Otitis media (8%).

Children referred for assessment commonly have some degree of at least one of the following:

- Developmental delay (either global, or specifically language).
- Disorders of language or the autistic spectrum.
- Behavioural disturbance.

- Outer or middle ear disorders (transient or persisting).
- Sensorineural hearing loss.
- An associated syndrome, sometimes genetic.

The source of referral is varied, and includes:

- Child & Family Health staff (47% of referrals).
- Speech pathologists from community health centres and private practice (15%).
- Paediatricians (10%).
- GPs (8%).
- Parents of children under 4 who request directly to HAC (8%).
- Follow-up requests from the UNHS program (3%).

Department of Education and Children's Services

In fulfilling the Commonwealth *Disability Discrimination Act 1992*, DECS ensures that families with newly diagnosed babies with impaired hearing, who are potentially in a period of adjustment and vulnerability, are fully informed about the range of available interventions, communication modes and likely outcomes when making decisions that will effect their child's life achievement. DECS is proactive in providing access for all children and students with impaired hearing in addition to providing specialist support and targeted programs.

To reduce the long term effect of impaired hearing upon language and speech development, DECS has worked with SA Health to develop a process where all babies receiving a positive diagnosis in the UNHS are referred to an officer in the DECS to ensure engagement with an early intervention service.

DECS Early Intervention Service has used the most recent and comprehensive meta-analysis of research into effective interventions for families with babies with impaired hearing to ensure that interventions are effective[13]. DECS officers have worked with the principal author of this research in implementing its recommendations.

Students with impaired hearing undertaking the SA Certificate of Education (SACE) are entitled to allowances when being assessed. In recognition of the lower linguistic skills of students with impaired hearing, and the additional time required for processing information, the allowances are often also applied in the lower secondary years.

Classroom acoustics and amplification

Recognising that reverberant teaching spaces and classrooms which are subjected to intrusive levels of background noise are not conducive to learning, especially for those

[13] Kumar S. Literature review of Current Best Practice in Early Intervention for Children with a Permanent Hearing Loss. Technical report produced for Queensland Health. 2008.

with impaired hearing, DECS has made a series of improvement to the acoustics of classrooms.

Acoustic assessment is now part of the core business of Hearing Services Coordinators (emulating countries where classroom acoustics are regulated such as Belgium, Germany, Italy, and Switzerland). The criteria applied when making acoustic assessments of learning spaces are based upon the Australian New Zealand Standard for Acoustics (2000), which form the basis of the DECS' Acoustic Performance Standards (2008). All acoustic modifications made to teaching spaces for children and students with impaired hearing aim to bring noise levels and reverberation within these Standards.

DECS is the only Australian education department to have developed and applied Acoustic Performance Standards and to have developed an acoustic measurement kit with staff trained in measuring acoustics.

All new teaching spaces are equipped with acoustic ceilings and DECS now provides a pool of forty five soundfield systems for trialling in schools.

The provision of public funded adult cochlear implant services

Flinders Medical Centre is the only provider of adult, public cochlear implant services in South Australia. Referrals are accepted from any source and most commonly come from ENT specialists, other audiologists or audiometrists and General Practitioners. Self referrals are also accepted.

The Flinders Medical Centre provides ten implants per year. Services provided in audiology include preoperative assessment as well as postoperative audiological management of all publicly funded implantees. Services are also provided for patients who are 18 years of age and transfer to the adult program from the paediatric implant program at Women's & Children's Hospital.

Audiological follow-up in the first year is most intensive, with patients seen at a minimum of five times in the first three months and then at six months and 12 months post surgery. Many patients require additional appointments. After the first year, patients are reviewed annually and as needed for repairs. As the base number of implantees expands, so too does the number of patients who require life-long follow-up.

