// PROJECT H I E D I
N E W S L E T T E R

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1) PROGRESS AND NEWS

Welcome to the 50th edition of our Project HIEDI newsletter.

This newsletter contains information about conferences during 2009, expanded screening in Western Australia, and monitoring of screening programmes. We also have abstracts from three new papers, including one on parental perspectives of early audiological management.

JOINT MINISTRIES UPDATE ON THE PROGRAMME
Update to Project HIEDI
Submitted by Vickie Rydz and Mark Hutton

Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP)
The following nine DHBs (Phase 2) are implementing newborn hearing screening in 2008/2009: Lakes, Bay of Plenty, Capital and Coast, Whanganui, Taranaki, MidCentral, Hutt Valley, Canterbury and South Canterbury.

An implementation workshop for phase two DHBs took place in Auckland in September. There was full representation from the Phase 1 and Phase 2 DHBs representing 12 of the 21 providers who will begin screening in the 2008/2009 financial year. It was a full day of enthusiastic discussions, review of the DHB implementation checklist and sharing of information and experience from those who are or have been involved in newborn hearing screening programmes.

Backgrounds of the participants include: audiologists, DHB planning and funding DHB provider, nursing, people who've worked in screening programmes overseas, programme managers from the three Phase 1 DHBs and people with management experience in the health sector. This group with its diversity of experience will be working together to implement Phase 2 UNHSEIP.

Workforce development
The Ministry is close to finalising discussions with potential providers of newborn hearing screener training and audiology upskilling. Screener training is planned to begin in January 2009 to allow time for the newborn hearing screening training provider to coordinate the training for the first group of DHBs offering newborn hearing screening. The Phase 2 DHBs have put forward the names of the audiologists to attend the upskilling. The start date for training has yet to be established.

Implementation Timeframe
Because newborn hearing screener training will begin in January 2009, the Phase 2 DHBs and the Ministry have adjusted the screening start dates to coincide with the screener training schedule. The start date for screening will still be dependent on each DHB's demonstration of readiness to the Ministry of Health. The Ministry of Education is working with the Ministry of Health to ensure early intervention services will be available to newborns detected with a hearing loss as the DHBs begin their screening programmes.

Resources/Communications
The Ministry has funded four parent resources. They are now printed and are available in PDF version on the National Screening Unit website: www.nsu.govt.nz
The resources are available to all DHBs involved in the UNHSEIP.

Programme Monitoring and Evaluation Measures
The NSU continues its work on the interim data collection for DHBs to use in order to monitor implementation and future quality evaluation of the programme.

Conferences
Vickie Rydz, Programme Manager Newborn Hearing Screening gave presentations about UNHSEIP at the New Zealand Society of Otolaryngology 61st Annual General and Scientific Meeting and Conference and Pediatric Society of New Zealand 60th Scientific Meeting.

Ministry of Education
Resources
A stock take confirms there are still around 500 copies of The Family Book available nationally. AoDCs will ensure these are distributed across the country according to demand.

We continue to review internal resources for re-printing. This includes the Professional Resource Folder, the Family File and the Monitoring Protocol. Timeline for completing the printing is by the end of the year. Once available we will distribute copies of these resources to interested third parties and place them on line.

Visual Communications
In March a visual communications working group developed a proposal for a visual communications service. The Deaf Association took part in the working group and has offered expertise to progress this. We will now approach the Association to develop this further.

Professional Development
Responses to a self-evaluation questionnaire for GSE employed speech language therapists and psychologists have now been collated. The collated data will now be analysed to inform priorities for future professional development.

FURTHER INFORMATION
Those parents or professionals wanting further information about progress towards a national newborn hearing screening and early intervention programme should visit the website of the National Screening Unit or contact the National Programme Manager, Vickie Rydz or contact Mark Hutton from Group Special Education. Vickie Rydz can be reached at vickie_rydz@moh.govt.nz and Mark Hutton at mark.hutton@minedu.govt.nz.

