

# UNIVERSAL NEWBORN HEARING SCREENING AND EARLY INTERVENTION PROGRAMME

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## UNIVERSAL NEWBORN HEARING SCREENING IMPLEMENTATION ADVISORY GROUP

### TERMS OF REFERENCE December 2007

The aim of New Zealand's Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP) is for early identification of newborns with hearing loss so that they can access timely and appropriate interventions, thereby improving the outcomes for these children, their families and whānau, communities and society, and reducing inequalities.

An effective UNHSEIP will identify babies with permanent congenital hearing loss soon after birth and will initiate health and education interventions during the period of critical language development between 0 and 6 months of age. International evidence shows that those babies who receive appropriate interventions within 6 months are more likely to maintain language, social and emotional development commensurate with their physical development.

#### **Background**

As part of the child health funding package included in the May 2006 Budget, the Government announced \$16 million over the next four years for the implementation of Universal Newborn Hearing Screening in New Zealand. Since this announcement, the Ministries of Health and Education have been working together to provide advice to both Ministers on preferred options for national programme design and implementation. It is vital that the Ministries work together to create a seamless pathway for families and whānau from screening, through diagnosis and treatment to early health and education intervention. While screening can be viewed as the responsibility of the Ministry of Health and early intervention services as the responsibility of the Ministry of Education, building the pathway from screening through diagnosis to early intervention is the joint responsibility of both health and education.

In late 2006, Ministers agreed that the UNHSEIP should be designed around diagnostic audiology services, as these services, in both the public and private sector, are unevenly distributed throughout the country and could be a limiting factor for the programme. To best utilise these limited resources, it is proposed that the Programme be based around lead providers with well-resourced audiology services, potentially covering more than one District Health Board.

The decision to focus the Programme around diagnostic audiology services is also in keeping with the Universal Newborn Hearing Screening Advisory Group recommendation that there must be strong links between diagnostic audiology and early intervention services in order for screening to make a difference to long term outcomes.

While a significant amount of policy work towards planning the Programme has been completed, further work is needed to make sure we achieve a high quality and truly universal newborn hearing screening and early intervention programme. Some of this work will be occurring concurrent with the initial phase of implementation.

Ministers have agreed that the UNHSEIP should have phased implementation over three years, beginning with regions that have adequate service capacities for both health and education, while working to build capacity in other regions. The first phase of implementation began on 1 July 2007.

### **Role of the Group**

The National Screening Unit (NSU) of the Ministry of Health is responsible for providing leadership and strategic direction for screening in New Zealand. The NSU is establishing the Universal Newborn Hearing Screening Implementation Advisory Group to support the NSU to achieve its vision, namely:

*Saving lives, reducing inequalities, and building the Nation's health by leading the delivery of screening programmes, uncompromising in their quality and trusted by the communities we serve.*

The role of the Universal Newborn Hearing Screening Implementation Advisory Group will be primarily to provide multidisciplinary advice on matters pertaining to the national implementation of the newborn hearing screening programme. It is also acknowledged that the pathway from screening, through diagnosis and treatment to early health and education intervention, needs to be made seamless for families and whānau.

### **Principles**

The Group will be guided by the Principles in Appendix A, and will:

- ensure the active engagement of all key stakeholder groups
- use the best available evidence to inform its work
- have a strong focus on quality improvement and equity
- have a population health perspective with an understanding of the principles of screening programmes.

There is an expectation that Group members will make every effort to attend all meetings and devote sufficient time to become familiar with the affairs of the Group and the wider environment within which it operates.

### **Term of Group**

It is anticipated that membership of the Universal Newborn Hearing Screening Implementation Advisory Group will be for a period of three years, throughout the phased implementation of the Programme.

If a vacancy arises, the NSU will appoint a replacement after taking into account the advice of the Group regarding desirable skills and experience.

### **Composition and working arrangements of the Group**

The Group will comprise members who collectively have wide knowledge and experience in newborn care, screening programmes, hearing loss and associated interventions and/or follow-up. The NSU will appoint members, after discussion with relevant stakeholders including providers, consumer groups and professional groups. The Group may co-opt other member(s) as required, and recommend the setting-up of short-term working groups, to address specific areas.

