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## 1) PROGRESS AND NEWS

We have a number of items in this update which we hope will be interesting to readers including: information about the Como conference; an update from the Ministries of Health and Education; and a selection of new literature.

Project HIEDI members have been busy participating in both the Implementation Advisory Group and its subgroups over the past few months. We also look forward to our continued involvement in the Group Special Education Reference Group, and its working groups, including the newly formed group focused on visual resources.

One of the key working groups established by the Implementation Advisory Group has been the Workforce Working Group which has focused on developing a workforce strategy and action plan. This strategy is now completed, and a subgroup will be meeting later this month to discuss the best ways to ensure services can be delivered to those living outside main centres, among other things.

### JOINT MINISTRIES UPDATE

27 February 2008,  
Submitted by Vickie Rydz (MOH) and Mark Hutton (GSE)

#### **Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP)**

The National Screening Unit (NSU) has contacted and received feedback from the remaining 18 District Health Boards (DHBs) about their readiness to roll out newborn hearing screening in their area. Consultation and discussions are underway with those DHBs (approximately 9) who have expressed interest in a 2008/2009 roll out. The Ministry of Education is collaborating with the Ministry of Health with respect to implementation planning to ensure early intervention services will be available to newborns detected with a hearing loss as the DHBs begin their screening programmes.

#### **Workforce development**

The Workforce Working Group has completed its primary task by finalising the Workforce Strategy and Action Plan. The group will meet in April to begin planning the implementation of initiatives outlined in the Action Plan.

In January Sue Lewis from the UK spent four days training 40 Advisers on Deaf Children and Service Managers on the UK Early Support Monitoring Protocol and working in partnership with families. This training will enable Advisers to work with families in a supporting capacity so that families can use the monitoring protocol. The protocol enables families to track their child's achievements and development and understand their needs more effectively.

A gap analysis paper has been circulated to Advisers asking that they self-evaluate gaps between their current skills and the skills required to provide intervention to babies and very young children. The analysis is based on the UK Joint Initiative on training issues for professionals working with children under five and their families. The Adviser responses have been collated and will contribute to a wider GSE workforce strategy plan. It is expected that this will then enable further targeted training.

In early March, the NSU will be seeking Registrations of Interest from organisations for the development and delivery of training for newborn hearing screeners and upskilling training for audiologists who will be working within the UNHSEIP.

### **Resources**

The NSU is continuing its development of newborn hearing screening resources for parents, families and whānau. The NSU plans to test these resources with parents and families/whānau.

The Ministry of Education is organising a second printing of family and professional resources in preparation for the implementation of phases two and three of the UNHSEIP. These will be distributed to Advisers and to the families and whānau of newborns identified through the UNHSEIP. These resources have been reviewed and updated to reflect improvements in the UK "Early Years" material they were based on.

### **Programme Evaluation Measures**

The Monitoring Policy and Information System Working Group has completed its task to develop a Monitoring Framework for UNHSEIP. The Framework will be used with DHBs that have established their newborn hearing screening programmes.

The National Screening Unit Implementation Advisory Group has agreed to Ministry of Education programme measures which report on (i) the number of families who are contacted within 2 days of referral and (ii) the number of days taken to start providing an early intervention service.

The Ministry of Education is developing a proposal for an early intervention outcome measure protocol. This protocol will identify the key measures of the efficacy for the early intervention services delivered for young children with hearing loss. The measures will both inform discussions of individual child progress and allow aggregate data to be collected nationally to inform the programme as a whole. A working group of stakeholders and MOE staff will be formed to assist with this task.

## **EARLY SUPPORT MONITORING PROTOCOL IMPLEMENTATION IN NZ**

As many of you will know, the UK's Early Support Monitoring Protocol for deaf babies and children is being modified for implementation in New Zealand. I have provided links to materials that can be found on the [Early Support website](#), so that New Zealand professionals and parents can have a look at these materials.

