

Deafness Notification Report (2011)

Notified cases of hearing loss (not remediable by grommets) among New Zealanders under the age of 19

Janet Digby, August 2012



Citation: Digby JE, Purdy SC, Kelly AS (2012) Hearing Loss in New Zealand Children: 2011, New Zealand Audiological Society, Auckland, New Zealand.

This and previous reports are available on the New Zealand Audiological Society website:
<http://www.audiology.org.nz>

This report can be freely quoted, copied and circulated with appropriate acknowledgement.

2011 Deafness Notification Dashboard

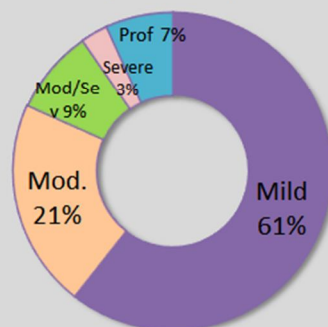
Number notifications

↑ **187** 2011

180 2010

187 Average

Degree, Bilaterals (ASHA Clark)



Subject heading

Total/average

Previous average ↑↓ Trend

DHBs Audiologists

↑ **20** 2011

18 2010

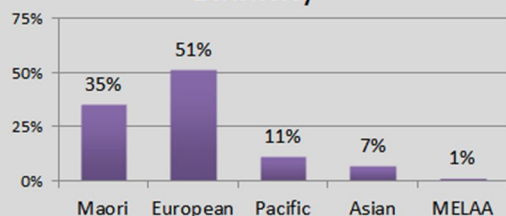
↑ **56** 2011

45 2010

Overall Av age at diagnosis

↓ **57** months 2011

Ethnicity



Hearing loss first suspected by:

1. Parent or caregiver
2. Medical professional
3. Vision Hearing Technician

Other disabilities

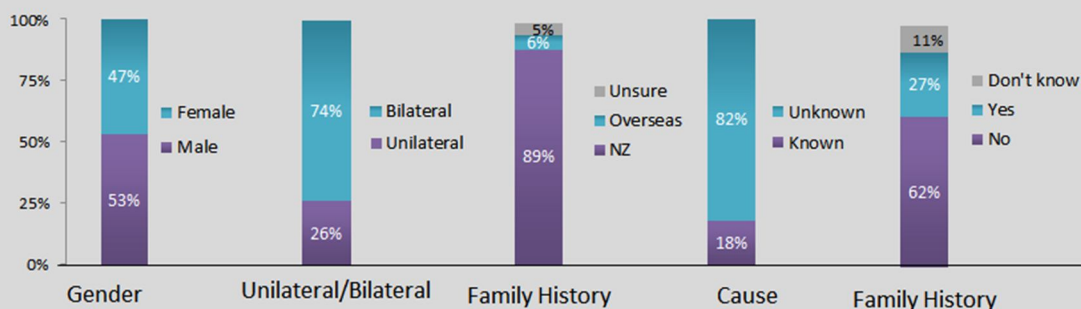
14% confirmed

5% unconfirmed

Newborn hearing screening

Av. age at diagnosis **8** months 2011 ↓ 10 months in 2010

Prop. of notfns from n/born screening **27%** 2011 ↑ 19% in 2010



For notifying audiologists

The authors of this report would like to extend a huge thank you to all audiologists who have provided notifications to the database for the 2011 calendar year. We understand you don't have to provide this information and we know busy you are. Thank you for contributing to our understanding of hearing loss among New Zealand children and young people.

Audiologists (including non NZAS members) are encouraged to make future notifications to the database by following this link: <https://www.surveymonkey.com/s/DeafnessNotificationDatabase>

Further information about the database, including consent forms, can be found at the NZAS website. We would appreciate it if you could keep the following points in mind when making future notifications:

1. Send us your notifications as soon as possible following diagnosis

Traditionally, the administrators of the Deafness Notification Database have attempted to collect all notifications in the year the diagnosis was made e.g. a newly diagnosed case from 2004 was to be notified to the database in 2004 and information from this notification was to be included within the 2004 report. However, not all notifications have historically been provided in the year in which the diagnosis was made.

We strongly encourage all audiologists to get their notifications into the database as soon as possible following diagnosis and always before the end of January the following year i.e. 2012 notifications should be provided by the end of January 2013.

This ensures these reports contain accurate information about those children notified during each calendar year.

2. Read questions carefully and provide as much information as possible

Please read the online form carefully when making your notifications and provide as much specific information as possible in the spaces provided.

3. Submit notifications online, no paper forms please

Notifications to the database can only be made online – please do not submit paper forms for inclusion.

4. Complete audiometric data

Please provide audiometric data for 0.5, 1.0, 2.0 and 4.0kHz. Without this data we cannot calculate severity information for all records.

5. Suspicion and confirmation of hearing loss

Please provide information on the suspicion and confirmation of hearing loss as requested in the notification form.

Age at suspicion: this is the age at which the hearing loss was first suspected.

Date at confirmation: this is the age of which the hearing loss was first diagnosed. In most cases this would mean the audiologist has completed air and bone conduction testing.

Contents

FOR NOTIFYING AUDIOLOGISTS	4
INTRODUCTION.....	6
HISTORY OF THE DND	6
NOTIFICATIONS.....	6
INCLUSION CRITERIA	7
WEAKNESSES OF THE DATABASE	8
FUTURE RENAMING OF THE DATABASE.....	8
THE 2011 REPORT.....	9
FOR THE READER	9
ACKNOWLEDGEMENTS.....	9
CONTACT DETAILS.....	9
NOTIFICATIONS.....	10
GENERAL INFORMATION	10
NUMBERS OF NOTIFICATIONS.....	10
REGIONAL REPRESENTATION	12
OTHER DISABILITIES.....	13
BIRTHPLACE	14
ETHNICITY AND HEARING	14
NOTIFICATIONS AND ETHNICITY	16
UNILATERAL HEARING LOSSES	17
SEVERITY	18
AUDIOMETRIC DATA	18
CLASSIFICATIONS.....	18
COMPARISONS WITH PREVIOUS DATA.....	21
BREAKDOWNS BY ETHNICITY AND DEGREE OF LOSS.....	22
HEARING AIDS AND COCHLEAR IMPLANTS.....	23
HEARING AIDS.....	23
COCHLEAR IMPLANTS	25
CAUSE OF HEARING LOSS.....	26
FAMILY HISTORY	28
IDENTIFICATION OF HEARING LOSSES	29
WHO FIRST SUSPECTED THE HEARING LOSS?	29
AGE AT IDENTIFICATION	30
NEWBORN HEARING SCREENING	33
DELAYS IN DIAGNOSING HEARING LOSS	36
APPENDIX A: HIGH FREQUENCY HEARING LOSSES	39
TABLES AND FIGURES.....	40
REFERENCES.....	41

Introduction

History of the DND

The Deafness Notification Database (DND) was New Zealand's annual reporting system for new cases of hearing loss among children and young people from 1982 to 2005. This system included data on the number and age of children diagnosed with permanent hearing loss and annual reports describing collected notifications were released. The database was managed by the National Audiology Centre on behalf of the Ministry of Health and later by Auckland District Health Board.

The database provided the only source of information from which the prevalence of permanent hearing loss could be estimated, and from which the characteristics of new cases of hearing loss among children and young people could be understood.

In 2006, the Auckland District Health Board discontinued its contract to provide services associated with this database. No new provider was sought by the Ministry of Health. Prior to this, the National Audiology Centre held national contracts for a number of projects, including the collection and reporting of deafness data.

Between 2006 and 2009, a number of groups expressed concern that information on the number and nature of new hearing loss diagnoses among children in New Zealand was no longer being collected.

The DND was seen to have even greater importance since 2007, the start of implementation of the Universal Newborn Hearing Screening and Early Identification Programme (UNSHEIP). Information from the DND was seen as providing an important measure of changes in the age of identification and as only way to identify potential false negatives within the screening programme.

In 2010 the DND was re-launched, with audiologists around the country encouraged to notify diagnosed hearing losses through a new online form. This re-launched database was funded by the New Zealand Audiological Society with help from Janet Digby.

We are delighted that the Ministry of Health began funding the Deafness Notification Database from the start of 2012. The database is now managed through a contract with Accessable and will build on the work funded by the New Zealand Audiological Society.

Notifications

Although the Database was restarted by the New Zealand Audiological Society, efforts have been made to publicise the database to non-members of the Society in an attempt to collect as many notifications as possible.

Notifications are collected through an online survey form, to reduce data entry errors and to try and make it as easy as possible for audiologists to notify cases. A revised consent process was also implemented on re-launch to ensure all information is collected with the consent of the family. Data is backed up regularly and information is sent through a secure link. Standardised methods for data analysis are now being used.

Inclusion criteria

The original criteria for inclusion in the Deafness Notification Database were based on the Northern and Downs definition below and was applied to data until the end of 2005:

“Children under 18 years with congenital hearing losses or any hearing loss not remediable by medical or surgical means, and who require hearing aids and/or surgical intervention. They must have an average bilateral hearing loss (over four audiometric frequencies 500-4000Hz), greater than 26dBHL in the better ear (Northern and Downs classification 1984)¹.”

There was a strong view among audiologists consulted that the previous definition (above) was ‘medically-focused’ and didn’t adequately acknowledge or include hearing losses, particularly mild and unilateral losses, where the family might not want hearing aids fitted or where hearing aids may not be appropriate.

The criteria for inclusion were modified for the 2010 re-launch of the database, based on feedback from a small working group². The new definition now includes children and young people 18 years or younger and is aligned with the age range used for the paediatric cochlear implant programmes.

In addition, this database now includes children:

- with an average hearing loss of 26dBHL or greater over four audiometric frequencies (0.5, 1.0, 2.0 and 4.0kHz) in one *or both ears*³
- who are born inside or *outside* of New Zealand

Specific guidance has been provided to audiologists to clarify the type of cases which are included in the new database:

- Included within the database; atresia, congenital ossicular fixation, meningitis, acquired hearing losses
- Excluded from the database; hearing losses which can be remediated by the use of grommets (ventilation tubes), such as hearing loss associated with otitis media

High frequency hearing losses

Based on feedback from the audiological community, high frequency hearing losses which would not meet the original criteria were collected as a trial from July 2011. Unfortunately, we only received eight completed notifications from this time until the end of 2011. We will continue to trial inclusion of this special group within the database during 2012, but if we don’t receive a more significant number of notifications during the 2012 period, we will discontinue collection of notifications from this category. A limited analysis of data from high frequency hearing losses notified in 2011 can be found in Appendix A: High frequency hearing losses at, on page 39.

¹ Northern JL, Downs MP (1984) Hearing in Children, Williams & Wilkins.

² This group comprises: Professor Suzanne Purdy, Dr Andrea Kelly, Lesley Hindmarsh, Dr Robyn McNeur and Mr Colin Brown.

³ While cases of unilateral hearing loss have been technically excluded from the database until 2005, there were still large numbers of notifications sent to the administrators of the database and these cases were routinely excluded. Professionals consulted in the development of the re-launched database unanimously believed this group should be included within the database, at least in part as there is strong evidence that this group is at risk of poorer educational outcomes.

Weaknesses of the database

While every reasonable effort has been made to ensure the newly re-launched database improves understanding of the characteristics of newly diagnosed permanent hearing losses among NZ children and young people, there are two main weaknesses associated with the database which readers should note:

1. **Incomplete dataset:** There is no way of knowing how far away we are from having a complete dataset, but estimates (see section Numbers of notifications on page 10) suggest there are likely to be a number of notifications not included within the current year. There may be certain types of cases which are underrepresented and as a result inferences made from the data contained in this report should be taken as indications only.

We hope that as time passes further efforts can be made to increase the proportion of notifications received, improving the ability of the database to inform the Ministry of Health, Ministry of Education and other service providers about the number and nature of new diagnoses of hearing loss among New Zealand children and young people.

In future, it is hoped that the database will be able to be linked to applications for hearing aids, meaning that audiologists will be asked to provide less data, and making notifications more automated. The authors of this report hope that this change will increase compliance among audiologists with regards to provision of notifications.

2. **Comparability:** While efforts have been made to retain as many questions as possible from the previous notification form some questions have changed, and in some cases the context around questions has altered making longitudinal comparison difficult or impossible for some items.

Future renaming of the database

The name of the database (Deafness Notification Database) is still being reconsidered. A new name may better reflect the purpose and nature of the database, particularly as changes to the inclusion criteria mean cases of unilateral hearing loss are now included within the database.

If the reader of this report has any ideas on what the database might be called in future, these will be gratefully received by Janet Digby, email: janet@levare.co.nz.

The 2011 Report

For the reader

Steps have been taken to ensure that key data is comparable with previous deafness notification data where-ever possible. In some cases, individual questions have been amended to make these more specific and/or to reflect improved understanding in a particular area (such as family history) and as a result many longitudinal comparisons with pre 2006 data are not possible.

The 2011 report contains some changes in the way various metrics have been calculated and presented. The authors of the report hope that these changes will improve information available to readers, and ask that those same readers be patient with the changes to the way information is presented, and in some cases analysed.

We hope the addition of the one-page 'dashboard' summary on page two of this report will be useful for readers who would like a briefer and more graphical summary of the results.

Please note when reading this report:

- Unless otherwise specified, analyses within this report describe characteristics of the full number of 2011 notifications for which data was provided.
- No information can be reported on the potential number of new diagnoses which could not be notified to the database as parents declined consent for their information to be provided.

