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<http://www.audiology.org.nz/Userfiles/file/Deafness%20Notification%20Database%20-%202012%20Report.pdf>

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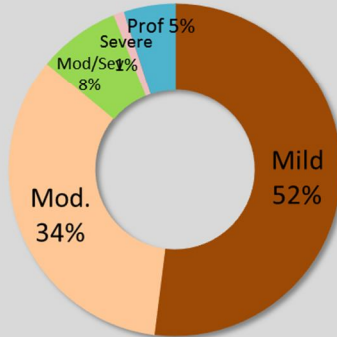
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2012 Deafness Notification Dashboard

Number notifications



Degree of loss Bilaterals (ASHA Clark)



Subject heading

Total/average

Previous average ↑↓ Trend

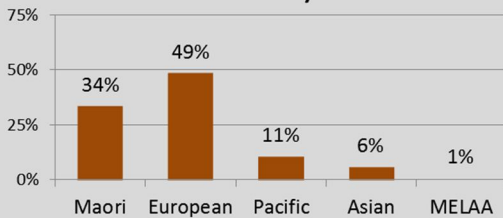
DHBs Audiologists



Overall Av age at diagnosis



Ethnicity



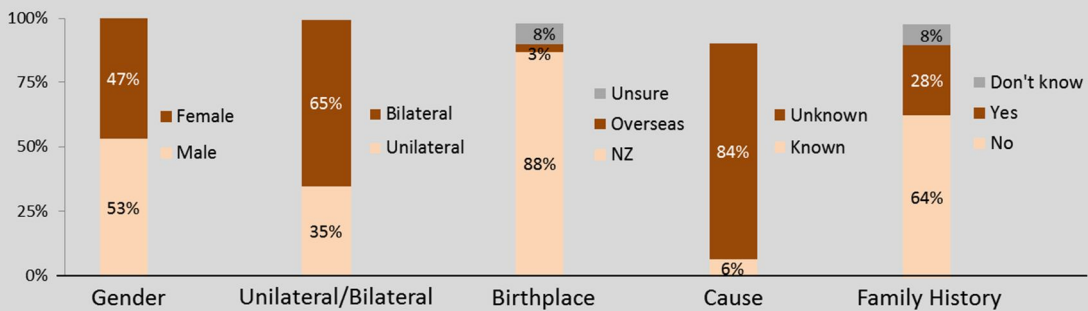
Hearing loss first suspected by:

1. Parent or caregiver
2. Vision hearing technician
3. Newborn hearing screener

Other disabilities



Newborn hearing screening



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 2012 calendar year. We understand you are not compelled to provide this information and we know how busy you are. Thank you for contributing to our understanding of hearing loss among New Zealand's children and young people.

Audiologists (including non NZAS members) are strongly encouraged to make future notifications to the database by following this link:

<https://www.surveymonkey.com/s/DeafnessNotificationDatabase>

We would appreciate it if you could keep the following points in mind when making future notifications:

1. If you have any questions at all, please contact Janet Digby: janet@leware.co.nz or by telephone (09) 4456006.

2. 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. 2013 notifications should be provided by the end of January 2014.

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

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. 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.

5. Complete audiometric data

Please provide audiometric data for 0.5, 1.0, 2.0 and 4.0 kHz where-ever this is possible.

6. 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. This may relate to the age the child was referred from the newborn hearing screening programme.

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

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The 2012 Report

Introduction

Welcome to the third report describing notifications to the re-launched Deafness Notification Database. This report includes diagnoses throughout New Zealand during the 2012 calendar year.

Since the Deafness Notification Database was re-launched in 2010, the following definition has been used to determine which cases are included within the Deafness Notification Database and therefore within in the analysis for this report.

Children and young people 18 years or younger, born in NZ or overseas, with:

- a permanent hearing loss in one or both ears
- an average loss of 26dBHL or greater over four audiometric frequencies (.5, 1.0, 2.0 and 4.0 kHz)¹

Historical information about the database's inclusion criteria can be found in Appendix A: History of the database on page 38 of this report.

Steps have been taken to ensure that key data contained within this report are 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 a number of longitudinal comparisons with pre 2006 data are not possible.

Please note that unless otherwise specified, analyses within this report describe characteristics of the full number of 2012 notifications for which data was provided.

Generally, 2010 data¹ within figures is provided in teal (the main colour of the 2010 report), while 2011² data is presented in purple (the main colour of the 2011 report) and 2012 data presented in orange. Tables and figures containing externally sourced data are grey, while long-term comparisons are shown in black/grey.

Contact details

The authors of the report hope that ongoing changes made to the way information is analysed and presented will improve the value of these reports over time. We ask that readers get in touch to provide us with feedback on this report to assist with its further development.

Feedback on this report and any 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.

¹Based on feedback from the audiological community, high frequency hearing losses which would not meet the original criteria have been collected as a trial from July 2011. We will continue to trial inclusion of this special group within the database. A limited analysis of data from high frequency hearing losses notified in 2012 can be found in Appendix B: High frequency hearing losses, on page 40.

Completeness of notifications

While every reasonable effort has been made to ensure the newly re-launched database improves understanding of permanent hearing losses among NZ children and young people, there is no way to know the proportion of new cases which meet the criteria which are not notified to the database.

There may be certain types of cases, such as those which are mild and/or unilateral, which are underrepresented within notifications, and as a result inferences made from the data contained in this report should be taken as indications only. (See the section titled *Numbers of notifications* on page 8 for further information.)

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 able spend less time collecting and entering data. Such a change is likely to increase the number of notifications provided to the database.

Acknowledgements

Thank you to the 191 families who provided consent for their child or young person's data to be included within the database. As a result of your willingness to share basic information about your child's diagnosis, service providers will be better informed about current and future demand for services, including the skills required to better serve the needs of families.

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 had its own unique challenges.

This report has been funded by Accessable, through a contract with the Ministry of Health. We would like to thank the Ministry of Health for funding the database from 2012. Without this support, those working with children who are deaf and hearing impaired would not have up to date information about the number and nature of new diagnoses in New Zealand.

We would also like to acknowledge the New Zealand Audiological Society for funding towards the re-launch of the Deafness Notification Database in 2010 and 2011.

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.

Dr David Welch, Mr Colin Brown and Professor Peter Thorne are also acknowledged for their contribution to these reports.

Notifications

General information

191 notifications pertaining to the 2012 calendar year and meeting the criteria for inclusion were received by the 31st of January 2013. These notifications were received from a total of 49 audiologists, with notifications from 19 of the 20 district health board areas. This is up slightly from the 187 notifications received in 2011, which were received from 20 DHBs and 56 audiologists.

It not possible 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 enter using the online form, as was the case during 2010 and 2011.

Of those children and young people whose hearing loss was notified to the database, more diagnoses were made in the middle of the year. This may be the result of the general shortage of audiologists nationwide and the timing of their holidays, or due to other reporting pressures, which are considerable.

Slightly more of the cases notified were male (53%) than female (47%). The ratio of boys to girls has been falling slightly since the database was re-launched, from 1.18 in 2010, to 1.125 in 2011 and 1.122 in 2012.

Boys are commonly found to have higher rates of hearing loss than girls in overseas research with male cases comprising between 52% and 58% of the total reported in various jurisdictions within 2011's Comprehensive Handbook of Pediatric Audiology³.

Numbers of notifications

Notifications are collected through an online survey form, to reduce data entry errors and make it as easy as possible for audiologists to notify cases.

Efforts have been made to publicise the database to all audiologists working with children and young people, in an attempt to collect as many notifications as possible.

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. 1982-2012;
- 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; and
- Data for 2010 to 2012 relate to notifications provided to the newly re-launched database. Notifications were removed from the main analysis for the reasons stated below.

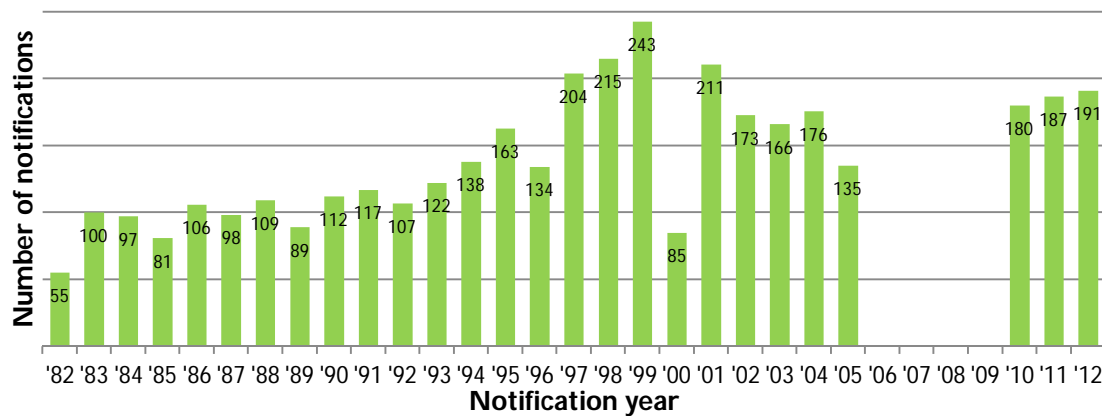


FIGURE 1: NOTIFICATIONS BY YEAR 1982-2005 AND 2010-2012^{i,4,5,6,7,8}.

Figure 1 illustrates the variability in the number of notifications provided to the original database, particularly in the last six years of its operation.

