Deafness Notification Report 2022

Rīpoata Whakamōhiotanga Turi

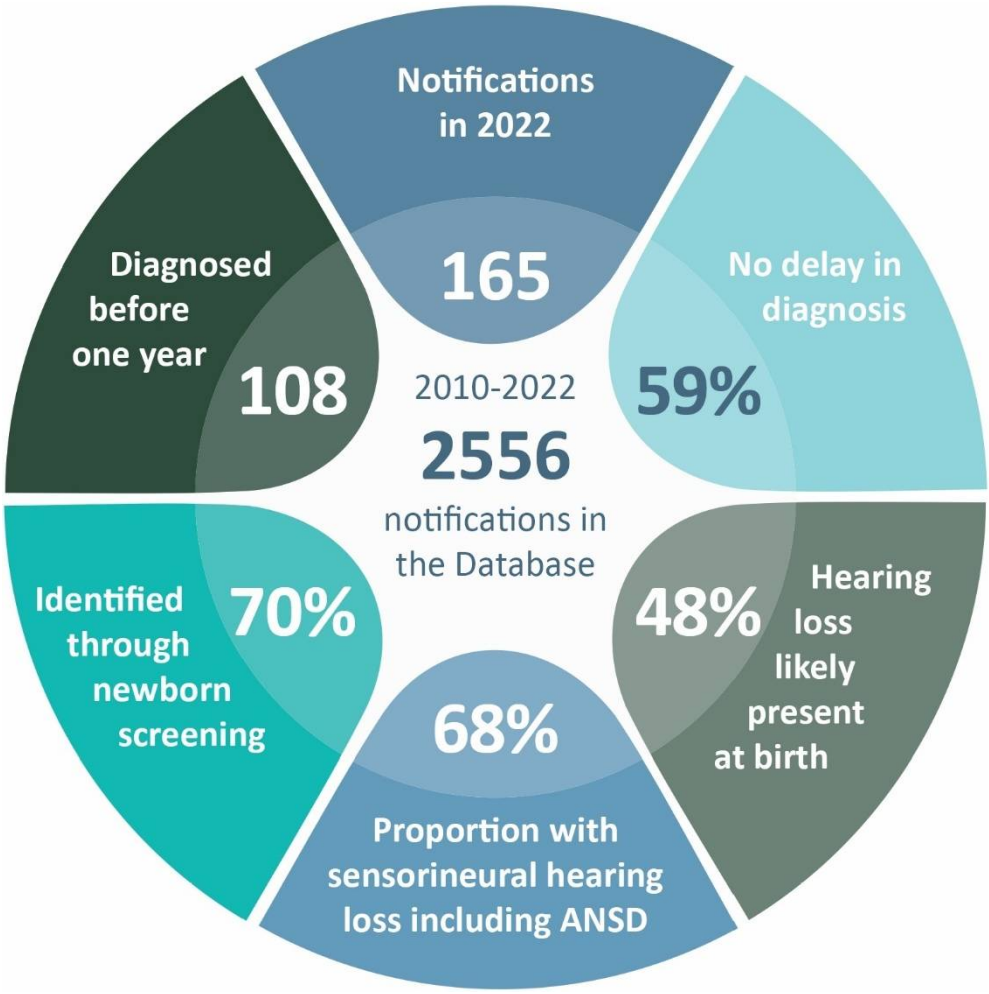
Janet Digby, Levare Limited

December 2022

Enable NEW ZEALAND

Summary

Whakarāpopoto



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- **Our sincere thanks to the mātua (parents)/kaitiaki (caregivers) and rangatahi (young people) who consented to share details of their child's/their own hearing loss, and to the many clinicians around the motu for sending us notifications. Ngā mihi maioha ki a koutou.**
- **By entrusting us with their data, we have been able to understand more about those children and young people diagnosed with hearing loss in Aotearoa New Zealand and the nature of their hearing losses. This, in turn, is being used to inform clinicians, decision makers and whanau to help those diagnosed to date and in the future.**

Introduction

Nau mai, haere mai ki te putanga tuangahuru o tēnei raupapatanga o ngā rīpoata ā-tau, e whakaahua ana i ngā whakaaturanga ki te Raraunga Turi o Aotearoa. Kei roto i tēnei rīpoata ngā raraunga mō ngā tamariki me ngā rangatahi i kohuratia i te tau 2022.

Welcome to the tenth in this series of annual reports describing notifications to the New Zealand Deafness Notification Database (DND). This report includes data for children and young people diagnosed during the 2021 calendar year.

The DND was established in 1982 by Dr Bill Keith to collect information on children and young people under the age of 19 who have been diagnosed with permanent hearing loss.

After a hiatus from 2006, the Database was relaunched in 2010, and since has included three additional groups of children and young people; those born overseas, those with unilateral hearing losses and those whose hearing losses are acquired after birth.

Where parents (mātua) or caregivers (kaitiaki) provide consent for this information to be shared, audiologists and audiometrists from around the country send notifications electronically following diagnosis of a child or young person with hearing loss[i]. Whānau of children who have had their hearing screened through the Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP) sign a consent that includes sharing information with this Database, while others sign a separate consent presented by the audiologist or audiometrist.

> *"Ka mua, ka muri"*
>
> This Māori whakataukī translates to 'walk backwards into the future' and is about learning from those who have gone before us.

The analyses contained in this report generally pertain to 2556 children and young people notified with a hearing loss diagnosed between the start of 2010, when the DND was relaunched, and the end of 2022, where notifications were provided before our March 2023 cut-off date.

Since 2010, the Database has included children and young people 18 years or younger, born in Aotearoa New Zealand or overseas, with:

- a permanent hearing loss in one or both ears,

i Further information about consent processes can be found in the section on Notifying Cases on page 76.

- an average loss of 26 dB HL or greater over four frequencies (0.5, 1.0, 2.0 & 4.0 kHz) for pure tone audiometry and 30dB HL or greater over four frequencies for ABR.

The database has included tamariki born overseas, those with acquired hearing losses and those with hearing losses which include one ear (unilateral) only since 2010.

This report and the DND generally exclude children with Auditory Processing Disorders (APD). For those interested, comprehensive *New Zealand Guidelines* were published by the New Zealand Audiological Society in 2019.

Steps have been taken to allow data contained in this report to be compared with pre-2010 deafness notification data. However, in some cases questions have been amended to make these more specific and/or to reflect improved understanding in a specific area, such as family history. As a result, longitudinal comparisons are not always possible.

For further information, please see the table of contents on page 4 for a full list of appendices and the glossary on page 82 of this report.

Acknowledgements

We extend our sincere and heartfelt thanks to the 165 parents (mātua), caregivers (kaitiaki) and young people (rangatahi) who consented to share details of their child's/their own hearing loss for the Database in 2022.

As a result of this willingness to share basic diagnostic information, service providers can be better informed about current and likely future demand for services, factors most likely to result in delays in diagnosis, and other information that will help them better serve the needs of children, young people and their families/whānau and caregivers in future.

The time taken by audiologists and audiometrists to make notifications and to do this in such a careful and considered way is also greatly appreciated. It is clear from how this is done, including by departments which are under strain, that diagnosing clinicians care deeply about the well-being of both their patients and their whānau.

This report has been funded by Enable New Zealand, through a contract with Whaikaha - Ministry of Disabled People. The report's current authors would like to thank the Ministry and previously Manatū Hauora | Ministry of Health for funding the management, analysis and reporting of the relaunched Database from 2012.

The primary author gratefully acknowledges the significant support and guidance of co-authors: Professor Suzanne Purdy (Te Rarawa, Ngāi Takoto) of the University of Auckland and Dr Andrea Kelly of Auckland District. Their input into these reports is greatly appreciated. Ngā mihi nui ki a kōrua.

Contributions to sections of the report by specific people are appreciated and are acknowledged in those sections.

Contact details

Feedback on this report is always welcome. Questions and feedback about the DND reports should be directed to its primary author, Janet Digby. Janet can be contacted by email here.

Notifications

Ngā Whakamōhiotanga

- **Notifications were made before the deadline for 165 children and young people diagnosed during 2022, most of whom were born in Aotearoa New Zealand. Notification numbers have been trending down since 2018.**
- **While 2022 did not see any of the COVID-19 lockdowns that were so disruptive in 2020 and 2021, for the first-time widespread COVID infections became commonplace among the population.**
- **Males are more likely than females to be diagnosed with a hearing loss and notified to the DND.**
- **The presence of one or more so-called additional disabilities (ADs) can have a significant impact on outcomes for children/young people with a hearing loss. Thirteen percent of tamariki and rangatahi notified to the Database between 2010 and 2022 had one or more confirmed 'additional disabilities' at the time their hearing loss was notified. The most common types are syndromic, medical and neurodevelopmental in nature.**
- **Around two thirds of notifications to the DND are for children and young people with bilateral hearing losses, with the rest being for those with unilateral hearing losses.**
- **Research suggests that, as with more severe hearing losses, both mild and unilateral hearing losses (UHL) are associated with poorer outcomes.**
- **Māori are more likely to have bilateral hearing losses and mild and moderate hearing losses than their European counterparts. Māori also have more 'mixed' hearing losses and less permanent conductive losses than their European counterparts.**
- **Almost one in five of those whose information was notified to the Database have an immediate family member with a permanent hearing loss.**

General information

One hundred and sixty-five children and young people diagnosed during 2022, and whose hearing losses met the criteria for inclusion, had their information notified to the Database by 10th March 2023, this year's cut-off date for notifications[i, ii]. There are now 2556 cases included in the main dataset that forms the basis for analysis within this report.

These notifications were received from a total of 51 audiologists and audiometrists, with notifications from 19 of the 20 districts around the motu.

Number of notifications

Figure 1 shows the number of notifications that met the criteria for the main dataset in each year.

i Reports prior to 2006 contained information about diagnoses notified in each calendar year, rather than diagnosed in that year. As a result, the number of notifications varied, increasing in years in which greater efforts were made to encourage audiologists to send in notifications. For example, in 2004 there were an additional 288 retrospective notifications received from a Children's Hearing Aid Fund (CHAF) audit.

ii It is not possible to ascertain how long, on average, audiologists took to make each individual notification, as online forms are often left open for a number of hours. However, it is clear that many individual notifications took fewer than five minutes to enter using the online form, as was the case in previous years.

Since 2010, these totals may differ from the number of notifications reported in each annual report as not all are received by the cut-off date[i]. One reason for late notifications is that in some cases an audiologist may not be able to notify a case in the year the diagnosis was made as they are unable to gain consent from the family/ whānau by the deadline for notifications.

This figure illustrates variability in the number of notifications provided to the original Database, particularly in the last six years of its operation[ii]. It also shows a downward trend in notifications since 2019.

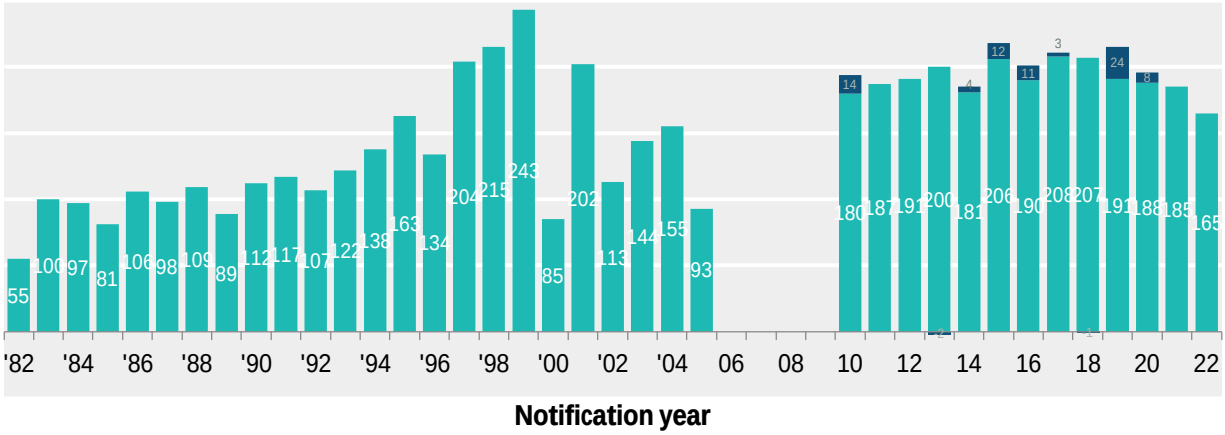

Figure 1: Notifications by year 1982-2005 and 2010-2022 (*number of records contained in the database as at the time of publication in turquoise with subsequent additions in dark blue)*

Falling number of notifications

The falling number of notifications, particularly for this year, is a potential concern as it may indicate a drop in the proportion of hard-of-hearing children who are being diagnosed.

Possible causes of this drop are categorised in the Table 1.

Possible cause	- A fall in the number of children diagnosed (several districts are reporting this is the case for them). - A fall in the proportion of children whose diagnosis was reported to the database. - A fall in the proportion of children being seen for monitoring or diagnostic appointments. - Increased pressure on public audiology services as the private sector recovers from COVID and increases recruitment activities, meaning vacancies are again harder to fill. - A drop in the number of births, meaning there are fewer children with hearing loss. The total number of live births in 2020-2022 at 175,119 was only slightly down on the previous three years, at 177,267[1]. Auckland District however notes a significant 28% drop in the number of children born in the area between 2010-11 and 2022-23.
Unlikely cause	- A reduction in maternal infection rates given increased hand hygiene and people being more likely to isolate when sick. - A slightly earlier cut-off date for notifications and download of data for analysis (this does not seem to have been a reason given the low number of late notifications for 2022 received after the cut-off date, as examined in November 2023).
Unknown likelihood	- Reductions in the proportion of children being identified through the newborn screening programme. - The proportion of children identified as a direct result of their screening is at a high for 2022 though no official data is available on screening coverage rates during 2022.

Table 1: Consideration of possible causes for the drop in notifications

i Please note the 2001-2005 figures, included in previous DND reports, were later revised by the Database's contracted provider at the time, ADHB. Reports in this current series show the total number of notifications that met criteria for inclusion that had been received by the cut-off date each year. In recent years this cut-off date has been in mid-March the following year.

ii Greville completed an analysis of the data in 2005 and noted that data reported in previous reports contained a number of duplicates, presumably from previous year's notifications; these are excluded from the data reported in this report. Specific changes are described in detail in the reports in which these were first made. Previous DND reports can be found on the New Zealand Audiological Society website.

Further information from districts on reductions in the number of notifications can be found in district data from page 12.

These drops coincide with falls in the number of cochlear implants provided by the Northern and Southern programmes in recent years, particularly in the Southern region. These are described in Cochlear implants on page 93. The extent of the drop in the number of children receiving cochlear implants is significant, though the cause is not yet known, and we don't know if this is related to the reduced number of notifications to the DND.

An unusual year

Before detailing further findings relating to notifications received for the 2022 calendar year, it is important to again acknowledge the challenging nature of the year resulting from the COVID-19 pandemic. While 2020 and 2021 saw extraordinary disruption to services resulting from lockdowns, 2022 did not see such interruptions. However, it was the first time that Aotearoa New Zealand had widespread COVID-19 infections across the population, though much of the population had been vaccinated by this point. As a result, many people were unwell and/or isolating at home at least once during the year.

COVID-19 vaccination of 5–17-year-olds began in January of 2022 with most tamariki aged 5 to 11 eligible for two paediatric (child) doses of the Pfizer vaccine eight weeks apart. As of June 2023, only 26.5% of that group had received their second dose. Vaccination coverage across the country for Māori tamariki was even lower, at 12.7% and only 18.4% for Pāsifika children[i].

During the year, the National Screening Unit, in collaboration with district health boards (before June 30th 2022) and later Te Whatu Ora Districts and the New Zealand Audiological Society's Paediatric Technical Advisory Group (PTAG), retained and expanded the National COVID-19 Strategy to support newborn hearing screening and diagnostic audiology provision across all alert levels.

Gender

Background

In overseas research, males are commonly found to have higher rates of hearing loss than females. These figures range between 51.5% and 58% for males (1:1.06 and 1:1.38) in various jurisdictions, as reported in the 2011 *Comprehensive Handbook of Pediatric Audiology*[2] and also in Feder *et al*.'s 2017 Canadian study on the prevalence of hearing loss among children and young people aged 3-19 years[3].

Hearing Australia's data on those under the age of 26 who have hearing aids or cochlear implants[ii] show a similar pattern, with higher numbers of hearing loss among males (51.4%) than females (48.5%) as at December 2021[4], although a number of states (Tasmania, ACT and Southern Australia) have a ratio approaching 1:1 and among those aged 21-25 years of age there is a predominance of females.

DND data

From 2018, a third option has been available for selection in the notification form, meaning the notifying professional can specify an additional gender option.

Of the 2556 cases (2010-2022) contained in the main dataset, 45% of these are listed as female (n=1152) and 55% male (n=1403), with one case listed as 'other', or non-binary and one with no gender listed. This represents a ratio of 1: 1.24 of females to males. This gender difference was particularly noticeable in 2016 and 2020, which approached or reached a ratio of 60 males for every 40 females notified.

i Unite Against Covid (2023) Map of COVID-19 vaccination rates in New Zealand | Unite against COVID-19 (covid19.govt.nz) accessed 19th June 2023.

ii This source reports on children and young people, under the age of 26 who received services from Australian Hearing (now Hearing Australia).

When examined by ethnic group, a higher proportion of children and young people in the Database are male in all of our ethnic groups: MELAA (60%), Asian (58%), Pacific Peoples (57%), Māori (56%) and Europeans (53%).

Birthplace

Tamariki born outside Aotearoa New Zealand have been formally included in the Database since 2010.

Figure 2 shows the proportion of cases notified by birthplace for the 2010-2022 period. During that time, 6% of children and young people notified have been born overseas, with the birthplace of an additional 5% being uncertain.