Generally, 2010 data within figures is provided in dark turquoise (the main colour of the 2010 report), while 2011 data is presented in purple (the main colour of the 2011 report). Tables and figures containing externally sourced data are orange, while long-term comparisons are shown in green/grey.

Acknowledgements

Thank you to the 187 families who provided consent for their child or young person's data to be included within the database. We hope providers will be able plan and offer better future services for families as a result of your willingness to share basic information about your child's diagnosis.

The time taken by individual audiologists around the country to make notifications and request consent from families is also very much appreciated, as are efforts of those who have completed the analysis for reports prior to 2006, which has its own unique challenges.

This report, and the re-launch of the Deafness Notification Database, was made possible through funding from the New Zealand Audiological Society. Without this support, those working with children who are deaf and hearing impaired would have remained in the dark about the number and nature of new diagnoses in New Zealand.

In addition to thanking the New Zealand Audiological Society for their commitment to this project, the primary author of this report gratefully acknowledges the significant support and guidance of Prof. Suzanne Purdy of the University of Auckland and Dr Andrea Kelly of Auckland District Health Board.

Finally, the support of the following individuals is also acknowledged: Dr David Welch, Lesley Hindmarsh, Dr Robyn McNeur, Mr Colin Brown and Professor Peter Thorne.

Contact details

Feedback on this report and questions about the Deafness Notification Database should be directed to the primary author of the report, Janet Digby. Janet can be contacted at: PO Box 32 374, Devonport, or by email: janet@levare.co.nz or telephone (09) 445-6006.

Notifications

General information

187 notifications which met the revised criteria were received for the 2011 reporting period by the 31st of January 2012. These notifications were received from a total of 56 audiologists, with notifications representative of each of the 20 district health board areas. This is up slightly from the 180 notifications received in 2010, which were received from 18 DHBs and 45 audiologists.

It is difficult to ascertain how long, on average, audiologists took to make each individual notification as some online forms were left open for a number of hours or even overnight. However, it is clear that many individual notifications took less than five minutes to make using the online form, as was the case during 2010.

This year, we were able to compare 2011 notifications from those received previously (for 2010) and also with notifications included within the ADHB dataset for 1982-2005. Duplicates were identified based on NHI and by name, using fuzzy matches to detect potential duplicates which couldn't be identified based on the NHI due to missing information or data entry errors in the ADHB dataset.

Slightly more of the cases notified were male (53%) than female (47%). This is a similar ratio (1.13:1) of boys to girls as has been found elsewhere ($\approx 1.2:1$), with boys commonly found to have higher rates of hearing loss than girls within overseas research⁴. It is also similar to the 1.18:1 ratio reported in last year's report.

Numbers of notifications

Figure 1 shows the number of notifications meeting the criteria in each year. Notifications have been reported based on calendar years throughout the period of operation of the database i.e. 1982-2011. The period from 1982 to 2005 contains notifications to the original National Audiology Centre/ADHB administered database. No data are provided for 2006-2009 as the database was not operating during this period. Data for 2010 and 2011 contain notifications provided to the newly re-launched database. Notifications were removed from the main analysis for the reasons stated below.

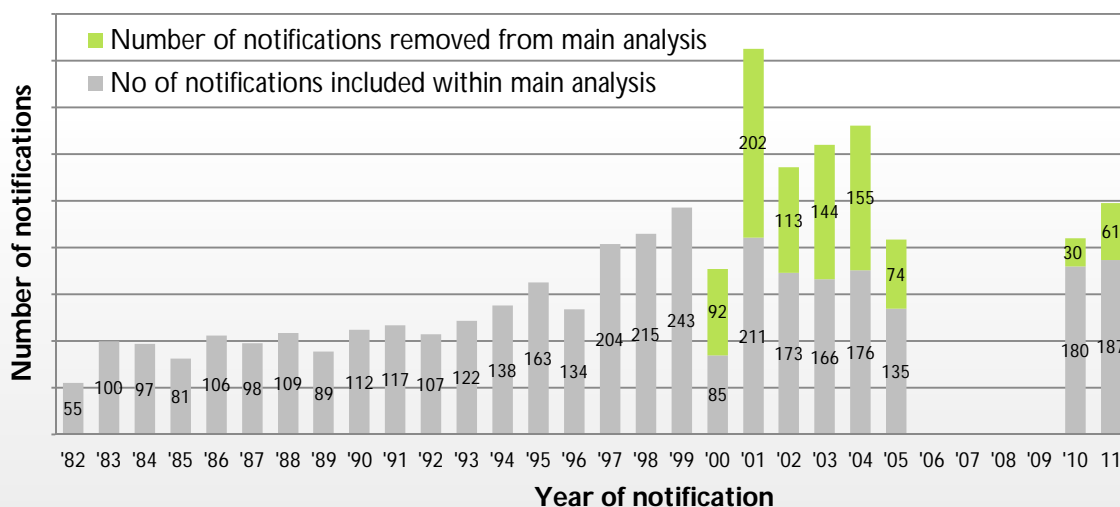


FIGURE 1: NOTIFICATIONS BY YEAR 1982-2005 AND 2010-2011

⁴ Mehra S, Eavey RD, Keamy DG, (2009) The epidemiology of hearing impairment in the United States: Newborns, children, and adolescents. *Otolaryngology-Head and Neck Surgery*, 140, 461-472.

Figure 1 illustrates the variability in the number of notifications provided to the original database, particularly in the last six years of its operation. From 2000, the number of notifications shown is split between those included in the main analysis and those excluded from the main analysis as they did not meet inclusion criteria. Those included in the main analysis are shown in blue, with those excluded from the analysis in purple.

The following types of notifications were removed from the main analysis as per the criteria:

- slight losses (those not meeting the 26dBHL average across four frequencies in at least one ear);
- cases where the child or young person was reported as having mild hearing loss with normal bone conduction thresholds⁵ (assumed to be a transient conductive hearing loss unless stated otherwise);
- notifications with significant missing information; and
- notifications where consent had not yet been provided by the parent/caregiver

In addition, in early 2012, Auckland District Health Board kindly allowed access to their dataset (1982-2005) so that new notifications could be checked against those received previously to ensure no duplicates were being included in the current analyses.

Access to this dataset allowed the authors to confirm that the notifications included in the database prior to 2005 included some duplicates, and we can confirm that the number of notifications reported during before 2005 was artificially inflated as a result.

The lower number of notifications which met the criteria in 2005 was attributed at the time to removal of duplicate entries and to the fact that audiologists were receiving less encouragement from Auckland District Health Board to send in their notifications.

Estimating the total number of new diagnoses per year

As no prevalence information for permanent hearing loss among New Zealand children and/or young people exists, it is not possible to accurately estimate how close the database is to collecting data on all new cases of permanent hearing loss which meet the inclusion criteria. We can however use: the number of notifications provided to the database until 2005 and estimates of hearing loss prevalence among children and young people, to provide some indication of the number of new diagnoses of hearing loss annually among children and young people:

1. Reviewing the number of notifications to the DND in recent years, and without knowing the exact extent of over-reporting due to cases being notified in more than one reporting period, it would seem reasonable to assume that between 50% and 80% of all new diagnoses may have been notified in 2011, the same proportion estimated in 2010. However, this method is somewhat compromised, as the criteria for inclusion in the database have changed since the database was re-launched in 2010 and so comparisons are problematic.
2. Although there are a number of difficulties using prevalence from overseas jurisdictions, estimates of overall prevalence in children and young people from international data⁶ would

⁵ Hearing losses meeting the criteria listed on page 6 were included within the dataset. This included a number of permanent conductive losses.

⁶ Fortnum et al (2001) estimated that, for every 10 children detected through newborn hearing screening with a hearing loss averaging 40dBHL, an additional 5-9 cases of permanent childhood hearing impairment might be detected in the post-natal years. Fortnum's prevalence at birth is 1.06 per thousand births and this rate is very close to more recent prevalence estimates from programmes such as those in New South Wales and Victoria which report an approximate additional figure of 0.5 per thousand for unilateral hearing losses. Using this information and including an estimate for children with unilateral and mild hearing losses

suggest that given there are approximately 1.167 million children and young people in New Zealand under to the age of 19 years old⁷ there may be approximately 245 new hearing loss diagnoses made annually which fit the new criteria. Using this method the notifications collected in 2011 may comprise approximately 76% of the number of 2011 diagnoses.

Work is continuing in 2012 to encourage audiologists to report new cases to the database and it is hoped that the number of notifications to the re-launched database will grow over time and will approach 100% of all new diagnoses within the population under consideration.

Regional representation

Table 1 contains the percentage of 2011 notifications from each district health board (DHB) and compares this with the percentage of the population under the age of 20⁸. The authors of this report are delighted that cases from all 20 DHBs are now represented in notifications, up from 18 in 2010.

In addition to the natural fluctuations in the number of hearing losses diagnosed in a given year, other factors influencing notification levels may include; the number of FTE audiologists employed by each district health board; workload of these audiologists; and, the level of commitment among staff to making notifications to the database.

	Percentage of notifications received 2011 (under 19 years)	Percentage of population under the age of 20 (NZ 2006 Census)
Auckland	8%	9%
Bay of Plenty	6%	5%
Canterbury	14%	11%
Capital and Coast	13%	6%
Counties Manukau	11%	13%
Hawke's Bay	6%	4%
Hutt	2%	4%
Lakes	5%	3%
Midcentral	1%	4%
Nelson Marlborough	2%	3%
Northland	3%	4%
South Canterbury	2%	1%
Southern	8%	7%
Tairāwhiti	1%	1%
Taranaki	3%	3%
Waikato	7%	9%
Wairarapa	3%	1%
Waitemata	5%	12%
West Coast	1%	1%
Whanganui	1%	2%

TABLE 1: PERCENTAGE OF NOTIFICATIONS (2011) COMPARED WITH PERCENTAGE OF POPULATION UNDER 20 YEARS OF AGE BY DISTRICT HEALTH BOARD

we can make a rough estimate of the prevalence of permanent congenital hearing loss among 0-18 year olds in New Zealand of 4 per thousand.

⁷ Statistics New Zealand (2006) 2006 Census Data: QuickStats About New Zealand's Population and Dwellings – Table 3 <http://www.stats.govt.nz/Census/2006CensusHomePage/QuickStats/quickstats-about-a-subject/nzs-population-and-dwellings.aspx> accessed on March 22nd, 2011

⁸ This group is used as an approximation of the size of the population under the age of 19.

Other disabilities

80% of cases notified for the 2011 period were not thought to have any disabilities in addition to hearing loss at the time the notification was made although in 5% of cases there was uncertainty regarding whether the child or young person had an additional disability.

This proportion is not directly comparable to data reported prior to re-launch of the database in 2010, as an 'unsure' category has been added to allow for cases where an additional disability may be suspected but has not yet been confirmed. When the 'unsure' figure is added to the proportion of cases with an additional disability the total is within the range reported prior to 2006.

The lower rate of reported additional disabilities among notified children and young people diagnosed in 2010 and 2011 may also be explained in some measure by the changing perceptions around the term 'disability'.

Interestingly, these figures are generally lower than the 27.4% figure reported by Fortnum et al (2002) from a sample of 17,169 UK children studied with hearing loss. The most common additional disabilities reported in this study were learning difficulties (11%) and visual impairment (6%).

As pointed out in 2010's report, children with hearing loss in New Zealand may not be routinely assessed by a pediatrician and hence additional disabilities may be under-diagnosed.

Notification Year	Proportion of cases with a known additional disability	Proportion of cases with a possible additional disability	Proportion of cases with additional disability (2002-2005) Total confirmed and possible (2010-2011)
2002	-	-	29%
2003	-	-	21%
2004	-	-	23%
2005	-	-	18%
2010	12%	10%	22%
2011	14%	5%	19%

TABLE 2: PROPORTION OF CASES WITH A KNOWN ADDITIONAL DISABILITY

For the 26 children and young people reported to have additional disabilities, 33 specific conditions were listed. The most common of these were those related to a specific syndrome (6 children), physical disabilities or differences (5 children) and vision problems (5 children).

It is interesting to note that vaccination programmes have reduced rates of meningitis in New Zealand and this reduction is expected to have led to a reduction in rates of (more severe) hearing loss⁹. A reduction in the number of cases may not be visible in the overall figures as the number of cases each year is small. It is difficult to compare the number of cases of meningitis over time as this information was not collected prior to the re-launch of the database in 2010.

Of the cases of hearing loss diagnosed in 2011 and notified to the database four were listed as being the result of meningitis. This compares with six cases listed as being the result of meningitis in 2010.

⁹ Turner N, (2011) Cases of Meningitis in New Zealand, personal communication to J Digby March 21st 2011.

Vision problems

As mentioned above, 5 of the 26 children and young people recorded as having an additional disability had compromised vision. A 2006 review examined 191 papers on the subject of vision problems among hearing impaired children, finding that while the overall quality of evidence in the literature was very low, the prevalence of ophthalmic problems in deaf children is very high, and likely to be between 40% and 60%¹⁰. No local data is available on the rates of vision problems among deaf and hearing impaired populations in New Zealand.

Some professionals recommend routine referral for ophthalmological assessment for children diagnosed with significant hearing impairment, although this is not yet commonplace in New Zealand.

Birthplace

This is the second year children and young people born outside of New Zealand have been formally included within the database. As shown in the figure below, of the 187 cases included in the main analysis in 2011, 11 or 6% were known to be born outside New Zealand. This is a similar proportion to the 8% of notified individuals born overseas in 2010. Birthplace was uncertain in a further 5% of cases reported to the database in 2011.