The following types of notifications are not accepted into the database based on the current inclusion 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 thresholdsⁱⁱ (assumed to be a transient conductive hearing loss unless a permanent conductive hearing loss was stated, e.g. due to ossicular fixation);
- 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 datasetⁱⁱⁱ (1982-2005) so that new notifications could be checked against those received previously to ensure no duplicates were being included in the current analyses. Duplicates were identified based on National Health Index (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.

One 2012 notification received had been previously notified to the ADHB database, and so was excluded from this year's dataset.

ⁱ The lower number of notifications which met the criteria in 2005 and were described in the 2005 DND report was attributed by the author to removal of duplicate entries.

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

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

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 a number of methods to provide some indication of the number of new diagnoses of hearing loss annually among children and young people.

Firstly, by reviewing the number of notifications to the DND in recent yearsⁱ, it would seem reasonable to assume that between 50% and 80% of all new diagnoses may have been notified in 2012, the same proportion estimated in 2010 and 2011. However, this approach is somewhat flawed, as the criteria for inclusion in the database have changed since the database was re-launched in 2010 and so comparisons are problematic.

Secondly, although there are a number of difficulties using prevalence from overseas jurisdictions, estimates of overall prevalence in children and young people from international data^{ii,9} would suggest that given there are approximately 1.167 million children and young people in New Zealand under to the age of 19 years old¹⁰ there may be approximately 245 new hearing loss diagnoses made annually which fit the new criteria. Using this method the notifications collected in 2011/12 may comprise approximately 76% of the number of 2011 diagnoses.

Work is continuing in 2013 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 continue to grow over time and will approach 100%.

Birthplace

This is the third year in which children and young people born outside of New Zealand have been formally included within the database and its main analysis.

As shown in the figure below, of the 191 cases included in the main analysis in 2012, 3% were known to be born outside New Zealand. Birthplace was uncertain in a further 8% of cases reported to the database in 2012.

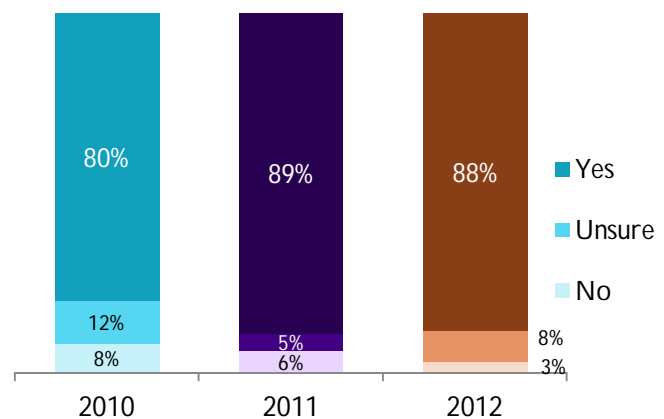


FIGURE 2: PROPORTION OF 2011 CASES BORN IN NEW ZEALAND

ⁱ We are unsure of the level of over-reporting as to cases being notified in more than one reporting period and as no record exists of which records were included in the analysis for given reports before 2006.

ⁱⁱ 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. These areas also report an approximate additional figure of 0.5 per thousand for unilateral hearing losses.

Regional representation

Table 1 contains the percentage of 2012 notifications from each district health board (DHB) and compares this with the percentage of the population under the age of 20ⁱ.

In addition to the natural fluctuations in the number of hearing losses diagnosed among children and young people in a given year, other factors influencing notification levels may include;

- the size of the population within the age range for the database;
- 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 2012 (under 19 years)	Percentage of population under the age of 20 (NZ 2006 Census)
Auckland	4%	9%
Bay of Plenty	2%	5%
Canterbury	12%	11%
Capital and Coast	4%	6%
Counties Manukau	14%	13%
Hawke's Bay	7%	4%
Hutt	5%	4%
Lakes	2%	3%
Midcentral	3%	4%
Nelson Marlborough	5%	3%
Northland	8%	4%
South Canterbury	4%	1%
Southern	12%	7%
Tairāwhiti	1%	1%
Taranaki	4%	3%
Waikato	8%	9%
Wairarapa	1%	1%
Waitemata	3%	12%
West Coast	0%	1%
Whanganui	2%	2%

TABLE 1: PERCENTAGE OF NOTIFICATIONS (2012) COMPARED WITH PERCENTAGE OF POPULATION UNDER 20 YEARS (2006) OF AGE BY DISTRICT HEALTH BOARD

Other disabilities

The presence of one or more additional disabilities can have a significant impact on both outcomes for children and young people with hearing loss and on the level of support they might require, particularly from special education services.

Of cases notified for the 2012 period, 16% were thought to have disabilities *in addition* to hearing loss at the time the notification was made. In a further 11% of cases there was uncertainty regarding whether the child or young person had an additional disabilityⁱⁱ.

For the 29 children and young people reported to have additional disabilities, 34 specific conditions were listed. The most common of these were those related to a specific syndrome (8

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

ⁱⁱ The proportion of New Zealand children with a hearing impairment (diagnosed at any time) who also have an additional disability which affects their learning is not known.

children), vision problemsⁱ (6 children), global developmental delays (4 children) and speech disorders (4).

The proportion of children notified with additional disabilities 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 rises the figure is more consistent with those reported before the re-launch of the database.

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%
2012	16%	11%	27%

TABLE 2: PROPORTION OF CASES WITH A KNOWN ADDITIONAL DISABILITY

Earlier identification of children with hearing loss is likely to result in lower levels of reported additional disabilities as these are reported at the time of diagnosis of the hearing loss; children may have not yet been diagnosed with these conditions, or they have not yet developed (e.g. vision impairments are more common with older children and diagnoses of autism spectrum disorder are typically not made in the first year of life).

Other possible reasons for downward pressure on the proportion of children reported with additional disabilities include:

- Children with hearing loss in New Zealand may not be routinely assessed by a pediatrician and hence additional disabilities may be under-diagnosed; and
- Immunisation coverage in New Zealand has risen significantly since vaccination for children became a PHO Performance Programme (PPP) indicator in January, 2006 (a funded indicator from July, 2008). Achievement rates for the indicator 'age-appropriate immunisations completed by age two years' have risen from approximately 45% in 2007 to 92% in March 2012¹¹. Such improvements have reduced rates of meningitis in New Zealand and this may have an impact on the proportion of children with hearing loss with additional disabilities, although the numbers are likely to be smallⁱⁱ.

ⁱ No local data is available on the rates of vision problems among deaf and hearing impaired populations in New Zealand but some professionals recommend routine referral for ophthalmological assessment for children diagnosed with significant bilateral hearing impairment.

ⁱⁱ 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. Further information on meningitis cases can be found on page 17.

Overseas additional disability data

It is difficult to compare reported rates of additional disabilities among hearing impaired children as the definition for hearing loss and for disabilities differ and is not always described within scientific papers.

A recent review (2012) of 12 relevant papers containing information and rates of additional disabilities among hearing impaired children found visual impairment (4-57% depending on the definition), neurodevelopmental disorders (2-14%) and speech language disorders (61-88%) were the most common additional disabilities¹².

Rates of additional disabilities among children and young people notified to the DND are lower than the 27.4% figure reported by Fortnum et al (2002)¹³ from a sample of 17,169 UK children studied with hearing loss. They are much lower than the 38.7% of children found to have one or more additional clinical or developmental problems in the study of PCHI in the Trent region of England conducted by Fortnum and Davis in 1997¹⁴, although this study used a wide definition of additional needs.

In the US, Holden, Pitt and Diaz estimated that 20-40% of all US children with a hearing loss had an additional disability¹⁵, while Gallaudet's Research Institute estimate 20-50% of all deaf and hard of hearing children have accompanying disabilities¹⁶.

In Australia, the Lochi study which examined 260 children with hearing impairment born in Queensland, NSW and Victoria between 2002 and 2007 who are receiving intervention from Australian Hearing, has reported that 18% of children within their sample have one additional disability, 10% with two and 9% with three or more¹⁷.

CRIDE (The Consortium for Research into Deaf Education) conduct an annual UK-wide survey on educational staffing and service provision for deaf children. In the 2011/12 financial year, this study found that 21% of deaf children (including unilateral and bilateral and mild to profound losses) had an additional special educational need in addition to their hearing impairment¹⁸. NZ DND figures are more similar to these estimates of the proportion of deaf children with an additional educational need, although this is unlikely to be a fair comparison due to their inclusion criteria.

Bilateral and unilateral loss

Unilateral hearing losses are now known to have significant effects on educational performance and a significant proportion of these hearing losses progress over time¹⁹. 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.

Although unilateral hearing losses were not included in the DND before 2006, a number of these cases were notified to the database each year and these numbers were provided in the annual reports. Comparisons with previous DND data (prior to 2005) are not possible as unilateral hearing losses were not within the criteria for the database and as they were therefore likely to be under-reported.

The figure below shows the overall proportion of unilateral and bilateral hearing losses by year.

Differences between the proportions of unilateral notifications in each severity category are shown in Figure 12, below.

