NATIONAL FRAMEWORK FOR NEONATAL HEARING SCREENING

August 2013

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Why a National Approach to Neonatal Hearing Screening?

There are over 297,900¹ births in Australia annually. All States and Territories in Australia have universal neonatal hearing screening. It is widely acknowledged that delays in the identification and treatment of permanent childhood hearing impairment may profoundly affect quality of life in terms of language acquisition, social and emotional development, and education and employment prospects. It must be noted that approximately 50% of hearing impairment at birth is without a risk factor.²

There is clearly a need for a National Framework for universal neonatal hearing screening and early management of interventions in Australia. A national approach will aim to screen all babies in Australia for potential permanent childhood hearing impairment, and provide access to interventions to minimise the impact of hearing impairment.

National Approach to Neonatal Hearing Screening

According to the international literature, moderate to profound (>40 dB) bilateral permanent childhood hearing impairment (PCHI) occurs in 1.3 per 1,000 babies. Unilateral PCHI of similar severity occurs in 0.6 per 1,000 babies. This suggests that, each year in Australia, approximately 331 children are born with bilateral PCHI, and 174 children are born with unilateral moderate to profound PCHI. This is a total of 551 children each year³.

Children with slight or mild hearing loss (26-40 dB) have not been included in the treatment and early intervention pathway guidance encompassed within this framework. However, families with children with this level of hearing loss should have access to information about how they can monitor their child's hearing loss and who they might consult if they have concerns about their child's ongoing development.

It has been suggested that the prevalence of PCHI increases substantially with age. The consequences of the condition include life-long impairment of language skills and possible delays in social development and academic achievement. The severity of the outcome is influenced by the degree and duration of hearing loss, the age at which the hearing loss first appeared, and the hearing frequencies affected. Developmental delays are particularly apparent for children with severe and profound hearing impairment. Children with hearing impairment are more likely to experience lower self-perceived health status than those without hearing loss. Early management of childhood hearing impairment provides many benefits, including improved communication and language ability, mental health, and future employment prospects⁴.

¹ Australian Bureau of Statistics, Births Australia 2010, cat no.3301.0, Canberra, 2011

² Thompson, D et al (2001) Universal Newborn Hearing Screening: Summary of Evidence *Journal of the American Medical Association*, 286 (16) 2000-2010

³ Medical Services Advisory Committee (MSAC) 2007. *Universal neonatal hearing screening assessment report.* Reference 17. Commonwealth of Australia,

⁴ Schroeder L. et al, 2006. The economic costs of congenital bilateral permanent childhood hearing impairment. *Paediatrics* 117(4): 1101-1112.

Purpose and structure of this document

The purpose of this document is to provide an overarching framework which outlines the principles of a National Approach to Neonatal Hearing Screening. The framework provides high level guidance for a progressive implementation of Neonatal Hearing Screening in Australia. Some key ideas are prominent in the document, namely the importance of effective communication with, and education of, parents.

This document includes background information and a brief discussion on the merits of a National Neonatal Hearing Program, followed by the National Neonatal Hearing Screening Framework under which the proposed program will operate. The screening pathway guidance is also outlined including a discussion of the major components from screening to post screening follow-up which are:

- recruitment of the target population;
- the progression from screening to diagnosis;
- early intervention, treatment and management;
- coordination, monitoring and evaluation of screening and early intervention; and
- necessary professional education that both practitioners and families will have available.

An in depth list of the objectives, standards expected and performance indicators for each part of the program are provided at the end of the document. The objectives, standards and target performance indicators are intended to provide principle-based standards for screening services and post screening follow-up. These can guide the development of implementation specific protocols, clinical guidelines, key performance indicators or accreditation standards.

The National Framework recognises that the development of neonatal hearing screening has developed separately across jurisdictions with various levels of sophistication. The National Framework has been developed in consultation with jurisdictions with an aim of achieving harmonisation of these efforts. It is intended as a resource for jurisdictions to use when developing neonatal hearing screening services.

Introduction

Hearing impairment may be categorised as slight or mild, moderate, severe or profound. The grades of hearing impairment differ across organisations and countries. The World Health Organisation has defined hearing loss (in the better ear) in adults:

• at 26-40 dB as slight or mild hearing impairment. With this impairment, an individual should be able to hear and repeat words spoken in a normal voice at a distance of one metre⁵ in an environment with no background noise. Children with this impairment may experience difficulty in comprehending speech and oral language in normal circumstances. The child's articulation and language development may be compromised. Speech and language usually develop

⁵ WHO. 1991. Report of the Informal Working Group on Prevention of Deafness and Hearing Impairment Programme Planning WHO/PDH/91.1

normally if a child is fitted with hearing aids early⁶ and is provided with sustained intervention;

- at 41-60 dB as moderate impairment. With this impairment, an individual can hear and repeat words spoken in a raised voice at a distance of one metre⁷ in the absence of background noise. Speech and language development are generally affected unless a hearing aid and quality early intervention are provided;
- at 61-80 dB as severe hearing impairment. With this impairment, an individual is able to hear some words when shouted into the better ear⁸. However this is inadequate for access and acquisition of spoken language. Speech and language do not develop spontaneously in a child born with this degree of impairment. Hearing aids amplify many speech sounds and will assist a child to develop speech, but speech quality is likely to be affected⁹; and
- at 81 dB or greater as profound hearing impairment, including deafness. Individuals with this type of impairment are unable to hear and understand a shouted voice¹⁰. Learning to speak and understand spoken language is difficult for children born with a profound hearing loss. Many children with profound hearing loss are now fitted with a cochlear implant¹¹.

The target condition for detection and follow up by the Program is defined as congenital permanent bilateral, unilateral sensory or permanent conductive hearing loss including neural hearing loss (e.g. Auditory Neuropathy Spectrum Disorder) of >40 dB.

There is strong evidence that babies who are identified with moderate-to-profound hearing loss in the first six months of life, and provided with immediate and appropriate intervention including amplification and/or cochlear implantation as appropriate, have significantly better outcomes than later-identified infants and children in vocabulary development, receptive and expressive language syntax, speech production and social-emotional development. Children enrolled in early intervention within the first year of life have also been shown to have language development within the normal range of development at five years of age¹².

Early intervention is necessary to achieve optimal outcomes for hearing-impaired children. Research shows that family involvement is associated with positive language outcomes, and that parental involvement, particularly school based parental involvement (e.g. participation in individual educational plan meetings and parent meetings) will predict early reading skills. Importantly, maternal communicative skills are even more predictive of language and literacy. Maternal communicative skill is a strong aspect of parental involvement, given that a parent must be highly involved to develop effective mutual communication with a deaf or hearing impaired child¹³.

⁶ Australian Hearing (2005). *Choices*. Australian Hearing, Chatswood.

⁷ MSAC 2007 as footnote 4

⁸ As footnote 6

⁹As footnote 7.

¹⁰ As footnote 6

¹¹ Australian Hearing (2005) as footnote 7.

¹² JCIH (2007), Kennedy et al (2006), Yoshinaga-Itano (2004a)

¹³ Mueller M.P. (2000). Early intervention and language development in children who are deaf and hard of hearing. *Paediatrics* 106, Ed. 43. Accessed 25 June 2009 at www.paediatrics.org.

Background

In March 2002, the National Health and Medical Research Council (NHMRC) released a report titled *Child Health Screening and Surveillance: A Critical Review of the Evidence*. The Report found that there was evidence to recommend national neonatal hearing screening, but urged serious consideration of the logistics and quality of the testing system, and the follow up systems for babies who test positive, before the implementation of a national neonatal hearing screening program.

In July 2002, the Australian Health Ministers Conference (AHMC) requested the Medical Service Advisory Committee (MSAC) undertake an assessment on the safety, effectiveness and cost-effectiveness of universal neonatal hearing screening. In 2008, MSAC released the *Universal Neonatal Hearing Screening Assessment Report*¹⁴, which addressed these issues but did not make recommendations with a view to establishing a national neonatal hearing screening program.

In March 2008, the Screening Subcommittee of the then Australian Population Health Development Principal Committee¹⁵ (APHDPC) agreed to examine the feasibility of a national approach to neonatal hearing screening. It established the Neonatal Hearing Screening Working Group¹⁶ with the following terms of reference:

- 1. Assess neonatal hearing screening against the Population Based Screening Framework¹⁷.
- 2. Develop minimum national standards for screening services and post screening follow-up with regards to audiology, medical intervention, family counselling, early intervention and education.
- 3. Consider and develop screening pathway to improve population coverage for neonatal hearing screening in Australia.
- 4. Develop a national quality and reporting framework for consideration by the Screening Subcommittee of the Australian Population Health Development Principal Committee and Australian Health Ministers' Advisory Council.
- 5. Establish an agreed national approach to data collection and management and data sharing.

In July 2009, the Council of Australian Governments (COAG) agreed to a proposal that universal neonatal hearing screening would be available in all states and territories by the end of 2010.

Assessing neonatal hearing screening against the AHMAC Population Based Screening Framework

The Population Based Screening Framework takes into account the World Health Organisation (WHO) principles and elaborates on them in the Australian context. The Framework, developed with input from a wide range of experts in screening, is based

¹⁴ MSAC, 2007 as previously noted

¹⁵ The Australian Population Health Development Principal Committee is now known as the Community Care and Population Health Principal Committee (CCPHPC)

 $^{^{16}}$ See <u>Appendix B</u> for membership

¹⁷Australian Population Health Development Principal Committee, Screening Subcommittee. 2008. *Population Based Screening Framework*. Canberra: AGPS. .

on the latest available evidence and informed by experience with existing Australian population screening programs¹⁸. The Framework has been divided into two parts:

- the criteria used to assess whether screening should be offered, or a screening program introduced, for diseases or conditions; and
- the key principles for the implementation and management of screening programs.

The Framework, like all population screening programs, is underpinned by the principles of access and equity. It is intended to provide information and guidance on the key issues to be considered in the development of a population screening program in Australia. An assessment of the national approach to neonatal hearing screening against the Framework's criteria is at <u>Appendix C</u>.

Aims and Objectives of Neonatal Hearing Screening

The aim of neonatal hearing screening is for all babies to be screened for PCHI, and, if necessary, to have access to appropriate intervention to minimise the impact of their hearing impairment. This will improve the quality of life for children with PCHI in terms of their communication and language skills, subsequent education and employment prospects, and psychological wellbeing.

The objectives of neonatal hearing screening are to:

- maximise the early detection of PCHI in Australian babies through the use of an approved screening test (see page 10), and appropriate follow up medical, and support services;
- ensure that all Australian families are offered the opportunity to participate in neonatal hearing screening;
- ensure equitable access to neonatal hearing screening for all Australian babies, irrespective of their geographic, socioeconomic or cultural background;
- ensure that assessment services provided to babies requiring follow up care and intervention as a result of screening are timely, acceptable and appropriate and are undertaken in accordance with professional standards;
- ensure families with babies diagnosed with impaired hearing are referred and have the opportunity to, engage with an early intervention service following diagnosis;
- maximise benefit and minimise harm to the individual; and
- achieve consistent standards of screening management, co-ordination, quality and safety, service delivery, monitoring and evaluation and accountability and ensure that the national approach to neonatal hearing screening is implemented in a manner that is cost effective and will significantly increase quality of life for Australian children with PCHI.

National Approach to Neonatal Hearing Screening Framework

There are six major components that could make up the National Neonatal Hearing Screening Framework (National Framework) as Figure 1 illustrates.

¹⁸ A copy of the Screening Framework is available at <u>http://www.cancerscreening.gov.au/</u>

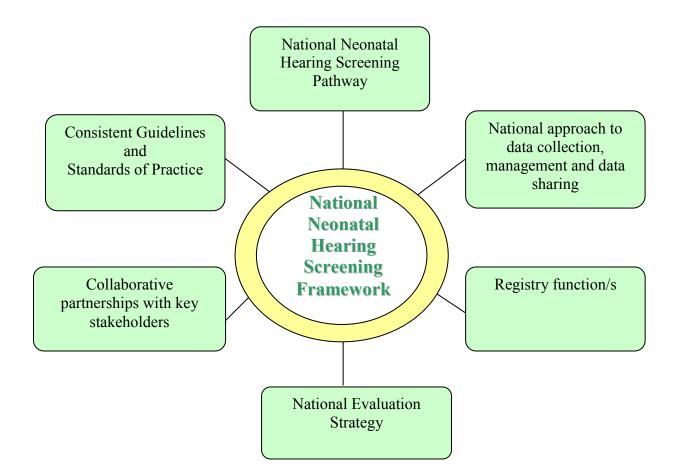


Figure 1: Components of the National Neonatal Hearing Screening Framework

The National Framework focuses on having standardised screening pathway guidance across Australia, supported by evidence based standards of practice. It is supported by a national approach to data collection, management and data sharing through a national data set. The National Framework is a joint initiative between the Australian and state and territory Governments in collaboration and partnership with specialists in the field of paediatric hearing and in consultation with families of children with hearing loss.