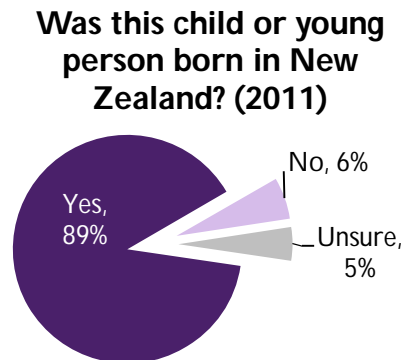


FIGURE 2: PROPORTION OF 2011 CASES BORN IN NEW ZEALAND

Ethnicity and hearing

While no individual project which has focused on defining prevalence of hearing loss among New Zealanders has ever definitively confirmed a difference in prevalence of hearing loss between Māori and European New Zealanders, the difference noted above between these groups in rates of hearing loss among 2010 and 2011 notifications may be supported by data from other sources listed below.

Household Disability Survey

Four Household Disability Surveys between 1991 and 2006 sampled a subset of individuals responding to the New Zealand Census and asked basic questions about hearing loss. This survey defined people 'who have difficulty hearing or cannot hear what is said in a conversation with one other person and/or a conversation with at least three other people' as having a being deaf or hearing impaired¹¹.

These surveys provide some information about hearing loss in the New Zealand population, although there are a number of limitations with this data as this survey is quite general, not age specific and categorises hearing disability in different ways. For example, in the 2001 Survey, children wearing hearing aids have been included in those labeled deaf or hearing impaired, while adults wearing hearing aids have not¹².

¹⁰ Nikolopoulos, T P, Lioumi, D, Stamatakis, S, O'Donoghue, G M. (2006) Evidence-based overview of ophthalmic disorders in deaf children: a literature update. *Otology & Vol.* 27(2Suppl1), pp.S1-24.

¹¹ Statistics New Zealand (2012) 2006 Disability Survey http://www.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey2006_HOTP06/Technical%20Notes.aspx accessed on August 4th 2012.

¹² Greville A (2005) Hearing impaired and deaf people in New Zealand: an update on population numbers and characteristics. Greville Consulting. Auckland

According to the latest Household Disability Survey (2006), Māori have:

- higher rates of disability overall compared with non-Māori (children and adults)
- higher rates of hearing loss among (children)

Unfortunately, in addition to possibly having higher rates of hearing loss, according to the Household Disability Survey Māori have higher rates of unmet need for equipment/technology over all age groups and lower rates of equipment use than non-Māori (across all disabilities)¹³.

B4 School Check

The B4 School Check aims to screen all children before they reach school, and to identify and provide intervention to those children identified with those conditions. Part of this Check involves screening children for hearing loss. This screening should be completed on all children not already under the care of an ENT or audiologist following their fourth birthday. Those not screened before they reach school should be screened after their arrival at school.

This screening involves audiometry, usually conducted by a Vision hearing Technician¹⁴. If the child passes this test, no further referrals are required. Should the child refer on the audiometry, tympanometry is conducted.

As shown in Table 3 according to B4 School Check records, as reported by Searchfield et al¹⁵ Māori children are also more likely to be referred from the B4 School Check hearing screening, which is to be completed when the child is 4 or 5 years of age. It is important to note that high referral rates for Maori may indicate higher rates of ear disease as these figures do not just relate to hearing loss.

Ethnic group (grouped total responses)	Māori Children screened to 6 May 2010	Non-Māori Children screened to 6 May 2010
Referred	9%	5%
Retest	10%	9%
Pass bilaterally	71%	77%
Not recorded	3%	3%
Declined	7%	6%

TABLE 3: RATES OF REFERRAL FROM B4 SCHOOL CHECK, SEARCHFIELD, BAE AND CRISP (2011)

Universal newborn hearing screening

While only 47% of audiological data was available to describe outcomes for children referred through the Universal Newborn Hearing Screening and Early Identification Programme from October 2010 to March 2011, considerable referral rate data has been reported for this programme. Data for babies referred between October 2010 and March 2011 show the referral rate for those of Māori ethnicity is 2.4%, considerably higher than the 1.2% referral rate for those recorded as European ethnicity¹⁶.

¹³ Statistics New Zealand (2010) 2006 Household Disability Survey. Wellington.

¹⁴ National Vision Hearing Screening Protocols (2011) Wellington: Ministry of Health.

¹⁵ Searchfield G, Bae S, Crisp A, (2011) Whakarongo Mai and Māori hearing loss statistics, access and barriers. Presented at the Oticon Foundation Hearing Education Centre Spring Symposium: Hearing Health Issues Facing the New Zealand Population. November 2011. School of Population Health, University of Auckland.

¹⁶ Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP) Monitoring Report on Newborn Hearing Screening Service Provision October 2010 – March 2011 (2012) National Screening Unit, Auckland.

Notifications and ethnicity

The method used within this report to classify ethnicity is the total response method, where every person identifying with a particular ethnicity is included within that specific grouping. For example, if someone considers their child to be of Samoan and Māori ethnicities they are recorded under both these groups. This means the total number of ethnic groups selected by respondents is usually greater than the number of respondents.

Using this method provides a more detailed and realistic measure of the relative size of the groups identifying with a particular ethnicity when compared with older survey methods which required respondents to select only one ethnicity with which they mostly identified. Using this method also aligns the database with The New Zealand Census, which began explicitly instructing respondents that they could select more than one category for their ethnicity in 1996.

The proportion of notifications within each ethnic group was calculated differently in DND reports before 2006 with respondents being coded initially as belonging to one 'race' and later as one 'ethnic group'. Categories used have also changed. As a result, direct comparison with data from before the re-launch in 2010 is not possible.

The New Zealand Census (2006) categorises respondents into five major groupings as per and these groupings will continue to be used for the next Census. These groups are; Māori, Pacific Peoples, Middle Eastern/Latin American/African (MELAA), European and Asian.

2010 and 2011 notifications (including those children and young people born overseas) are reported in Figure 3 below. As a comparison, the percentage of the population under the ages of 20 years and 5 years in each ethnic grouping from the 2006 Census is also provided¹⁷.

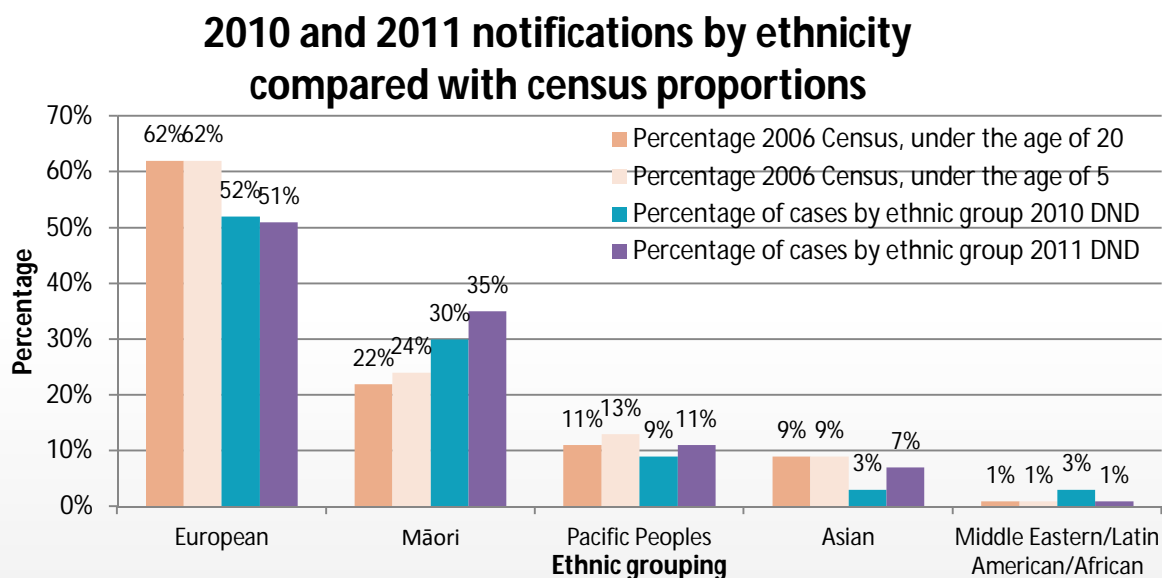


FIGURE 3: 2010 AND 2011 NOTIFICATIONS BY ETHNICITY COMPARED WITH CENSUS PROPORTIONS

¹⁷ Statistics New Zealand 2006 Census Data: Quick Stats about Culture and Identity – Table 3
<http://stats.govt.nz/Census/2006CensusHomePage/QuickStats/quickstats-about-a-subject/culture-and-identify.aspx>, accessed on 22nd March 2011.

This figure shows that 'Māori' are over-represented in 2011 and 2010 notifications compared with Census figures for Māori under 20 and under 5 years of age. In addition, those recorded as having 'European' ethnicity are underrepresented in notifications compared with Census figures for Europeans under 20 and less than 5 years of age. Please note that MELAA and Asia groups are particularly small samples.

All but five of the 2011 notifications contained one or more ethnicity codes. Of those with one or more codes, 92% of respondents' selected one code for their child's ethnicity, while 8% selected two codes.

Unilateral hearing losses

Unilateral hearing losses were not included in the DND before 2006, although a number of these cases were notified to the database each year.

Unilateral hearing losses are now known to have significant effects on educational performance and a significant proportion of these hearing losses progress over time¹⁸. As a result, cases of unilateral loss where these losses are greater than 26dBHL in the hearing impaired ear have been included in the DND since its re-launch in 2010.

Comparisons with previous DND data (prior to 2005) are problematic, as unilateral hearing losses were not within the original criteria for the database and therefore were likely to be under-reported.

Last year's notifications (2010) showed that exactly one third of the notifications included within the main analysis were unilateral hearing losses; this year this figure has dropped to 26%. Differences between the proportions of unilateral notifications in each severity category are shown in Figure 6, below. Please note small sample sizes for MELAA and Asian groups. As they were last year, rates of bilateral hearing losses are higher for Māori than for European children.

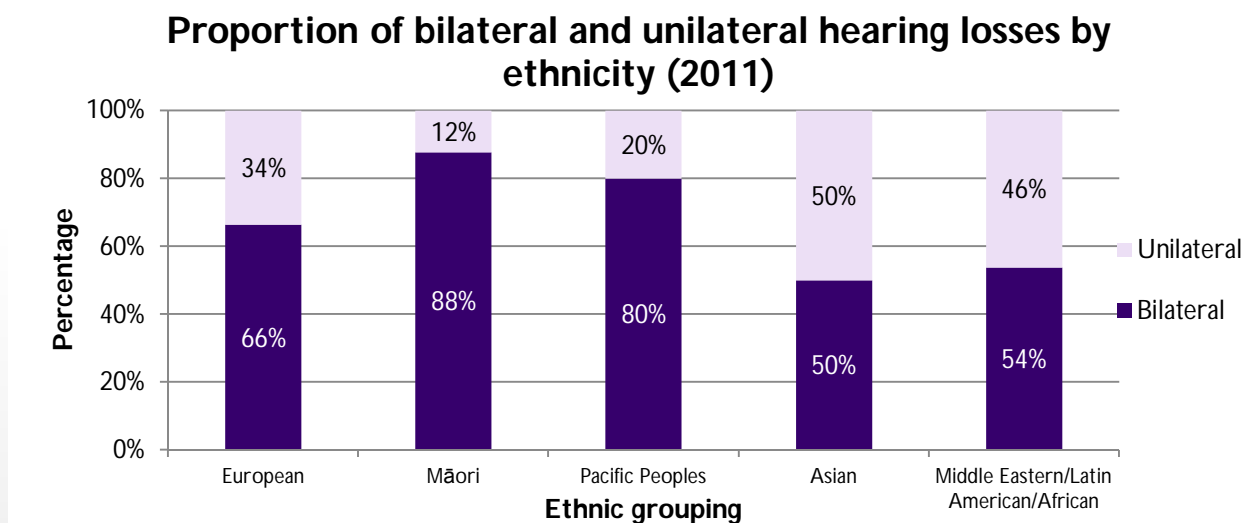


FIGURE 4: UNILATERAL AND BILATERAL LOSSES BY ETHNICITY (2011)

Some professionals are curious about whether New Zealand rates of unilateral loss could be reduced if immunization rates for conditions such as mumps could be increased.

¹⁸ Yoshinago-Itano C (2010) Personal Communication, J Digby, 7/4/2010.

Severity

Audiometric data

Audiometric data was requested for both right and left ears. Audiologists notifying cases to the database were asked to provide air conduction thresholds from the pure tone audiogram. In cases where the young age of the child meant the audiologist was unable to obtain audiometric data, audiologists were asked to estimate thresholds from the ABR using correction factors of 5, 5, 0, and -5dB for 0.5, 1.0, 2.0 and 4.0kHz respectively as contained in Appendix F Diagnostic and Amplification Protocols within the National Screening Unit (2009) Universal Newborn Hearing Screening and Early Intervention Programme National Policy and Quality Standards.

Examining the four data points for each ear shows that this data was provided for 149 and 155 of the 187 cases notified to the database, for right and left ears respectively. This proportion is not ideal, and notifying audiologists are being encouraged to provide more complete audiometric data for cases being notified. Only cases where all 8 audiometric data points are present are now being included for severity calculations.

Where a significant air bone gap was present, bone conduction thresholds at the appropriate frequencies were also collected and correction factors of -5 for 0.5 and 2.0kHz were given to audiologists on the online notification form¹⁹.

77% of cases notified contained data taken from the behavioural pure tone audiogram, with the remaining 20% based on the ABR. This figure is an indication that children being assessed are in large part old enough to have their hearing assessed behaviourally. We would hope to see this figure drop in future years as newborn hearing screening programme coverage rates increase and hearing loss is diagnosed at younger ages.