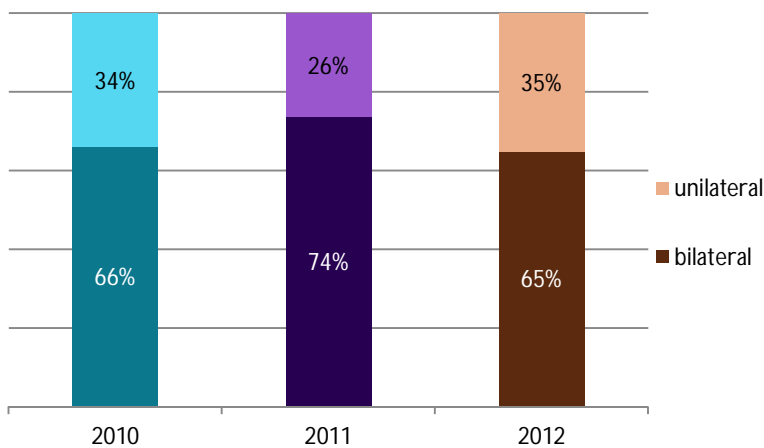


FIGURE 3: PROPORTION OF BILATERAL AND UNILATERAL HEARING LOSSES (2010-2012)

As immunisation coverage (including conditions such as mumps) in New Zealand has risen significantly from 45% in 2007 to 92% in 2012²⁰ it will be interesting to see whether a drop in the proportion of newly diagnosed unilateral hearing losses can be detected over time. Falling rates of measles, mumps and meningitis may contribute to such a decline, although the numbers are likely to be very small.

Ethnicity

Ethnicity and hearing

While no individual project focusing on defining prevalence of hearing loss among New Zealanders has 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 notifications from 2010 to 2012 may be supported by data from other sources such as:

- The Household Disability Surveys (1991-2006²¹) – these suggest Māori may have higher rates of hearing disability (children and adults) and higher rates of unmet need for technology and equipment when compared with non-Māori²². For more about the limitations of this data, please see the 2011 DND Report²³.
- Referral rates from the B4 School Checkⁱ (2011) show higher rates of referral from hearing screening for Māori children (9%) compared with non-Māori (5%)²⁴. It is important to note that high referral rates for Māori may indicate higher rates of ear disease as these figures do not just relate to permanent hearing loss.
- Universal newborn hearing screening: While only limited programme data is available to describe diagnoses resulting from newborn hearing screening Māori children were being referred at higher rates (2.4%) compared with their European counterparts (1.2%) between October 2010 and March 2011²⁵.

For further information on ethnicity coding within the database, please refer to Appendix D: Notifications and ethnicity on page 42.

Representation

All but one of the 2012 notifications contained one or more ethnicity codes. Of those with one or more codes, 88% of respondents' selected one code for their child's ethnicity, while 12% selected two codes.

2010 and 2011 notifications (including those children and young people born overseas) are reported in Figure 4 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 provided²⁶.

This figure shows that Māori are over-represented in notifications compared with 2006 Census figuresⁱⁱ for Māori under 20 years of age. 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.

i The B4 School Check aims to screen all children before they reach school, and to identify and provide intervention to those children identified with targeted 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 Technician. If the child passes this test, no further referrals are required. Should the child refer on audiometry, tympanometry should be conducted.

ii Why are we still using 2006 Census data? Please note that the 2011 Census was cancelled due to the Christchurch earthquakes. We look forward to having access to more recent data from the 2013 Census.

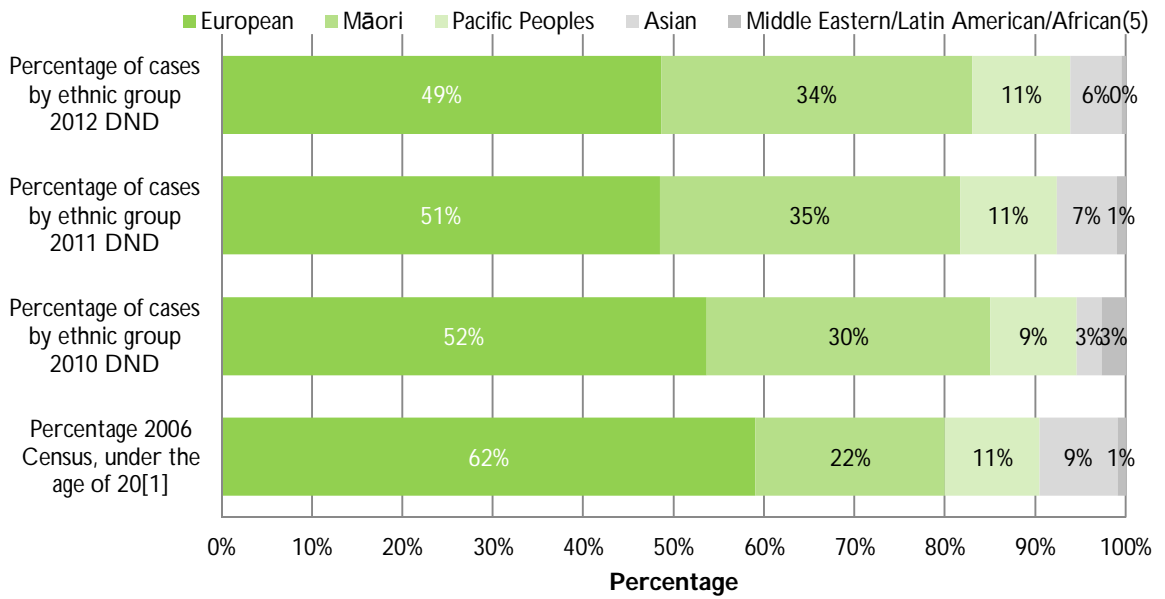


FIGURE 4: 2010-2012 NOTIFICATIONS BY ETHNICITY COMPARED WITH CENSUS PROPORTIONS

Unilateral and bilateral loss

Figure 5 below shows a comparison of the percentage of 2012 notifications, split by ethnicity, which are bilateral and unilateral in nature. Please note that MELAA is a very small sample of one individual.

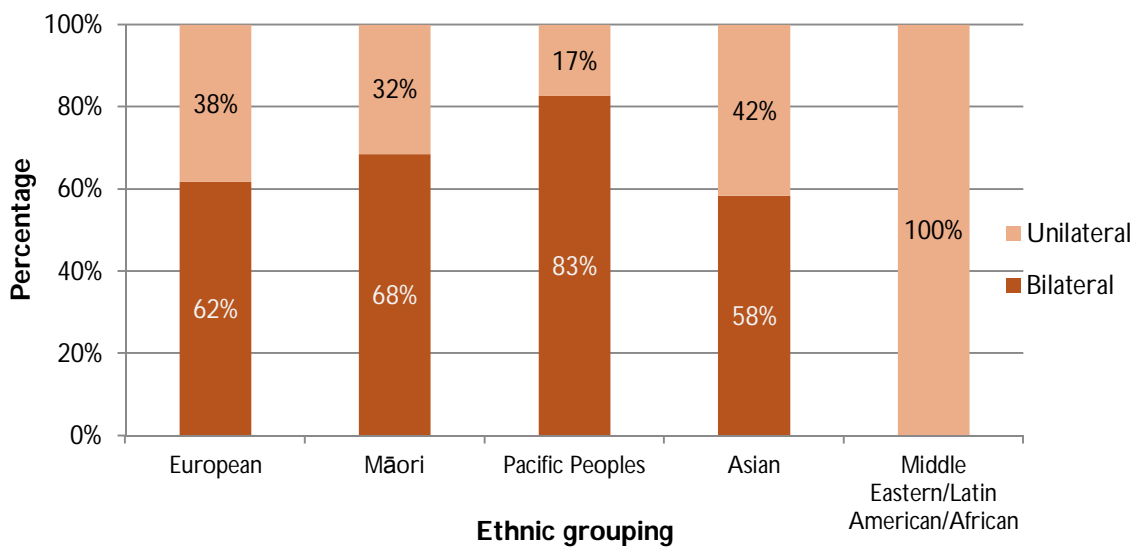


FIGURE 5: UNILATERAL AND BILATERAL HEARING LOSSES BY ETHNICITY (2012)

Cause of hearing loss

As seen in Figure 6 below, the proportion of hearing losses where the cause was thought to be known has decreased significantly in 2010 -2012 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 notification form has been made more specific.

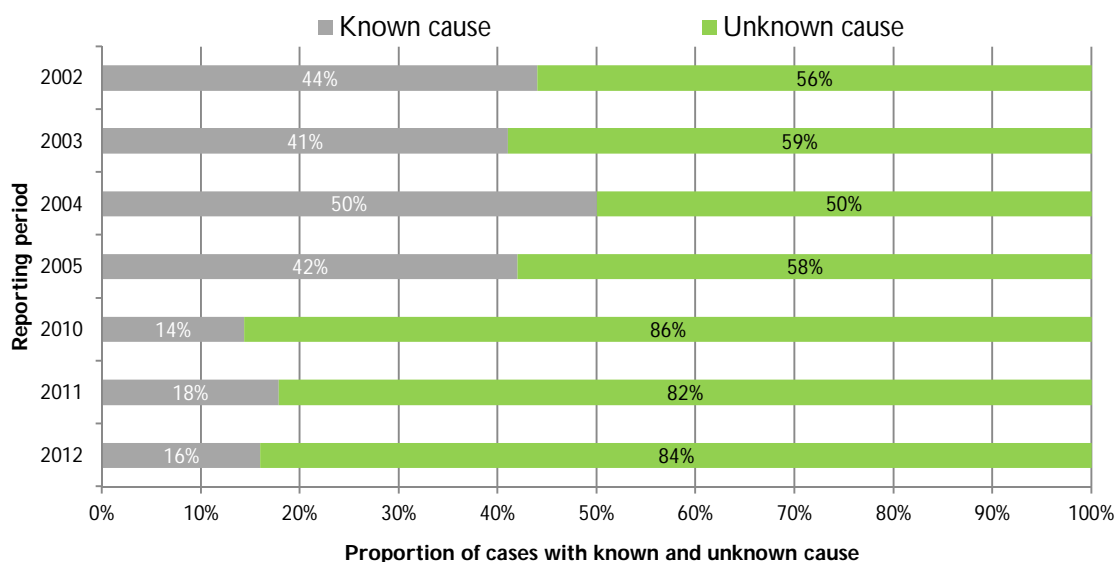


FIGURE 6: PROPORTION OF HEARING LOSSES OF KNOWN AND UNKNOWN CAUSE NOTIFIED TO THE DND BY YEAR

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.

