Senate Community
Affairs References Committee

Submission to:

Senate Community
Affairs References Committee
Inquiry into Hearing Health in Australia

On behalf of:

Australasian Newborn Hearing Screening Committee

Presented by:

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1. Summary Recommendations

The Australasian Newborn Hearing Screening Committee recommends that the report of this Senate Inquiry should:

1. endorse and affirm the important objective of achieving full population coverage by Universal Newborn Hearing Screening (UNHS) by no later than the end of 2010;

2. endorse the development of quality standards for Newborn Hearing Screening programs in Australia by the Screening Sub-Committee of the Australian Population Health Development Principal Committee (APHDPC);

3. endorse and encourage (a) the acceptance of those quality standards as a basis for evaluation and monitoring of all state-based UNHS programs and (b) the development and implementation of appropriate mechanisms to ensure compliance with those standards by all jurisdictions;

4. strongly endorse the aim of the APHDPC Screening Committee to develop a process for national data collection and management in regard to UNHS programs. As part of that endorsement, it should be strongly recommended that any national system of data collection and management should be based on the collection of "person-level" data so as to provide:
    - the capacity to accurately calculate the incidence and prevalence of permanent childhood hearing impairment in Australia;
    - a basis for ensuring that children identified through UNHS programs are not lost to follow-up (i.e., that they receive the necessary intervention services and other supports that are required to capitalize on their early identification) regardless of their location or movement within Australia;
    - access to a population database of children for research on aspects such as aetiology and epidemiology; and
    - a basis for tracking the long-term outcomes and cost-effectiveness of UNHS programs.

5. strongly endorse the need for continual monitoring of childhood hearing, including the possible introduction of hearing screening programs for preschool age children in jurisdictions where such publicly funded programs are not in operation. Further, that there should be the assurance of publicly funded and available audiological assessments through early childhood for children with known risk factors for hearing loss.

2. Brief Background

The Australasian Newborn Hearing Screening Committee (hereafter, “the Committee”) has been active in advocacy for the introduction and subsequent development of newborn hearing screening since 2001. At that time, the Committee (then the National Newborn Hearing Screening Committee) was responsible for the development, wide endorsement, and dissemination of the Australian Consensus Statement on Universal Neonatal Hearing Screening (a copy of which is attached as Appendix A).

The Committee comprises a broad range of professionals representing the fields of Otolaryngology, Paediatrics and Child Health, Education of the Deaf, Population Health, Audiology, and Nurse Audiometry. The Committee’s membership includes a Coordinator/Director (or equivalent role) from every Australian state-based Universal Newborn Hearing Screening program, as well as representatives from the Deafness Forum, Australian Hearing, the Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP) of the National Screening Unit in New Zealand, and representatives of parents of children with impaired hearing, including the newly formed ANZPOD (Australian and New Zealand Parents of Deaf Children) group. The current membership of the Committee is listed as Appendix B.

A core goal of the Committee is the establishment of a national quality and reporting framework for universal newborn hearing screening in Australia (and, indeed, Australasia). To this end, the Committee has:

- Advocated for the implementation and development of newborn hearing screening programs across Australia to the relevant Australian Government Ministers (including the Prime Minister, Minister for Health, and Minister for Ageing and Hearing Services) and various State Premiers, Ministers for Health and Ministers for Children’s services (most recently particularly in Victoria and Western Australia);
- Advocated for such a framework with relevant bodies including Australian Hearing, the National Perinatal Statistics Unit, and the Australian Population Health Development Principal Committee;
- Provided members and extensive draft documentation for a national working party on the development of standards for newborn hearing screening under the auspices of the Screening Subcommittee of the Australian Population Health Development Principal Committee;
- Collated information about the protocols and practices associated with the various state screening programs with a view to advocating for acceptable minimum nationals standards of care in regard to UNHS;
- Strongly advocated for a national approach to data collection and management, in which our members have considerable knowledge and expertise; and
- Obtained the strong support of members of every state’s program for such endeavours.

In addition, the Committee:

- Continues to advocate for full national coverage of universal newborn hearing screening and has actively lobbied governments in both Victoria and Western Australia to see that situation improved; and
- Has staged five National Conferences on Universal Newborn Hearing Screening. The 5th Australasian Newborn Hearing Screening Conference was held in May 2009, in Adelaide.

3. Response to the Terms of Reference

This submission specifically addresses issues pertaining to terms of reference (c) and (d), those being:

(c) the adequacy of access to hearing services, including assessment and support services, and hearing technologies; and
(d) the adequacy of current hearing health and research programs, including education and awareness programs.