*Early Support* is a programme for families with babies or children under five with additional support needs associated with disability or emerging special educational need. It's designed to help families access better co-ordinated services for their children, and is particularly relevant where families are in contact with lots of different people. Families and the professionals who work with them have been involved in shaping and refining Early Support at every level.

Please note that some of the files are rather large.

This material is designed for families with a young deaf child and for the professionals who work with them. It enables parents to track their child's development, helping them to record and

celebrate progress through the early years. It supports partnership working between families and professionals by providing a shared basis for discussion and a common frame of reference when many different people are in contact with a child. It supports effective early intervention in a more general way by improving everyone's understanding of the developmental processes involved.

The UK Monitoring protocol, now in its second edition (see below), is made up of a number of parts:

- *How to use this protocol* – an introductory booklet that explains what the material is for and how to use it
- *Developmental profiles* – that provide summaries of what a child is doing, based on information collected in the more detailed Developmental records
- *Development records* – that describe typical patterns of development for babies and young children in five main areas of development – communication, attending, listening and vocalisation, social-emotional, play and other developmental milestones
- Summary sheets (*'summative records'*) – that enable users to consider different aspects of a child's development side by side
- *Glossary* of terms used
- *Development of 'fridge' cards* – that make suggestions for how to support different aspects of development at each stage
- *Level 2 materials* – that help professionals and families look in more detail at a child's development and identify particular strengths and needs.

## 2) NHS 2008 - COMO CONFERENCE ON NEWBORN SCREENING

### *Beyond Newborn Hearing Screening: Infant and Childhood Hearing in Science and Clinical Practice*

19-21 June 2008, Cernobbio, Italy. Villa Erba Congress Centre  
Cernobbio (Lake Como), Italy

The 'NHS2008' Conference will include keynote addresses as well as poster presentations, round tables and platform communications by colleagues from throughout the world, in a truly international framework. [Gary Rance](#) and [Ed Rubel](#) are the keynote speakers at the 2008 conference.

As a specific component of the NHS, a special event is being planned, a Guidelines Development Conference on Auditory Neuropathy (AN), with state-of-the-art information on identification, diagnosis and management of children with AN.

This event is co-sponsored by the Bill Daniels Center for Children's Hearing, The Children's Hospital - Denver, Deborah Hayes and Yvonne Sininger, Co-Chairs. Scientific sessions will be complemented by a comprehensive Exhibition. Ample time will be allowed for all attendees to visit the exhibits and speak with exhibit representatives. The program schedule is arranged to maximize contact among participants.

### **New Zealand Contingent**

The Project HIEDI team hopes that there will be a strong New Zealand contingent at this conference, as there has been at previous events. For those update subscribers who have not attended this event in previous years, it is widely regarded as *the* key newborn hearing screening and early intervention conference, with delegates attending from around the world and presentations on a very broad range of NHS and EI topics.

### **Important dates:**

Please note that early registrations close 15 March. If you register before this date you pay only 475 Euros as opposed to 650 after this date. The NHS2008 website contains lots of useful information and is found [here](#).