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 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.

Table 3 below shows the breakdown of aetiology where this was known.

Aetiology breakdown	2010 (n=)	2011 (n=)	2012 (n=)
Acquired hearing loss	11	16	17
Genetic cause (non-syndromic)	3	2	3
Syndromic	3	4	6
Other	6	6	3
Not listed	2	5	4

TABLE 3: NUMBER OF CASES OF KNOWN AETIOLOGY BY TYPE (2010)

Of the cases of hearing loss diagnosed in 2012 and notified to the DND, three were listed as being the result of meningitis, while one was suspected to have been the result of meningitis when the child was younger. This compares with six cases listed as being the result of meningitis in 2010 and four cases in 2011²⁸.

Predictably, aetiology is more likely to be investigated in cases of bilateral hearing loss, and where the hearing loss is more severe in nature compared with unilateral cases or cases which are milder in terms of their severity²⁹.

Internationally, as reported by Davis and Davis (2011), it is common for a high proportion of cases (between 15% and 57%) of hearing loss to be of unknown aetiology. Genetic causes are likely to increase over time as a reported cause as more cases in a population become understood in terms of their aetiology. It is worth noting that identification of one aetiology does not exclude another aetiology. For example, the A1555G mitochondrial mutations may predispose a patient to hearing loss, and this hearing loss is expressed when the certain antibiotics are used³⁰.

Further related information, on Family History of cases, can be found in Appendix C: Family History on page 41.

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 118 of the 169 children and young people known to have been born in NZ and who were diagnosed in 2012.

Among these notifications, parents or caregivers were the most likely to first suspect the hearing loss, followed by Vision Hearing Technicians (VHTs) and Newborn Hearing Screeners. It is pleasing to see a rise in the proportion of cases now being suspected for the first time by newborn hearing screeners¹.

The proportion of cases first suspected by parents between 2010 and 2012 is aligned with the 34% and 52% of cases in this category notified to the previous database between 2000 and 2005.

2010	2011	2012
Parent or caregiver (49%)	Parent or caregiver (42%)	Parent or caregiver (33%)
VHT (22%)	Medical Professional (21%)	VHT (23%)
Medical Professional (12%)	VHT (15%)	Newborn hearing screener (23%)

TABLE 4: 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 7, below. Although 27% of notifications were a direct result of referral from newborn hearing screening, the newborn hearing screener is only listed in 23% of cases as the person first suspecting the loss. While this may be accurate, 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.

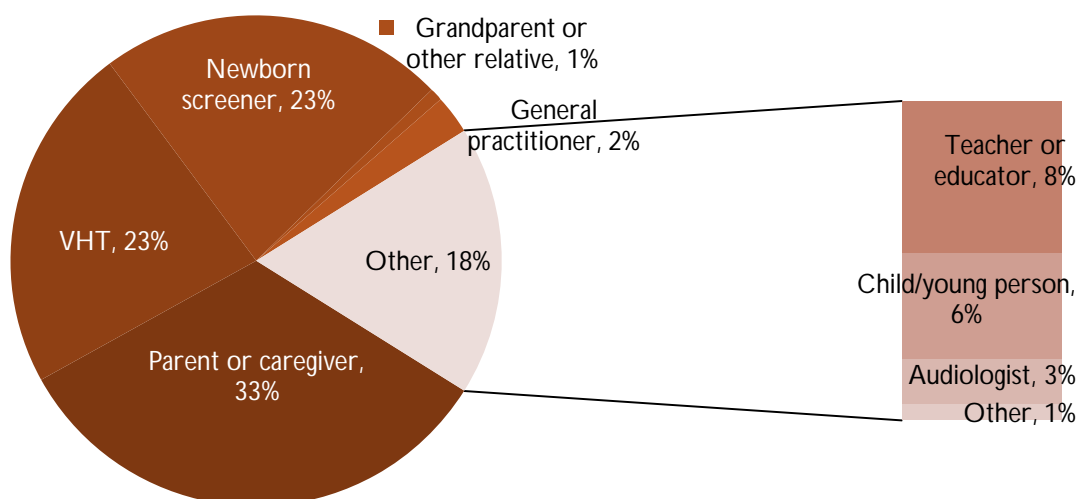


FIGURE 7: FIRST SUSPICION OF HEARING LOSS FOR CHILDREN BORN IN NZ (2012)

¹ Further information was added to the notification form in 2012 to ensure audiologists are clear about how to code the answer to this question should the child have been identified through newborn hearing screening. This change may be responsible for the increasing role of newborn hearing screeners in first suspecting the hearing loss in 2012 as the UNHSEIP coverage rates have not increased significantly since 2011.

Age at identification

Figure 8 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 and 12 than in 2010, presumably due to increased coverage of this programme (mainly seen in 2011) and as the proportion of cases being diagnosed before 6 months has risen (seen in 2012).

A further peak can be seen for five year olds; this is likely to correspond to the B4 School Check³¹. (See page 15 for further information on the B4 School Check.)

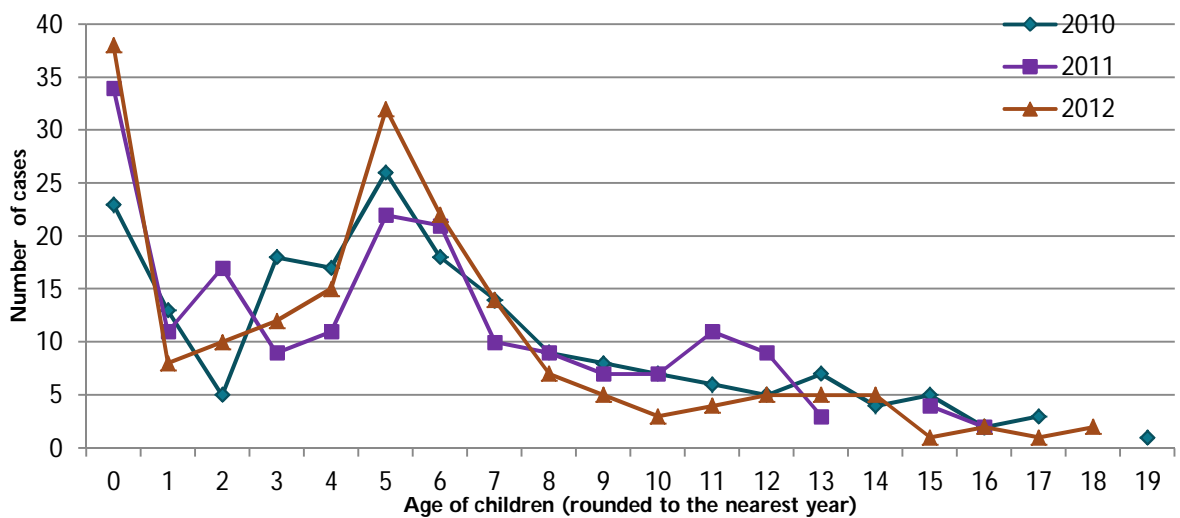


FIGURE 8: NUMBER OF CHILDREN DIAGNOSED BY AGE (2010 AND 2011)

Average overall 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 have some meaning 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).

Keeping this proviso 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 61 months (compared with 57 in 2011 and 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 availableⁱ, 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 have their hearing losses identified later, including those:

- with acquired hearing losses e.g. late onset, progressive and trauma related (72 month average)
- with hearing loss suspected *not* to have been present at birth (82 month average)
- who are born overseas (105 months on average)
- with mild and moderate hearing losses (78 and 69 months respectively)
- those with unilateral hearing losses (82 months)

Age at diagnosis by severity of hearing loss

Table 5 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)	Average months at diagnosis (2012)
Mild	81	78
Moderate	71	69
Moderately severe	43	42
Severe	48	NA (not enough cases)
Profound	39	22

TABLE 5: DEGREE OF HEARING LOSS BY AVERAGE AGE AT DIAGNOSIS (2010)

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.

ⁱ 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 and reduce data entry errors.

Age at diagnosis and ethnicity

Figure 9 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 data was provided.