At present, there are approximately 60 adults for whom referrals have been received and assessment is being undertaken to determine their candidacy for cochlear implantation. Not every patient who is assessed is an appropriate candidate for implantation. Preoperative assessment encompasses at least three and sometimes four or five

assessments in audiology, CT scan and sometimes MRI assessment as well as two or more appointments with the cochlear implant surgeons.

Patients are prioritised based on several factors including date of referral, degree of hearing loss and communication difficulties, effect of the hearing loss on the patient's current employment or ability to obtain a job, isolation caused by the hearing loss, social supports available to assist with rehabilitation, progression and nature of the hearing loss, age of onset of deafness, patient motivation and realistic expectations regarding the benefits of cochlear implantation.

3.2 Improving access to hearing services and programs in South Australia

Counseling services

Improved provision of counseling services to families during the screening or definitive audiology assessment process would be beneficial. Evidence suggests anxiety and fear of possible diagnosis leaves many families feeling isolated, confused and angry. Family feedback indicates families would like support services as early as just after the second screen.

Rural and remote access

Generally children and students outside the metropolitan area are less likely to be provided with hearing aids, cochlear implants or other assistive listening devices. For people in rural and remote areas there are also low rates of attendance to screening programs, failure to access services following referral by medical officer, and prescriptions for medication not being filled or non-compliance with prescribed medication.

Workforce

Workforce planning and the recruitment of skilled staff are challenges for both HAC and UNHS. There are a limited number of skilled paediatric audiologists in South Australia.

Improved data collection

The provision of a reliable and accurate model of data collection is required that is capable of recording and reporting child outcomes and system performance and able to articulate with the national data collection being developed through COAG. The database in South Australia contains most of the data on the screening process and the audiological assessments but information on medical outcomes, early intervention pathways and outcomes is not currently included.

While tracking of clients identified with hearing impairment and their respective outcomes occurs through UNHS, DECS and Australian Hearing, tracking of patient outcomes has yet to be addressed with all stakeholders nationally. A National Database would provide:

- Accurate calculation of incidence and prevalence of hearing impairment in Australia.
- Basis for ensuring efficacy of UNHS systems.
- Continuous improvement of quality.
- Access to a population database of children for research on aspects such as aetiology and epidemiology.
- A basis for tracking the long-term outcomes and cost-effectiveness of UNHS.

Cochlear Implants

Patients undertaking surgery for Cochlear Implants have to go through a range of preoperative assessments and tests. This process can take some time with some children and adults experiencing delays in access for some tests such as CT scans and ENT appointments. The time from referral to actual surgery for adults can be around two years. Delays are a mix of priority and access issues, particularly in the case of ENT workforce capacity issues.

Further work needs to be undertaken in looking at funding models for replacement speech processors. As the number of South Australians with a publicly implanted cochlear implant grows, so does the need for replacement speech processors. Adults receiving services under the Australian Government's Office of Hearing Services are able to receive upgrades and replacement hearing aids but not cochlear implant speech processors. A Cochlear implant is useless without the speech processor, which has a working life of about 7-10 years. Without appropriate funding support for patients with Cochlear implants, the high cost of replacement speech processors will result in patients who can hear from their implant having to return to total hearing impairment.

Patients who are referred into the cochlear implant program often have long term hearing loss which has impacted upon their success in life and their relationships with others, so their needs are generally complex. Patients would benefit significantly from psychosocial assessment and support and this would aid in the determination of candidacy for implantation, ensure support is available and ensure that patients have appropriate expectations regarding the change that an implant may make in their lives.

Other challenges for hearing health

There is a range of other challenges facing hearing health including:

- Maximising the provision of allied health and education services during the preschool years, including Aboriginal Early Childhood Centres and Childcare Centres.
- Making services known and available to culturally diverse populations where the impact of hearing impairment is not understood.