Specifically, the submission deals with the current status of newborn hearing screening programs in Australia and identifies areas where a more coordinated and systematic national approach to such programs could achieve better outcomes for Australian children and their families.

3.1 The current situation in regard to UNHS in Australasia

In regard to coverage by UNHS, the situation in Australia is continually improving. Governments in many (most) states are to be commended for their action in securing the introduction of viable and effective programs of screening.

In 2008, the Committee worked closely with the Australian Institute of Health and Welfare to have newborn hearing screening included as one of the key national indicators of children's health, development and wellbeing in the publication of the 2009 edition of "A picture of Australia's children". Detailed data has been provided by each of the state health departments for that purpose. That publication reports data up until the end of 2007.

This Committee, however, is able to provide a more up-to-date snapshot of the current situation, based on reports from the field and, specifically, members of the Committee. From our understanding, the national situation is currently as follows:

- New South Wales, Queensland, South Australia, and the Australian Capital Territory, and, most recently, Tasmania have achieved true population coverage (i.e., with greater than 95% of the state's entire population routinely able to access newborn screening).
- In Victoria, the program is currently in an advanced stage of "roll-out" and covers all metropolitan birthing hospitals in Melbourne, a satellite program in Wodonga, and an increasing number of regional sites. It is estimated that population coverage in Victoria is currently at 57%.
- In the Northern Territory, funding for a territory-wide UNHS program was approved to commence in 2006 but difficulties in recruiting a permanent coordinator hampered the roll-out of the program. A new coordinator has recently been appointed. Screening of newborns occurs at Royal Darwin Hospital and at one private hospital (Darwin Private). The roll out to the other three public birthing hospitals is planned to commence in the near future (i.e., Alice Springs, Katherine and Nuhlanbuoy). Approximately 55% of the territory's births are covered by UNHS.
- In Western Australia there is currently no state-wide program of UNHS. Coverage of the states total population through the publicly funded component of a Perth-based program currently stands at 45% with additional coverage being achieved by a "fee for service" system ($85 per screen) operating in all private hospitals in Perth and one hospital in Bunbury. Planning is underway in regard to ensuring total population coverage but without any additional funding. Coverage will continue to rely on a hybrid of public funding and fee for service screening in private hospitals. Overall population coverage through the two (public and private) components stands at approximately 65%.

Taken together (as indicated in the printed figures that appear as Appendix C), this means that approximately 84% of all children born in Australia are being screened for hearing impairment as neonates. This can be compared with the situation in England where full coverage of all 600,000 annual births was achieved in March/April 2006, and with the United States where the National Centre for Hearing Assessment and Management reports a national coverage rate of greater than 93%.

Considered another way, the current gap in population coverage by UNHS programs in Australia means that approximately 45,000 newborns **will not** be screened for hearing impairment this year. This creates the potential for as many as 50 children to be born with significant hearing impairment that will not be identified until much too late into their development (potentially not until after their second birthday).

3.2 Issues to be addressed in implementing and developing UNHS programs

Full population coverage by UNHS programs across every part of Australia is the standard that this Committee remains committed to seeing achieved. In that regard, the Committee was greatly encouraged by the statement released by the Office of the Prime Minister on the eve of the COAG meeting in June (29th) this year stating:

> "The Prime Minister will call on Premiers and Chief Ministers at the forthcoming Council of Australian Governments meeting to fast-track the introduction of universal and standardised newborn hearing screening"

The Committee trusts that governments at every level are committed to this aim and confidently trusts that state governments are on track to achieve that aim. Nevertheless, additional advocacy to ensure that is the case is still seen as being necessary. Therefore, the Committee recommends *that the report of this Inquiry should endorse the important objective of achieving full population coverage by UNHS* ***by no later than the end of 2010****.*

In addition, there are other issues of national significance in regard to the delivery of UNHS programs that are constantly on the agenda of the ANHS Committee. Principally, our advocacy relates two key areas:

- The need for a national quality standards framework and systematic monitoring of outcomes, and
- The need for a national data collection & management system.