The number of children about whom the notifying professional was uncertain about the location of their birth has dropped from a high of 12% in 2010 to 1-3% in 2017-2022. This may be, at least in part, because professionals are more likely to have information about the child's birthplace in cases where their hearing loss is identified because of newborn hearing screening.

Of the 165 notifications to the Database in 2022, 4% were known to be born outside Aotearoa New Zealand. Lack of certainty around birthplace was listed in a further 2% of cases.

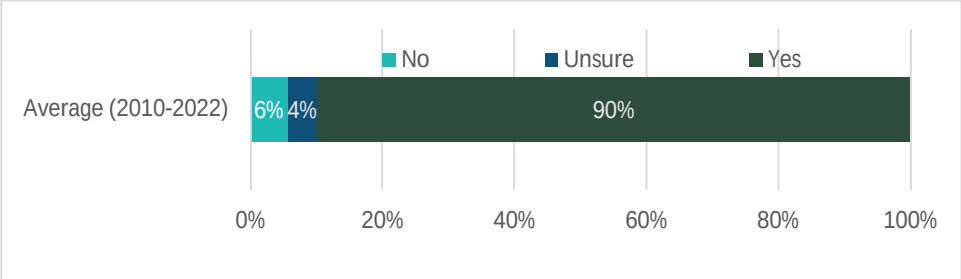

Figure 2: Proportion of cases born in New Zealand (2010-2022)

Geographical representation

Table 2 contains the percentage of 2022 notifications from each district and compares these with the percentage of the population under the age of 20 from the 2018 Census[i].

The third column in the table shows the percentage of notifications received for 2010-2022 from each district. This can be compared with the relevant percentage in the population for those under the age of 20.

Tamariki notified to the Database are more likely to be of Māori ethnicity than their proportion in the general population would predict. As a result, districts with more than 20% of their population identifying as Māori are shown with shading in Table 2[5].

Notification levels

In addition to these factors, and natural fluctuations in the number of hearing losses diagnosed among tamariki in each year, other factors influencing notification levels, are likely to include:

- the size of district populations within the age range for the Database;
- the prevalence of hearing losses within district populations;
- the date the child or young person was diagnosed, and whether the clinician decides it is appropriate to ask for consent for the Database at the time of diagnosis, or whether this is best done at a later appointment, which may be after the cut-off date for notifications;

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

District Health Board	Percentage of population under the age of 20 (Statistics New Zealand, 2018 Census[6])	Percentage of notifications received in 2022 (under 19 years)	Percentage of notifications received 2010-2021 (under 19 years)
Auckland	9%	7%	6%
Bay of Plenty	5%	9%	7%
Canterbury	11%	7%	13%
Capital and Coast	6%	5%	9%
Counties Manukau	13%	13%	13%
Hawke's Bay	4%	5%	3%
Hutt Valley	3%	5%	4%
Lakes	3%	5%	3%
Midcentral	4%	8%	2%
Nelson Marlborough	3%	2%	4%
Northland	4%	7%	6%
South Canterbury	1%	0%	2%
Southern	6%	4%	7%
Tairāwhiti	1%	4%	3%
Taranaki	3%	13%	3%
Waikato	9%	1%	8%
Wairarapa	1%	3%	1%
Waitematā	13%	0%	5%
West Coast	1%	1%	1%
Whanganui	1%	0%	1%

Table 2: The estimated percentage of population under 20 years of age by district (2018 Census, using DHB populations) compared with percentage of notifications (2022) and (2010-2022)[i]

- the number of hearing professionals working in each district;
- levels and patterns of deprivation in districts and other factors influencing the ability of whānau to engage with services;
- the workload of these hearing professionals; and
- the level of capacity and commitment among staff to making notifications to the Database.

A recent local study, described in more detail in previous DND reports, found that only 56% of tamariki/rangatahi were still in the care of the notifying clinic (often the DHB's audiology service) seven to eight years after their diagnosis[7]. Of the 163 children and young people for whom follow up information was provided, the notifying clinic held no information about fifty-nine children and young people. For those who were still in the care of the notifying clinic, 31% had not been seen by that clinic for at least two years[ii].

These figures demonstrate the importance of both functional clinic information systems and communication between clinics to ensure tamariki and rangatahi are not lost to follow-up when families move between areas.

We understand from speaking with audiologists on the Paediatric Technical Advisory Group

i It is worth noting that, historically, many clinicians believe there is a preponderance of deafness in Auckland and Christchurch as families have moved to these places from the regions, so their tamariki could be schooled at what was Kelston Deaf Education Centre (KDEC) (Auckland) or van Asch Deaf Education Centre (VADEC) (Christchurch) and is now Ko Taku Reo .

ii This study conducted by Digby and Purdy and was not published. Data for 78% of notifications where the diagnosed child or young person was listed as Māori were received, compared with 81% of non-Māori.

(PTAG), that it is possible districts who provided notifications to the Database may have been asked for information on the child or young person by any new provider (with communications moving between their medical records departments, for example), without the original audiologist's knowledge. This means the notifying professional (usually an audiologist) may not know details of where the child or young people receives care after they leave their service.

Some district audiology services can search for individuals outside their catchment (e.g. there is a database for those in the South Island that is searchable), while others don't have that ability. This may be improved by the new 'regional teams' focus.

As noted earlier in this report, there has been a downward trend in the number of notifications since 2019, with the lowest number of notifications reported in 2022. Two districts with drops in the number of 2022 notifications noted:

- *"Those are the only notifications we have for last year – there was a marked lull in new identifications in 2022."* Staff later suggested that perhaps there may have been a reduction in maternal infection rates given the increased hand hygiene/isolation protocols, adding *"Anecdotally we also saw an overall reduction in prevalence of middle ear dysfunction in children last year too, so everyone seemed more well overall. But realistically, we just don't know."*
- *"I know we have recently done an internal audit [redacted] and we are conscious of reduced diagnoses in the past year compared to normal. Hopefully no missed hearing losses as the lack of leadership for our programme has meant things are not running nearly as well as in the past".*

Additional Disabilities

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)[i].

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, such as developmental delay and cerebral palsy, are included, this figure will increase[8].

Children with hearing loss are thought to have a high rate of additional disabilities because many risk factors for hearing loss also predispose children to have other conditions. Rates of additional disabilities among children with hearing loss are particularly high among those who have a syndrome, and this can place an additional burden on families when compared with those tamariki and rangatahi without additional disabilities.

As outlined in Nelson and Bruce's 2019 review paper on this topic[9]:

- the population of children and young people who are hard-of-hearing and who have one or more additional disabilities are difficult to characterise due to the range of conditions included and the type and severity of the various disabilities;
- specific aetiologies, including hereditary syndromes, maternal infections, prematurity and meningitis, indicate a higher likelihood of specific 'concomitant' disabilities, including those which are intellectual or developmental, autism spectrum disorder, learning disabilities, ADD, ADHD, emotional disabilities, speech and language impairments and vision issues;
- individual children may have one or several disabilities and each can vary in both presentation and degree;
- the presence of 'additional disabilities' makes compensation for loss of hearing more difficult;
- early identification has been found to positively impact outcomes across domains for

i Children with such additional disabilities are sometimes referred to as being 'deaf plus' or Deaf with Disabilities (DWD). The authors of this report are yet to come across a term that is inclusive given the broad range of conditions and differences that are included in this section. Suggestions for a better term are most welcome.

children with additional disabilities, though it is common for these children to begin to receive intervention at later ages than those without; and

- there is a great deal yet to be discovered about prevalence, how to accurately diagnose and assess progress in young people in this group and provide them with optimally effective interventions.

The presence of one or more so-called 'additional disabilities' can have a significant impact on outcomes for tamariki, and also on the level of support they may require, particularly from *Learning Support*, Ministry of Education (previously Special Education).

Overseas data

It is difficult to compare reported rates of additional disabilities between groups of children who are hard-of-hearing, as the definition for hearing loss and for disabilities differ and are not always described in journal papers. A selection of rates from various jurisdictions are described in Table 3. The first paper listed shows the huge variability in rates, presumably at least in part the result of definitional differences.

Source	Date	Location	Details	Rates
Nelson and Bruce[9]	2019	United States	Review paper	25-51% of d/Deaf or hard-of-hearing (DHH) students in the United States, with higher rates reported among those with severe and profound sensorineural hearing loss (SNHL)
LOCHI[10]	2013	Australia	Study examining 260 children in Australia born with hearing impairment	18% of children in their sample have one additional disability, 10% with two and 9% with three or more
Ear Foundation for National Deaf Children's Society[11]	2012	United Kingdom Review	Review of twelve papers from 2002-2012 containing prevalence rates thought to be relevant to the United Kingdom, United States, Australia, New Zealand	Most common additional disabilities: • visual impairment (4-57% depending on the definition) • neurodevelopmental disorders (2-14%) • speech language disorders (61-88%)
The Consortium for Research into Deaf Education[12]	2011/12	United Kingdom	Annual national survey of educational staff	21% of deaf children (including unilateral and bilateral and mild to profound losses) had an additional special educational need in addition to their hearing impairment
Kennedy *et al.*[13]	2006	United Kingdom	Sample of 120 British children with hearing loss with a mean age of 7.9 years	An additional disability present among 19.2% of the sample
Fortnum *et al.*[14]	2002	United Kingdom	Sample of 17,169 children with hearing loss	27.4% with additional disabilities
Fortnum and Davis[15]	1997	United Kingdom	Trent region study of permanent congenital hearing impairment	38.7% of children found to have one or more additional clinical or developmental problems, although this study used a wide definition of additional needs.
Holden-Pitt and Diaz[16]	1998	United States	60% of deaf and hearing im-paired children in the United States in the 1996/97 year	20-40% of all United States children with a hearing loss had an additional disability

Table 3: Additional disabilities, selected overseas rates for comparison

Outcomes for this diverse group

Cupples *et al.* (2014) found that there were differences in outcomes for the 119 children included in their study based on the type of additional disability. Children with autism, cerebral palsy, and/ or developmental delay showed poorer outcomes compared with children who had vision or speech output impairments,

syndromes not entailing developmental delay, or medical disorders[17].

Cupples *et al.* (2018) analysed language ability in 67 children who were enrolled in the LOCHI study at three and five years of age, using several standardised assessments. While across the entire cohort these children had stable outcomes, the authors note that children with autism, cerebral palsy and/or developmental delay showed a decline in standard scores during this time. They conclude that the type of additional disability can provide an indication of expected language development where formal assessment of cognitive ability isn't possible[18].

Among 470 children in the Australian Learning from the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study, children with additional disabilities who had better language outcomes were more likely to have earlier fitting of HAs, less severe hearing loss, higher cognitive ability, use of speech for communication, and higher level of maternal education[19].

DND data

A wide definition of additional disability is used within the Database – the one used at the start of this section. Of the 2556 records in the main dataset, including all children and young people diagnosed with hearing loss in 2010-2022, the majority (76%) have no 'additional disability' listed. Eleven percent are listed with a possible although as-yet unconfirmed additional disability. Twelve percent have one or more confirmed additional disability(ies)[i].

2022 data

Of the 2022 notifications, 12% of children and young people were known to have one or more disabilities in addition to their hearing loss at the time the notification was made. In a further 11% of cases there was uncertainty regarding whether the child or young person had an additional disability[ii].

The majority of those who were listed as having an additional disability had one additional disability listed, though some had no detail provided. Smaller numbers of children and young people had two, three, four or even five additional disabilities noted. Some forms had 'yes' selected, noting an additional disability was present, but further details were not provided. In those cases the selection was changed to 'unsure'.

New Zealand DND figures are similar to Australian estimates of the proportion of hard-of-hearing children who have an additional educational need. However, this is unlikely to be a fair comparison owing to jurisdictional differences in how additional disabilities are defined, and because our data showing the proportion of children with an additional disability are 'point in time' figures at the time of the hearing loss diagnosis.

Additional disability	Number of tamariki	Percentage
Yes	318	13%
Unsure whether AD exists, no confirmed diagnosis	273	11%
No additional disability	1936[iii]	76%
No data	26	1%
Total	**2553**	**100%**[iv]

Table 4: Proportion of cases by additional disability status (2010-2022)

i From the 2021 report, higher numbers of cases are shown in many years compared with previous figures. This is 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.

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

iii This figure is lower than in last year's report as those who have been listed as having atresia in the UNHSEIP part of the form have been included as having an additional disability in this year's figures.

iv Rounding means this figure does not sum to 100%.

Comparison with previous data

The proportion of tamariki notified with one or more additional disabilities is not directly comparable to data reported prior to the re-launch of the Database in 2010, as an 'unsure' category has been added to allow for cases where an additional disability may be suspected but has not been confirmed.

Column four of Table 5 shows the total proportion of confirmed and unconfirmed cases with an additional disability. This figure is more consistent with those reported before the Database's re-launch in 2010.

Notification Year	Cases with a known additional disability	Cases with a possible but unconfirmed additional disability	Cases with additional disability (2002-2005) and total confirmed and possible (2010-2022)
2002	-	-	29%
2003	-	-	21%
2004	-	-	23%
2005	-	-	18%
2010	14%	11%	25%
2011	17%	5%	22%
2012	16%	10%	26%
2013	12%	12%	24%
2014	18%	9%	27%
2015	10%	11%	21%
2016	9%	9%	18% (peak immunisation coverage)
2017	10%	10%	20%
2018	13%	10%	23%
2019	15%	8%	23%
2020	14%	14%	28%
2021	12%	15%	27%
2022	11%	14%	26%
Average 2010-2022	**13%**	**10%**	**23%**

Table 5: Proportion of cases with a known additional disability (2002-2022)

Factors influencing rates of additional disabilities included in the DND

Previously, the authors of this report believed that the earlier identification of tamariki with hearing loss was the likely reason behind the drop in the proportion of those with confirmed additional disabilities reported at the time of diagnosis of the hearing loss.

The logic suggested at the time was that tamariki may have not yet been diagnosed with these conditions, or they had conditions that have not yet developed at the time the notification to the Database was made. For example, diagnoses of autism spectrum disorder are typically not made in the first year of life.

Other possible reasons for what was previously a general downward trend in the proportion of tamariki reported with additional disabilities, included higher immunisation coverage, particularly between 2007 and 2013,[i, 20] and that

i Previous increases in coverage occurred after vaccination for children became a Primary Health Organisation (PHO) Performance Programme indicator in January 2006, and a funded indicator from July 2008. Achievement rates for the indicator 'age-appropriate immunisations completed by age two years' have doubled from approximately 45% in 2007 to 91% in September 2013.

tamariki with hearing loss in Aotearoa New Zealand are not all routinely assessed by a paediatrician, though some are seen by an ENT who will take on some of that role and refer to a paediatrician if it is appropriate.

More recent notifications to the DND (shown in Table 5) show the general downward trend from 2012-2016 has reversed, particularly since 2020.

By further interrogating these data, we can see that rates of additional disabilities present at the time of notification are higher among those diagnosed over the age of two years old, as expected. Even with average age at diagnosis falling, we can see growth in the proportion of cases with a possible additional disability. The 2020-2022 figures are now at their highest levels since the Database was relaunched in 2010. While it's not possible to know for sure the reason for this shift, there are several possibilities:

1. many parents were spending considerably longer with their tamariki than usual due to COVID related school closures, meaning issues they noticed resulted in more prompt identification of additional disabilities compared with before the pandemic;
2. additional disabilities are now more likely to be diagnosed; and
3. reduced immunisation coverage, which has been worsening since before the pandemic.

Immunisation rates

In Aotearoa during recent years there has been concern expressed regarding immunisation rates, which have fallen from their peak in 2016. These rates were particularly low for Māori tamariki and those who live in income poverty[21].

Since the start of the pandemic, further reductions in the numbers of children receiving immunisations have been reported, resulting in record low coverage rates. (This mimics the trend reported by The World Health Organisation and UNICEF, that believe the COVID-19 pandemic has exacerbated further drops in immunisation coverage in many countries[22].)

Overall coverage rates in Aotearoa New Zealand have fallen from nearly 80% in 2017 to around 65% in June 2022. Rates of immunisation among Māori and Pāsifika are particularly concerning[23, 24]; just 47% of Māori aged 18 months had full immunisation coverage over the past year, a drop of 26% since the start of the pandemic[25].

Dr Nikki Turner, Medical Director of The Immunisation Advisory Centre reports there are a range of challenges facing local immunisation programmes in Aotearoa New Zealand, particularly since the start of the COVID-19 pandemic. For Māori, she reports that coverage and timeliness had fallen prior to the pandemic, which she attributes to target fatigue and challenges in the sector, including for general practices and enrolment issues. Dr Turner notes the fall in coverage accelerated with COVID-19's appearance and was exacerbated by a very fatigued primary care sector with staff shortages and community polarisation. Worsening hardship for many can see preventative measures dropping down on the list of what is possible for some whānau.

This fall in immunisation coverage rates has meant that immunisation has again become a focus for government. Te Whatu Ora (Health NZ) is working with Te Aka Whai Ora (the Māori Health Authority) to prioritise sector-wide improvements to lift immunisation rates[26].

Most common types of additional disabilities

There is a wide variety of reported conditions contained within notifications, including those related to a specific syndrome, cerebral palsy, general or global developmental delays, intellectual disability, and vision problems[27, i].

To better describe the range of additional disabilities seen among children and young people whose data were contained in the Database, we developed a framework to group these, and this has been applied to all records.

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.

While notifying professionals generally completed this part of the form well, descriptions were sometimes unclear[i].

Rates of additional disabilities and the effect of age at diagnosis

When we examine cases of hearing loss diagnosed among children under and over the age of two years, there is a clear difference in the proportion with confirmed additional disabilities. Those over the age of two at diagnosis have a higher rate of confirmed additional disabilities when compared with their peers who are diagnosed under the age of two (12% vs 6%).

This difference in rates among these groups is likely to be due to the time it takes to confirm additional disabilities, the age at which these conditions appear and because these conditions may take time to become noticeable to parents, caregivers, or medical professionals[ii].