- Ensuring there are processes for representative consumer group involvement in policy making.
- Ensuring health services comprehend the educational impact of hearing loss and need for referral.
- Generating equity of service provision for country families.
- Providing families with reliable data on long term outcomes where an intervention is based on a single approach.
- Providing families with reliable data on the long term outcomes of cochlear implantation.
- Providing for the mental health needs of children and students with impaired hearing.
- Addressing the under-employment of adults with hearing impairment.
- Ensuring that screening programs are part of a continuum of services.
- Addressing the shortage of educational staff with expertise in hearing impairment.
- Ensuring that good acoustics are a basic requirement for all educational structures.
- Ensuring that all educational spaces are equipped with amplification, and that staff have training in the use and maintenance of the systems.
- Mapping achievement on national education standards for all students with impaired hearing.

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

Areas in which further research into hearing health needs to be undertaken include:

- The rate of identification of audioneuropathy.
- The effects/implications of Cytomegalovirus (CMV) infections and the hearing health of the child. Results from findings may lead to early detection of the cause of hearing impairment, hence screening women whilst pregnant for active infections of CMV and providing early treatment could in turn prevent hearing impairment during development of the fetus and postnatally.
- Identification of the most common causes of hearing impairment.
- Comparison of children diagnosed with hearing impairments compared with their normal hearing peers in language and general development.
- A literature review on the issue of screening using OAE method Vs AABR method, including:
    - Cost of OAE machines Vs AABR machines.
    - Incidence of mild hearing loss detected by OAE Vs AABR.
    - Incidence of Auditory Neuropathy in ‘well babies’.
    - Specificity and sensitivity of OAE Vs AABR.
- Quantification of the noise exposure of a representative sample of young people, with identification of significant sources of noise and their contribution to total exposure, so that proposed strategies to combat harmful exposure practices can be directed most efficiently at those sources contributing most to the exposure of the young population as a whole.

Areas in which further education and awareness into hearing health would be of benefit include:

- The recognition of the impact of mild and unilateral losses upon neural development and learning.
- The need for education to promote a better understanding of screening within the community through:
    - Educating and training clinicians to ensure they have the skills to safely and effectively conduct screening and assessment services, including providing psychosocial support services.
    - Educating families about the importance of hearing health.

5. Specific issues affecting Indigenous communities

5.1 Extent

The incidence of otitis media amongst Australia's Aboriginal population is the highest in the world and remains at a level that surpasses the World Health Organization pandemic criteria. There is also a high incidence amongst the Inuit, Native American and Maori populations. There is currently no medical explanation for why otitis media presents differently amongst Indigenous populations when compared to the non-Indigenous population.

Otitis media is a serious infection and the World Health Organization reports over 50,000 deaths annually amongst children less than five years of age result from middle ear disease.

The Office of Aboriginal and Torres Strait Islanders Health (OATSIH) published a systematic review and guidelines on the management of otitis media in 2001 which showed that Aboriginal children suffer high levels of ear disease (acute otitis media (AOM), otitis media with effusion (OME) and suppurative otitis media (SOM) and develop ear disease at a much earlier age compared to non-Aboriginal children[14].

Young Aboriginal children in remote Australia have a 15% to 24 % prevalence of chronic supportive obits media by age 24 months[15].

Aboriginal students in the metropolitan area fail a hearing test in one or both ears at a rate of between 25.2% - 35.9%[16], compared with a "fail" rate amongst the non Aboriginal population of 3% – 4%.

74.2% of Aboriginal school aged children in the APY lands fail a hearing test in one or both ears[17].

In the adult population, research indicates that Aboriginal inmates in prison fail hearing assessments at much higher rates than non-Aboriginal inmates[18].

[14] The Systematic Review of Existing Evidence and Primary Care Guidelines on the Management of Otitis Media in Aboriginal and Torres Strait Islander Populations, March 2001, OATSIH
[15] Mackenzie GA et al, BioMed Central Pediatrics 2009, 9:14
[16] Sanchez, L., Iskov, Q., et at., unpublished data, The ear health and hearing of school age indigenous children in metropolitan Adelaide, 2007-2008, Flinders University in collaboration with The Dept. of Education and Children's Services (SA), 2009.
[17] Sanchez, L. and Sparrow, K., in collaboration with the Anangu education Service (DECS, SA), unpublished data, The ear health and hearing of school age indigenous children on the APY Lands, 2003-2007, Flinders University, 2009.