Audiometric data ...	taken from the pure-tone audiogram	based on the ABR
2010	79%	21%
2011	77%	23%

TABLE 4: AUDIOMETRIC DATA SOURCE (2010 AND 2011)

Classifications

A large number of classification systems are used to categorise hearing loss severity, locally and in overseas jurisdictions. These differing systems make it difficult for meaningful direct longitudinal and geographical comparisons of the proportion of children in a particular severity category.

There does not seem to be a clear standard developing internationally for classifying hearing loss, or a consistent definition for where a hearing loss begins for the purposes of epidemiological comparison. In addition these systems, by and large, do not acknowledge any differences which may exist between the way hearing losses in children, young people and adults might best be categorised i.e. there is one system of classification for all groups.

¹⁹ Correction factors for ABR and bone conduction were provided within the online notification form. These are from National Screening Unit (2009) Universal Newborn Hearing Screening and Early Intervention Programme National Policy and Quality Standards Appendix F Diagnostic and Amplification Protocols June 2010 and were accessed from <http://www.nsu.govt.nz/health-professionals/2940.asp> on the 22nd of March 2011.

While the New Zealand Deafness Notification Database (DND) collected some audiometric data for a number of years until the end of 2005, this did not allow comparisons to be made easily with data from overseas. The newly re-launched database requests full audiometric data from audiologists notifying cases in the hope that more meaningful comparisons can now be made with overseas data.

Table 5 shows some of the differences between local and overseas severity classifications. (These systems use an average of the pure-tone thresholds at 0.5kHz, 1kHz, 2kHz and 4.0kHz.) Please note that audiologists in New Zealand are commonly using Clark's 1981 (ASHA) classifications within their clinical practice.

	1996-2005 NZ DND	1982-1996 NZ DND	Clark 1981 (ASHA website) ²⁰	Jerger and Jerger (ASHA website) ²¹	World Health Organisation ²²	CDC ²³
Normal			-10-15dBHL		≤25dBHL	
Slight			16-25dBHL	0-20dBHL	26-40dBHL	
Mild	26-40dBHL	30-55dBHL	26-40dBHL	20-40dBHL		21-40dBHL
Moderate	41-65dBHL		41-55dBHL	40-60dBHL	41-60dBHL	41-70dBHL
Moderately Severe		56-85dBHL	56-70dBHL			
Severe	66-95dBHL		71-90dBHL	60-80dBHL	61-80dBHL	71-90dBHL
Profound	>95dBHL	≥86dBHL	≥91dBHL	≥81dBHL	≥81dBHL	≥91dBHL

TABLE 5: COMPARISON OF AUDIOMETRIC SEVERITY CLASSIFICATION SYSTEMS

Calculating severity for notifications

As the previous database did not keep records of exactly how the analysis was conducted, it may not be possible to exactly replicate the inclusions made to calculate these figures. For example, we are unsure whether some or all database analysis prior to 2005 excluded cases which did not contain all eight audiometric data-points.

Table 6 shows the severity of hearing loss calculated in two ways, firstly using the better ear (which will be used from this report onwards), secondly using the worse ear. Data for the worse ear is shown for bilateral and unilateral hearing losses. As a result unilateral hearing losses are not included with bilateral hearing losses within severity analyses in this report. From this year, only cases containing all eight audiometric data-points are included for severity calculations.

Severity within recent notifications

Calculations in Table 6, and other charts and figures below, are based only on cases with all eight audiometric data-points completed within the notification. This analysis categorises severity based on the ASHA Clark codeframe in common use by New Zealand audiologists. Sample sizes on the bottom

²⁰ Clark JG, (1981) Uses and abuses of hearing loss classification. ASHA, 23, 493–500.

²¹ ASHA (2010) Information Series- Hearing Loss Types from <http://www.asha.org/uploadedFiles/aud/InfoSeriesHearingLossTypes.pdf>, accessed on 1st February 2011.

²² WHO Prevention of blindness and deafness – grades of impairment from http://www.who.int/pbd/deafness/hearing_impairment_grades/en/index.html accessed on 1st February 2011.

²³ CDC-EHDI Hearing Screening and Follow-up Survey (HSFS): 2006 Explanations (Version B) accessed on 21st March 2011 from http://www.cdc.gov/ncbddd/hearingloss/2006-data/2006_HSFS_Explanations_B.pdf

row of Table 6 below reflect this. Please note that these severity data in Table 6 are not comparable to those reported in Table 7 as the severity codeframes differ.

Degree of loss using ASHA	Categories are based on...					
	Better ear		Worse ear		Worse ear	
	Bilateral 2010	Bilateral 2011	Bilateral 2010	Bilateral 2011	Unilateral 2010	Unilateral 2011
mild	56%	61%	45%	49%	54%	43%
moderate	25%	21%	27%	25%	19%	14%
moderately severe	12%	9%	15%	11%	11%	25%
severe	2%	3%	6%	5%	6%	5%
profound	5%	7%	7%	11%	11%	14%

TABLE 6: COMPARISON OF SEVERITY CLASSIFICATIONS BASED ON METHODOLOGY

Figure 5 below, compares 2010 and 2011 data for bilateral hearing losses graphically, again using the ASHA Clark codeframe in common use by New Zealand audiologists. These data are categorised based on audiometric data from the better ear. Those children and young people born both in New Zealand and overseas are included, but only those with complete audiometric data.

Bilateral hearing losses by degree (2010 and 2011)

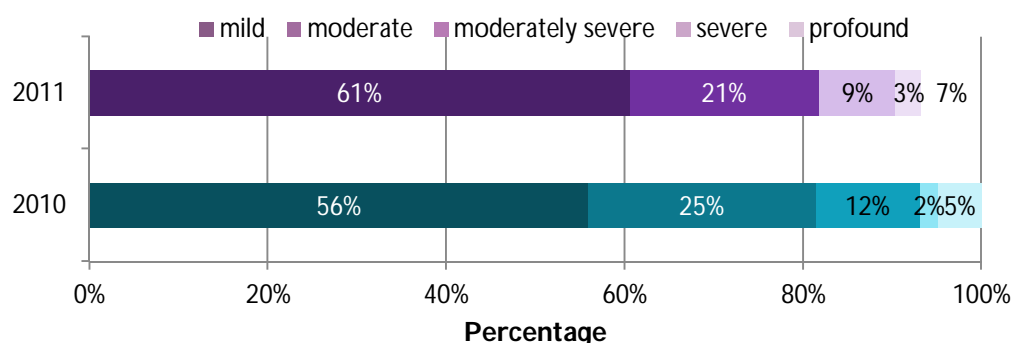


FIGURE 5: PROPORTION OF BILATERAL HEARING LOSSES BY SEVERITY GROUPING (2011)

Figure 5 below, compares 2010 and 2011 data for unilateral hearing losses graphically, again using the ASHA Clark codeframe in common use by New Zealand audiologists. Those children and young people born both in New Zealand and overseas are included, but only those with complete audiometric data.

Unilateral hearing losses by degree (2010 and 2011)

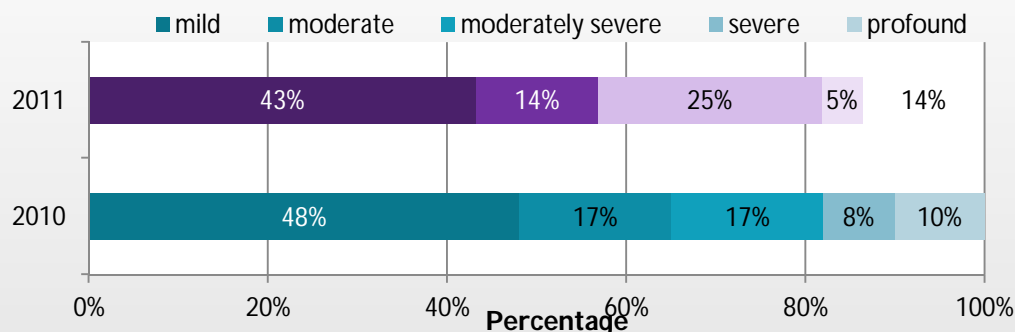


FIGURE 6: UNILATERAL HEARING LOSSES BY SEVERITY (2010 AND 2011)

Comparisons with previous data

By categorising the notifications using the severity codeframe used by the DND from 1996-2005, a longitudinal comparison of the proportion of children in each group is possible using data reported between 1996 and 2005. Table 7, below, shows the proportion of hearing loss notifications in each category in 2010 and 2011 and compares this with data from 2001-2004²⁴. 2010 and 2011 figures shown here exclude those children born overseas, unilateral hearing losses and those with acquired hearing losses as reports prior to 2005 excluded these cases.

Last year we found that the severity profile for cases seemed to be different from previous years – we noted that we would be watching 2011 data closely to see whether the severity profile returned to a pattern which more closely matched those seen before 2005.

This year, the authors of this report have altered the way we calculated severity, to more closely match the way this was calculated in 2005 and previous years and to tighten up on which cases are included within this analysis.

Table 7 compares proportions by severity with previous DND data. As this data contains only those cases with bilateral hearing loss, it cannot be compared with figures reported in the 2010 report.

Proportion of cases notified by degree of hearing loss	2001	2002	2003	2004	Average 2001-2004	2010	2011
Mild	47%	47%	56%	43%	48%	59%	60%
Moderate	35%	39%	33%	34%	35%	33%	28%
Severe	10%	9%	6%	15%	10%	4%	5%
Profound	8%	5%	5%	7%	6%	5%	3%

TABLE 7: NOTIFICATIONS BY DEGREE OF HEARING LOSS USING 1996-2005 CLASSIFICATION SYSTEM, BILATERAL LOSSES ONLY

It is difficult to determine why rates of more severe hearing loss seem to be lower than in previous reports. As noted previously, vaccination programmes have reduced rates of meningitis in New Zealand and this reduction is expected to have led to a reduction in rates of (more severe) hearing loss²⁵. However, the reduction in the number of more severe cases may not be visible in the overall figures as the number of cases each year is small.

²⁴ 2004 data is used as it is unclear from the 2005 report which figures relate to which of the ASHA categories.

²⁵ Turner N, (2011) personal communication to J Digby March 21st 2011.

Breakdowns by ethnicity and degree of loss

The 2005 DND report noted that Māori children notified in 2005 and between 1990 and 2005 were more likely to have a mild hearing loss than other ethnic groupings. This pattern is repeated with 2011 data.

Figure 7 shows the proportion of cases in each of the various degrees of loss which were notified to the database, split by ethnicity grouping. Only bilateral hearing losses are included in this figure as and severity is categorised by the ASHA Clark classification system, and as a result it is not comparable to data reported in 2010.

Please note that the Asian and MELAA categories contain particularly small samples.

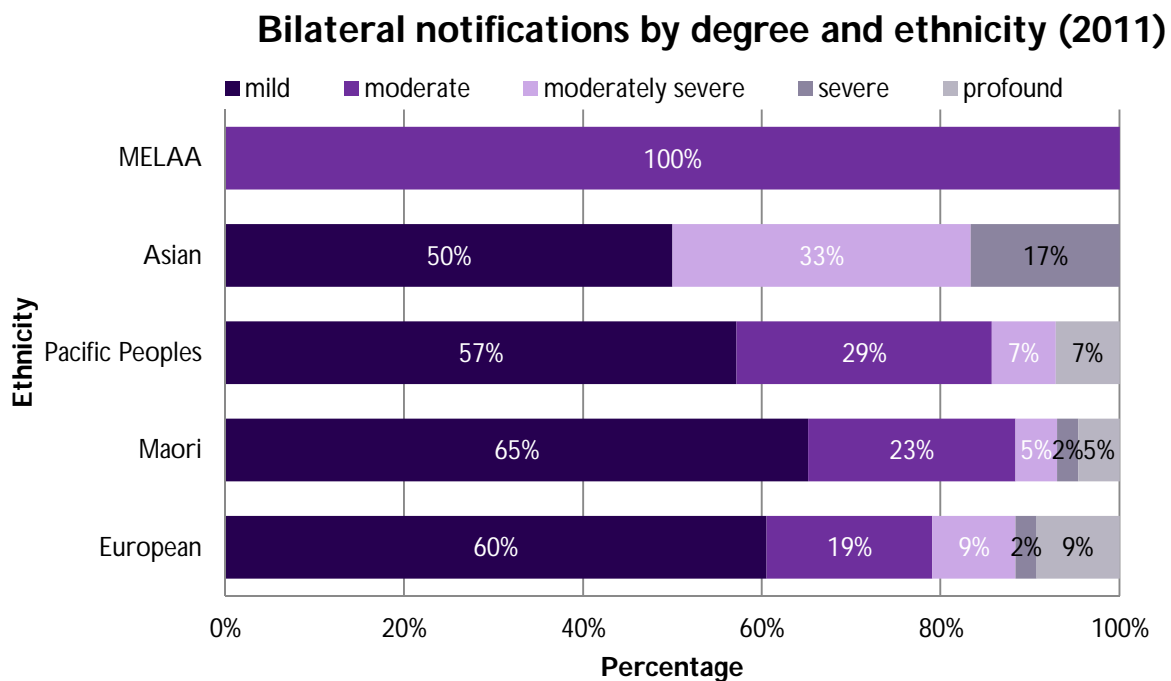


FIGURE 7: 2011 BILATERAL NOTIFICATIONS BY DEGREE AND ETHNICITY

Hearing aids and cochlear implants

Hearing aids

As was the case with 2010 data, the majority of children and young people with a hearing loss which was first diagnosed in 2011 are to be fitted with two hearing aids.