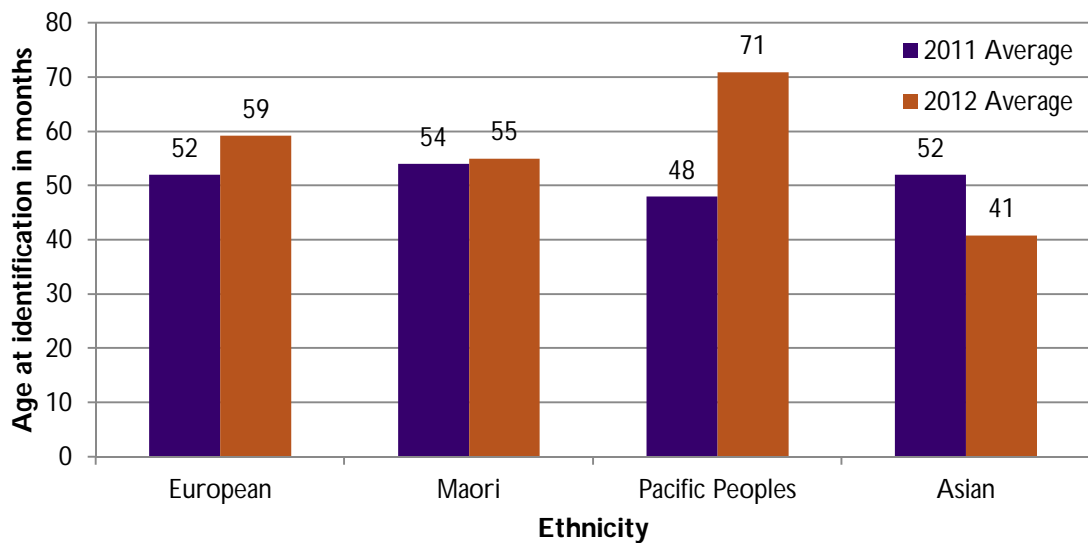


FIGURE 9: AVERAGE AGE AT DIAGNOSIS BY ETHNICITY (2011 AND 2012)

The large increase in the average age of identification among Pacific Peoples seems likely to be the result of a reduction in the proportion of severe and profound hearing losses identified in 2012 and as a result of a small number of children and young people whose hearing loss was identified at much older ages. The median age of identification for Pacific Peoples moved from 57 months in 2011 to 64 months in 2012.

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 report¹.

¹For 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 Māori and Pacific children.

Longitudinal comparison

Figure 10 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 cases where the hearing loss is unilateral, acquired or mild and those where the children are born overseas or where birthplace is uncertain. The reader will note removal of these cases significantly reduces the average age at identification and the number of cases included within the analysis. No data are provided for 2006-2009 as the database was not operating during this period.

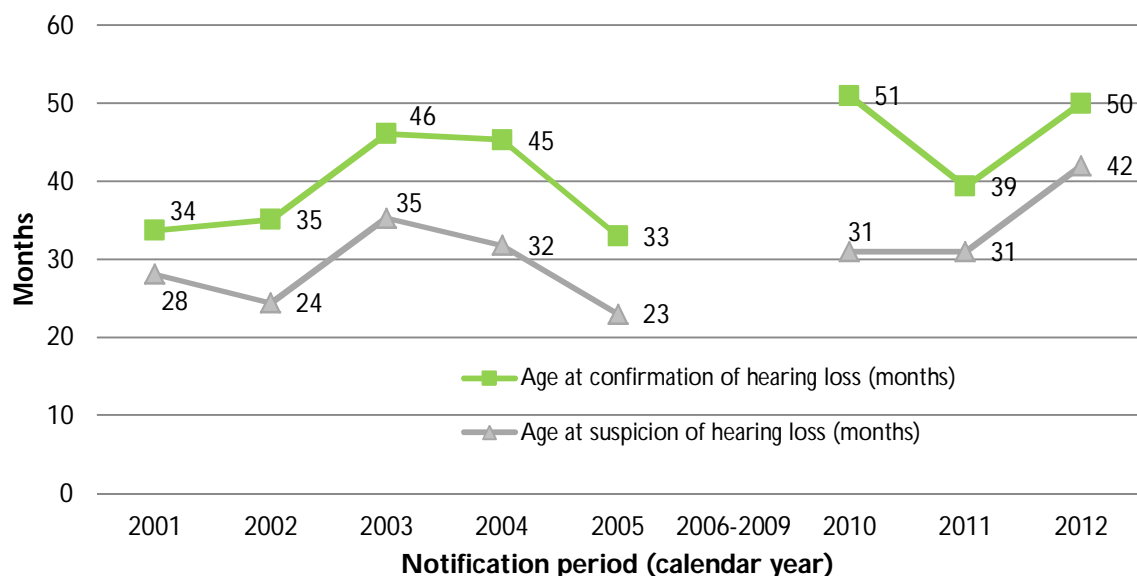


FIGURE 10: SUSPICION AND CONFIRMATION OF HEARING LOSSES – LONGITUDINAL COMPARISON (EXCLUDING APPROPRIATE CASES)^{i,32,33,34,35, 36}

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-outⁱⁱ 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 screening by April 2010.

As with last year, all district health boards were screening babies for the full 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 6 shows the screening status of NZ born children notified in 2010 and 2011. 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. 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.

ⁱ Please note, no data are provided for 2006-2009 as the DND was not operating during this period.

ⁱⁱ 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	2012
No	No, a screening programme was not in place, but the child was directly referred to audiology due to atresia	3%	4%	4%
	No, this service was not available at the time (at the time of diagnosis)	69%	54%	55%
Unsure	Unsure whether screening was offered to this family	7%	4%	6%
Yes	Yes screening was offered but this child was not screened...	1%	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%	2%
	Yes, this child was screened and passed	1%	7%	5%
	Yes, this diagnosis is a result of a refer on the screening test	19%	27%	27%

TABLE 6: SCREENING STATUS OF CHILDREN BORN IN NEW ZEALAND, 2010 AND 2011

Of particular interest were the six children who were referred from their newborn hearing screen and for whom follow-up did not occur at the time but were later diagnosed with a hearing loss, and those children who were screened and passed this screening.

Please note that the children notified range from 0 to 18 years of age. More than half (55%) of the cases (90) notified for 2012 were not screened as no screening service was available in their area at the time of their birth. Twenty four 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. These cases were either not screened as the programme was not completely rolled out in their area at the time of their birth, or they were not screened because the family declined screening or were not approached and offered a screen for their baby.

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 1.0 to 1.1 per thousand babies for bilateral hearing losses, and approximately an additional 0.5 per thousand unilateral hearing losses^{37, 38, 39, 40}. 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 annumⁱ.

A total of 45 of the 2012 notifications related to children born in New Zealand diagnosed as a direct result of newborn hearing screening. While Table 7 shows a large increase in the number of diagnoses made as a result of UNHS in 2011, when compared with 2012, the number has now plateaued at 27% of notifications.

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	2012
Number of diagnoses resulting from universal newborn hearing screening	28	44	45
...As a proportion of total notifications	16%	27%	27%

TABLE 7: DIAGNOSES RESULTING FROM NEWBORN HEARING SCREENING IN NZⁱⁱ

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

ⁱⁱ Please note that the table shown in the 2011 report contained data for all cases, whereas this table contains data only for children born in NZ

The latest National Screening Unit monitoring report covering data from October 2011 to March 2012 reports that:

- Approximately 88% of babies born across the country during this period completed their newborn hearing screening;
- Of the 408 (1.5%) of babies referred from screening, audiological data was provided to NSU for 60% of these; and
- 30 babies were recorded as identified as having a permanent congenital hearing loss (auditory neuropathy, mixed or sensorineural) identified in at least one ear⁴¹. This number excludes permanent conductive hearing losses identified through the UNHSEIP

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 identification 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 New Zealand newborn hearing screening programme 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 pleasing reduction in the average age at diagnosis of cases referred from newborn hearing screening in NZ, from 10 months in 2010 to 8 months in 2011 and 5 months in 2012.

Of the 45 cases notified in 2012 and identified as a result of newborn hearing screening within NZ, 33 (73%) were diagnosed by the recommended three months of age. This is an improvement from 59% in 2011.

Of the 12 children diagnosed after 3 months of age, one or more reasons for the delay were reported in all cases. The most commonly reported reason for the delay in diagnosis among this group was the 'audiologist having difficulty getting a confirmed diagnosis'. Reasons provided are listed below:

- audiologist having difficulties getting a confirmed diagnoses (n=6);
- waiting time to see a hearing professional (n=2);
- parents not attending appointments (n=5) or parents had no concern (n=1); and
- ongoing middle ear dysfunction/disease (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 programme⁴².

Ten of the children identified with hearing loss during 2012 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 cases of hearing loss.

When those with a known acquired hearing loss are removed from this group, the ten cases identified drops to seven. This figure drops further to five when cases which may have been present at birth are removedⁱ.

Of these cases, there was one identified which was thought to have been present at birth and which was not an acquired hearing loss.

This case is a confirmed false negative, and was reported as being due to tester failure. This case was found as a result of the recall of 3,422 babies in 2012, 2,064 of whom had been incorrectly screened. Of these 901 children had been rescreened by November 28, 2012⁴³. There may be further false negative cases associated with these problems which have not yet had their hearing loss identified due to the low rescreening rate.

Cases included in the potential false negative category (below) may be due to deviation from the protocol on the part of the screener, hearing loss being progressive or acquired or because the screening technology and/or protocol did not identify a child with a milder hearing loss or one with an unusual configuration.

	2010	2011	2012
Total cases identified by year who were screened previously (i.e. are not referrals from the UNHSEIP) and who passed this screening	3	11	10
Number of potential false negatives from regional screening programmes or from the UNHSEIP (cases of acquired loss [3] and those not thought to be present at birth are removed)	3	5	5

TABLE 8: POTENTIAL FALSE NEGATIVES AND CASES PREVIOUSLY REFERRED FROM HEARING SCREENING

ⁱ Audiologists completing the notification form were asked to answer 'yes', 'no' or 'unsure' to the question 'Was the hearing loss thought to have been present at birth?'. This provides only a rough indication as we cannot know whether the hearing loss was indeed present at birth.

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 9 months. While this is a significant average delay between first suspicion of a hearing loss and confirmation of this loss, this figure is much improved on previous years. A great deal of this improvement is likely to be due to the introduction of newborn hearing screening throughout New Zealand.

