# Deafness Notification Report 2024

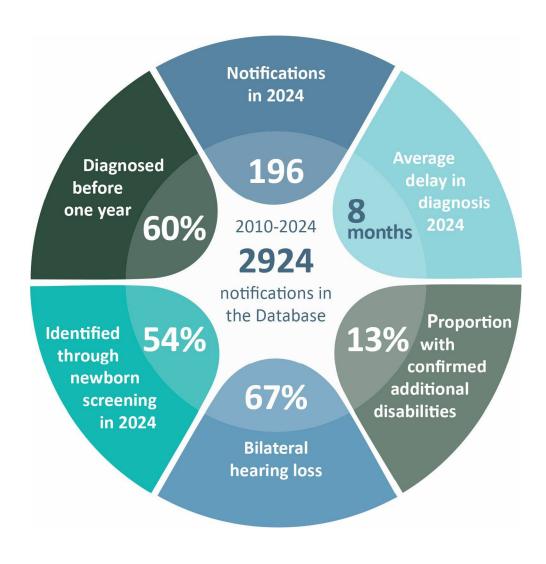
Rīpoata Whakamōhiotanga Turi



Janet Digby, Levare Limited August 2025 Enable

# **Summary**

# Whakarāpopoto Ngā



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# **The Deafness Notification Database**

# Te Pātengi Raraunga Whakamōhiotanga Turi

- Our sincere thanks to <u>mātua</u> (parents)/<u>kaitiaki</u> (caregivers) and <u>rangatahi</u> (young people) who
  consented to share details of their child's/their own hearing loss (HL), and to the many clinicians
  around the motu (country) for notifying cases with such care and attention.
- Understanding about children and young people diagnosed in Aotearoa New Zealand and their hearing has grown considerably, because of information shared.
- These reports aim to inform clinicians, decision-makers and researchers and so they can benefit those diagnosed in the future, and their <a href="https://www.mbanau">whānau</a>, helping them to thrive.

#### Welcome and introduction

Nau mai, haere mai ki tēnei rīpoata ā-tau e whakaahua ana i ngā whakamōhiotanga ki te Pātengi Raraunga Whakamōhiotanga Turi o Aotearoa (DND). Ka tāpaetia atu tēnei rīpoata i runga i te manawanui me te whakamihi ki ngā whānau tonu i koha mai i ā rātau raraunga. E whakamihi ana ngā kaituhi ki ngā iwi taketake o te motu me te tokomaha tāngata e taki whai wāhi mai ana ki ngā mahi nei.

Kei tēnei rīpoata ko ngā mōhiohio mō ngā tamariki me ngā rangatahi kua whakatauria e turi niwaniwa ana mai i 2010 tae mai ki te mutunga o 2024. Ko tāna kaupapa he whakamōhiohio i ngā mahi whai take a te hunga e mahi ana puta noa i te motu ki te whakaahei i ngā tamariki turi, āhua turi hoki me ō rātau whānau kia taurikura. Te ora me te oranga ki a tātau katoa.

A warm welcome to this annual report describing notifications to the New Zealand Deafness Notification Database (DND) between 2010 and the end of 2024. Its purpose is to inform the valued work of those around the nation to enable all deaf and hard-of-hearing children, and their whānau, to thrive. This report is presented with respect and with gratitude particularly to whānau who gift us their data. The authors acknowledge the indigenous people of this land and the many connected people who have and continue to contribute to this work. ightharpoonup p59

The Database was established in 1982 and now includes children and young people 18 years or younger, born in Aotearoa New Zealand or overseas, with a permanent hearing loss (HL) in one or both ears. Where parents/ caregivers or rangatahi consent, audiologists and audiometrists from around the country <u>make a notification</u> following the child or young person's diagnosis.

Annual DND reports offer information about children and young people diagnosed, their characteristics and those of their hearing, diagnosis and intervention. They are created to inform the mahi (work) of clinicians, educators, officials and policymakers around the <a href="motu">motu</a> to further enable all deaf and hard-of-hearing children and their whānau to thrive. Thriving tamariki are at the heart of a flourishing future for us all.

## **Acknowledgements**

We extend sincere and heartfelt thanks to the 196 parents, caregivers and young people who consented to share details with the Database in 2024. As a result of their willingness to share basic diagnostic information, clinicians, service providers and other decision-makers can be better informed so they can better serve the needs of children, young people and their whānau.

Audiologists and audiometrists from around the country make notifications following diagnosis of a child or young person with hearing loss. It is clear from how this is done, including by departments under strain, that diagnosing clinicians care deeply about the wellbeing of children and their whānau.

This report is possible because of funding from Te Manatū Whakahiato Ora - Ministry for Social Development's Disability Support Services, through its contract with EnableNZ.

The primary author of these reports gratefully acknowledges the support and guidance of co-authors Professor Suzanne Purdy (Te Rarawa, Ngãi Takoto) of the University of Auckland and Dr Andrea Kelly of Te Whatu Ora Te Auckland. The authors are grateful to Alexia Searchfield for additional analyses and to all contributions to the reports now and in previous years. Ngã mihi maioha ki a koutou katoa.

# **Perspectives**

There are various perspectives or lenses through which one can view hearing and deafness, including those of the Deaf community, Māori and Pacific communities. Awareness of such perspectives can inform clinical practice and decision making with a view to reducing inequities in access to and through the health and education systems. The authors of this report acknowledge a focus on western and health perspectives, with an equity lens, within this series of reports.  $\longrightarrow p56$ 

## These reports

#### Visual cues

All reports can be found on the New Zealand Audiological Society <u>website</u>. Further information can be found in the Glossary (p6969) and appendices (p54). Appendix A sections relate to the DND while Appendix B includes information about other specific topics.

Where tables and figures contain data from external sources the dominant colour is grey as with blocks of text from external sources.



• Read more icons look like this. These are linked for those reading electronic versions.

#### Significance and interpreting odds ratios

Odds ratios (OR) are used in this report to compare the likelihood of a variable being present in one group with the likelihood of it happening in another group. Confidence intervals are all calculated at 95%, and differences that are significant to that level are described. No p-values are included in this report though these can be provided on request. Where ratios are provided, those less than 1.0 show a lower probability of a specific outcome, while those greater than 1.0 indicates a higher probability.

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# Overview of children/young people notified

# Tirohanga whānui ki ngā tamariki/rangatahi kua whakamōhiotia

- Notifications were made for 196 children and young people diagnosed during 2024, most of whom have <u>bilateral</u> hearing loss (HL).
- The largest number of notifications to the DND are listed as European, though numbers have dropped since 2010, while for Asian <u>tamariki</u> numbers has risen, both in line with population changes.
   European children are underrepresented in notifications given their relative population size.
- Māori are overrepresented in notifications based on their population, and they are more likely to have bilateral or mixed hearing losses.

#### **General information**

One hundred and ninety-six children and young people diagnosed during 2024, and whose hearing losses met the <u>criteria for inclusion</u>, had their information notified to the Database by the middle of March 2025. There are now data for 2,924 children and young people included in the main dataset that forms the basis for analysis in this report. These notifications were received from 18 of the 19 <u>districts</u> around the motu.

#### **Number of notifications**

In summary, for 2010-2024 European children are under-represented and Māori overrepresented within notifications, relative to their population size. Notifications for Europeans have fallen by half during that period and those for Asians have tripled, in line with their changing proportions in the population<sup>i</sup>. Notifications are highly dependent on deprivation, increasing as deprivation rises. The proportion of children under the age of one diagnosed with hearing loss has more than quadrupled since 2010, because of the implementation of newborn hearing screening programmes around the country.

The downward trend in notifications from 2019 has reversed in 2024<sup>ii</sup>. The authors believe this is due to an increase in reporting rather than an increase in the number of diagnoses. Thanks to the Health NZ Audiology Leaders Group and district teams for their efforts to increase notifications in 2024.

#### **Key factors are thought to influence notification levels by year and location:**

ethnic, age, socioeconomic and population profiles of each district over time

number of tamariki diagnosed each year

number of hearing professionals working within each district, their workloads, understanding and ability to notify cases to the Database

dates of diagnosis, and whether consent korero are appropriate at the time of diagnosis

**Table 1: Factors influencing notification levels** 

i Note that there is a strong concentration of Asian families in Auckland and Waitematā districts, more than double the average proportion for the whole country.

ii Since 2010, these totals may differ from the number of notifications contained in each report as notifications can be submitted after the cut-off date.

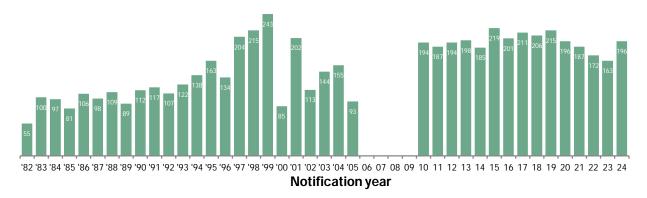


Figure 1: Notifications by year 1982-2005 and 2010-2024i

# **Geographical representation**

The proportion of 2010-2024 notifications are compared with the percentage of the population under the age of 20 from the 2018 Census and the percentage of 2024 notifications from each district in Table 2.

District	Percentage of population under the age of 20 (Statistics NZ, 2018 Census¹)	Percentage of notifications received in 2024 (under 19 years)	Percentage of notifications received 2010-2024 (under 19 years)
Auckland	9%	4%	6%
Bay of Plenty	5%	8%	7%
Canterbury	11%	21%	13%
Capital, Coast, Hutt Valleyii	9%	8%	12%
Counties Manukau	13%	13%	13%
Hawke's Bay	4%	7%	3%
Lakes	3%	3%	3%
Midcentral	4%	1%	2%
Nelson Marlborough	3%	3%	3%
Northland	4%	5%	6%
South Canterbury	1%	2%	2%
Southern	6%	6%	7%
Tairāwhiti	1%	1%	3%
Taranaki	3%	3%	3%
Waikato	9%	8%	9%
Wairarapa	1%	1%	1%
Waitematā	13%	6%	5%
West Coast	1%	0%	1%
Whanganui	1%	1%	1%

Table 2: Estimated percentage of population under 20 years of age by district (2018 Census, using DHB populations) compared with percentage of notifications (2024) and (2010-2024)<sup>||||</sup>

i The Database was not operating between 2006 and 2009.

ii Hutt Valley and Capital and Coast notifications are now reported under "Capital, Coast and Hutt Valley", to reflect the newly formed District, meaning there are now only 19 districts in the list.

iii The difference in age ranges reflects the range of easily available population data from the 2018 Census. Also note that historically, many clinicians believed there has been a preponderance of deafness in Auckland and Christchurch as families have moved to these places from the regions, so their tamariki attend Kelston Deaf Education Centre (Auckland) or van Asch Deaf Education Centre (Christchurch).

## **Ethnicity**

#### **Recording ethnicity**

Ethnicity options available on the notification form are: European<sup>i</sup>, Māori, Pacific Peoples, Asian, and Middle Eastern, Latin American and African (MELAA),<sup>ii</sup> and families and young people can choose all groups that apply<sup>iii</sup>. Most notifications (89%) contain one code, and a smaller proportion contain two, three or four codes (9.5%, 0.7% and 0.04%), respectively<sup>iv</sup>.

In these reports, use of aggregated ethnicity codes aims to reduce the burden on notifying professionals<sup>v</sup>. The reliance on top-level ethnicity codes is limiting for several reasons, including that it masks differences within subgroups. Such differences are likely to be more significant for those from Pacific, Asian and MELAA groups, which are far from homogenous.  $\longrightarrow p59$ 

#### **Prevalence of hearing loss**

Most notifications provided to the Database since its re-launch in 2010 relate to tamariki of European and/or Māori ethnicity. Comparing notification rates for Māori with their population size for under 20s from the 2023 Census (Figure 2) shows there are fewer notifications for European children and young people than would be expected, and more Māori than expected, given their population sizes. Notifications for Pacific Peoples, Asian and MELAA are notified in approximately the same proportion as would be expected by their populations under 19 years of age.

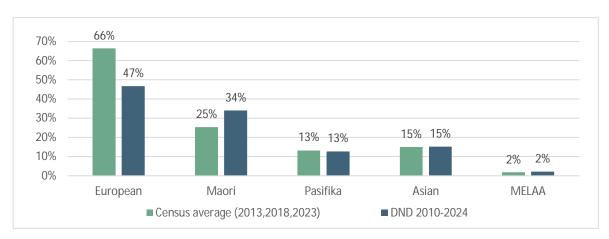


Figure 2: Average population by ethnicity for under 20-year-olds (from the 2013, 2018 and 2023 Censuses) compared with DND notification rates 2010-2024<sup>vi</sup>

i The term European is used in this report to mean all those of European descent. Most notifications to the Database are for those born in New Zealand, i.e. are 'New Zealand European'.

ii The MELAA category relates to people of Middle Eastern, Latin American or African ethnicity. An 'other' category is also listed for situations where the notifying audiologist is unsure which category a specific ethnicity falls into. These are re-coded using Statistics New Zealand's Ethnicity Classification's Level 1 codes, before analysis.

iii This system of coding (total response) is a more complete reflection of ethnicity than those that either force participants to provide one code or use a prioritisation framework to re-code for ethnicity, allowing only one ethnicity code per participant.

iv A little over 1% of notifications do not contain any ethnicity code and this number has fallen over time.

v Ideally, while we would like to ask notifying clinicians to provide detailed information on ethnicity, ethnicity coding is not that easy to get right without training and, as we are relying on the help of busy clinicians to provide notifications, we don't want to make notifying cases more onerous.

vi Multi-code 2013, 2018 and 2023 Census data are included for comparison in Figure 6. As individuals can, through this method, identify (or be identified by their parents) as belonging to more than one ethnicity, the totals generally add to more than 100%. DND data are also multicode.

While there has been no definitive prevalence survey to determine rates of hearing loss (HL) among children and young people in Aotearoa New Zealand, research adds to our understanding of likely differences between specific groups:

- numerous sources, including the DND, indicate Māori children are very likely to have higher prevalence of hearing loss, often measured against rates in the general population or with their European counterparts (see Prevalence and ethnicity from p65); and
- several sources support higher rates of hearing loss among Pacific populations.

However, Māori and Pacific may still be underrepresented among notifications as some hearing losses, particularly those that are milder, may go undiagnosed, and as these groups have poorer access to and through the health system. • 2021 report and from p65

#### Gender

#### **Background**

In overseas research, males are commonly found to have higher rates of hearing loss than females. Reported figures range between 51.5% and 58% for males (1:1.06 and 1:1.38<sup>2, 3</sup>).

Hearing Australia's most recent data on those under the age of 26 who have hearing aids or <u>cochlear implants</u> show a similar pattern, with higher numbers of hearing loss among males (51.2%) than females (48.6%) with a smaller proportion being intersex (0.1%)<sup>4, i</sup>.

#### **DND** data

This pattern is also found here in Aotearoa with 45% of 2010-24 notifications listed as female and 55% male, with one case listed as other or non-binary (1:1.22). This difference can be seen across all ethnic groups and was greatest in 2016 and 2020, when it was  $\approx 1:1.33$ .

When considering that male babies were more common among 2021-2023 births (1:1.053<sup>5</sup>), more notifications of hearing loss are still reported for males than expected if incidence was equal by gender.

## **Birthplace**

Notifying professionals were uncertain about the location of a child's birth in a high of 12% of cases in 2010, dropping to 1-4% in 2017-2024.

During 2010-2024, the great majority of children notified were born in Aotearoa New Zealand, with the rate varying between three and nine percent during this time. Nine percent of 2024's notifications were known to be born outside Aotearoa New Zealand.

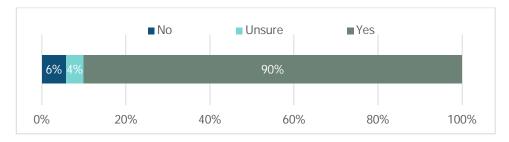


Figure 3: Proportion of children notified born in Aotearoa New Zealand (2010-2024)

i The 2021 Australian Hearing report noted a predominance of females among 21–25-year-olds. This analysis is not described in the 2022 report, and no 2023 or 2024 reports appeared to be available at the time of writing.

#### **Additional Disabilities**

#### **Background**

A disability is any condition that makes it more difficult for a person to do certain activities or effectively interact with the world around them (socially or materially)<sup>i</sup>. Children may have one or several additional disabilities (ADs) and these can vary between individuals in both presentation and degree, making descriptives and comparisons challenging.

Estimates of the global burden of childhood disability from 2020 suggest that more than one in ten children and adolescents are affected by epilepsy, intellectual disability, vision, or hearing loss. When other conditions are included, this figure will rise<sup>6</sup>.

It is difficult to compare reported rates of additional disabilities, including for children who are hard-of-hearing, as the definitions for both hearing loss and disabilities differ and are not always described in the literature. A selection of studies from various jurisdictions shows very large variance in rates (4-57%), as described in previous DND reports.

Children with hearing loss are thought to have a high rate of additional disabilities, particularly those that are developmental<sup>7</sup> as many risk factors for hearing loss also predispose children to other conditions. Rates of additional disabilities among children with hearing loss are particularly high among those with a syndrome.

Outcomes for children who are hearing impaired and have additional disabilities are difficult to characterise due to their range, type and severity, 8 though diagnosis of a specific syndrome may provide an indication of expectations where formal assessment isn't possible 9.

The presence of one or more disabilities can place an additional burden on families and can have a significant impact on outcomes for tamariki, and on the level of support they may require, particularly from *Learning Support Services*, Ministry of Education | Te Tāhuhu o te Mātauranga.

High immunisation coverage had been associated with a reduction in the incidence of vaccine preventable diseases such as measles and mumps, which can result in disabilities including hearing loss. Specific hearing loss aetiologies, including hereditary syndromes, maternal infections, prematurity and meningitis, result in a higher likelihood of specific 'concomitant' disabilities. ightharpoonup p59

#### **DND** data

The widest definition of AD is used within the DND. Of the children and young people in the Database (2010-2024), the majority (76%) have no 'additional disability' listed. Thirteen percent have one or more confirmed additional disability(ies)<sup>ii</sup>. Rates of confirmed and unconfirmed cases with an AD fluctuate between 16% and 29% of all cases between 2010 and 2024.

Since implementation of newborn hearing screening around the motu, the declining average age of diagnosis has likely reduced the proportion of additional disabilities that are diagnosed by the time notifications are made. Figure 4 shows that confirmed plus suspected cases during 2010-2024 are roughly similar to the proportion of confirmed cases in the earlier iteration of the Database.

i Children with such additional disabilities are sometimes referred to as being 'deaf plus' or Deaf with Disabilities (DWD). Suggestions for an inclusive term are welcome.

ii Higher numbers of cases are shown in many years compared with previous figures because those who are listed in other parts of the notification form as having atresia and/or microtia are now included within the 'yes' category, regardless of the response to this question on the notification form. Most children listed with an additional disability have one listed, while smaller numbers have two to five recorded.

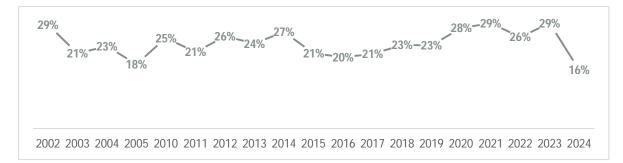


Figure 4: Proportion of notified cases with a confirmed AD (2002-2005) and with a confirmed plus potential AD (2010-2024)

Comparisons between DND figures and those from other jurisdictions are problematic due to definitional challenges and as DND data showing the proportion of children with an AD are 'point in time' figures at the time of the hearing loss diagnosis.

The considerable variety of reported conditions contained in the DND include specific syndromes, cerebral palsy, general or global developmental delays, intellectual disability, and vision problems<sup>10, i</sup>.

The most common types are syndromic (n=99) neuro-developmental (n=92), followed by medical (n=90), with smaller numbers with confirmed medical developmental (n=56) and neurological (n=34) conditions.

Among children with one or more AD, significant differences exist with:

- these children are diagnosed later (an average of 13 months) than those without;
- these children are 1.5 times more likely to be European (compared with non-European);
- children more likely to have a bilateral (2.8 times), permanent conductive (2.6 times), or mixed (1.5 times) HL; and
- children are half as likely to have sensorineural HL or a close family history of HL.

Additional disability	Average percentage
Yes, one or more confirmed ADs	13%
Unsure whether AD exists, no confirmed diagnosis	11%
No additional disability	76%

Table 3: Proportion of cases by additional disability status (2010-2024)

## i Clinicians should keep in mind that:

- children with ADs find compensation for loss of hearing more difficult<sup>10</sup> and tend to begin intervention later<sup>11</sup>;
- children with autism, cerebral palsy, and/or developmental delay show poorer average outcomes compared with those with vision or speech output impairments, syndromes not entailing developmental delay, or medical disorders<sup>8</sup>;
- earlier identification, earlier fitting of hearing aids, lesser hearing loss, higher cognitive ability, use of speech for communication, and higher level of maternal education<sup>12</sup> have been found to positively impact language outcomes.