5.2 Causes

A significant proportion of Aboriginal hearing loss is attributable to temporary and long term effects of middle ear infections. Middle ear infections (otitis media) are caused by viruses and bacteria. Overcrowding and poor housing is considered the leading determinant of ear disease. Research indicates factors related to increased levels of otitis media include exposure to cigarette smoke, lack of breast-feeding, attendance at day care facilities and possibly swimming in dirty water, presumably because of the impact upon increased susceptibility and cross infection.

While it is understood that otitis media presents differently in Aboriginal and non-Aboriginal children, the causes for this difference are not yet understood. There is an earlier onset of otitis media in Aboriginal children, who usually have their first episode of otitis media in the first few weeks of life[19]. The disease also lasts longer in Aboriginal children who commonly have middle ear disease for more than two and a half years during childhood. The equivalent figure for non-Aboriginal children is three months[20].

The OATSIH systematic review reported that the high prevalence of Otitis media with effusion in Aboriginal children continued over the age of seven years when the prevalence in non-Aboriginal children declined after this age. However, it was concluded that Aboriginal children not only had more ear infections but also had a reduced capacity to recover once chronic disease was established compared to non-Aboriginal people. Otitis media is a continuing infection for Aboriginal children; the disease is not self-limiting as in non-Aboriginal children, and Aboriginal children have repeated infections which continue into adult life. Successful treatment of ear disease should be initiated before a pattern of chronic disease is established.

5.3 Implications

Otitis media in the general population has been shown to have significant effects upon learning, behaviour and assessment of intelligence. It has been estimated that repeated occurrences of otitis media/conductive hearing loss result in a ten point decrease in measures of intelligence due to the communication breakdown[21].

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[18]Howard D. Indigenous Hearing Loss and the Criminal Justice System: A Background Paper(2004)http://www.eartroubles.com/attachments/Crinal%20justice%20and%20hearing%20loss-%20background.pdf (accessed September 2009)

[19] Boswell J, Nienhuys T. *Onset of otitis media in the first eight weeks of life in Aboriginal and non-Aboriginal Australian infants.* Annals of Otology, Rhinology and Laryngology, 1995. 104, pages 542-549.

[20] The Systematic Review of Existing Evidence and Primary Care Guidelines on the Management of Otitis Media in Aboriginal and Torres Strait Islander Populations, March 2001, OATSIH

[21] Bennett KE, Haggard MP, Silva PA, Stewart IA. *Behaviour and developmental effects of otitis media with effusion into the teens.* Archives of Disease in Childhood, 2001. **85**, pages 91-95.

Fluid accumulation in the middle ear can cause educationally significant hearing impairment. Ear disease and consequent hearing loss affects neurological development, language acquisition and impacts upon participation and achievement in schooling. In SA, Aboriginal students are at 2.5 times the average student's risk of exclusion from school, and at three times the average student's risk of leaving school early.

The long term impact of otitis media includes an increased risk of coming in contact with the criminal justice system[22].

The implications of hearing impairment for individuals and the community is a lack of community support for the individual, especially on a social and professional level. Although support is available through government programs, there is still the stigma that hearing loss or problems lowers an individual's character or standing in a community.

The OATSIH systematic review and guidelines on the management of otitis media in 2001 reported that poor ear health leads to deafness, speech and language deficits and subsequently poor educational outcomes. This in turn contributes to unemployment, ongoing poverty and increases the risk of offending behaviour.

5.4 Access to Services

Access to the Department of Education and Children's Services Programs

To verify a student as having impaired hearing in SA, DECS requires a hearing assessment report and audiogram from a health service.

