

In this update:

- 1) [Progress and News](#)
- 2) [Information from conferences and presentations](#)
- 3) [New literature](#)



1) PROGRESS AND NEWS

This update includes a progress report from the Ministry of Health, a section on the importance of reducing 'loss to follow-up' and abstracts from a selection of newly published articles.

If there is anything in particular you would like me to include in future updates, please don't hesitate to get in touch. You can also sign up to receive future updates by contacting the author of these updates, Janet Digby on (09) 4456006 or by e-mail: janet@leware.co.nz

UPDATE FROM THE NATIONAL SCREENING UNIT

Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP)

22 March 2010

Update to Project HIEDI from the National Screening Unit

Submitted by Vickie Rydz, Programme Leader Newborn Hearing Screening

District Health Boards Update

The roll out of UNHSEIP across New Zealand continues with the goal of all 21 DHBs screening by 30 June 2010.

Since the last update in December, four more DHBs have implemented their newborn hearing screening programmes; West Coast, Nelson Marlborough, MidCentral and Waitemata DHBs.

By the end of April 2010, Auckland, Counties Manukau and Northland DHBs will be screening. Roll out dates for Wairarapa, Otago and Southland DHBs are being finalised.

Audiology Upskilling

The NSU is pleased to be able to announce the programme details and dates for the upskilling of audiologists working with newborns. The upskilling will be delivered by the University of Canterbury in three phases.

1. Phase I: On-line preparation commences April 2010
2. Phase II: Assessment and Amplification One-day Workshops
3. Phase III: Regional follow-up workshops in August

PHASE I – Online preparation

This is to ensure that all audiologists attending the upskilling are practising from a shared knowledge base. This will commence three weeks prior to the first hands-on workshop. During this phase audiologists are expected to have read the programme protocols, reviewed the materials provided by the workshop leaders and submitted ABR waveforms (anonymous).

PHASE II – Two one-day workshops (one for assessment, one for amplification)

Assessment

The first one-day workshops will take place in May 2010. These will be lead by Professor Gary Rance from The University of Melbourne. The focus of this assessment workshop will be wave-form interpretation.

Amplification

The second one-day workshops will take place in June 2010. This amplification workshop will be lead by Dr Theresa Ching from National Acoustics Laboratory in Australia. Dr. Ching is the project leader for the Longitudinal Outcomes of Children with Hearing Impairment Study (LOCHI) in New South Wales.

PHASE III – Regional Follow-ups

The regional follow-ups will involve one-day workshops/sessions in a number of regional centres (six-eight locations) during the month of August. They will be facilitated by a fully qualified audiologist employed by the University of Canterbury. The workshops will be an opportunity for audiologists from the region to get together, present cases, ask questions, develop collegial support and liaise with the facilitator as well as national and/or international experts.

Data Collection

The NSU has developed an interim database that will facilitate the monitoring of the screening and audiology indicators from the UNHSEIP Monitoring Framework. The database will store the information collected manually on forms by hearing screeners and audiologists. The NSU has appointed a data administrator to enter the data from the forms into the information system.

The information system will generate standard reports based on the Monitoring Framework allowing the NSU to monitor the programme and share information with DHBs and UNHSEIP stakeholders. The information system will also allow for specific queries and one off reports to provide further detail for programme monitoring.

The NSU and other teams within the Ministry of Health are continuing to work on the development of the permanent UNHSEIP Information System.

PARENT MENTORING

And Federation for Deaf Children has established a Trust to provide Parent Mentoring services from June the 1st. Thanks to Barbara O'Neill for putting the following piece together for our update:

Beacon New Zealand is a parent mentoring programme which is administered by a trust established by New Zealand Federation for Deaf Children and will provide mentoring to all families who have a child diagnosed with a hearing loss. Although it was established to run alongside the newborn hearing screening programme, it is also intended for families whose child has a later diagnosis.

The aim of the Trust is to have parents professionally trained to provide support to families through a parent's perspective and it has three objectives:

- To support families with a child diagnosed with a hearing loss;
- To help empower families to make the choices that are right for their family; and
- To link families with other families and/or parent groups

The mentors will be voluntary but will all have gone through a training and assessment programme conducted by professional trainers. The training programme and resources have been gifted to the Trust by Deaf Children Australia and were adapted from the ones used by Hands and Voices in Colorado. It has been further modified for use in New Zealand. At this point, it is planned that the mentor training will begin in May with training taking place in Christchurch and Auckland.