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

# **Identification of hearing losses**

# Te tautuhi i ngā take i turi ai

- Hearing loss may be present at birth or develop at any time; as a result, the overall identification age
  of children is only somewhat related to how well systems are working to identify children with
  hearing loss.
- Prior to implementation of newborn hearing screening, the average age of tamariki across Aotearoa
  New Zealand at the time of diagnosis was very late by international standards. Since, there has been a
  surge in the number of Aotearoa New Zealand tamariki whose hearing loss is identified before one
  year of age.
- Groups identified later are those born overseas, those with one or more additional disabilities, milder degrees of hearing loss, or acquired and or unilateral hearing loss, Pacific children and those living in higher deprivation areas.
- European children are less likely to have a hearing loss thought to be present at birth, while Māori and Asian children are more likely. Pacific, Māori and European children and young people have the latest average ages of identification.
- Pacific children and young people have later average ages of diagnosis compared with other ethnicities; this difference is very close to significance.
- For the first time in eight years, Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP) monitoring data for the current year has been made available and is summarised in this report.
- B4 School Check coverage has fallen from historically higher levels in recent years and is particularly poor for Pacific and Māori tamariki.

# Groups first suspecting the child's hearing loss

Information on who first suspected the child or young person's hearing loss is summarised in Table 4, which shows the top three groups that first suspected the hearing loss among notified cases *during selected years* since 2010.

Behavioural methods relied upon by professionals some years ago for identifying a hearing loss were not an accurate method of screening for hearing loss in infants<sup>13, 14, 15</sup> and it is difficult for parents to identify hearing loss in their child, particular for unilateral or milder degrees of hearing loss.

It is pleasing that the move towards use of objective approaches to identify newborns with hearing loss, reducing reliance on behavioural methods and parental suspicion, has resulted in earlier average ages of diagnosis and intervention.

	2010	2021-24	2024
Most likely	Parent or caregiver screener (37%)	Newborn hearing screener (64%)	Newborn hearing screener (77%)
Second most likely	<u>VHT</u> (17%)	VHT (10%)	VHT (6%)
Third most likely	Medical professional (10%)	Parent or caregiver, audiologist (6%)	Parent or caregiver (5%)

Table 4: Top three groups most likely to first suspect hearing loss (Selected periods, for tamariki born in Aotearoa New Zealand, 2010-2024)

# Age at diagnosis

Aotearoa New Zealand had a very high average age of identification when compared with similar jurisdictions prior to the nationwide implementation of universal newborn hearing screening. Following implementation, a significant rise in the number of diagnoses before the age of one can be seen, though the figure is down from the peaks in 2020 and 2021 (n=116, 132).

Data show an enormous shift in both average and median ages at diagnosis, one that will make a real difference to the lives of these children and their whānau, as it enables early intervention, and/or monitoring to begin. The overall average age at diagnosis across 2011-2024 is 45 months, while for 2024 this average is 37 months, the highest since 2020 and the same as 2017 and 2018 averages.

Having said that, while the reduced average age of diagnosis is a good sign, it is not possible to know when hearing losses that develop after birth may develop and how many of these may exist. This means it is not possible to know how well systems are performing for children and whānau just by examining the average age at diagnosis. Nuanced analyses are therefore needed, and a focus on length of delays to diagnosis is helpful.

A smaller peak in diagnoses can been seen among four and five-year-olds; this peak is very likely to correspond to the <u>B4 School Check</u>. The number of tamariki being identified between the ages of four and six years has fallen from an average of 58 in the years 2010-2016 to 30 in 2018-2024. This drop likely shows children who were previously being identified by childhood screening at or around school age are now being identified through newborn hearing screening, though it may also reflect the reductions in B4 School Check (B4SC) coverage in more recent years. For example, the overall proportion of children not checked has been high for some time compared with historic levels, rising to 18% before falling slightly in the 2023/24 year.

Impressively, considerable service disruptions during the early years of the pandemic (2020-2021) did not result in later average or median ages in identification during those years, likely due to considerable efforts by clinicians and their districts, including significant collaboration.

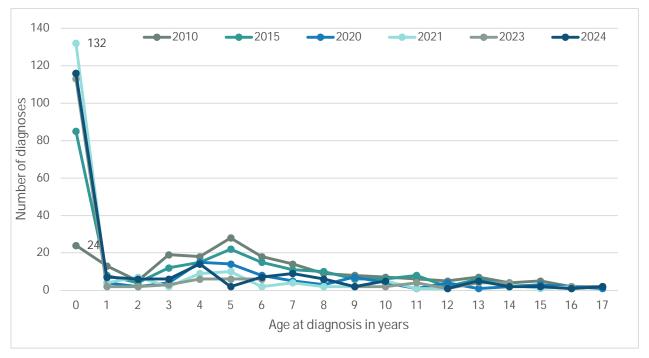


Figure 5: Number of children diagnosed by age (selected years)

#### Patterns in median and average ages at diagnosis

Groups with later median ages of diagnosis are shown in Table 5. Please note that differences in the profiles of hearing losses found among each ethnic group, such as degree of loss and the proportion of cases present at birth, influence these figures, meaning average and median ages at diagnosis may not be a direct reflection of how systems are performing for each group. In addition to those noted in the table, it's worth noting that Pacific children and those living in Quintile 5 (highest deprivation) areas are still identified later (5 and 7 months on average) than other groups, but this does not reach significance.

#### The following groups are likely to be identified later (average months later in brackets):

born overseas (60 months later)

acquired losses (30 months later)

mild, moderate or moderately severe losses (23 months later than severe/profound)

unilateral losses (24 months later)

living in Quintile 5 compared with Quintile 1 (7 months later)

additional disability/ies (13 months later) and those where there is uncertainty about an AD (24 months)

Pacific vs non-Māori non-Pacific (6 months later, very close to significance)

#### Table 5: Significantly later average ages of identification (2010-2024)

Māori and/or Pacific children were identified later than European children in historical DND reports (including those from 1995-2005) although this difference was not reported in every one of these<sup>i</sup>. Looking at changes in medians over time by ethnic group (Figure 6), it is pleasing to see that every ethnic group shows improvements (decreases) in these ages between 2010 and 2024, particularly since 2020<sup>ii</sup>.

Pacific Peoples had the latest median age at identification initially and a steep decline in median age can be seen for this group. It is pleasing to see that both Māori and Pacific groups now have median and average ages that are broadly comparable to those for non-Māori non-Pacific, though as mentioned above this improvement may not be entirely due to improvements in system performance for these groups.

Māori tamariki have more mild and moderate hearing losses than among their European peers and these hearing losses are, on average, identified later than those of greater severity. They are also more likely to have bilateral hearing losses than their European peers and these hearing losses are, on average, identified earlier than unilateral losses. These opposing effects make it hard to understand how the system is performing to enable early detection of hearing losses among tamariki Māori.

i Historical reports in this context refers to reports before the current series, between 1982 and 2006. 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 Europeans being identified earlier than Māori and Pacific tamariki.

ii Medians are less sensitive to outliers than averages. Please note there were greater numbers of extreme values in the 2023 data.

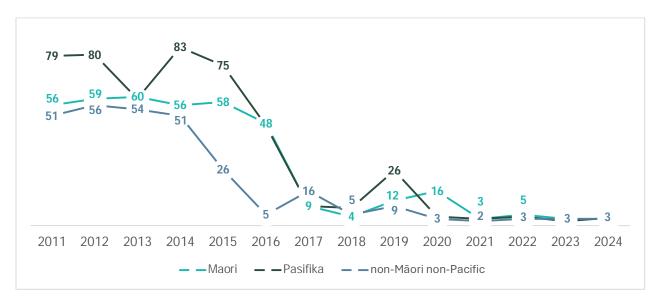


Figure 6: Median ages at diagnosis by ethnicity (2010-2024)

Though not seen in Figure 6, when looking at the average age at identification over time:

- Asian children and young people seem to have benefitted quickly from the implementation of newborn hearing screening when compared with other groups. It is also worth noting that the median age at diagnosis for Asian tamariki across the full period (2010-2024), is the lowest of all ethnic groups at three months. However, figures do fluctuate from year to year, and 2022 saw a rise in the age at diagnosis for this group. Asian children and young people are also the most likely group to have their hearing loss identified under the age of one year old.
- Middle Eastern, Latin American and African (MELAA) children and young people have had a high
  average age at identification over the years. It is worth keeping in mind this group is commonly
  born overseas and not diagnosed in New Zealand this factor is highly correlated with later age at
  diagnosis. It is also worth noting that this group is historically very small and large variations exist in
  the averages for this group over time.
- For 2010-2024 notifications, children in higher deprivation quintiles are diagnosed later than those in lower quintiles. This difference is significant for those in Quintile 5 who are identified, on average, seven months later when compared with Quintile 1 children<sup>i</sup>.

Figure 7, below, shows the greatest variability in the age at diagnosis is found for mild and moderate hearing losses, which is understandable given that these losses can be difficult to identify regardless, and as not all mild hearing losses present at birth will be detected through newborn hearing screening<sup>ii</sup>. This group took longer to benefit from reducing ages at diagnosis.

Degree of hearing loss shown in Figure 7 is categorised as either mild where it is mild, moderate or moderately severe, or severe for hearing losses that are severe or profound. It shows that the benefits of newborn hearing screening did reduce ages at identification in three of four groups shown, though mild unilateral hearing losses are still identified much later than others.

Those with mild bilateral hearing losses began with higher median ages of diagnosis but these dropped considerably from 2015 and are now comparable to severe losses. Mild unilateral hearing losses retain high median ages of diagnosis though have been somewhat lower recently than in earlier years.

i This model looked at the independent effect of deprivation.

ii Please note that the notification form contains information at the time of diagnosis and so does not include information about progressive losses.

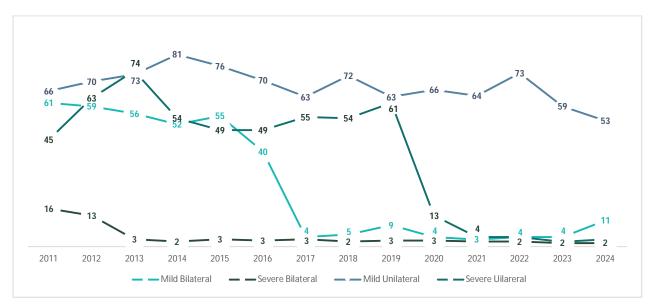


Figure 7: Median age at diagnosis (2011-2024) by category

# Newborn hearing screening

The UNHSEIP is jointly led by Te Whatu Ora<sup>i</sup> | Health New Zealand and the Ministry of Education | Te Tāhuhu o te Mātauranga. In Te Whatu Ora the UNHSEIP is one of the Antenatal & Childhood Screening Programmes within the National Public Health Service, Prevention Directorate Screening.

The target condition for the UNHSEIP is any hearing loss greater than 35 dB eHL at 500 Hz and greater than 30 dB eHL at any frequency in the range 1–4 kHz, in either ear<sup>16, ii, iii</sup>.

#### Screening status among notifications

One hundred and five of this year's cases were diagnosed because of newborn hearing screening, down from a high of 119 in 2021 but still more than three times as many as in 2010.

Last year's analysis across 2010-23 notifications showed that as deprivation increases, families are less likely to be offered/or take-up the offer of screening, though this difference was not significant. This year's analysis (2010-2024) adds another correlation, with Asian and Māori children both more likely than other groups to be diagnosed as a direct result of newborn hearing screening.

i In Te Whatu Ora the UNHSEIP is one of the Antenatal & Childhood Screening Programmes within the Prevention Directorate, National Public Health Service.

ii The target for the UNHSEIP includes conductive impairment associated with structural anomalies of the ear but does NOT include temporary impairment attributable to non-structural middle ear conditions. The threshold itself is commonly found in newborn hearing screening programmes, as referred to by Neumann et al. in the International Journal of Neonatal Screening January 2019 and by Matulat and Parfitt in the same journal in September 2018.

iii See the 2021 DND report on the goals of the screening programme and the appendices in this document for more information.

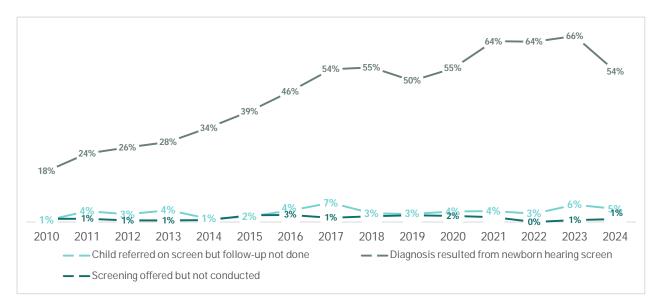


Figure 8: Newborn screening status of New Zealand born children diagnosed with hearing loss, 2010-2024, selected fields (percentages of total)

#### **UNHSEIP** monitoring data

#### Birth prevalence

Even without consistent monitoring data, implementation of newborn hearing screening has still provided valuable insights that bolster understanding of local birth prevalence of the types of hearing losses that are the target of this screening.

The most recent UNHSEIP data has demonstrated our rates of hearing loss at birth are likely to be somewhat higher than those reported in similar jurisdictions overseas<sup>i</sup>, at around 1.2-1.5 cases of bilateral hearing loss for every thousand babies screened, plus an additional 0.8-0.9 cases of unilateral hearing loss<sup>17</sup>. Considerable variability is reported by district<sup>18</sup>.

#### **International benchmarks**

The Joint Committee on Infant Hearing (JCIH) recommended in 2000 that all children should be screened by one month of age, diagnosed by three months and begin intervention by six months of age (1-3-6)<sup>19</sup>. This advice was extended in 2019 to indicate those meeting this 1-3-6 benchmark should attempt to reach 1-2 and 3 months<sup>20</sup>. Making such improvements, as Thangavelu *et al.* notes, "... are very demanding and can only be achieved with considerable financial and infrastructural expenditure"<sup>21</sup>.

#### Recent data

Comprehensive UNHSEIP data<sup>22</sup> has been limited or unavailable for the years 2016-2023 though some data was made available for 2016, 2017 and 2020. Unfortunately, as we are missing programme data from 2017 to 2019 and from 2021 to 2023, it is not possible to understand the extent of any programme improvements made during those years or to help us understand the effects of the COVID-19 pandemic on programme performance. This year it is pleasing that some 2024 data has been made available.

#### The Antenatal and Childhood Screening team has provided the following update (abridged)<sup>18</sup>

It is worth noting that from 2020, various improvements were made in how data is managed and transferred securely to the National Office. Crossmatching of screening records is now done with the National Health Index (NHI) register to check for data errors and identify babies enrolled that have not been screened. Operational and monitoring reports are now able to be generated, and data is sent to the districts for corrections, additions and follow up of unscreened babies.

i For example, the UK and Australia have birth prevalence of approximately 1.0-1.1 per thousand for bilateral and 0.5 per thousand for unilateral hearing losses.

The number of unscreened babies during the last year has significantly decreased, with a corresponding increase in overall screening percentage, particularly for our priority populations, i.e. Māori and Pacific Peoples.

The most recent data available on newborn hearing screening is for the 2024 year. This is preliminary data and will be confirmed later this year once the maternity data set is complete. The data covers screening offers, declines, screening by one month, screening completion and referral rate to audiology.

- 99% of eligible babies were offered newborn hearing screening and 96.3% of eligible babies completed screening within the period 1 January 2024 to 31 December 2024. This is very close to the target of 97% and an increase of 2.1% from the screening completion rate of 94.2% in 2020.
- Declines of newborn hearing screening were 0.9%.
- 92.3% of babies had their newborn hearing screening completed by 1 month of age. This is close to the target of 95% and an increase of 7.8% from 2020.
- The one-month screening completion rates for districts have improved at 83.6% 96.8% an increase from 67% 93% in 2020.
- Screening completion rate by one month is lower for Māori (86.8%) and Pacific Peoples (90%) but improved for these groups on previous levels, while overall screening completion rates are: Māori (93.2%) and Pacific Peoples (95.3%).
- 96.3% of eligible babies completed screening within the period 1 January 2024 to 31 December 2024.
- 1.5% of babies screened during the period were referred to audiology. This is within the standard of <2 percent of babies who completed screening being referred to audiology.

The authors of the DND reports are looking forward to having audiology completion, diagnostic and educational intervention data from the Programme in future as these are key measures of programme performance.

#### **DND** data

The DND reports provide measures over time of the significantly reducing age at identification and proportion of notified tamariki identified before three months of age because of the UNHSEIP. These figures have been particularly important given the lack of data from the UNHSEIP since 2015.

During 2024, for the 105 babies born in Aotearoa New Zealand and diagnosed as a direct result of newborn hearing screening, eighty percent were diagnosed by the internationally recommended age of three months<sup>i</sup>, the highest proportion reported to date.

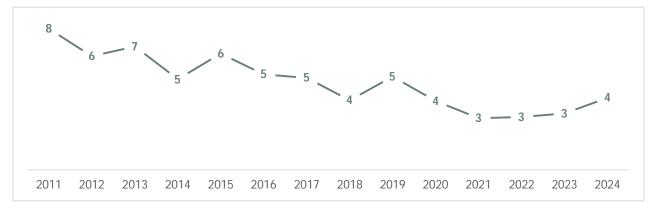


Figure 9: Average months at diagnosis for children referred from and diagnosed as a direct result of newborn hearing screening (2011-2024)

i We are calculating this figure based only on records where a specific date of diagnosis is provided. As a result, it is not directly comparable to previously reported figures. No 2010 figure is shown as the specific date field wasn't added to the notification form until 2011.

Analysis of the 2010-2024 data shows a diagnosis because of a 'refer' result on the UNHS was significantly more likely for Māori and Asian children than other groups. No relationship between deprivation and a diagnosis because of a 'refer' result from newborn hearing screening and was found. • p62

#### Identification of false negatives

The implications of <u>false negatives</u> from the newborn hearing screening programme can be significant for children and their whānau. The DND provides the only method for identifying potential false negatives $^{23}$ .

Cases included in this category may be due to; deviation from the protocol on the part of the screener, hearing losses being progressive or acquired, or as the screening technology and/or protocol did not identify a child with a milder hearing loss<sup>i</sup> or one with an unusual configuration. We have no information on which, if any, of these factors might account for false negatives in the Aotearoa New Zealand context.

In 2024, no cases notified to the Database were explicitly identified on the form as having a delayed diagnosis resulting from a possible or confirmed error on the UNHSEIP or B4SC screening<sup>ii</sup>.

Forty-two of the tamariki who were born in Aotearoa New Zealand and identified with hearing loss during 2024 had been screened previously as part of the UNHSEIP and passed this screening. As newborn hearing screening programme coverage rose over time it was expected that there would be a rise in the number of children and young people who *could* be possible false negatives from the screening programme. This growth isn't necessarily of concern as many tamariki develop hearing losses later, or these may not have met the targeted severity criteria for screening as babies<sup>iii</sup>.

By removing those listed as born outside Aotearoa New Zealand, those with acquired hearing losses, and those where the hearing loss was not thought to be present at birth<sup>iv</sup>, we can see that thirteen cases in 2024 remain. Of this group with the greatest chance of potential false negative cases, the age of identification for these tamariki ranged from nearly two, to nine years of age.

#### **B4 School Check**

#### **Background**

The B4 School Check (B4SC) is a nationwide programme aiming to screen all tamariki before they reach school. It offers a free health and development check for four-year-olds to identify and provide intervention to those identified with targeted conditions. The Check aims to identify and address any health, behavioural, social, or developmental concerns that could affect a child's ability to benefit from school. It is the final core contact of the <u>Well Child Tamariki Ora Schedule</u>. Screening audiometry and tympanometry (if required) are administered as part of this check by <u>Vision Hearing Technicians</u> around the country.

This screening should be completed on all tamariki not already under the care of an ENT specialist or audiologist following their fourth birthday. Those not screened before they reach school should be screened after their arrival at school. If the child passes this test, no further referrals are required. Should the child refer on audiometry, tympanometry should be conducted.

i Mild hearing losses are not a primary target of the UNHSEIP.

ii This doesn't indicate that one or more additional babies diagnosed in 2024 were not incorrectly passed at their newborn hearing screening, just that none notified to the Database were recorded as such.

iii In addition, this figure was likely to rise for some period following the discovery of 2,064 incorrectly conducted screenings in 2012. Of the 485 children who attended the recall in the Counties Manukau District Health Board, two children with bilateral profound hearing loss were identified and received cochlear implants at three years of age.

iv 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?'. The answer to this question provides only a subjective clinical indication, as we cannot know whether the hearing loss was indeed present at birth.