DECS has formulated a proactive approach in recognition of the fact that many Aboriginal children fail hearing screening at their local health service but do not proceed to a complete hearing assessment with an audiological service and so are unable to provide medical evidence of impaired hearing.

DECS has worked towards providing a service that recognises the significant educational implications of otitis media through the development of sustainable programs that address otitis media by making these programs core business for service providers, in conjunction with other government and non-government agencies. This includes working with local Aboriginal health services to facilitate the earliest possible identification, with consistent intervention following diagnosis at a whole-of-school/classroom level.

[22] Howard D. Indigenous Hearing Loss and the Criminal Justice System: A Background Paper(2004)http://www.eartroubles.com/attachments/Crinal%20justice%20and%20hearing%20loss-%20background.pdf (accessed September 2009)

Some of DECS work has included:

- Generation of criteria for 'conductive hearing loss' so that students with otitis media can be verified under the Students with a Disability policy and attract support.
- Participation in, and presentations at significant forums:
    - Goldfields Ear Health Conference, WA, 2005 and 2009
    - Hear, Speak, Live Conference, Qld, 2007
    - ANZCED 2007 & 2009 (Aust. & NZ Association for Educators of the Deaf)
    - Advancing Speech Pathology Innovation, Research and Excellence, 2009.
- Joint work with Health agencies:
    - Ministerial Advisory Committee: Students with Disabilities report, Otitis Media and Conductive Hearing Loss Information Strategy
    - Otitis Media Clinical Support Services Project with Country Health SA
    - Evaluation of Aboriginal ear health at enrolment with Child and Youth Health
    - Hearing assessments in the Anangu Pitjantjatjara Yankunytjatjara Lands with Flinders University and Australian Hearing
    - Hearing assessments for Aboriginal students at country schools with Australian Hearing
    - Ear health program at Kaurna Plains Preschool, Muna Paiendi.

Acoustics

In support of schools seeking to install soundfield amplification, DECS provides funding support to schools with a significant Aboriginal enrolment when purchasing soundfields. All new Aboriginal school buildings and special education facilities have skeleton wiring for soundfields built-into each room.

During 2008/09, DECS provided 52 soundfields for Aboriginal schools, which included ensuring all classrooms in the APY Lands have soundfields. This has included installation, staff training and maintenance.

DECS and Flinders University Otitis Media project

In the absence of medical evidence about prevalence, DECS initiated a project with Flinders University in 2006 to assess the prevalence of otitis media amongst Aboriginal students at metropolitan primary schools.

The project delivers hearing assessments to students on school sites and rotates through the metropolitan regions. Support service staff coordinate the process and provide whole-of-class intervention following assessment.

The work is aimed at facilitating the earliest possible identification of students with otitis media and amelioration of the effects on curriculum access, including sustained intervention following diagnosis at a whole-of-school or classroom level. Specific projects include:

- Provision of training and resources for support staff to promote inclusive methodology. Following identification of those with otitis media, these resources are delivered to schools to increase capacity to better cater for the educational needs of those with otitis media. Resources include:
  - *Can't hear, can't learn* teacher resource
  - *Do you hear what I hear?* WA training package
  - *Morning Talks package*, Deadly Ears Team, Queensland
  - Otitis media teacher *resource package*
  - The Anangu Pitjantjatjara Yankunytjatjara Lands Pools project which provides research to support the project to build pools on the APY Lands and ongoing support for pool management. Access to well-maintained community swimming pools has been shown to be beneficial for Aboriginal middle ear health[23].