**March 7, 2008** - Notification of acceptance and format (poster/oral)

**March 15, 2008** - Deadline for Early Registration

**April 30, 2008** - Deadline for Hotel reservation

### 3) NEW LITERATURE

#### **Hearing screening and diagnostic evaluation of children with unilateral and mild bilateral hearing loss.**

**Authors:** Ross DS, Holstrum WJ, Gaffney M, Green D, Oyler RF, Gravel JS.

**Source:** Trends Amplif. 2008 Mar;12(1):27-34.

**Abstract:** More than 90% of newborns in the United States are now being screened for hearing loss. A large fraction of cases of unilateral hearing loss and mild bilateral hearing loss are not currently identified through newborn hearing screening. This is of concern because a preponderance of research has demonstrated that unilateral hearing loss and mild bilateral hearing loss can lead to developmental delays and educational problems for some children. To help address this probable under-identification of unilateral hearing loss and mild bilateral hearing loss among infants and children, the Centers for Disease Control and Prevention Early Hearing Detection and Intervention program and the Marion Downs Hearing Center convened a workshop in Breckenridge, Colorado, in July 2005. During this workshop, several issues related to screening and diagnosing unilateral hearing loss and mild bilateral hearing loss were identified, as well as recommendations for future research in this area. Issues identified included the lack of standardized definitions for permanent unilateral hearing loss and mild bilateral hearing loss; the use of screening protocols that are primarily designed to identify bilateral and unilateral hearing losses of a moderate degree or greater (eg, above 40 dB); calibration of screening equipment; availability of facilities that can provide the full range of audiologic, diagnostic, and management services to this pediatric population; and an overall lack of awareness by many professionals and families about the potential effect of unilateral hearing loss and mild bilateral hearing loss. Suggestions for future research, such as identifying ways to improve the identification of cases of unilateral hearing loss and mild bilateral hearing loss, were also discussed.

#### **Universal newborn hearing screening: a question of evidence.**

**Authors:** Durieux-Smith A, Fitzpatrick E, Whittingham J.

**Source:** Int J Audiol. 2008 Jan;47(1):1-10.

**Abstract:** The objective of this paper is to present data on the ages of diagnosis and hearing-aid fitting of children with permanent congenital or early-onset hearing loss who were identified through neonatal hearing screening (NHS) programs or medical referral. Data were collected for 709 children born between 1980 and 2003. Children who were screened were diagnosed significantly earlier (mean 6.3 months) than referred children (mean 39.5 months). For the referred children, the ages of diagnosis and amplification improved over time but remained unacceptably high. In addition, there was an inverse relationship between degree of loss and age of diagnosis, with children with lesser degrees of hearing loss identified later than those with severe to profound hearing loss. These results contribute to the evidence that NHS programs lower the ages of diagnosis and amplification and lead to earlier improved hearing. It is argued that early access to hearing should be the desired primary

outcome of NHS. The numerous studies demonstrating improved ages of diagnosis resulting from NHS programs constitute adequate evidence to support these initiatives.

## **Universal newborn hearing screening: parental reflections on very early audiological management.**

**Authors:** McCracken W, Young A, Tattersall H.

**Source:** Ear Hear. 2008 Jan;29(1):54-64.

**Objective:** This article seeks to understand very early audiological management from a parental perspective, after the early identification of their child's hearing loss through universal newborn hearing screening (UNHS).

**Design:** Data are taken from the national evaluation of the introduction of UNHS in England. Forty-five parents and caregivers participated in a qualitative, narrative study within which they identified key challenges generated by the audiological management of very young babies with hearing loss at home.

**Results:** Concern centered on the virtual timetable constructed by parents after screening, the practical daily management issues and the need to establish infant rather than a child focus in audiological practice. In addition, specific challenges relating to moderate hearing loss were identified.

**Conclusions:** Results are of particular relevance to pediatric audiologists, teachers of the deaf and those offering early intervention services.

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## **PROJECT HIEDI**

Project HIEDI is run by an independent group established in 2002 to see the introduction of a national newborn hearing screening and early intervention programme in New Zealand. It has a Steering Team of volunteers, and a part-time Project Manager. The Steering Team is: Professor Peter Thorne (Project Leader), Dr Bill Keith, Dr Dianne Webster, Oriole Wilson, Margaret Cooper and Janet Digby (Project Manager).

For further information about Project HIEDI you can contact the Project Manager for HIEDI and author of these updates, Janet Digby by phoning (09) 445 6006 or e-mailing [janet@levare.co.nz](mailto:janet@levare.co.nz). You can also visit the Project HIEDI webpage at the National Foundation for the Deaf website <http://www.nfd.org.nz/nfdnews/projecthiedi/>

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