National Neonatal Hearing Screening Pathway Guidance

The National Neonatal Hearing Screening Pathway Guidance is evidence-based and includes recruitment, initial screening tests to the point of definitive diagnosis and post screening follow up. A flow-chart is at <u>Appendix D</u>. To highlight the continuum of care, the interaction between screening and early intervention and management services is included. The major components of the screening pathway guidance are:

• **Recruitment** - The target population is all babies >34 weeks gestation screened within 24 to 72 hours of birth with an aim to complete screening by

four weeks corrected age¹⁹. Corrected age takes into account the time between premature birth and the actual due date of a full term pregnancy. Calculating corrected age provides a truer reflection of what the baby's developmental progress should be. Protocols should be in place to ensure that screening can occur up to six months of age for babies not screened within the target time frame.

- **Screening** The screening tools used in Australia to identify babies with possible PCHI are currently the transient evoked otoacoustic emissions (TEOAE) test and the automated auditory brainstem response (AABR). It is important that the screening equipment used is validated for sensitivity and specificity for the targeted condition.
- **Diagnosis (confirmation of hearing loss)** A definitive audiological diagnosis and medical investigation needs to be made following a positive result (often referred to as a refer result) on the screen. Recommendations on the appropriate time between screening and diagnostic assessment, referral for medical evaluation and referral to Australian Hearing are included in the standards.

The intervention and management specific pathway components include:

• *Early intervention, treatment and management* - all families of babies with a confirmed hearing impairment, bilateral and unilateral, should be provided with unbiased information on the range of services available, including services provided by Australian Hearing and other early hearing intervention services. All families of babies with a confirmed hearing impairment should be referred and have the opportunity to access Australian Hearing and other early intervention services before three months of age for advice, including amplification fitting services and cochlear implantation candidacy evaluation. These services should be provided by professionals with expertise in hearing loss and should be available from time of diagnosis to school entry. Early intervention and management services provided following diagnosis of a confirmed hearing impairment.

Program supporting and enabling components include:

- **Quality Management Plan** A Quality Management Plan will be developed to assist with the planned implementation of quality initiatives to support the delivery of high quality neonatal hearing screening.
- *Coordination, monitoring and evaluation* Registry function/s may be developed to assist coordination and monitoring and evaluation.
- **Professional education** Families have access to safe and sensitive services provided by appropriately qualified, skilled and experienced professionals. Consideration will need to be given to the training and certification of professionals carrying out screening tests. All professionals, including support workers, should be trained in hearing issues.

¹⁹ Newborn Hearing Screening Programme (2008). *Quality Standards in the NHS Newborn Hearing Screening Programme*. National Health Service, United Kingdom.

Consistent Standards of Practice

The National Framework includes national guidance on standards of practice that all states and territories will be able to use to ensure a consistent national approach to neonatal hearing screening. These standards are supported by an evidence-base to ensure quality outcomes. The development of standards of practice has been a collaborative approach between all stakeholders.

Governance

States and territories are responsible for neonatal hearing screening within their jurisdictions. They have agreed to be part of the national approach to neonatal hearing screening as an attempt to harmonise standards across Australia.

Monitoring of the national approach to neonatal hearing screening will be through the Standing Council on Health (SCoH) to reflect the collaboration between the Australian Government and the states and territories.

The Standing Committee on Child and Youth health (SCCYH) of the Community Care and Population Health Principal Committee (CCPHPC) will oversee the work and provide advice and seek endorsement from the CCPHPC and AHMAC. The SCCYH may also consult with the Standing Committee on Screening as required.

Further work has now been undertaken by the Australian Institute of Health and Welfare (AIHW), assisted by a cross jurisdictional advisory panel, to develop national performance indicators to underpin a national reporting system for neonatal hearing screening in Australia. AIHW's proposed performance indicators are based on the aims, standards and objectives for neonatal screening outlined in this guidance document. The AIHW paper, *National performance indicators to support neonatal hearing screening in Australia*²⁰, contains the full data standards and proposed national performance indicators. An excerpt from this paper is at <u>Appendix A</u>.

Collaborative Partnership with Other Key Stakeholders

The Department of Health and Ageing is coordinating and leading the evidence-based policy development for the national approach to neonatal hearing screening in Australia. Policy development will be in partnership with states and territories, health professionals and organisations, who will have implementation responsibility for the Program.

The national approach recognises that all partners play a pivotal role in the effective implementation of a national approach to neonatal hearing screening in collaboration with the Australian Government. State and local coordination of a national approach to neonatal hearing screening implementation, workforce capacity and communications are essential for success.

To support the national approach to neonatal hearing screening, state and territory governments will:

²⁰ Australian Institute of Health and Welfare (2013), *National performance indicators to support neonatal hearing screening in Australia*, Canberra

- work towards providing uniform information in respect to results of neonatal hearing screening; and
- work with the Australian Government to:
 - adopt a timeframe for implementation of a national approach to neonatal hearing screening in their jurisdiction;
 - address infrastructure issues, such as workforce, training, service capacity and clinical quality;
 - o develop and implement a review strategy; and
 - implement communication strategies to ensure consistent key messages are delivered across the country.

Agreed National Approach to Data Collection, Management and Data Sharing Options for a national data set for state and territory neonatal hearing screening and post screening services have been developed by the AIHW under the direction of an inter-jurisdictional advisory group. The AIHW paper, National performance indicators to support neonatal hearing screening in Australia, contains the data standards and proposed national performance indicators. An excerpt from this paper is at <u>Appendix A</u>.

A national data set will:

- enable the monitoring and evaluation of neonatal hearing screening programs;
- enable monitoring of engagement with early intervention services;
- underpin the development of a nationally consistent quality and standards framework;
- permit national and international benchmarking and collaboration; and
- enable research into risk factors and health conditions associated with PCHI.

All jurisdictions have introduced state-wide universal neonatal hearing screening programs and are examining data collections and quality issues. This is an opportune time to introduce consistent standards for data collection. The national standards underpin and are integral to a national data set and a quality framework in neonatal hearing screening.

Registry function

Options and implementation steps for a registry function could be established as part of the national approach to neonatal hearing screening. A registry function could support the coordinated collection and management of all data. The data parameters are yet to be finalised. Consultation with key stakeholders would have to be undertaken to determine the most appropriate registry structure and associated parameters for neonatal hearing screening data.

The key principle underpinning a registry function is the management of data for monitoring and evaluation purposes, in accordance with the requirements of the Commonwealth Privacy Act and relevant state and territory Privacy Acts. It would be anticipated that AIHW analysis of the monitoring data set for the Program will include breakdowns by state and territory. Access to data held on a registry may also be provided for ethically approved research projects.

National Evaluation Strategy

A standardised data approach to national neonatal hearing screening is essential to the development of a comprehensive evaluation strategy. The strategy will be developed in consultation with key stakeholders to determine the degree that the national approach to neonatal hearing screening is meeting its aims and objectives.

The objective of the evaluation is to understand what components of the Program work, and why, and to strengthen screening practices and administrative processes to further improve outcomes for Australian children.

A comprehensive and rigorous evaluation will:

- assess the effectiveness of the national approach to neonatal hearing screening in meeting its objectives;
- assess overall appropriateness, efficiency and effectiveness of the national approach to neonatal hearing screening and its initiatives, including post screening follow up and enrolment in Early Hearing Intervention; and
- inform current and future health policy interventions.

The final scope of the evaluation will be agreed between the key stakeholders in the national approach to neonatal hearing screening in Australia.

Further consideration

Equitable Access

The Population-Based Screening Framework emphasises the principle of equity for all participants in terms of their geographical location, socio-economic status, cultural background and timeliness.

The major issues relate to:

- the specific needs of regional, rural and remote communities, including how to test and provide follow up care and intervention in light of the availability of facilities and geographic isolation;
- cultural factors that may influence participation, and the development of communication and other strategies to address these;
- access to intervention and follow up services for people who are living in regional, rural and remote areas and other disadvantaged groups;
- access to intervention and follow up services for families facing multiple, co-existing issues (such as family violence, mental health and substance abuse); and
- the need to develop culturally acceptable and feasible approaches for Aboriginal and Torres Strait Islander communities, particularly in remote areas.

Cross agency collaboration with services offering infant programs may be helpful mechanisms to assist families to engage with hearing screening and assessments (particularly intensive family support services connected with statutory child protection services, family violence and culturally specific programs).

In addition to consultation with state and territory governments, other relevant groups such as the Office of Aboriginal and Torres Strait Islander Health will be consulted on the national approach to neonatal hearing screening in Aboriginal and Torres Strait Islander communities.

Possible Risks

The Medical Services Advisory Committee (MSAC) report examined potential harms that may result from universal neonatal hearing screening, including from the screening process itself, from false positives, false negatives and harms that may arise from early diagnosis. The report found that there was no evidence of physical or psychosocial harm from universal neonatal hearing screening although no data were found on the harms caused by false reassurance.²¹

Newborn hearing screening is a multifactorial assessment including:

- repeat testing protocols for infants at risk of hearing loss;
- skilled application through a well trained workforce; and
- well calibrated equipment.

AABR testing has approximately 99.8% specificity on the normative sample of infants screened. With approximately 290,000 babies born in Australia each year, this means statistically there is potential for 1–2 hearing impaired infants to miss being identified in a universal screening program each year. False positives are minimised by the adoption of a two stage process prior to diagnostic testing as described on page 17. In the context of false negative results families participating in neonatal hearing screening should be provided with full information on the meaning of negative screening results, as well as the potential for developing a hearing loss if at risk.²²

National Standards for Newborn Hearing Screening

The national standards aim to provide the principles for the progressive implementation of minimum policies, procedures and practices for neonatal hearing screening across Australia.

The standards address all aspects of the screening pathway, including recruitment, screening, assessment, management, early intervention, technical quality assurance, education, counselling, data management and training.

The standards recognise the need to achieve the best possible outcomes for all babies within the context of a screening program. The needs of individual infants and their families must therefore be met through participation in decision making. Families' rights and needs as consumers should be actively considered at all points of the screening pathway and clearly acknowledged. The program should ensure that interventions are acceptable to babies and their families, and that the screening process minimises anxiety.

Universal neonatal hearing screening standards have been developed to assist in achieving overall outcomes critical to a high quality program. Appropriate

²¹ MSAC (2007) as previously noted.

²² Petticrew MP, Snowden AJ, Lister-Sharp D, Wright K. 'False negative results in screening programmes:systemic review of impact and implications.' *Health Technology Assessment.* 2000;4 (5).

organisational and management systems will exist to ensure the efficacy and effectiveness of the program. Specific performance indicators relevant to implementation may be developed from these high level indicators. Effective monitoring and evaluation of clinical and intervention activities, recruitment, resource management, data collection and training activities are recognised as essential to the delivery of a comprehensive and successful program.

The high level, overarching standards apply to all components of the pathway²³.

²³ The objectives, standards and target performance indicators for each stage of the pathway support these high-level standards

High-Level Principles for Newborn Hearing Screening

- Newborn hearing screening is equitable and accessible.
- All screening is undertaken by an approved test.
- Communication with families is timely and appropriate.
- Informed decision-making is supported.
- Information provided to families during engagement with services is relevant, unbiased and culturally and linguistically appropriate.
- Family-centred care is encouraged along the pathway.
- Appropriate support services are provided to families for those who:
 - receive a positive screening test and require further testing for definitive diagnosis; and
 - require early intervention.
- Systems exist to support progression along the pathway.
- Engagement with services along the pathway is encouraged.
- Providers and health professionals are competent and manage their performance to ensure delivery of evidence-informed high quality services.
- Systems exist to provide accurate, reliable and consistent data collection and reporting.
- Effective governance arrangements and accountability are clearly defined and supported by efficient systems.
- Continuous review and improvement is encouraged through monitoring and evaluation activities, which are in accordance with the relevant health service and national ethical standards.
- Data is stored in accordance with state and Commonwealth privacy legislation.

The following rationale descriptions broadly represent the objectives and indicators for each stage of the pathway:

Recruitment

Recruitment encompasses identification of the target population, engagement with the screening process, determination of eligibility and population capture, and antenatal/postnatal community education about newborn hearing screening.

The target indicator for completion of a screen is >97% of newborn babies born in Australia. Some states are already achieving this target, whilst others will need to implement strategies to increase their coverage.

In order to achieve >97% coverage, provision needs to be made for those babies who may miss out on the initial screen because of home birth, early discharge, or transfer to another hospital.

Parents must be fully informed about the purpose and nature of the screen, as well as what the results will mean and how they will be used. In addition to verbal communication, written information that explains the purpose of screening and describes the screening process should be available at antenatal visits and parent education programs.