#### **Programme monitoring**

There has never been a national monitoring framework to enable understanding of the efficacy of hearing screening done as part of the B4 School Check, or its predecessor programme to test school and/or preschool aged children, though in recent years it is believed estimates of screening coverage rates have been more accurate and previous rates recalculated using the improved methodology<sup>i</sup>.

As a result of the lack of a full monitoring programme, key information is unknown, including the proportion of children who go on to receive diagnostic assessment, complete that assessment, are diagnosed, begin intervention as a result and benefit from that screening in terms of improved outcomes<sup>24</sup>.

#### Programme coverage

Even prior to the pandemic, the proportion of tamariki listed as 'not checked' was increasing and has increased significantly since 2014-15.

Outcome	Description	Description All cases Māori		Pacific	Asian	MELAA	European
Pass Bilaterally	The child was screened and passed	70%	64%	61%	67%	67%	76%
Referred	The child was screened and referred to a relevant service	5%	6%	8%	5%	3%	5%
Rescreen	The child was unable to complete the screen, so a rescreen has been booked, normally in around 6 months	5%	8%	6%	5%	5%	5%
Under care	The child is already under the care of a relevant service	3%	4%	4%	3%	3%	3%
Decline	The hearing check was declined by the caregiver	0.5%	0.7%	0.4%	0.4%	0.5%	0.5%
Not Checked	The child did not receive a hearing check	16%	18%	21%	20%	21%	11%

Table 6: B4 School Check Hearing Screening data by ethnicity (2023/2024)ii, iii, 25

Glaring differences exist within the B4SC, with Māori and Pacific, as well as children living in more deprived areas, less likely to have their hearing screen and having higher rates of flat tympanograms (likely indicating middle ear dysfunction)<sup>26, 27</sup>. These groups already have significantly poorer access to primary healthcare to enable appropriate follow-up and management. Differences in rescreen and referral outcomes also warrant further examination.

i Reviewed data with improved denominators show 'not checked' figures were likely to be (on average) around 15% in 2021 rather than the 5% previously reported.

ii An 'other' ethnicity category is included in the B4SC data provided by the Ministry of Health and is excluded from this table. The children in this category are listed as 'not checked' in 3% of cases, a marked drop on previous figures.

iii This is the third year for which we describe multi-coded ethnicity data from by the Ministry of Health. This aligns with DND ethnicity coding for children and young people.

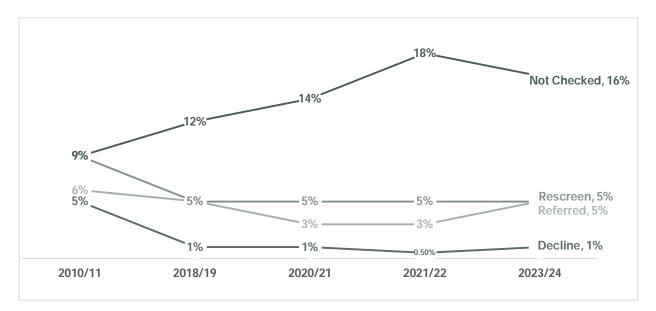


Figure 10: B4 School Check Hearing Screening data (tamariki screened in selected years and fields only)<sup>i, 25</sup>

**Education and health decision-makers and clinicians** should note there are reports of inconsistent use of the 'mop-up', to catch any children and young people who didn't complete the B4SC before they reach school. In addition, the Ministry's B4 School Database only contains information on children up to five years and seven days in age and not all results from this database are transferred into ENROL (Education enrolment Database), meaning it is not always easy to identify children who haven't had their check, hampering efforts to address this.

#### Screening timing and effectiveness

In Aotearoa New Zealand, the UNHSEIP and the B4 School Check aim to identify specific types of hearing loss and are part of the Tamariki Ora Well Child surveillance.

Data suggests several areas of concern could be addressed to improve programme performance:

- 1. Coverage data, and academic analyses of the limited data that exists, suggest Māori and Pacific and those in areas of high deprivation are unlikely to be receiving equal benefit from these nationwide screening programmes. Such disparities and others have been understood for many years and yet the recent data indicates further backward slides in coverage<sup>24, 28</sup>.
- 2. Current screening protocols/instruments may exacerbate rather than narrow pre-existing inequalities for these groups of children (due to thresholds set for referral, which exclude some milder losses, for example).
- 3. Systems and practices that are Euro-centric may reduce the chance that hearing losses are identified promptly when they develop outside the two- or three-points during childhood at which hearing is currently screened. (see overleaf for the final item)

i Column figures don't always sum to 100% due to rounding.

- 4. Further consideration of screening at additional points in childhood to identify chronic middle ear disease, milder permanent hearing loss, and auditory processing difficulties, would also seem useful, as indicated by various recent studies and reviews that have:
  - noted the lack of prevalence data from the B4SC and absent or only summary level data in all but one year since 2015 from the UNHSEIP;
  - found issues in understanding screening coverage rates for those not enrolled with a PHO;
  - recommended hearing screening activities all sit within the National Screening Unit, though due to changes they could now lie with the Antenatal and Childhood Screening team<sup>i</sup>;
  - recommended early OME screening for at-risk populations;
  - recommended work to provide equitable outcomes for Māori and Pacific children, those in areas of high deprivation tamariki with young mothers and those with worse health status; and
  - a redesign or strengthening of the Well Child Tamariki Ora<sup>29</sup> framework. Including a schedule of hearing screening for school age children which would ease identification of children with progressive and late onset hearing losses<sup>26, 24, 30, 31, 32, 33, ii</sup>.

Changes to New Zealand's childhood screening are supported by international sources including:

- the American Academy of Audiology (AAA) recommended preschool screening frequency as prescribed by our Well Child Tamariki Ora schedule in New Zealand, plus screening at ages 5, 6, 7, 10 and 12 or 14 years at a minimum<sup>34</sup>; and
- the World Health Organisation noted the value of screening in childhood particularly for late onset and progressive hearing losses<sup>35</sup>.
- **Decision makers** may know that several protocols and policies, including those of the UNHSEIP, focus on identifying and supporting those with more severe hearing losses. The needs of those with more severe hearing losses are important, as outcomes tend to worsen as the degree of hearing loss rises. Milder hearing losses also have negative impacts, but not all are identified through screening or receive intervention.

Long-standing disparities in screening coverage rates among Māori and Pacific children have not been remedied and have even worsened for the B4 School Check. This programme doesn't fall under the care of the National Public Health Service, as the UNHSEIP does.

Therefore, it is important to consider how systems are arranged to ensure benefits are evenly spread for all. For example, Māori have more hearing loss overall, less severe hearing loss that is prone to later identification, and higher than average deprivation. Districts and clinical leads can usefully focus on how they might seek to further equalise benefit across all groups.

i This Unit now no longer has responsibility for the UNHSEIP. The Antenatal and Childhood Screening team is situated within the National Public Health Service.

ii Leversha et al. (2017) questioned the appropriateness of the B4SC Parental Evaluation of Developmental Status (PEDS) with New Zealand families as a tool for identifying concerns about child development.

# **Delays in Diagnosis**

# Ngā takaroa ki te whakatau māuiui

- Delays in diagnosing and the start of intervention for children with hearing loss are a known contributor to poorer outcomes for children and young people.
- The average delay between first suspicion of a child or young person's hearing loss and its
   <u>confirmation</u> has been between seven and eight months over the last five years, an improvement on
   historical levels.
- Even this much improved average delay remains too long, with some children and young people
  waiting months, or even years, between when their hearing loss is first suspected and diagnosed, and
  intervention begins.
- Children with one or more additional disabilities, born overseas, with unilateral mild, moderate or moderately severe hearing loss, Māori, and those in the top deprivation quintile have significantly longer median delays.
- When restricting notifications to those from 2021-2024, 'audiologist had difficulties confirming
  diagnosis' is most listed as a reason for delay followed by 'parents did not attend appointments/
  delayed or rescheduled these (for any reason including service failed to engage family)', second equal
  with 'waiting time to see a hearing professional'.

## **Background**

There are many variables correlated with a hard-of-hearing child's communication and learning outcomes. These include access to health and education support, the quality of this support and child-specific factors like cognitive ability, family factors such as the level of maternal education and socioeconomic status, plus factors related to the hearing loss itself, such as its severity.

Calls for earlier identification of babies with a hearing impairment have been made for 80 years<sup>36</sup>. Early identification is associated with early intervention and therefore improved outcomes. Early diagnosis seeks to maximise benefit during sensitive periods of neurological and linguistic development and limit children from falling behind<sup>37, 38, 39, 40, 41</sup>.

This screening in Aotearoa New Zealand relies on the UNHSEIP and the B4 School Check. Newborn hearing screening programmes often use the 1-3-6 goals. Implementation of newborn hearing screening has proven to be successful in reducing age at identification and delays in Aotearoa New Zealand and overseas.

There are several ways to limit delays to diagnosis, including early and regular screening of children and young people for hearing loss.

Efforts to reduce delays were particularly noteworthy during the initial years of the COVID-19 pandemic, when effective collaboration and significant effort was made by professionals to minimise the effect of lockdowns. Supplementary efforts are now needed to further limit diagnostic and, therefore, interventional delays further improving outcomes for tamariki and whānau.

#### Recent local research

Recent analyses of audiology data by Waikato DHB were included in the DND's 2021 report and found Māori with bilateral moderate or greater hearing loss were diagnosed later than non-Māori. Factors

contributing to delays among Māori were middle ear issues<sup>i</sup>, delayed referrals from screening and, in one case, a DNA for an audiology appointment<sup>42</sup>.

Longer wait times are associated with decreased attendance rates. Non-attendance rates of 21-38% have been reported in audiology and <u>ENT</u> services in Aotearoa New Zealand though this rate can be much higher for Māori and Pacific children, even after adjusting for socioeconomic deprivation. Telephone consultation did not improve attendance rates overall, nor for ethnicity subgroups. Māori and Pacific are generally not well represented within the audiology workforce. Approaches to improve cultural safety may be also helpful<sup>43</sup>.

- **(i) Decision makers and clinicians** should note that several types of changes can be used to reduce diagnostic delay within hearing services:
  - service culture, resourcing, and employment;
  - individual and workforce clinical practice;
  - systems, policies and processes, screening coverage and consideration of milder hearing losses; and
  - education of the public and other groups about hearing loss and when to seek help.

Naturally, those running district clinics cannot be expected to address many of the fundamental barriers for families to engage well with services, such as high levels of deprivation<sup>44</sup>.

Some changes will result from hearing services acknowledging their responsibility for differential quality of care, including between Māori and non-Māori.

## Presence and length of delays

## **Presence of delays**

Data show an improvement over time with many fewer cases with a diagnostic delay of one month or more and one or more reasons for delay listed. In 2010 this was 90% while in 2024 it was 82%.

In 2024, the proportion of cases that have no reasons for delay<sup>ii</sup> has risen, from an average of 51% over 2010-2013 to, to 68% for 2021-2024.

#### Length of delay

Those notifying cases to the Database were asked to provide information about the length of delay in identifying a child or young person's hearing loss<sup>iii</sup>.

#### Average delays

Average delays in the last five years have improved on the previous highs though remain long enough to have a negative effect on outcomes<sup>iv</sup>. The average between first suspicion and <u>confirmation</u> of the child or

i Household crowding was associated with a larger increase in otitis media incidence for Māori in Bowie *et al.*'s 2014 study. Attendance at daycare rather than household crowding was correlated with presence of otitis media in the study's Pacific cohort.

ii In addition to selecting from one or more pre-coded reasons for delay, notifying professionals can comment further on the notification form regarding the reason(s) for delayed diagnoses.

iii When the current database was launched in 2010 the length of delay was calculated based on the date of diagnosis and the age of the child at the time the hearing loss was first suspected, given in years and months. From 2023 year, these DND reports include only cases where a specific date of diagnosis was provided on the form, meaning only precise age at diagnosis are being used. This change to the notification form occurred from early 2011 and relates to 203 cases.

iv 2010 and 2011 coincided with the completion of the nationwide roll-out of newborn hearing screening. Please keep in mind that these delay figures are not always directly comparable with previous years owing to the changing composition of notifications from year to year. For example, the severity profile of cases can differ from year to year, as can the proportion of children with acquired or progressive hearing loss.

young person's hearing loss national delay in 2024 was eight months<sup>i</sup>. Figures varied considerably between districts, with average delays between six and 19 months reported with longer average delays often found for districts with smaller populations.



Figure 11: Average delay in months by year of notification (2011-2024)

Most groups, including Māori and Pacific tamariki and rangatahi, have seen steady overall declines in average delays from first suspicion of a hearing loss to diagnosis since the Database was relaunched in 2010. Māori, Pacific and European children and young people now have the longest average delays.

#### Groups with significantly longer average delays (months later in brackets):

mild, moderate or moderately severe hearing loss (6 months later than those with a severe or profound loss)
born overseas (4 months later than those born locally)
additional disability or where there may be one present (3 months later than those without)
living in the highest deprivation quintile (3 months later than those in the lowest quintile)
unilateral hearing loss (2.5 months later than bilateral)
Māori (2 months later when compared with non-Māori non-Pacific)

Table 7: Groups with significantly longer average delays (2010-2024)

#### Asian children and young people

Asian children had the shortest average delays during 2010-2024 at 7 months. In addition, it is worth noting that this group:

- have a high proportion of severe and profound hearing losses;
- are far from homogenous so overall figures likely mask differences between subgroups;
- have a higher likelihood of living in the lowest deprivation areas (scores 1, 2 and 3 on the deprivation scale), meaning as a group they will be less likely to have poorer health and will face fewer barriers accessing the health system; and
- tend to have more successful access to and through at least some specific parts of the health system, as demonstrated by their high rates of participation in other health promotion efforts, including COVID-19 vaccination<sup>45</sup>.

i Previous reports (prior to 2006) included only children with moderate or greater losses, which were not thought to be acquired in nature, and children born in Aotearoa New Zealand.

# **Causes of delay**

The notification form asks those notifying cases for the reason(s) for the any delay. Not all notification forms included one or more reasons for the delay, including some for which there was a delay calculated.

The analysis that follows examines only reasons for delay where one or more reasons were listed and where the delay was reported to be one month or greater (measured from the date the hearing loss was first suspected until the time when the hearing loss was diagnosed) and this year only including those where the length of delay was present.

#### 2010-2024 cases

The most common reasons for delay across 2010-2024 are listed below, and each are associated with a reasonably long average delay:

- 1. Audiologist had difficulties confirming diagnosis.
- 2. Parent did not attend appointments or delayed or rescheduled those for any reason.
- 3. Waiting time to see hearing professional or accessing services in their area<sup>ii</sup>.

Māori and Pacific families are more likely to have delays that are the result of 'parents did not attend appointments or delayed or rescheduled those for any reason'. Asian families are more likely to have the delays due to the 'child being born overseas' or 'waiting times to see a hearing professional or accessing services in their area'. They are also less likely to have two or more reasons for a delay.

Specific cases can have one or more reasons listed for delay. Reasons associated with the longest average delays are: 'difficulty getting a referral to audiology', 'loss to follow-up', 'family moved addresses' and 'parents, child or educator suspected something else or had no concern'. For Pacific children, UNHS or B4SC being delayed is associated with the longest delays.

#### 2021-2024 cases

During 2021-2024, the three most cited reasons for delay in diagnosis remain the same as the 2010-2024 period though 'waiting time to see a hearing professional' moves up to second equal along with 'parents not attending appointments for any reason'. The average delay for this period is seven months.

Clinicians note Māori and Pacific whānau have higher rates of non-attendance at appointments. They are also more likely to live in areas of high deprivation when compared with European whānau, meaning significant additional barriers can exist to prevent their engagement.

It has been suggested that higher rates of middle ear issues among Māori (and Pacific) children may require multiple appointments when there is an underlying sensorineural hearing loss and that this can result in delays in diagnosis<sup>46</sup>. This points to the need for strong collaboration between audiology and ENT services and the need for early bone conduction testing as indicated by relevant protocols.

i Delays for children and young people born overseas are included in this table, as are those from 2010 and part of 2011 where precise length of delay cannot be calculated.

ii Please note that this third most common reason was incorrectly listed as 'parents/child/carers or educators suspected something other than hearing' in last year's report.

#### This year's cases

Overall, the average delay in 2024 was eight months, the same as the 2023 average though greater than the 6-7-month average from 2020-2022.

Children and young people whose hearing loss was diagnosed as a direct result of a referral from the newborn hearing screening programme had an average delay to diagnosis during 2024 of three months, the highest delay for this group since 2017.

Reason	Number of 2024 cases
audiologist had difficulties getting a confirmed diagnosis	21
parents did not attend appointments/delayed or rescheduled these, for any reason	16
waiting time to see hearing professional or accessing services in their area	14

Table 8: Most common reasons for delay (2024) for cases with at least a one-month delay and with at least one reason for delay listed

**Decision-makers and clinicians** are aware information and tracking systems are valuable to ensure families don't fall through the cracks, including when they move districts, ensuring consistent care.

While information systems are not perfect, clinicians can seek information on individual children from referring districts via their clinical records department (requesting their chart from their previous district), through Regional Clinical Portals, through their district's Vision Hearing Technicians (VHTs can look up B4SC results in their system), and for UNHSEIP results through the National Public Health Service. Hearing aid information can be sought from the Hearing Aid Services Provider – EnableNZ. These processes plus good clinical notetaking smooth transitions as families move areas, reducing the risk of loss-to-follow-up and delays.

## Contributing issues and approaches to reducing delays

#### **Audiology practice**

Quickly and accurately diagnosing children with permanent hearing loss can be challenging, particularly for those children who are unwell, young children older than three months of age being tested using ABR, those who don't respond well to VRA and those who have conductive hearing losses.

Districts report they can minimise delays by ensuring they have appointment availability for retesting children and building relationships with ENT departments.

#### Staffing and delays

Hearing care for children and young people in Aotearoa New Zealand is generally provided by the public health system, through district services. Public vacancies have risen since the first years of the pandemic, particularly for districts outside the main centres, and reports suggest some positions are unable to be filled due to district funding limitations. Resulting waits are associated with lower attendance levels<sup>47</sup>.

Internationally there is a health workforce shortage, including of allied healthcare workers and hearing professionals<sup>48</sup>. There is also growing concern that the aging population will require greater hearing care.

Availability of hearing professionals can contribute to delays in diagnosis as well as issues with timeliness of the start of intervention and follow-up and this is clear in our DND data, with 'Waiting time to see hearing professional or accessing services in their area' being the most common causes mentioned for delays in Aotearoa New Zealand during the last four years<sup>i</sup>.

i Last year it was also the most commonly mentioned reason though this was incorrectly displayed in the 2023 report, which listed 'Parents not attending appointments for any reason'.

Category	Focus	Quote
Screening	UNHSEIP	No follow up  "Should have been seen for Targeted follow up from NBHS [newborn hearing screening] but  can't see a referral to Audiology for this."
		Late referral from the UNHSEIP  "Referred from Newborn hearing screening late."
	B4SC	Child missed by B4SC "Passed NBHS. Missed B4SC".
		Lack of follow-up/poor records
		"This child [came] to us following a refer result on a hearing screening test at school locally with <u>VHT</u> here in Oct 2023. Apparently, this child had a refer result on their B4SC in [other area] in 2021, but we don't have the results of this nor any record of any f/up occurring in [that area]."
	Both B4SC and UNSHEIP	"Did not attend NBHS [newborn hearing screening]. First B4SC noted as 'rescreen'. No other records available. Referred to [District] Audiology 10/2024 by VHT following failed school hearing screening."
Middle ear or other ENT related issues	Referral and/or wait for ENT services/resolutio n of middle ear	"This child was born overseas and had recurrent EI and ongoing conductive hearing loss. She had several sets of grommets overseas, and was reviewed by ENT in NZ in Feb 2024 then referred to audiology here COVID affected some of the follow up, then the family moved. Once in NZ she was referred to ENT (not Audiology) and there was a wait of 10 months to see ENT."
		"Sudden hearing loss treated as an ear infection. Hearing test delayed."
		Hearing loss thought to be temporary and resolution delayed diagnosis:  "The ABR indicated possible SNHL [sensorineural hearing loss] but bilateral middle ear dysfunction was present. Subsequent monitoring was arranged (this child has been seen for several appointments since the ABR) and once the middle ear dysfunction resolved true thresholds were able to be obtained."
		"Originally just thought to be temporary hearing loss due to retraction of the left pars tensa / chronic OME and discharge. Only discovered Cholesteatoma at time of surgery."
Audiologist had difficulties making diagnosis	Masked thresholds difficult to obtain	"Unilateral HL - difficulties in obtaining accurate masked thresholds AC and BC."
Parents did not attend	For any reason	"After hearing loss initially suspected ABR under sedation was arranged. Family did not attend first sedation and this was rescheduled. The child did not sedate. Further delay was waiting for theatre availability for GA ABR."
Multiple reasons	Multiple contributors	"This child was a bilateral refer on NBHS and subsequent ABR yielded a conductive hearing loss with BC at passing levels. Further testing confirmed that the middle ear dysfunction had resolved, with present DPOAEs. The family moved to a different region and were re-referred to Audiology due to parental concern, but were not seen for 8 [months]. The family then moved back to our region and this child was seen for further testing over three appointments in order to obtain the confirmed hearing levels today."