Figure 8 below, shows the number of hearing aids fitted or to be fitted, comparing 2010 and 2011 data when the notification was made. The reduction in the proportion of cases to receive aids may be the result of the lower overall age of children being identified with hearing loss and/or difficulties in accurately diagnosing hearing losses among younger children. The proportion of cases where there is uncertainty around whether hearing aids are to be fitted may also signal this.

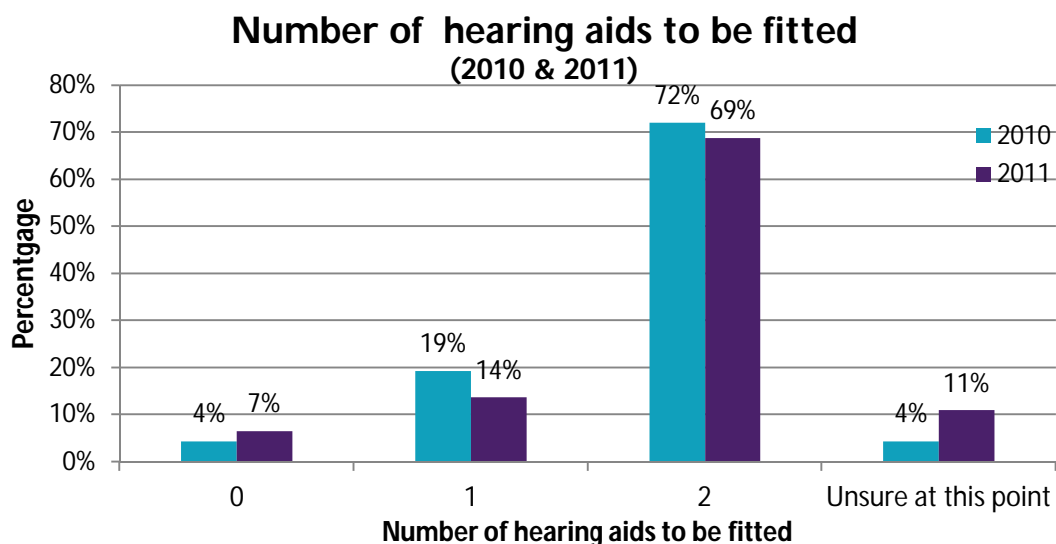


FIGURE 8: NUMBER OF HEARING AIDS TO BE FITTED (2010 AND 2011)

Overall in 2011, children with unilateral hearing losses were less likely to receive one or more hearing aids (74%) than those with bilateral losses (89%).

It is worth noting that some children with unilateral hearing losses were reported to be receiving more than one hearing aid as, although the average threshold for the better ear does not meet the 26dBHL average required for inclusion in the database, one or more hearing thresholds are seen as sufficiently poor to warrant amplification in the better ear. This is indicative of one of the limitations related to classification systems which average hearing thresholds across four frequencies and categorise children into broad severity groups.

For example, in one case reported to the database, the child's hearing loss was profound in the left ear (110+dB at each of the four frequencies 0.5, 1.0, 2.0 and 4.0 kHz). Although the average hearing level over the same four frequencies in the right ear was not enough (26dBHL or greater) to put this child's hearing loss into the bilateral category there was a 40dBHL loss at a single frequency (4.0kHz) in the better ear and so the child was being fitted with two hearing aids.

In such cases unilateral hearing loss indicates asymmetry, but it does not indicate that the child doesn't require help to ensure they can hear in the better ear.

The figure below shows the number of hearing aids to be fitted by severity for 2011 notifications. This shows mild hearing losses are more likely to receive no hearing aids, while severe or profound hearing

losses are more likely to be fitted with one or more hearing aids. Please note: These figures for the proportion of cases receiving aids differ from those in Figure 8 as only those cases where full audiometric data were available are included below.

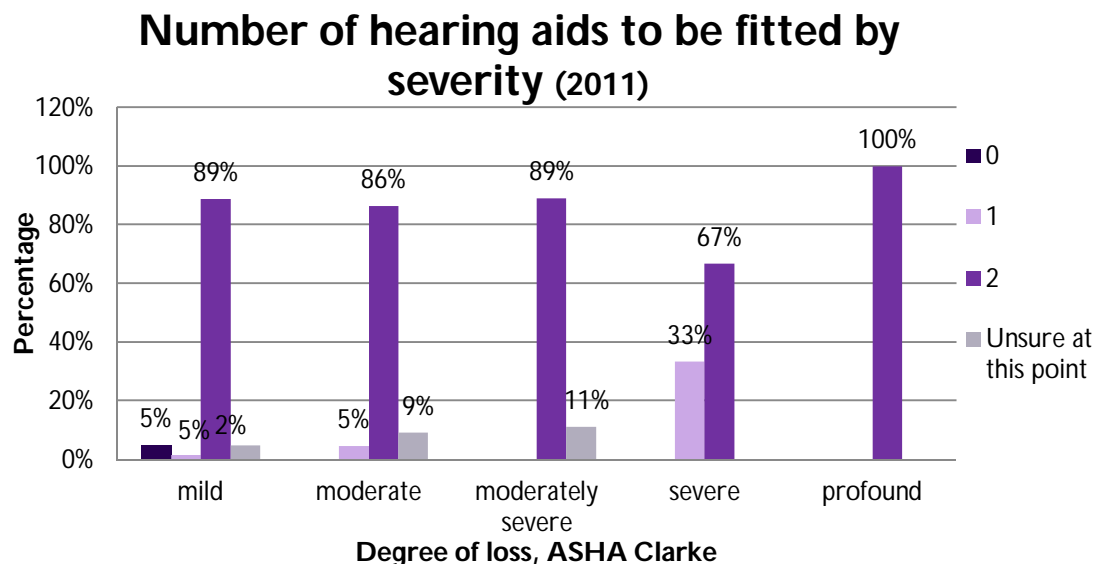


FIGURE 9: NUMBER OF HEARING AIDS TO BE FITTED, BY SEVERITY OF HEARING LOSS (ASHA CLARK SEVERITY CODEFRAME)

In an attempt to provide some context for these figures, data provided by the Ministry of Health which funded hearing aids for children and young people through a contract with Enable NZ until the end of June 2011²⁶ are shown below.

Number of service users	Year ending 30 June 2011
NZ European	720
NZ Māori	460
Pacific Island	208
Other ethnicity	185
Total	1543

TABLE 8: MINISTRY OF HEALTH STATISTICS ON FUNDING OF CHILDREN'S HEARING AIDS BY ETHNICITY FOR FINANCIAL YEAR ENDING 30TH JUNE 2011

Number of service users	Year ending 30 June 2011
Aged 0-5 yrs	358
Aged 6-18	1121
Aged 18+	95
Total	1574

TABLE 9: MINISTRY OF HEALTH STATISTICS ON FUNDING OF CHILDREN'S HEARING AIDS BY NUMBER OF SERVICE USERS FOR FINANCIAL YEAR ENDING 30TH JUNE 2011

²⁶ Ministry of Health Statistics on Children's Hearing Aids 2010-11 Financial Year, provided by Hamlin, S of the Ministry of Health, personal communication to Digby J, April 26th 2012. Wellington

Cochlear Implants

Although we don't presently collect information about cochlear implants in the database, the authors of this report thought it would be useful to provide some information about the number of cochlear implants provided to children and young people in New Zealand, and some background about the funding for these implants.

Cochlear implants are provided to children and young persons through funding from the Ministry of Health. This funding is administered by two cochlear implant trusts. The Northern Cochlear Implant Trust covers the area northwards from a horizontal line extending roughly through Taupo and the Southern Hearing Charitable Trust covers south of this line.

The majority of children receiving cochlear implants have severe or profound hearing losses or have progressive hearing losses which are becoming more severe. Some children have high frequency losses which are severe-profound in the higher frequencies and normal or near normal in the lower frequencies.

During the 2011 calendar year there were 16 cochlear implants provided in the Northern Region and 17 in the Southern Region to children and young people under the age of 19.

Cochlear Implant Trust	Year ending 31 December 2011	Year ending 31 December 2010
Northern Cochlear Implant Trust	16	17
Southern Hearing Charitable Trust	17	18
Total publicly funded new implants in NZ	33	35

TABLE 10: PUBLICLY FUNDED COCHLEAR IMPLANTS IN NZ

During this same period there were 10 cases notified to the database where the child or young person had a bilateral hearing loss which was severe or profound in the better ear. While this may be an indication that the DND is missing some notifications for children within the severe and profound categories, there are a number of other reasons why this figure is low compared with the number of children implanted during the same period.

One reason is that some children who were notified to the database as having less severe hearing losses may develop more significant losses over time, something which is currently not tracked by the database. For example, The Northern Cochlear Implant Programme reports that an increased and significant number of children and young people receiving cochlear implants over the last two years have had progressive hearing losses. In such cases, the hearing losses would have been less severe at the time of initial identification and notification to the database.

Cause of hearing loss

As seen in Figure 10: Proportion of hearing losses of known and unknown cause notified to the DND by year

below, the proportion of hearing losses where the cause was thought to be known has decreased significantly in 2010 and 2011 when compared with earlier figures. At least some of this difference is thought to be the result of changes in the cause information requested, as the DND form has been made more specific.

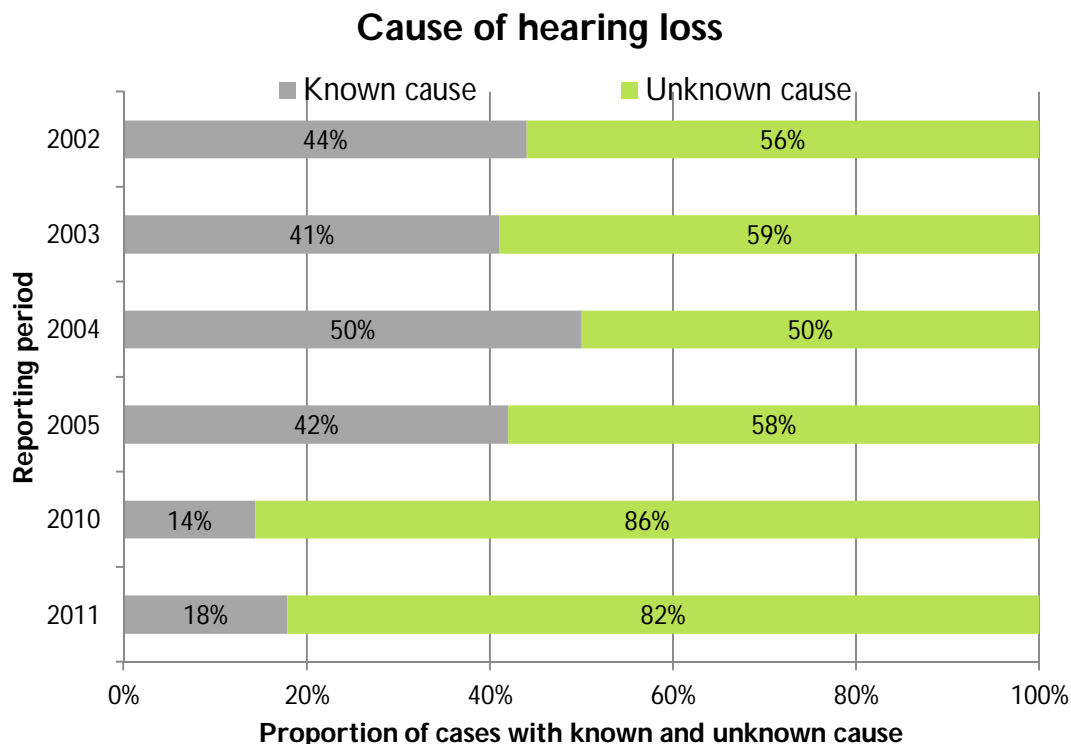


FIGURE 10: PROPORTION OF HEARING LOSSES OF KNOWN AND UNKNOWN CAUSE NOTIFIED TO THE DND BY YEAR

There is a drive among the ENT community in New Zealand to increase the proportion of hearing losses which undergo aetiological investigations such as genetic testing performed and it will be interesting to see whether the proportion of reported hearing losses with a known cause increases over time.

Although practice varies, ENT's generally refer young people/families of children with hearing loss, where there is no clear explanation of the cause of this hearing loss (such as Down Syndrome) for genetic testing. Over time, more genes and more mutations are being added to those for which testing is available. The most common mutations found are in the GJB2 and Pendrin genes. ENT specialists request the tests and counsel patients about the results. If there are multiple or unusual mutations the ENT specialists refer to genetic services²⁷.

²⁷ Brown, C (2012) Policy, Personal communication to Digby J, 23rd January 2012.

Table 11 below shows the breakdown of aetiology where this was known.

Aetiology breakdown	2010 (number of cases)	2011 (number of cases)
Acquired hearing loss	11	16
Other	6	6
Genetic cause (non-syndromic)	3	2
Syndromic	3	4
Not listed	2	5

TABLE 11: NUMBER OF CASES OF KNOWN AETIOLOGY BY TYPE (2010)

Of the cases of hearing loss diagnosed in 2011 and notified to the database, four cases were listed as being the result of meningitis. This compares to 5 in 2010.

Cases recorded as 'other cause' include those with cholesteatoma. One of the cases where genetic cause had been confirmed is GJB2 with another listed as bilateral atresia.