Bilateral and unilateral loss

Proportion of unilateral and bilateral hearing losses

Calculating the exact proportion of cases thought to be bilateral is somewhat problematic as not all audiometric data contained on notification forms corresponds to the categories selected by the notifying professional (e.g. normal hearing, sensorineural hearing loss, etc.).

The proportion of 2010-2022 cases in the Database thought to be bilateral is approximately 69:31, or as low as 65:35, depending on the methods used[iii].

Influences on the proportion of bilateral/unilateral hearing losses

Immunisation coverage (including for conditions such as mumps) in Aotearoa New Zealand has been falling as described in the previous section. Mumps is one cause of unilateral hearing loss.

The number of cases resulting from changes in immunisation is likely to be small, and so the impact on numbers of cases of hearing loss diagnosed that have been notified to the Database will likely not be visible.

Genetic and/or epigenetic factors[iv] 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[28].

Unilateral hearing losses

Background

Unilateral hearing loss prevents the auditory system from processing and integrating input from both ears. This is important for improved understanding of speech in noisy situations and for sound localisation[29, 30].

A series of studies in the United States in the early 1980s caused the significance of unilateral hearing losses (UHL) to be re-evaluated by professionals, who had previously minimised the implications of unilateral hearing loss in children[31, 32, 33].

There is evidence that children with unilateral hearing losses have reduced educational performance, language delays and higher rates of behavioural issues, which are reported as significant in about a third of all cases[34, 35, 36, 37].

To reflect the now acknowledged importance of unilateral loss, cases where these average more

i For example, some forms noting additional disability/ies were present only included detail on aetiologies and not the specific additional disabilities, while others didn't provide any detail in terms of the implications of a particular diagnosis, e.g. Cytomegalovirus. Not all forms that had 'yes' selected to this question, noting an additional disability was present, contained details, while others contained details of suspected rather than confirmed diagnoses.

ii For example, for a child whose hearing loss is identified as a direct result of universal newborn hearing screening, this may be the first condition that has been identified. Before the implementation of newborn hearing screening, other conditions were often identified first, followed by a diagnosis of hearing loss.

iii 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. The interpolated data includes a good deal more cases and so we will focus on this figure from now on in these reports, as it is likely to be a more accurate reflection of all tamariki whose data is included in the Database.

iv Epigenetic factors are those where behaviours and the environment result in changes in whether genes are turned 'on' or 'off'.

than 26 dB HL in the child/young person's hearing-impaired ear[i] have been included in the DND since its re-launch in 2010[ii, iii].

Bagatto *et al*. completed a review in 2019 that draws on the views of an international panel of experts, along with a parent advocate, and a review of the literature[38]. This review defines unilateral hearing loss 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 aetiology, with normal hearing in the opposite ear. The majority of cases of UHL were due to cochlear malformations and Mondini dysplasia[iv], and environmental causes were also commonly implicated. As a result, aetiologic assessment following diagnosis, including complete otologic evaluation including imaging, was recommended.

A recent review by Purcell *et al.* (2020) reported that Cochlear nerve aplasia and cytomegalovirus are among the most common aetiologies for unilateral hearing loss[39].

Prevalence

Prevalence of unilateral hearing loss (UHL) is difficult to understand, not least because the definition for UHL differs between studies, and samples often don't include the complete group being described[40].

Newborn hearing screening programme data from Finitzo *et al.* (United States) suggest around one in 1000 babies are born with a UHL, about a third of the total babies identified with a hearing loss[41]. Prevalence data also from the United States show rates rise with age to between 3.0 and 6.3% among children 6-19 years of age, according to Ross *et al.*[42]

As described by Vila *et al.* in 2015[43], one in ten or more of the children diagnosed with UHL will see this hearing loss progress to affect their other ear[44, 45, 46].

Recommendations

The Joint Committee on Infant Hearing (JCIH) noted in its 2007 statement that 'All families of infants with any degree of bilateral or unilateral permanent hearing loss should be considered eligible for early intervention services.'[47] This statement recommended that developmental monitoring should also occur at regular six-month intervals for those with permanent unilateral hearing loss because these children are at risk of speech and language delay.

A supplement was produced in 2013 stating that all children with unilateral or bilateral hearing loss should be referred to early intervention services for evaluation and consideration of enrolment. It stated that most infants and children with bilateral hearing loss and many with unilateral hearing loss benefit from some form of personal amplification device[48].

The American Academy of Audiology recommended in 2013 that children with unilateral hearing loss should be provided with hearing aids on a case-by-case basis[49].

In New Zealand, Project HIEDI (an advocacy rōpū formed to see the introduction of universal newborn screening) recommended in 2010 that families of children with unilateral hearing loss be offered advisory services (from an Advisor on Deaf Children) and that such children be regularly assessed to quickly determine if they are beginning to fall behind and to determine what support is appropriate[50].

Management

While there is limited high-quality evidence on how to best manage unilateral hearing loss in young children, consensus-based principles of technology management for children with UHL are described in Bagatto *et al.*'s 2019 review[38, v].

i Averaged over four frequencies – 0.5, 1.0, 2.0 and 4.0 kHz.

ii In DND reports between 2010 and 2014, the proportion of bilateral and unilateral losses was calculated based only on cases with full audiometric data and in 2014 this was broadened to include those for whom data could be interpolated.

iii Although unilateral hearing losses were not included in the DND before 2006, several of these cases were notified to the Database each year and these numbers were provided in the annual reports at that time. However, comparing the proportion of unilateral/bilateral notifications with previous DND data (prior to 2005) is not possible because reporting prior to 2006 was incomplete in this older dataset.

iv Progressive hearing losses are common in such cases as described here.

v To further investigate the impact of unilateral hearing loss on young children, The Children with Unilateral Hearing Loss (CUHL) study is being conducted by the National Acoustic Laboratories (NAL), Australia.

DND data

About a third of all notifications to the Database since 2010 (31-35%) are for children and young people diagnosed with unilateral hearing loss. Over time, a proportion of those children will go on to have hearing loss develop to include their other ear.

Here in Aotearoa New Zealand, a recent analysis of data provided for 163 of the 189 notifications to the DND in 2010 (unpublished)[7] described in the 2019 report[51], showed 32% of those children or young people with a unilateral hearing loss ended up with a bilateral hearing loss by the time the follow-up data was provided. This is not easy to characterise as not all children and young people's data pertained to 2017/2018; some data provided related to information collected much earlier than that, at their last appointment with the clinic, for example. However, these data suggest higher rates of progression may exist locally than those described by Vila *et al.* (2015).

In our full dataset, those children and young people with unilateral hearing losses are:

- more likely to have an acquired hearing loss (5.5% vs 3.7% for those with bilateral hearing loss); and
- more likely to have congenital hearing loss listed as being the result of atresia (8% of unilateral cases compared with 2.2% of bilateral cases).

Single-sided deafness

Definition and management

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

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[52, 53]. 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[54]. Fitzpatrick *et al.* (2017) from Canada, suggested an SSD prevalence of 3% of among Canadian school children.

A study by Dewyer *et al.* (2022) found SSD was rare (0.36%) among the 52,878 children and young people in a single US institution's database that had had at least one audiogram conducted before their 18th birthday. Twenty five percent of the 109 children identified had the aetiology of their hearing loss confirmed as cochlear nerve deficiency (hypoplasia or aplasia), as found through MRI and/or CI. 66% of those with SSD were categorised as able to benefit from cochlear implantation[55].

Zhan *et al*. considered the challenges and characteristics of single sided deafness in children (2020), noting the clinical implications have been underappreciated despite the literature. Cochlear nerve deficiency, inner ear malformation and congenital cytomegalovirus infection were the most common aetiologies. Device usage was poor as were follow-up rates at or after 1 year[56].

One reason for examining the proportion of unilateral losses categorised as SSD, is that there are differences in the types of hearing technology that may benefit tamariki in this group. For example, those with SSD may be more likely to receive cochlear implants compared with those with less severe degrees of unilateral hearing loss, who may receive a bone conduction hearing aid (e.g. if there is a permanent conductive hearing loss due to aural atresia).

DND data

Cases of SSD in our analysis are defined as children and young people in the main dataset 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[i].

i These average thresholds have been chosen considering the ASHA (American Speech-Language-Hearing Association) codeframe for severity, as 26 dB HL is the lower limit for average notifications to be accepted into the Database and as a 70 dB HL average is the boundary between moderately severe and severe hearing losses. This

The data contained in Table 6 show the proportion of total notifications each year that met the DND's definition for SSD[i]. The proportion of all 2010-2022 cases[ii] that met the criteria for SSD is 5.2%.

Notification Year	Proportion of cases with single sided deafness	Cases which met the criteria for SSD plus those may meet those criteria but not all datapoints were available.
2010	6%	7%
2011	4%	5%
2012	8%	8%
2013	10%	11%
2014	8%	8%
2015	5%	9%
2016	5%	8%
2017	6%	9%
2018	4%	9%
2019	5%	8%
2020	4%	12%
2021	2%	5%
2022	2%	5%
Average 2010-2022	**5%**	**8%**

Table 6: Single-sided Deafness Cases by Year (2010-2022)

The inconsistent nature of these figures, which have ranged from a high of 12% in 2020 and a low of 5% this year, 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.

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. At that time all four thresholds in each ear (or one in cases of unilateral hearing loss) were complete for 93% of children and young people. This has now dropped to 46% in 2022, a decline on the 37% in 2021 because the proportion of cases diagnosed using ABR has risen during this time. As a result, Table 6, below, now contains the proportion of cases that meet criteria for SSD as well as this figure, plus those who may meet criteria but for whom incomplete audiometric data was provided.

Cochlear implants in Aotearoa New Zealand

Children and young people in this category[iii] 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 ACC[57].

It is likely a good number of these tamariki will not have a robust auditory nerve[56] meaning implantation is not valuable for them. This indicates that an early scan is useful for those in this rōpū, to manage whānau expectations.

Types of hearing loss

A question about the type of hearing loss was added to the notification form part way through 2013. This question asks audiologists to describe the type of loss in each ear. Options provided are: 'sensorineural', 'mixed', 'permanent conductive', 'normal hearing[iv]', 'other' and 'don't know'.

The 2013-2021 data for this question are contained in Figure 3. 'ANSD' (Auditory Neuropathy Spectrum Disorder) is offered as an option within sensorineural hearing loss (SNHL) and is split out in the Figure.

70 dB HL average for the lower limit will eliminate most cases of atresia, as these are mostly conductive, and therefore not severe enough to meet this threshold criterion. Such children will benefit from a bone conduction hearing aid and are, as a result, a different group to those we categorise as having SSD.

i These cases have been identified from data containing all threshold information in addition to those that have had one missing datapoint completed by interpolation.

ii Based on determinations including interpolated data.

iii Where the worse ear has a severe hearing loss or worse from 1kHz to 8Khz.

iv Those notifying cases could also select normal hearing – a useful category for those children and young people with unilateral hearing loss.

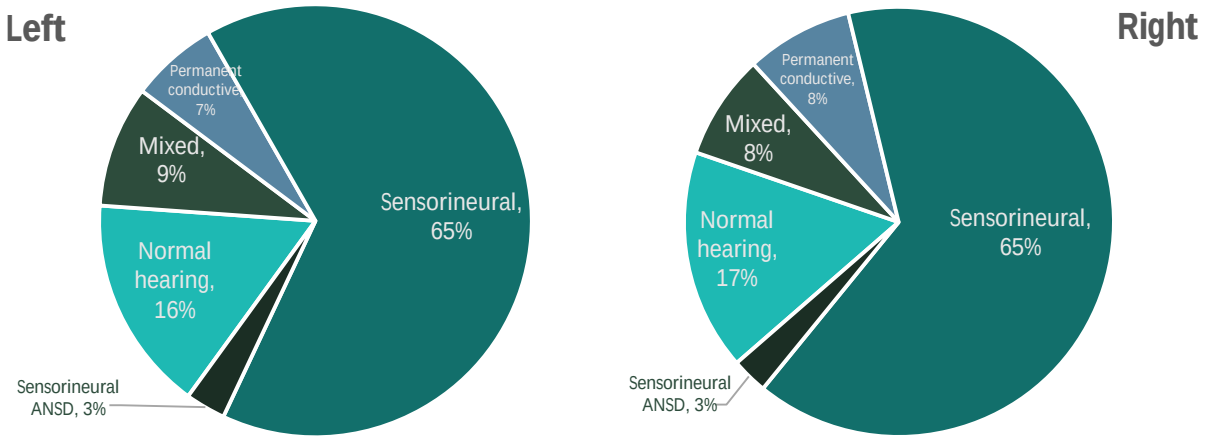

Figure 3: Type of hearing loss (2013-2022)

The most reported type of hearing loss contained in notifications was sensorineural (65% in the left and right), followed by normal hearing (16% in the left ear and 17% in the right).

Please note that the cases with normal hearing in one ear relate to those children and young people with a unilateral hearing loss, indicating they have normal hearing in one ear.

Auditory Neuropathy Spectrum Disorder

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.

Three percent of 2013-2022 cases (right and left ears) in the Database were listed in the ANSD category.

Prevalence of ANSD among those children with permanent hearing loss may be approximately 10%, according to a 2015 review by Rance[58]. Among those from the Avon newborn hearing screening programme in England[59] 15.7% were identified to have abnormal air and bone conduction thresholds and found to have ANSD.

These figures seem to suggest that New Zealand may have lower rates of ANSD than other similar jurisdictions. This difference could relate to our different population, which is also supported by our lower proportion of severe and profound hearing losses when compared with other jurisdictions.

One factor contributing to variations in reported prevalence of ANSD could be differences in whether auditory nerve hypoplasia or aplasia are included[60]. In Aotearoa, some of these cases may be included in the SNHL category.

An analysis of the types of hearing loss among 2010-2016 notifications, included in the 2016 DND report[61], found significant differences in the type of hearing loss between Māori and Europeans (Fishers exact test: p=.0037). More Māori had 'mixed' hearing losses than expected (11.9% for Māori vs 6.1% for Europeans, p=.0317, Z-test for proportions), and fewer Māori were recorded as having 'permanent conductive' hearing losses than expected (6.5% for Māori versus 12.1% for European, p=.0313)[i].

A repeat analysis of the type of loss by ethnicity for 2010-2020 data also found higher proportions of mixed losses in this group, and lower proportions of this type of hearing loss among those children and young people identified as Asian.

i Data for those with missing hearing loss type data was excluded from this analysis.

Microtia and atresia

Microtia is a congenital malformation where the external ear is underdeveloped and usually occurs with aural atresia, a condition where the auditory ear canal is underdeveloped or closed. A survey of mothers with 699 infants with anotia or microtia and 11,797 other infants, found that children with microtia were more likely to be male, their mothers were more likely to have health conditions associated with obesity and/or pre-pregnancy diabetes, and it was less likely among mothers taking folic acid containing supplements[62].

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[63]. Unilateral atresia is more common than bilateral, in the order of three or four cases to one[64].

Aural atresia (AA) is commonly associated with maximal conductive hearing loss in atretic ears, and children with bilateral AA benefit from amplification.

A 2014 paper from the United States found that of 74 children with AA, high rates of speech therapy were common among those whose atresia was bilateral and unilateral, as were educational interventions. This paper suggests that those children with unilateral AA may be at increased risk of speech and learning challenges[65].

A later paper from Jonas *et al.* (2022, also from the USA) found that older and younger children alike benefitted from audiometric improvement resulting from atresia repair[66]. This paper also describes pre- and post-operative audiometric thresholds for children with AA.

Microtia affects one rather than both ears in most cases[63]. 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. Inner ear abnormalities are often seen in those with aural atresia, particularly when they also have congenital facial paralysis[67].

These conditions affect hearing, often resulting in moderate or greater hearing loss, and requiring ongoing medical care, ideally from a team including an ENT and involving audiology expertise.

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).

Treatment and support in Aotearoa

Aural atresia is almost always identified soon after birth in Aotearoa New Zealand.

Speech therapy or educational interventions are not always in place for children in New Zealand with atresia. This group should be referred to an Advisor on Deaf Children and potentially to a Speech Language Therapist who will provide ideas and strategies for the family to support the child.

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 previous subsection are funded for children by Te Whatu Ora. Once rangatahi reach adulthood they would all be eligible for the universal hearing aid subsidy, which is $1022.22 every six years.

It is worth noting that different jurisdictions offer hearing services and devices to different age ranges. Australian Hearing for example, offers

these at no charge to all children and young adults under the age of 26 years of age.

DND data

Within the Database, considerably more children have permanent conductive hearing losses among those who also have a syndrome (44% in right ears and 33% in left) than those who do not (8% in right ears and 7% in left ears). The rates of these hearing losses are also considerably higher among those with unilateral hearing loss (15%) compared with those who have a bilateral loss (5%).

Ethnicity	Bilateral	Unilateral
NZ European	6%	14%
Māori	3%	15%
Asian	3%	19%
Pacific Peoples	6%	15%

Table 7: Permanent conductive hearing losses by ethnicity (2013-2022)[i]

A total of 5.2% of all cases (n=132/2556) had been diagnosed with atresia/microtia or both. This figure was lower for children and young people whose ethnicity was listed as MELAA (2.2%), European (4.7%) or Māori (5.0%) and higher for those listed as Pāsifika (7.4%) or Asian (5.9%). ENT surgeon Mr Brown noted that several professionals believe that Pāsifika and Asian populations have higher rates of aural atresia, and this anecdotal suspicion is consistent with these data.

Of the 132 cases in our Database, 11% are listed as bilateral, 26% are left side only, 39% are right side only, and 23% are not able to be determined. This breakdown is somewhat reflective the ratios of unilateral to bilateral cases seen in the overseas literature though in some cases we don't have enough information to be sure how many ears are affected among children in our database.

Other local data

Auckland and Waitematā districts kindly provided data for cases of atresia and microtia from 2010 to the middle of 2023. During that time, they conducted 3893 diagnostic appointments; 91 cases were listed as 'permanent conductive' and of these 19 (21%) were bilateral, fewer than the overseas ranges reported. Of the remainder, 40 were right side, and 32 were left side[68].