Screening

All parents of newborns must be given the opportunity to participate in a newborn hearing screen. Parents must also be provided with appropriate information to give informed consent for their baby to be screened - consideration should be given to the means by which this information is provided – ie. additional strategies may need to be employed where written literacy levels are low (such as pictorial or verbal means). Written information should be made available in multiple languages. All eligible babies should complete a hearing screen before four weeks corrected age.

Universal newborn hearing screening programs in Australia predominantly use a two stage screening process, whereby babies who receive a 'refer' result on the initial screen are tested on a second occasion. Then, only if the baby receives a 'refer' result on this second screen are they referred for diagnostic audiology assessment.

Communication

All families should receive an explanation of the screen result so that they understand the outcome and the importance of follow-up when indicated. The result should be communicated effectively and considerately, particularly where there is a refer result.

Monitoring and evaluation

In order to provide comprehensive monitoring and program evaluation, data from babies with a refer result will be collected, with written consent from the parents. All data will be stored in accordance with state and commonwealth privacy legislation.

Higher risk

Children at higher than average risk of an acquired hearing loss require additional individual monitoring. This is out of scope of the neonatal hearing screening pathway.

Parents with children at higher risk will require specific information about their child's risk factors, as identified at <u>Appendix E</u>.

Babies with a risk factor who pass the neonatal screening test should have at least one diagnostic audiology assessment by 12 months of age. More frequent assessment may be indicated for children with a family history of hearing loss, cytomegalovirus (CMV) infection, syndromes associated with progressive hearing loss, craniofacial abnormalities, neurodegenerative disorders, birth trauma or culture-positive postnatal infections associated with sensorineural hearing loss.

Diagnosis (Confirmation and Investigation of Hearing Loss)

Comprehensive audiological evaluation of babies who are referred from newborn hearing screening should be performed by audiologists experienced in paediatric hearing assessment. The initial audiological assessment to confirm a hearing impairment in babies must include physiologic measures and, when developmentally appropriate, behavioural methods. Confirmation of a baby's hearing status requires a range of audiological tests to: assess the integrity of the auditory system in each ear; estimate hearing sensitivity across the speech frequency range; determine the type of hearing loss; establish a baseline for further monitoring; and to provide information for fitting an amplification device. A comprehensive assessment should be performed on both ears, even if only one ear failed the screening test²⁴.

Confirmation of hearing loss should be completed by three months of corrected age to allow referral for medical evaluation by three months of age and timely access to early intervention services²⁵.

All babies with confirmed hearing loss and/or middle-ear dysfunction should be referred for otologic and other medical evaluation to determine the aetiology of their hearing loss, to identify related physical conditions, and to provide recommendations for medical/surgical treatment as well as referral to other services including intervention services.

Medical investigations, including those designed to search for the cause of deafness, must be available to families of babies with significant hearing loss. Investigation into the aetiology of sensorineural hearing loss is a part of the medical support and management for families of hearing impaired children.

Parents must be given comprehensive, up-to-date and unbiased information about proposed medical investigations that may help in identifying the cause of their child's hearing impairment, and the likely diagnoses and treatment of any coexisting conditions including both the benefits and disadvantages of the tests.

On confirmation of hearing impairment, all families should be provided with appropriate information, support and counselling for managing their child's hearing loss. The information should be provided in a culturally appropriate way. Parents should be given every opportunity to further discuss their views and concerns to allow

²⁴ US Joint Committee on Infant Hearing (JCIH) (2007). Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *Pediatrics* 120: 898-921 ²⁵ JCIH (2007).

informed decision making (See <u>Appendix D</u> for a visual representation of the screening pathway).

Early diagnosis allows families to obtain information and receive counselling support over a longer period of time. Under these circumstances, intervention is commenced before the children become delayed in their language development. This intervention provides children with access to language, enabling their language development to approximate normal developmental timeframes and patterns.²⁶.

Treatment (Early Intervention and Management)

Once hearing impairment is diagnosed in a child, a referral should be initiated to an early intervention program and to Australian Hearing for advice about ongoing management of the hearing loss, including amplification options. Unbiased advice on the range of early intervention and management services available should be provided to families to support informed choice and decision making. The initiation of early intervention services should begin as soon as possible following diagnosis but no later than six months of age.

Families referred for early intervention need to be informed about the possible range and nature of service options available in order to facilitate timely engagement with a specialist service. Support and advocacy services are also able to facilitate engagement with services at the earliest possible time.

In order to deliver a quality program all early intervention programs should comprise a range of professionals with appropriate expertise and qualifications in assessing language skills, cognitive skills, auditory skills, speech, vocabulary, and socialemotional development of all children with hearing impairment. The quality of medical, audiological and educational intervention is likely to have a significant impact on developmental outcomes for hearing-impaired children²⁷. Quality services during infancy, preschool and primary school are also essential if early diagnosis of hearing impairment is to achieve the desired benefits²⁸.

Family Support

In order for families to experience a positive outcome, the delivery of services and the manner in which they are delivered should be family centred. Continuity and coordination of support are essential components of a successful population screening program. Service providers need to work in partnership with families to ensure that the desired outcomes are achieved and to ensure that parents and families understand the information they are receiving and the processes involved.²⁹

²⁶ Yoshinaga-Itano, C (2004) 'Early Identification for Earlier Intervention' in Power, D and Leigh G, (2004) *Educating Deaf Students*. Gallaudet University Press. Washington D.C.

²⁷ Yoshinaga-Itano C. (2003). Early intervention after universal neonatal hearing screening: impact on outcomes. *Mental Retardation and Developmental Disabilities Research Reviews* 9:252-266.

²⁸ Wake M., Poulakis Z., Hughes E.K., Carey-Sargeant C. & Rickards F.W. (2005). Hearing impairment: a population study of age at diagnosis, severity, and language outcomes at 7-8 years. *Archives of Disease in Childhood* 90: 238-244.

²⁹ ANZPOD (2009). Quality Standards for Newborn Hearing Screening Services – Supporting Families.

Parents must be provided with unbiased information that is delivered sensitively and in a culturally and linguistically appropriate format. This will assist families to make informed decisions regarding early intervention for their child.

Parents commonly experience difficulties and frustrations during confirmation of their baby's hearing loss and beyond³⁰. Demands placed on parents throughout this process can impact on the developing parent-child relationship at this important time, and is a matter of concern. This impact can be minimised by good quality and relevant information, rapid and effective follow up, sound diagnostic protocols, consistent use of adequate parental education and information, and by designating a staff member to be responsible for family support.

Every professional involved in assisting the families of a hearing-impaired child has a role in promoting a continuity of care and positive health and wellbeing outcomes. To enhance outcomes families should be offered access to a trained family support worker throughout the screening pathway to assist with decision making, emotional and adjustment needs and access to services. This role should be family centred and provide independent advocacy. Access to a family support worker should always be offered on confirmation of hearing loss, regardless of the level or type of hearing loss, including mild and unilateral losses that may be identified during the diagnostic process. A family support worker should be able to advocate for families and provide a broad range of informal, community and formal support and resources to enable families to develop their own support systems e.g. local parent support and Deaf community organisations and access to financial assistance such as travel assistance.

Isolation from families with hearing children is often reported by parents of a hearingimpaired child. However, there is also isolation from other families with hearingimpaired children, especially in rural and remote areas and isolation from resources needed to assist the child (e.g. sign language classes). Parents of hearing-impaired children often speak of the importance of talking with other parents in a similar situation, and say that these encounters are an important source of emotional support^{31,32}. In these circumstances, family support workers may assist families in communicating with other parents of hearing-impaired children, and may facilitate access to support networks and parent led groups.

Coordination, Monitoring and Evaluation

An integral part of any successful population screening program is the establishment of robust and sustainable systems for co-ordinating, monitoring and evaluating all components of the screening pathway to ensure quality control at every stage.

Work is being undertaken to determine the best way to capture and record the hearing screening tests of all newborn babies. This will involve consideration of using

³⁰ Morton C.C. and Nance W.E. (2006). Newborn hearing screening – a silent revolution. *New Engl. J. Med* 354: 2151-64.

³¹ ANZPOD (2009). Quality Standards for Newborn Hearing Screening Services – Supporting Families ³² Hearing Impairment – Early Detection and Intervention (HIEDI) (2004). *Improving outcomes for children with permanent congenital hearing impairment: the case for a national newborn hearing screening and early intervention programme for New Zealand.*. The National Foundation for the Deaf, Auckland.

existing systems (such as the peri-natal register system, immunisation register, etc) or the development of new systems.

A registry function may be established for those identified as having hearing loss. In addition, to ensure quality control, the performance of the screening program as a whole will be monitored in a systematic way by the ongoing collection and analysis of relevant data.

A uniform national dataset is recommended for the program to ensure that data are collected and reported in a consistent and timely manner. Critical performance data are yet to be defined for the program, but should include the number of babies born, the proportion screened (first and second screen), the proportion referred for audiological assessment by three months of age, the mean, median and minimum age of diagnosis of hearing loss and the proportion with hearing loss receiving intervention by six months. The dataset will be developed in collaboration with the AIHW and states and territories.

Services should actively encourage and support representation of key stakeholders on committees or reference groups. Participation of key stakeholders, including consumer participation in service management structures, helps ensure that the service provided is of a high quality. Consumer representation is required to represent the views of families affected by hearing loss, and is recognised as critical to the development of health systems which promote the health and wellbeing of communities³³.

Professional Education

A range of health professionals are involved in providing professional input into a newborn hearing screening program. Health professionals involved in the program include screeners, audiologists, ENT specialists, clinical geneticists, developmental paediatricians, ophthalmologists, general paediatricians and general practitioners. Other professionals include teachers of the deaf, auditory verbal therapists, speech pathologists, psychologists, social workers, family support officers, occupational therapists, physiotherapists and technicians involved in the maintenance of equipment.

All those providing services to a universal newborn hearing screening program need skills and competencies to work with babies, and in-depth understanding of deafness as a lived experience in all its permutations. Staff should have the appropriate training and expertise and participate in ongoing training, continuing education and quality improvement programs. The expertise, experience and training required for staff are outlined in <u>Appendix F</u>.

Professional training and education for counselling and provision of support to parents and families during screening and during and following diagnosis is needed by all professionals who are involved.

³³ Department of Health and Aged Care (DoHAC) (2000). *Strategic plan 1997/98-2000/01: strengthening the focus on consumers in health services planning, delivery, monitoring and evaluation in Australia.* Commonwealth Department of Health and Aged Care, Canberra.

Framework

The first draft of the *National Framework for Neonatal Hearing Screening* included a draft standards framework. The draft standards framework is provided at <u>Appendix H</u> as an indication of the Neonatal Hearing Screening Working Group's initial consideration on a framework. It was agreed by jurisdictions through the APHDPC that the draft standards framework would be further developed by the AIHW to allow collection and reporting at a national level. This resulted in the 77 performance indicators previously suggested in the draft standards framework being collapsed into seven indicators. The 7 AIHW indicators are listed below and further information on them including technical standards can be found in the AIHW paper – *National performance indicators to support neonatal hearing screening in Australia*. An excerpt of this paper is at <u>Appendix A</u>.

Performance indicators	Aim	
Indicator 1 Participation	To maximise the number of eligible infants screened for	
1.1 Participation in screening	permanent childhood hearing impairment	
Indicator 2 Screening	To maximise the identification of infants with potential hearing impairment while minimising parental anxiety and cost	
2.1 Positivity rate of the screening test		
2.2 Positive predictive value of the screening test		
Indicator 3 Audiological assessment and diagnosis	To accurately identify infants born with permanent childhood hearing impairment	
3.1 Audiological assessment		
3.2 Detection of permanent childhood hearing impairment		
Indicator 4 Early intervention and management	To maximise engagement of infants identified as requiring a service with early intervention services	
4.1 Attend early intervention service		
4.2 Infants fitted with an assistive hearing device		

The previous draft standards framework indicators are included at <u>Appendix H</u> to provide context for jurisdictions and health providers as they implement the national framework at a local level. The draft standards framework provides for the statement of each of the desired standards in terms of:

- 1. the objective for including the standard;
- 2. the standard to be achieved; and
- 3. a target performance indicator that describes how the achievement of the standard will be recognised.

It is not intended that the indicators and targets at <u>Appendix H</u> be collected or monitored at a national level.

Appendix A

Proposed national performance indicators

This appendix is an excerpt from the AIHW paper – *National performance indicators to support neonatal hearing screening in Australia*. The AIHW paper should be referred to for further information on proposed indicators and their technical standards.