Initial referral to the programme will be through the freephone number (0800) 535 636 and this will connect directly to the programme administrator. It is anticipated that the contacts will come from the families, Advisers on Deaf Children or audiologists. Once contact has been made, families will be

matched to a mentor and will initially receive three visits. If either the family or the mentor considers that it is appropriate, more visits will be arranged.

It is planned that the service will begin on June 1st 2010 but, in the meantime, anyone who would like more information is welcome to make contact with the programme at beacon.newzealand@gmail.com

CORRECTION –ADELAIDE ADVERTISER ARTICLE IN PREVIOUS UPDATE INCORRECT

The last HIEDI update included an article in the Adelaide Advertiser which *claimed* that there was a long waiting list for hearing assessments of older children at Australian Hearing.

It seems the article I included within this update misrepresented the facts, and I have included a copy of the letter to the Editor sent by Australian Hearing which provides a more accurate picture – see below. Many thanks to Alison King (from Australian Hearing) for taking the time to get in touch and ensure I was made aware of this letter.

You can find out more about Australian Hearing and the services they provide by clicking [here](#). Australian Hearing provide a full range of services to those under the age of 21 years of age, and to eligible adults.

Melvin Mansell
Editor
Adelaide Advertiser

RE: Article in the Adelaide Advertiser – Hearing Impaired face long wait (25/11/09)

I refer to the article by Miles Kemp that appeared in the Adelaide Advertiser on Wednesday 25 November. This article made several references to Australian Hearing (AH) which are profoundly inaccurate and misleading.

The article refers to long waiting lists for hearing assessments of older children at Australian Hearing. Australian Hearing does not maintain waiting lists for assessment. Children who have been diagnosed with a permanent hearing loss are our highest priority and it is our policy to offer these children an appointment in most cases within two weeks of their referral to us, regardless of age. Children who are at risk for permanent hearing loss are seen with high priority; others are referred to appropriate secondary level diagnostic services.

Furthermore, the article refers to a Parents of Hearing Impaired SA (PHISA) submission to the Federal Senate Inquiry into Hearing Health and implies that Australian Hearing delayed appointments for recipients of infants diagnosed by the State Government's infant screening program up to 93 weeks after a referral was received. Again, this is grossly incorrect. In the PHISA submission reference is made to delays in referral to Australian Hearing rather than waiting times. On page eight of this submission it states: "data showed that too many children were not being referred. So instead of reaching AH in a timely fashion there were some instances where children did not get to AH until 93 weeks after diagnosis." The submission also refers to the fact that once these infants are referred to Australian Hearing they are seen within two weeks of that referral.

Australian Hearing is funded by the Australian Government to provide hearing services including amplification to Australian citizens and permanent residents under the age of 21 years. Australian Hearing is recognised internationally as a leading provider of paediatric hearing services. Children receive high quality digital hearing aids, personal FM systems for use in

educational settings and upgraded cochlear implant speech processor technology at no cost to families.

As a specialist provider of hearing services our focus is on children who have a long term hearing loss that requires ongoing management.

Steven Grundy
Managing Director
Australian Hearing

NHS 2010 – BEYOND NEWBORN HEARING SCREENING: INFANT AND CHILDHOOD HEARING IN SCIENCE AND CLINICAL PRACTICE

June 8-10th, Lake Como, Italy

This conference has been held every two years since 2000 and brings together attendees from many countries. The 2010 conference will include keynote addresses, special sessions, workshops, a number of satellite events, free communications and massive poster sessions.

To find out more about this year's conference you can click [here](#)

Key dates for the Como conference:

Abstract submission: 8 February 2010 (changed from December)

Notification of acceptance (oral or poster): March 8, 2010

Early registration: April 12, 2010

Hotel accommodation: April 12, 2010

QUEENSLAND PROGRAMME

Many of you will be aware of the strong and growing reputation of the Queensland UNHS programme. I have included some information from the programme below from the programme's [website](#):

- This [background document](#) will provide you with a good overview of the programme
- "[FACE to FACE: the experiences, decisions, issues, and needs of parents who have a child who is Deaf or has a hearing loss](#)"
- [Protocols and guidelines](#) for the programme
- And finally, a comprehensive review document entitled: [A systematic review of the literature on early intervention for children with a permanent hearing loss](#). This document is very large, and comes in two volumes, so think carefully about hitting that print button. I would recommend the core learning section beginning on page 492 (Volume one) for those who would like a summary of conclusions from this review.

