

Deafness Notification Database Re-launch: Information for Audiologists

May 2010

The Deafness Notification Database (DND) collected childhood deafness notifications from 1982 to 2005. This database was the only local source of information on the number and age of children diagnosed with a hearing impairment, and it also provided information on the types and degree of hearing loss.

The database was previously managed by the National Audiology Centre (NAC). The last report from NAC contained data from the 2005 calendar year.

The New Zealand Audiological Society is re-launching the Deafness Notification Database to ensure:

- Local data on the number and nature of notifications not lost, and is available for service planning and monitoring of trends;
- The hearing sector has an understanding of age of detection and how this is improving with the introduction of newborn hearing screening in district health boards; and
- There is a method for identifying potential false negatives in the newborn hearing screening and early intervention programme.

We need your help to make this re-launch work – so please do send us your notifications from January 1st 2010.

Who should notify diagnoses?

Any audiologist who diagnoses a hearing loss in a child or teenager under the age of 18 with a hearing loss.

Which hearing loss diagnoses should be notified?

We have slightly modified the definition after feedback from the audiology community.

The new definition includes children and young people 18 years or younger:

- With a permanent hearing loss in one or both ears
- 26dBHL or greater over four audiometric frequencies
- The child can be born in NZ or overseas

The criteria for inclusion have now been modified from those which have been used previously:

- **to allow cases of unilateral losses to be included within the database. Cases of unilateral loss have been notified previously – we are just**

formalising this. We welcome notification of cases of unilateral loss dating back to January 1st, 2010.

- **It was also felt the definition was medically focused and didn't adequately acknowledge or include hearing losses where the family might not want hearing aids fitted, for example**

The following examples may help you decide whether notification is appropriate:

Included within the database: Atresia, congenital ossicular fixation, meningitis, acquired hearing losses.

Excluded from the database: Losses which are can be fixed by the use of grommets e.g. Otitis media.

If you are unsure as to whether to notify a particular case, please *do* notify your case and provide as much information in the space provided. We will review these to ensure the right cases are included within the analysis.

What is changing?

Not too much. The form is going online to make it easier to send notifications, and we are keeping many of the questions the same so we can compare to previous data. We think we can make some improvements in the way the information is analysed and presented.

Recently, following requests from audiologists, a Special Interest Group decided to formally include unilateral hearing losses within this database and to modify the definition of who is included, to bring this into line with notified cases and current practice.

Data security

The data is encrypted using SSL 128 bit encryption (Verisign Certificate, Version 3). In addition to this, a number of measures are taken by the provider (Survey Monkey) and by the NZAS to ensure the data is stored securely. Please get in touch if you would like further information.

What do I have to do?

We know how busy you are and so we want to make it as easy as possible for you to notify us of newly diagnosed cases of hearing loss among children. Hence, we are using an online form.

After 1 January 2010 when you diagnose a child or young person under 18 years of age with a hearing loss which meets the criteria above, please help us by:

1. Getting a consent form [here](#) and ask the parents to sign this to allow collection of this information. You don't need to send this to us but please keep it on file.
2. You can either:
 - a. Print a PDF copy of the [notification form](#) and complete it on paper while you are with the parent(s) (You may wish to keep this hardcopy on file at the clinic.), then you can go online [here](#) and complete enter the information through the online form; OR
 - b. You can enter the information directly into the online form [here](#).

To enter multiple notifications please click on the link again once you have completed each notification.

What about notifications from previous years?

Although no data has been collected we are limiting collection of data to 2009 and 2010. You will see a drop down box at the beginning of the survey and you can set this to 2009 if you wish to notify cases from that year.

What will happen to the results?

Analysis of the database will occur annually and the report will be made freely available to all those who have an interest in childhood hearing impairment.

Consent process

Parents must sign the consent form on the NZAS website in order for data to be collected. Individual information will be aggregated within the report so that no family can be identified.

Who should I contact if I have a question or would like more information?

You can contact Janet Digby who is managing the database for us: by phoning (09 4456006) or e-mailing janet@levare.co.nz or NZAS President Lesley Hindmarsh by phoning (09 5208184) or e-mailing lesley.h@dilworth.co.nz.