Our thanks to Mr Colin Brown for his contribution to this section of the report.

Hearing loss present at birth

Of all 2010-2022 cases, 99% contained information indicating whether the audiologist believed the child's hearing loss was likely to have been present at birth.

Of those where a response to this part of the form was provided, the audiologist indicated they were 'unsure' in 38% of cases, with the hearing loss likely to have been present at birth in 48% and not to have been present at birth in 14% of cases.

The advent of universal newborn hearing screening in New Zealand has resulted in a growing proportion of notifications where the hearing loss was thought to be present at birth, rising from 29% in 2010 to 67% in 2022. A similar reduction in the proportion of cases where the professional was unsure about whether the hearing loss was present at birth is also seen.

Analysis of 2010-2016 cases, described in the 2016 DND report, found that the proportion of Europeans *without* 'hearing loss thought to be present at birth' was significantly higher than for Māori (Z Test: 95% CI (0.054, .132), p<.0001). Because of the number of 'unsure' answers for this question, one cannot assert that Māori have more hearing losses present at birth. Further research is needed to determine whether progressive hearing loss is more common among non-Māori.

The 2010-2022 data continues to show a similar pattern, with European children and young people

i No MELAA children or young people were listed as having permanent conductive hearing loss.

less likely (45%), and those listed as Māori and/or Asian being the most likely (51% and 58%), to have been listed as having a hearing loss thought to be present at birth.

Family hearing history

The question in the DND relating to family history is 'Does an immediate family member (only a mother, father or sibling) have a permanent hearing loss?[i] (or had a permanent hearing loss if they have died).' This question was introduced part way through 2014.

The results for this question are shown in Figure 4[ii] and shows data from 2015-2022 notifications – years containing responses to this question for all cases.

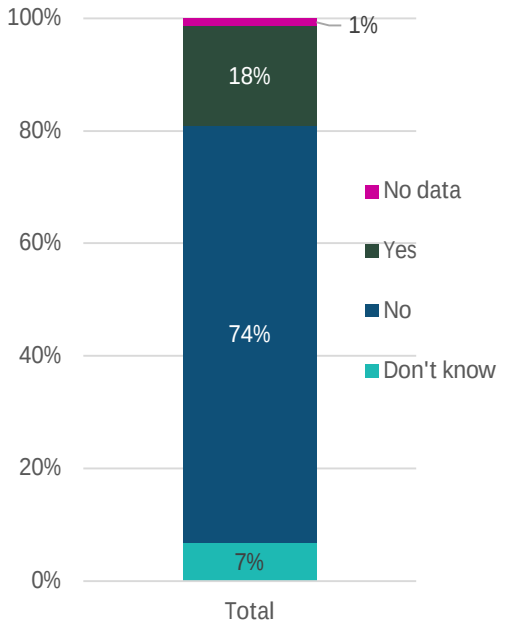

Figure 4: Immediate family member with hearing loss (2015-2022)

The proportion of notifications pertaining to children and young people who are listed as having no immediate family member(s) with a permanent hearing loss ranged from 65% to 83% during that time, with between 12% and 22% listed as having one (or more).

When 2022 figures are examined in isolation, they show the highest proportion of children diagnosed with no family history of hearing loss since 2010 (83%).

This year, the likelihood of children and young people having an immediate family member (only a mother, father or sibling) with a permanent hearing loss was examined for each of the largest ethnic groups.

Further analyses, summarised in Table 8, shows that:

- Asian children and young people are the least likely to have a close family member with a permanent hearing loss (7%);
- Māori children and young people in the database are the most likely to have close family member(s) with a permanent hearing loss (23% respectively); and
- Pacific Peoples are also more likely to have one or more family members with a permanent hearing loss (21%).

See also the section in this report on Aetiology which begins on page 37.

Connexin variants are known to be the most common genetic cause of hearing impairment among those without syndromes in many populations. A systematic review of the published literature, including 571 studies, found different distributions of Connexin in Asian compared with European populations[69]. No studies have been undertaken to establish which groups in Aotearoa New Zealand have the highest prevalence of hearing loss related to genetic changes.

i The DND reports prior to 2005 showed that a relatively high proportion of cases recorded 'family history' as the cause of the hearing loss (family history was reported as the cause of the hearing loss in 24-32% of cases between 2001 and 2005). In 2010, when the Database was re-launched, changes were made to this question to gain more specific responses about the nature of the family history. Questions on this topic began with a general question asking whether there was a family history of hearing loss. More specific questions were then asked about whether the relative was a parent, sibling or grandparent, and then about each specific relative. Between 13% and 24% of cases reported a 'family history of hearing loss' between 2010 and 2013.

ii During 2014, the questions in this section of the notification form were changed, in part to make them easier to complete (this section had not been well completed previously), and to bring the questions into line with developing international practice. Data from 2014 contains information from approximately half the notifications for that period, as the question was changed in the middle of the year, hence data from 2015-2020 is included in Figure 5.

Ethnicity	No	Yes	Don't know
Asian	87%	7%	6%
European (this includes NZ European)	77%	19%	4%
Pacific Peoples (includes Cook Island Māori)	73%	18%	9%
Māori	68%	23%	10%

Table 8: Likelihood of close family member with permanent hearing loss (2015-2022)[i]

i Figures without data have not been included in this table. In each case they comprise 2% or less in each year.

Aetiology

Ngā pūtake

- **Almost all (99%) of the records in the Database contain information about whether the aetiology (cause) of the child or young person's hearing loss was known at the time of the notification, and nine out of every ten cases have an unknown cause.**
- **The aetiology of hearing loss is either genetic or non-genetic in nature. The proportion of hearing losses that have a confirmed genetic cause is increasing.**
- **Children and young people recorded as European are more likely to have a known aetiology when compared with their Māori and Pāsifika and Asian counterparts.**
- **Just over 3% of the children and young people in the Database are reported to have one of 35 specific syndromes recorded, the most common being Down Syndrome, followed by Goldenhaar Syndrome.**

Causes of deafness

The aetiology or cause of hearing loss is either genetic (syndromic or non-syndromic), or non-genetic. It may be known or unknown depending on whether testing has been completed and whether a cause is able to be identified.

Further detail about the aetiology of hearing loss can be found in the 2021 DND report, though estimates of the proportion of prelingual hearing losses thought to be genetic are likely to be sit at 50% or greater, with the remainder being environmental[70].

In addition to detail previously included, information on cytomegalovirus, a leading cause of hearing loss, and promising work to reduce hearing losses caused by ototoxic medications, is provided below.

Cytomegalovirus

Cytomegalovirus (CMV) is the leading non-genetic cause of hearing loss in overseas studies, thought to cause between 10 and 20% of cases in those under the age of five[71].

Typically, the infection itself is benign and innocuous, presenting as cold symptoms, but that is not the case for those who are pregnant and have no antibodies. It is difficult to predict which children with congenital CMV infection (cCMV) will develop hearing loss and whether hearing will continue to deteriorate[72]. 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.

Grosse *et al.*'s systematic review (2008) found that approximately 14% of children with cCMV infection develop a sensorineural hearing loss, and 3-5% develop one which is bilateral and moderate to profound in nature[73]. An estimated 15-20% of cases were categorised as attributable to congenital infections from the virus.

A 2014 analysis of data on 178 infants with congenital CMV infection in the United States found that those identified because of clinical suspicion had more severe disease at birth and more sequalae than those identified at newborn screening[74].

Minnesota, in the United States, is the first jurisdiction to introduce a universal screening programme, and this programme will be very helpful to understand prevalence and how many people go on to be diagnosed with other issues 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 New Zealand blood donors in 2009. The highest prevalence was found among Pacific Peoples (93.2%) and the lowest in Caucasians (54.8%)[75]; and
- A recent analysis of cases of cCMV disease was conducted by Jeong utilising the National Minimum Dataset (NMD). This dataset contained 1,617,854 births between January 2000 and April 2021, of which 225 babies tested positive for cCMV disease. This analysis found that Māori had the highest rate (0.025%) followed by Pacific Peoples at 0.022%, MELAA at 0.013% and 0.0009% for Asian and European populations. The association between ethnicity and cCMV occurrence was statistically significant. 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. Please note that groupings for this study were prioritised[76].

A surveillance study in New Zealand is underway.

There are 21 cases in the DND that mention CMV (some within the aetiology fields and others within 'additional disabilities'), but these data are likely to be incomplete and some reflect investigations that are underway.

Thanks to Professor Holly Teagle for sharing her knowledge for this section in the report.

Reducing hearing loss resulting from ototoxic medications

Those with A1555G mitochondrial mutations may be predisposed to hearing loss when certain antibiotics are used. In a world-first, a genetic test taking 25 minutes and used with critically ill babies identifies whether this mutation is present. It has been developed and piloted by the National Health Service in the UK, and could prevent hundreds of babies there from developing hearing loss[77].

DND data

Known vs unknown causes

A little over 99% of the 2556 records in the dataset (2010-2022) contain information about the aetiology of the child or young person's hearing loss – that is, whether the hearing loss is of known or unknown cause.

Of those with aetiological information, 89% are of unknown cause, with the remaining 11% of cases listed as having a hearing loss with a known cause. The number of cases for which aetiology was not provided was lower this year, with none of the 165 cases notified falling into this category.

A change on historic levels

For the 2001-2005 period, the proportion with an unknown cause was generally between 50 and 59%, with 2001 at 70%[78]. The proportion with a known cause has been falling since the Database was relaunched in 2010 but has lifted since 2018 and has remained at 10-12%.

This means the proportion of children whose hearing loss is of an unknown cause is considerably higher than those reported in the original series of Database reports. These now higher rates of unknown aetiology are very likely to reflect our reduced average age at identification since the introduction of nationwide newborn hearing screening. As a result, more tamariki are being diagnosed with hearing loss earlier, owing to the introduction and roll-out of newborn hearing screening. For example, now that more babies are being diagnosed with hearing loss, genetic testing is less likely to have been performed at the time the hearing loss is diagnosed and the case notified. In addition, newborn hearing screening can mean that hearing loss may now be identified before a full picture of possible other issues is established, perhaps reducing the likelihood of hearing losses that are part of a syndrome being identified at the time of notification.

Other variables

In Aotearoa New Zealand during the 2010-2022 period, those children and young people with bilateral hearing losses that were recorded as severe or profound in severity were more likely to have a known aetiology than those categorised as having a mild and or unilateral hearing loss.

When analysing these data by ethnicity, 14% of those listed as European have a known aetiology, compared with 10% of Māori, 10% for Pacific Peoples, 9% for MELAA and only 7% for those children and young people of Asian ethnicity.

Aetiology types

Of those children with a known aetiology, 5.7% have a congenital hearing loss (with most of these having atresia/microtia or both), 4% have an acquired hearing loss, 3.4% have a syndrome and a further 0.7% have hearing loss of genetic cause that is not syndromic in nature.

Children with bilateral hearing losses are less likely to have an acquired hearing loss, less likely to have a congenital hearing loss due to atresia and more likely to have hearing loss that is due to non-atretic/microtic congenital causes (e.g. cholesteatoma).

When considering ethnicity, acquired hearing losses are most common among children and young people identified as Māori or European, congenital hearing losses are most common among Pacific Peoples (and mostly result from atresia) and genetic hearing losses are most common among European children and young people.

Row Labels	All cases	European	Māori	Pacific Peoples	Asian	MELAA
Unknown aetiology/no data	86%	83%	87%	86%	90%	91%
Acquired hearing loss	4%	5%	5%	3%	1%	4%
Total congenital	6%	5%	5%	8%	6%	4%
Congenital (non-atretic)	1%	2%	1%	1%	1%	2%
Congenital (atresia)	4%	4%	4%	7%	5%	2%
Genetic causes	4%	6%	3%	3%	3%	0%
Genetic cause (non-syndromic)	1%	1%	0%	0%	1%	0%
Genetic cause (syndromic)	3%	5%	3%	3%	2%	0%
Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**

Table 9: Aetiology types (2010-2022)

Specific causes and types of causes

Mumps, measles and meningitis were previously often considered by audiologists as possible causes of hearing loss; however, this had become less common because of generally increased immunisation coverage. Coverage levels have recently fallen considerably. The impact of the recent measles epidemic[79] is not yet known.

It is worth noting that the current concern regarding mumps incidence in Aotearoa New Zealand, which is thought to relate to immunisation dose timing and coverage rates, may be having an impact on incidence and should again be a clinical consideration[80].

Congenital CMV is likely to be a common cause of hearing loss, particularly for those children and whānau living in the most deprived quintile, though it may not have been diagnosed.

Children and young people with syndromes

The proportion of DND cases listed as genetic is much lower than the proportion expected from the literature. This is likely to relate to the fact

that notifications are mostly made at or soon after the time the child or young person's hearing loss is diagnosed, meaning genetic testing has not yet been done. It is not possible to know whether the rates of genetic testing for children with hearing loss could also be a factor.

Those with hearing loss of known genetic cause can be split into those with syndromic and those with non-syndromic hearing losses.

Among the 2,556 children and young people in the Database, thirty-five specific syndromes been confirmed by the time the notification was made, affecting 87 children and young people. This number represents 3.4% of the children and young people in the main dataset.

The most common syndromes identified were Down Syndrome (also referred to as Trisomy 21), which was identified at the time of the notification for 23 children and young people, Pierre Robin Syndrome/Goldenhar Syndrome and which were present in 15 children and young people[i].

i For information on syndromes, we recommend the OMIM Catalog of Human Genes and Genetic Disorders. It provides comprehensive and well referenced online information on a large variety of genes and genetic disorders and is freely accessible. The links to the most common syndromes listed above take the reader to their respective pages in this catalogue. It may be helpful for audiologists to better understand syndromes of those in their care so they can determine an appropriate plan for clinical management.

Ethnicity

Mātāwaka

- **The largest number of notifications are listed as European, although there are fewer than would be expected in this group based on the size of their population.**
- **Disparities across the health system have been well-documented for Māori in terms of their access to, and through, the health system. Research on equity for hearing services is limited but shows similar patterns.**
- **Hearing losses among Māori children and young people may not be notified to the Database as consistently as other groups. The number of notifications from those of Māori ethnicity are still higher than expected based on their number in the population and this pattern is confirmed by other sources.**
- **European children are underrepresented in the database in relation to their population size. Overall, Pāsifika, Asian and MELAA children and young people are notified to the Database in proportions roughly equivalent to their relative population size for this group. The number of children and young people listed as MELAA is the smallest group by far, at 2% of notifications; a similar proportion to their population size.**

Representation

Background

The DND notification form records information about the ethnicity/ethnicities of tamariki diagnosed with hearing loss. Options available on the form are: European[i], Māori, Pacific Peoples, Asian, and Middle Eastern, Latin American and African (MELAA)[ii, iii].

Please keep in mind that the multi-code system used for the DND means that some records contain more than one selection for ethnicity, and so a participant may appear in more than one group. The authors of this report believe this system of coding 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.

For further information on ethnicity coding in the Database, please refer to *Appendix B: Notifications and ethnicity*, on page 73.

Full dataset

Of the 2556 notifications in the main dataset (covering 2010-2022) all but 29 contain at least one ethnicity code. The number of notifications without one or more ethnicity codes has dropped from an average of 1.74% in 2010-2015 to 0.75% in 2016-2022.

Most notifications (89%) contain one code, and a smaller proportion (9%, 0.8% and 0.04%) contain two, three or four codes, respectively.

Multi-coded 2018 Census data are included for comparison in Figure 5. As individuals may identify (or be identified by their parents) as belonging to

i The term European is used in this report to mean all those of European descent. However, most notifications to the Database are for those born in New Zealand and can be considered 'New Zealand European'.

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

iii 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 Ethnicity Classification's Level 1 codes, before analysis.

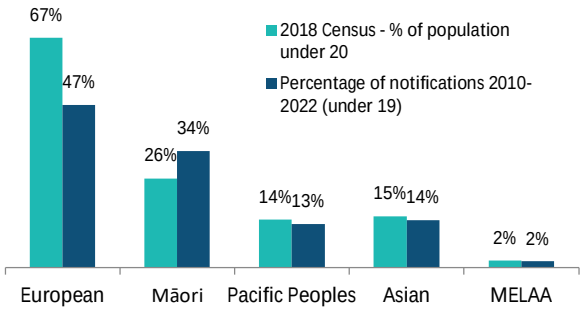

Figure 5: Notifications by ethnicity (2010-2021) compared with Census data (2018)[81]

more than one ethnicity, the totals add to more than 100%.

This figure shows the total response count for ethnicity from the 2018 Census (for those under the age of 20) and compares this to the ethnicity breakdown for notifications from 2010-2022[i]. Please note that MELAA figures for bilateral and unilateral hearing losses reported in this figure relate to a very small number of cases (n=45).

Those of Māori ethnicity are over-represented in the Database, comprising 34% of notifications and 26% of the population under 20 years of age.

Those children and young people of Asian or Pāsifika ethnicities are being diagnosed in approximately the same proportions as would be expected by their population under 20 years of age.

Note that 29% of notifications from Auckland and Waitematā districts (2010-2022) are listed as Asian, more than double the average proportion for the whole country. These districts report that Asian children are overrepresented in their diagnoses when compared their relative population size.

The European ethnic group is the largest in the Census by a significant margin, at 67% of the population under 20 years of age but only makes up 47% of notifications to the Database.

Unilateral and bilateral hearing losses

Of 2010-2022 cases, including those with interpolated audiometric data, 65-69% are recorded as bilateral, while the remaining 31-35% are unilateral.

Māori tamariki have higher rates of bilateral hearing loss than their New Zealand European counterparts as described in previous reports and the conclusions from the 2014 paper by Digby *et al*.

MELAA children and young people have the highest proportion of bilateral hearing losses, at 76% in total, followed by Māori (72%) and Pāsifika children (66%). Asian and European children have fewer bilateral hearing losses (at 60% and 62% respectively)[ii] and a greater proportion with unilateral hearing loss.