Indicator 1 Participation

Indicator 1.1 Participation in screening

Definition:

Proportion of infants born in a calendar year who complete a neonatal hearing screen through a jurisdictional neonatal hearing screening program

National Framework Objectives:

- **1.1:** To enable early identification of all infants with a congenital hearing loss of >40dB HL, including: bilateral, unilateral, sensory or neural hearing loss (e.g. Auditory Neuropathy Spectrum Disorder) and permanent conductive hearing loss
- **2.1:** Families are able to make an informed decision on hearing screening and diagnostic services
- 2.2: All eligible infants complete a hearing screen

National Framework Target:

• >97% of eligible infants complete a hearing screen before 1 month corrected age (Framework target 2.2.1)

Rationale:

This indicator measures the proportion of the population who are screened by a jurisdictional neonatal hearing screening program. Higher participation is necessary for achieving the overall aim of improving linguistic, educational and social outcomes for infants born with PCHI. Early identification of PCHI allows early engagement with intervention services which research has shown is necessary for achieving the overall aim of improving linguistic, educational outcomes for infants with research has shown is necessary for achieving the overall aim of improving linguistic, educational and social outcomes for infants with permanent hearing loss. Therefore, it is necessary to monitor the age at which screening is occurring so the program is being run to maximum benefit.

Because the age at which an infant completes their neonatal hearing screen is closely tied to the identified aim of improving outcomes for infants born with PCHI, the calculation associated this indicator will present data disaggregated by age.

Calculation:

This calculation measures the number of infants who complete a neonatal hearing screen through a jurisdictional screening program as a proportion of all infants born in a calendar year

Disaggregation:

The data will be presented by the following stratifications:

- Jurisdiction
- Sex
- Remoteness
- Socio-economic status
- Aboriginal and Torres Strait Islander status
- CALD
- Preterm birth

Indicator 1.1 Participation in screening

• Age completed screen – disaggregated as <1 month, 1–3 months, 3–6 months, >6 months corrected age

Issues for consideration:

- Infants who do not enter the screening pathway before being discharged from hospital may be at a higher risk of not completing a hearing screen. To ensure equitable access for all infants, those who do not enter the screening pathway by receiving at least their first screen prior to discharge should be followed-up to ensure they complete their hearing screen. It is noted that this is a jurisdictional issue best monitored at the jurisdictional level.
- The denominator should be the number of live births. The National Perinatal Data Collection (NPDC) provides a comprehensive validated dataset of all live births in Australia, but is only is available after a two-year delay. State/territory neonatal screening programs are able to provide a suitable and timely alternative.
- While the aim of neonatal hearing screening is for all infants to be screened for congenital PCHI by 4 weeks of (corrected) age, the *Draft National Framework* (NHSWG 2010) restricts this to eligible infants. Infants who are not eligible for screening include infants deemed to be medically unfit for screening. It is anticipated that this subgroup of infants will be very small and best monitored at the jurisdictional level.

Indicator 2 Screening

Indicator 2.1 Positivity rate of the screening test

Definition:

The proportion of infants who are screened and test positive for potential permanent childhood hearing impairment

National Framework Objective 2.7:

To ensure that the number of infants referred for assessment and subsequently diagnosed with the target condition is appropriate for the population and is consistent with international standards

National Framework Target:

• <4% of infants who are screened test positive for potential PCHI and are referred for audiological evaluation (Framework Target 2.7.2)

Rationale:

The positivity rate of the screening test provides an indication of how well the screening test is functioning as a test of potential PCHI. Current research suggests that a positivity rate higher than 4% could mean the screening test is yielding too many false positives (NHSWG, 2010). Additionally, a positivity rate higher than 4% (along with the confirmed diagnosis rate) may be an indication of an increase in PCHI among infants in Australia which would be a public health concern.

Another indication of how well the screening test is functioning can be obtained from the positive predictive value of the screening test, which is the proportion of infants who receive a positive hearing screen who after further examination are diagnosed with PCHI. The disaggregations for this indicator will ensure that the screening test is performing equally for all population sub-groups.

Calculation:

This calculation measures the number of infants who returned a positive neonatal hearing screen as a proportion of all infants screened

Disaggregations:

The data will be presented by the following stratifications:

- Jurisdiction
- Sex
- Remoteness
- Socio-economic status
- Aboriginal and Torres Strait Islander status
- CALD
- Preterm birth
- Age disaggregated as <1 month, 1–3 months, 3–6 months, >6 months corrected age

Issues for consideration:

• The two approved screening technologies, OAE and AABR, have different positivity rates (i.e. AABR should be <2%, OAE <4%).

Indicator 2.2 Positive predictive value of the screening test

Definition:

The proportion of infants who test positive on their screening test for potential PCHI and upon further assessment receive a definitive diagnosis of PCHI

National Framework Objective 2.7:

To ensure that the number of infants referred for assessment and subsequently diagnosed with the target condition is appropriate for the population and is consistent with international standards.

National Framework Target:

• A target for the expected positive predictive value of the screening test needs to be developed, in the interim it is recommended that the target be that the number of infants referred for assessment and subsequently diagnosed is appropriate to the population and consistent with international standards (Framework objective 2.7)

Rationale:

Currently, a combination of the otoacoustic emissions (OAE) test and the automated auditory brainstem response (AABR) test are used as the screening procedure for neonates in Australia. The screening process in neonatal hearing screening, like other screening tests, is not intended to be diagnostic. Rather, screening aims to identify infants who are more likely to have hearing impairment, and therefore require further investigation from diagnostic tests.

In order to understand the characteristics of the screening test, it is useful to compare the results of screening tests performed with the "truth". To do this, the number of infants with a positive screening test who are subsequently diagnosed with PCHI is viewed as a proportion of the number of infants with a positive screening test. These data can also be used to compute the number of false positives the screening test is yielding. It is important to monitor how well the screening test is functioning to ensure the screening process does not cause unnecessary anxiety or distress to families; and that the program is not unnecessarily resource intensive by referring too many infants for further investigation.

Indicator 2.2 is an important indicator to be interpreted in conjunction with indicator 2.1 as it ensures that of the infants who are being referred to audiological assessment, an appropriate number of these infants are found to have the target condition.

Calculation:

The number of infants who test positive on their screening test for potential PCHI and upon further assessment are given a definitive diagnosis of PCHI as a proportion of all infants who test positive for potential PCHI

Disaggregations:

The data will be presented by the following stratifications:

- Jurisdiction
- Sex
- Remoteness

Indicator 2.2 Positive predictive value of the screening test

- Socio-economic status
- Aboriginal and Torres Strait Islander status
- CALD
- Preterm birth
- Age disaggregated as <1 month, 1–3 months, 3–6 months, >6 months corrected age

Issues:

- In the short term, it is recommended that the target for this indicator be that the number of infants diagnosed with PCHI is appropriate for the population and consistent with international standards. Research needs to be conducted as to the incidence of PCHI in Australia. In the long term, an appropriate target for this indicator needs to be researched and developed.
 - According to the Medical Services Advisory Committee's Universal Neonatal Hearing Screening Assessment Report (2007) the PPV of TEOAE is 1.5% and of AABR is 2.2%. Research needs to be conducted on the PPV of the screening process that is used by jurisdictional screening programs.

Indicator 3

Indicator 3.1 Audiological assessment

Definition:

The proportion of infants who test positive for potential PCHI that complete audiological assessment

National Framework Objectives:

- 2.6: To ensure infants identified at risk of PCHI are referred for assessment in a timely manner
- 4.1: To ensure that infants who meet the defined criteria for referral receive follow-up audiological and medical evaluations in a timely manner

National Framework Target:

• >97% diagnostic audiology assessment is commenced by three months of corrected age (Framework target 4.1.1)

Rationale:

This indicator measures the proportion of infants who returned a positive neonatal hearing screen and complete diagnostic assessment. It is important to ensure that infants who are referred to audiological assessment following a positive screen receive that assessment so they can continue to receive an intervention as appropriate.

Calculation:

This calculation measures the number of screened infants who test positive for potential PCHI and complete audiological assessment as a proportion of all infants who test positive on their screening test

Disaggregations:

The data will be presented by the following stratifications:

- Age of infant when completed audiological assessment disaggregated as <1 month, 1–2 months, 2–4 months, 4–6 months, >6 months corrected age
- Jurisdiction

Issues:

• The NDSS recommends the below National Framework target >97% of infants diagnosed with a permanent hearing loss are referred to Australian hearing (Framework target 5.5.1) be considered as a target for this indicator. Adding a time element could improve this target.

Indicator 3.2 Detection of permanent childhood hearing impairment

Definition:

The proportion of infants who are diagnosed with PCHI

National Framework Objective 2.7:

To ensure that the number of infants referred for assessment and subsequently diagnosed with the target condition is appropriate for the population and is consistent with international standards

National Framework Target:

• Approximately 0.1% of infants screened are diagnosed with the target condition (Framework target 2.7.1)

Rationale:

The detection of PCHI is an indicator of program performance. Variation in this indicator over time could indicate an increase in the incidence of PCHI or that the screening and diagnostic instruments are not functioning properly.

When expressed as a proportion of the number of infants who test positive for potential PCHI, these data form Indicator 2.2 *positive predictive value of the screening test*. Annual monitoring of these data with various stratifications (such as age or location) may reveal findings of concern that need to be addressed by the program, or positive trends that let the program know it is performing well.

This indicator will also monitor the age that PCHI is diagnosed.

Calculation:

This calculation measures the number of screened infants who are diagnosed with PCHI as a proportion of all infants screened.

Disaggregations:

The data will be presented by the following stratifications:

- Age at diagnosis disaggregated as <2 months, 2–4 months, 4–6 months, >6 months corrected age
- Jurisdiction
- Degree, configuration and type of hearing loss

Issues:

- The disaggregation of age at diagnosis (presently <2 months, 2–4 months, 4–6 months, >6 months corrected age) needs to be agreed upon.
- A further issue that requires consideration is whether infants are diagnosed with either congenital permanent childhood hearing impairment or no congenital childhood hearing impairment or whether there are there other possible diagnoses.
- Hearing status for any individual person is not static. For the purposes of newborn hearing screen, this indicator's definition could be hearing status based on a completed newborn audiological assessment, with a maximum age at assessment of 6 months.

Indicator 4 Early intervention and management

Indicator 4.1 Attend early intervention service

Definition:

The proportion of infants diagnosed with PCHI who attend an early intervention service

National Framework Objective: to be created

To ensure that families and infants engage with an early intervention service

National Framework Target:

• A suitable target needs to be created

Rationale:

It is important that infants who are diagnosed with PCHI attend early intervention services. This is necessary to achieve the program's overall aim of improving linguistic, educational and social outcomes for infants with congenital hearing loss which is of clear benefit to the infant, family and the community.

It is important to capture these data to monitor the reasons infants are not progressing through the screening pathway as the *Draft National Framework* (NHSWG 2010) posits that all eligible infants should proceed as far through the screening pathway as their hearing status warrants so that all Australian infants can benefit from the best possible linguistic, educational and social outcomes. Legitimate reasons that infants may not progress through the screening pathway include the family not consenting, or the infant having other medical problems that prevent attendance.

Indicator 4.1 compares the number of infants diagnosed with PCHI who attend an early intervention service as a proportion of the number of infants diagnosed with PCHI whose parents are referred to early intervention. This is because infants who are captured in Indicator 4.1 should be referred through the program.

Calculation:

This calculation measures the number of infants diagnosed with PCHI and attend early intervention services as a proportion of the number of infants diagnosed with PCHI

Disaggregations

The data will be presented by the following stratifications:

- Jurisdiction
- Age at attendance at early intervention services disaggregated as <2 months, 2–4 months, 4–6 months, >6 months corrected age
- Time (weeks) elapsed between date of completing diagnostic services and attending early intervention services disaggregated as <6 weeks, 6–9 weeks, 9–12 weeks, >12 weeks

Issues:

• A suitable objective and target need to be created. A possible objective could be *To ensure that families and infants engage with an early intervention service.*

Indicator 4.2 Infants fitted with an assistive hearing device

Definition:

The proportion of infants diagnosed with PCHI who are fitted with an assistive hearing device

National Framework Objective:

Infants who have a permanent, moderate or greater bilateral sensorineural hearing loss are provided with amplification/implants in an appropriate time frame for optimal speech and language development.

National Framework Target:

- >97% babies diagnosed with a permanent hearing loss are referred to Australian Hearing (Framework target 5.5.1)
- 100% of referrals received by Australian hearing are confirmed to the referral agency within 5 days (Framework target 5.5.2)
- >85% of children diagnosed with bilateral hearing loss >40dBHL are fitted with amplification by 6 months of age (Framework target 5.5.5)
- >95% of children diagnosed with bilateral hearing loss >40 dBHL are fitted with amplification by 12 months of age. (Framework target 5.5.6)

Rationale:

It is appropriate to monitor factors around hearing aid fitting and cochlear implants. Monitoring these data will assist in service provision and understanding of the types of devices commonly used. It is important to note that audiological management of a hearing impaired child may not always involve a device fitting.