PRESS RELEASE: WESTERN AUSTRALIAN PREMIERE COMMITS TO EXPANDING SCREENING IF RE-ELECTED
4 September 2008
Title: Labor to boost help for new-borns and their parents

Every baby in Western Australia will have their hearing tested when they are born, if Labor is reelected to Government this weekend. The universal screening is one of a series of initiatives announced by Premier Alan Carpenter today for babies and young children, which also includes a home visit to every newborn baby within their first two weeks.

Mr Carpenter said the early development of children was crucial to their health and well-being as adults.

"Being a parent, especially for the first time, can be a daunting experience," he said. "It can be even more difficult if your baby has health problems or if you have nowhere to turn for help and advice."
The Premier said a re-elected Labor Government would:

- introduce hearing tests for all newborn babies in the State;
- ensure all new babies are visited by a community child health nurse within their first two weeks;
- employ an extra 139 community health staff to support parents of children from birth to four years;
- provide funds to enable a 24-hour helpline for new parents;
- increase efforts to assist mothers of indigenous children, including a Community Matriarchs
- Program that will use elder indigenous women to help support younger mothers; and
- work with the Commonwealth Government to make early learning centres available to all Western Australian children up to the age of five.

He said the suite of initiatives, costing almost $35 million over four years, would ease some of the pressure of early parenting.

"With a hearing test for every new baby, a home visit within a fortnight, and a helpline available at all hours of the day and night, no parent should feel cut adrift without support and advice," he said.

The helpline would enable the non-Government organisation Ngala to expand its existing line from 12 hours a day to 24 hours a day. It already receives 20,000 calls a year.
"With an extra 139 community health staff, we will be able to deliver a much more direct service to parents," the Premier said.

"As well as ensuring every baby is visited within a fortnight, we will increase the number of babies who are visited even earlier – within 10 days – and increase the level of support for families who have higher needs."

Mr Carpenter said the universal hearing tests would have far-reaching benefits.
"It is now possible to detect hearing problems within a few days of a baby being born," he said. "With this type of technology now available, we can provide immediate intervention to minimise hearing-related problems in language and speech development, educational outcomes and, ultimately, employment prospects."

CONFERENCES

Below is a list of conferences for 2009 which may be of interest, just click on the link(s) to go to their respective webpages:

NHS Newborn Hearing Screening Programme Annual Conference 2009: Achieving Better Outcomes, 17 March 2009, London

Early Hearing Detection and Intervention Conference, March 9-10, 2009, Dallas, TX

NZ Audiological Society, 33rd Annual Conference 2009, Taupo, 1st July to 4th July 2009

2) MONITORING EDHI PROGRAMMES

Colorado Newborns at Most Risk Miss Hearing Screening Tests
By Star Lawrence, Contributing Writer
Health Behavior News Service

A new study of Colorado birth records shows that infants with low Apgar scores — the widely used measure of newborn health — are 10 times less likely to receive an initial hearing loss screening than babies with normal Apgars. Low-weight babies also are four times more likely to go untested. In both cases, these babies are at greater risk for the most common birth defect: hearing loss.

"While the data do not suggest why these babies are missed, we can clearly conclude that clinical measures showing poor health are strongly associated with both missed screening and risk of hearing loss," said lead study author Mathew Christensen, Ph.D.

Christensen is the program evaluator at the Colorado Department of Public Health and Environment. He and his colleagues analyzed more than 200,000 state birth records from January 2002 to December 2004.

The study appears online and in the December issue of the American Journal of Preventive Medicine.

Ninety-eight percent of the infants received hearing screening a day or so after birth, but the 2 percent who did not undergo screening were likely to be those who needed it most. Moreover, of those who had a positive test — indicating loss of hearing — 18 percent did not receive timely follow up, which is a function of individual hospitals' outreach programs.

Such tests are the standard of care in the United States and 42 states require them, according to the Web site of the National Center for Hearing Assessment and Management.