Prevalence

New Zealand European and Māori are most notified groups

Most notifications provided to the Database since its re-launch in 2010 relate to tamariki of New Zealand European and/or Māori ethnicity.

As mentioned previously, while the proportion of notifications from those of European ethnicity are considerably lower than one would expect based on the size of their population, notifications from those of Māori ethnicity are higher than expected.

Sources, including Whakarongo Mai (1989), Greville (2001), UNHSEIP programme data and Household Disability services, demonstrate higher prevalence of hearing loss among Māori when compared with Europeans. *Details of these sources can be found in Appendix D.* Our DND data also reflects this same pattern, as shown in Figure 5 above.

Despite a good number of sources pointing to higher rates of hearing loss among young Māori, this group may still be underrepresented in DND statistics because of:

i Individual year age data for ethnicity is not freely available from Statistics New Zealand. Notifications include children and young people under the age of 19 years.

ii 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.

- their greater chance of having a less severe hearing loss – it is probable that less severe (especially mild) hearing losses are less likely to be identified; and
- disparities in access to, and within, the health system[82] suggest fewer cases may be found and/or notified when compared with those in the European population.

The risk of underrepresentation is higher for older Māori children and young people whose hearing was not screened as newborns and for those children and young people who develop a hearing loss after birth.

It is worth keeping in mind that Aotearoa New Zealand's Universal Newborn Hearing Screening and Early Intervention programme (UNHSEIP) does not target or identify all mild hearing losses[i]. Māori have higher proportions of these hearing losses when compared with other ethnic groups including Europeans. The B4 School Check targets mild and greater hearing losses[83].

Asian tamariki

It is important to note that (as with Pacific Peoples) Asian New Zealanders are far from a homogenous group. This broad 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.

Keeping that in mind, there is good alignment between the overall proportion of Asian children and young people identified with hearing loss and notified to the database, and their proportion in the population under the age of 20. This does not tell us whether the subgroups within the Asian category are well-represented in the notifications, in part as population prevalence among these subgroups is not well understood.

According to the 2018 Census, 28% of those in the Auckland region identified as having Asian ancestry. Sixty two percent of the of the Asian population in Aotearoa reside in Auckland[84].

The proportion of Asian tamariki has grown rapidly in the recent decades, with the fastest growing subgroups being those identifying with Indian, Chinese, Korean, or Filipino ancestry. These were also the most populous subgroups within the diverse Asian category[85] .

Scragg (2019) describes that, in 2013, Asians had the lowest rate of enrolment with primary health providers (GPs) although this may reflect their better health. This figure was still low in 2022, at 84%, one percent higher than Māori[86]. Breast and cervical screening rates were also low compared with other groups[87]. Dr Lam, quoted by Scragg believes culturally and linguistically appropriate resources are required to meet the needs of this group[87].

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 good health of those coming to live in New Zealand is often referred to as the "healthy immigrant effect", however this doesn't negate the fact that aggregation of such a large and diverse group can hide disparities. It is also worth noting that Asians report the highest rates of discrimination of all Level 1 ethnicity groups[87].

Asians tend to have mixed access to and through other parts of the health system, as demonstrated by their high vaccination rates[88] and low rates of enrolment with GPs and for some screening services.

Unequal health access and outcomes for Māori

Disparities documented in numerous areas of our health systems demonstrate Māori[ii] have poorer access 'to, and through' the health system[89, 90, 82], that they receive a poorer and slower service, and are less likely to receive appropriate levels of care[91], resulting in poorer health outcomes. Despite the presence of national policy frameworks, work to address disparities has often

i "The UNHSEIP is not designed to identify babies with mild hearing losses." Ministry of Health's 2016 Universal Newborn Hearing Screening and Early Intervention Programme: National policy and quality standards: Diagnostic and amplification protocols.

ii In this report the New Zealand Māori ethnic group is referred to as Māori.

not been successful. Please see *Appendix D: Māori, hearing and health* from page 76 for more information.

Hearing service disparities

There has been limited research on inequalities within hearing services.

Thorne *et al.* (2008) found considerably lower rates among ACC claims for Māori (and Pacific Peoples) relative to Europeans, despite the overrepresentation of these groups in industries where noise exposure is higher, and a higher prevalence of hearing loss overall[92].

An article by McCallum *et al.* (2015) in the *New Zealand Medical Journal* examined hospital admissions for under 15-year-olds (2002-2008) and first ENT appointments (2007-2008) and found disparities in access to ventilation tubes for 0-4-year-olds, with the greatest inequalities being for Māori, Pāsifika and Asian tamariki[93].

The latest data from the Atlas of Healthcare Variation (Surgical Procedures) suggests that public grommet insertion rates are low in some areas compared with the national average, particularly in 0–4-year-old Māori and Pāsifika [94]. (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.)

As described by Pokorny *et al.* (2022) referral rates for Māori do not reflect their increased rates of hearing loss and ear disease[140]. Māori appointment attendance rates remained 64% lower in their analysis than non-Māori even after adjusting for socio-economic deprivation, waiting times and telephone contact.

As shown in the section on *Identification of hearing losses*, screening coverage rates for programmes, such as the UNHSEIP and the B4 School Check, show those recorded as Māori are less likely to have their screening completed than their European counterparts.

A recent study by Seo *et al.* (2022) examined ventilation tube (commonly known as grommets) insertion practices around Aotearoa New Zealand by ethnicity and district. The results were 'incongruent with evidence that Māori and Pāsifika children in New Zealand experience a greater burden of middle ear disease than NZ European children'[95].

While the specific nature of the barriers to access are not generally described, research into whether such disparities exist for tamariki accessing other hearing services, such as those provided by audiologists, is needed. Such investigations are particularly important as there is no service specification for audiology services nationally, meaning that services offered by districts[i] differ, as do waiting times.

A recent ear and hearing care scoping review focused on First Nations children suggests 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[96].

Work to reduce disparities

Two projects underway to address disparities in hearing health care in Aotearoa New Zealand are described below.

Equitable ear and hearing health outcomes

To accelerate shifts in the inequitable ear and hearing health of Māori and Pāsifika tamariki, the Eisdell Moore Centre funded a research project led by Dr Rebecca Garland (ORL, Pōneke) with clinicians Dr Rachelle Love (Ngā Puhi & Te Arawa, ORL, Ōtautahi), Dr Alice Springer (ORL, Pōneke), Kylie Bolland (Audiologist, Hutt Valley DHB) and Alehandrea Manuel (Ngāti Porou, Audiologist, EMC Māori Research Coordinator)[ii].

i District-based public clinics see most tamariki and rangatahi with hearing loss with only a small proportion being seen in the private sector.

ii A collaboration across health and education arose from the observations of many people involved in the lives of those who are Deaf and hard-of-hearing, and focused specifically on service

A multi-disciplinary Working Group was formed and released a draft report in 2022 (Equitable ear and hearing health outcomes for Māori and Pacific Tamariki Report) based on a survey and a series of virtual hui. Six suggestions for collective action were recommended and updated in 2023, including advocacy, examination of the B4 School Check Database and a publication for a special edition on hearing health for the Royal Society on this project's strategy and its mahi.

Paediatric ORL Pathway – Redesign for Equity

The goal of the Paediatric ORL[i] Pathway Redesign for Equity project has been to design and implement a regional service in the Northern Region which provides equitable access for all children (tamariki Māori and Pāsifika children in particular) to paediatric ORL services via end-to-end integrated care pathways that work seamlessly, ensuring consistent, high-quality care and support.

This redesign project has an associated rōpū working on developing National guidelines on OME, including diagnostics and has been collecting existing evidence. They have been advocating for hearing health with Te Aka Whai Ora and contributing to health system reforms. Chair of this Working Group, ORL Michel Neeff (ORL Clinical Director at Starship Hospital) is grateful to the whānau and 'aiga whose insights and feedback is driving change across the pathway of care.

To date this mahi has included:

- prioritisation of tamariki Māori and Pāsifika children at each point of the pathway, from referral through to surgery and follow-up;
- expansion of the community ear-nurse model; enabling our senior nurses in community to do more in whānau-friendly settings, where the parking is free, and appointments are easy to attend;
- post-operation follow-up for grommets taking place in community settings for all routine cases;
- leading work to improve the information whānau receive for both grommets and tonsillectomy/adenoidectomy surgery; and
- ongoing review and improvement of the management of ORL conditions, depending on outcomes (outcome measures)[97].

provision, resulting in some children missing out on intervention opportunities because of limitations of engaging with whānau because of the pandemic.

i ORL relates to otorhinolaryngology. This specialty is also sometimes known as ENT (Ear Nose and Throat).

Deprivation

Pōharatanga

- **Deprivation scores in the New Zealand Index of Deprivation are drawn from Census data and indicate the level of deprivation for each of many small areas in Aotearoa New Zealand. New Zealand deprivation data show that children under the age of 17 are more than twice as likely to be living in income poverty than those over the age of 65 years.**
- **Those around the motu with one or more disabilities are also more likely to live in areas of higher deprivation than those without. No such correlation exists in the United Kingdom, where disability allowances are much higher.**
- **Our DND data show that children and young people notified to the Database who are of European ethnicity are much less likely to be living in the most deprived areas than those of Māori and/or Pāsifika ethnicities.**
- **As income and poverty are significant determinants of health, professionals seeing children with hearing loss can expect to see poorer health among families diagnosed with hearing loss, but even more so for those identified as Māori and/or Pāsifika. Those in deprived areas are likely to experience greater barriers to engagement with hearing and other services.**

Overview

International data demonstrates prevalence of congenital hearing loss is lower in countries with higher incomes. Lower levels in higher income countries are thought to be due to lower infection rates and better access to preventative measures and healthcare services[98].

The New Zealand Child Poverty Monitor reports that children in Aotearoa New Zealand 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[99].

Tamariki with disability and deprivation

Child Poverty Action Group (NZ, 2015) report that children with disabilities in Aotearoa New Zealand are at a greater risk of living in low-income households than those without such disabilities[100].

Statistics New Zealand reports that overall, 11% of children under the age of 15 have a disability[101]. Once adjustments are made for differences in age profiles by population, Māori and Pāsifika groups are also more likely to be living with low incomes.

This pattern is also found in the United States, where Boss *et al.* (2011) evaluated disparities in socio-economic status among hearing impaired children nationwide through the 1997-2003 National Health Interview Survey. It found that families of children with hearing impairment live closer to the poverty level and use some medical services less frequently[102].

However, Child Poverty Action Group (NZ) also note that such disparities are not inevitable and cite the United Kingdom's much higher disability allowance, which is thought to be the reason there is no correlation between childhood disability and poverty in that country[103].

Introduction to the New Zealand Deprivation Index

Here in Aotearoa New Zealand, we are fortunate to have deprivation data from The New Zealand Index of Deprivation devised and calculated by the University of Otago (Wellington).

This Index draws on New Zealand Census data relating to income, home ownership, employment, qualifications, family structure, housing, access to transport and communications, allocating a deprivation score to every meshblock (small area) containing a median of 81 people around the motu. 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[104]. See the 2021 report for further details on this index and how its calculated.

The deprivation scores are provided for each National Health Identifier (NHI) by Te Whatu Ora | Health New Zealand[i] based on primary addresses they have listed. Deprivation data has been included in our DND analyses since the 2016 report[ii]. Data for this report are based NZDep2013 and NZDep2018. Of the 2556 tamariki now contained in the main dataset, 98% had deprivation data available[iii].

Notifications

Tamariki in our dataset (2010-2022) are much more likely to live in high deprivation areas than lower deprivation areas when compared with the population at large, and with children generally[iv]:

- 6% of children in our dataset are living in NZDep areas that scored a 1 on the index (the lowest deprivation areas), compared with 10% in the New Zealand population at large;
- in comparison, 20% of children included in the dataset are living in NZDep areas that scored a 10 on the index (highest deprivation areas), almost double the 10% found in the New Zealand population at large;
- those who live in the most deprived areas are also much more likely to be of Māori and/or Pāsifika ethnicities, and much less likely to be European, than those in the least deprived areas.

Figure 6 shows the distribution of cases by deprivation status, grouped by ethnicity.

To further illustrate deprivation profiles for each Level 1 ethnic group in the Database we have grouped the proportion of tamariki who are living in the most deprived 30% of areas (with scores of 8-10 on the scale), the middle 40% (with scores of 4-7) and the least deprived 30% (with scores of 1-3). A visual representation of this analysis can be found in Figure 7.

Implications

These data demonstrate that audiologists (and other hearing professionals working with young people who are hard-of-hearing) are likely to see a high proportion of families living in deprived areas and experiencing the effects of financial hardship.

Professionals should keep in mind that income and poverty are significant determinants of health[105]. As a result, many of the families they see are more likely to experience poorer overall health[105] (including greater barriers to accessing health services[106] and lower housing stability

i Please note that NZDep scores relate to the addresses at which tamariki were living at the time the Ministry of Health provided the deprivation score of their area from the NHIs provided – it does not relate to specific individual's level of deprivation.

ii Recent reports now include deprivation data for the full dataset.

iii Data were unavailable for tamariki whose: NHI was not valid, those who had no NHI listed, those whose notification came after the deprivation scores were provided by 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 this year was completed.

iv The 2016 report included comparisons for those children and young people notified to the Database during 2010-2016 for children 0-5 years of age, and those 6-17 years of age. DND distributions for these age groups both skewed more towards the higher deprivation scores than the national distribution for tamariki of the same age. This was particularly the case for tamariki aged 6-17, which contained a preponderance of those living in the four most deprived area groupings when compared to the national figures.

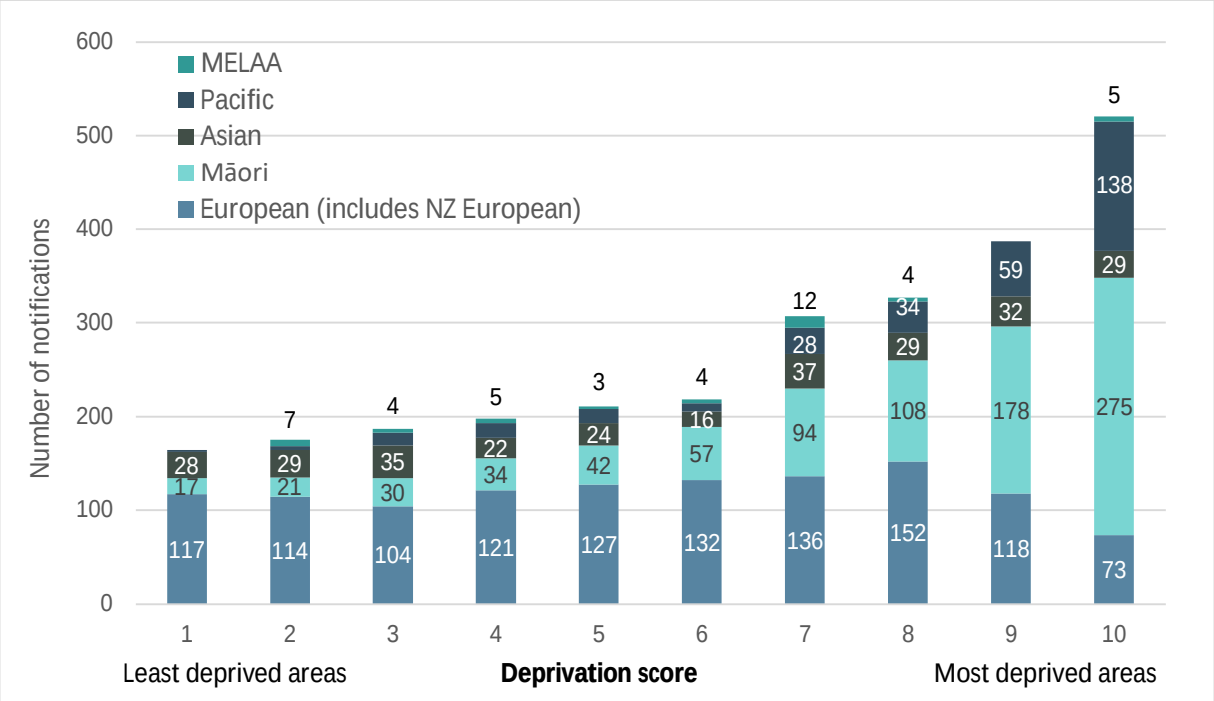

Figure 6: Deprivation scores (NZDep2013) of tamariki in the DND by ethnicity (2010-2022)

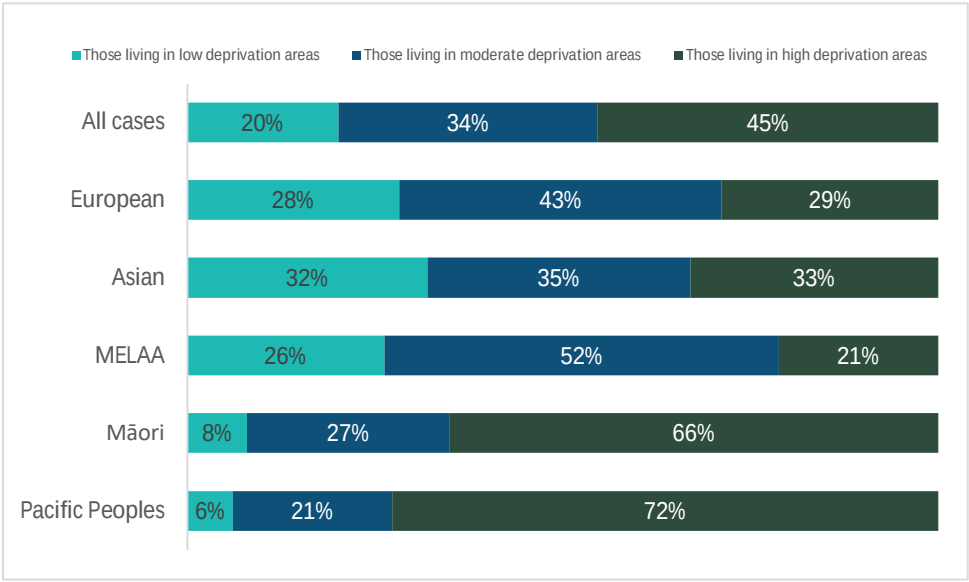

Figure 7: Deprivation scores grouped by deprivation and ethnicity (2010-2022 cases)

stability[107]) and higher rates of stress and mental health issues for adults[108], young people and children[109, 110] than those in less deprived areas. These factors are likely to result in greater barriers for families to engaging with services, including audiology and ENTs.