2) REDUCING LOSS TO FOLLOW-UP (LTF)

Earlier this month, the Centers for Disease Control and Prevention (CDC) included a [review of data from US newborn hearing screening programmes](#) in their Morbidity and Mortality Weekly report (MMWR).

Although there are issues with definition and comparability of data between states and over time, there seem to have been significant improvements in the proportion of babies screened in the United states (only 46.5% of babies were screened in 1999 while now the reported rate is 97%).

To put this data in perspective, by 2007, 47 states and territories reported that 3,345,629 infants had their hearing. This report paints quite an impressive picture, particularly considering that we are talking about implementation of separate screening programmes across all 50 states, the District of Columbia, Guam, the Northern Mariana Islands, Puerto Rico, and the U.S. Virgin Islands.

The CDC article link above includes details on how the screening programmes are moving closer toward the 1-3-6 goals. i.e. children being screened by 1 month of age, diagnosis confirmed by 3 months and enrolled in intervention services by 6 months of age.

There is still concern over a lack of documentation however, with more than 45% of infants who referred on the screening not having recorded follow-up. This means there is no way of knowing whether those children received appropriate diagnostic and or intervention services. This is however an improvement over 2005 rates when more than 60% of children who had not passed their final or most recent screening were listed as loss to follow-up/loss to documentation.

Of particular note is that Massachusetts and Colorado programmes, among other programmes which actively follow-up with families and providers reported much lower rates of LFU/LTD in 2007 (5.6% and 6.4% respectively).

For those who are interested in reading more, there is a very [good article in *Pediatrics*](#), by Liu, Farrell, MacNeil and Stone from the Massachusetts UNHS programme which examines loss to follow-up. The researchers found a number of factors were significant in predicting where limited resources should be directed to reduce loss to follow-up. This research found that important factors included: whether the mothers were unmarried, smoking during pregnancy, being an ethnic minority and whether the mothers had completed less than a high school education.

Where in the UNHS programme can loss to follow-up occur?

Loss to follow-up can occur anywhere within the programme pathway as described by [Karen Munoz, Yusnita Weirather, \(2005\)](#):

- Screening Phase: Children born at a hospital with newborn hearing screening, but do not return for recommended outpatient screening
- Diagnostic Phase: Children who refer from the screening process but do not receive diagnostic confirmation
- Intervention Phase: Children who are diagnosed with a hearing loss but do not receive intervention

There is also a good review from the American Speech-Language-Hearing Association (2008) titled [Loss to Follow-Up in Early Hearing Detection and Intervention](#) [Technical Report]. This article splits issues related to loss to follow-up into those related to the system (primary care provider barriers, communication of results, coordination among service providers, privacy regulations, funding, personnel involved) and those related to the family (Possible family factors – educational and literacy levels of mothers and the age of mothers, maternal marital status, maternal substance abuse, maternal smoking, number of children at home, insurance status, family history of hearing loss, receipt of prenatal care, and poverty level and 2. Child factors - severity of hearing loss, birth weight, race, gender, resident of neonatal intensive care or well-baby nursery, and neonatal surgery and ventilator status).

This review concludes that it remains unclear which babies are at greatest risk for LTF, and how programmes can reliably lower the rates of LTF due to a dearth of evidence.

What does this mean for New Zealand's UNHS programme?

Until such a time as evidence becomes available which is relevant to the New Zealand situation, local programmes will likely [work on reducing the number of infants needing outpatient screening](#) and experiment with different approaches to meet programme goals in this area.

A number of strategies have been employed overseas to reduce the loss to follow-up in screening programmes and more generally within the health system. Some strategies and tactics outlined by relevant bodies are summarised in the table below and provide a useful reference for NZ programme managers. The author of these updates would be very interested in feedback from programme managers as to which, if any of these strategies have been effective in their areas.