Access to Children, Youth and Women's Health Service programs

The UNHS does its best to cover the Aboriginal population, relying heavily on the dedication of the Remote and Isolated Children's Exercise (RICE) nurse, who covers Ceduna, Oodnadatta and the APY lands. RICE nurses are trained in screening infants, referring, as appropriate, to the UNHS program. Not all areas are accessible and poor attendance is a large issue when attempting to identify and capture this population. Many Child and Family Health nurses in the rural setting provide transport for these children ensuring that both screening and audiological assessment occurs. In addition, there is a need to think beyond assessment to the availability of treatment options for hearing loss, including services available to clients requiring further intervention.

The Hearing Assessment Centre ensures that all services offered are as accessible as possible to Aboriginal children and young people, their families and caregivers. The HAC visits Murray Bridge four times a year, and twice yearly at major rural centres, most of which have significant Aboriginal populations, including Mt Gambier, Naracoorte, Pt Augusta, Whyalla, Pt Lincoln, Pt Pirie and the Riverland. HAC visits the Pika Wiya Health Service in Pt Augusta and the Pt Lincoln Aboriginal Health Service each twice a year, and is preparing to trial a clinic on the Yorke Peninsula and has visited other Aboriginal communities on several occasions in response to specific requests.

Well-trained Aboriginal ear health workers and community educators are a basic requirement in improving the ear health of young Aboriginal children. Aboriginal children are completing the UNHS process in SA in a similar timeframe to that which applies to

[23] *Lehmann D et al., BMJ 2003;327:415-419 (23 August), doi:10.1136/bmj.327.7412.415*

all children in the state, but referral rates from UNHS are higher for Aboriginal children. UNHS is providing definitive audiology assessment for Aboriginal infants in relatively remote locations. Aboriginal children in more remote communities require occasional access to audiological technology and expert medical and other opinion.

The Otitis Media Clinical Support Systems Project

The Otitis Media Clinical Support Systems Project was a partnership between SA Health, DoHA and Country Health SA. The project aimed to improve ear health of Aboriginal children aged 0-8 residing in the North and Far West regions of South Australia.

The Otitis Media Clinical Support Systems Project was a vehicle for implementing the:

- National Guidelines for Ear Health; Systematic Review of Existing Evidence and Primary Health Care Guidelines on the Management of Otitis Media In Aboriginal and Torres Strait Islander Populations (March 2001).
- The Management of Middle Ear Infection in Aboriginal and Torres Strait Islander Populations (March 2001).
- Plain language summary of the systematic review on the Management of OM in ATSI populations.
- Recommendations for Clinical Care Guidelines on the management of OM (March 2001), Authorised by Office for Aboriginal and Torres Strait Islander Health Australian Government Department.

One highlight of the Otitis Media Clinical Support Systems Project was that the Project provided agencies an opportunity within each community to work together, representing a coordinated approach by the Commonwealth and State governments, the core primary health care providers in the remote areas of South Australia, the Aboriginal Community Controlled Health sector, and in partnership with bodies like the Aboriginal Health Council of SA (AHCSA).

Access to services through the Australian Government

Australian Hearing provides services to eight communities through its AHSPIA Program (Australian Hearing Specialist Program for Indigenous Australians). This program is funded by the Commonwealth through Community Service Obligation funding. Australian Hearing has a Service Delivery Agreement with Nganampa Health Council and Anangu Education. They have a regular team of two senior audiologists who travel to the APY Lands from Alice Springs three times per year. Nganampa Health Council will screen children prior to referral. The focus of the team will be assessing referred children and where appropriate providing them with amplification options (hearing aids, and/or placement in a classroom with a Soundfield Amplification system).

Australian Hearing reported that they have visited two hundred and thirty Indigenous communities throughout 2007 -08.

Australian Hearing has also developed clinical protocols for Indigenous children, for the audiological management of preschool aged children in remote communities. They are also piloting lightweight infant test equipment, and if successful the use of this equipment will be extended, which will enable testing of children within their communities and reduce the need to families to travel large distances to test their children for hearing loss. Australian Hearing also reported providing and fitting hearing aids to 46 Aboriginal children in South Australia during 2007-08.