Calculation:

This calculation measures the number of infants who are fitted with an assistive hearing device as a proportion of all infants diagnosed with PCHI

Disaggregations:

The data will be presented by the following stratifications:

- Jurisdiction
- Age at fitting of first assistive hearing device disaggregated as <2 months, 2–4 months, 4–6 months, >6 months corrected age
- Type of first assistive hearing device hearing aid, cochlear implant, other

Indicator 4.1 Attend early intervention service

Issues:

- Australian Hearing can report on hearing aids. Jurisdictional health departments should report on cochlear implant fitting.
- The following Framework targets could be considered after initial implementation:
 - **5.3.1** Age of initiation of formal early intervention is recorded centrally in the program for all children diagnosed with permanent hearing impairment.
 - **5.3.2** >97% of babies with permanent hearing impairment are engaged in formal early intervention by four months of corrected age.
 - **5.5.3**: >97% of families attend appointment within three weeks of the referral

Appendix B

Membership of the Neonatal Hearing S	Screening Working Group
Ms Melinda Bromley	Chair of Working Group
(Screening Subcommittee representative)	Assistant Secretary
(Population Health Programs Branch
	Department of Health and Ageing
Professor Melissa Wake	Director, Research
	Associate Director
	Centre for Community Child Health
	The Royal Children's Hospital, Melbourne
Professor Greg Leigh	Chair, RIDBC Renwick Centre
	Royal Institute for Deaf and Blind Children
	Conjoint Professor of Education
	The University of Newcastle
Dr Elisabeth Murphy	Senior Clinical Advisor
(Child Health and Wellbeing Subcommittee	Maternal & Child Health
representative)	Primary Health & Community Partnerships
	NSW Department of Health
Ms Elizabeth Low	Director
	Strategies and Support Section
	Office of Hearing Services Branch
	Department of Health and Ageing
Ms Jane McEntee	Manager
New Zealand	Antenatal and Newborn Screening
	Health and Disability, National Services Directorate
	New Zealand Ministry of Health
Ms Jan MacLean	West Australian Newborn Hearing Screening
	Programme
Ms Renee Garuccio	NT Hearing Services
	NT Department of Health and Families
Ms Chris Sturrock	Unit Head
	Health Registers and Cancer Monitoring Unit
	Australian Institute of Health and Welfare
Ms Alison King	Principal Audiologist, Paediatric Services
Wis Alison King	Australian Hearing
Ms Tina Carter	Australia and New Zealand Parents of Deaf Children
wis filla Caller	
	(ANZPOD) representative
Secretariat	
Mr Alan Keith	Director, Screening Section
	Population Health Programs Branch
	Department of Health and Ageing
Ms Karen Granton	A/g Assistant Director, Screening Section
	Population Health Programs Branch
	Department of Health and Ageing

Appendix C

Summary of Assessment of Neonatal Hearing Screening against the National Population Based Screening Framework for suitability as a National Population Based Screening Program (considered by the Screening Subcommittee August 2009)

National Population Based Screening Program (cons	sidered by the Screening Subcommittee August 2009)
CRITERIA TO BE MET FOR A NATIONAL	NEONATAL HEARING SCREENING
POPULATION BASED SCREENING PROGRAM	
CONDITION	

CONDITION

The condition should:

- be an important health problem; and
- have a recognisable latent or early symptomatic stage.

Permanent congenital hearing loss occurs in one to two per 1000 babies born. It is believed that 'children with hearing loss have delayed development in vocabulary, grammar, conversation and hearing' (Helfand et al 2001, as cited in MSAC, 2007).

Hearing impairment:

- occurs when there is a reduction in the ability to perceive sound, resulting from an abnormality anywhere in the auditory system (MSAC, 2007);
- can be categorised as either congenital or acquired. Congenital hearing impairment is present at birth or arises shortly thereafter as a consequence of progressive loss, whereas acquired hearing impairment occurs later in the lifespan (Australian Hearing 2003, as cited in MSAC, 2007);
- may be unilateral or bilateral. In unilateral hearing impairment, one ear has normal hearing and the other is hearing impaired. Bilateral hearing impairment indicates that there is hearing loss in both ears;
- can be associated with or result from disorders of the auricle, external auditory canal, middle ear, inner ear, auditory nerve, central auditory pathways and auditory cortex (Braunwald et al 2001, as cited in MSAC, 2007); and
- may be defined as slight or mild, moderate, severe or profound.

There is evidence that early detection and intervention (before six months) helps children to achieve normal language skills, with around 80% of children with congenital hearing loss developing age appropriate language and communication and therefore able to attend normal schooling (HEIDI. National Foundation for the Deaf, 2004).

Research currently undertaken at the National Acoustic Laboratory, a research division

of Australian Hearing, indicates that children who receive intervention before six months of age develop expressive and receptive language abilities that are more in keeping with their chronological age than children who received amplification and intervention after six months. This research continues and is now demonstrating the benefits of Universal Neonatal Hearing Screening.

TEST

The test should:

- be highly sensitive;
- be highly specific;
- be validated;
- be safe;
- have relatively high positive predictive value;
- have relatively high negative predictive value; and
- be acceptable to the target population, including participants from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander peoples, and people from disadvantaged groups and people with disabilities.

There are two screening tools being used in Australia to identify infants with possible permanent congenital hearing impairment that may require further diagnostic assessment – the otoacoustic emissions (OAE) and the automated auditory brainstem response (AABR) tests. These two methods may be used alone or in combination.

Otoacoustic Emissions Testing

Measures sounds generated by the outer hair cells of the cochlea in response to clicks or tone bursts emitted and recorded by a tiny microphone placed in the infant's external ear canal. The presence of these sounds indicates a functioning inner, middle and outer ear.

Automated Auditory Brainstem Response Testing

For screening with AABR methodology, soft ear phones are placed on the infant's ears and a series of soft clicks introduced at the 30-40 dB level. The auditory brainstem response in the form of electroencephalographic (EEG) waves is measured through electrodes attached to the infant's scalp. The technology of AABR is evolving and the second generation AABR technology is now available.

Both these methods of screening are non-invasive, relatively quick and easy to perform. The OAE is affected by fluid in the middle or outer ear or debris in the infant's ear canal. The AABR requires the infant to be in a quiet state, but is less affected by the state of the ear canal. Currently, conventional AABR testing is the gold-standard for the diagnosis of hearing impairment in infants.

There are no reported cases of physical harm caused by universal hearing screening in any of the available studies. The data available on the psychosocial harms from universal hearing screening are of poor to average quality. The most commonly reported psychosocial outcome was maternal anxiety regarding: the screen,; a false positive result; and a screening positive result. Overall, anxiety levels were within the normal range.

Overall, states and territories stand to save on special education and rehabilitation, and the Government to save on disability support pensions.

Comparison of OAE and the AABR testing methods

Otoacoustic Emissions	Automated Auditory Brainstem Response
Testing time – approx 5 minutes	Testing time – approx 8-20 minutes
Easy to perform	More complicated to perform
Less expensive machine and consumables	More expensive machine and consumables
Sensitivity 78-99%	Sensitivity 96-99%
Specificity 90-99%	Specificity 99-100%
Referral rates 10-20%	Referral rates 0.2-2.5%
Source –NSW Statewide Infant Screening – Hearing (SWISH) program 2009	

A two-staged screening protocol is used, to improve the predictive value of the result and reduce the false positive referrals

False positives associated with either test could be reduced with the introduction of a second-stage or third-stage screen of initial failures, prior to diagnostic testing. This may, however, result in unnecessary anxiety to families concerned with added costs and delays in rehabilitation.

ASSESSMENT

Systems should be in place for evidence based follow-up assessment of all people with a positive screening text regardless of rurality, ethnicity, socio economic status or disadvantage status.

Universal neonatal hearing screening (UNHS) involves the testing of all newborns, regardless of their risk factor status. This usually involves testing just prior to discharge from hospital or within a few days of delivery. Community based initiatives have only been piloted in one state, South Australia. In this program initial screening was conducted in a tertiary setting but with comprehensive community-based follow-up

(Child and Youth Health 2001, as cited in MSAC, 2007).

The highest level of evidence available (Kennedy et al 1998 and Kennedy et al 2006) indicates that infants who receive UNHS are nearly three times more likely to be referred for diagnostic testing within 6 months than infants who are not screened universally. In practical terms this means that 1,619 infants would need to be universally screened for hearing impairment, as compared to not screening to ensure the referral for diagnostic testing of one infant under the age of 6 months (MSAC, 2007).

Data indicate that the majority of UNHS programs manage to screen over 90 per cent of infants in their catchment area. These programs are largely hospital-based with initial screening occurring prior to discharge. Community-based studies also obtain very good coverage when screening is 'piggy backed' on other health or immunisation checks at the health clinic or when it occurs at home. Losses to follow-up commonly occur when there is a long delay prior to re-screening or diagnostic testing of the infant, or when infants and mothers are discharged early from hospital.

In recent years, all state and territory governments have introduced or are trialling screening programs to assess the hearing function of newborns, however these screening programs vary from jurisdiction to jurisdiction with some providing hearing screening services in selected metropolitan hospitals only. Currently it is estimated that hearing screening is being provided to 74% of newborn children across Australia.

The Neonatal Hearing Screening Working Group of the Screening Subcommittee will work to develop national evidence based neonatal hearing screening guidelines in consultation with experts in the field.

The tracking and follow up of babies who do not pass the screening test is crucial to the success of the screening program. An overarching data management and tracking system which links the screening process with audiological services is an important component of the follow up process.

DoHA, in conjunction with the AIHW, is working towards developing a national data and reporting framework for neonatal hearing screening, which will incorporate an agreed national approach to data collection, management and data sharing across the screening pathway.

TREATMENT

The treatment must be effective, available, easily accessible and acceptable to all patients with the recognised disease or condition.

Advances in the technology of hearing screening mean that babies with congenital hearing loss can now be detected within a few hours of birth. This allows for intervention (e.g. hearing aids, cochlear implants, specialist education and speech therapy) during the first six months of life which is critical to the development of speech and language skills. Without newborn hearing screening, three quarters of children with congenital hearing loss are still undiagnosed by 12 months and the chance of normal language and cognitive development is greatly diminished.

Australian children can access hearing aids, cochlear implants and other assistive devices at no cost:

- High quality hearing aids are available at no cost to families through Australian Hearing. Australian Hearing is funded by the Australian Government to provide hearing aids, maintenance and ongoing audiological management of children with permanent hearing loss from birth until 21 years of age.
- Cochlear implants are available at no cost to families through either public or private health funds. Maintenance of cochlear implants for children, along with upgraded technology when required, is provided through Australian Hearing.
- Systems are currently being put in place to ensure that families in remote areas will be eligible for assisted transport for audiology follow-up.

SCREENING PROGRAM

High level evidence is essential to make a decision about screening programs as screening is offered to healthy people and has the potential for causing harm that would not have occurred if they had not participated in screening. *Most of the criteria outlined on page 11 of the Population Based Screening Framework for this section have been addressed above excluding cost effectiveness and education/promotion.* The MSAC report states that the economic questions are whether the value to Australian society of implementing a UNHS program is likely to be greater than that of the current situation, and how widespread the screening coverage should be. The existing situation is varied, and the design of a comprehensive screening system that will cover all Australian infants remains to be completed. Information published up until 2003 on the cost-effectiveness of UNHS was limited and at time contradictory – no Australian UNHS program has yet to be reported in detail in literature.

In the short term it can be concluded from available literature that the costs for the additional cases identified and diagnosed by UNHS are greater per unit than those of

targeted screening. However, taking a societal perspective over the long term suggests that identifying a larger proportion of hearing-impaired infants at an early stage (ie ≤ 6 months of age) would result in a cost saving overall. The validity of these estimates of long-term cost savings should be regarded with caution as they are primarily based on observational data and expert opinion.

The detection and long-term management of permanent congenital hearing impairment involves public expenditures from both Federal and state/territory levels of government, and from both health and non-health departments. Over the long term, the states and territories stand to save on special education and rehabilitation, and the Federal Government to save on disability support pensions.

TREATMENT AND ONGOING MANAGEMENT

Treatment and management considerations:

- Ongoing management referral protocols must be established for individuals who have the disease or condition detected through the screening program.
- There needs to be an established policy for the management of individuals who are identified at high risk of developing the disease or condition.

The Neonatal Hearing Screening Working Group of the Screening Subcommittee will work to develop national evidence based neonatal hearing screening guidelines and implementation plan in consultation with experts in the field. The implementation plan will provide advice on education/recruitment strategies to enable participants to make an informed choice about participating in the program and to support those requiring further assessment/treatment.