Family History

Deafness Notification Database reports prior to 2005 note a relatively high proportion of cases were recorded as having 'family history' as the cause of the hearing loss. (Family history was reported as the cause of the hearing loss in 24-32% of cases between 2001 and 2005.)

Changes have been made to this question to try and gain more specific responses about the nature of the family history.

Of the 27% of 2011 cases where a family history was specified, half of these cases related to extended (non-direct) relatives.

Of the cases where the family member or members with hearing loss include the child/young person's sibling(s) and/or parent(s) and/or grandparent(s):

- Families were asked to tell the audiologist whether the relative still had the hearing loss to get some kind of indication as to whether the hearing loss may be/have been permanent. In 95% of cases the family of the notified child or young person confirmed that the hearing loss was still present, while the family were unsure whether this loss was still present in 2% of cases. This leaves the remaining 4% of cases where the relative no longer had the hearing loss²⁸.
- The majority of these family members use/used one or more hearing aid or cochlear implant (57%), while 23% did not and in the remainder of cases there was uncertainty regarding whether the relative used such a device
- The majority of these close relatives (70%) had their hearing loss from childhood while 13% did not, and the families were unsure in 18% of cases

Is there a family history of hearing loss?
2011

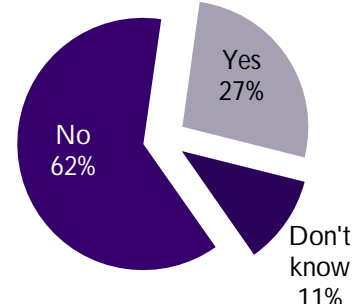


FIGURE 11: INITIAL FAMILY HISTORY (2011, ALL CASES)

²⁸ These figures are rounded and hence do not total 100%

Identification of hearing losses

Who first suspected the hearing loss?

Information on who first suspected the child or young person's hearing loss was recorded for 149 of the 167 children and young people known to have been born in NZ and who were diagnosed in 2011.

Among 2011 notifications, parents or caregivers were the most likely to first suspect the hearing loss, followed by medical professionals and Vision Hearing Technicians (VHTs). Previous DND reports also observed that parents were most likely to suspect a child's hearing loss in 34% and 52% of cases notified to the database between 2000 and 2005.

2010	2011
Parent or caregiver (49%)	Parent or caregiver (42%)
Vision Hearing Technician (22%)	Medical Professional (21%)
Medical Professional (12%)	Vision Hearing Technician (15%)

TABLE 12: THREE GROUPS MOST LIKELY TO DETECT A HEARING LOSS BY YEAR OF NOTIFICATION

Further information about those first suspecting the child's hearing loss is contained in Figure 12, below. Although 27% of notifications were a direct result of referral from newborn hearing screening, the newborn hearing screener is only listed in 9% of cases as the person first suspecting the loss. Further information has been added to the notification form to ensure audiologists are clear how to code the answer to this question should the child have been identified through newborn hearing screening.

Who first suspected the child's hearing loss? (2011)

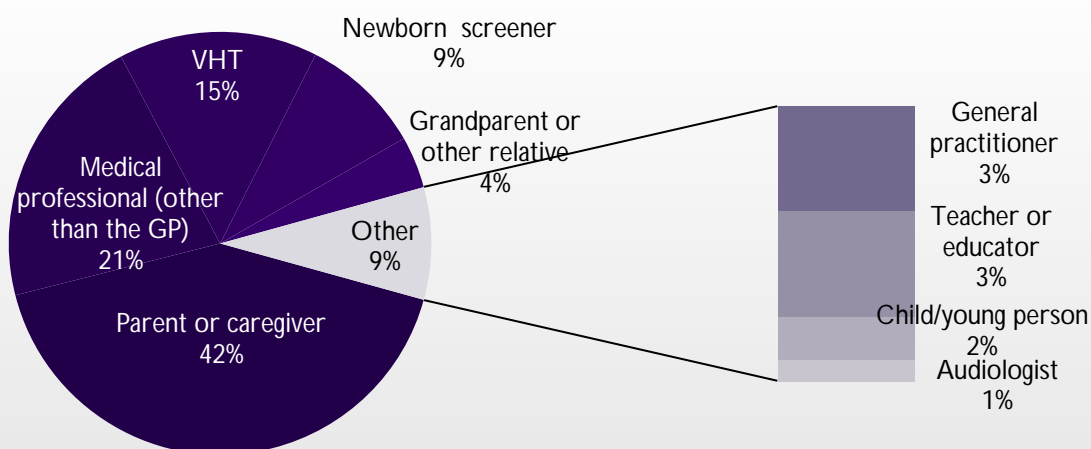


FIGURE 12: FIRST SUSPICION OF HEARING LOSS FOR CHILDREN BORN IN NZ (2011)

Age at identification

Figure 13 shows the number of cases identified by the age of the child. Please note that these ages are rounded to the nearest year, and as a result there is one 18 year old whose age was rounded up to 19 years of age.

There is a notable peak in the number of notifications during the first year of life this is likely to be due to identification as a result of the universal newborn hearing screening programme. This peak is more pronounced in 2011 than in 2010, presumably due to increasing coverage of this programme.

A further peak can be seen for five year olds which is likely to correspond to the B4 School Check. Children should have their hearing screened at four years of age under this programme, and those who do not should be screened at five years of age.

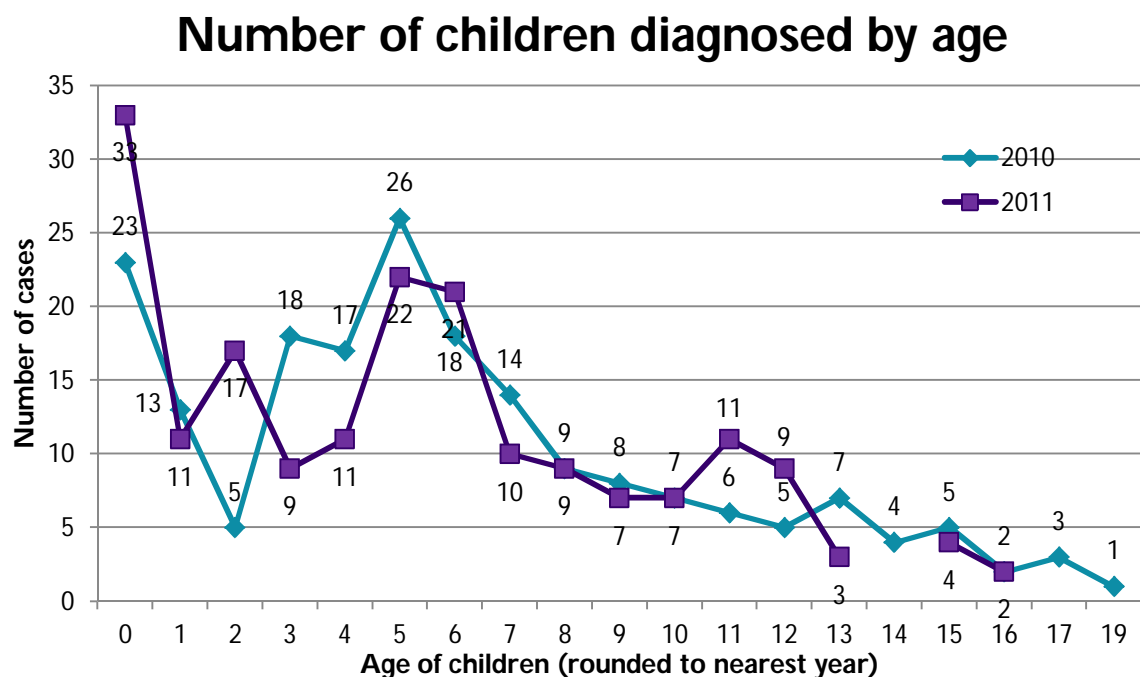


FIGURE 13: NUMBER OF CHILDREN DIAGNOSED BY AGE (2010 AND 2011)

Issues with using a single measure for 'age at identification'

There are a number of issues with reporting the average age at identification (diagnosis) for all groups of children. While this may be somewhat useful as it describes the average age at which providers will begin working with children to provide interventions of some type, the average relates to all newly diagnosed children as it is not possible to separate out children with hearing losses which are late onset (such as progressives and acquired hearing losses).

Average overall age at identification

Keeping this in mind, the average age at diagnosis of children with all degrees of hearing loss, including those with acquired hearing losses and those born overseas is 57 months, compared with 68 months for 2010. It is important to remember this average age includes all children diagnosed in the

notification period for whom specific confirmation age data was available²⁹, including those born before newborn hearing screening was implemented and those with acquired or progressive hearing losses.

For the purpose of comparison with previous data, the average age at diagnosis is presented, but this average age has also been split by further subgroups to add meaning to this measure. A number of groups are having their hearing losses identified later, including those with:

- acquired hearing losses e.g. late onset, progressive and trauma related (73 month average) compared with those not thought to be acquired (56 month average) and those with hearing loss suspected to have been present at birth (26 month average)
- born overseas (107 months on average)
- mild and moderate hearing losses (81 and 71 months respectively)

Age at diagnosis by severity of hearing loss

Table 13 shows the average age at diagnosis (confirmation of hearing loss) for children and young people with bilateral hearing loss in each of the ASHA severity categories. As expected, mild and moderate hearing losses are identified later than more severe losses.

Degree of hearing loss (ASHA, Clark, classification system)	Average months at diagnosis (2011)
Mild	81
Moderate	71
Moderately severe	43
Severe	48
Profound	39

TABLE 13: DEGREE OF HEARING LOSS BY AVERAGE AGE AT DIAGNOSIS (2010)

Figure 14 shows the spread of age at diagnosis by severity for those children born in New Zealand. The greatest variability in the age at diagnosis is for mild and moderate hearing losses, although there are a number of very late diagnoses for children and young people with profound loss, including two cases of bilateral hearing loss. Please note that the severe group contains a very small sample.

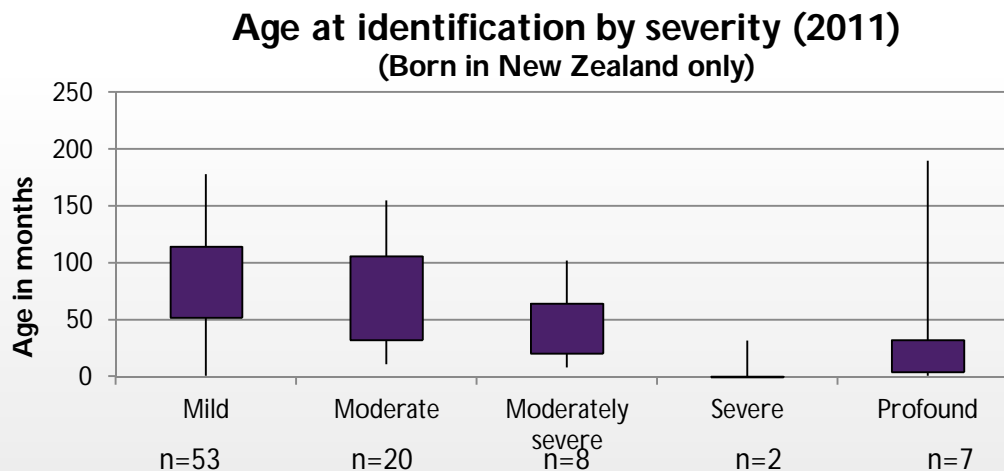


FIGURE 14: AGE AT CONFIRMATION BY DEGREE OF HEARING LOSS 2011

²⁹ Confirmation age data is now being requested as a date of diagnosis, rather than an age at diagnosis to improve the quality of this data. This information is also being requested at the same time as suspicion age, to emphasise the differences between these two pieces of information.

Age at diagnosis and ethnicity

Figure 15: Average age at diagnosis by ethnicity (2011) Figure 15 shows the spread of ages of identification by ethnic group for those children and young people born in New Zealand and diagnosed in 2011. No MELAA group data is contained in this graph as there are no cases of MELAA children or young people born in NZ for whom full audiometric data was provided.

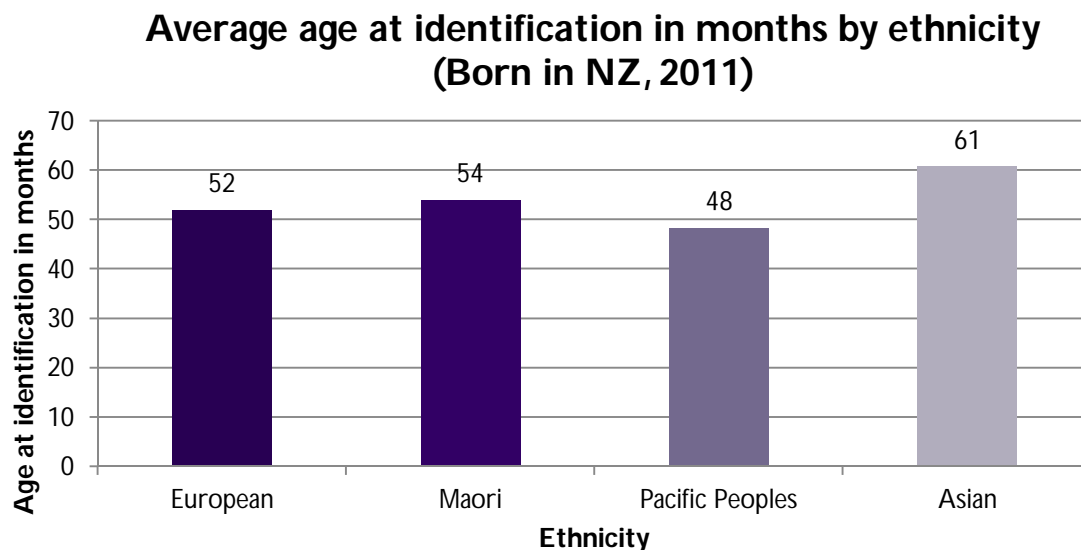


FIGURE 15: AVERAGE AGE AT DIAGNOSIS BY ETHNICITY (2011)

A number of previous DND reports (1995-2005) noted that Māori and/or Pacific children were identified later than European children although this difference was not reported in every DND report³⁰.