Table 9: Selected comments from notifying professionals on the cause(s) of diagnostic delay (2024)

#### Efforts to improve engagement

Parents did not attend appointments/delayed or rescheduled these (for any reason including service failed to engage family) has been a common reason for delay, coinciding with various reports of reduced engagement with health services since the start of the pandemic.

Cases where the whānau or young person did not attend the appointment have historically been referred to as DNAs (Did Not Attend). It is now becoming more common for clinics to refer to these delays as being the result of services not attracting patients or whānau, relabelling these cases as "Did Not Attract" while retaining the same acronym. This shift places the onus on the service to do what is needed so whānau/patients can attend appointments, also improving service efficiency.

"People are struggling to pay their bills and feed their kids...If people can't pay their power, they certainly are not going to have money to go to appointments." Marewa Glover, Massey School of Public Health

Reducing rates of non-attendance has at times been an area of focus in some district health boards, not always in a sustained way, as resources, support and ongoing funding for continued efforts are not always available. However, significant improvements have been achieved for periods of time in districts such as Capital and Coast, and Taranaki, because of this increased focus.

Common factors thought to be important in reducing barriers to access include removing cost barriers, addressing transport and childcare issues<sup>51</sup>, knowing the client population, personal engagement, a non-judgemental approach<sup>52</sup>, strengthening cultural safety, and flexibility in service arrangements<sup>53</sup>.

# **Deprivation**

# Te takaonge

- Deprivation scores in the New Zealand Index of Deprivation are calculated from Census data and indicate the level of deprivation for each of many small areas in Aotearoa New Zealand.
- In the general population, New Zealanders who are Māori, Pacific Peoples and under the age of 17 are more likely to be living in income poverty than those over the age of 65 years, and those with one or more disabilities are also more likely to live in areas of higher deprivation than those without.
- There is a preponderance of those living in high deprivation areas within the Database with the rate of notifications rising with increasing deprivation.
- Māori children in the DND are 16 times more likely, and Pacific children 40 times more likely, to live in a Quintile 5 area compared with non-Māori, non-Pacific children.

# Hearing, disability and deprivation

Patterns relating to hearing, disability and deprivation include:

- a country's hearing loss prevalence falls with rising income<sup>54</sup>;
- overall, New Zealand children under the age of 17 are more than twice as likely to be living in income poverty than adults over the age of 65 years<sup>55, 56</sup> and 11% of children under the age of 15 are thought to have a disability<sup>57</sup>;
- Māori and Pacific children along with those with disabilities are at a greater risk of living in low-income households<sup>58</sup> even after adjustments for differences in age profiles;
- on top of challenges associated with deprivation, children with hearing loss may face discrimination and social exclusion, reducing their access to resources and support systems necessary for their development;<sup>58</sup> and
- while hearing loss is correlated with deprivation in some jurisdictions, including New Zealand and the United States<sup>59</sup>, the United Kingdom has a much higher disability allowance meaning there is no correlation between childhood disability and poverty<sup>60</sup>.

## **Introduction to the New Zealand Deprivation Index**

Aotearoa New Zealand is fortunate to have deprivation data from The New Zealand Index of Deprivation. The Index was created, and is revised regularly, by staff at the University of Otago (Wellington).

The Index draws on New Zealand Census data relating to multiple measures<sup>i</sup>, allocating a deprivation score to every meshblock (small area) containing an average 60-120 residents, around the motu. • 2023 report

The scores allocated to each are between 1 and 10, with scores of 1 being allocated to the 10% of areas that are the least deprived, and scores of 10 allocated to the 10% of areas that are the most deprived<sup>61</sup>.

These scores do not relate to specific individual's level of deprivation. Data for this report are based on NZDep2013, NZDep2018 and NZDep2023<sup>62, i, ii</sup>.

#### Quintiles

Sometimes differences are investigated by <u>quintile</u>. Each quintile represents 20% of the population. This means Quintile 1 relates to children who live in areas scoring the lowest on the deprivation index (1 or 2), up to Quintile 5 that relates to children who live in areas with the greatest deprivation scores (9 or 10).

#### **Notifications**

#### Comparisons with the general population

Among notifications to the DND, high levels of deprivation are more common than for the New Zealand population at large, with thirteen percent of notifications from Quintile 1 areas, compared with 20% in the general population while 33% of children are living Quintile 5 compared to only 20% in the population.

Population data by quintile are available for 2013, 2018 and now for the 2023 Census, enabling an average calculation of notifications by deprivation category for every 10,000 people under 19 years of age.

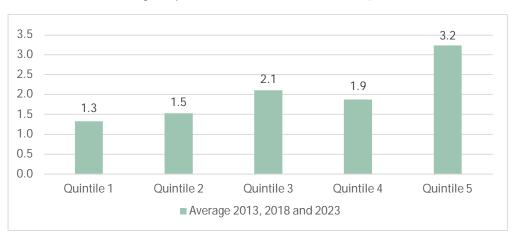


Figure 12: Estimated prevalence per 10,000 children and young people, based on DND notifications for 2013, 2018 and 2023 for the under 20 Census populations in those years<sup>iii</sup>

## **Deprivation and ethnicity**

Figure 13 illustrates the distribution of children and young people within the Database by deprivation status, grouped by ethnicity. Last year's analysis found glaring differences in the distribution of deprivation by ethnicity for two groups:

• Māori children and young people were 16 times more likely to be in a Quintile 5 area compared with non-Māori, non-Pacific children.

i Deprivation scores are provided for each National Health Identifier (NHI) by Te Whatu Ora | Health New Zealand. Please note that these scores relate to the addresses at which tamariki were living at the time of notification. 99% of cases in the Database have deprivation data available. Data were unavailable for tamariki whose: NHI was not valid, those who had no NHI listed, those whose notification were submitted after the deprivation scores were provided by Health NZ | Te Whatu Ora, and those who live outside New Zealand. For those whose NHI was not valid or missing, NHIs were sought but a small number were not provided or not provided until after the analysis for a specific report was completed.

ii The deprivation scores are provided for each National Health Identifier (NHI) by Te Whatu Ora | Health New Zealand. Please note that NZDep scores relate to the addresses at which tamariki were living at the time the notification was made.

iii Census data by deprivation within the 2023 report had not yet been published last year and the label implied that the comparison was for the full 2010-2024 period, where it was actually for the 2013, 2018 and 2023 DND notifications and Census populations.

 Pacific children were 40 times more likely to be living in a Quintile 5 area compared with non-Māori, non-Pacific children<sup>i</sup>.

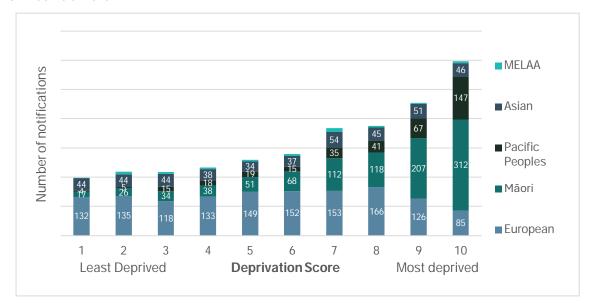


Figure 13: Deprivation scores of tamariki in the DND by ethnicity (2010-2024)

**(i)** Clinicians can expect many families they see will have significant engagement barriers

Those working with young people who are hard-of-hearing can expect to see a preponderance of children from families living in deprived areas and therefore experiencing the effects of financial hardship. The odds of high deprivation rise enormously for families who identify as Pacific and/or Māori.

Professionals should keep in mind that income is a significant determinant of health<sup>63</sup>. As a result, families clinicians see are more likely to experience poorer health<sup>64</sup> (including greater barriers to accessing health services<sup>65</sup> and lower housing stability<sup>64</sup>) and higher rates of stress and mental health issues across the lifespan<sup>66, 67, 68</sup> than those in less deprived areas. These factors result in greater barriers for families to engage with services, including screening, audiology, education, and specialists such as ENTs.

Those services should consider ways they can assist families to engage so their child or young people can benefit from ongoing support to improve outcomes.

i The confidence interval in this case is large (17.4-91.6) as it reflects the small sample size for the Pacific Peoples ethnic group within each deprivation quintile.

# **Hearing loss characteristics**

# Ngā āhuatanga o te turi haere

- When notified, just over half of children notified were thought to have hearing losses present at birth and almost one in five had a parent or sibling with hearing loss.
- Bilateral and/or sensorineural hearing losses are most common.
- The presence of one or more additional disabilities (ADs) can have a significant impact on outcomes for children/young people with a hearing loss and this group is more likely have their hearing loss identified later than those without.
- Twenty four percent of tamariki and rangatahi notified to the Database had one or more *confirmed or suspected* 'additional disabilities' at the time their hearing loss was notified.

## Hearing losses at birth

Just over half of 2010-2024 notifications were for children and young people whose hearing losses were thought to have been present at birth. This proportion has risen since newborn hearing screening was implemented nationwide, growing from 31% in 2010-2013 to an average of 67% in 2021-2024.

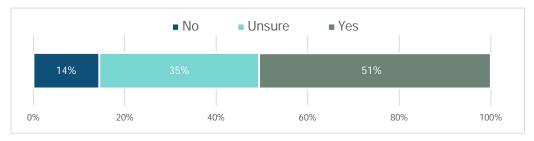


Figure 14: Hearing loss present at birth (2010-2024)

More likely to have a hearing loss present at birth	Less likely to have a hearing loss present at birth
<ul> <li>Asian children (compared with non-Asian)</li> <li>Pacific children (compared with non-Māori non-Pacific children) - note this is marginally significant with a p-value of 0.059.</li> <li>Māori children (compared with non-Māori non-Pacific)</li> </ul>	European children (compared with non- European children)

Table 10: Groups significantly more and less likely to have a hearing loss present at birth (2010-2024)

In addition, children with a hearing loss thought to be present at birth are more likely to have a severe or profound hearing loss than those without, and those hearing losses are more likely to have sensorineural or auditory neuropathy spectrum disorder (ANSD) than other types. -p62

# Close family hearing history

The notification form asks whether a mother, father or sibling of the child has a permanent hearing loss<sup>i</sup>. This question was introduced part way through 2014 (Figure 15).

Having one or more parents or siblings with permanent hearing loss is most common for Māori children (23%), then Pacific and European children (18%), MELAA children (17%) and least common for Asian children (8%).

Further examination shows significant differences, with:

- children with an additional disability *less likely* to have a close family history of hearing loss;
- Maori children are *more likely* to have a close family history than non-Maori, and Pacific children and are more likely to have no information listed about whether a close family history exists; and
- Asian and European whānau less likely to have a close family history of hearing loss. p62

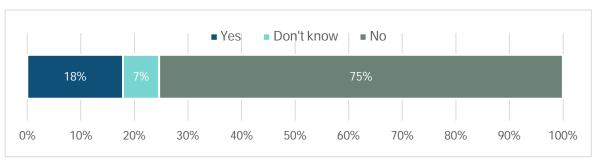


Figure 15: Immediate family member with hearing loss (2015-2024)

# Unilateral and bilateral hearing losses

Both bilateral and unilateral hearing loss can have significant impacts on outcomes for children and young people.

### Bilateral hearing loss

International literature suggests <u>bilateral</u> hearing losses affect approximately 1.1-1.3 babies born in every 1,000, depending on criteria for inclusion, growing to around 3.5 per thousand children by adolescence<sup>69, 70, 71, 72</sup>. Children's speech development, and educational, social, emotional, and cognitive development can be impacted. Noisy educational settings can be particularly challenging for these children.

These hearing losses can be the result of specific aetiologies such as genetics (often non-syndromic<sup>73</sup>), infections like measles and ototoxic medications. They are more common among those with sensorineural, mixed hearing losses and among children with developmental disabilities.<sup>10</sup>

## **Unilateral hearing loss**

Unilateral hearing loss (UHL) can be defined as any degree of permanent hearing loss in one ear (using pure tone averages over 0.5, 1.0 and 2.0 kHz) that is greater than 15 dB HL, regardless of <u>aetiology</u>, with normal hearing in the opposite ear. Most cases of UHL in a recent review were attributed to cochlear malformations, including Mondini dysplasia (progressive hearing losses are common in such cases<sup>74</sup>), and environmental causes were also commonly implicated. Cochlear nerve aplasia and cytomegalovirus are also commonly implicated<sup>75</sup>.

UHL prevents the auditory system from processing and integrating input from both ears. This is important for optimal understanding of speech in noisy situations and for sound localisation<sup>76, 77</sup>.

Prevalence of UHL is difficult to understand, not least because the definition used differs between studies,

i Or had a permanent hearing loss if they have died.

and samples often don't include the complete group being described<sup>78</sup>. In the United States, around one in 1,000 babies are born with a UHL, about a third of the total identified with a hearing loss<sup>79</sup>, while in Canada 20% presented with a UHL at diagnosis<sup>80</sup>. Prevalence data from the US, show rates rise with age to between three and six per thousand<sup>81</sup> with rates of progression to include a second ear varying from more than one in ten<sup>82, 83, 84</sup> to 17% found in one Canadian study<sup>85</sup>.

In the early 1980s the significance of UHL was re-evaluated by professionals<sup>80, 86, 87, 88</sup>. There is evidence that on average children with UHL have reduced educational performance, language delays and higher rates of behavioural issues<sup>89, 90, 91, 92</sup>.

#### **DND** data

The DND reports have contained children with UHL since 2010. Of 2010-2024 cases, including those with interpolated <u>audiometric</u> data, 67% are recorded as <u>bilateral</u>, while the remaining 33% are <u>unilateral</u><sup>i</sup>, close to the birth prevalence noted above by Finitzo (USA) and other sources. The proportion of all 2010-2024 cases that met the criteria for single sided deafness is 5.1%<sup>ii</sup>.

Within the DND, bilateral hearing losses are associated with significantly higher levels of sensorineural, mixed hearing loss and auditory neuropathy spectrum disorder (ANSD) and significantly lower levels of permanent conductive hearing losses. — p46 and p65

MELAA children and young people have the highest proportion of bilateral hearing losses, at 76% in total, followed by Māori (73%) and Pacific children (65%). European and Asian children have fewer bilateral hearing losses (at 64% and 63% respectively)<sup>iii</sup>.

Further examination finds significant differences, with:

- Māori children (compared with both non-Māori, non-Pacific children and with Pacific) more likely to have a bilateral hearing loss;
- those with bilateral losses are more likely to have sensorineural or mixed hearing loss;
- children with ANSD are 0.64 times as likely to have a bilateral hearing loss, compared to a unilateral hearing loss; and
- Pacific and Asian children and young people more likely to have severe or profound unilateral hearing losses compared to the other groups.

A 2018 analysis of data provided for 2010 notifications (unpublished)<sup>93</sup>, found 32% of those children or young people with a unilateral hearing loss ended up with a bilateral hearing loss seven to eight years later. This is higher than the 10% plus rate noted earlier from the literature.

i From 2015, these reports have contained data for cases that contained completed audiometric data for all eight datapoints, as well as data for those which are interpolated. Manual determinations are made on those cases with fewer thresholds listed. Interpolated data includes a good deal more cases and so we will focus on this figure from now on in these reports.

ii The inconsistent and falling proportion categorised as having SSD is thought to relate to the growing proportion of children and young people who are suspected to fall into this category but where not all frequencies were included on the DND notification form.

iii Based on interpolated data and manual checks to determine bilateral/unilateral status. These figures don't quite compare with those from previous reports as the calculation method has been altered and more cases without all datapoints are included in this analysis.

## (i) Recommendations for clinicians, educators, and policymakers:

- All those with hearing loss benefit from early identification, enabling early intervention, better language, and quality of life<sup>94</sup>.
- All families of infants with any degree of permanent hearing loss should be considered eligible for early intervention services and children with unilateral hearing loss should receive developmental monitoring at six-month intervals (JCIH 2007<sup>95</sup>).
- Limited high-quality evidence exists for children with UHL, though consensus-based principles of technology management should inform practice (Bagatto *et al.*<sup>96, i</sup>).
- Families of children with UHL should be offered advisory services from an Advisor on Deaf Children (Project HIEDI, 2010<sup>97</sup>).
- Children with UHL should receive aetiologic assessment following diagnosis, including complete otologic evaluation, including imaging<sup>96</sup>. Many of these children benefit from some form of personal amplification device (JCIH 2013 supplement<sup>98</sup>).

## Types of hearing loss

Differences between left and right ears are small and so this year the rates for all ears are found in Figure 16. Sensorineural is the most common type of hearing loss, irrespective of ethnic group and deprivation level, followed by normal hearing (which applies to those with unilateral hearing loss<sup>ii</sup>).

Three percent of 2013-2024 cases (right and left ears) in the Database were listed in the <u>ANSD</u> category<sup>iii</sup>. Overseas prevalence data suggests Aotearoa New Zealand may have lower rates of ANSD than other similar jurisdictions<sup>99, 100</sup>. This difference could relate to our unique population, including lower proportions of severe and profound hearing loss, and potential differences in whether cases of auditory nerve hypoplasia or aplasia are included<sup>101</sup>.

Auditory nerve insufficiency/deficiency, aplasia and hypoplasia, absent or poorly formed cochlea nerve terminology are used interchangeably in the literature. In some cases, these cases are included in the ANSD category<sup>17, 102, 103</sup>.

i The Children with Unilateral Hearing Loss study is being conducted by the National Acoustic Laboratories (NAL), Australia to further investigate this topic.

ii Please note the cases with normal hearing relate to those children and young people with a unilateral hearing loss.

iii In New Zealand, in cases where a scan confirms presence of these conditions, they may be categorised as sensorineural hearing loss rather than ANSD. As scans are routinely performed in New Zealand and this may be less common elsewhere, this may explain our lower ANSD rates.

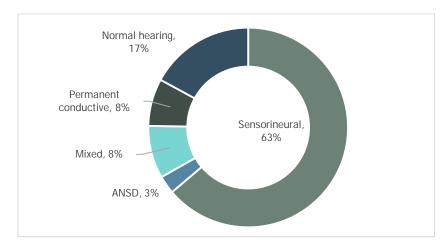


Figure 16: Type of hearing loss for left plus right ears (2013-2024)

Differences by type of hearing loss are found in Table 11.

Types of hearing loss	More likely	Less likely
Sensorineural loss	Asian children (compared with children from other ethnicities)	children with additional disabilities (compared to those without)
ANSD	<ul> <li>Asian and Pacific children (compared with non-Asian non-Pacific)</li> <li>severe or profound hearing loss (compared with less severe losses)</li> </ul>	those from the lowest deprivation <u>quintile</u> (compared with children from higher deprivation areas)
Mixed hearing loss	<ul> <li>Maori children (compared with non-Māori non-Pacific)</li> <li>those from moderate deprivation areas (compared with those from low or high deprivation areas)</li> <li>children with have an additional disability (compared to those without)</li> </ul>	
Permanent conductive loss	<ul> <li>Pacific children (compared with children from other ethnicities)</li> <li>children with an additional disability (compared to those without)</li> </ul>	Maori children (compared with children from other ethnicities)

# **Aetiology**

## Ngā pūtake

- Aetiology of hearing loss is either genetic or non-genetic in nature. The proportion of hearing losses with a confirmed genetic basis is rising as more genes are found to be associated with hearing.
- Cytomegalovirus (CMV) is the leading non-hereditary cause of hearing loss in overseas studies.
- Fourteen percent of cases have a known cause at the time of notification with congenital hearing losses the most common (5%), followed by acquired (5%) and syndromic<sup>i</sup> (3%).
- Just over 3% of the children and young people in the Database are reported to have one of 39 specific syndromes recorded, the most common being Down, followed by Pierre Robin/Stickler, Goldenhaar, Noonan, and Charge syndromes.

## **Causes of hearing loss**

The aetiology (cause) of hearing loss is either genetic (syndromic or non-syndromic), or non-genetic, though not all syndromes have a current identified genetic cause. The cause of hearing loss may be known or unknown depending on whether testing has been completed by the time the case was notified and whether a cause is able to be identified.

Estimates of the proportion of prelingual hearing losses thought to be genetic was around 50% in 2022, with 30% of those (15-20% overall) associated with a recognised syndrome<sup>104</sup>. A significant proportion of late onset hearing loss is due to genetic causes<sup>105</sup>. Progression in genetic testing now allows rapid testing methods, including testing for a panel of genes, whole exome and genome testing<sup>106</sup>.