Most families in areas of high deprivation are of Pāsifika, Māori and/or MELAA ethnicities. Children and young people of Pāsifika ethnicity are 2.5 times as likely than those who are European to live in an area with high deprivation.

Deprivation and Congenital CMV (cCMV)

Families living in deprived areas are also more likely to be diagnosed with cCMV. A recent analysis of the National Minimum Dataset found that approximately 40% of all cases diagnosed with cCMV resided in the most deprived quintile[i].

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

Identification of hearing losses

Te tautuhi i ngā take i turi ai

- **Hearing loss may be present at birth or develop at any time. The DND contains information about the age at which children have their hearing loss identified, and the age at which a hearing loss was first suspected.**
- **For very young infants and those with disabilities, behavioural methods for identifying hearing loss may be unreliable, hence objective methods are used to diagnose these children. Prior to implementation of objective newborn hearing screening across Aotearoa New Zealand, the average age of tamariki at the time of diagnosis was, understandably, very high. Parents were the group most likely to first suspect their child's hearing loss.**
- **There are two peaks for identification of hearing losses among New Zealand tamariki – those identified as a result of newborn hearing screening, mostly before the age of one year, and a smaller peak for those diagnosed around the time the child starts school, often associated with the B4 School Check.**
- **In the Database, those born overseas, with hearing losses thought to present at birth or acquired hearing losses, along with those live in the most deprived areas, have seen larger falls in their average age at identification. Pāsifika children and young people have seen particularly large reductions in median age at diagnosis over recent years.**
- **Understanding how the system is performing for Māori is not easy as their hearing losses differ from those in non-Māori. In addition, inequities in the social determinants of health, and access to and through the health system, disadvantage whānau Māori.**
- **Since implementation of newborn hearing screening, the proportion of children and young people born in Aotearoa New Zealand whose hearing losses have been identified before the age of one has increased greatly from 24 in 2010, to over 100 in recent years.**
- **The latest data from the newborn hearing screening programme (from 2020) shows an estimated 94.2% of the eligible population had their hearing screened. Eighty two percent of eligible children were screened by the B4 School Check during the 2021/2022 year.**
- **Newborn hearing screeners have been the most likely group to first suspect hearing losses among children and young people in Aotearoa New Zealand since 2013. Sixty seven percent of the 106 children notified in 2022 as a result of a newborn screening referral were diagnosed by the internationally recommended age of three months.**

Who first suspected the child's hearing loss?

Information on who first suspected the child or young person's hearing loss was recorded for 94% of tamariki born in Aotearoa New Zealand and diagnosed in 2022.

Table 10 shows the top three groups that first suspected the hearing loss among notified cases *during selected years* since 2010.

	2010	2016	2022
Most likely to suspect	Parent or caregiver (37%)	Newborn hearing screener (56%)	Newborn hearing screener (68%)
Second most likely to suspect	VHT (17%)	VHT (15%)	VHT (12%)
Third most likely to suspect	Medical professional (10%)	Medical professional (8%)	Parent or caregiver (6%)

Table 10: Groups most likely to first suspect hearing loss (Selected years, tamariki born in Aotearoa New Zealand)

The proportion of cases first suspected by parents or caregivers has generally remained below historic levels, including rates reported from the original Database. This group have gone from being most likely to first suspect a child or young person's hearing loss, in more than a third of cases in 2010 and 2011, to being first in an average of 8% of cases during the last five years (2018-2022). Newborn hearing screeners were not in the top three groups to suspect a hearing loss in 2010 or 2011[i] and yet they are now first to suspect more cases than any other group, 68% in 2022.

Evidence exists that behavioural methods relied upon some years ago for identifying a hearing loss were not an accurate method of screening for hearing loss in infants including some children with additional disabilities[111, 112, 113].

In addition, the challenges parents face in trying to identify their child's hearing loss are considerable, particularly when their hearing loss is not so severe as to prevent speech from developing or to cause significant delays in speech development.

Therefore, it is very pleasing to see that there has been a noticeable change over recent years in the groups most likely to first suspect a hearing loss among tamariki. This shift resulted from a move towards use of objective methods such as newborn hearing screening.

Age at diagnosis

Figure 8 shows the number of children whose hearing loss is identified by age[ii] for selected years 2010 to 2022. There continues to be a notable peak in the number of notifications during the first year of life, undoubtedly in large part the effect of the newborn hearing screening programme.

One hundred and eight tamariki received a diagnosis during their first year of life in 2022. This is down considerably from the 132 in 2021 and mirroring the smaller number of children notified during the year. One hundred and six of this year's cases were listed as having their diagnosis made as a direct result of newborn hearing screening.

A further, smaller peak in diagnoses has been seen among four and five-year-olds, though this is a smaller peak in more recent years than seen previously; this peak is very likely to correspond to the B4 School Check[iii, 83].

The number of tamariki being identified at between the ages of four and six has fallen from an average of 30% in the years 2010-2016 to 18% in 2017-2022. This drop may reflect that some children who were previously being identified by childhood hearing screening at or around school age are now being identified through newborn hearing screening.

i Further information was added to the notification form in 2012 to ensure audiologists were clear about how to code the answer to this question, should the child have been identified through newborn hearing screening. This change may be partially responsible for the reported increase in the role of newborn hearing screeners in first suspecting the hearing loss from 2012, given that the UNHSEIP coverage rates had not at that time increased significantly from 2011 levels.

ii Please note that the majority of tamariki also having their B4 School Check since the end of 2013 will have been screened for hearing loss soon after birth.

iii The B4 School Check aims to screen all tamariki before they reach school, and to identify and provide intervention to those tamariki identified with targeted conditions. Part of this Check involves screening tamariki for hearing loss. 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. This screening involves audiometry and is usually conducted by a Vision Hearing Technician. If the child passes this test, no further referrals are required. Should the child refer on audiometry, tympanometry should be conducted.

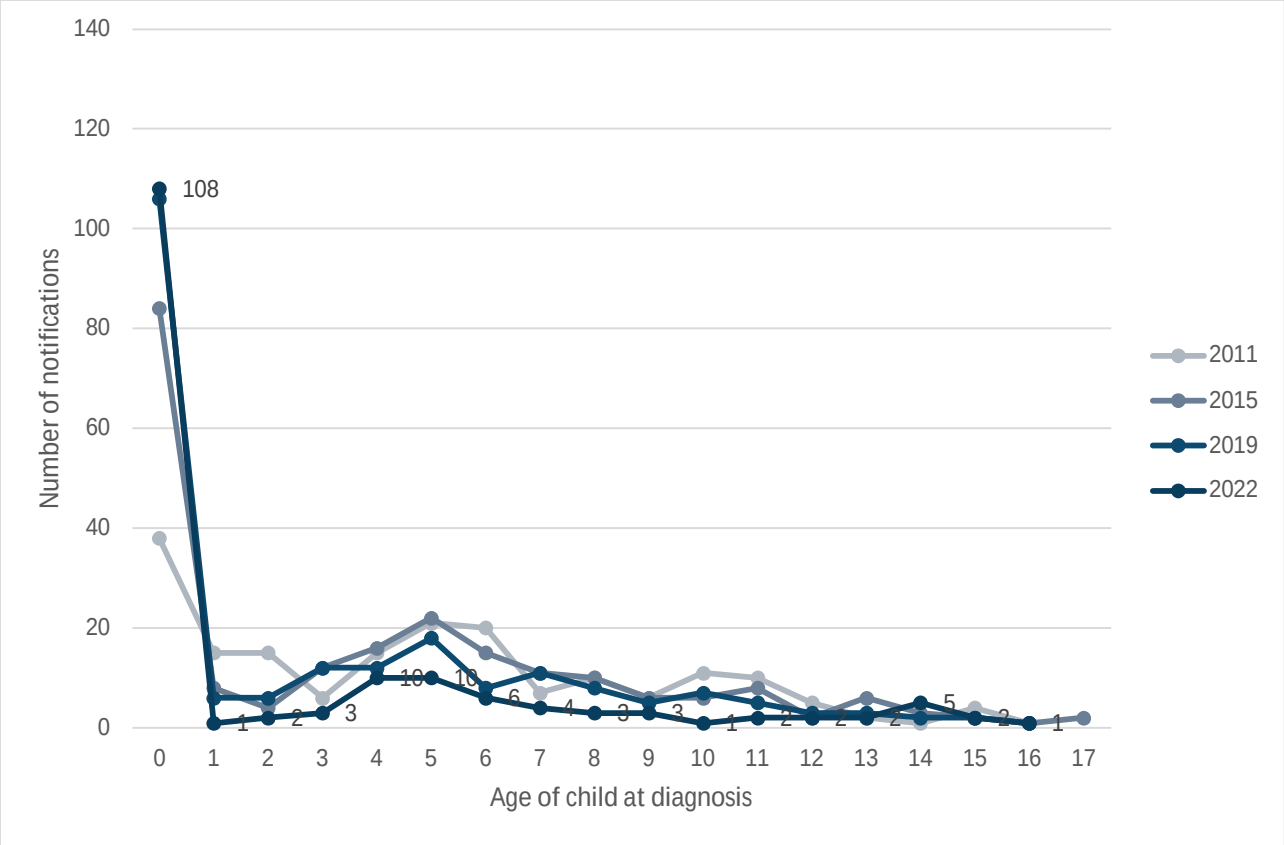

Figure 8: Number of children diagnosed by age in years (selected years, 2010-2022)

Tamariki more likely to be identified later	Tamariki more likely to be identified earlier
born overseas	born more recently
unilateral and/or mild hearing losses	born in Aotearoa New Zealand
acquired hearing losses, e.g. late onset, progressive and trauma related	bilateral hearing losses, particularly bilateral profound, severe or moderately severe hearing loss
live in areas with a deprivation score of 8, 9 or 10 (the most deprived areas)	hearing loss thought by the clinician to have been present at birth

Table 11: Early and late average ages of identification (2010-2022)

It is worth noting that Aotearoa New Zealand had, historically, a very high average age of identification when compared with similar jurisdictions prior to the implementation of universal newborn hearing screening nationwide.

Coverage rates for the B4SC had been thought to be high in previous official data, though revised figures show the proportion of children not checked is significant and has risen to 18% in 2021-2022. [See the section on the B4 School Check, which begins on page 47, for further information.]

Age at diagnosis and severity of hearing loss

Table 12 shows the average age at diagnosis (identification of hearing loss) for children and young people with bilateral hearing loss in each of the American Speech-Language-Hearing Association (ASHA) severity categories. As expected, mild and moderate hearing losses are identified later than more severe losses.

Degree of hearing loss (ASHA, Clark, classification system)	Average months at diagnosis (2010-2022)
mild	61
moderate	34
moderately severe	31
severe	20
profound	9

Table 12: Average age at diagnosis, in months, for *bilateral* hearing losses by degree (ASHA codeframe) using interpolated data with manual checks (2010-2022)[i]

Children under the age of four are more likely to be missing some severity data[ii], meaning some cases could not be classified for Table 12. This may be the reason why reductions in average age of diagnosis are not as clear in these data.

The greatest variability in the age at diagnosis is for mild and moderate hearing losses, understandable given that these losses can be difficult to identify regardless, and as not all mild hearing losses present at birth are detected because of newborn hearing screening. The notification form does not include information about the proportion of losses that are thought to be progressive in nature.

Age at diagnosis and ethnicity

Table 13 shows the median and average at identification (2010-2022, 2022) for each ethnic group[iii], for all children and young people notified where ethnicity information was included on the form.

Please note that differences in the characteristics of hearing losses among each ethnic group, such as degree of loss and the proportion of cases present at birth, influence these figures, meaning they are not a direct reflection of how systems are performing for each group.

Several of the previous DND reports (1995-2005) noted that Māori and/or Pāsifika children were identified later than European children, although this difference was not reported in every one of these reports[iv].

Children and young people in all ethnic groups show improvements in average age at diagnosis when looking across the 2010-2022 period.

Median ages in months have tipped into considerably lower territory since 2020 due to the high numbers of newborn notifications. However, averages during 2022 rose for all ethnic groups. It is pleasing to see the this given the challenges clinics have faced during the pandemic. However, medians are less sensitive to outliers than averages, indicating a larger presence of extreme values in the 2022 data.

Pāsifika children

It is worth noting that before the introduction of nationwide universal newborn hearing screening Pāsifika tamariki were on average identified later than any of the large ethnic groupings.

On average in 2015 their average age at identification was 83 months and they had not experienced the falls in average age other groups had seen. However, it is pleasing to see their average age has now dropped to be one of the lowest or the lowest at 18 months in 2021 and 24 months in 2022. This is an enormous shift and will make a real difference to the lives of these children and their ‘aiga, as it enables early intervention, and/or monitoring to begin.

Pāsifika children have also seen pleasingly large reductions in median age at diagnosis during the most recent years. These reductions may in part be related to changing characteristics within the cohorts identified over time, or they may reflect better system performance for this group.

i Some 2011 and 2012 figures contained in this table differ from those reported previously, owing to small differences in the way these data are calculated, and also small reductions in the number of notifications included in the Database since the original dataset was provided.

ii A number of factors may influence this pattern, including that babies can wake during testing and that younger tamariki can be difficult to test.

iii When viewing data on ethnicity, please keep in mind that Table 13 is based on multi-code data, hence several cases are in two or more ethnicity groups at one time.

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

Ethnic Groups	Median months at diagnosis (2010-2022)	Median months at diagnosis (2022)	Average months at diagnosis (2022)
European	39	3	36
Māori	41	3	34
Pacific Peoples	44	3	24
Asian	3	2	22
MELAA	30	94	94[i]
All groups	38	3	33

Table 13: Average and median months at diagnosis by ethnicity (2010-2022 and 2022)

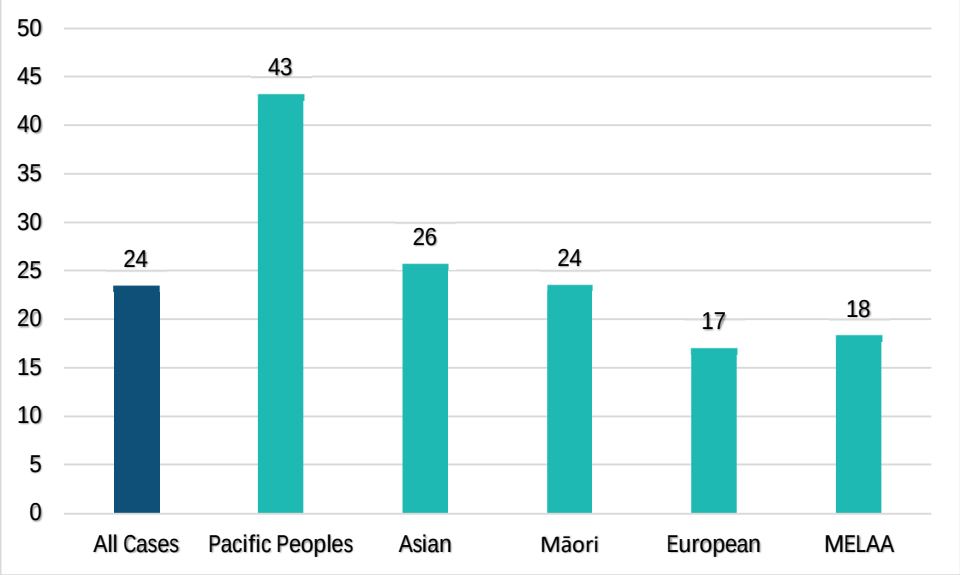

Figure 9: Average reduction in age at diagnosis between 2010-2016 and 2017-2022, by ethnicity (months)

Māori tamariki

Māori tamariki and rangatahi were identified at an average age of 47 months over the full period, the same as their European counterparts.

Māori children and young people have a higher proportion of mild hearing losses, which can often be diagnosed later than their counterparts with hearing losses of greater severity. With this in mind, it's perhaps not surprising they have their hearing losses identified later than some other groups, though this doesn't indicate that systems are working well for Māori whānau.

However, it is not quite that simple, as Māori are also more likely to have bilateral hearing losses (which are on average identified earlier than unilateral losses). These types of hearing losses are on average identified earlier than those that are of greater severity as seen in the DND reports and in Digby *et al.* (2014)[114].

These opposing effects make it difficult to understand how the system is performing to detect hearing losses early among Māori tamariki and rangatahi. It is worth noting that the proportion of cases reported as Māori in the Database has grown since 2010. This could be an indication of some improvement in accurate coding of ethnicity, or of improvements in the health system's ability to reduce inequalities for Māori, although we have no evidence to support these suggestions.

Asian tamariki

When examining the average age at identification over time, children and young people in this ethnic group seem to benefit quickly from the implementation of newborn hearing screening

i Note this group is very small, containing two children and young people who are identified as MELAA.

when compared with others. It is also worth noting that the median age at diagnosis for Asian tamariki across the full period (2010-2022) is the lowest of all ethnic groups, at three months. However, figures do fluctuate from year to year and 2022 saw a rise in average age at diagnosis for this group, to 32 months.

MELAA tamariki

MELAA children and young people have a high average age at identification over the years, at 54 months. It is worth keeping in mind that this group is historically very small, so large variations exist in the averages for this group over time.

Newborn hearing screening

The target condition for the Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP) includes 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[115, i, ii].

See the 2021 DND report on the goals of the screening programme and *Appendix G: Key screening goals and history* on page 78 for more information.