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 remains at 52 months as shown in Table 9, belowⁱ.

Year	Age in months at confirmation of hearing loss	Delay in months
2012	52	9
2011	52	20
2010	50	19
2005	33	10
2004	45	14
2003	46	11
2002	35	11

TABLE 9: DELAY COMPARISONS WITH PREVIOUS DATA (EXCLUDING ACQUIRED, UNILATERAL, BORN OVERSEAS AND MILD LOSSES)

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 2012, 54% of notifications contained one or more reasons for the delay in identifying the child or young person's hearing loss. Of the 2012 notifications, 21 had two reasons listed for the delay, while ten had two or more 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 2012 related to difficulties the audiologist reported in 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.

ⁱ 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.

Reasons for delay	Number of cases where option selected 2010	Number of cases where option selected 2011	Number of cases where option selected 2012
Audiologist had difficulties getting a confirmed diagnosis (e.g. child unwell)	28	37	35
Parents did not attend appointments (for any reason)	12	18	29
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	27
Difficulty getting a referral to audiology (e.g. GP or other health professional dismissed parent concern and no referral was made)	8	13	8

TABLE 10: REASONS FOR DELAY BETWEEN SUSPICION AND CONFIRMATION OF HEARING LOSS 2010 AND 2011

Other common/important reasons for delay included:

- Parents suspected something other than hearing loss (n=14) or parents had no cause for concern (n=6)
- Follow up lost in the system (n=13)
- Ongoing middle ear disease (n=13)
- In two cases the delays were reported to be due to the ABR traces being misinterpreted, both these were bilateral hearing loss – as a result they were identified 40 and 41 months.

Three children referred from newborn hearing screening were diagnosed late (in 2012) as they never received an audiological assessment following referral from newborn hearing screening. This is lower than the six children in this category in 2011. One baby notified to the database was incorrectly screened and identified as a result of the recall mentioned previously.

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 10, above:

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

- *"Grommets inserted privately and no audiology referral [was] made."*
- *"Incorrect contact details on hospital system and with referral. No referral made to Audiology despite reported meningitis at 1 year of age. No notes on file, so child may have been at another DHB when this occurred and have been lost to follow-up."*
- *Child was initially referred by their GP to [DHB] Audiology in [redacted]. The family DNA's appointments in September 2009 and June 2010. They were finally seen in July 2010 results indicating type A tymps with absent DPOAEs and normal or near-normal soundfield results, but the reliability of responding was poor with many false positives. The family DNA'd a follow-up appointment in September 2010 and were discharged without follow-up. They subsequently moved to [another area] and were re-referred by a speech and language therapist in August 2012. They attended further appointments that resulted in today's diagnosis.*
- *Multiple professionals involved and an ABR under GA had to be arranged in a different city (Baby has high needs)*
- *The initial diagnostic ABR was incomplete as the baby woke. His mother did not want to do another ABR but rather opted to wait until the child was old enough for behavioural testing. Behavioural testing proved challenging due to limited attention span and persistent glue ear (along with non-tolerance of bone conductor).*

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 from the National Screening Unit (2009) Universal Newborn Hearing Screening and Early Intervention Programme National Policy and Quality Standardsⁱ.

Examining the four data points for each ear shows that this data was provided for 150 and 144 of the 187 cases notified to the database, for right and left ears respectively. Notifying audiologists are being encouraged to provide more audiometric data for cases being notified. Only cases where all 8 audiometric data points are present are able to be included for severity calculations, although in future years interpolation of data may be used where surrounding data-points are of the same value.

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 2.0 kHz were provided to audiologists on the online notification formⁱⁱ.

76% of cases notified contained data taken from the behavioural pure tone audiogram, with the remaining 24% based on the ABR.

As shown in Table 11, below, this figure is dropping slowly, from 79% in 2010 to 76% in 2011. This is likely to be an indication that fewer children being assessed are old enough to have their hearing assessed behaviourally. We would hope to see this figure drop further in future years as newborn hearing screening programme coverage rates continue to 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%
2012	76%	24%

TABLE 11: AUDIOMETRIC DATA SOURCE (2010-2012)

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.

ⁱ Correction factors: 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

ⁱⁱ 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 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 was insufficient to allow comparisons to be made easily with data from other jurisdictions. From 2010, the re-launched database has requested full audiometric data from audiologists notifying cases in the hope that more meaningful comparisons can now be made with overseas data.

Table 12 shows some of the differences between local and overseas severity classifications. (These systems use an average of the pure-tone thresholds at 0.5 kHz, 1.0 kHz, 2.0 kHz and 4.0 kHz.) 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) ⁴⁴	Jerger and Jerger (ASHA) ⁴⁵	World Health Organisation ⁴⁶	CDC ⁴⁷	Proposed code from Davis and Davis (2011)
Normal			-10-15dBHL		≤25dBHL		
Slight			16-25dHBL	0-20dBHL	26-40dBHL		
Mild	26-40dBHL	30-55dBHL	26-40dHBL	20-40dBHL		21-40dBHL	30-39 dBHL
Moderate	41-65dBHL		41-55dHBL	40-60dBHL	41-60dBHL	41-70dBHL	40-69 dBHL
Moderately Severe		56-85dBHL	56-70dHBL				
Severe	66-95dBHL		71-90dHBL	60-80dBHL	61-80dBHL	71-90dBHL	70-94 dBHL
Profound	>95dBHL	≥86dBHL	≥91dBHL	≥81dBHL	≥81dBHL	≥91dBHL	95+ dBHL

TABLE 12: 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 or whether interpolation or averaging over fewer frequencies was used.

Table 13 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 and only hearing impaired ear, for unilateral losses only.

Severity for recent notifications

Calculations in Table 13, 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.

Categories are based on...

Degree of loss using ASHA severity codeframe	Better ear			Worse ear		
	Bilateral 2010	Bilateral 2011	Bilateral 2012	Unilateral 2010	Unilateral 2011	Unilateral 2012
mild	56%	61%	52%	54%	43%	48%
moderate	25%	21%	34%	19%	14%	21%
moderately severe	12%	9%	8%	11%	25%	6%
severe	2%	3%	1%	6%	5%	20%
profound	5%	7%	5%	11%	14%	5%

TABLE 13: COMPARISON OF SEVERITY CLASSIFICATIONS BASED ON METHODOLOGY

Figure 11 below, compares bilateral hearing loss data 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.

Please note, this data relates to the better hearing ear for those children and young people with bilateral hearing loss.

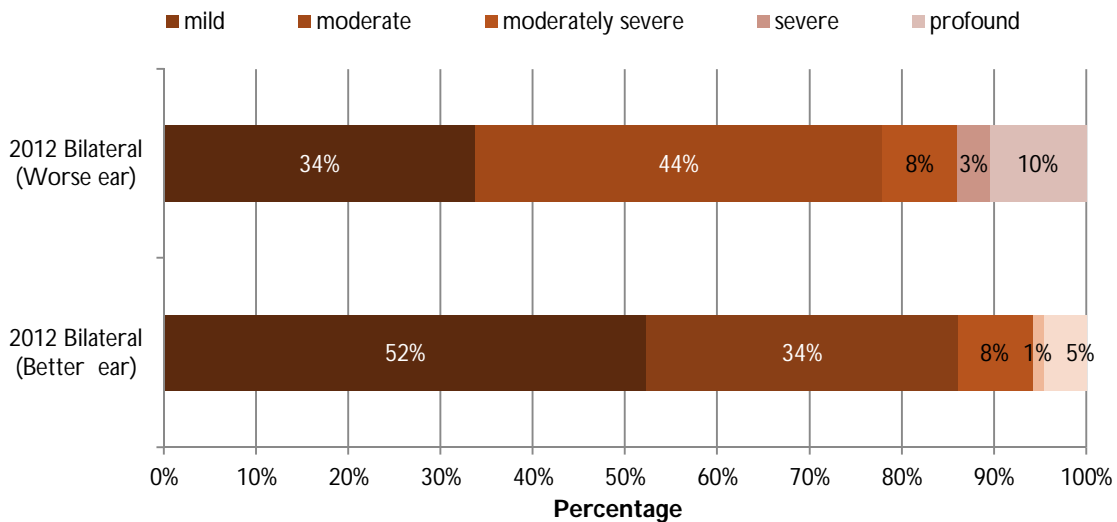


FIGURE 11: BILATERAL HEARING LOSS BY DEGREE (2012)

Figure 12 below, compares unilateral hearing loss data graphically, again using the ASHA Clark codeframe in common use by New Zealand audiologists. These data are categorised based on audiometric data from the hearing impaired ear. Those children and young people born both in New Zealand and overseas are included, but only those with complete audiometric data.