The Group will include representation and perspectives from the following areas:

- Screening Programme/Health Service Development and Provision
- Parents
- Maternity Care
- Paediatrics
- Well Child Tamariki Ora
- Audiology
- Otorhinolaryngology (ORL/ENT)
- Special Education
- Primary Care
- Ministry of Health
- Ministry of Education
- Public Health/Epidemiology

The NSU will select a Chairperson for the Group, and will provide administrative and analytical support to the Group. Meetings will be held as required.

If necessary, Group members may nominate a proxy to attend a meeting on their behalf. It is the responsibility of that member to ensure their proxy is well informed about the Group and the topics for discussion at the meeting.

## **Conflicts of interest protocol**

When Group members believe they have a conflict of interest on a subject that will prevent them from reaching an impartial decision or undertaking an activity consistent with the Group's functions, they must declare a conflict of interest and withdraw themselves from the discussion and/or activity. The Group will then decide what part the member may take in any relevant discussion. Further guidance can be found in the document '*Conflict of Interest Protocol for Ministry of Health Advisory Groups*'.

## **Confidentiality**

Agenda material can be shared with professional colleagues unless identified as confidential. Meeting minutes are to be kept confidential until they have been finalised and approved by the Implementation Advisory Group. When finalised and approved, the minutes will be made available on the National Screening Unit's website and will be in the public domain. Group members must ensure that Group documents are kept secure to ensure the confidentiality of Group work is maintained. Release of Group correspondence or papers can only be made with the approval of the Group. The work of the Group is subject to the provisions of the Official Information Act 1982.

## **Media policy**

Group members are not to represent themselves as agents of the Ministry of Health and are not permitted to speak on behalf of the group, the NSU or the Ministry of Health. However, this does not restrict members from making media statements relating to their personal expertise and/or organisational role. All media inquiries are to be referred to the NSU to be passed on to the Ministry's communications section.

**APPENDIX A**  
**Principles for the Universal Newborn Hearing Screening Programme**

<b>1. Governance</b>	Accountability is clear and arrangements have the capacity to ensure desired outcomes are achieved.
<b>2. People Centred</b>	The programmes involve families, whanau and other stakeholders in a collaborative partnership and is responsive to their needs and values.
<b>3. Equity and Access</b>	People receive equivalent services on the basis of need and likely benefits and the programmes reduce inequalities.
<b>4. Efficiency</b>	The programmes give the greatest possible benefit for the resources used.
<b>5. Effectiveness</b>	The programmes achieve an expected measurable benefit.
<b>6. Coverage/Yield</b>	The programme provides opportunity for the highest participation rate and identifies all positive cases of significant hearing loss.
<b>7. Safety</b>	Harms are minimised.
<b>8. Integration/Interface</b>	The service user can move through the screening and intervention pathways and between Health and Education with ease.
<b>9. Ethical Implications</b>	The programmes ensure that babies with hearing loss identified through the screening programme can access effective intervention services.
<b>10. Service Impact and Workforce Implications</b>	The programmes can be delivered within the current health and education context and workforce impact can be managed.  The skills and competency of the screening and intervention workforces are maintained over time.
<b>11. Outcome Focussed</b>	Programmes are designed to achieve the pre-determined end outcomes of an EIP.

<b>12. Information Provision</b>	High quality information is available for all involved in the programmes.
<b>13. Evidence Informed</b>	Programmes are informed by current evidence of effective practice.
<b>14. Ecological Approach</b>	Services are underpinned by an ecological approach that takes account of a range of interacting factors, e.g. home, educational, cultural and community settings.
<b>15. Culturally affirming</b>	The programmes respect cultural diversity and support the child's place within their cultural context.
<b>16. Preventative</b>	The programmes intervene as early as possible to prevent future problems.
<b>17. Well coordinated and collaborative</b>	The programmes across education and health are well coordinated and well aligned. Health and Education work together to resolve any service or workforce issues.
<b>18. Consistent with government strategies</b>	The programmes recognise and support the wider government strategies for children.