CONCLUSION

In March 2002 the National Health and Medical Research Council released a report titled *Child Health Screening and surveillance: A Critical Review of the Evidence*. The Report found that there was fair evidence to recommend UNHS. However, the Report urged serious consideration of the logistics and quality of the testing system, and follow up system for neonates who test positive before any decisions are made regarding UNHS.

In 2008 the Medical Services Advisory Committee (MSAC) released the *Universal Neonatal Hearing Screening Assessment Report* (November 2007 – MSAC reference 17) which provided an assessment of the safety, effectiveness and cost-effectiveness of UNHS. The report did not, however, make specific recommendations on these issues with a view to establishing a national neonatal hearing screening program.

As the next step it would be reasonable to assess neonatal hearing screening as a national population based screening program by assessing it against the key principles of the implementation and management of screening programs as recommended in the Population Based

Screening Framework.

There are also a number of 'grey areas' that require consideration, including the lack of Australian studies on neonatal hearing screening and research on providing neonatal hearing screening for babies from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander babies and babies from disadvantaged groups or those with disabilities.

References:

Hearing Impairment: Early Detection and Intervention (HIEDI) (November 2004), Improving outcomes for children with permanent congenital hearing impairment: The case for a national newborn hearing screening and early intervention programme for New Zealand.

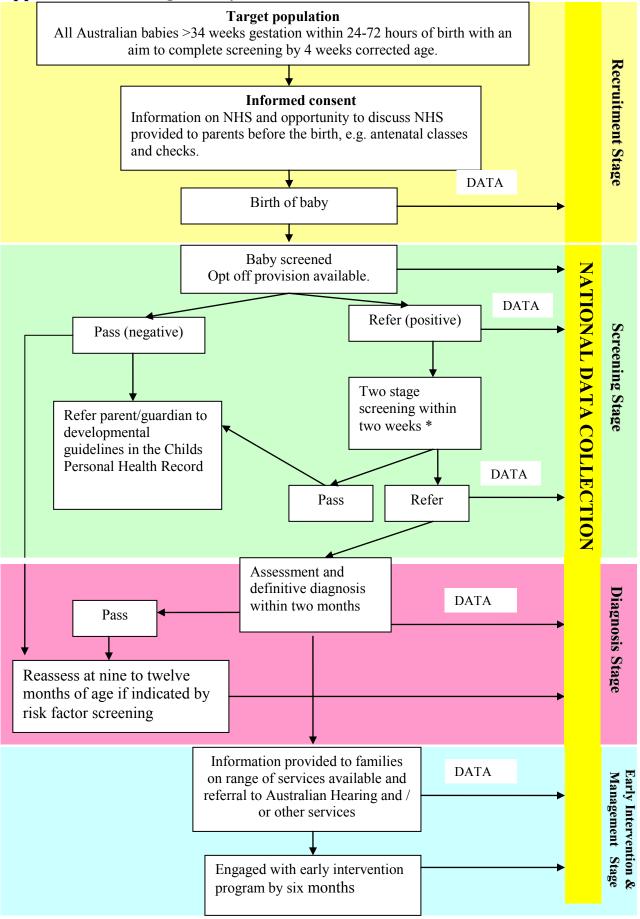
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Kennedy, C.R, McCann, D.C et al (2006). 'Language ability after early detection of permanent childhood hearing impairment', *N Engl J Med*, 354 (20), 2131-2141.

Medical Services Advisory Committee (MSAC) (November 2007), Reference 17, Universal Neonatal Hearing Screening – Assessment Report.

WA Newborn Hearing Screening Steering Committee, Child and Community Health Directorate (2006), A Universal Newborn Hearing Screening Program for Western Australia

Appendix D: Screening Pathway



* Note: South Australia uses a three stage screening process, with the aim to complete this process by one month corrected age.

Appendix E Risk Factors

Risk indicators as defined by JCIH (JCIH 2007) are:

- 1. Caregiver concern regarding hearing, speech, language, or developmental delay.
- 2. Family history of permanent childhood hearing loss.
- 3. Neonatal intensive care of more than 5 days or any of the following regardless of length of stay: ECMO, assisted ventilation, exposure to ototoxic medications (gentimycin and tobramycin) or loop diuretics (furosemide/Lasix), and hyperbilirubinemia that requires exchange transfusion.
- 4. In utero infections, such as CMV, herpes, rubella, syphilis, and toxoplasmosis.
- 5. Craniofacial anomalies, including those that involve the pinna, ear canal, ear tags, ear pits, and temporal bone anomalies.
- 6. Physical findings, such as white forelock, that are associated with a syndrome known to include a sensorineural or permanent conductive hearing loss.
- 7. Syndromes associated with hearing loss or progressive or late-onset hearing loss, such as neurofibromatosis, osteopetrosis, and Usher syndrome; other frequently identified syndromes include Waardenburg, Alport, Pendred, and Jervell and Lange-Nielson.
- 8. Neurodegenerative disorders, such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich ataxia and Charcot-Marie-Tooth syndrome.
- 9. Culture-positive postnatal infections associated with sensorineural hearing loss, including confirmed bacterial and viral (especially herpes viruses and varicella) meningitis.
- 10. Head trauma, especially basal skull/temporal bone fracture that requires hospitalization.
- 11. Chemotherapy.

Appendix F

Professionals Associated with Hearing Impairment

Note: The information below was current as of 2011, and thus may be indicative only.

Screeners

Screeners come from a variety of backgrounds (which may include qualifications in childcare or a health-related field, eg midwives) and are trained to use hearing screening equipment.

Screeners explain the test and its results to parents/guardians, perform the screen, and record the results. After the hearing screen parents/guardians are given the results sheet explaining the results and reinforce the need for ongoing childhood hearing surveillance. The results of the screen are recorded in the baby's hospital records and personal health record. A referral is made to an Audiologist if a newborn has a refer result.

Audiologists

Audiologists are specialists who assess how people hear, and who use various technologies and therapies to help people with hearing and balance problems. Audiologists are university graduates with extensive and ongoing postgraduate training in hearing sciences and human communication. Audiologists provide clinical services in hospitals and community health centres, hearing aid clinics, private practice, university clinics, and in some medical practices. Audiologists are involved in the diagnosis of hearing loss.

Audiologists can offer the following:

- hearing assessment;
- supply and fitting of hearing aids and personal FM (radio frequency) aids if required;
- ongoing monitoring of a child's hearing and hearing aids;
- liaison with medical, educational and other professionals who work with children;
- visits to specialist schools for hearing impaired students; and
- information to help families understand and manage the hearing loss.

Paediatric audiologists provide a family focused approach in the hearing assessment of children, and, where required, assist parents in choosing the most appropriate hearing management for their child. Their key role is to ensure a child has adequate hearing to develop to their full potential (speech and language development, progress at school etc.). Paediatric audiologists work in collaboration with medical officers, early intervention services and other relevant allied health professionals (speech pathologists, psychologists etc.).

Audiologists are represented professionally by Audiology Australia (ASA) -<u>www.audiology.asn.au</u>. Audiology Australia awards the Certificate of Clinical Practice (CCP) to Audiologists who have completed a Clinical Internship and attained Full membership of the ASA. Audiologists who meet these requirements and who participate in a Continuing Professional Development program monitored by the ASA are entitled to use the letters MAudSA (CCP). An ASA MAudSA (CCP) Audiologist has demonstrated that they have up-to-date clinical knowledge and skills.

Paediatrician

A Paediatrician is a doctor who provides specialist medical care to infants, children and adolescents. To become a paediatrician, doctors must complete six years of extra training on completion of their medical degree.

Oto-rhino-laryngologists (ear, nose and throat specialists)

Oto-rhino-laryngologists are medical specialists involved with any condition that affects the ears, nose or throat. Examples of common medical ear conditions are deafness, tinnitus (ringing in the ears), dizziness, ear infections, ear drum problems. Oto-rhino-laryngologists can specialise in areas of interest, such as Paediatric Oto-rhino-laryngology.

General Practitioners (GPs)

GPs have a wide range of medical and surgical knowledge and care for a diverse range of patients. Ideally a GP should coordinate the overall medical care of their patients. This includes focusing on preventive medicine as well as caring for acute and chronic conditions as they arise. A GP will refer their patients for specialist management when required and will communicate with the various specialists involved to ensure optimal patient care. It is not unusual for GPs to develop a specialty area of interest, for example Paediatrics.

Psychologists

Psychologists study human behaviour, conduct research and provide treatment and counselling in order to reduce distress and behavioural and psychological problems. Psychologists work on a broad range of issues with clients, including children, adults, couples, families and organisations.

Psychologists may perform the following tasks:

- conduct therapeutic interviews and provide counselling;
- give psychological tests and assess the results;
- research psychological aspects of topics such as study motivation, teaching skills and occupational behaviour;
- provide follow-up services to groups and individuals for support and evaluation purposes
- evaluate the results of programs aimed at improving personal and organisational effectiveness;
- construct tests to assess and predict emotional states, as well as performance; and
- conduct academic research.

It is a legal requirement for psychologists to be registered with the relevant Psychologists Registration Board of the State/Territory in which they practise. To become a full member of the Australian Psychological Society (APS) applicants are required to complete an accredited six-year sequence of study comprising a fouryear degree course and a two-year postgraduate qualification in psychology. Membership of the APS is not compulsory.

Counsellors

Staff providing counselling will have completed, or be working towards completing, formal nationally recognised/accredited training in counselling.

Medical officers

Medical officers hold a current registration as a medical officer in the relevant State or Territory. Medical officers may perform a number of varied roles in different Services. These may include communicating with general practitioners about results, referral for follow-up, answering parents/guardians questions about assessment and coordinating assessment.

The role which the medical officer plays in screening and assessment will need to be identified by the Service. Medical officers should be able to demonstrate competence in the areas in which they are involved.

Nurses

Nurses will hold a current registration as a nurse with the relevant state regulatory body.

Occupational therapists

Occupational therapists are graduates of an accredited Australian occupational therapy tertiary course, Occupational Therapists have specialised skills and training to look at the child's developmental level of play, fine motor skills and daily living skills.

Speech Pathologists

A speech pathologist has been trained to assess and treat people who have a communication disability. Speech Pathologists either undertake a four year undergraduate degree, or a two year master's degree that encompasses all aspects of communication including speech, writing, reading, signs, symbols and gestures. Pathologists have the necessary expertise to assess, diagnose and treat all types of communication disorders, covering areas such as speech, language voice and fluency in both hearing and hearing impaired/deaf populations.

Registration is only required in the state of Queensland, and membership of the professional organization, Speech Pathology Australia, is optional, although it is encouraged.

Clinical Geneticists

Clinical geneticists are doctors who have undergone specialist training in the way in which diseases or characteristics are passed from one generation to the next.

Teachers of the deaf

A teacher of the deaf has received specialist training in teaching children who are deaf or hearing impaired. A teacher of the deaf works with parents to help the child achieve their full potential for development in speech, language, cognition, audition, social, emotional and motor skills. (Australian Hearing, Choices).

Social workers

The Australian Association of Social Workers reviews and accredits social work degrees offered by Universities throughout Australia to establish whether graduates are eligible for membership of their professional association. An AASW accredited Bachelor of Social Work (BSW) degree or AASW accredited Master of Social Work (Qualifying) (MSW) degree is required for entry into the profession of social work, and to meet the minimum eligibility requirements for AASW membership. There is no legal registration for Social Workers in any State of Australia. However, the AASW is the standard-setting body for social work and many jobs require eligibility for membership of the AASW.

Appendix G

Information required to Australian Hearing in order for an appropriate hearing aid fitting to occur

- 1. Sufficient frequency specific, air conduction evoked potential data to quantify the degree and configuration of hearing loss in each ear.
 - At least one low-frequency (500 or 1000 Hz) and at least one high-frequency threshold (2000 or 4000 Hz) in each ear.
 - If click evoked ABR thresholds have been measured then the next priority is to obtain low frequency information.
- 2. Information to exclude/confirm the presence of Auditory Neuropathy Spectrum Disorder in children who have no recordable response to ABR testing or who have an abnormal ABR wave form
 - ABR + Cochlear Microphonic testing
- 3. Information about middle ear status
 - High frequency probe tone tympanometry for children <6 months of age.
- 4. When tympanometry indicates middle ear pathology at least one ABR bone conduction threshold is recommended to assist in counselling families about the likelihood of hearing threshold improvement

Appendix H

Draft Standards Framework

Note: 77 indicators were originally developed, however, it was recognised that this should be refined. The AIHW has refined the original indicators, resulting in 7 final indicators. The original 77 indicators are only provided here as guidance. It is not intended that they be collected or reported.

1. Recruitment

Objective

1.1 To enable early identification of all babies with a congenital hearing loss of >40dB HL, including: bilateral, unilateral, sensory or neural hearing loss (e.g. Auditory Neuropathy Spectrum Disorder) and permanent conductive hearing loss.