2011 data shows a wider range in ages of identification for Māori than in 2010. It will be interesting to see whether more detailed analyses of the 2011 data show a difference between average ages of notification by ethnicity and whether Māori are found to have a greater proportion of milder hearing losses and/or less unilateral losses than other groups.

Longitudinal comparison

Figure 16 on page 33 shows a longitudinal comparison of the suspicion and confirmation ages for children notified by calendar year. In an attempt to replicate the analysis completed before 2006, this figure excludes 2010 cases where the hearing loss is unilateral, acquired or mild and those where the children are born overseas. The reader will note removal of these cases significantly reduces the average age at identification. Please note, no data are provided for 2006-2009 as the DND was not operating during this period.

³⁰ For example, the 1997 DND report noted a similar age of identification between Māori and non-Māori while the 2002 – 2004 reports noted a difference with European children being identified on average, earlier than Maori and Pacific children.

Suspicion and confirmation of hearing losses (excluding cases of unilateral hearing loss, those born overseas, acquired and mild hearing losses)

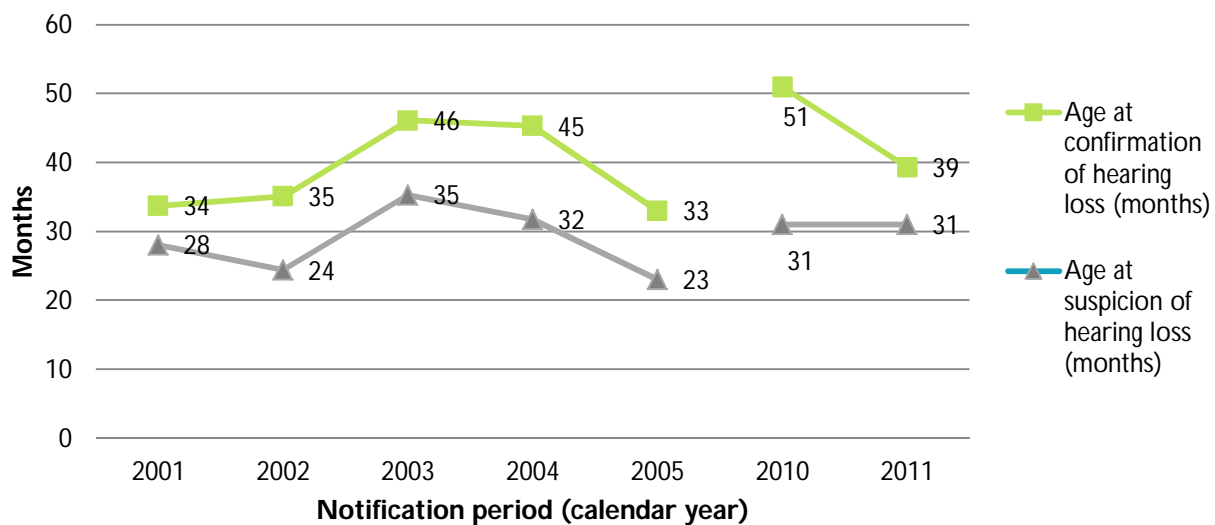


FIGURE 16: SUSPICION AND CONFIRMATION OF HEARING LOSSES - COMPARISON WITH PREVIOUS DATA (EXCLUDING APPROPRIATE CASES)

Newborn hearing screening

Implementation of New Zealand's Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP) began in 2007 and the last eight district health boards to be included within the roll-out³¹ began screening between July 2009 and July 2010. It is worth noting that the large Auckland DHBs (Counties Manukau, Waitakere and Auckland) had all begun their screening programmes by April 2010.

As a result, for the first time all district health boards were screening babies for the full 2011 calendar year and therefore the full notification period. Data in this section of the report relate only to those children born in New Zealand.

Screening status

Table 14 shows the screening status of children notified in 2010 and 2011, with the exception of those born overseas. As expected, the proportion of children being diagnosed as a result of a referral from the UNHSEIP is increasing, and the proportion of notifications not offered screening is falling. Please note that this table shows children diagnosed at varying ages, and hence it includes children who were born before the UNHSEIP was fully rolled out.

³¹ Northland, Waitemata, Auckland, Counties Manukau, Wairarapa, Nelson/Marlborough, Southern and West Coast

Was universal newborn hearing screening (using aABR or aOAE) offered to this family after this child or young person's birth?		2010	2011
No	No, a screening programme was not in place, but the child was directly referred to audiology due to atresia	3%	4%
	No, this service was not available at the time (at the time of diagnosis)	69%	54%
Unsure	Unsure whether screening was offered to this family	7%	4%
Yes	Yes screening was offered but this child was not screened...	1%	1%
	Yes, the child was screened and referred but follow-up did not occur at the time, and so this is a delayed diagnosis	0%	4%
	Yes, this child was screened and passed	1%	7%
	Yes, this diagnosis is a result of a refer on the screening test	19%	27%

TABLE 14: SCREENING STATUS OF CHILDREN BORN IN NEW ZEALAND, 2010 AND 2011

Of particular interest are the six children who referred from their newborn hearing screening but for whom follow-up did not occur at the time and those who were screened and passed this screening.

Please note, the children notified in 2010 and 2011 ranged in ages. 54% of cases (89) notified for 2011 were not screened as no service was available in their area at the time of their birth. Fifteen of these cases were for children under the age of four at the time of diagnosis i.e. were born after the start of implementation for the UNSHEIP but not offered screening.

Referrals from the UNHSEIP

Overseas, a number of comparable newborn hearing screening programmes (such as those in the UK and Australia) seem to be converging at a birth prevalence of approximately 1.10 per thousand for bilateral hearing losses, and approximately an additional 0.5 per thousand unilateral hearing losses. This suggests that if and when the UNHSEIP achieves high coverage and low loss to follow up we may expect up to 90 diagnoses directly from the programme each year, based on 62,000 births per annum³².

A total of 44 of the 2011 notifications related to children born in New Zealand who were diagnosed as a direct result of newborn hearing screening. It is encouraging to see in Table 15 an increase in the number of diagnoses made as a result of UNHS in 2011 although the number of diagnoses made as a result is still small.

It is not known how many cases of hearing loss are currently missed as these children were either not screened by the UNHSEIP or are being lost to follow-up.

	2010	2011
Number of diagnoses resulting from universal newborn hearing screening	28	44
...As a proportion of total notifications	16%	24%

TABLE 15: DIAGNOSES RESULTING FROM NEWBORN HEARING SCREENING

While some programme staff are again reporting the number of diagnoses resulting from newborn hearing screening is smaller than they expected, very little can be inferred from 2010 and 2011 notification data, primarily as the:

- completeness of the DNDs dataset is not known;
- prevalence of permanent congenital hearing impairment been estimated; and as
- the number of babies completing screening, particularly within some DHBs is still relatively small and the number of diagnoses may be 'lumpy' as a result.

³² This is an approximation of the number of births reported in 2010.

The latest National Screening Unit monitoring report covering data from October 2010 to March 2011 reports that:

- Approximately 86% of babies born across the country during this period completed their newborn hearing screening;
- Of the 223 babies referred from screening, audiological data was complete for 47% of these; and
- 16 babies were recorded as identified as having 'auditory neuropathy' or 'sensorineural' hearing loss in at least one ear³³.

Key screening goals – age at diagnosis

The UNHSEIP was implemented in New Zealand to reduce the age of intervention for children born with hearing loss, as this approach has been successful overseas in improving outcomes. Screening programmes achieve this by significantly reducing the age at diagnosis for hearing losses present at birth compared with approaches reliant on risk factors. Key aims of newborn screening programmes include the screening of children by one month of age, diagnosis of hearing loss by three months and the start of intervention by six months of age. These are known as the 1-3-6 goals, and are commonly used in newborn hearing screening programmes internationally.

Measuring the proportion of children with hearing losses identified before the benchmark of three months of age as a result of a referral from newborn hearing screening will be an important measure of the success of the newborn hearing screening in future. The authors of the Deafness Notification Database hope to provide useful data to show how the overall age at identification changes over time.

There has been an overall reduction in the average age at diagnosis of these cases, from 10 months in 2010 to 8 months in 2011.

39 babies born in from 2009 to 2011 were reported to the database as being diagnosed in 2011 as a direct referral from newborn hearing screening. Of these 23 (59%) were diagnosed by the recommended three months of age.

Of the 9 children diagnosed after 6 months of age, two were reported to have other known disabilities. This can make diagnosis more challenging for the audiologist, and in some cases identification of hearing loss may be a lower priority when compared with other more urgent health conditions.

Again, of the 9 children diagnosed after 6 months of age, one or more reasons for the delay were reported in 7 cases:

- audiologist having difficulties getting a confirmed diagnoses (n=4)
- waiting time to see a hearing professional (n=3)
- parents not attending appointments (n=1)

Identification of false negatives

The Deafness Notification Database provides probably the only method for identifying potential false negatives from the newborn hearing screening programme.

11 of the children identified during 2011 had been screened previously and passed this screening. This is not in itself a concern as many children develop hearing losses after birth, approximately half of all

³³ Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP) Monitoring Report on Newborn Hearing Screening Service Provision October 2010 – March 2011 (2012) National Screening Unit, Auckland.

cases of hearing loss. This number is understandably higher than last year, as a greater proportion of those identified with a hearing loss will have been screened as babies.

When those with an acquired hearing loss are removed from this group, the eleven cases identified drops to 9. Four of these cases were not thought to have been present at birth - a rough indicator as we cannot know whether the hearing loss was indeed present while in another four cases the notifying audiologist was unsure as to whether the hearing loss was present at birth. One case identified had a hearing loss which was thought to have been present at birth, and where the hearing loss was not acquired. This is the most likely false negative case.

	2010	2011
Total cases identified by year who were screened previously (i.e. are not referrals from the UNHSEIP) and who passed this screening	3	11
Number of potential false negatives from regional screening programmes or from the UNHSEIP (cases where the losses are not acquired and the loss may have been present at birth)	3	5

TABLE 16: POTENTIAL FALSE NEGATIVES AND CASES PREVIOUSLY REFERRED FROM HEARING SCREENING

Delays in diagnosing hearing loss

The average delay between first suspicion of the hearing loss and confirmation of the loss, for all cases, *including* those born overseas and those with acquired hearing losses, was 20 months. This represents a significant average delay between first suspicion of a hearing loss and confirmation of this loss among children notified to the database.

Comparisons with the length of delay in previous years requires the removal of cases of acquired hearing loss, those born overseas, those with unilateral hearing loss and those with mild hearing losses. When this is completed, the average age drops slightly to 19 months as shown in Table 17, below.

Year	Age in months at confirmation of hearing loss	Delay in months
2011	52	20
2010	50	19
2005	33	10
2004	45	14
2003	46	11
2002	35	11
2001	34	7

TABLE 17: DELAY COMPARISONS WITH PREVIOUS DATA (EXCLUDING ACQUIRED, UNILATERAL, BORN OVERSEAS AND MILD LOSSES)

Some previous notification reports have calculated the proportion of cases with a significant delay of six months or more between first suspicion and confirmation of the hearing loss. As the number of newborns identified with hearing loss grows, and as the goal for identifying these losses is before 3 months of age, applying this six month threshold for determining whether a delay exists no longer seems appropriate.

Delay causes

The notification form also requests information on the reasons for a delay between suspicion of a hearing loss and confirmation of the loss through diagnosis.

In 2011, 49% of notifications contained one or more reasons for the delay in identification of the child or young person's hearing loss. This is similar to the 42% of cases which contained this delay information in 2010. Of the 2011 notifications, 21 had two reasons listed for the delay, while three had two reasons listed. It is a concern that such a high proportion of cases contained delays.

The most frequently mentioned cause of delay relating to children and young people identified in 2011 related to difficulties the audiologist had getting a confirmed diagnosis. This figure rose significantly from 2010, perhaps due to the audiological challenge presented by the growing number of younger children being seen by audiology as a result of implementation of the UNHSEIP.

Worryingly, six children referred from newborn hearing screening were diagnosed late (in 2011) as they never received an audiological assessment following referral from newborn hearing screening.