The National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes will have a significant impact on Aboriginal and Torres Strait Islander communities. In South Australia there will be a range of strategies that will assist in addressing ear health:

- Aboriginal Well Health Teams ($6.7m over 4 years) will be conducting ATSI Child Health Checks (MBS Item 708), which includes a hearing assessment.
- The Health Promoting Aboriginal Children's Centres initiative which involves a partnership between health, education, community services with Indigenous families and community organisations could provide services.
- The Indigenous Environmental Health Worker Program will provide environmental support for healthy environments.
- Employment related housing in regional areas is a performance indicator for the Remote Indigenous Housing National Partnership, which could assist in reducing barriers to service provision.

The Australian Government announced in February 2009 funding of $58.3 million nationally over four years to expand eye and ear health services for Indigenous Australians. This will provide additional services in the management of eye and ear problems that will support the Closing the Gap goals agreed by COAG.

Lessons learned from the Aboriginal Cardiac Care Program

SA Health has invested significantly in programs to improve the management of Aboriginal people with cardiac conditions. There is an opportunity to use the knowledge developed in these programs to improve hearing health programs for Aboriginal South Australians. The transferable lessons identified through the Remote Area Liaison Cardiac Nurse role are:

- Establishing trust through communicating in their first language.
- Establishing a model of care that brings the treatment to the community. Given that cardiology interventions cannot be directly compared with interventions for hearing disease, the option of setting up a mobile operating theatre that provides

the services to those in need in their own community is preferable to having these children transferred to hospital for management.

- Recognition that each remote community is different and therefore a one size fits all approach is not appropriate.
- The issue of reciprocity has been recognised as important. When research is conducted in Aboriginal communities the locals do not hear back about the results. Therefore a process for feeding back the results of the research should be developed.
- Opportunities for better communication between remote health centres and metropolitan centres allow for better follow up.

Challenges for Aboriginal parents of children with hearing impairment

Aboriginal parents face difficulties in ensuring the ear health of their children. Some of these difficulties include;

- Children not having symptoms before developing tympanic drum rupture.
- Difficulty accessing medical care and specialist follow-up.
- Lack of access to refrigeration for storing antibiotics and practicalities of giving antibiotics to small children up to three times a day.
- Poor parental understanding of the importance of treatment and follow-up to long term hearing outcomes.
- A lack of trust in the hospital system, lack of effective communication (which includes keeping family members fully informed about proposed treatments) and past experiences with relatives who have died in hospital perpetuates fear of hospitals amongst surviving family and friends because they associate hospitals with death.

Challenges for hearing services in Aboriginal communities

Challenges for providing hearing services to rural Aboriginal communities include:

- Poor attendance rate, though this is increased if transport can be provided by an Aboriginal Health worker.
- Appropriate filling out of prescriptions for medications and compliance with prescribed medication.
- ENT surgeons provide a visiting service only, restricting timely access.
- Soundproof rooms used are not appropriately designed for use with children and young people, so clinicians are forced to attempt to test hearing in poor and noisy conditions elsewhere.
- Addressing living conditions, including standard of housing, overcrowding and poor hygiene.
- Addressing predisposing factors for middle ear disease, noting that premature infants of low birth weight occur significantly more frequently among Aboriginal mothers who are more likely to smoke and have poor nutritional status.

- Streamlining and simplfying funding systems for Aboriginal hearing health. A more coordinated approach at a national level, would ensure engagement with all of the Aboriginal Community Controlled Health Services and the Aboriginal Health Council of SA.
- Improvements in access to appropriate anti-infection topical ear treatments. Sofradex is available on the PBS system but is of limited effectiveness and potentially ototoxic (damaging to hearing), particularly if used for prolonged periods or in situations of perforated membrane and inflammation where it may have more direct access to the cochlea. The more effective and non-toxic Ciprofloxacin is not available on the PBS and therefore very costly for Aboriginal Health Services.