Connexin variants are the most common genetic cause of hearing impairment among those *without* syndromes in many populations. Different distributions of Connexin have been reported in Asian compared with European populations<sup>107</sup>, though no studies have established the groups in New Zealand that have the highest prevalence of hearing loss resulting from genetic differences.

The following subsections outline common causes of hearing loss. Other medical investigations can also be helpful to identify associated conditions that include ophthalmic evaluation, cardiac evaluation for those with prelingual sensorineural hearing loss, and vestibular dysfunction<sup>17</sup>.

Cytomegalovirus (CMV) is the leading non-hereditary cause of permanent hearing loss in overseas studies<sup>108</sup>, thought to cause between 10 and 20% of cases<sup>106, 109</sup>. Those who are pregnant and have no antibodies may pass on infection to their babies.

Recent reviews suggest approximately 13-14% of children with cCMV infection develop a sensorineural hearing loss <sup>108, 110</sup>. Hearing loss resulting from CMV can be delayed and can fluctuate and/or worsen<sup>109</sup>.

New Zealand data on CMV is limited though seroprevalence in Aotearoa is thought to be highest among Pacific Peoples<sup>109</sup>. local rates of cCMV disease are thought to be highest among Māori and Pacific populations<sup>111</sup>. A seroprevalence study is underway. Some professionals suggested that it is possible Aotearoa New Zealand has a greater prevalence of progressive hearing losses because of our high rates of CMV.

A recent local analysis of the National Minimum Dataset by Jeong (2023) found that approximately 40% of all cases diagnosed with cCMV resided in the most deprived quintile<sup>ii,</sup> countries<sup>112</sup>.

i Last year this figure was mistakenly listed as 'genetic'.

ii The quintile is a 20% segment. In this case it refers to families whose area scores a 9 or 10 on the Index.

Sincere thanks to Associate Professor Holly Teagle for sharing her knowledge on CMV. • p67

- **Recommendations** for clinicians and decision makers: see Choi et al. (2024) for more detail<sup>17</sup>:
  - early medical investigation is essential to identify common causes of hearing loss, including cCMV<sup>17</sup>;
  - imaging can be useful, particularly for those considering a cochlear implant, those with moderate or bilateral severe to profound hearing loss and to check for cochlear nerve insufficiency<sup>17</sup>;
  - there are currently no guidelines for use of genetic testing with children and young people diagnosed with permanent hearing loss in Aotearoa New Zealand, though universal approaches to genetic testing are long standing in some countries<sup>17</sup>;
  - it seems that use of genetic testing may be somewhat inconsistent and may be in more commonly offered for children being referred for cochlear implants; and
  - genetic testing can be useful as:
    - 1) it can give the family clarity on the cause of the hearing loss;
    - 2) it can provide potential peace of mind and/or inform future family planning;
    - 3) it may aid the clinician in the management of expected outcomes with parents/caregivers;
    - 4) it can identify candidates for gene therapy as this becomes more common e.g. for those with variations of the Otoferlin gene; and
    - 5) in rare occasions it can indicate presence of syndrome that is not already identified and that may benefit from specific treatment. 2021 report

#### **Immunisation**

Mumps, measles and meningitis were previously often considered by audiologists as potential causes of hearing loss; however, this has become less common, likely due to generally increased immunisation coverage.

In Aotearoa, concern has been expressed about falling immunisation coverage since 2016. Since the start of the pandemic, rates have fallen further, resulting in record low coverage rates. This mimics international trends reported by The World Health Organisation and UNICEF that are thought to have been exacerbated by the COVID-19 pandemic in many countries<sup>112</sup>. Immunisation rates are particularly low for tamariki Māori, Pacific and those who live in income poverty<sup>113</sup>.

The fall in immunisation coverage rates has meant that immunisation has again become a focus for successive governments. The new target for 24-month immunisation coverage has been set at 95%<sup>114</sup>.

Clinicians: The current concern regarding mumps incidence in New Zealand, which is thought to relate to immunisation dose timing and coverage rates, may be impacting incidence and should again be a clinical consideration<sup>115</sup>. Impact of the recent measles outbreak is not yet known<sup>116</sup>.

### Atresia and microtia

Microtia is a congenital difference where the external ear is underdeveloped. It affects one rather than both ears in most cases<sup>117</sup>. The specific cause of microtia is typically unknown, but it is thought to occur during the first trimester of pregnancy when the ear is forming.

Microtia usually occurs with aural atresia (AA), a condition where the ear canal is also underdeveloped or closed. The literature suggests unilateral atresia is more common than bilateral, in the order of three or four cases to one<sup>118</sup>. Inner ear abnormalities are often seen in those with aural atresia, particularly when they also have congenital facial paralysis<sup>119</sup>.

Atresia and microtia are relatively common congenital malformations, with the incidence of microtia reported to be 0.5 to 3 per 10,000 live births, and aural atresia reported in 55% to 93% of individuals with microtia<sup>120</sup>. Atresia always causes hearing loss while microtia may cause hearing loss.

These conditions often result in moderate or greater hearing loss and require ongoing medical care, ideally from a team including an ENT specialist and involving audiology. Aural atresia (AA) is commonly associated with maximal conductive hearing loss in affected ears, and children with bilateral AA benefit from amplification.

A 2011 review of microtia-<u>anotia</u> prevalence found these conditions were more common among in native Americans or Alaskan Natives, Hispanics and Asian or Pacific Islanders<sup>121</sup>.

Patterns from the overseas research include that:

- children with microtia or anotia are more likely to be male, mothers were more likely to have health conditions associated with obesity and/or pre-pregnancy diabetes, and less likely to be taking folic acid supplements<sup>122</sup>;
- high rates of speech therapy and educational interventions are common among those with AA, particularly those with bilateral AA<sup>123</sup>;
- children with right sided or bilateral AA may be at increased risk of speech and learning challenges<sup>117</sup>; and
- older and younger children benefit from audiometric improvement after atresia repair 123, 124. p68
- (i) Aural atresia is almost always identified soon after birth in Aotearoa New Zealand, but speech therapy/educational interventions are not always in place for this group. Clinicians should refer children with atresia to an Advisor on Deaf Children and potentially to a Speech Language Therapist who will provide ideas and strategies for the family to best support the child.

## **Unilateral hearing losses**

Genetic and/or epigenetic factors<sup>i</sup> are thought to play a role in some cases of unilateral hearing loss. Further research is required to establish the aetiological patterns of unilateral hearing loss<sup>123</sup>.

Falling immunisation coverage is again a concern, including for conditions such as mumps that can result in unilateral hearing loss. The influence of this trend is not likely to be visible within the DND data.

i Epigenetic factors are those where behaviours and the environment alter whether genes are turned 'on' or 'off'.

### **DND** data

#### Known vs unknown causes

Of the 99% of notifications containing aetiological information, 86% are of unknown cause, with the remaining 14% of cases listed with a known cause.

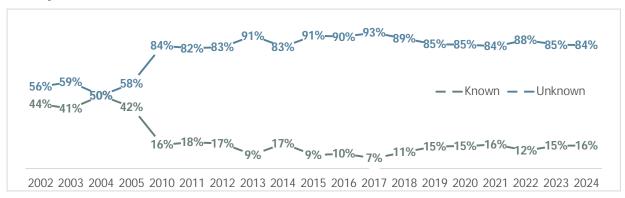


Figure 17: Proportion of cases with known/unknown aetiology at the time of notification

For the 2002-2005 period, the proportion of cases with an unknown cause was between 50 and 59%, with 2001 at 70%<sup>125</sup>. This proportion has risen since the Database was relaunched in 2010 and has been 82% to 93%, reflecting our significantly reduced average age at identification since the introduction of nationwide newborn hearing screening. As a result, aetiological testing is less likely to have been done by the time the child is notified to the Database.

During 2010-2024, children and young people with severe or profound bilateral hearing losses were more likely to have a known aetiology than those categorised as having a mild hearing loss.

## **Aetiologies by type**

#### Other findings

Of all notified children during 2010-2024, 5% have a congenital hearing loss (with most of these having atresia, microtia or both), 5% have an acquired hearing loss, and 3% have a syndrome.

Those with acquired hearing loss likely include some progressive hearing losses that were undetected as they were too mild to be identified through newborn hearing screening. These hearing losses are often genetic<sup>110</sup>.

Within the DND, low numbers of notifications (<1%) mention CMV or mumps, measles or meningitis (some within the aetiology fields and others within 'additional disabilities'), but as there is no specific question to capture presence of these infections, reporting is likely to be incomplete and some reflect investigations that are underway but not confirmed.

Aetiology	All cases
Unknown aetiology/no data	86%
Total congenital	5%
Congenital (non-atretic)	1%
Congenital (atresia)	4%
Acquired hearing loss	5%
Genetic causes	4%
Genetic cause (non-syndromic)	1%
Genetic cause (syndromic)	3%

Table 12: Aetiology types (2010-2024)

Though sample sizes are too small to test for significance, some patterns exist within 2010-2024 data, including that children and young people with:

- bilateral losses are less likely to have an acquired hearing loss (4% cf. 7% for those with unilateral hearing losses);
- bilateral losses are less likely to have a congenital hearing loss (4% cf. 9% for those children with unilateral hearing losses);
- acquired losses appear most commonly among children identified as MELAA, European and are least likely among Asian children; and
- Pacific and Asian children are most likely to have congenital hearing losses.

#### Atresia and microtia in the DND

Among notifications, four percent of children and young people are listed as having atresia, microtia or both; atresia is the most common sub-category and is more common in the right ear.

In the literature, Pacific children are thought to have relatively high rates of these conditions<sup>117</sup>. Pacific children also have significantly higher rates of atresia, microtia<sup>i</sup> or both within the DND when comparing with non-Māori non-Pacific children. Māori children are less likely to have atresia (compared with non-Māori non-Pacific, or than Pacific children). In addition, no association between deprivation and rates of microtia/atresia was found.  $\longrightarrow p62$ 

#### Children and young people with syndromes

Those with hearing loss of known genetic cause can be split into those with syndromic and those with non-syndromic hearing losses<sup>ii</sup> though not all syndromes have a current identified genetic cause.

Almost three and a half percent of the children and young people in the main dataset were diagnosed with a syndrome at the time the notification was made. Among those, 39 specific syndromes are listed, affecting 98 children and young people. The most common syndromes are Down Syndrome (affecting 26 children and young people) followed by Pierre Robin/Stickler Syndrome, Goldenhaar Syndrome, Noonan, and Charge Syndrome.

The proportion of DND cases listed as 'genetic' is considerably lower than the proportion found in the literature, understandable given notifications are now made at younger ages and soon after the time the child or young person's hearing loss is diagnosed, meaning genetic testing is less likely to have been done. It is not possible to know whether referral rates and/or availability of genetic testing for children with hearing loss could also be a factor.

i Pacific children are 4 times more likely to have both microtia and atresia when compared with non-Māori, non-Pacific children. They are 2.1 times more likely to have microtia or atresia only, compared with non-Māori, non-Pacific children.

ii In preparing this report, an exercise was undertaken to check all names of conditions listed as syndromes and confirm these fit this category. Autosomal dominant hyperphosphatemic rickets and Septo-optic Dysplasia are not classified as syndromes because they do not meet the criteria of having a predictable cluster of symptoms beyond the primary condition described, so cases of these conditions have been removed from this category.

# Severity

## Taumaha

- Audiometric data is now much more likely to be estimated from the ABR than from the pure tone audiogram as children are being diagnosed at younger average ages.
- Māori are less likely to have severe or profound bilateral hearing losses, while Europeans are more likely. Asian and Pacific children are more than twice as likely to have severe or profound unilateral hearing losses.
- New Zealand DND data suggest a relatively higher proportion of children and young people with mild and/or moderate hearing loss, and fewer with severe/profound hearing loss than in other similar jurisdictions.

## **Audiometric data**

<u>Audiometric data</u> are requested for both the right and left ears of all tamariki and rangatahi notified to the Database. Those notifying cases were asked to provide air and bone conduction thresholds from the pure tone audiogram or thresholds from the ABR using correction factors from the National Screening Unit's (NSU) policy and quality standards<sup>i, ii</sup>.

Professionals who notified cases were approached where significant information was missing and were able to fill in some gaps. Of the cases that still contained missing data, data are more commonly reported for 0.5 kHz and 2.0 kHz<sup>iii</sup>.

The proportion of cases for which the thresholds were determined through ABR has been rising, from 21% in 2010 to 60% in 2024, with a high of 72% in 2021 (Figure 14). This change is due to reducing numbers of tamariki being old enough to have their hearing assessed behaviourally, a result of the UNHSEIP.

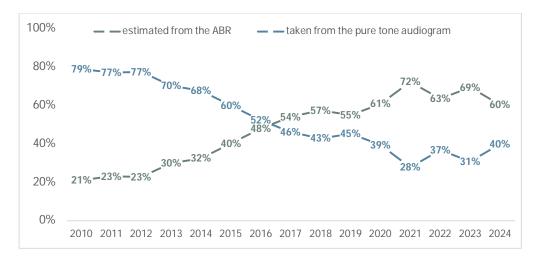


Figure 18: Proportion of cases containing thresholds from ABR and the Pure Tone Audiogram, by year (2010-2024)

i Correction factors: 5, 5, 0, and -5 dB for 0.5, 1.0, 2.0 and 4.0 kHz respectively as contained in 2023's Diagnostic and amplification protocols.

ii Notifying clinicians are encouraged to provide as much audiometric data as possible for each case they are notifying to the Database.

iii This demonstrates that frequencies that are typically tested at the end of the protocol for testing young tamariki are less likely to be complete (i.e., 4.0 kHz and 1.0 kHz). Where a significant air-bone gap was present, bone conduction thresholds at the appropriate frequencies were also collected, and bone conduction ABR correction factors of -5 for 0.5 and 2.0 kHz were provided in the online notification form. Correction factors for ABR and bone conduction were provided in the online notification form. These are from National Screening Unit (2016) Amplification protocols.

## Classifications

In Aotearoa New Zealand, as the Clark (ASHA) code-frame is most used in clinical settings, this is the one used to describe the severity of notifications to the DND.

Degree of loss	Clark 1981 (ASHA) <sup>126</sup>
Normal	-10-15 dB HL
Slight	16-25 dB HL
Mild	26-40 dB HL
Moderate	41-55 dB HL
Moderately Severe	56-70 dB HL
Severe	71-90 dB HL
Profound	≥91 dB HL

As noted elsewhere, vaccination programmes had reduced rates of meningitis in Aotearoa New Zealand and this reduction was expected to have led to a reduction in rates of (more severe) hearing loss<sup>127</sup>. However, more recently, coverage rates have fallen.

Several viral infections can cause hearing loss, which can be congenital or acquired, unilateral or bilateral and is typically sensorineural<sup>128</sup>. Mumps, for example, almost always causes single-sided deafness. Any reduction in the number of more severe cases due to meningitis is likely to be small. CMV infection is most likely to result in severe to profound hearing loss<sup>109</sup>.

Clinicians might keep in mind that those children and young people with milder degrees of hearing loss are at increased risk of not wearing hearing aids prescribed to them<sup>129, 130</sup>, and that those families with children who have cochlear implants are managing and promoting device use more than those with hearing aids<sup>131</sup>.

## **Calculating severity for notifications**

From 2010, the re-launched DND form has requested full audiometric data for each case<sup>i</sup>. • p59

Of the 2924 cases within the main dataset (2010-2024), 82% contain enough data to calculate severity. This means for those children and young people with bilateral hearing loss, all eight datapoints were provided or could be interpolated, while for unilateral cases there were four after any interpolation.

When comparing the severity profile of cases from 1996-2005 data with 2010-2024 data, using the exclusion criteria from the original database<sup>ii</sup>, the proportion of milder hearing losses notified has increased.

i While the DND collected some audiometric data for several years until the end of 2005, this information was insufficient to allow comparisons to be made easily with data from other jurisdictions. As the original Database (1982-2005) did not keep detailed records of 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 that did not contain all eight-audiometric data-points, or whether interpolation or averaging was used for records with fewer tested frequencies.

ii The original Database excluded cases of unilateral hearing losses, tamariki born overseas and those with acquired hearing losses.

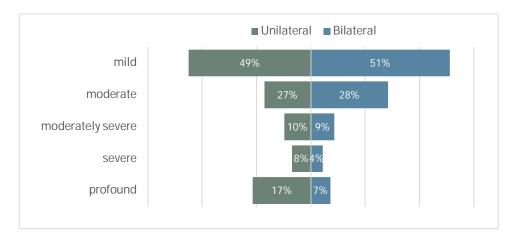


Figure 19: Degree of hearing loss by tamariki for unilateral and bilateral hearing losses (worse ear, better ear; 2010-2024, including interpolated values)<sup>i</sup>

Children with a hearing loss thought to have been present at birth are ≈ three times as likely to have a severe or profound hearing loss (unilateral or bilateral).

#### Single sided deafness in the DND

The proportion of all 2010-2024 cases that met the criteria for SSD is 5.1%ii.

An inconsistent and falling proportion of children and young people is categorised as having SSD. This is thought to relate to the growing proportion of children and young people suspected to fit in this category but where not all frequencies were included on the DND notification form.

Clinicians should note that children and young people with SSD are not eligible for publicly funded cochlear implants except in the case of meningitis but can opt for privately funded implants or receive implants if they are covered by Accident Compensation Corporation (ACC)<sup>132</sup>.

It is likely a good number of these tamariki will not have a robust auditory nerve<sup>133</sup> meaning implantation is not valuable for them. This means early imaging is useful for those in this ropū, enabling informed korero with whānau to help them understand what options are likely to be available.

#### Mild hearing losses

Definitions of what constitutes a mild hearing loss vary in the literature, as does prevalence rates, though this group is often the largest in terms of the degree of hearing loss among children and young people<sup>iii, 134</sup>.

The implications of mild hearing losses have been re-evaluated in recent years and are often associated with persistent educational and communication difficulties<sup>88, 135</sup> though often data in this area focus on children with hearing losses in the upper end of the mild range<sup>134</sup>.

Some research suggests that that children with mild hearing loss may have worse outcomes than those with hearing losses of greater severity, likely because children with these hearing losses often have them

i Please note that the 2023 report incorrectly stated the proportion of moderate bilateral losses was 27 rather than 17%.

ii The number of children and young people with complete audiometric data on their notification form has been falling since the Database was relaunched in 2010 and this drop is thought to relate to the rising proportion of cases diagnosed using ABR.

iii Children with minimal hearing loss are not included in the Database.

identified later and receive less support and fewer assistive devices<sup>136</sup>. In some cases, mild hearing losses may not be identified at all.

Here in Aotearoa New Zealand, the UNHSEIP does not aim to detect all mild hearing losses. The policy and quality standards for the UNHSEIP note that, while children with mild hearing losses below the programme's threshold may not be 'candidates for amplification, these children should still be monitored audiologically, as they may be at risk for progressive hearing loss and the deleterious effects of additional temporary conductive hearing loss'16.

**i** Decision makers and clinicians should note that those with less severe hearing losses are less likely to have their hearing loss identified through screening, to receive hearing technology and other support (such as hearing aids and cochlear implants, as well as speech and language development).

While those with more severe hearing losses should undoubtedly receive and therefore benefit from additional support, it is helpful to consider how New Zealand's hearing systems and settings are designed to ensure that Māori and other groups are not disadvantaged.

## **Ethnicity and severity profiles**

Overall, there are a greater proportion of mild or moderate bilateral hearing losses among Māori tamariki (84%) than other ethnic groups.

Previous analyses, including some going back some years<sup>137</sup>, looked at significant differences between severity profiles of Māori and other groups, finding these children and young people were more likely to have milder degrees of hearing loss than other groups, including European children and young people.

Our current analyses splits severity categories into two groups: 1 - those with mild/moderate and moderately severe together; and 2 - those with severe/profound hearing losses, and examines those with unilateral and bilateral hearing losses. These analyses find:

- Māori are less likely than both Pacific and non-Māori non-Pacific children and young people to have a severe or profound bilateral hearing loss; and
- Asian and Pacific children are more than twice as likely to have severe/profound unilateral hearing losses when compared with non-Pacific and non-Asian children<sup>i</sup>. (Please note that this was incorrectly listed as severe and profound bilateral hearing losses in the 2023 report.)

While this newer analysis does not find an overall significant difference in the proportion of Māori with severe or profound hearing losses, this looks to be related to the inclusion of moderately severe hearing losses in the first category. p62

## Comparisons with international data

Despite differences in cohort, previous analyses show a consistent difference between severity profiles in New Zealand versus those from other countries and jurisdictions, with a relatively higher number of cases with mild and/or moderate hearing loss in New Zealand, and a smaller number of cases with severe or profound hearing loss. Several factors are likely to contribute to this, including the higher numbers of milder degrees of bilateral hearing loss found among Māori children and young people. • p67

i Keep in mind diversity within the Pacific and Asian categories likely hides subgroup differences.