1.2 To ensure that all parents are aware of newborn hearing screening and its benefits and risks.

Standard

- 1.1.1 The Program identifies permanent congenital hearing loss of moderate or greater severity in all affected newborn babies.
- 1.1.2 There is a mechanism in place to ensure all babies are followed up if they have not received a screen.
- 1.1.3 All programs should have a mechanism in place for babies who have not had a hearing screen by three months of age to be referred to an outpatient screen by no later than six months of age.
- 1.2.1 Written information that explains why and how screening is conducted is provided to parents in antenatal packages.
- 1.2.2 Parents receive written information on hearing screening immediately prior to being offered a hearing screen.
- 1.2.3 All communication materials are provided in culturally and linguistically appropriate formats.

Target Performance Indicators

- 100% of eligible babies are offered hearing screening
- >97% of eligible babies complete a hearing screen
- All babies not screened prior to hospital discharge are followed up within one month.
- The number of babies screened between one and six months of age is recorded.
- Written information that describes the screening process and the reason for screening is provided to parents.

2. Screening

Objective

2.1 Parents are able to make an informed decision on hearing screening and diagnostic services

Standard

- 2.1.1 All parents are provided with sufficient information in a culturally and linguistically appropriate format to allow informed decision making.
- 2.1.2 Easily accessible written information is provided for families throughout the pathway, from screening to engagement with early intervention services.
- 2.1.3 Consent is provided by parents/guardians to perform the screen.
- 2.2 All eligible newborns complete a hearing screen.
- 2.3 All babies in Neonatal Intensive Care Units (NICU) and Special Care Units are screened with technology capable of identifying Auditory Neuropathy Spectrum Disorder.
- 2.4 Results of screening processes are communicated to families accurately, effectively and considerately
- 2.5 Informed consent processes are followed for referral to diagnostic audiology.

- 2.2.1 >97% eligible newborns are screened before one month of corrected age.
- 2.3.1 All babies admitted to NICU and Special Care Units for more than five days are screened using AABR based protocol.
- 2.4.1 Communication of screening outcomes is conveyed to families in a culturally appropriate, sensitive and effective manner.
- 2.4.2 Communications regarding results of screening for babies referred to diagnostic audiology clearly indicate the possibility that the baby may have hearing loss.
- 2.5.1 Parents of each newborn referred to diagnostic audiology are provided with adequate information for informed consent.
- 2.5.2 Protocols are in place to ensure timely

Target Performance Indicators

- Written parental consent is obtained to perform a screen.
- All parents who decline screening have been provided with sufficient information to make an informed decision.
- A decline form is signed by all parents who choose to decline a screen.
- A decline to participate in screening is recorded appropriately in the infant's medical file.
- Written consent is obtained to collect data for those babies with a refer (positive) result on the screen.
- >97% eligible babies complete a hearing screen before one month corrected age.
- All babies with a 'refer' (positive) result are referred for audiological assessment.
- All babies admitted to NICU are screened according to NICU protocols.
- All results are provided verbally and in written form. Outcomes are recorded.
- >99% parents of babies with a refer result consent to diagnostic assessment.
- A referral is made to diagnostic assessment within three days of completion of the

2.6 To ensure newborns are referred in a timely manner.

- 2.7 To ensure that the number of babies diagnosed with the target condition is appropriate for that population and is consistent with international standards.
- 2.8 To provide parents with information explaining that changes can occur in their child's hearing over time.

management of referrals.

- 2.6.1 Newborn babies referred for audiology are tracked and followed up in accordance with best practice.
- 2.7.1 The number of screened babies who are diagnosed with the target condition is appropriate for that population and/or consistent with international standards.
- 2.7.2 The program has protocols in place to minimise false positive results.
- 2.7.3 The program has protocols in place to minimise false negative results.
- 2.8.1 Parents are provided with appropriate information about hearing and signs of hearing loss.
- 2.8.2 Ongoing monitoring of age-appropriate communication skills and behaviour responses.
- 2.8.3 Parents with children at higher risk are provided with clear information of their risk factors.³⁴.

screening process.

- >97% babies with a refer (positive) result are referred, monitored and followed up through to diagnostic services.
- >97% of referrals are made in less than five days.
- At least 0.1% of babies screened will be diagnosed with the target condition.
- <4% of babies are referred for audiological evaluation.

All parents of babies screened are provided with a check list of developmental milestones for hearing and signs of hearing loss.

 Parents with children at higher risk are provided with clear written information of their risk factors.

³⁴ Babies with a congenital high risk of deafness require an alternate pathway for screening and assessment States and territories are developing an agreed alternate pathway for babies at higher risk.

3. Parent Support

Objective

3.1 To ensure that parents and families are appropriately supported throughout the screening, diagnosis and intervention process.

3.2 To ensure screening, diagnosis & intervention processes are family centred.

Standard

- 3.1.1 All families are offered the opportunity to access a key support worker or parent support group with other parents of children with hearing impairment to assist emotional and adjustment needs.
- 3.1.2 All families with children at risk or diagnosed with permanent hearing loss are offered support and advocacy to assist decision making, emotional adjustment and access to services.
- 3.1.3 All families are given information concerning access to support and advocacy services within three working days following a refer (positive) newborn screening result.
- 3.1.4 Support and advocacy services for a family are ongoing (up to six years of age) and promote a continuum of service for the family to enhance positive child development, including speech and language and health outcomes.
- 3.1.5 Families receive minimum contact with the support and advocacy service once every three months.
- 3.2.1 All care/management plans are developed in partnership with families in accordance with individual family needs.
- 3.2.2 All care/management plans are reviewed in partnership with families and in a timely manner
- 3.2.3 Parents of hearing-impaired children are represented in the development and review of service delivery, standards and protocols.

Target Performance Indicator

- Access to key support worker or parent support group is offered throughout the screening, diagnosis and intervention.
- Families giving consent to support and advocacy services will be contacted within one week.
- Support and advocacy services are available until the child reaches six years of age.

- Policies are in place to facilitate development of individual management plans, in partnership with families.
- Care/management plans are reviewed on a regular basis in partnership with families, at least every three months.
- There is evidence of mechanisms to engage parents in the development and review of service delivery, standards and protocols.

4. Diagnosis (confirmation of hearing loss) Objective Standard

- 4.1 To ensure that babies who meet the defined criteria for referral receive follow-up audiological and medical evaluations in a timely manner.
- 4.1.1 All babies have access to diagnostic audiology services no later than two months of corrected age.
- **Target Performance Indicator**
- >97% diagnostic audiology assessment is completed by three months of corrected age, to allow referral for medical evaluation by three months of age and timely access to intervention services including Australian Hearing.
- >97% of families are referred to Australian Hearing within three days of confirmed hearing loss.
- All children referred are tested with a full range of diagnostic electrophysiological tests in accordance with agreed national standards.
- Diagnostic electrophysiological tests and behavioural test outcomes are clearly and accurately documented.
- Results are included with referrals to Australian Hearing.
- Families are provided with an explanation of the results on completion of the diagnostic assessment.
- Families are provided with a written copy of the results within five working days.

- 4.2 To define the degree, configuration and type of hearing loss in each ear for fitting of hearing devices.
 - 4.2.1 Audiologists with appropriate training and experience carry out a comprehensive range of assessments to confirm the nature and degree of hearing loss.
 - 4.2.2 Audiologists are provided with sufficient information in order for an appropriate hearing aid fitting to occur as indicated at <u>Appendix F</u>.
 - 4.2.3 Confirmation of hearing loss is communicated sensitively and considerately.

- 4.3 To ensure babies have been referred and have the opportunity to access, otologic, ophthalmic and developmental assessment and the opportunity for aetiological investigation including genetic advice/counselling.
- 4.3.1 All families and babies diagnosed with PCHI are referred for appropriate medical evaluation.
- 4.3.2 All babies fitted with hearing aids must first be examined by a otolaryngologist or paediatrician to exclude any medical contraindications to hearing aid fitting.³⁵
- 4.3.3 All families are offered appropriate support/counselling for managing their child's hearing loss.
- 4.3.4 All babies with hearing loss are reviewed by an ENT surgeon, developmental paediatrician, ophthalmologist, audiologist and are given the opportunity to meet with a clinical geneticist if required.
- An appointment with an otolaryngologist /paediatrician with expertise in paediatric hearing loss should be made within two weeks of confirmation of hearing loss.
- Following confirmation of hearing loss, all babies are referred for otological and other appropriate medical evaluation so that a medical management plan including other interventions, can be developed by three months of age in collaboration with the family.
- All families are provided with a written explanation of the implications of the outcomes of aetiological investigation.
- There is evidence of processes for reviewing and correlating clinical, neurological, audiology (etc) findings for hearing loss that has been detected as a result of screening.
- >97% of babies are seen within targeted timeframes.

³⁵ Australian Hearing's Protocols For Services To Children (2000) require that otological clearance is obtained prior to hearing aid fitting.

5. Early Intervention and Management

Objective

Standard

options.

5.1 Early intervention, support and advocacy services are family centred.

- 5.2 All families remain engaged with an early intervention service provider.
- 5.2.1 Families remain engaged with early intervention services throughout early childhood and are assisted to transition to pre-school and/or school age support services as/when appropriate.

5.1.1 Services provide and source accurate, unbiased

information for families to support decisions

regarding technology and early intervention

5.1.2 Parents of hearing-impaired children should be

standards and protocols.

strategies to promote and enhance communication

represented in the development of service delivery

- 5.2.2 Families that disengage are offered support to reengage with an alternative early intervention service provider as appropriate to the needs of the family.
- 5.2.3 Early intervention service providers and families notify education service providers prior to enrolment to facilitate the development and implementation of a transition plan.

Target Performance Indicator

- >97% of families are provided with a range of options regarding amplification technology, communication and intervention within six weeks of diagnosis.
- Families (particularly in rural and remote areas) are provided with information on eligibility and access to travel assistance particularly for rural and remote areas.
- Services provide evidence of a mechanism to engage parents in the development of service delivery standards and protocols.
- Services demonstrate that protocols have been put in place to provide a smooth transition process between other hearing impairment services.
- Early intervention providers report on continuing enrolment or disengagement quarterly.
- Families that disengage with an early intervention service provider are offered support through central family advocacy/support services to engage with alternative providers within two months.
- Service providers assist in the development of a transition plan six months prior to enrolment in an educational system.

Habilitation

- 5.3 All families are informed about the range and nature of early intervention service options in order to facilitate timely engagement with early intervention.
- 5.3.1 All families have timely and coordinated access to high quality services.
- 5.3.2 Support and advocacy services facilitate engagement with early intervention services at the
- Age of initiation of formal early intervention is recorded centrally in the program for all children diagnosed with permanent hearing impairment.

earliest possible time.

- 5.3.3 Services provide families with unbiased information on all options regarding approaches to communication to assist informed decision making.
- 5.3.4 Early intervention services are commenced by four months of age and no later than six months of age.
- 5.3.5 Services are responsive to cultural and language differences to allow first language development in a language other than English.
- 5.3.6 Engagement with specialist early intervention specific to hearing impairment should be facilitated in cases where hearing impairment is not the primary disabling condition.
- 5.4.1 Services comprise professionals with appropriate expertise and qualifications specific to hearing impairment, including teachers of the deaf, speech-language pathologists, and audiologists.
- 5.4.2 All early intervention programs provide coordinated, ongoing measurement of outcomes for children in oral or visual language.
- 5.4.3 All parents are provided with information on the status of their child's development.
- 5.4.4 All assessments are completed using a common standardised assessment instrument (to be determined) at six-month intervals during the first three years of life.

- >97% of babies with permanent hearing impairment are engaged in formal early intervention by four months of age.
- Families who do not attend audiology or early intervention services are notified to the family's GP and/or Maternity and Child Health Nurse for follow-up within four weeks.

- Services demonstrate that all professional staff members have the skills/qualifications that are necessary for providing families with the highest quality of service specific to children with hearing impairment.
- Services have a comprehensive orientation and training program for staff involved in the delivery of services to children and their families.
- >97% of babies with confirmed hearing impairment receive a full developmental assessment with standardised assessment protocols (not criterion reference checklists) for language, speech, and nonverbal cognitive development by 12 months of age.
- >97% of babies with confirmed hearing impairment in early intervention programs receive a language, cognitive skills, auditory skills, speech, vocabulary, and socialemotional assessment at six-month intervals during the first three years of life.

5.4 All early intervention programs assess language skills, cognitive skills, auditory skills, speech, vocabulary, and socialemotional development of all children with hearing impairment.