Screening status

Table 14 shows the screening status of New Zealand-born children notified to the Database (and therefore diagnosed) in the period 2010 to 2022.

As expected, the proportion of children being diagnosed as a direct result of referral from the UNHSEIP has grown, and the proportion of children notified who were not offered screening is (generally) falling.

As Was universal newborn hearing screening (using aABR or aOAE) offered to this family after this child or young person's birth?		2010	2016	2019	2020	2021	2022
No	No, a screening programme was not in place, but the child was directly referred to audiology due to atresia	3%	4%	0%	1%	2%	1%
	No, this service was not available at the time	67%	12%	7%	4%	1%	3%
Unsure	Unsure whether screening was offered to this family	7%	3%	6%	5%	2%	3%
Yes	Yes, a screening programme was in place, but the child was directly referred to audiology due to atresia	0%	5%	3%	5%	3%	1%
	Yes, screening was offered but this child was not screened	1%	3%	2%	2%	2%	0%
	Yes, the child was screened and referred but follow-up did not occur at the time, and so this is a delayed diagnosis	1%	5%	3%	4%	4%	1%
	Yes, this child was screened and passed	1%	16%	19%	15%	13%	19%
	Yes, this child was screened and referred but passed the resulting diagnostic test*	0%	1%	5%	2%	2%	2%
	Yes, this diagnosis is a result of a referral from screening	18%	52%	52%	60%	69%	70%
Other	Other	0%	0%	0%	0%	1%	1%
	No data	1%	1%	1%	2%	1%	0%

Table 14: Screening status of children born in Aotearoa New Zealand and diagnosed during selected years[iii]

i The target permanent congenital hearing loss includes conductive impairment associated with structural anomalies of the ear but does NOT include temporary impairment attributable to non-structural middle ear conditions.

ii This is a common threshold 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 Please note that some figures in this table have been rounded and so not all sum to 100%. These figures are slightly different from those reported in previous years, due to small numbers of retrospective notifications, a small change in the codeframe this year to include a small number of cases which don't fit the codeframe and the inclusion of the proportion of cases which didn't contain data for this question.

Please note that this table includes screening status for those diagnosed at varying ages because there are some rangatahi in each year who were not screened as newborns because no UNHSEIP service was available in their area at the time of their birth.

UNHSEIP monitoring data

No officially published UNHSEIP annual monitoring reports were available for the years 2015 to 2022, though summary level reports were produced for the 2016 and 2017 years.

Since the 2017 UNHSEIP Summary Report, there have been significant improvements in the mechanism for collecting newborn hearing screening data and now all screening data are submitted electronically from three different sources[i]. This means data is now available and a 2020 annual report has been released, meaning it is possible to see how this important programme was performing within that year.

Unfortunately, as we are missing programme data from 2017 to 2019 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 (2020-2022 years) within these data.

The most recent Ministry of Health | Manatū Hauora monitoring report[116] relates to babies under 3 months of age that were eligible for and commenced screening between 1 January 2020 and 31 December 2020. This was during the first year of the COVID-19 pandemic and timeliness in delivering the UNHSEIP was impacted by COVID-19 and associated lockdowns.

Key points for the 2020 year include:

- Approximately 84.5% of babies had this screening by the target of one month (corrected age), with one month screening completion rates for DHBs ranged from 67% to 93%;
- 94.2% of babies born during 2020 completed screening within the period, below the ≥ 97 percent target;
- of those babies who completed screening, 1.4% were referred to audiology;
- 82.1% of the 786 babies referred to audiology had audiology assessment data reported to NSU by the date of data extraction for the report, this is below the 90% target, though six DHBs 97% or greater coverage;
- 65.4% of babies referred had their assessment completed by the target time of three months of age, which is below the target of 90%;
- screening coverage by one month of age was lower for Māori and Pāsifika babies, as were assessment completion rates;
- an additional 10.6% (n=83) were categorised as either DNA, lost contact or declined, 49 of these tamariki were Māori;
- 134 babies in total were identified with permanent hearing loss during the period;
- Pāsifika babies who received their audiological assessment were most likely to receive a diagnosis of permanent hearing loss detection at 4.9 per thousand, followed by Māori at 3.3 per thousand and Asian babies at 2.8 per thousand. Other category babies (including NZ European and MELAA) had the lowest rates of diagnosis at 1.3 per thousand;
- given that Māori and Pāsifika babies are less likely to be screened, more likely to have a hearing loss and less likely to complete audiological assessments than other groups, the true prevalence of hearing loss in these groups may be higher than reported;
- nationally, 74 percent of eligible whānau were contacted by Early Intervention education services within 10 working days. While the standard was not met, 74% is a 7% increase from 2018;
- 97% of referrals to early intervention services began receiving services by six months of age, higher than the 90% target. [At this time, we have no data to help us understand ongoing access rates.]

i A UNHSEIP data warehouse has been developed to combine data from the different sources to enable accurate national monitoring reporting – effectively providing a national IT solution for recording, managing and sharing information.

Most of these metrics are similar or somewhat better when compared to the 2017 data though the proportion of cases categorised as either DNA, lost contact or declined has risen from 7.4% to 10.6%. Rates of hearing loss detected by the programme by ethnic group are considerably higher for Māori and Pāsifika babies than reported in 2016.

The rates of identification by ethnic group for 2020 are quite different to those reported previously.

Considering the challenges posed by the first year of the COVID-19 pandemic, the overall results may be seen in a positive light. However, our UNHSEIP 2020 coverage rates, for example, compared poorly with those from our Australian neighbours during the first year of the pandemic. Queensland's Healthy Hearing Programme for example screened 98% of newborns in 2020 and 2021[117].

There is particular concern relating to progress for Māori and Pāsifika babies throughout the screening, diagnostic and intervention pathway, as these groups they are more likely to have a hearing loss, less likely to be screened, less likely to have their audiological assessment complete than their peers. Loss to follow-up is a significant issue for newborn hearing screening programmes internationally.

Birth prevalence

The implementation of newborn hearing screening has generally provided Aotearoa New Zealand with much needed local data to help us understand birth prevalence of the types of hearing losses that are the target of this screening. It is a great pity that annual published programme data has not been consistently available for this national screening programme.

This UNHSEIP data to 2017 demonstrated that our rates of hearing loss at birth are somewhat higher than those reported in similar jurisdictions overseas[i], at around 1.2 cases of bilateral hearing loss per thousand babies screened, plus an additional 0.8 per thousand cases for unilateral hearing loss per thousand babies[59]. The 2020 UNSHEIP data suggests even higher rates of bilateral hearing loss (1.5 cases per thousand), with unilateral hearing losses at 0.9 cases per thousand. Considerable variability is reported by Te Whatu Ora district.

DND data

During 2022, a total of 106 of notifications were for babies born in Aotearoa New Zealand who were diagnosed as a direct result of newborn hearing screening. This has risen considerably from the 28 identified in this way during 2010, while newborn hearing screening was still being rolled out around the motu.

Our UNHSEIP's 1-3-6 goals are:

- 1 - ≥ 95 percent of babies to be screened by one month of age;
- 3 - ≥ 90 percent of audiology assessments to be completed by three months of age;
- 6 - initiation of appropriate medical, audiological, and early intervention education services by six months of age.

Measuring the proportion of tamariki with hearing losses identified before the benchmark of three months of age, as a result of a referral from newborn hearing screening, continues to be an important measure of the success of the New Zealand newborn hearing screening programme. The DND reports provide data to show how the overall age at identification has changed over time.

There has been a pleasing overall reduction in the average age at diagnosis for cases referred from newborn hearing screening in Aotearoa New Zealand (therefore born in Aotearoa New Zealand), from fourteen months in 2010, to three months in 2022.

Of the 106 cases within the DND notified in 2022 that were identified as a direct result of newborn hearing screening in Aotearoa New Zealand, 67% were diagnosed by the internationally

i Overseas, a number of comparable newborn hearing screening programmes (such as those in the United Kingdom and Australia) seem to be converging at a birth prevalence of approximately 1.0 to 1.1 per thousand babies for bilateral hearing losses, and approximately an additional 0.5 per thousand unilateral hearing losses. Using these overseas rates and including unilateral hearing losses, we might expect approximately 95 diagnoses directly from the newborn screening programme each year, based on an average figure of 59,803 births per year in the period 2010-2017. Because overall population prevalence in Aotearoa New Zealand is not known for the types of permanent hearing loss included in the Database, we previously used these rates as a guide to the number of cases that may be found in Aotearoa New Zealand when the UNHSEIP achieves high coverage and low loss to follow-up in all regions.

recommended age of three months[i]. This is the highest proportion reported to date with the previous highest figure being 74% in 2021.

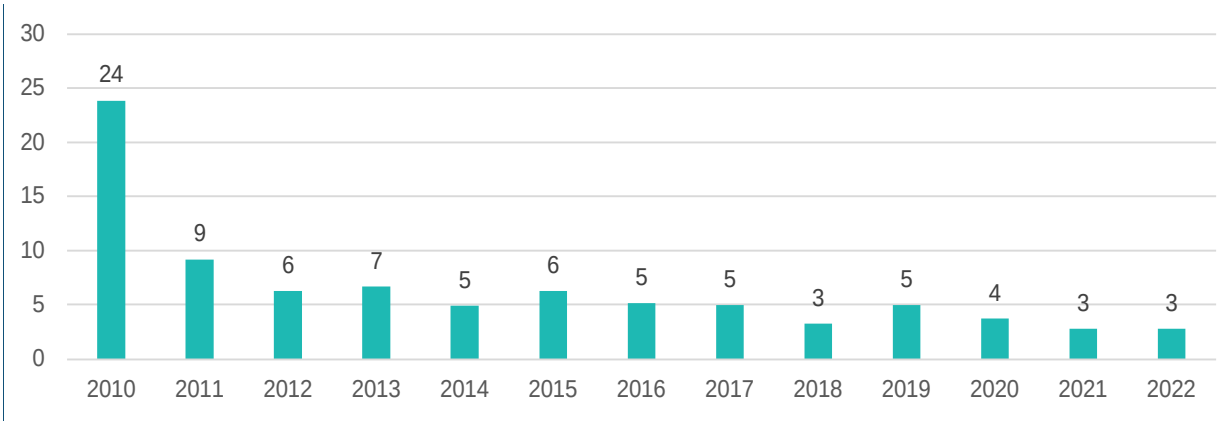

Figure 10: Average age at diagnosis for children referred from and diagnosed as a direct result of the newborn hearing screening programme (2010-2022)

Identification of false negatives

The DND provides the only method for identifying potential false negatives from the newborn hearing screening programme[118, ii].

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

In 2022, two 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 and because of the thresholds for screening. Both those cases contained further detail on the notification form, indicating suspected prelingual hearing loss not identified as a result of their newborn hearing screen:

- "Passed screening. Loss was found by Before School check. Child had previously passed hearing screening with Vision Hearing Technician in 2018 and 2019. Speech pronunciation would suggest to me that this loss has been present pre-lingually. Possible that previous screening no[t] accurate (behavioural assessment) - good case for implementation of objective screening at 4 years such as DPOAEs. Uncertain of place of birth re if aABR or DPOAEs/ newborn hearing screening completed – will follow this up."
- "Child with mild SNHL, likely to have been present at birth, and passed newborn aABR given mild degree. Significant paternal fHx hearing loss. Refer from B4SC hearing screen, but parental concern prior to this. Connexin 26 and 30 testing negative, but likely unknown (to date) hereditary/ genetic cause."

This is not to say that one or more babies diagnosed in 2022 were not incorrectly passed at their newborn hearing screening, just that none notified to the Database were recorded as such.

Twenty-nine of the tamariki who were born in New Zealand and identified with hearing loss during 2022 had been screened previously as part of the UNSHEIP and passed this screening. This

i We are using a more accurate method for calculating this figure now, based on all records where a specific date of diagnosis is provided. As a result, it isn't directly comparable to previous figures. Using the previous method, this year's proportion of cases diagnosed by three months would have been 75%.

ii In 2012, there was a Ministry of Health initiated recall of 3,422 babies, 2,064 of whom had potentially been incorrectly screened; 901 of these tamariki had been rescreened by 28 November, 2012.

figure is not necessarily a concern, as many tamariki develop hearing losses after their initial diagnosis, and as over time more tamariki are being screened.

Of those 23 cases, it is possible to remove two groups to help us narrow the focus on the most likely potential false negatives; this has been done in Table 15.

The first of these groups have known acquired hearing loss, while the second is those with hearing losses where the diagnosing clinician believed this was not present at birth[i]. (Some professionals have posited that it is possible Aotearoa New Zealand has a greater prevalence of progressive hearing losses because of our high rates of CMV.)

Of the four 16 cases identified as *potential* false negatives in Table 15, the age of identification for these tamariki ranged from three, to almost twelve years of age.

	2010	2014	2018	2020	2021	2022
Total cases identified by year who were screened previously (i.e., are not currently referrals from the UNHSEIP) and who passed this screening	2	20	32	24	24	29
Group most likely to contain false positives[ii]	2	10	19	11	8	16

Table 15: Potential false negatives and cases previously referred from hearing screening, selected years, tamariki born in Aotearoa New Zealand only.

B4 School Check

Background

The B4 School Check is a nationwide programme offering a free health and development check for four-year-olds. 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 Well Child Tamariki Ora Schedule. Screening audiometry and tympanometry (if required) are administered by Vision Hearing Technicians around the country.

What we know about the programme

There is no national reporting that helps us understand the efficacy of hearing screening done as part of the B4 School Check. As a result, key information is unknown[125], including the proportion of children who:

- are referred from the hearing screening who go on to receive diagnostic assessment,
- complete this assessment as a result of this screening including those diagnosed,
- begin intervention,
- benefit from this screening in terms of improved outcomes.

Unequal screening coverage between groups suggests it is likely that groups under-served by our health services (such as Māori and Pāsifika) are not benefiting equally from this screening programme when compared with New Zealand Europeans. Without any basic measures of programme efficacy, it is not possible to confirm the degree of inequity or its causes.

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

ii Number of cases from regional screening programmes, or from the UNHSEIP, that passed screening, which were not thought to be acquired loss, and where the notifying professional answered 'yes' or 'unsure' to the question about whether the loss was thought to have been present at birth and who were born in Aotearoa New Zealand

B4 School Check data

Outcome	Description	2010/11	2014/15	2018/19	2020/21	2021/22
Pass Bilaterally	The child was screened and passed.	71%	76%	74%	74%	71%
Referred	The child was screened and referred to a relevant service.	6%	5%	5%	3%	4%
Rescreen	The child was unable to complete the screen, so a rescreen has been booked, normally in around 6 months.	9%	5%	5%	5%	5%
Under care	The child is already under the care of a relevant service.	1%	3%	3%	2%	2%
Decline	The hearing check was declined by the caregiver.	5%	1%	1%	1%	1%
Not Checked[i]	The child did not receive a hearing check.	9%	9%	12%	15%	18%
Population	**Derived from the B4SC Database**	**52,681**	**65,651**	**66,675**	**66,705**	**66,922**

Table 16: B4 School Check Hearing Screening data (tamariki screened in selected years)[ii, 119]

B4 School Check hearing screening data for selected cohorts from selected years are shown in Table 16 (see previous reports for previous data). Please note that these data include children having their fifth birthday during the 2010/2011 – 2021/2022 financial years[iii]. See the 2021 report for further details on the changes to how these figures are calculated by Manatū Hauora.

The data source used by the Ministry of Health has shifted to include more children in the denominator and so these data are not comparable with previously reported data contained in DND reports[iv]. While true figures previously reported may have understated the number of children not screened, it is worrying that these figures show a doubling in the number of children 'not checked' since 2014-15. Having more accurate data through using the revised denominator for coverage calculations is helpful to inform efforts to reduce inequalities in access to B4 School Check screenings.

For the second time, below is multi-coded ethnicity data provided by the Ministry of Health. This aligns to how we describe ethnicity for children and young people within our own database.

i The number not checked is calculated by finding the difference between the total count of children turning 5 in the financial year and those with hearing outcomes.

ii Note that column figures don't always sum to 100% due to rounding.

iii These figures exclude children who, sadly, have a date of death against their record.

iv The data source now used is the Before School Check Database and includes records of children having their 5th birthday during the equivalent financial years. The Ministry of Health reports this is a change from previous reports (prior to 2019/20) so as to align the numerator and denominator better using the same date of birth range as well using the same data source for both the numerator and denominator. Previous reports used the PHO enrolled population, which has the limitation of excluding children who are unenrolled. The B4SC database is a national information system for capturing and storing information about children receiving their B4SC. The B4SC database receives input from the National Enrolment Service (NES) of children between 0 and 7 years of age. While the B4SC database could potentially miss children not enrolled with a PHO, it also contains records of some families who come into contact with the B4SC Program directly, e.g. via Early Childhood Education Centres (ECEs). The aim of using the B4SC database is to provide a more comprehensive dataset as a single source for both the numerator and denominator for a more accurate representation of hearing outcomes by ethnicity including the estimate of those not checked. The Ministry also notes that the "B4SC data used combines the records of children who have been assigned to a provider and those not yet assigned. However, unassigned data were only available from 2017 onwards. Hence, the number not checked prior to 2017 may be slightly underestimated and the pass rate may be overestimated." Also, the dataset could potentially include children who have moved overseas, as there is currently no systematic way of excluding these records.