# Intervention and support

# Wawaotanga me te tautoko

- In 2024, The Ministry of Education | Te Tāhuhu o te Mātauranga provided services funded support for children and young people who are deaf and hard-of-hearing from birth to Year 13 through: First Signs support (Deaf Aotearoa) birth to five years of age; cochlear implant habilitation programmes and habilitation support; and Ko Taku Reo Deaf Education NZ.
- They provided support to approximately 1,912 children under the age of eight, including 775 babies and young children identified because of the UNHSEIP.
- Ko Taku Reo are a key provider, offering services through their enrolled school, NZSL@School, early
  enrolment services and specialist support and through their outreach school which supported 3,103
  students.
- Professionals notifying cases expected 53% of the children and young people 2024 would receive two
  hearing aids. Public funding meant that 1,881 received hearing aids while 41 children and young
  people received cochlear implants during 2024.

## Ministry of Education | Te Tāhuhu o te Mātauranga

In the 2024 calendar year, the *Ministry of Education, Learning Support* provided service to approximately 1,912 children who are deaf and hard-of-hearing, birth to eight years of age (Year 3 at school) through the Adviser on Deaf Children Service<sup>i, 138</sup>.

This included support to children in the following areas:

- Support for babies, infants and children under the age of five identified as deaf and hard-of-hearing through the UNHSEIP) and their families and whānau **number supported 775**;
- Support for babies, infants and children under the age of five and their families identified as deaf and hard-of-hearing not through the Universal Newborn Hearing Screening programme (UNHSEIP) and their families and whānau number supported 341; and
- Support for school-aged children (Year 1 to Year 3, at school) identified as deaf and hard-of-hearing with moderate communication and learning needs **number supported 945.**

For the calendar year 2024 the Ministry of Education, Learning Support provided service to approximately 150 children identified with hearing loss through the Universal Newborn Hearing Screening and Early Intervention Programme:

- 65.5% of children and their whānau were contacted within 10 working days of receipt of a request for support;
- 83.1% of children and their whānau began receiving support by one month following receipt of request for support; and
- 90.5% of requests for support for children under six months of age began receiving support by six months of age.

i Please note that this number is approximate, as some learners received multiple services across the year.

The Ministry also funds support for children and young people who are deaf and hard-of-hearing from birth to Year 13 at school through:

- First Signs support (Deaf Aotearoa), birth to five years of age;
- Cochlear Implant Habilitation programmes, habilitation support; and
- Ko Taku Reo Deaf Education NZ<sup>139</sup>.

## Ko Taku Reo Deaf Education New Zealand

Ko Taku Reo Deaf Education New Zealand is the national provider of education services for Deaf and Hard-of-Hearing (DHH) children. It operates as a bilingual and multicultural organisation, using both New Zealand Sign Language (NZSL) and English across its services and settings. With a workforce of over 400 specialist staff, it has specialist schools in Auckland, Wellington, and Christchurch. The organisation embraces Māori culture and language through culturally sustaining pedagogy, ensuring that its diverse student body is supported in ways that honour their cultural and linguistic identities.

The strategic direction of Ko Taku Reo, guided by its Board, focuses on fostering collaboration with families, whānau, and the Deaf community. The overarching goals are to ensure DHH students can contribute meaningfully to society, feel socially included, and have the tools to pursue their aspirations.

#### **Services Provided**

#### 1. Enrolled School:

Ko Taku Reo operates 13 school sites across Auckland, Christchurch, and Wellington. In 2024, enrolments increased from 108 in Term 1 to 120 by Term 4. Auckland hosted the majority of students (n=76), followed by Christchurch (n=38), and Wellington (n=6). Residential accommodation is available for students aged 11–21 at Kelston (Auckland) and Sumner (Christchurch).

### 2. Outreach – School Resource Teachers Deaf (RTDs):

This service supports 3,103 students in mainstream schools through a tiered support model. Services include specialist teaching, technology, and NZSL support. Most recipients are aged 4.5 to 21 years. Around 10% are verified under the Ongoing Resourcing Scheme (ORS). Funding is a combination of ORS allocation and moderate needs contracts.

#### 3. Early Involvement Services:

Ko Taku Reo runs a licensed preschool in Auckland and an Early Years Whānau Centre across two sites in Christchurch. At the end of 2024, 18 deaf and 7 hearing children were enrolled in the Auckland preschool, while 22 deaf and 14 hearing children were enrolled in Christchurch. Additionally, 12 Preschool Residential Courses were held, attended by 28 families.

#### 4. Specialist Support for ORS-verified Students:

Mainstream and specialist school students with ORS verification receive support where Ko Taku Reo provides specialist teacher time. Additional support (e.g. teacher aides, therapists, Kaitakawaenga) is funded directly to the student's enrolled school by the Ministry of Education.

#### 5. NZSL@School:

This initiative aims to enhance NZSL access for DHH students who learn best in NZSL, ensuring their academic and wellbeing needs are met in mainstream settings. In 2024, the program supported 146 students through 131 Communication/Education Support Workers and 14 Educational Interpreters.

#### **Continuing Initiatives**

NZSL Immersion Day Schools provide weekly curriculum delivery in NZSL for students in mainstream schools. In 2024, 60 DHH students and 9 hearing students attended across five locations, with a sixth site preparing to launch in 2025. Additional regional NZSL Immersion Hubs and Language Days are also in place.

NZSL Playgroups in Wellington and Dunedin, along with a newly established virtual playgroup, serve as language and community support pathways. In 2024, 14 DHH and 15 hearing children attended in-person playgroups, while the virtual group engaged 19 families in its first six months.

This comprehensive approach ensures tailored, inclusive, and culturally responsive education for New Zealand's DHH children.

## **Hearing aids**

In each notification form audiologists/audiometrists were asked "How many hearing aids are to be fitted?". The resulting data represent the clinician's stated plan at the time of notification. There are several reasons why the plan may not be followed in individual cases (e.g., parental preference, worsening hearing loss, diagnosis of additional needs).

The pattern of plans has shifted when compared with 2010-2013 levels, with a reduction in the proportion of cases where prescription of one or two hearing aids is expected; and a rise in the proportion of cases in which the professional notifying the case is unsure whether hearing aids will be provided (Figure 20)<sup>i</sup>. This is understandable as the average age at diagnosis and therefore when the notification is completed is now much earlier than in the previous period.

For 2023 and 2024 the pattern has changed again, showing the lowest proportion since 2010 being expected to receive two hearing aids, and the highest proportion with the hearing professional being unsure at this time about whether hearing aids are likely to be fitted.

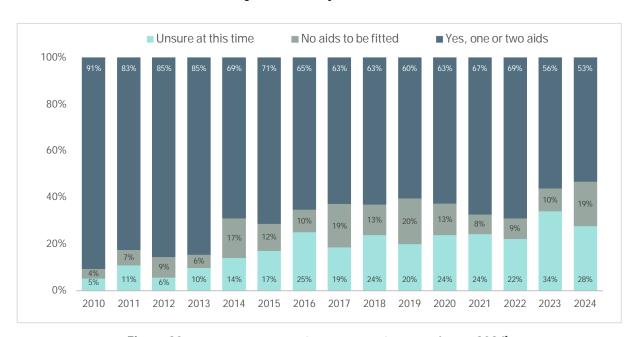


Figure 20: Hearing aids to be fitted by notifications (2010-2024)

i Of the cases notified to the Database for 2024, 99% contained information about whether hearing aids were to be fitted.

## Intention to fit, ethnicity and deprivation

DND data on the number of hearing aids audiologists predicted would be prescribed are aligned with our previous assertions that Māori are more likely to have bilateral hearing losses than their European counterparts.

Previous analyses that held severity constant, showed more European and fewer Māori children with zero or one hearing aid to be fitted, reflecting the proportion of bilateral hearing losses in these groups. At that time no significant differences were found between the level of deprivation and whether the clinician expected hearing aids would be prescribed. • 2016 report

## Public funding for hearing aids

To provide some context for these figures, data from the public provider for Hearing Aid Services during the period covered by this report, are shown in Table 14.

These data show health funded hearing aids for tamariki under the age of nineteen, and those in fulltime education and under the age of 21 during the 2024 calendar year<sup>1</sup>. A total of 1,881 tamariki and rangatahi received hearing aid(s) during this period, slightly up on the previous two years.

It is worth noting that New Zealand's system of funding hearing aids for children and young people is not the most generous. Australian Hearing, for example, offers these at no charge to all children and young adults under the age of 26 years of age.

Ethnicity	0-3 years	4-5 years	6-15 years	16-18 years	Grand total
Māori	130	77	338	21	551
European	138	81	480	70	754
Pacific Peoples	28	18	91	10	145
Other	85	71	262	20	431
Total	381	247	1171	121	1881

Table 14: MSD funding of Children's Hearing Aids, Calendar Year ending 31 December 2024, EnableNZ<sup>ii, 140</sup>

### **Contributors to improved outcomes**

Several factors have been identified as contributors to improved outcomes for those with hearing aids/cochlear implants:

- the earlier hearing aids or cochlear implants are first fitted the better early language achievement<sup>141, 142</sup> including for those with additional disabilities<sup>143</sup>;
- the impact of later fitting of hearing aids increases with the degree of hearing loss<sup>142</sup>;
- the earlier first fitting with a hearing aid or cochlear implant the better speech, language and functional performance outcomes<sup>141</sup>;
- consistent hearing aid use is positively correlated with improved language abilities<sup>144</sup> and their consistent and high usage, while it can be challenging, behavioural change techniques, loaner devices and education to increase confidence for undertaking sound checks can be helpful<sup>145, 146</sup>;
- psychosocial performance is correlated with better language and functional performance<sup>141</sup>.

i Please note, these data pertain to all tamariki receiving hearing aids and not just those receiving hearing aids for the first time.

ii The current provider (EnableNZ) does not include repair or replacement requests, bone-anchored hearing aids, ear molds, insurance excess or remote microphone (FM and RM) systems, or funding for parts, or accessories in these data.

Australian Hearing has found that fitting rates increased for those who have less severe degrees of hearing loss. This was thought to be the result of factors such as improved technologies and increasing options for those with mild and unilateral hearing loss, including provision of cochlear implants<sup>4</sup>.

They also find significant geographic differences by state and that Aboriginal and Torres Strait Islander children are now more likely to be first fitted with hearing aids and that this occurs much later than their non-indigenous Australian counterparts. Higher rates of hearing losses at birth for these groups and persistent middle ear infections are thought to contribute.

### Prescribing, usage and data in Aotearoa New Zealand

Waikato DHB (now Waikato District) found that for both Māori and non-Māori with moderate or greater hearing loss, hearing aid fitting occurred on average approximately six weeks after diagnosis, though medians for Māori were considerably higher at 19 weeks<sup>42</sup>.

An Aotearoa New Zealand study (unpublished) followed up children and young people notified to the DND in 2010, seven to eight years later. For those where data was available, only 40% had been wearing their device(s) consistently since they were fitted. Double the proportion of Māori children in the cohort (46%) had inconsistent, seldom or no device use, compared with Europeans<sup>93</sup>.

A lack of recent UNHSEIP data means the proportion of children screened who are diagnosed by three months is unknown, as is information on the proportion who receive hearing aids by six months of age. This information would be helpful to enable us to understand whether screening is resulting in appropriately early intervention for those who receive hearing aids.

Recent research suggests those children with milder degrees of hearing loss who were previously unaided, can have poorer phonological memory and morphosyntactic skills, raising questions about leaving mild hearing loss untreated<sup>147</sup>, although research focusing on mild hearing losses remains limited.

## **Cochlear implants**

While the DND notification form doesn't request specifics about cochlear implant (CI) referrals, this report includes information on the number of cochlear implants provided to children and young people in Aotearoa New Zealand, and some background on the funding for these implants.

Funding from Whaikaha – Ministry for Disabled People is administered by two cochlear implant trusts<sup>i</sup>. These implants are provided based on candidacy criteria for children and young people who are assessed by the cochlear implant teams.

Most children receiving cochlear implants have severe/profound hearing losses, or progressive hearing losses that are becoming more severe.

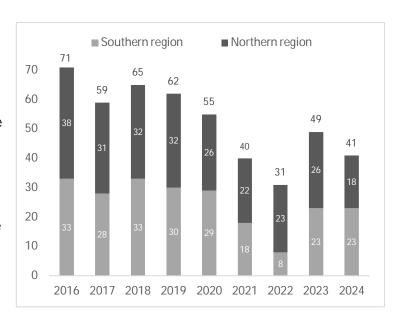


Figure 21: Number of children receiving cochlear implants by year, split by cochlear implant programme (2016-2024)

i The Northern Cochlear Implant Trust covers the area northwards from an almost horizontal line extending roughly through Taupō, and the Southern Hearing Charitable Trust covers the area south of this line.

During the 2024 calendar year there were 38 publicly funded cochlear implant devices provided in the Northern Region and 40 in the Southern Region to those under the age of 19. Also shown is the number of children receiving those implants. This year's numbers are a significant rise on those for 2022 for the Southern Region. A summary showing this change can be seen in Table 15.

Children receiving cochlear implants	Southern Cochlear Implant Programme		Northern Cochlear Implant Programme	
	Ears	Children	Ears	Children
ACC cases	0	0	1	1
Public Funding - (1 Jan to 31 December)	37	20	32	16
Private procedures	1	1	2	2
Re-implants – recalled, failed integrity tests, or soft failures	1	1	1	1
Sequential or retrospective second cochlear implants	1	1	2	1
	40	23148	38	18 <sup>149</sup>

Table 15: Publicly funded cochlear implants provided in Aotearoa New Zealand during 2024<sup>i</sup>

i In some years the number of cochlear implants provided exceeds the number of profound or severe cases notified to the Database. While the DND may be missing some notifications for children in the severe and profound categories, there are several other reasons why this figure is low compared with the number of children implanted during the same period. One is that some children who are notified to the Database as having less severe hearing losses develop more significant losses over time, something that is not tracked by the Database.

# **Increasing equity**

# Te whakapiki haere i te mana taurite

- These reports demonstrate longstanding inequities in hearing care for children and young people that need to be addressed for tamariki and whānau to thrive.
- Understanding various worldviews and perspectives, including of Māori, deaf/Deaf people and Pacific Peoples is essential for developing services that are responsive and appropriate for all.
- Health and education inequities are documented globally and have a web of historical and contemporary causes.
- Enduring collaborative commitment across multiple domains is required to address inequities.
- Recommended approaches to increasing equity include: providing cultural safety training, and increasing workforce representation, affordable community-based services, whānau-centred care and interpersonal connection, compassion and warmth, are among.

## **Perspectives**

There are several valuable lenses through which hearing and deafness can be viewed. These lenses are important to consider when working to reduce inequities for those who are Deaf, deaf or hard-of-hearing.

As described by Deaf Aotearoa<sup>150</sup>, Deaf people (Deaf with a capital D – denoting this unique community) often see being Deaf as a difference, a way of life for those with shared experiences. Society is considered a disabling force when using this lens.

Manuel *et al.* (2022)<sup>151</sup> describes the significance of hearing for Māori as a <u>taonga</u> for kaumātua, while Holt *et al.* (2024)<sup>152</sup> illustrates that Pacific Peoples have a deep cultural appreciation for hearing, with it being perceived as a 'qift' critical to identity, ancestry and connections.

## Why equity?

This section of the report focuses on improving equity. Equity and equality are related concepts, but they have different meanings. Equality focuses on individuals, or groups of people, being given the same resources or opportunities. Equity recognises that each person or group has different circumstances and needs, and allocates the resources and opportunities needed to reach equal outcomes.

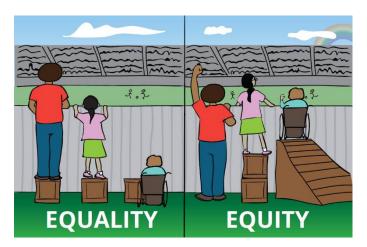


Figure 22: Equality vs equity, source: The Equity Tool.

## Inequities in health and education services

Health and education inequities are well documented globally<sup>153, 154</sup>. The causes of inequities are complex and include historical and contemporary political, legal, social, economic, structural and institutional arrangements and processes that shape how power and resources are distributed<sup>155</sup>.

### Inequities in health and hearing health

Equal access to the determinants of good health is a fundamental human right, supported by the United Nations and the Universal Declaration of Human Rights<sup>156</sup>. In New Zealand, as in many countries, the determinants are not distributed evenly across society with specific groups experiencing disadvantage, including Māori, those living in more deprived areas, and those with living with disability<sup>157</sup>.

This and previous DND reports outline various inequities relevant to those tamariki and rangatahi with hearing loss and their whānau. For example, the section on deprivation shows children with hearing loss are much more likely to live in high deprivation areas than the general population, and there are startling differences for Māori and Pacific families compared with other ethnic groups in the Database.

Equity within hearing services is not well understood, though key hearing research has found geographic, socioeconomic and/or ethnic disparities among rates of: middle ear problems, ventilation tubes for children<sup>43, 158, 159, i</sup>, exposure to risk factors for middle ear conditions and hearing loss<sup>160</sup>, attendance rates at appointments<sup>161</sup> and screening coverage.

Reduced access to hearing healthcare and a disproportionate impact of unassisted hearing loss were also found for Māori and Pacific children and their whānau<sup>160</sup>, with McCarthy *et al.*'s 2025 review<sup>160</sup> finding persistent 'inequities in hearing loss and middle ear conditions' especially for Māori and Pacific.

### Health inequities for Māori

The health status of Māori, as with other First Nations populations, has been undermined by Aotearoa New Zealand's colonial history, which has seen resources taken from Māori, with further marginalisation through cultural oppression and the introduction of new social systems based on European norms and values<sup>162, 163, 164, 165</sup>. • King M, Smith A, Gracey M (2009)<sup>166</sup>

Disparities documented in many areas of health demonstrate Māori have poorer access 'to, and through' the health system<sup>167, 168, 169</sup>, that they receive a poorer and slower service, and are less likely to receive appropriate levels of care<sup>170</sup>, resulting in poorer health outcomes.

Despite relatively strong national policy frameworks, these have not been successfully implemented and there are some recent indications that engagement with and recognition of Māori has been dismantled in some areas<sup>171,172,173</sup>.

Both the Waitangi Tribunal 2575 inquiry (Stage One, 2019)<sup>174</sup> and the New Zealand Health and Disability System interim report (2019)<sup>175</sup> identified the ongoing failure of the Crown to deliver health equity for Māori and called on the Crown to abide by its obligations under Te Tiriti o Waitangi<sup>ii</sup>.

The Tribunal's report recommended extending the principles derived from Te Tiriti by the Royal Commission on Social Policy (partnership, participation, and protection) to also include the principles of equity, active protection, options, and tino rangatiratanga, aligning with the Tribunal's finding that these are necessary to ensure the Crown's obligations are met in the health sector. The report also asserted that District Health Boards (DHBs) and other health agencies were not doing enough to reduce inequities.

i It is worth noting there are differing views about the efficacy of grommets as a treatment for middle ear disease. Regardless, it is unlikely that differences in otologic treatment practices would be applied based on ethnicity.

ii A summary of policies and legislative statutes that underpin government's commitment to Māori, including within health, and those in selected other countries with indigenous populations can be found in Ferdinand *et al.* (2020)<sup>171</sup>, see the references section for details.

Several districts have, in recent years, re-asserted their commitment to achieving equity for Māori, including Northland<sup>176</sup> and Auckland<sup>177</sup>, and reference the important role of eliminating institutional racism in achieving equity. • Penney et al. (2011)<sup>178</sup> and Graham and Masters-Awatere (2020)<sup>179</sup>

### Inequities in education

The 2023 briefing from Te Tāhuhu o te Mātauranga Ministry of Education to incoming ministers emphasised that the education system does not deliver excellent and equitable outcomes for all, particularly for Māori, Pacific Peoples, deaf people and those with disabilities or from low socioeconomic backgrounds.

Achievement gaps in Aotearoa are some of the widest compared with other countries<sup>180</sup> and PISA data (a global Programme for International Student Assessment) from 2022 show the scores of low-achievers are falling more than high-achievers<sup>181</sup>.

The Controller and Auditor-General (2024)<sup>182</sup> reported long standing disparities between girls and boys in different subjects, for students in lower socioeconomic areas, and for Māori and Pacific students. It recommended better information gathering and greater collaboration to improve performance and tackle inequities.

Education access and outcomes are influenced by health access and outcomes, and are in themselves a determinant of health, as they are 'strongly associated with life expectancy, morbidity, [and] health behaviours'. In addition, 'educational attainment plays an important role in health by shaping opportunities, employment, and income' 183.

Evaluation of the educational achievement of children with permanent hearing loss in Aotearoa New Zealand is very limited.