Appropriate data management systems are needed to:

- 1) Develop an understanding of follow-up rates and how these can be increased across the programme; and, to
- 2) Ensure individual referred children can be tracked (through the programme pathway including when they move outside their area) so that children who do not attend follow-up appointments can be easily identified and steps put in place to maximise the chance that they will access follow-up services.

[Hearing Review, Newborn Hearing Screening Follow-Up: The Essential Next Step by Michael A. Primus, PhD. \(2005\)](#)

Topic – Newborn hearing screening programmes

- Commitment by major players.
- Centralized coordination and tracking: A single coordinator oversees the entire program and communicates personally with major players. Directing the entire program has assisted the coordinator in helping state personnel to understand the program and in garnering their support. Through this contact, the individuals who supervise follow-up scheduling understand the rationale for their efforts, and they know whom to call if problems occur.
- Continuity: The coordinator tracks every referred child in the state. The continuity provided by centralized tracking is one of the essential elements in program success. A strategy for easy communication across programs, including across state lines, could perhaps reduce the loss of infants who leave the region.
- A relatively small population of newborns: Small numbers of newborns make the program more manageable and child-centered. Any child who fails the screening becomes highly visible at both state and local levels, and the child receives the personal attention of the program to ensure progression to follow-up stages. The program is responsive to a delay or other problem in an individual child's progress. Data are meaningful because of the personal experience with children that they represent. The small size of the program also lends itself to uniformity. Hospital personnel are trained by the same group of trainers, and they use the same referral criteria, data management, and reporting procedures. Smaller numbers allow a simpler administrative structure, including more efficient tracking of patients and control of data.
- Commitment by major players: Individual commitment of professionals to referred infants is integral to program success. As an example, local Public Health and WIC (Women/Infant/Children) Nurses readily assume responsibility for locating "lost" children. Rarely is a child not found—even in special circumstances like name change or transient family residence. The dynamics of personal acquaintance and face-to-face communication among professionals and with the coordinator appear to enhance each professional's personal stake in assisting a child.
- Perseverance: Each referred infant is known to the coordinator, and the program is diligent in completing follow-up.

- Personal contact with the parent: When standard procedures (e.g. appointment scheduling, notification letters, etc) do not bring the child to follow-up, the coordinator's office makes personal contact with the parent. Parent noncompliance often represents lack of appreciation for the importance of follow-up testing, and personal conversation with the parent almost always yields cooperation. The personal phone call is recognized as one of the most important techniques in the program for achieving successful follow-up. It is apparent that, in many cases, letters alone are ineffective.
- Transportation funding: Assistance is available for transportation, and occasionally state personnel (e.g. Public Health Nurses) provide transportation. In a few instances follow-up screening has been performed in the home.

National Health Service (UK), NHS Better Care, Better Value Indicators, 2.4 Clinical productivity - acute trusts (2009)

Topic – general information on reducing DNA rates

- Reduce patient anxiety by ensuring that they know what is going to happen and when; clear information is the key e.g. thorough pre-operative assessment.
- Send reminders to patients, especially in specialties with high rates of non-attendance or for patients who receive appointments a long time in advance.
- Text messages are a useful way of sending reminders from three weeks to one day before an appointment. (This may be more useful for some groups of patients than others)
- Provide a clear and easy contact point for patients to cancel and re-book appointments.
- Analyse your DNA rates to identify where these are out of line with the expected levels.

Effective Practices to Reduce Loss to Follow-Up, NICHO Learning Collaborative (HRSA, 2009)

Topic – general information on reducing loss to follow-up

- Scripting the message given the parents when an infant does not pass the initial screening test.
- Getting a second point of contact for the family (e.g., a relative or friend).
- Verifying the identity of the PHCP or clinic before the parents leave the hospital.
- Making the next appointment for the family and explaining why is it important to keep the appointment before they leave the hospital.
- Reminder calls before appointments that include the reasons why the appointment is important.
- Making two audiology appointments so that the infant who can't be completely tested at the first appointment is already scheduled to return in a reasonable timeframe.
- Use of the fax-back to alert the PHCP of screening results and the need for prompt follow-up
- Use of the fax-back between specialists, including the audiologist and PHCP.
- Obtain a Consent for Release of Information at first contact with early intervention, so information can be entered in the state database.

