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## 1) PROGRESS AND NEWS

Dear Stakeholders,

Project HIEDI is very pleased to have received funding from the Oticon Foundation in New Zealand which will enable us to continue our work during 2011.

While we are delighted that the national newborn hearing screening and early identification programme has been implemented in New Zealand, as we reported in December 2010, our Project HIEDI group has serious concerns regarding aspects of the programme.

Of primary importance to us is that it is nearly four years since rollout of the national programme began, but no official data on the programme's performance has been released.

Understanding key programme metrics, particularly those contained within the [Monitoring Framework](#), is vital to many aspects of the programme including workforce development, ongoing programme improvement efforts and tracking of children diagnosed to ensure they receive referrals to, and services from intervention providers such as Special Education.

Information about the programme's performance needs to include the whole pathway, from screening to diagnostic and intervention services (both audiological and educational) and this information must be available in a timely manner. We look forward to formation of the new Advisory Group as we understand a key focus of this group will be to monitor data from the programme when this becomes available.

One of the areas we believe is crucial to the success of the programme is that there is a high degree of cohesion between those parts of the programme managed by Health and Education to maximise benefit to children and their families. Project HIEDI has written to Deputy Director General, Special Education, Mr Nick Pole to raise issues regarding the:

- importance of integration of health and education services as a key success factor for newborn hearing screening and early intervention programmes;
- lack of progress on the development of outcome measures within the Ministry of Education; and
- lack of regular reporting on agreed measures relating to Special Education services included within the Programme's [Monitoring Framework](#).

Since the letter above was sent we have been contacted by Ms Tricia Fitzgerald who has been tasked with completing a scoping report for the Ministry of Education. The aim of this work is to establish what needs to be done to make sure that the Ministry of Education selects the right measures and systems to monitor a range of outcomes for hearing impaired and deaf children accessing early intervention services. Ms Fitzgerald consulted with a range of groups and individuals and we understand this work is now complete. We hope to provide an update on progress in this important area in a forthcoming update.

Project HIEDI has previously raised concerns regarding monitoring and other topics within our Issues Papers, links to which are included below:

**Project HIEDI Issue Paper 1: July 2009**

[Monitoring the UNHSEIP](#)

**Project HIEDI Issue Paper 2: June 2009**

[Identification of false negatives in the UNHSEIP](#)

**Project HIEDI Issue Paper 3: April 2010**

[Identification and management of children with mild and unilateral hearing losses](#)

Readers may be interested to review the [2005 Advisory Group Report](#) which contains a number of useful recommendations regarding the establishment of a UNSHEIP in New Zealand.

We hope to consult with stakeholders over the coming months and communicate further specifics in future HIEDI updates.

*The Project HIEDI team*

**UPDATES**

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@levare.co.nz](mailto:janet@levare.co.nz)

## 2) Project HIEDI – Upcoming 2011 Snapshot Survey

Last year Project HIEDI completed its first newborn hearing screening and early intervention Snapshot Survey and results were distributed to stakeholders in August 2010.

The 2010 Snapshot Survey included partial or completed responses from 19 of the 20 District Health Board's surveyed and this provided us with a good indication of the stage each DHB was at in implementing their programme; for example whether a specific DHB had extended screening to include well babies at the time of the survey. It also provided us with some basic information about how the DHBs were doing in understanding their own performance with regard to the goals of completion of screening by 1 month, completion of diagnostic tests by 3 months and the initiation of intervention by 6 months, known as the 1-3-6 goals.

We would like to extend our sincere thanks to all those programme coordinators (some of whom are also audiologists) who responded to the 2010 Snapshot Survey. From speaking with some of you we have an idea of the huge amount of work required to establish and manage your regional screening programmes – we do appreciate the time you took to complete last year's survey and we hope you will forgive us for asking you to again provide us with some basic information about your programme.

The more DHBs which participate in the upcoming survey the more complete this information will be and then coordinators, screeners and audiology staff will all be able to how things have progressed around the country since the 2010 Snapshot. We hope to send this year's survey out in May.

### 3) NEW LITERATURE AND CONFERENCE PRESENTATIONS

Readers may be interested in an excellent series of presentations now available online from the recent Phonak conference titled [A Sound Foundation Through Early Amplification](#).

This Chicago conference was held in November 2010 and included a very impressive list of speakers. I can recommend these presentations to those who are interested in newborn hearing screening and early intervention programmes.

Presentations in this series include:

- Karl White (USA) – [Conference Keynote Address on Universal Infant Hearing Screening – Successes and Continuing Challenges](#)
- Martyn Hyde (Canada) - [Buzz Off, I know what I'm Doing - The Role of Protocols in EHDI](#)
- Janet DesGeorges (USA) - [Working with Challenging and Under-involved Families](#)
- Alys Young (United Kingdom) - [Parental Satisfaction, Service Quality and Outcomes](#)

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#### PROJECT HIEDI

Project HIEDI is managed 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 on the [National Foundation for the Deaf website](#).

#### ACKNOWLEDGEMENTS

Project HIEDI would like to acknowledge significant funding provided by [The Oticon Foundation in New Zealand](#) which will enable us to continue our work.

The Oticon Foundation in New Zealand and the Oticon Foundation in Denmark have been significant contributors to Project HIEDI since 2004.

Project HIEDI would also like to acknowledge the financial support of: The Todd Foundation, The NZ Guardian Trust as trustee of the N R & J H Thomson Charitable Trust, Phonak New Zealand Ltd, the JR McKenzie Trust, Scanmedics (Australia), GN ReSound (New Zealand), Quota International of Papakura, Quota International of Auckland, Quota International of Takapuna, North Shore City 100 Voice Choral, The National Foundation for the Deaf and the Auckland Medical Research Foundation.

Without support from organisations like these, the work of Project HIEDI would not be possible.