## Fertile ground for equity efforts

Addressing persistent health and education inequities for groups such as Māori and Pacific Peoples, those in high deprivation areas or with one or more additional disabilities, the geographically isolated, new immigrants to New Zealand and those with milder and/or unilateral hearing loss, is a valuable focus.



Figure 23: Family facing headwinds

These groups face 'headwinds' that mean engagement with early intervention programmes requires more time, effort, and resources from these families compared with others. Unlike a single "barrier," these headwinds are continuous conditions that constantly push against progress. Rather than episodic challenges, these can layer and interact to create even greater obstacles for such groups. These ongoing, structural realities require additional support or system change to overcome.

Involving those most effected, and considering their worldviews and perspectives, beliefs and values<sup>184</sup>, is essential in developing appropriate and responsive<sup>152</sup> services.

A recent scoping review, focused on First Nations children in Australia, New Zealand, Canada, and the United States, suggests hearing programmes should be sustainable and located within a connected system of care, and that future planning should involve First Nations communities at every age of development, implementation and evaluation<sup>185</sup>.

For hearing and education professionals, their sphere of influence is generally limited to individual, interpersonal, and organisational levels, while decision-makers and funders are likely to have at least some influence over the social determinants of health and policy and practice of key agencies.

Projects such as the Paediatric ORL Pathway - Redesign for Equity (Tāmaki Makaurau) and Equitable ear and hearing health outcomes (nationwide) have been collaborative efforts focused on equity.

The Database demonstrates areas of fertile ground for efforts to improve equity and examples are included, broadly grouped by role, in Table 16. The top three reasons for delay noted described in this report are particularly helpful to inform work to improve impact.

Source & focus	Findings and examples of recommended actions
Researchers and funders	leverage the leadership of, and prioritise Pacific and Māori-led research, building local capacity <sup>186</sup>
	<ul> <li>evaluation of approaches for provision of effective, affordable, sustainable, and accessible community-based hearing services for children and young people<sup>187</sup></li> </ul>
	<ul> <li>testing options for addressing specific barriers in a sustainable way for whānau accessing hearing services<sup>i</sup></li> </ul>
	• incorporate indigenous health models (e.g. 'Te Whare Tapa Wha') into thinking, planning and practice <sup>188</sup>
Decision-makers at local and national levels,	<ul> <li>bolster a renewed focus on prevention<sup>158</sup> and targeted interventions for groups such as rural communities<sup>189</sup>, Māori (utilise Te Tiriti o Waitangi to guide equalisation efforts) and Pacific Peoples</li> </ul>
including clinical	influence policy and practice changes through collaboration and peer learning
leads	• provide cultural safety training for staff <sup>190</sup> and consider hiring practices to increase workforce representation for under-served groups
	<ul> <li>work with local leadership to reduce or remove barriers to services and reduce waiting times (e.g. flexible appointments, improved hiring practices, educational resources, strengthening relationships with <u>ENTs</u>, refined scheduling to reduce delays for second appointments)</li> </ul>
	<ul> <li>efforts to improve screening coverage rates<sup>191</sup>, improve understanding of outcomes and impact for key screening programmes, and consideration of targeted earlier screening for children residing in lower socioeconomic areas<sup>187189</sup></li> </ul>
Individual clinicians	• improve understanding of the realities for those facing significant headwinds, including those who are living in deprivation, rurally located, Māori, Pacific, new migrants, and/or ESOL, and use this to inform equity improvement efforts <sup>184, 192</sup>
	<ul> <li>work on efficient, effective clinical practice to complete assessments over fewer appointments (See 2016's Diagnostic and amplification protocols<sup>193</sup>)</li> </ul>
	<ul> <li>further consider how to frame and approach addressing high non-attendance rates among specific groups, consider reframing to 'Did not attract'</li> </ul>
	<ul> <li>engage with professional development (including antiracism, Te Tiriti and implicit bias training) and mentoring opportunities</li> </ul>
	influence policy and practice through collaboration and contribution to change initiatives

Table 16: Examples of recommended actions to reduce inequities<sup>ii</sup> by professional groups

i Such investigations are particularly important as there is no service specification for audiology services nationally, meaning that services offered by districts differ, as do waiting times.

ii See also Table 22 in the 2021 DND report.

Key papers describing perspectives on hearing loss and hearing services for Māori and Pacific Peoples can be found from p66. Awareness of bigger picture influences, and their implications, is valuable for both professionals and decision makers. See Gustafson *et al.* (2023)<sup>154</sup>. • Previous DND reports

Through the Database it is clear children and young people who have permanent hearing loss in Aotearoa have significant headwinds, in addition to their hearing loss, that mean it is harder for them/their whānau to benefit from health and education resources.

**Clinicians** should note that Māori and Pacific whānau often live in areas of high deprivation and are less likely to be enrolled with a primary care provider<sup>194</sup>. Their consequent higher health needs, plus higher rates of disabilities and barriers to access, make it more difficult for this group to engage with services.

**Decision-makers** should consider that, while health and education interventions have often focused on patients or ideally on families/whānau (e.g. increasing knowledge or behaviours), inequity is a systemic issue and requires a systemic approach. Inequities should be considered and addressed at several levels; individual, interpersonal, organisational, community and societal<sup>154</sup>.

# **Appendices**

## Ngā āpitihanga

## **Appendix A: DND related information**

### Making notifications to the Database

The authors of this report would like to extend their sincere thanks to all hearing professionals who have completed notifications for the Database.

Your contribution to our understanding of permanent hearing loss among Aotearoa New Zealand's children and young people is greatly appreciated.

Audiologists and audiometrists are asked to make future notifications to the Database by following this link.

### Notes for those completing notifications:

- Send us your notifications as soon as possible following diagnosis: we strongly encourage those making notifications to the Database to get these in as soon as possible following diagnosis, and wherever possible, before the end of the notification period in mid-March of the following year.
- **Resources for clinicians** making notifications can be found <a href="here">here</a> these include a PDF version of the notification form, background information about the Database and previous Database reports.
- **Consent:** Babies screened by the UNHSEIP are legally consented for entry into the Deafness Notification Database (DND), and there is no need to get the families to sign a separate consent form.

Other children and young people diagnosed need to be notified after a consent has been signed by the parent or caregiver, or for older rangatahi, by the young person themselves. This form should be kept on file by the diagnosing clinic.

#### Inclusion criteria:

- included in the Database: atresia, congenital ossicular fixation, meningitis, acquired hearing losses;
- excluded from the Database: hearing losses which can be remediated using grommets (ventilation tubes), such as temporary hearing losses associated with otitis media.

Questions: For answers to any pātai (questions), please email Janet Digby.

## **History of the Database**

#### The original Database

The original Deafness Notification Database (DND) was New Zealand's annual reporting system for new cases of hearing loss among tamariki from 1982 to the end of 2005.

The Database included data on the number and ages of tamariki diagnosed with permanent hearing loss and annual reports describing collected notifications were released. It was managed by the National Audiology Centre on behalf of the Ministry of Health, and later by the Auckland District Health Board.

Dr Bill Keith and Oriole Wilson are acknowledged for their roles in creating and continuing the collection and reporting of these important data.

The original criteria for inclusion in the DND were based on a Northern and Downs definition, below, and were 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 26 dB HL in the better ear (Northern and Downs classification, 1984)<sup>195</sup>".

They required the hearing loss to meet the audiometric criteria in *both ears*, for the child or young person to have been born in Aotearoa New Zealand, and that they have a congenital (non-acquired) hearing loss.

From 1982 to 2005 notifications went to the National Audiology Centre/Auckland District Health Board (ADHB) administered Database.

No annual reports were completed for the years 2006 to 2009 as the Database was not operating during this period.

#### Re-establishment

When Auckland District Health Board no longer wanted the contract for the DND, funding was split across all District Health Boards and, unsurprisingly, the Database was no longer operational.

The DND was seen to have even greater importance from 2007, as nationwide implementation of the UNHSEIP had begun.

The DND was known to provide an important measure of changes in the age of identification and as the only way to identify potential false negatives within the newborn screening programme. Efforts to encourage the Ministry of Health to re-establish the Database from 2006 to 2010 were unsuccessful.

The current re-launched Database was initiated by Janet Digby in 2010 with support from Dr Andrea Kelly and Professor Suzanne Purdy. At the time of the relaunch the New Zealand Audiological Society (NZAS) raised some funding to contribute to its first year of operation through a small grant, and by allowing messages to go to its members to encourage notifications.

Notifications to the re-launched Database, previously made on paper forms, moved to an online form to reduce data entry errors, and to try to make it as easy as possible for hearing professionals to notify cases. Janet Digby conducted analysis and compiled the reports with support from her co-authors, as still happens today.

#### The current iteration of the Database

The criteria for inclusion were modified for the 2010 re-launch of the Database, based on feedback from a small working group<sup>i</sup>.

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

The criteria from 2010 included children and young people 18 years or younger<sup>ii</sup> with an average hearing loss of 26 dB HL or greater over four audiometric frequencies (0.5, 1.0, 2.0 and 4.0 kHz) in one or both ears<sup>iii,iv</sup>. These children may be born in New Zealand or overseas and can have acquired or non-acquired hearing losses.

This report and the DND generally exclude children with Auditory Processing Disorders (APD).

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

ii To align with the age range used for the paediatric cochlear implant programmes.

iii While cases of unilateral hearing loss were technically excluded from the Database until 2005, there were still large numbers of notifications sent to the administrators of the Database, although these were not included in the main analysis. Professionals consulted unanimously indicated this group should be included in the Database.

iv For several years after the relaunch of the Database, cases of high frequency hearing loss were being collected. Because only a small number, and an unknown but likely small proportion were being notified, we have not described this group in recent years, and we are no longer seeking notifications for these cases.

The authors of this report were delighted that the Ministry of Health began funding the DND from the start of 2012.

The Database is now managed through a contract with *Enable New Zealand* (who have a contract with the Ministry for Social Development's Disability Support Services Directorate) and builds on the relaunch work.

The Database provided and still provides the only source of information from which the prevalence of permanent hearing loss among tamariki can be estimated, and from which the characteristics of new cases can be understood.

#### **Consenting changes**

A revised consent process was implemented on re-launch of the Database to ensure all information is collected with the consent of the family. Later this was paired with amendments to the newborn hearing screening consent, which included consent from whānau to have their child's data included in the DND.

#### Potential renaming of the Database

Over the years, feedback on the name of the Database was sought from parents of deaf and hard-of-hearing tamariki, Advisors on Deaf Children (AODCs), and audiologists, on a possible change to the name of the Database. This feedback did not result in 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 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.

A new name ideally would better reflect the purpose and nature of the Database, particularly as changes to the inclusion criteria mean cases of unilateral hearing loss are included in the Database.

Ideas for a new name for the Database will be gratefully received by <u>Janet Digby</u>.

## **Completeness of notifications**

There is no way of knowing how many new cases that meet the criteria are not notified to the Database.

There may be certain types of cases that are under-represented within notifications, and as a result, inferences made from the data contained in this report may not be representative of the population of new cases diagnosed.

The authors believe it is likely that the Database has been receiving notifications for between 70% and 90% of all new cases diagnosed each year.

## **Notifications and ethnicity**

The New Zealand Census (2006 and 2013) categorises respondents into five primary major groupings. These groups are Māori, Pacific Peoples, Middle Eastern/Latin American/African (MELAA), European and Asian.

While it would be greatly preferable to collect more detailed information on ethnicity, we understand this information may not be available for all cases and want to avoid any deterrents that would prevent cases being notified because, either we are requesting more detail than is easily available to the notifying professional, or we are adding to the time taken to complete the form.

The method used to classify ethnicity is the total response method as this provides a more accurate and detailed reflection of ethnicity<sup>196, 197, i</sup>, in which every person identifying with a specific group is included in that group. It 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.

i Previously, common methods required respondents to select only one ethnicity, the one with which they mostly identified, or used protocols to include only one ethnic group per individual using a predetermined hierarchy.

#### Asian New Zealanders – limitations of aggregation

It is important to note that Asian New Zealanders are a particularly diverse group making aggregation particularly problematic, as for Pacific Peoples.

The Asian category contains children and young people from many different countries and ethnicities. Headline statistics reporting the good health of Asians can be misleading as they can mask significant disparities between subgroups.

The good health of those coming to live in Aotearoa New Zealand is often referred to as the "healthy immigrant effect". While most Asians are first-generation immigrants and must pass various health and skills hurdles to come to Aotearoa New Zealand, a growing number are New Zealand born.

The aggregation of such a large and diverse group can hide significant disparities. It is also worth noting that Asians report the highest rates of discrimination of all Level 1 ethnicity groups<sup>198</sup>.

Overall, Asian New Zealanders tend to have mixed access to and through other parts of the health system, as demonstrated by their high vaccination rates<sup>199</sup>, and low rates of enrolment with GPs<sup>200</sup> and for some screening services<sup>198</sup>.

The proportion of tamariki listed as Asian among the New Zealand population and within notifications to the DND has grown rapidly in recent decades, with the fastest growing subgroups moving here being those identifying with Indian, Chinese, Korean, or Filipino ancestry. These were also the most populous subgroups within the diverse Asian category<sup>201</sup>. Most Asians in Aotearoa lived in the Auckland region at the time of the 2018 Census<sup>202</sup>.

## Terminology used in this report

There are several terms used by young people with a hearing loss and their families/whānau.

Those whose information is included in this report range from those whose hearing losses are unilateral and mild in severity, through to those whose hearing losses are bilateral or profound. The terms commonly used differ both within these groups as well as between them.

Some families and young people prefer terms such as 'hearing impaired' or 'hard-of-hearing', while others use the term 'Deaf' or 'deaf'. For the purposes of this report, we need to have a term or set of terms and use these consistently where possible to aid in the report's readability. In doing this it is not the authors' intention to exclude those who use or prefer other terms.

The reports use children/tamariki and young people/rangatahi where possible within the report to acknowledge that those approaching the top of the age range for the DND (19 years) are no longer children. However, at times the term 'children' is used alone either as the age group being considered is younger, or to improve readability.

## **Use of interpolation**

This document includes information on the severity profile of children whose diagnoses were notified between 2010 and the recent year.

While the Database contains estimates for those children and young people for whom all eight data-points are available, we also rely on interpolated datapoints, to provide a more complete picture of the severity of hearing losses reported among children and young people notified to the Database.

Interpolation is only used where two data points surrounding the interpolated point are provided. The key thresholds under analysis in this report are: 0.5 kHz, 1.0 kHz, 2.0 kHz and 4.0 kHz.

This technique is becoming increasingly valuable as more tamariki are being diagnosed earlier, meaning they cannot have their hearing assessed behaviourally, so not all frequencies may be available.

#### Table of odds ratios

All odds ratios found in the table below are significant; within each group the ratios are sorted from the most to least likely. See <a href="here">here</a> for information on how to interpret odds ratios.

Topic	Description		
Additional disabilities (ADs)	<ul> <li>Children with one or more ADs are 2.8 times as likely to have a bilateral compared to a unilateral hearing loss than those without</li> <li>Children with one or more ADs are 2.6 times as likely to have a permanent conductive hearing loss than those without</li> <li>Children with one or more ADs are 1.5 times more likely to have a mixed hearing loss than those without</li> <li>European children are 1.5 times as likely to have an AD compared to non-European children</li> <li>Children with one or more ADs are 0.5 times as likely to have a sibling or parent with a permanent hearing loss than those without</li> <li>Children with one or more ADs are 0.5 times as likely to have a sensorineural hearing loss than those without</li> </ul>		
Hearing losses thought to have been present at birth	<ul> <li>Children with a bilateral hearing loss are 3.1 times as likely to have a hearing loss thought to have been present at birth compared to children with a unilateral hearing loss</li> <li>Those with a hearing loss thought to be present at birth are more likely to have sensorineural (1.3 times) or ANSD (2.9 times) than other types of hearing loss</li> <li>Those with a hearing loss thought to be present at birth are more likely to have a severe or profound unilateral hearing loss (2.2 times as likely) or a bilateral hearing loss (2.9 times as likely)</li> <li>Asian children are 2.0 times as likely to have a hearing loss thought to have been present at birth compared to non-Asian children</li> <li>Māori tamariki are 1.6 times as likely to have a hearing loss present at birth compared with non-Māori non-Pacific</li> <li>Pacific children are 1.5 times as likely to have a hearing loss thought to have been present at birth compared to non-Maori non- Pacific children – note this difference is marginally significant</li> <li>European children are 0.6 times as likely to have a hearing loss thought to have been present at birth compared to non-European children</li> </ul>		
Family history	<ul> <li>Māori tamariki are 1.9 times as likely to have a close family history of permanent hearing loss compared with non-Māori non-Pacific</li> <li>European tamariki are 0.7 times as likely to have no data on family history than non-European children</li> <li>Pacific tamariki are 0.6 times as likely to have no data on family history than non-Pacific children</li> <li>Asians are 0.3 as likely to have a family history of hearing loss compared to non-Asian children</li> <li>Children with an additional disability are 0.5 times as likely to also have a family history of hearing loss than those without</li> </ul>		
Atresia/Microtia or both	<ul> <li>Pacific children are 1.9 times as likely to have atresia, 3.7 times as likely to have microtiai and 3.9 times as likely to have both compared with non-Māori non-Pacific</li> <li>Māori children 0.6 times as likely to have atresia (compared with non-Māori non-Pacific and 0.3 times as likely as Pacific children to have atresia</li> </ul>		
Newborn hearing screening	<ul> <li>Asian children 2.3 times as likely to have a diagnosis as a result of a 'refer' on their hearing screen when compared with other ethnic groups</li> <li>Maori children are 1.2 times as likely to have a diagnosis as a result of a 'refer' result on their hearing screen when compared with other ethnic groups</li> </ul>		
Intention to fit hearing aids	<ul> <li>Maori children are 2.3 times as likely to have hearing aids intended compared with other ethnic groups (non-Asian)</li> <li>Asian children 0.4 times as likely to have hearing aids intended compared with other ethnic groups (non-Asian)</li> </ul>		

i Pacific children are 4 times more likely to have both microtia and atresia when compared with non-Māori, non-Pacific children. They are 2.1 times more likely to have microtia *or* atresia only, compared with non-Māori, non-Pacific children.

Topic	Description		
Bilateral and unilateral hearing losses	<ul> <li>Children who have a hearing loss thought to have been present at birth are 2.8 times as likely to have a severe/profound bilateral hearing loss</li> <li>Children who have a hearing loss thought to have been present at birth are 2.2 times as likely to have a severe/profound unilateral hearing loss</li> <li>Children with a bilateral hearing loss are 3.1 times as likely to have a hearing loss thought to have been present at birth compared to children with a unilateral hearing loss</li> <li>Māori children are 1.5 times as likely as their non-Māori, non-Pacific counterparts to have a bilateral hearing loss</li> </ul>		
Type of hearing loss	<ul> <li>Sensorineural hearing loss</li> <li>Asian children are 1.6 times as likely to have a sensorineural hearing loss than non-Asian children</li> <li>Children with bilateral hearing loss are 1.4 times as likely to have sensorineural hearing loss than children without a sensorineural hearing loss</li> <li>Children with an additional disability are 0.5 times as likely to have a sensorineural HL than children without an additional disability</li> <li>ANSD</li> <li>Asian children are 4.0 times as likely to have ANSD than non-Asian children</li> <li>Children from Quintile 1 are 2.1 times as likely to have ANSD than children from Quintile 5</li> <li>Pacific children are 1.8 times as likely to have ANSD compared to non- Pacific children.</li> <li>Children with a ANSD hearing loss are 0.64 times as likely to have a bilateral hearing loss, compared to a unilateral hearing loss</li> </ul>		
	<ul> <li>Permanent conductive (PC) hearing loss</li> <li>Children with an additional disability are 2.6 times as likely to have a PC hearing loss than children without an additional disability</li> <li>Pacific children are 1.7 times as likely to have a PC hearing loss compared to non- Pacific children</li> <li>Māori children are 0.7 times as likely to have a PC hearing loss than non-Māori, non-Pacific children</li> <li>Children with a unilateral hearing loss are 0.3 times as likely to have a PC hearing loss than children with a bilateral hearing loss</li> <li>Māori children are 1.6 times as likely to have a mixed loss than non-Māori, non-Pacific children</li> <li>Children with an additional disability are 1.5 times as likely to have a mixed loss than children without an additional disability</li> </ul>		

Table 17: Odds ratio (2010-2024 unless otherwise specified)

## **Appendix B: Further information about specific topics**

## Key newborn screening goals and history

New Zealand's UNHSEIP was implemented to reduce the length of time between birth (or when a hearing loss develops) and the start of intervention for children born with hearing loss. This approach had been successful overseas in improving outcomes.

Newborn screening programmes achieve this by reducing the age at diagnosis for many children, compared with previously common identification approaches reliant on risk factors or subjective testing.

Common aims of newborn screening programmes include the screening of tamariki by one month of age, diagnosis of hearing loss by three months and the start of intervention by six months of age.