Screening is just the beginning: Follow-up Issues in EHDI, EDHI 2005, Karen Munoz, Yusnita Weirather, (2005)

Topic – Newborn hearing screening programmes

- Meet parents or guardians to explain the role of hearing in a child's language development
- Present a hearing screening brochure in their language
- Present a separate paper with hearing screening results and a phone number to call for outpatient screening, write down the date and time of the appointment and the location if different than the inpatient screening
- Update contact information and pediatrician's name
- Share optimism about the benefits of intervention
- Clarify the process in writing using a diagram complete with pertinent information
- Make an immediate referral to EI or contact the pediatrician if parents desire.
- Communicate your belief that parental involvement is the key in this journey and that we are respectful of their decision.

Interventions to Improve Follow-Up of Abnormal Findings in Cancer Screening

Topic – Cancer screening

Cancer

- Reminders delivered by mail or telephone have been shown to lead to improved follow-up.
- Interventions that provided education and addressed fears related to an abnormal finding through telephone counselling, pamphlets, or other materials also were largely successful in improving timely follow-up.
- Interventions delivered via the telephone were particularly effective, leading to improvements in follow-up of 24–26% compared with usual care.
- Intervention strategies that addressed barriers associated with a lack of health insurance and attempted to improve patient compliance through payment vouchers or transportation incentives are also associated with increased follow-up compliance.
- Strategies that may increase social support, such as use of lay health workers selected from the target population, have been tested in observational studies and appear to be feasible, but study design limitations preclude assessment of efficacy

3) NEW LITERATURE

Clinical Practice for Children with Mild Bilateral and Unilateral Hearing Loss.

Authors: Fitzpatrick EM, Durieux-Smith A, Whittingham J.

Source: Ear Hear. 2010 Jan 5.

OBJECTIVE: Historically, children with mild bilateral and unilateral hearing loss have been reported to experience difficulties related to language and academic functioning. In the context of Universal Newborn Hearing Screening, there is an increasing focus on determining optimal clinical interventions for this population of children. The objectives of this study were to determine the prevalence of mild bilateral or unilateral hearing loss identified in a clinical population from 1990 to 2006 and to document clinical practices related to recommendations and uptake of amplification.

DESIGN: This population-based study consisted of a detailed retrospective chart review of all children identified with mild bilateral or unilateral hearing loss in a Canadian pediatric center between 1990 and 2006. Hearing loss and patient characteristics were extracted to describe the clinical population. Amplification recommendations and uptake of amplification were documented. Clinical decisions regarding amplification practices were explored as a function of age of identification and severity of hearing loss.

RESULTS: A total of 670 children were identified with permanent hearing loss during the 16-yr study period, of which 291 were presented with a mild bilateral or unilateral hearing loss. Detailed reviews of the 255 available medical charts showed that at diagnosis, 178 children presented with mild bilateral, 31 with mild bilateral high frequency, and 46 with unilateral hearing loss. Eighty percent of children had been referred through conventional medical processes before the implementation of universal hearing screening and 20% had been exposed to screening. The average age of identification for the entire group was 54.2 mos (interquartile range, 30.1 to 76.9 mos). Amplification was prescribed for 91.4% of children but there was considerable delay from confirmation of hearing loss to amplification for both children identified with and without screening. Overall, 54.1% received an initial recommendation for amplification and a further 37.3% received a recommendation more than 3 mos after hearing loss confirmation. Practice patterns varied according to category of hearing loss with 60.1% of children with mild bilateral hearing loss receiving an initial recommendation compared with 26.1% of those with unilateral hearing loss. Clinical decision making relative to amplification needs was also changed during the course of audiologic care. The decision to amplify was significantly related to age at identification and degree of hearing loss in the mild bilateral group but not in the unilateral group. Although, more than 90% of children received a recommendation for amplification, chart documentation revealed that less than two thirds of children consistently used their amplification devices. Use of amplification did not vary among children with mild bilateral, mild bilateral high frequency, and unilateral hearing loss.

CONCLUSIONS: This research suggests that there is considerable uncertainty related to clinical recommendations of intervention for this population of children. The impact of parental indecision regarding the benefits of amplification is unknown. Further studies are required to document the potential benefits and factors affecting amplification recommendations and use in the current practice environment where children with mild bilateral or unilateral hearing loss are identified early through newborn hearing screening.

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 on the [National Foundation for the Deaf website](#).

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