Audiological

- 5.5 Babies who have a permanent, moderate or greater bilateral sensorineural hearing loss are provided with amplification/implants in an appropriate time frame for optimal speech and language development.
- 5.5.1 All babies and families have access to amplification edvices of high quality technology, including hearing aids by six months of age in accordance with best practice.
- 5.5.2 All babies and families have access to high quality cochlear implant technology, as appropriate to their hearing loss by 12 months of age.
- >97% babies diagnosed with a permanent hearing loss are referred to Australian Hearing
- 100% of referrals received by Australian Hearing are confirmed to the referral agency within 5 days
- >97% of families attend appointment within three weeks of the referral.
- Australian Hearing confirms attendance at initial appointment of all referred newborns.
- >85% of children diagnosed with bilateral hearing loss >40 dBHL are fitted with amplification by six months of age.
- >95% of children diagnosed with a bilateral hearing loss >40 dBHL are fitted with amplification by 12 months of age.
- >97% of children with 3FAHL of ≥90 dBHL at the initial diagnostic audiology appointment are offered referral for cochlear implant candidacy
- Other children are offered a cochlear implant referral when appropriate to the family's program.³⁶
- All amplification devices are fitted according to Australian Hearing protocols and standards.
- All cochlear implant speech processors are fitted within documented clinical protocols.

- 5.6 To ensure hearing aids and/or other devices are programmed to optimise functional auditory capacity.
- 5.6.1 Audiologists who fit hearing aids to babies abide by Australian Hearing's standards and protocols for services to children.
- 5.6.2 Audiologists who assess children with cochlear implants abide by documented clinical protocols.

 $^{^{36}}$ Other reasons for referral include: parents' wish to obtain information about cochlear implantation, child's functional auditory performance is measured to fall > 2 standard deviations below average for the child's age; aetiology of the hearing loss is one where research suggests that the child may benefit from a cochlear implant.

6. Co-ordination, Monitoring and Evaluation Objective Standard Monitoring

- 6.1 To ensure all data collected is accurate, reliable and reported in a consistent and timely manner thus enabling confidence in the program.
- 6.1.1 The program has quality assurance processes in place which ensure ongoing quality improvement.

6.1.2 Processes should be acceptable and appropriate to the needs of the child and family.

 6.1.3 The safety of newborn babies is protected through

 a comprehensive risk management and incident reporting system and complaints are appropriately managed.

Target performance Indicator

- There is evidence of comprehensive quality assurance program protocols including documented strategies for auditing programs relative to these standards.
- Data collected is stored and accessed in accordance with privacy legislation.
- There is evidence of comprehensive risk management, incident reporting and complaint management protocols.
- There is an appropriate risk management process for missed infants in screening and diagnosis.
- There is an appropriate risk management process for families who decline screening and diagnostic assessment of their infant.
- There is an appropriate risk management process for infants who failed to attend screening or diagnostic assessment appointments.

Evaluation

- 6.2 To ensure the program's protocols for conducting and participating in evaluation activities are in accordance with those of their host health service and national ethical standards.
- 6.2.1 The program/service has protocols in place for conducting and/or participating in evaluation activities in accordance with established research institutes of Australia and for use of program information for research purposes.
- 6.2.2 Services actively seek feedback from families on the acceptability and appropriateness of screening and assessment.
- There is evidence that state and territory protocols for conducting and participating in evaluation activities are in accordance with those of their host health service and national ethical standards.
- There is evidence of strategies to encourage and record client feedback, regardless of hearing outcomes, throughout the screening and assessment pathway.

- 6.3 To ensure accurate and reliable monitoring of assessment outcomes.
- 6.4 To ensure best practice in selection of model and equipment used by a screening program.
- 6.5 To ensure equipment is used and maintained appropriately.
- 6.6 To ensure that data integrity is maintained and that potential for loss of data is minimised

- 6.3.1 Outcomes of all diagnostic audiology assessments shall be recorded and maintained at a state/territory level and audited at regular intervals.
- 6.4.1 The model/equipment used to perform a screen is based on best available evidence.
- 6.5.1 Preventative maintenance and repair of imaging equipment meets manufacturer's recommendations or other appropriate standards.
- 6.6.1 The program has protocols in place to ensure information systems used to record results and monitor follow-up are kept secure.

- Outcomes are available for all babies who have had a diagnostic audiology assessment following referral from their last stage screen.
- Outcomes are recorded in compliance with the minimum national dataset.
- Hearing screening equipment has TGA approval and has documented (peer reviewed) evidence of sensitivity and specificity for identification of the target condition.
- The program has protocols in place to ensure equipment is regularly checked in accordance with manufacturers instructions.
- Equipment checks and re-calibration is documented.
- There is evidence that the data collection system is backed up daily, and that a detailed and up to date disaster recovery plan is in place.

7. Professional Education

Objective

7.1 Parents and babies have access to safe services provided by appropriately trained and qualified health professionals.

Standard

7.1.1 Services demonstrate that all members of the multidisciplinary team have relevant training and qualifications and are recognised by an appropriate professional body to undertake neonatal hearing services.

Target Performance Indicator

- There is evidence of relevant training and qualifications of all members of the multidisciplinary team involved in the screening and assessment of babies. As outlined in <u>Appendix E.</u>
- Deaf awareness and child protection training is included in the induction period for all nonclinical staff.
- 7.1.2 All audiological, medical and habiliation services provide professional, evidence-based, accessible and culturally sensitive services.
- 7.2 Professionals are appropriately trained in counselling services.
- 7.2.1 All professionals are provided with access to training in counselling by a nationally recognised course.
- All services provide evidence of regular participation in professional development.
- Documented protocols are evidence based.
- All professionals have access to training in support and counselling by a nationally recognised course.

Glossary

Auditory Brainstem Response Test (ABR)

The ABR is an electrophysiological test that measures electrical activity generated in various parts of the nerve pathway from the ear to the brain when a sound is presented. Electrodes (small metal disks) are attached to the child's head and sounds are presented to the child's ears through ear plugs or earphones.

Audiologist

An audiologist is a university-trained professional who is specially qualified to measure hearing, diagnose the degree, configuration and type of hearing loss, advise on the non-medical management of hearing disorders, and supply and fit hearing aids and other hearing devices to suit.

Audiology

A field of research and clinical practice devoted to the study of hearing disorders, assessment of hearing, hearing conservation, and aural rehabilitation.³⁷

Auditory Neuropathy Spectrum Disorder (ANSD) (aka Auditory Neuropathy, Auditory dys-synchrony)

A hearing disorder in which the transmission of signals from the inner ear to the brain is impaired. People with Auditory Neuropathy Spectrum Disorder may have normal hearing, or hearing loss ranging from mild to profound. Some but not all people with ANSD experience greater difficulty in understanding speech than would be predicted based upon their hearing threshold levels. Hearing aids and cochlear implants help some but not all children who have ANSD.

Unlike the situation for infants who have a sensorineural or conductive hearing loss, the degree and configuration of hearing loss for infants with ANSD cannot be predicted from Electrophysiological tests.

Automated Auditory Brainstem Response (AABR)

A non-invasive screening ABR test that is used to identify whether a child is at risk for having a hearing loss.

Bilateral hearing loss

A hearing impairment in both ears.

Corrected age

Corrected age takes into account the time between premature birth and the actual due date of a full term pregnancy. Calculating corrected age provides a truer reflection of what the baby's developmental progress should be.

Cochlear implant

Unlike hearing aids, which simply amplify sound, a cochlear implant is a surgically implanted device that bypasses the part of the ear that is not working and electrically stimulates the hearing nerve directly. (Choices, Australian Hearing 2005).

³⁷ Mosby's Medical Dictionary. 2009. 8th Edition. Elsevier.

Conductive hearing loss

Conductive hearing loss can be acquired or congenital and is caused by blockage or damage in the outer and/or middle ear. A conductive hearing loss leads to a loss of loudness and can often be helped by medical or surgical treatment (Australian Hearing 2008).

Decibel (dB)

The unit of measurement for the loudness of a sound. The higher the decibel level, the louder the sound.

Degree of hearing impairment

Describes the impact of a measured hearing loss on an individual's communication ability.

Hearing levels are measured in the better ear:

Mild: 26-40 dB. Affected individuals are able to hear and repeat words spoken in a normal voice at a distance of one metre. Speech and language usually develop normally if a child is fitted with hearing aids early.

Moderate: 41-60 dB. Affected individuals can hear and repeat words spoken in a raised voice at a distance of one metre. Speech and language development are generally affected if a hearing aid is not provided early to a child born with this degree of loss.

Severe: 61-80 dB. Affected individuals are able to hear some words when shouted into the better ear. Speech and language do not develop spontaneously. Hearing aids will greatly assist a child to develop speech, but speech quality is likely to be affected.

Profound: 81 dB or greater, including deafness. Individuals with this level of impairment are unable to hear and understand a shouted voice. Learning to speak is difficult for children born with a profound hearing loss. Many children with profound hearing loss are now fitted with a cochlear implant (Australian Hearing 2005).

Diagnostic Audiology Assessment

An assessment that occurs after a child has received a 'refer' result in a second hearing screen. The assessment is performed by an audiologist, and includes diagnostic hearing tests to assess the type and degree of hearing impairment.

Double refer

A double refer occurs when a child has not passed the screen on two separate occasions and further investigation is required by an audiologist."

Ear, nose and throat surgeon (ENT surgeon) (aka Otolaryngologist)

A surgeon who specialises in medical problems of the ear, nose and throat.

Early intervention programs

Programs which aim to provide hearing impaired children in the first six months of life with immediate intervention. Children who undergo early intervention have

significantly better outcomes than later-identified children in both speech and socialemotional development.

Electrophysiological test

Electrophysiological tests measure the physical response of a *specific part* of the auditory system to sound. Results from electrophysiological tests can also be helpful in determining which part of the complex auditory (hearing) system is involved in a hearing loss.

General practitioner (GP)

A general practitioner is a doctor who provides continuing, whole-patient care. A general practitioner is the first point of contact for most people who seek medical care.

Clinical geneticist

In a newborn hearing screening program, a clinical geneticist can provide genetic information to individuals and families with birth defects/genetic disorders (e.g. hearing impairment) including information about recurrent risks.

Hearing Aid

An electronic device that amplifies sound and conducts it to the ear.

Hearing Screening

Hearing screening aims to identify children who are at risk for a hearing loss, so that they can be referred for further detailed assessment. A screening test result can be a pass (hearing is at levels required for normal speech and language development at the time of screen) or refer (at risk for hearing loss and requiring further assessment). Infants in Australia have their hearing screened with either AABR or OAE tests.

Informed consent

In order to provide informed consent, a consumer needs to know what options are available, what the expected outcomes are for each option, and what the success rates and incidence of side-effects are for each option (The Australian Health Consumer, Number One, 2005-2006).

Initial screen

The first hearing screen that occurs after a baby is born, within 24-72 hours of birth.

MCHN

Maternal Child Health Nurse

Otoacoustic Emissions (OAE) Test

The OAE test measures the response of the outer hair cells in the inner ear (cochlea) to sound. A small probe is placed in the ear canal. A series of clicks or tones is presented to the child's ear and a small microphone records echoes (emissions) that come from the cochlear.

Otolaryngologist (aka ENT surgeon)

A surgeon who specialises in medical problems of the ear, nose and throat.

Paediatrician

A doctor who specialises in medical care for babies, children and adolescents.

Pass (negative)

No hearing loss is detected at the initial newborn hearing screening test. A negative test result.

Post-diagnostic services

Services available to children who obtain a refer (positive) result in their assessment and definitive diagnosis.

Refer (positive)

A refer occurs when a child has not passed the newborn screen on two separate occasions and needs to undergo further testing conducted by an audiologist. A positive test result.

Rescreen

A second screening for babies who do not pass the initial screen. The rescreen should occur after 24 hours but within two weeks of the initial screen.

Sensorineural hearing loss

Sensorineural hearing loss can be acquired or congenital and is caused by damage to, or malfunction of, the cochlea (inner ear) or the hearing nerve. Sensorineural hearing loss leads to a loss of loudness as well as a lack of clarity. The loudness and the quality of sound are affected and sometimes may limit the benefit of a hearing aid

Speech Pathologist.

Speech Pathologists are trained to assess, diagnose and treat communication disorders coverin areas such as speech, language, voice quality and fluency.

Target condition

Babies with congenital permanent bilateral, unilateral sensory or permanent conductive hearing loss, including neural hearing loss, of greater than 40 dB.

Teacher of the deaf

A teacher of the deaf has received specialist training in teaching children who are deaf or hearing impaired. A teacher of the deaf works with parents to help the child achieve their full potential for development in speech, language, cognition, audition, social, emotional and motor skills. (Australian Hearing, Choices).

Three Frequency Average Hearing Loss (3FAHL)

The average of hearing thresholds at 500, 1000 and 2000 Hz in a given ear.

Triple refer

Three screens are required before referral to an audiologist. This system is currently in operation in the Australian Capital Territory and South Australia.

Unilateral hearing loss

A hearing impairment in one ear.

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