All districts in New Zealand have been screening babies for the full notification period (calendar years) since 2011.

This national screening programme was the result of long-standing advocacy from groups like Project HIEDI and the work of clinicians and managers in several district health boards, who introduce local screening programmes, some many years before nationwide implementation of the UNHSEIP.

## Single-sided deafness

Severe or profound unilateral hearing loss can be referred to as single-sided deafness (SSD). This category is a subgroup of the unilateral hearing loss.

Different case definitions for SSD are used internationally; for example, some definitions include only those with severe or greater hearing loss in the worse ear, and others only those with profound loss<sup>203, 204</sup>. The boundaries for these degrees of loss also differ depending on the jurisdiction.

With few studies on children and young people with a diagnosis of this type, there is no consensus on the advantages of early management for children with sensorineural SSD<sup>205</sup>.

SSD is thought to be relatively rare (0.36%), and 25% of the 109 children identified as having SSD had the aetiology of their hearing loss confirmed as cochlear nerve deficiency (hypoplasia or aplasia), as found through MRI and/or CI. A high proportion of those with SSD may be able to benefit from cochlear implantation. Good device usage may be challenging<sup>206</sup>.

The challenges of single sided deafness in children may have been underappreciated despite the literature. Congenital cytomegalovirus infection has also been identified as a common aetiology.

### **Cochlear implants in Aotearoa New Zealand**

It is likely a good number of these tamariki will not have a robust auditory nerve<sup>206</sup> meaning implantation is not valuable. This indicates an early scan is useful for those in this ropū, to manage whānau expectations.

However, some with SSD may benefit from cochlear implants, including those with less severe degrees of unilateral hearing loss<sup>133</sup>, who may receive a bone conduction hearing aid (e.g. if there is a permanent conductive hearing loss due to aural atresia).

In New Zealand, children and young people with SSD are not eligible for publicly funded cochlear implants except in the case of meningitis, but can opt for privately funded implants or receive implants if cover is provided by ACC.

## Prevalence and ethnicity

Several sources have outlined the prevalence of permanent hearing loss for Māori and for Pacific Peoples in Aotearoa New Zealand. These are summarised in Table 18 on the next page.

### Māori Pacific Peoples

Whakarongo Mai (1989) concluded that while the full extent of hearing impairment among Māori was not known, "a number of local and detailed studies convincingly demonstrate' higher rates among Māori people"<sup>207</sup>.

A 1991 survey of hearing among schoolchildren in the North Island found high prevalence of hearing impairment among Māori, with two percent or more of the children tested having a bilateral sensorineural hearing impairment<sup>208</sup>.

1991-2006 Disability Surveys<sup>209</sup> suggest Māori had higher rates of hearing disability (tamariki and adults) and higher rates of unmet need for technology and equipment when compared with non-Māori<sup>210</sup>.

Greville (2001) found higher prevalence of temporary and permanent hearing loss among Māori children<sup>211</sup>.

Data from the <u>B4 School Check</u> analysed by Searchfield *et al.* (2011), show higher rates of referral from hearing screening for Māori tamariki (9%) compared with non-Māori (5%) $^{212}$  and this pattern still holds with 2020-2021 <u>B4SC</u> data showing 4% referral rates for Māori, compared with 3% for European children and young people, as shown on page 21<sup>1</sup>.

The 2013 Disability Survey suggested Māori had higher unmet need for technology and equipment when compared with non-Māori<sup>213</sup> and lower rates of hearing disability compared with their European counterparts<sup>214</sup>, although this seems to relate to the lower age profile for Māori.

Findings from Digby *et al.* (2014) indicated young Māori have higher rates of permanent hearing loss than their European peers, based on the previous and post re-launch DND datasets (1982-2005 and 2009-2013)<sup>215</sup>.

Diagnoses from the newborn hearing screening programme (2017) show that Māori infants who are screened, and for whom diagnostic information is available, had higher rates of hearing loss<sup>216</sup>.

Thynne (2012) showed a prevalence of hearing losses (greater than or equal to an average of 20dBHL) of 13% among the better ears of Fijian adults<sup>187</sup>.

Joe (2012) described differences in average thresholds between ethnic groups among Fijian 13–22-year-olds<sup>187</sup>.

Koro (2019) found that there was a high prevalence of hearing loss (greater than or equal to an average of 20dBHL) in a small sample of Tokelauan adults<sup>217</sup>.

Purdy *et al.* (2018) aimed to determine the prevalence of hearing loss and ear problems in Pacific children, by assessing 920 Pacific children aged 11 years old. The authors concluded that hearing loss, abnormal tympanograms, and auditory processing difficulties were present in many Pacific children<sup>218</sup>.

## Table 18: Prevalence of permanent hearing loss among Māori and Pacific Populations – selected literature

## Improving equity for Māori and Pacific

Table 19 on page 67 describes some key papers on Māori and Pacific perspectives on hearing services and provides direction for equity improvement efforts.

Source and focus	Key findings and recommendations
Manuel et al. (2021) reviewed literature on the experience of hearing loss and hearing services among olderii Māori and whānau using a Kaupapa Māori approach and PRISMA guidelines <sup>219</sup>	Cost and poor patient-provider interactions were found to create barriers to hearing services for Māori with hearing loss, and whānau.  Approaches to creating equitable, whānau-centred, culturally safe services included: the need for cultural safety training; increasing Māori and Pacific Peoples in the hearing workforce; affordable (community-based) services and technologies; inclusion of Māori voices in service improvement; and improved communication regarding follow-up appointments. Whānau-centred care, destigmatisation efforts around hearing loss and care, education of students, and improving access to information, and more Kaupapa Māori centred research were also noted.
Ready et al. (2019) examined barriers to accessing hearing care services among older Pacific Peoples in Aotearoa New Zealand, using the Health Care Access Barriers model <sup>220</sup>	Several barriers were identified: community norms and attitudes; limited awareness of hearing care services; resulting cognitive barriers; communication limitations; financial, structural, family support barriers; and the absence of care for hearing available from general practitioners.  Work to eliminate or minimise modifiable barriers to hearing care, including development and/or improvement of culturally responsive models of hearing care, particularly given how underserved Pacific Peoples are currently in Aotearoa.
Holt <i>et al.</i> (2024) examined worldviews, knowledge and	The three key barriers to accessing hearing health services were: time, cost and work commitments.

ilt is important to note that high referral rates for Māori may relate to higher rates of ear disease, as referral doesn't only relate to permanent hearing loss.

ii Please note that barriers for younger people and whānau/ 'aiga accessing care may differ from those for older people.

beliefs regarding hearing health of Tongan and Samoan peoples through interviews and an online questionnaire<sup>3</sup> Generally, participants valued the importance of 'interpersonal connection between healthcare workers, including receptionists, and their patients'; empathy and warmth in healthcare interactions; compassionate care; use of Pacific languages, thorough appointments and non-jargonistic language. The role of parents and teachers in educating other parents and wider whānau about the importance of hearing health was emphasised.

Table 19: Barriers to equity and addressing these

### **Severity codeframes**

Unfortunately, there is no clear standard internationally for classifying hearing loss, or a consistent definition for where a hearing loss begins for the purposes of epidemiological comparison.

This makes it difficult for meaningful direct longitudinal and geographical comparisons of the proportion of tamariki in each severity category<sup>i</sup>.

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) are shown in Table 13<sup>ii</sup>.

Audiologists in Aotearoa New Zealand commonly use Clark's 1981 (ASHA) classifications in their clinical practice, as per the New Zealand Audiological Society practice guidelines.

A comparison of commonly used severity codeframes can be found in the 2023 report.

#### International severity comparisons

With the mounting evidence, as described in previous reports, it seems clear that Aotearoa New Zealand is likely to: a) have higher hearing loss prevalence overall; and b) have a smaller proportion of severe and profound hearing losses than other similar countries.

Potential contributing factors include:

- that Māori have a different severity profile to other ethnic groups;
- information about individual tamariki is collected at the time of first diagnosesii;
- some cases with audiometric datapoints in the severe and profound range do not contain complete audiometric data, meaning severe losses (and other degrees too) may be under-represented; and
- often children diagnosed with hearing loss have a sloping hearing loss and the better thresholds reduce the average degree of hearing loss.

## Cytomegalovirus

Typically, this infection is benign and innocuous, presenting as cold symptoms, but that is not the case for those who are pregnant and/or have no antibodies.

It is difficult to predict which children with congenital CMV infection (cCMV) will develop hearing loss and whether the loss will continue to deteriorate<sup>221</sup>. General knowledge about CMV and how to prevent infections, which are particularly common among those who work and/or live with young children, is not widely shared.

Approximately 14% of children with cCMV infection in a systematic review developed a sensorineural hearing loss, and 3-5% develop one that is bilateral and moderate to profound in nature<sup>110</sup>. An estimated 15-20% of cases were categorised as attributable to congenital infections from the virus.

i These systems, by and large, do not acknowledge any differences that may exist between the way hearing losses in children, young people and adults might best be categorised, i.e. there should be one system of classification for all groups.

ii Australian Hearing uses the following codeframe (0-40dBHL, 41-60 dB HL, 61-90dB HL, 91dB HL+), but they don't name the categories, so these are not included in Table 13.

iii A greater proportion of hearing losses are now being identified earlier thanks to the introduction of newborn hearing screening. As a result, progressive hearing losses have not yet had the time to worsen, meaning the recorded proportion of more severe losses may be smaller.

Those identified because of clinical suspicion had more severe disease at birth and more sequalae than those identified at newborn screening in one US study<sup>222</sup>.

Minnesota (United States) is the first jurisdiction to introduce a universal screening programme, and this programme will be helpful to understand prevalence of CMV infections and the proportion who go on to be diagnosed with resulting conditions, including progressive hearing loss.

#### New Zealand data on CMV

The relative importance of cytomegalovirus (CMV) infection as a cause of deafness among tamariki in Aotearoa New Zealand is not yet understood though there are some data:

- CMV seroprevalence was assessed from 9343 first-time Aotearoa New Zealand blood donors in 2009. The highest prevalence was found among Pacific Islanders (93.2%) and the lowest in Caucasians (54.8%)<sup>110</sup>; and
- a recent large-scale analysis of cases of cCMV disease found statistically higher rates for Māori (0.025%) followed by Pacific Peoples at 0.022%. MELAA had rates of 0.013%, and 0.0009% was found within Asian and European populations. As CMV is underreported, particularly with those babies who only have hearing loss or progressive hearing loss, this is not representative of actual incidence of CMV<sup>111</sup>.

#### **Atresia and Microtia**

#### **Treatment and support in Aotearoa**

It is common for those with bilateral atresia to have surgery when they are big enough, in the public system, with smaller centres referring to larger centres in some cases. There are reports that triage in some areas is an issue. Factors such as bone thickness will influence surgical decisions for bone conduction devices.

The available treatment options listed in the section on atresia and microtia from p41 are publicly funded for children. Once rangatahi reach adulthood they are eligible for the universal hearing aid subsidy, which is \$1022.22 every six years.

As outlined by Mr Colin Brown (ENT surgeon), several treatments are available for microtia and atresia, including:

- active transcutaneous Bone Conduction Implants (BCIs),
- bone-anchored hearing aids (in cases of atresia),
- surgery to create an ear from the patient's own cartilage (small numbers only),
- reconstruction using a plastic frame or prosthetics (not common in the case of microtia), and
- corrective surgery to widen the ear canal (occurs in cases where there is a cholesteatoma).

# **Glossary**

# Kuputaka

Accident Compensation Corporation (ACC): The Accident Compensation Corporation (ACC) is a New Zealand government agency that provides comprehensive, no-fault personal injury cover for all residents and visitors, helping pay for treatment and rehabilitation if they are injured in an accident, regardless of who caused it

Advisors on Deaf Children (AODCs): The Ministry of Education employs Advisers on Deaf Children to help families understand their child's hearing loss and to guide parents as they consider the technology and communication options available. Advisors also provide assessments and information about a child's development and behaviour to other professionals working with the family. They collaborate closely with teachers from Ko Taku Reo. AODCs work with an 'Early Years' focus, supporting those 0-8 years of age.

**Aetiology**: The cause or set of causes; in this report this refers to cause(s) of a child or young person's hearing loss.

American Speech-Language-Hearing Association (ASHA): This Association is relevant to the Deafness Notification Database in that they publish categories, which are widely used in Aotearoa New Zealand, to indicate the severity of hearing loss.

**Anotia:** This is the most severe form of microtia, where the external ear is completely missing.

**Auditory Neuropathy Spectrum Disorder (ANSD):** This condition causes problems in the transmission of sound from the inner ear through the auditory nerve that makes that sound more difficult to discriminate when it reaches the brain. Someone with ANSD can have difficulty distinguishing sounds even when their audiogram indicates a mild hearing loss, including speech, which can sound distorted.

**Atresia:** Aural atresia (AA) is a congenital absence or stenosis of the external auditory canal with a range of middle ear anomalies. It is almost always accompanied by a malformed (microtia) or absent (anotia) external ear.

**Audiometric data**: Audiometric data relates to a person's hearing acuity given variations in sound intensity and pitch (frequency). The Database collects information on the child's hearing thresholds at 0.5, 1.0, 2.0 and 4.0 kHz wherever possible.

**Audiometrist:** Audiometrists conduct hearing screening, audiological assessment, including diagnostic hearing assessment, rehabilitation and hearing aid fitting, and follow-up specific to adults and young people over the age of 16 with non-complex hearing loss.

**Auditory Neuropathy Spectrum Disorder (ANSD)**: This condition causes issues in the transmission of sound from the inner ear through the auditory nerve that makes sound more difficult to discriminate when it reaches the brain. Someone with ANSD can have difficulty distinguishing sounds even when the audiogram indicates a mild loss, including speech, which can sound distorted.

**B4 School Check**: The B4 School Check is a publicly funded programme that aims to screen all tamariki before they reach school, and to identify and provide intervention to those with one or more targeted conditions, including hearing loss. This screening takes place when the child is aged four, or five if they are not checked earlier.

Bilateral hearing loss: Hearing loss affecting both ears.

**Confirmation of hearing loss:** For the purposes of this report, 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 (behaviourally or via ABR).

**Cochlear implant**: A cochlear implant is an implanted electronic device which provides a sense of sound to the recipient by directly stimulating the auditory nerve with current pulses, rather than via amplified sound as occurs in hearing aids.

**Districts:** These are organisations established to provide health and disability services to populations within a defined geographical area. The previous name for these organisations was district health boards.

**ENT:** Ear Nose and throat specialist. This term is used interchangeably with otorhinolaryngologist (ORL).

**Enable New Zealand:** The Ministry of Health's contracted Services Manager, which administers and manages Hearing Aid Services nationally and which holds the contract for the management and reporting associated with the New Zealand Deafness Notification Database.

#### English as a Second Language (ESOL)

False negatives: False negative is a term used to describe anyone screened who is incorrectly categorised as having a low risk of the target condition. In this report, this term relates to potential false negatives resulting from the newborn hearing screening programme (UNHSEIP), i.e. a child who passed the screening test where it is possible that they had a hearing loss at the time the screening was conducted.

**Inclusion criteria**: The current Deafness Notification Database contains information about tamariki 18 years or younger, born in Aotearoa New Zealand or overseas, with:

- a permanent hearing loss in one or both ears,
- an average loss of 26 dB HL or greater over four audiometric frequencies (0.5, 1.0, 2.0 and 4.0 kHz).

**Kaitiaki:** Trustee, minder, guard, custodian, guardian, caregiver, keeper, steward (<u>Māori Dictionary</u>). In the context of this report, this refers to the caregiver of a child or young person whose information has been provided to the DND.

**Kelston Deaf Education Centre:** KDEC provided educational programmes and services to Deaf and hard-of-hearing students in the northern part of New Zealand, roughly from Taupo northwards until 2019. Since 2020, Ko Taku Reo has provided services nationwide, replacing van Asch and Kelston Deaf Education Centres.

**Ko Taku Reo – Deaf Education New Zealand:** New Zealand's provider of education services for Deaf and hard-of-hearing (DHH) children. Established in 2020, this organisation replaced the Kelston and van Asch Deaf Education Centres.

**Learning Support:** This is the name for what was previously termed 'Special Education' services provided by the Ministry of Education.

**Mātua**: (noun) parents - plural form of matua (Source: Māori Dictionary).

**Mahi:** (verb) to work, do, perform, make, accomplish, practise, raise (money) (Source: Māori Dictionary).

**Microtia**: A malformed (microtia) or absent (anotia) external ear. Often accompanied by atresia.

Motu: (Noun) island, country, land, nation, clump of trees, ship, anything separated or isolated (Source: Māori Dictionary).

**Notifications:** Notifications contain data about an individual child or young person, demographic information, and information on the hearing loss and its diagnosis.

**Odds ratios:** In this year's report we have included odds ratios to compare the *likelihood* of another variable being present in one group to the likelihood of it happening in another group. Where the odds are less than 1.0 this means there is a lower chance of a specific outcome, while those greater than 1.0 indicate a higher chance.

**Otitis media with effusion (OME):** Otitis media with effusion (OME) is a condition where fluid accumulates in the middle ear without signs of acute ear infection. This fluid build-up can cause a temporary conductive hearing loss, especially in children, and is sometimes called "glue ear".

Ongoing Resourcing Scheme: The Ongoing Resourcing Scheme (ORS) provides support for a very small number of students, with the highest level of need for learning support, to help them join in and learn alongside other students at school. This funding provides Specialist Services staffing for students (who are ORS funded) including school counsellors. This scheme was previously 'reviewable'.

**Project HIEDI** (Hearing Impairment, Early Detection and Intervention): An advocacy group established in 2002 to see the introduction of a nationwide newborn hearing and early intervention programme in Aotearoa New Zealand, to address New Zealand's very late average age at diagnosis and intervention.

**Quintile (deprivation):** Each quintile represents 20% of the population. This means Quintile 1 relates to children who live in areas scoring the lowest on the deprivation index (1 or 2), up to Quintile 5 that relates to children who live in areas with the greatest deprivation scores (9 or 10).

Rangatahi: (noun) youth/young person (Source: Māori Dictionary).

Resource Teachers: Deaf (RTDs): Resource Teachers of the Deaf (RTDs) provide a range of teaching and specialist services to deaf and hard-of-hearing students in mainstream schools around the country. Eligibility is decided based on individual need, and recognises the importance of language, communication and culture to a student's success. Caseloads are reviewed each term and measured against specific eligibility criteria.

**Rōpū:** group, party of people, company, gang, association, entourage, committee, organisation, category. (Source: <u>Māori Dictionary</u>).

**Single Sided Deafness (SSD):** The DND defines this group as children and young people who meet the criteria for the DND and who have a hearing loss of more than 70 dB HL over four frequencies (over 0.5, 1.0, 2.0 and 4.0 kHz) in the worse ear, and a hearing loss of less than

 $26\ dB\ HL$  over four frequencies (over 0.5, 1.0, 2.0 and 4.0 kHz) in the better ear.

**Tamariki:** (verb) to be young, (noun) children – normally used only in the plural (Source: Māori Dictionary).

**Taonga:** (noun) treasure, anything prized - applied to anything considered to be of value including socially or culturally valuable objects, resources, phenomenon, ideas and techniques. (Source: Māori Dictionary).

Tauira: (noun) student, pupil (Source: Māori Dictionary).

**Unilateral hearing loss:** Hearing loss affecting one ear. Regarding the DND, there may be minimal hearing loss in the other ear, but a specific case is categorised as unilateral where the hearing loss in the child's other ear does not meet the 26 dB HL four frequency average criterion.

Universal newborn hearing screening and early intervention programme (UNHSEIP): This Aotearoa New Zealand programme, managed by the National Screening Unit (NSU) as part of the Ministry of Health, aims to provide early and appropriate intervention services to all children born with permanent congenital hearing impairment. Children are screened soon after birth and those who 'refer' on this screening are directed to see an audiologist who conducts a full diagnostic assessment. Children diagnosed with a hearing loss then have access to the very important early intervention services they require to allow improved outcomes.

van Asch Deaf Education Centre: vADEC provided educational programmes and services to Deaf and hard-of-hearing students, from roughly Taupō southwards until 2019. Since 2020, Ko Taku Reo has provided services nationwide, replacing van Asch and Kelston Deaf Education Centres.

**Vision Hearing Technician (VHT):** Vision Hearing Technicians are employed by Te Whatu Ora districts, along with other Well Child providers, to screen children around the country for hearing and vision problems. Hearing screening involves audiometry and if the child refers on this screening, tympanometry is also conducted. The work of the VHTs includes vision and hearing screening done as part of the <u>B4 School Check</u>.

**Whānau:** Extended family, family group, a familiar term of address to several people. The primary economic unit of traditional Māori society. In the modern context the term is sometimes used to include friends who may not have any kinship ties to other members (Source: Māori Dictionary).

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