3.2.1 The need for a national quality standards framework

Internationally, there is a clearly understood need for some system for evaluation and monitoring of all UNHS programs. Such evaluation should be relative to a framework for quality assurance and associated service guidelines. The United States' Joint Committee on Infant Hearing (JCIH) has produced a set of guidelines that provide some guidance on this front. The basic JCIH benchmarks for timeliness of screening are apparently being met in all Australian jurisdictions. Further, we believe that Australian programs are world-leading in regard to the rates of follow-up to diagnostic audiology and early intervention. Nevertheless, there is a need for some framework to ensure that systems are monitored to these ends and that targets for achievement do not become defaults. Continuous improvement must be a hallmark of all UNHS programs.

There is a need for a framework to ensure that all aspects of programs, not just timeliness and population coverage, are in conformity with world's best practice. For example, the JCIH guidelines suggest that any UNHS system should

> "…be family-centered with infant and family rights and privacy guaranteed through informed choice, shared decision making, and parental consent. Families should have access to information about all intervention and

> treatment options and counselling regarding hearing loss. The child and family should have immediate access to high-quality technology, including hearing aids, cochlear implants, and other assistive devices when appropriate."

Evidence on how well this is occurring in all jurisdictions in Australia is simply not currently available. The systems across the country vary widely and the availability and quality of intervention processes are heavily dependent on non-government (typically charitable) supports in some states. This is an area where there is a strong need for evaluative mechanisms and further research to ensure that all of the necessary component follow-up services are in place and of high quality in regard to diagnosed children and their families.

Specifically, therefore, the Committee advocates that quality standards for system evaluation and development are required to ensure that:

- screening and diagnostic services are
  - effective
  - carried out to a high standard
  - carried out in a timely fashion;
- results are communicated to families effectively;
- comprehensive support **post-diagnosis** is assured;
- recording, reporting and improvement of system performance occurs across the screening pathway; and
- data are effectively captured and reported.

The Committee is pleased to report that this issue has recently been taken up by the Australian Health Ministers' Advisory Council (AHMAC) through the Australian Population Health Development Principal Committee (APHDPC). The Screening Subcommittee of the APHDPC has established a Neonatal Hearing Screening Working Group (NHSWG) to develop quality standards for Newborn Hearing Screening programs in Australia.

It is proposed that the standards will be organised into seven areas that broadly represent the stages of the pathways for newborn hearing screening and intervention. The seven areas as follows:

1. Recruitment/engagement with the Screening Process (identification of the target population, determination of eligibility, and population capture, antenatal/postnatal/community education about screening)
2. Screening (screening protocol, criteria for screening, target condition & consent)
3. Support for Families (screening to involvement in early intervention)
4. Diagnostics (audiological assessment and medical follow up)
5. Early intervention, management & long-term outcomes (transition to early intervention, ensuring engagement, availability and quality of program options and locations, outcome monitoring)
6. Co-ordination, monitoring & evaluation (program auditing, self-assessment, engagement with national data collection processes, and outcome measures)
7. Professional education (training and maintenance of professional skills at all levels of the program)

The ANHS Committee is committed to the standards development process and has as many as five members who are also members of that Working Party.

Therefore, the Committee recommends *that the report of this Senate Inquiry should endorse the development of quality standards for Newborn Hearing Screening programs in Australia by the APHDPC Screening Committee*.

Further, it is recommended *that the report of this Senate Inquiry should endorse and encourage (a) the acceptance of those quality standards as a basis for evaluation and* *monitoring of all state-based UNHS programs and (b) the development and implementation of appropriate mechanisms to ensure compliance with those standards by all jurisdictions.*

3.2.1 The need for a national quality standards framework

Recent evidence provided by colleagues at the National Acoustic Laboratories suggests that, although there are indeed very high rates of follow-up from screening to diagnosis for UNHS programs in Australia, there may be some children lost to follow-up at later points. Specifically, there is the suggestion that there may be children that are identified (i.e., formally diagnosed) through UNHS programs that fail to subsequently attend an appointment at Australian Hearing for fitting with hearing aids. It has been suggested that, min one state jurisdiction, this figure may be as high as 10 percent of all children diagnosed with significant permanent hearing impairment through the UNHS program(Ching, NAL, personal communication, 2009).

Unfortunately, because of the lack of adequate processes for collection and management of data relating to UNHS programs in Australia, there is currently very limited capacity to investigate these issues. There is also, more broadly, very limited capacity to monitor the performance of UNHS systems in regard to other criteria that are susceptible to investigation only through the interrogation of well defined and carefully collected data.