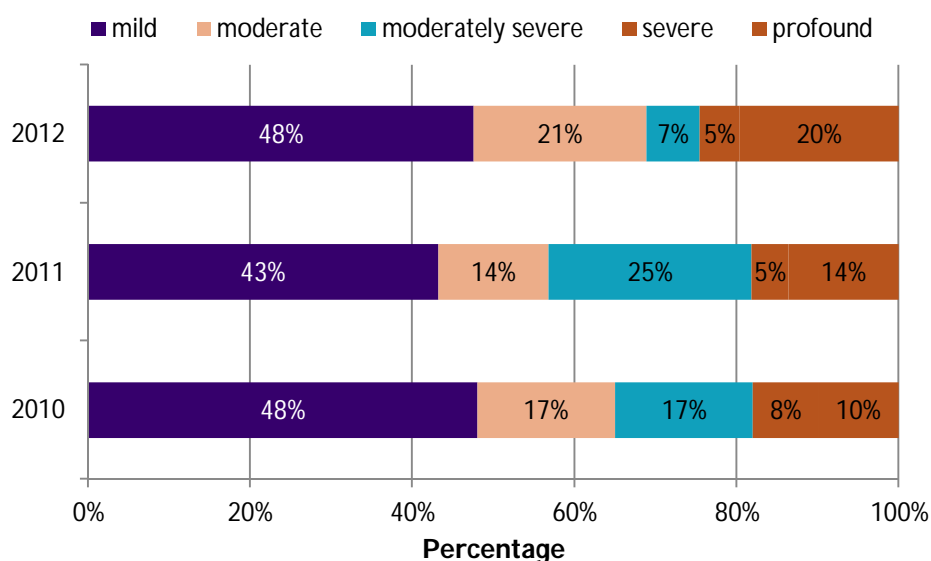


FIGURE 12: UNILATERAL HEARING LOSSES BY DEGREE (2010 AND 2011)

Severity profile differences between bilateral and unilateral hearing losses

A difference can be seen between the severity profile of bilateral hearing losses (less severe and profound losses and more moderate and mild losses) compared with unilateral hearing losses (more severe and profound losses and less moderate and mild losses). This is particularly the case when the comparison is made between unilateral losses and the better ear in cases of bilateral loss. Clearly these differences lessen when comparison is made with the worse ear in bilateral cases.

Other reasons for these differences may relate to:

- Unilateral hearing losses within the database, on average, found later than bilateral hearing losses and may have had more time to become more severe where these are progressive losses. Bilateral hearing losses are more likely to be identified more quickly and therefore have less time to progress.
- Low and mid frequency congenital hearing losses are more likely to be bilateral in nature and are more likely to be mild or moderate
- Unilateral hearing losses which are caused by environmental factors (for example those which develop during pregnancy) can result in a non-functioning ear, whereas those caused by genetic factors which are often bilateral in nature may affect one aspect of the hearing system but still allow some hearing to occur.

Comparisons with previous data

By categorising the notifications using the DND severity codeframe (1996-2005), a longitudinal comparison of the proportion of children in each group is possible using data reported between 1996 and 2005 and more recent data. Table 14, below, shows the proportion of hearing loss notifications in each category in 2010-2012 and compares this with data from 2001-2004ⁱ. 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.

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

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

This year, the authors of this report have altered the way we calculated severity, an in attempt 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.

Findings this year show a very small proportion of severe and profound hearing losses. Some reasons for the generally small proportion of more severe hearing losses are listed below:

- Some cases with audiometric data-points in the severe and profound range did not contain complete audiometric data and as a result severity could not be calculated and included in this reportⁱ.
- Often children diagnosed with hearing loss have a sloping hearing loss and the better thresholds drag up the average
- 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 loss⁴⁸. However, the reduction in the number of more severe cases is likely to be small.

It is interesting to note that some overseas data, including those contained in Figure 13 also indicates lower numbers in the severe category when compared with the profound category, even when the codeframes are standardised as they are in this case.

Table 14 compares proportions by severity with previous DND data. To do this some cases are removed – those with unilateral loss, born outside New Zealand and those known to have acquired hearing loss. For these reasons, these data cannot be compared with the full sample figures contained in the 2010 report.

Proportion of cases notified by degree of hearing loss	2001	2002	2003	2004	Average 2001-2004	2010	2011	2012
Mild	47%	47%	56%	43%	48%	59%	60%	54%
Moderate	35%	39%	33%	34%	35%	33%	28%	42%
Severe	10%	9%	6%	15%	10%	4%	5%	1%
Profound	8%	5%	5%	7%	6%	5%	3%	3%

TABLE 14: NOTIFICATIONS BY DEGREE OF HEARING LOSS USING 1996-2005 CLASSIFICATION SYSTEM, SELECTED CASES ONLY

For the purposes of this report, severity calculations require audiometric data in all four key frequencies - 0.5, 1.0, 2.0 and 4.0 kHz. Severity cannot be calculated for cases where full audiometric data is not provided.

One reason for the particularly low proportion of severe and profound hearing losses described below is that a disproportionate number of cases notified in 2012 which contained missing data (and to a lesser extent in 2010 and 2011) were likely to be classified as severe or profound. (For example, information was provided for one case which indicated a threshold of 110dB at 0.5, 2.0 and 4.0 kHz.)

Audiologists were approached about a number of cases, and were able to complete some missing information. Of the cases which still contained missing data, data is more commonly reported for 0.5 kHz and 2.0 kHz and less likely to be reported for 4.0 kHz and 1.0 kHz frequencies.

This demonstrates that frequencies which are to be tested at the end of the protocol are less likely to be complete (i.e. 4.0 kHz and 1.0 kHz).

ⁱ We have not been able to determine the criteria for calculating severity before 2006 making it difficult to attempt replication of the methods used.

Comparisons with international data

Considering cases with full audiometric data only, it would seem that New Zealand may have a smaller proportion of severe and profound losses than other similar countries. For example, the Figure 13 reproduces an analysis conducted by Davis and Davis (2011) showing the proportion of hearing losses of moderate or greater severity across three jurisdictions (UK, Finland and the US) and compares these with those reported in NZ's DND between 2010 and 2012.

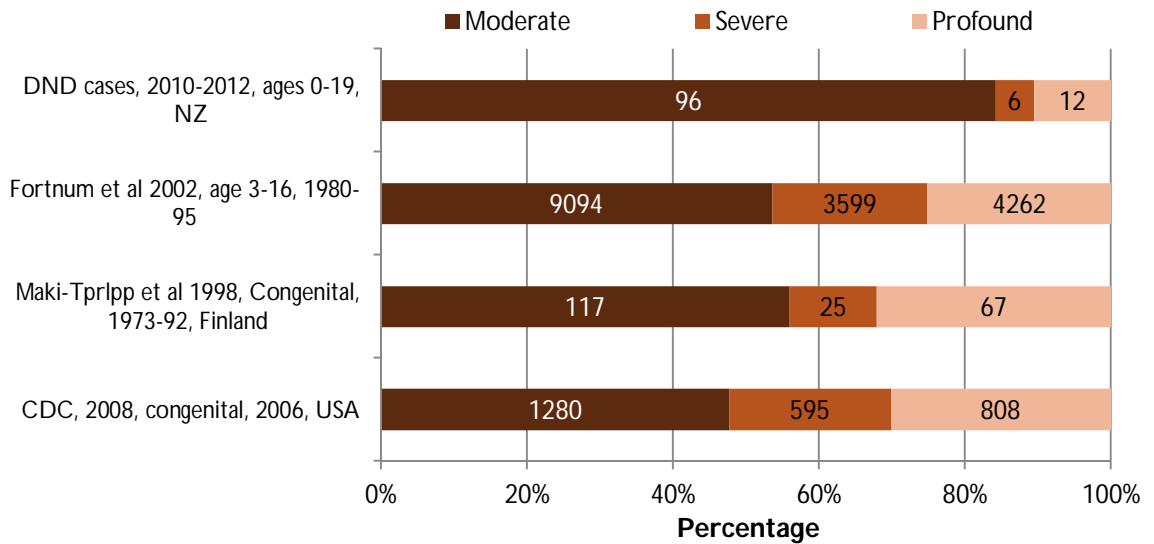


FIGURE 13: COMPARISON OF HEARING LOSS PROFILE BY DEGREE AND JURISDICTION, ADAPTED FROM DAVIS AND DAVIS (2011)

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 14 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 samples have been excluded from this figure as they contained particularly small samples.

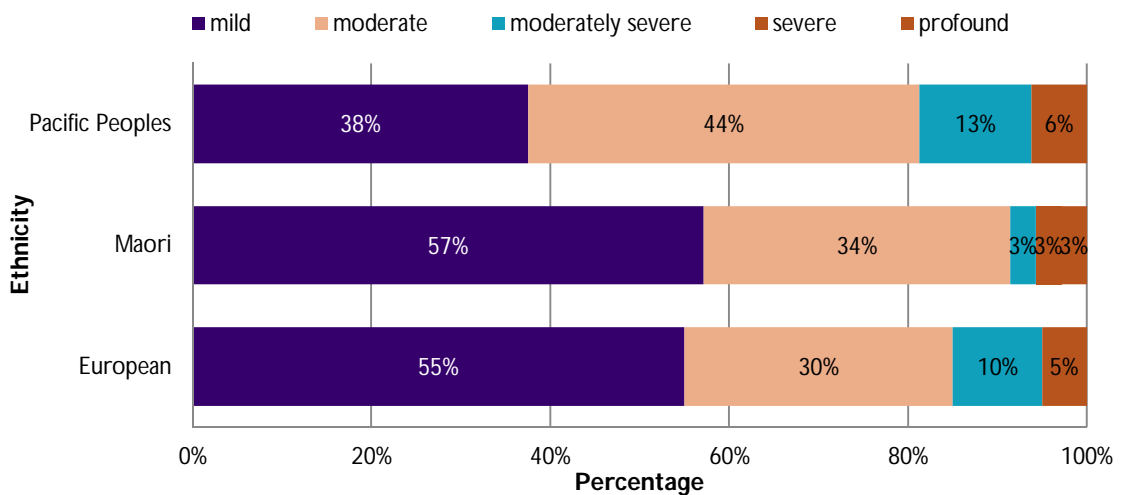


FIGURE 14: 2012 BILATERAL NOTIFICATIONS BY DEGREE AND ETHNICITY

Hearing aids and cochlear implants

Hearing aids

As was the case with 2010 and 2011 data, the majority of children and young people with a hearing loss which was first diagnosed in 2012 are to be fitted with two hearing aids.