Study co-author Vickie Thomson, Ph.D., director of newborn screening programs at the Department of Public Health and Environment, said that newborns' hearing is tested while they are resting or asleep and involves sending a signal of clicks and then measuring the reaction of the inner ear or brain to the sounds. Testing usually occurs four hours or more after birth or the next day.

Thomson said that her experience as an audiologist leads her to conclude that many small or low-Apgar babies could be too involved in other procedures or discharged too soon for clinicians to perform the test.

Karl White, Ph.D., director of the National Center for Hearing Assessment and Management at Utah State University, said this finding is not surprising but is important: "Basically, it says sick babies are less likely to get screened."

According to the researchers, studies show that intervention by age of six months results in a return to near-normal ability to develop speech and language.

"If hospital administrators would recognize that hearing screening is important and do something as simple as putting a check-off for this test on their discharge form," White said, "it would increase the probability of all babies being screened."

A MATTER OF DEFINITION?

One of the presentations from the Como conference which I mentioned in my previous update was from Gaffney, Gaffney and Green and outlined the difference between Loss to Follow-Up and Loss to Documentation.

A lack of documentation regarding a particular child may lead to an overstatement of the 'Loss to follow up', which is generally thought to be the result of non-responsive parents who never attend further appointments. Information on this distinction can be found here.

3) NEW LITERATURE

The need for standardization of methods for worldwide infant hearing screening: a systematic review.

Authors: Olusanya BO, Somefun AO, Swanepoel de W.
Source: Laryngoscope 2008, Oct: 118 (10): 1830-6

No uniform case definition presently exists for infant hearing screening programs worldwide especially for minimal hearing loss (HL). This article systematically reviewed the current practices in developing countries for programs aimed at early detection of "disabling" congenital and early-onset HL and found significant variations which undermine comparability of key findings in the reported studies. Implications for the exclusion of minimal HL are explored within the context of the International Classification of Functioning, Disability and Health (ICF) of the World Health Organization and its adapted version for children and youth (ICF-CY). A revised World Health Organization classification that accounts for all categories of HL based on ICF-CY may provide a suitable framework for improved uniformity in reporting standards.

A data collection system to audit post-newborn hearing surveillance programme: problems and possibilities.

Authors: Yoong SY, Spencer NJ.
Source: Child Care Health Dev. 2008 Sep;34(5):648-56

BACKGROUND: Guidance documents on post-newborn hearing surveillance and screen (Sutton et al.2006; Bamford et al. 2007) indicated the need for a wider system to identify children with hearing loss after neonatal hearing screening. Recommendations were made for systems to be in place for recording screening activity and audit of the school entry hearing screen to provide information on coverage, referral and yield.

METHOD: This project has two phases: * development of the data collection system for audit; * assess local service performance. The focus of the work was on data entered into the child health system from children eligible for universal infant and school entry hearing screen. Linking information from a paediatric register of hearing impaired children allowed analysis of birth cohort data related to new diagnoses of sensorineural hearing loss. Available guidelines have not specified gold standards for coverage rates and locally endorsed benchmarks were set at 80% as minimum standards. Analysis of data was carried out on 2003, 2004, 2005, 1998, 1999 and 2000 birth cohorts. The child health system and the paediatric register were the main data sources for the audit exercises. Data extracted were computed for coverage, referral and yield.

RESULTS: Factors and situations contributing to difficulties in establishing a robust system were identified and addressed. Usable information could be obtained to influence current practice. Coverage rates for 2003, 2004 and 2005 cohort were 64.7%, 78.1% and 73.1%. Their respective referral rates were 1.4%, 1.2% and 2.6%. Coverage rates for 1998, 1999 and 2000 cohort were 74.9%,75.6% and 71.4%. Their respective referral rates were 5.2%, 4.2% and 6.6%. The overall yield from universal screens was low.

CONCLUSION: Our study showed that it was achievable to collect and analyse data on childhood hearing loss in the context of routine surveillance. There were, however, limitations to analysis of data and findings have to be interpreted with this in mind.

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.

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. You can also visit the Project HIEDI webpage at the National Foundation for the Deaf website.

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