In this regard, the JCIH noted that "…information systems should be designed to interface with electronic health records and should be used to measure outcomes and report the effectiveness of (*UNHS*) services at the community, state, and federal levels." There is a patent need for attention to the issues of data management and information sharing in the Australian context. To this end the Committee has made detailed suggestions to the Screening Sub-Committee of the Australian Population Health Development Principal Committee. We are delighted that the Screening Sub-Committee has tasked the Neonatal Hearing Screening Working Group with developing a draft approach to national data collection and management. This is a critical task that must be seen through to a positive **national** outcome.

There are several possible approaches to data collection that may be pursued. The Committee is committed to the development of the best possible system. Preferably such a system would permit the collection and management of "person-level" data at a national level and would therefore provide:

- the capacity to accurately calculate the incidence and prevalence of PCHI in Australia;
- a basis for ensuring that children identified through UNHS programs are not lost to follow-up (i.e., that they receive the necessary intervention services and other supports that are required to capitalize on their early identification) regardless of their location or movement within Australia;
- access to a population database of children for research on aspects such as aetiology and epidemiology; and
- A basis for tracking the long-term outcomes and cost-effectiveness of UNHS.

To this end, the Committee recommends *that the report of this Senate Inquiry should strongly endorse the aim of the APHDPC Screening Committee to develop a process for national data collection and management in regard to UNHS programs. As part of that endorsement, the Senate Inquiry should strongly recommend that any national system of data collection and management should be based on the collection of "person-level" data so as to provide for the outcomes identified above.*

Finally, it should be noted that effective universal neonatal hearing screening will not replace the need for vigilance and for continued surveillance of hearing and language development to detect hearing impairment in children who, for whatever reason, have not received neonatal screening or who develop permanent hearing loss at a later age.

Since newborn hearing screening will only identify approximately one third of children who will eventually require intervention it is essential that access to hearing screening services be made available at later stages. As a high proportion of children are identified around the time of school entry, consideration should be given to maintaining and/or reinstituting early childhood hearing screening programs for pre-school age children. Although children in some states receive a hearing screen in pre-primary school years, this has not been maintained in all jurisdictions. Consideration should be given to the inclusion of an objective assessment of infant hearing as part of the child health check undertaken at or around 4 years of age. In particular (and at least) there should be provision of audiological assessments through early childhood for children identified with risk factors for hearing loss (family history, meningitis, TRCH infections).

The Committee recommends *that the report of this Senate Inquiry should strongly endorse the need for continual monitoring of childhood hearing, including the possible introduction of hearing screening programs for preschool age children in jurisdictions where such publicly funded programs are not in operation. Further, that there should be the assurance of publicly funded and available audiological assessments through early childhood for children with known risk factors for hearing loss.*

4. Conclusion

The Australasian Newborn Hearing Screening Committee acknowledges the work of state governments to in regard to implementation and development of newborn hearing screening programs.

Clearly, Australia is in a strong and continually improving position in regard to the implementation of UNHS. Nevertheless, there remains much to be achieved and there is clear need for vigilance to ensure that Australia continues to build on this strong position through continuous improvement. The Committee would be only too pleased to provide any additional information that the Senate Community Affairs References Committee may require.

Appendix A

AUSTRALIAN CONSENSUS STATEMENT
ON UNIVERSAL NEONATAL HEARING SCREENING,
Adelaide, March 2001

-Ratified by the Australian National Hearing Screening Committee, November 2001-

This Consensus Statement was agreed upon at '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, Adelaide. There were over 110 participants from all states and territories of Australia, including audiologists, teachers of the hearing impaired, neonatologists, paediatricians, ear, nose and throat surgeons, nurses, epidemiologists, and parents of children with hearing impairment

The Forum notes that:

1. Hearing impairment is a significant condition in newborns. Significant permanent hearing impairment (defined here as hearing impairment of more than 40 dB HL in both ears) affects 1-1.5 per 1000 live births,[1, 2] or approximately 250-400 births in Australia each year. This is more frequent than other conditions for which newborn screening occurs.[3] Significant bilateral hearing impairment, if undetected, will impede, and can have profound effects on speech, language, and cognitive development,[4] and thus emotional and social well-being. Unilateral and mild hearing impairments can also have significant educational impacts.[5]

2. Current international research indicates that babies whose permanent bilateral hearing impairment is diagnosed before the age of six months, and who receive appropriate and consistent early intervention, have significantly better language levels than those children identified after the age of six months.[6, 7] Of children aged 5 years with permanent significant hearing impairment, it is estimated that 80-90% have had the impairment since the neonatal period.[8, 9]