Figure 15 below, shows the number of hearing aids fitted or to be fitted by notification year. 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 in order to provide amplification. The proportion of cases where there is uncertainty around whether hearing aids are to be fitted may also signal this.

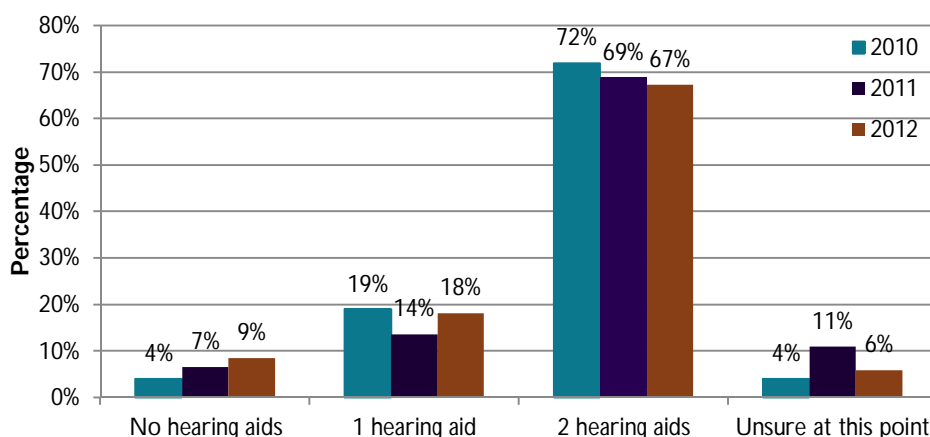


FIGURE 15: NUMBER OF HEARING AIDS TO BE FITTED (2010 AND 2011)

It is worth noting that some children with unilateral hearing losses were reported to be receiving more than one hearing aid. This is because although the average threshold for the better ear does not meet the 26dBHL average required for inclusion in the databaseⁱ, 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.

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

ⁱ Over the four audiometric frequencies: .05, 1.0, 2.0 and 4.0kHz

Funding for hearing aids

In an attempt to provide some context for these figures, data provided by the Accessable are shown below. Please note, these data pertain to all children receiving hearing aids, not those receiving hearing aids for the first time.

This shows MOH funded hearing aids for children and young people⁴⁹ during the 2012 calendar year. A total of 1,613 service users (adults and children) received hearing aids during this period, which corresponds to the reporting period for the DND.

Ethnicity	0-3 years	4-5 years	6-15 years	16-18 years	Total 0-18 years
NZ European	115	92	367	81	655
NZ Māori	76	79	355	28	538
Pacific	21	22	135	14	192
Other	22	33	155	18	228
Total	234	226	1012	141	1613ⁱ

TABLE 15: ACCESSABLE STATISTICS ON MOH FUNDING OF CHILDREN'S HEARING AIDS FOR FINANCIAL YEAR ENDING 30TH JUNE 2011

Cochlear Implants

Although we don't 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.

A single cochlear implant is funded by the Ministry of Health for all children and young people who meet the candidacy criteria. In cases where children have been deafened by meningitis, children receive two internal arrays and one processor.

Funding from the Ministry of Health 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 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.

ⁱ This data has not been compared to previous data as it pertains to the previous calendar year, rather than the financial year as last year's data did. Up to the end of June 2011, 1543 children received funding for hearing aids.

During the 2012 calendar year there were 13 cochlear implants provided in the Northern Region and 18 in the Southern Region to children and young people under the age of 19. These unilateral implants are provided based on clinical need meaning there is no waiting list for children who may benefit from a cochlear implant.

Cochlear Implant Trust	Year ending 31 December 2012	Year ending 31 December 2011	Year ending 31 December 2010
Northern Cochlear Implant Trust ⁵⁰	13	16	17
Southern Hearing Charitable Trust ⁵¹	18	17	18
Total publicly funded new implants in NZ	31	33	35

TABLE 16: PUBLICLY FUNDED COCHLEAR IMPLANTS IN NZⁱ

During this same period there were 5 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.

ⁱ In some years the number of cochlear implant provided exceeds the number of profound or severe cases notified to the database. 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 reported in 2011 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.

Appendix A: History of the database

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.

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)⁵².”

There was a strong view among audiologists consulted that the previous definition (above) which was used before 2006, 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 groupⁱ.

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.

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

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*ⁱ
- 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 database, to try and increase consistency in the types of losses notified:

- 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

Notifying cases

Although the Database was restarted by the New Zealand Audiological Society, efforts have been and continue to be 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.

Future renaming of the database

During 2012, feedback on the name of the database was sought from parents of deaf children, Advisors on Deaf Children (AODCs) and audiologists. This feedback did not provide a clear path for renaming the database.

Some individuals and groups felt that changing the name to a broader title, such as the Hearing Loss Notification Database, would have merit, as it would acknowledge the range of types and severity range of hearing losses included. Others felt changing the name of the database could cause confusion and reduce the number of notifications in the short term.

Despite our efforts, the name of the database (Deafness Notification Database) remains up for consideration. 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 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.

ⁱ 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 at risk of poorer educational outcomes.

Appendix B: 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. After receiving eight completed notifications from July until December 2011, ten notifications were received for the 2012 year.

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 2012.

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

- 60% of these 2012 cases were reported as being of Māori ethnicity, as were 63% in 2011
- Years of birth for this sample ranged from 2000 to 2009
- Eight of the children/young people notified in this category were born in New Zealand, with birthplace of the remaining two being uncertain
- Half of the children and young people notified to this category were to receive one or two hearing aids
- Eight of the ten children had a hearing loss in their right ears, while nine of the ten had hearing loss in their left ears
- In three of the ten 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)

The figures below show the audiometric data for the ten children or young people with high frequency hearing losses, contained within this category. Please note that not all children and young people in this category had hearing loss in both ears, and not all audiometric data points were provided for all children.

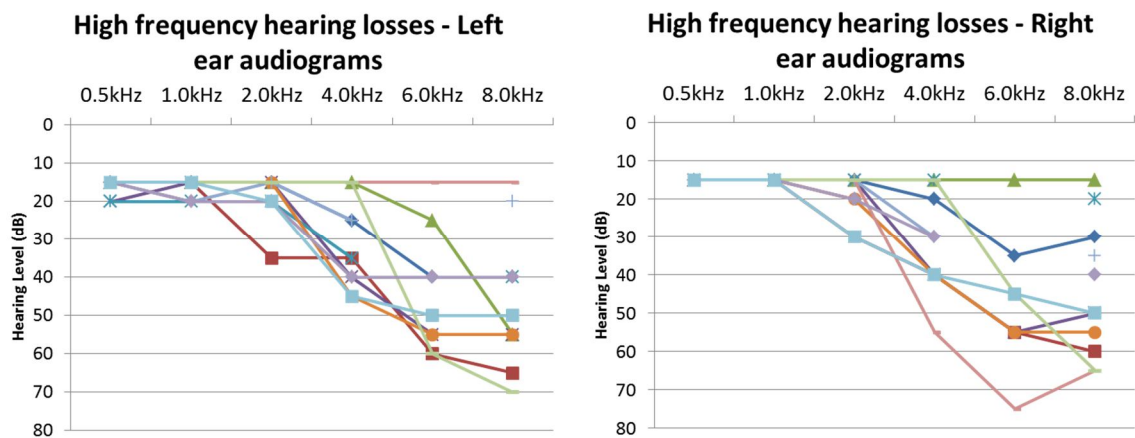


FIGURE 16: 2012 AUDIOGRAM DATA FROM HIGH FREQUENCY HEARING LOSSES FOR RIGHT AND LEFT EARS

We will continue to trial inclusion of this special group within the database during 2013.

Appendix C: 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.)

In 2010, when the database was re-launched, changes were made to this question to try and gain more specific responses about the nature of the family history.

Of the 28% of 2012 cases where a family history was specified, 63% 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 94% 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 3% of cases. This leaves the remaining 4% of cases where the relative no longer had the hearing lossⁱ.
- The majority of these family members use/used one or more hearing aid or cochlear implant (53%), while 44% 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 (63%) had their hearing loss from childhood while 13% did not, and the families were unsure in 25% of cases

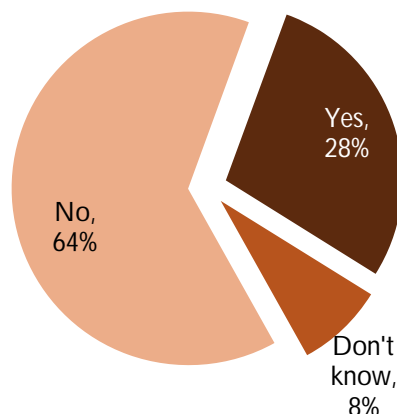


FIGURE 17: IS THERE A FAMILY HISTORY OF HEARING LOSS (2012, ALL CASES)

ⁱ These figures are rounded and hence do not total 100%.

Appendix D: 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 grouping⁵³. 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.

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⁵² Northern JL, Downs MP (1984) Hearing in Children, Williams & Wilkins.

⁵³ Statistics New Zealand (2009) Final report of a review of the official ethnicity statistical standard: 2009. Wellington.