Reasons for delay	Number of cases where option selected 2010	Number of cases where option selected 2011
Audiologist had difficulties getting a confirmed diagnosis (e.g. child unwell)	28	37
Parents did not attend appointments (for any reason)	12	18
Difficulty getting a referral to audiology (e.g. GP or other health professional dismissed parent concern and no referral was made)	8	13
Waiting time to see hearing professional (e.g. DHB waiting lists to see audiologist, no audiology staff at the DHB, limited staff resource)	11	26

TABLE 18: REASONS FOR DELAY BETWEEN SUSPICION AND CONFIRMATION OF HEARING LOSS 2010 AND 2011

Further information regarding causes of delays

There were a number of themes underlying comments made about the cause of delays, including those grouped by the categories in Table 18 above:

Audiologists having difficulties getting a confirmed diagnosis:

- *"Referred in November, 2011. Took several appointments to confirm results."*
- *"Possible auditory neuropathy or progressive loss but hearing loss suspected since very young and audiology assessment were either not performed competently or inconclusive results obtained."*
- *"Hearing loss suspected but audiologist did not complete assessment using NZAS preferred practice guidelines and hearing loss was not diagnosed until re-referred by VHT."*
- *"ABR also away for calibration and returned to us damaged."*

Problems relating to systems such as lost referrals and issues with calling families back for annual reviews were also mentioned a number of times as the reason for delays:

- *"Following concussion, received CT scan at hospital, but despite complaining of hearing loss then, received no audiology nor was he referred. Parents came to private clinic around two years later as hearing has not improved."*
- *"Past medical records suggest that the referral from one ENT to another appeared to have been lost in the system in 2010 - was initially referred to [our hospital] in May 2010 but was re-referred in Dec 2010."*
- *"I think [she] has a progressive hearing loss similar to her Father's. It appears to have started sometime in 2009. Previously she had been seen for hearing tests up until 2004 which showed*

normal hearing. Annual follow-up did not take place for some reason, so [she] was only seen when she and her mother really began to notice her hearing loss."

- *"Audiology [appointment] requested following grommets but [appointment] was not made. Lost in system."*

In a number of cases, the reasons for the delay were complex, indicating issues with staffing in the public sector and contact with a number of professionals which did not confirm a diagnosis:

- *"No audiologist at hospital. Audiometrist tested child and did not believe she had a hearing loss. Tested at another private practice by an audiologist but ENT did not believe findings. Referred to me for a 2nd opinion. Passed B4 school check. Difficulties put down to dyslexia."*
- *"Hearing loss first detected at private clinic, public visit was organised but parents did not attend as they did not think they could afford hearing aids based on quote given at private clinic."*

Other reasons for the delay included:

- *Issues attributed to language delay, developmental delay, naughty child, selective hearing*
- *Families either having moved to New Zealand from another country with poorer services, and families moving between DHB areas in New Zealand*

Appendix A: High frequency hearing losses

Based on feedback from the audiological community, high frequency hearing losses which would not meet the original criteria were collected as a trial from July 2011.

Unfortunately, only received eight completed notifications were provided from this time until the end of 2011.

As these cases are not included in the main analyses within this document, below is a limited analysis of data from high frequency hearing losses notified in 2011.

Other characteristics of this group of children/young people included:

- Of these cases five were reported as being of Māori ethnicity, two as European and one as Asian
- Years of birth ranged from 1995 to 2009, with an average of 2003
- All but two of these children and young people were to receive one or two hearing aids
- In three of the eight cases the audiologist reported delays were at least in part due to the audiologist having difficulties getting a confirmed diagnosis (e.g. conductive overlay, child unwell)

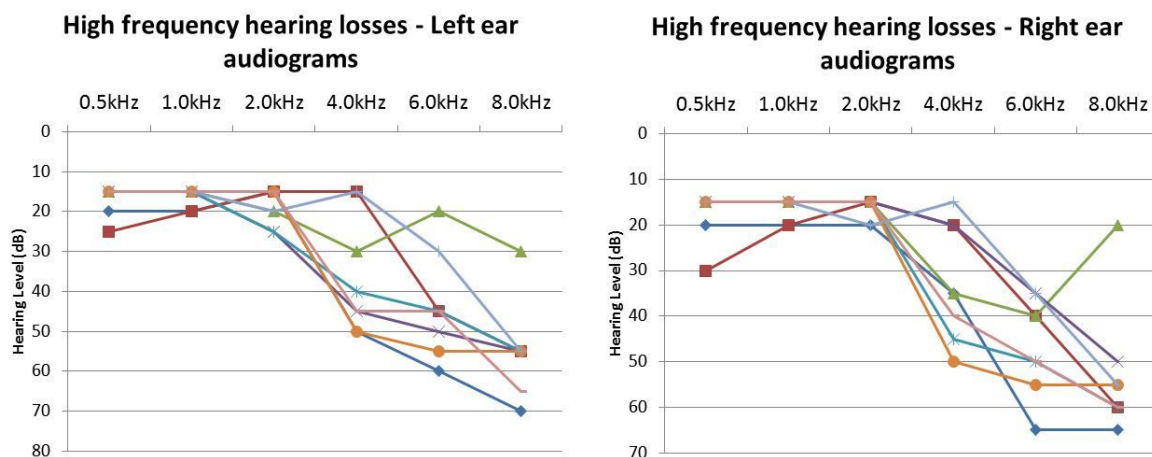


FIGURE 17: 2011 AUDIOGRAM DATA FROM HIGH FREQUENCY HEARING LOSSES FOR RIGHT AND LEFT EARS

While we will continue to trial inclusion of this special group within the database during 2012, if a greater number of notifications are not received during the 2012 period, we will discontinue collection of notifications from this category.

Tables and Figures

Table 1: Percentage of notifications (2011) compared with percentage of population under 20 years of age by district health board	12
Table 2: Proportion of cases with a known additional disability	13
Table 3: Rates of referral from B4 School Check, Searchfield, Bae and Crisp (2011).....	15
Table 4: Audiometric data source (2010 and 2011).....	18
Table 5: Comparison of audiometric severity classification systems.....	19
Table 6: Comparison of severity classifications based on methodology.....	20
Table 7: Notifications by degree of hearing loss using 1996-2005 classification system, Bilateral losses only	21
Table 8: Ministry of Health Statistics on Funding of Children's Hearing Aids by Ethnicity For Financial Year ending 30th June 2011	24
Table 9: Ministry of Health Statistics on Funding of Children's Hearing Aids by Number of Service Users For Financial Year ending 30th June 2011	24
Table 10: Publicly funded Cochlear implants in NZ	25
Table 11: Number of cases of known aetiology by type (2010).....	27
Table 12: Three groups most likely to detect a hearing loss by year of notification	29
Table 13: Degree of hearing loss by average age at diagnosis (2010).....	31
Table 14: Screening status of children born in New Zealand, 2010 and 2011.....	34
Table 15: Diagnoses resulting from newborn hearing screening.....	34
Table 16: Potential false negatives and cases previously referred from hearing screening	36
Table 17: Delay comparisons with previous data (excluding acquired, unilateral, born overseas and mild losses).....	36
Table 18: Reasons for delay between suspicion and confirmation of hearing loss 2010 and 2011	37
Figure 1: Notifications by year 1982-2005 and 2010-2011	10
Figure 2: Proportion of 2011 cases born in New Zealand.....	14
Figure 3: 2010 and 2011 Notifications by ethnicity compared with census proportions.....	16
Figure 4: Unilateral and bilateral losses by ethnicity (2011).....	17
Figure 5: Proportion of bilateral hearing losses by severity grouping (2011).....	20
Figure 6: Unilateral hearing losses by severity (2010 and 2011)	20
Figure 7: 2011 Bilateral Notifications by degree and ethnicity	22
Figure 8: Number of hearing aids to be fitted (2010 and 2011)	23
Figure 9: Number of hearing aids to be fitted, by severity of hearing loss (ASHA Clark Severity Codeframe)	24
Figure 10: Proportion of hearing losses of known and unknown cause notified to the DND by year...	26
Figure 11: Initial family history (2011, All cases)	28
Figure 12: First suspicion of hearing loss for children born in NZ (2011).....	29
Figure 13: Number of children diagnosed by age (2010 and 2011)	30
Figure 14: Age at confirmation by degree of hearing loss 2011	31
Figure 15: Average age at diagnosis by ethnicity (2011)	32
Figure 16: Suspicion and Confirmation of hearing losses - comparison with previous data (excluding appropriate cases)	33
Figure 17: 2011 Audiogram data from high frequency hearing losses for right and left ears	39

References

- ASHA (2010) Information Series- Hearing Loss Types from <http://www.asha.org/uploadedFiles/aud/InfoSeriesHearingLossTypes.pdf> accessed on 1st February 2011.
- Australian Hearing (2011) Report on Demographics of Persons under the age of 21 years with hearing aids – 2010.
- Brown, C (2012) Policy, Personal communication to Digby J, 23rd January 2012.
- Clark JG, (1981) Uses and abuses of hearing loss classification. ASHA, 23, 493–500.
- CDC-EHDI Hearing Screening and Follow-up Survey (HSFS): 2006 Explanations (Version B) accessed on 21st March 2011 from http://www.cdc.gov/ncbddd/hearingloss/2006-data/2006_HSFS_Explanations_B.pdf.
- Digby JE, Thorne PT, Webster D, Keith WJ, Wilson O, Cooper M, (2004) Improving outcomes for children with permanent congenital hearing impairment: the case for a national newborn hearing screening and early intervention programme, Project HIEDI, Auckland, New Zealand.
- Fitzpatrick EM, Durieux-Smith A, Whittingham J, (2010) Clinical Practice for Children with Mild Bilateral and Unilateral Hearing Loss. Ear & Hearing June 2010 - Volume 31 - Issue 3 - pp392-400.
- Fortnum H, Davis A, (1997) Epidemiology of permanent congenital hearing impairment in the Trent region 1985-1993. British Journal of Audiology, 1997, 31, 409-446.
- Fortnum H, Marshall DH, Summerfield AQ, (2002) "Epidemiology of the UK population of hearing impaired children, including characteristics of those with and without cochlear implants – audiology, aetiology, co-morbidity and affluence" International Journal of Audiology 41:170-179.
- Fortnum HM Summerfield AQ, Marshall DH, Davis AC, Bamford JM, (2001). Prevalence of permanent childhood hearing impairment in the United Kingdom and implications for universal neonatal hearing screening: questionnaire based ascertainment study. British Medical Journal 323, 536-539.
- Greville A, New Zealand Deafness Detection Data January - December 2005 (2005) Report prepared for National Audiology Centre, Auckland District Health Board, March 2007.
- HIEDI Issues Paper Two: False negatives and the Deafness Notification Database (June 2009) Project HIEDI, Auckland.
- Meadow, Donella H, (1994) "If the World were a village of 1,000 people" In Futures by Design, edited by Doug Aberley, presented by Christine Yoshinaga-Itano, The Oticon Lecture, New Zealand October 2009.
- Mehra S, Eavey RD, Keamy DG, (2009) The epidemiology of hearing impairment in the United States: Newborns, children, and adolescents. Otolaryngology–Head and Neck Surgery (2009) 140, 461-472.
- Ministry of Health Statistics on Children's Hearing Aids 2010-11 Financial Year, provided by Hamlin, S of the Ministry of Health, personal communication to Digby J, April 26th 2012. Wellington
- Ministry of Social Development (2010) The Social Report <http://www.socialreport.msd.govt.nz/people/ethnic-composition-population.html> accessed on February 2nd, 2011.
- National Screening Unit (2009) Universal Newborn Hearing Screening and Early Intervention Programme National Policy and Quality Standards Appendix F Diagnostic and Amplification Protocols June 2010 accessed from <http://www.nsu.govt.nz/health-professionals/2940.asp> on the 22nd of March 2011.

National Vision Hearing Screening Protocols (2011) Wellington: Ministry of Health.

New Zealand Deafness Notification Data: January - December 2001. Auckland: National Audiology Centre, 2002.

New Zealand Deafness Notification Data: January - December 2002. Auckland: National Audiology Centre, 2003.

New Zealand Deafness Notification Data: January - December 2003. Auckland: National Audiology Centre, 2004.

New Zealand Deafness Notification Data: January - December 2004. Auckland: National Audiology Centre, 2005.

Nikolopoulos, T P, Lioumi, D, Stamatakis, S, O'Donoghue, G M. (2006) Evidence-based overview of ophthalmic disorders in deaf children: a literature update. *Otology & Vol.* 27(2Suppl1), pp.S1-24.

Northern JL, Downs MP, (1984) *Hearing in Children*, Williams & Wilkins.

Searchfield G, Bae S, Crisp A, (2011) Whakarongo Mai and Māori hearing loss statistics, access and barriers. Presented at the Oticon Foundation Hearing Education Centre Spring Symposium: Hearing Health Issues Facing the New Zealand Population. November 2011. School of Population Health, University of Auckland.

Statistics New Zealand. (2009). Final report of a review of the official ethnicity statistical standard 2009. Wellington.

Statistics New Zealand 2006 Census Data: QuickStats About New Zealand's Population and Dwellings – Table 3 <http://www.stats.govt.nz/Census/2006CensusHomePage/QuickStats/quickstats-about-a-subject/nzs-population-and-dwellings.aspx> accessed on March 22nd, 2011.

Statistics New Zealand (2012) 2006 Disability Survey http://www.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey2006_HOTP06/Technical%20Notes.aspx accessed on August 4th 2012.

Statistics New Zealand 2006 Census Data: QuickStats about Culture and Identity – Table 3 <http://www.stats.govt.nz/Census/2006CensusHomePage/QuickStats/quickstats-about-a-subject/culture-and-identity.aspx>, accessed on March 22nd, 2011.

Statistics New Zealand (2010) 2006 Household Disability Survey. Wellington.

Turner N, (2011) Cases of Meningitis in New Zealand, personal communication to J Digby March 21st 2011.

Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP) Monitoring Report on Newborn Hearing Screening Service Provision October 2010 – March 2011 (2012) National Screening Unit, Auckland.

WHO Prevention of blindness and deafness – grades of impairment from http://www.who.int/pbd/deafness/hearing_impairment_grades/en/index.html accessed on 1st February 2011.

Yoshinaga Itano C, (2010) Personal Communication, J Digby, 7/4/2010.

Yoshinaga Itano C, (2009) Oticon Foundation Presentation. Raising the bar for children with hearing loss. Powerpoint Presentation delivered at the University of Auckland. New Zealand.