3. Acceptable technologies are now available, viz., measurement of otoacoustic emissions (OAE) and automated measurement of the auditory brainstem response (A-ABR), that enable effective screening of hearing impairment in newborns during natural sleep or quiet rest. Such technology has been used in screening programs since 1990.[9, 10]

   - Research studies of universal (i.e. non-targetted) screening programs using OAE and A-ABR show sensitivity (proportion of infants with abnormal hearing who fail the screen) close to 100%, and specificity (proportion of infants with normal hearing who pass the screen) above 90%.[10, 11]

   - Research studies using currently manufactured A-ABR equipment can achieve false-positive rates as low as 2%.[3]

4. The average age of diagnosis of hearing impairment in some centres which have implemented universal newborn hearing programs is reported be as low as 3 months.[2, 10] In contrast, the average age of diagnosis of hearing impairment in centres which screen only infants known to have pertinent risk factors is estimated at 24 months.[12] Data from Australian Hearing indicate that the median age at detection of Australian children with the most severe hearing impairment (>90dB) is between 12 and 18 months while the median age at detection of children with moderate hearing losses (40-60dB) is between 4 and 5 years.

5. Estimates of the cost of hearing screening per child are of the order of $25 to $50, depending on the technology used and how the program is delivered, and are consistent with experience in other countries.[3, 9, 10] Testing in more remote areas will be more expensive. It is likely that the cost of a successful program will be offset within a few years by the consequent reduction in the cost of the higher teacher-student ratio and greater life-long support required for children whose hearing impairment is diagnosed late.[3].

6. Although there is variable access to full audiological assessment for infants, especially outside metropolitan areas, Australia already has excellent facilities for audiological rehabilitation. The fitting and monitoring of hearing aids is financially accessible to all Australian children as a result of federal government funding.

7. Thus the WHO preconditions[13] for the establishment of a screening program are fulfilled.

8. The American National Institutes of Health Consensus Statement, 1993,[14] the European Consensus Statement, 1998,[15] the American Academy of Pediatrics, 1999,[4] and the US Joint Committee on Infant Hearing[16] have all supported the introduction of screening. It is mandatory to offer neonatal screening in

most states of the USA. Universal newborn hearing screening is being implemented nationally throughout England and Wales. A large scale trial of newborn hearing screening is currently under way in Western Australia.

The Forum believes that:

1. Universal neonatal hearing screening is feasible, beneficial, and justified.
2. Principles of equity and efficiency demand the establishment of a high quality program of universal neonatal hearing screening in Australia as soon as possible.
3. Prompt audiological assessment must be achieved for all neonates identified by hearing screening, and prompt, effective intervention must follow for those in whom the impairment is confirmed.
4. To be effective, a neonatal hearing screening program should
    - be universal (i.e., include all neonates), since selective screening based on high-risk criteria in practice detects at most half of all infants with congenital hearing loss.[2, 9]
    - achieve high coverage and follow-up rates, relative to the total number of births in the population.
    - be comprehensive in its approach, ie it should include training and supervision of personnel, full and accessible information for parents at all stages of the program, quality assurance, the follow-up of identified children, systems for reporting and monitoring outcomes, and counselling for parents of children with hearing impairment.[9]
5. Models for the delivery of a neonatal hearing screening program need to be designed to take account of Australian patterns of population distribution and service delivery.
6. Effective universal neonatal hearing screening will not replace the need for vigilance and for continued surveillance of hearing behaviour and language development to detect hearing impairment in children who have not received neonatal screening or who develop permanent hearing loss at a later age.
7. Further research is required to determine benefits, costs and harms of screening for children with unilateral and milder hearing impairments.

The Forum resolves that:

1. A program of universal neonatal hearing screening should be introduced across all states and territories in Australia in order to detect children with hearing loss at the earliest possible age.
2. The Australian federal government should work together with state and territory governments to establish a coordinated screening program.
3. A universal hearing screening program must be sufficiently resourced to enable high quality monitoring and evaluation.
4. A range of national strategies will be necessary to achieve effective and efficient universal neonatal hearing screening programs for all Australian children.
5. Clear time lines should be specified for the planning and implementation of universal neonatal hearing screening across Australia.
6. Audiological assessment, diagnosis and habilitation at the earliest possible age, as well as parental support, should be achieved for all Australian children with hearing impairment.

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Appendix B

Australasian Newborn Hearing Screening Committee Members

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Parent Representatives:	Tina Carter (Qld), Jo Quayle (Vic)
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Appendix C

State and National UNHS Program Coverage
(% of newborns offered screening)