Outcome	Description	*All cases*	Māori	Pacific Peoples	Asian	MELAA	NZ European
Pass Bilaterally	The child was screened and passed	***70.7%***	63.8%	60.1%	70.8%	68.5%	76.5%
Referred	The child was screened and referred to a relevant service	***3.6%***	4.3%	5.6%	3.0%	3.1%	3.0%
Rescreen	The child was unable to complete the screen, so a rescreen has been booked, normally in around 6 months	***5.2%***	7.1%	8.0%	4.7%	4.5%	3.9%
Under care	The child is already under the care of a relevant service	***2.4%***	2.9%	2.9%	2.1%	2.5%	2.2%
Decline	The hearing check was declined by the caregiver	***0.5%***	1.0%	0.5%	0.2%	0.3%	0.4%
Not Checked	The child did not receive a hearing check	***17.6%***	20.9%	22.8%	19.2%	21.1%	14.0%

Table 17: B4 School Check Hearing Screening data by ethnicity (2021-2022)[i, ii, 119]

Insights

Programme coverage

The proportion of tamariki overall who were listed as 'not checked':

- has increased in recent years (see Table 16) regardless of the denominator used (see previous DND reports for figures using the enrolled PHO population as the denominator); and
- is considerably higher among *non*-New Zealand European groups, particularly children recorded as Māori or Pacific (See Table 17).

In the last two years, the number of tamariki in this 'not checked' group has increased further, with re-analysed data with improved denominators showing 'not checked' figures were likely to be (on average) around 15% in 2021 rather than the 5% previously reported. This upward trend in the proportion of children not checked was evident even before the pandemic created additional and significant coverage challenges.

There is a 'mop-up', to catch any children and young people who didn't complete the B4SC before they reached school. Anecdotally, this may not have been consistently applied around the motu. 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 the ENROL (Education) Database, meaning it is not always easy to identify children who haven't had their check, so this can be addressed.

Other metrics

Referral and rescreen rates for Māori and Pacific tamariki are also higher than those for children listed as New Zealand European, Asian or MELAA.

For example, the new data from Ministry of Health shows the overall referral rate for tamariki completing the hearing screening completed as part of the B4 School Check is 3.6% (2021/2022). As with previous years, Māori and Pacific tamariki have higher referral rates (4.3% and 5.6%), with New Zealand European, Asian and MELAA tamariki having lower rates than the average (3.0%, 3.0% and 3.0%).

Children listed as New Zealand European, Asian or MELAA are almost half as likely to be booked for a re-screen (3.9-4.7%) when compared with those listed as Māori and Pacific (7.1% and 8%).

i An 'other' ethnicity category is included in the B4SC data provided by the Ministry of Health. As this is a very small group (n=642) we haven't included it in this table. The children in this category are listed as 'not checked' in 21.3% of cases.

ii Note that column figures don't always sum to 100% due to rounding.

Screening timing and effectiveness

In Aotearoa New Zealand, newborn hearing screening and the B4 School Check act as objective measures to identify some types of hearing loss and are part of the Tamariki Ora Well Child surveillance.

There is a growing body of evidence suggesting Māori and Pāsifika children would benefit particularly from improvements to national screening programmes. A focus on reducing disparities, consideration of additional screening in childhood to identify chronic middle ear disease and as yet unidentified permanent hearing loss and to consider the value of identifying auditory processing difficulties, could be valuable:

- Paterson *et al.'s* (2006) Pacific Island Families analysis found very high prevalence of chronic middle ear disease among 1,001 two-year-olds screened in Auckland. Serious cases of chronic middle ear disease can cause permanent hearing loss). Twenty five percent of these children were affected by OME, and the paper concluded that that consideration of national screening for this condition and other ontological disorders was warranted[120].
- Leversha *et al.'s* (2017) Welcome to School study focused on the health and development of students starting school in Tāmaki (an area in Auckland) in which 90% of the tamariki are Māori and/or Pāsifika. It found that although 75% of children had developmental delays and 64% had below average language skills, very few parents reported concerns about their child's development at the B4 School Check or school entry. This suggests that the B4 School Check Parental Evaluation of Developmental Status (PEDS) questions may not work well for all Aotearoa New Zealand children and the authors indicate it is therefore inappropriate in the Aotearoa New Zealand context[121].
- Burge's 2018 related thesis suggested that in some areas there was likely to be a considerable number of children not enrolled with a PHO who were not included in the reported figures, and this conclusion has now been confirmed[122, i].
- Dickinson *et al.'s* 2018 study on 485 South Auckland children aged two to three years of age, who attended a screening recall due to a problem with their newborn hearing screen, found Māori and Pāsifika ethnicity was significantly associated with hearing loss[123]. The authors concluded that "there is a high proportion of children in South Auckland with unsuspected hearing loss" and that "a different approach to screening is warranted for this population with high rates or middle ear disease at age 3".
- A recent paper by Gibb *et al*. (2019), published in the *British Medical Journal,* examined the hearing and ear status of 920 Pāsifika children aged 11 years living in Aotearoa New Zealand as part of the Pacific Island Families Study. This found a high prevalence of hearing loss, abnormal tympanograms and processing difficulties, and that Māori and Pāsifika children were less likely to complete the checks than non-Māori and non- Pāsifika children, along with other disadvantaged groups, such as those living in socio-economic deprivation, tamariki with younger mothers, and those with worse health status[ii, 124].

These findings have implications for Māori and Pāsifika whānau whose tamariki have a hearing loss. There are signs that current screening protocols/instruments may exacerbate rather than narrow pre-existing inequalities for these groups of children (for example, due to thresholds set for referral). In addition, systems and practices that are Euro-centric and create inequities may

i In addition, some children who were not enrolled with a PHO were screened, making it difficult previously to understand the overall coverage rate for the hearing screening completed within this Check.

ii The authors note that the 'patterns of non-participation suggest a reinforcing of existing disparities, whereby the children most in need are not getting the services they potentially require', and the authors suggest increased efforts to ensure all children are screened.

Please note that the data used for that paper were from 2014/15. The proportion of eligible children who were listed as 'not checked', 'decline' or 'under care' by the B4 School Check at that time was 10%, the same as in 2018-19.

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.

Given this understanding, it is therefore disappointing that Pāsifika and Māori, yet again, continue to experience lower rates of hearing screening within both the B4 School Check and the UNHSEIP programme, as shown in Table 17 and in the previous section.

A 2019 Better Start evidence review of Well Child Tamariki Ora hearing screening after the newborn stage (2019), found a lack of prevalence or efficacy data for the B4 School Check[125]. It recommended further investigations of OME screening for at-risk populations and careful consideration of thresholds for screening for groups like Māori who have higher prevalence of mild sensorineural hearing loss. It also suggested that school screening could be considered for Tauira in Year 3 and Year 5.

Su *et al*.'s 2020 examination of the feasibility of a hearing screening programme using otoscopy, distortion product otoacoustic emission screening (DPOAEs) and tympanometry, was conducted in an area of high economic deprivation in Auckland. This study found hearing screening in early childhood centres for three years olds was feasible, but that more work is needed to ensure efficient and effective community-based follow-up of screening referrals[126].

This was followed by a report from the Growth, Development and Screening Technical Advisory Group (and its Childhood Hearing Screening Technical Advisory Group) regarding the Well Child Tamariki Ora National Schedule[127]. It considered evidence from the Better Start Evidence review above and included recommendations that all hearing screening activities be transferred to the National Screening Unit. It also suggested strengthening Well Child Tamariki Ora engagement with two- to three-year-olds and retaining pure tone audiometry in four-year-olds with secondary use of DPOAE and tympanometry.

In 2011, the American Academy of Audiology (AAA) recommended preschool screening frequency as per our Well Child Tamariki Ora schedule in New Zealand, *plus* screening at ages 5, 6, 7, 10 and 12 or 14-year-olds at a minimum[128].

Organising for change

Perceived and ongoing failures of our nationwide screening programmes, particularly for Māori and Pāsifika children, have resulted in independent organising by groups of concerned individuals. A collective including Painga Project, clinicians from the University of Auckland's Audiology Department, The Hearing House, Ko Taku Reo and Quota Papakura, have begun a vision and hearing pilot programme to help bridge the gap for several South Auckland schools, and they intend to expand within the Counties Manukau District. Children with various stages of otitis media, as well as some with newly diagnosed permanent hearing loss, have been identified and followed up with evaluations as needed; rates of undiagnosed hearing issues have been concerning.

Delays in Diagnosis

Ngā takaroa ki te whakatau māuiui

- **Delays in diagnosing hearing loss among children and young people are a known contributor to poorer outcomes for children and young people. Such delays can be reduced by hearing professionals, researchers, advocates and decision-makers in several ways.**
- **The average delay between first suspicion of a child or young person's hearing loss and its confirmation is now six months. This is undoubtedly, in large part, due to nationwide implementation of the newborn hearing screening programme. However, even this much improved average delay remains too long, and some children and young people are waiting months or even years between when their hearing loss is first suspected and when it is diagnosed, and intervention can begin.**
- **Across 2010-2022:**
    - **Children and young people born overseas, those with mild to moderately severe bilateral or unilateral hearing losses, hearing losses not thought to have been present at birth and those living in the most deprived areas are among those groups more likely to experience diagnostic delays.**
    - **'Audiologists having difficulty getting a confirmed diagnosis' was the most commonly mentioned reason for delays in diagnoses across 2010-2022 and in 2022. Such delays can be the result of conductive overlay or the child being unwell.**

Background

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

One important variable influencing outcomes that hearing professionals can influence is how quickly the child's hearing loss is diagnosed; calls for earlier identification of babies with a hearing impairment have been made for nearly 80 years[129].

Early diagnosis seeks to maximise benefit during sensitive periods of neurological and linguistic development and limit children from falling behind their peers[130, 131, 132, 133, 134].

There are several ways to limit such delays, including early and regular screening of children and young people for hearing loss. This screening in Aotearoa New Zealand includes the UNHSEIP, which aims to identify hearing loss in the newborn period, and the B4 School Check, which aims to identify hearing losses among four-year-olds, before they reach school. These types of programmes aim to reduce the age at which interventions can begin.

Newborn hearing screening programmes commonly use the 1-3-6 goals, which aim for 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, to target these reductions.

This type of approach has proven overall to be successful overseas and in New Zealand at reducing diagnostic delays. While not all children notified to the database are born with hearing

loss, the overall average age at diagnosis for all New Zealand born children with bilateral hearing loss was 45 months in 2004 (prior to implementation of a national programme for screening newborns), and fell to an average of 27 months in 2022[i].

Additional efforts are needed to further limit diagnostic, and therefore interventional delays, to further improve outcomes for tamariki and their whānau.

There are several types of changes that can be the focus of work to reduce diagnostic delay within hearing services:

- service culture, resourcing, and employment;
- individual and workforce clinical practice;
- systems, policies and processes, including IT infrastructure;
- education of the public and other groups about hearing loss and when to seek help.

Change requires a sustained and collaborative effort. Some of the required change will come from hearing services acknowledging their "responsibility for differential quality of care, including between Māori and non-Māori, reducing a culture of blaming Māori for the state of their health and acknowledging Pākehā privilege within health services" [135].

McLean *et al.* (2014) examined qualitative and quantitative evidence on use of reminders and notifications in healthcare settings in the UK, resulting in the development of six themes influencing patient attendance[136]. This study found that the reminder plus approach was promising, though it had had weak but consistent evidence to support its use. Keep in mind that this research is not very recent, and technology and the effectiveness of strategies may or may not be relevant in Aotearoa New Zealand.

A paper from Kingsbury *et al.* (2022) found major barriers to paediatric hearing health care, and that public health information and communication between families and professionals can ameliorate the role of socio-economic status on hearing health disparities. Where a newborn refers on newborn hearing screening, education about the importance of follow-up is critical to reducing loss to follow up. Other potential strategies for overcoming barriers to access are discussed[137]. It notes: 'The possible strategies presented in this article are responses to a root cause but do not directly address the root cause itself. These strategies are merely band-aids in response to wounds created by the larger scale inequality… .'

Please see the 2021 report for its table titled *Approaches to reduce diagnostic and interventional delays and reduce inequalities for tamariki with hearing loss*, for various approaches to reducing diagnostic delays.

Presence and length of delays

Presence of delays

Overall, 42% of all notifications contained one or more reasons for a diagnostic delay. This figure was highest for those of Māori and MELAA ethnicity (51% and 50%), followed by Pacific Peoples (44%) and then European (29%) and Asian (31%) children and young people.

In 2022, 27% of all cases had one or more reasons for delay listed[ii]. This is a further drop on the number reported in 2018-2021 of 34-41%. The number of cases with no reasons listed for the delay has risen during recent years – this is not surprising given the reducing overall average age at identification and rising number of cases with no delay reported[iii].

Length of delay

Those notifying cases to the Database were asked to provide information about the length of delay

i These figures are not found elsewhere in the report as they represent only children born in Aotearoa New Zealand and diagnosed with a bilateral hearing loss, to approximate criteria for inclusion in the Database prior to 2005.

ii Seventy-four percent of those had one reason listed for the delay, and 26% had two or more reasons for the delay listed.

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

in identifying a child or young person's hearing loss.

The length of delay is calculated based on the date of diagnosis and the age of the child at the time the hearing loss was first suspected, which is given in years and months. In many cases, particularly with older children, there isn't a precise date for the child or young person's age at the time of first suspicion. As a result, calculated delay periods reported are in whole months, rather than days which are available for things like age at diagnosis[i].

Groups at increased risk of diagnostic delays include children and young people:

- who were born overseas;
- with a mild to moderately severe bilateral hearing loss;
- with a unilateral hearing loss and who the audiologist expects will receive a single hearing aid, e.g. due to asymmetry;
- with a hearing loss *not* thought to have been present at birth; and
- those who live in an area scoring 8, 9 or 10 on the deprivation index.

Average delays

The average delay in 2022, between first suspicion and confirmation of the child or young person's hearing loss, *including* those born overseas, and with mild, acquired, or unilateral hearing losses[ii], was six months. However, while average delays in the last five years are greatly improved on 2011's fifteen months[iii], this remains a significant average delay between first suspicion of a hearing loss and its confirmation.

Figures varied considerably between Te Whatu Ora districts, with a delay range of 0-31 months reported among children and young people diagnosed in 2022.

Year	Delay in months
2010	26
2011	15
2012	11
2013	12
2014	13
2015	11
2016	9
2017	9
2018	7
2019	10
2020	7
2021	6
2022	6

Table 18: Average delay in months by year, 2010-2022[iv]

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

Average delays for earlier years often showed Māori and or Pāsifika children experiencing the longest average delays to diagnosis. Since 2020, average delays for Māori and Pāsifika tamariki and rangatahi have been, on average, lower or about the same as those for New Zealand European children and young people, which is pleasing.

Interestingly, European children and young people experienced small rises in the average age at identification during 2021, though have again fallen in 2022 to six months.

i Exact date of diagnosis data was collected for every notified case from 2011.

ii 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.

iii 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.

iv Please note that some figures have changed slightly to those reported previously due to inclusion of retrospective notifications in the main dataset.

Ethnicity	European	Māori	Pacific	Asian	MELAA
Average (months, 2010-2022)	10	11	10	7	8
Average (months, 2022)	6	5	6	7	0

Table 19: Average months of delay by ethnic group (2010[i]-2022)

During some years, children and young people recorded as Asian had the lowest average months of delay when compared with those from other ethnic groups. These children were more likely to have delays of zero or one month than those from other ethnic groups.

However, this figure has risen since 2020 and is now the highest of all groups, at an average of seven months. This rising length of delay is a concern.

Keeping in mind that the 'Asian' group is far from homogenous, and these overall figures likely mask differences between subgroups. A number of variables could be influencing the length of delay:

- higher proportion of severe and profound hearing losses;
- lower likelihood of not attending appointments or having rescheduled these (for any reason) and to experience waits to see a hearing professional (see the next section for more information);
- higher likelihood of living in areas of the lowest deprivation (scores 1, 2 and 3 on the deprivation scale) and lower likelihood of living in areas of the greatest deprivation (8-10 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
- tendency to have mixed access to and through other parts of the health system[88], as demonstrated by their high rates of participation in other health promotion efforts, including COVID-19 vaccination[138] and their low rates of enrolments with GPs and for some screening services[87].

Causes of delay

2010-2022 cases

The notification form asks hearing professionals notifying cases for the reason(s) for the delay. Not all notification forms included one or more reasons for the delay listed, including some for which there was a length of delay recorded.

The analysis in Table 20 examines the reasons for delay where one or more reasons were listed and *where the delay was reported to be greater than one month*, measured from the time the hearing loss was first suspected until the time when the hearing loss was diagnosed[ii]. The pattern of the five most commonly mentioned reasons is the same whether data from 2020-2022 or the 2011-2022 years is considered[iii].

When delays in diagnosis are examined for 2010-2022, several patterns emerged:

- Māori and Pāsifika families and those living in areas of higher deprivation were considerably more likely than European or Asian groups not to attend appointments or to have delayed these for any reason;
- European and Māori families were more likely than other groups to have suspected something other than hearing loss, or to have had no concern about hearing mentioned, as a reason for delay;
- children and young people living in the least deprived areas (1, 2 and 3 on the scale) were significantly less likely to have 'Parents did not

i We have used 2011 data as the starting point for this series as during 2010 we weren't collecting specific dates of diagnosis, making delay calculations less accurate.

ii Delays for children and young people born overseas are included in this table.

iii It's only possible to include data from 2011 when a specific date of diagnosis began to be recorded.

attend appointments/delayed or rescheduled these (for any reason including distance, ill family member, cost, declined offer(s) of appointments)' as a reason for the delay; and

- in terms of reasons provided for delays, Māori were less likely than other groups to have no reasons listed for their delay.

Over time, the number of causes of delay noted on the forms as a proportion of the number of notifications has been declining from a high of one reason for delay mentioned for every 1.3 notifications during 2012 and 2013, to one reason for every 1.8 – 2.4 notifications during the 2018-2022 period.

Rank (most mentioned) 2020-2022	Reasons for delay
1st	Audiologist had difficulties getting a confirmed diagnosis (e.g. conductive overlay, child unwell)
2nd	Parents did not attend appointments/ delayed or rescheduled these (for any reason including service failed to engage family)
3rd	Waiting time to see hearing professional or accessing services in their area
4th	Parents/child/carers or educators (not health professionals) suspected something other than hearing loss or had no concern (e.g. speech delay, developmental delay, selective hearing, passed screening test)
5th	Child was born overseas/lived overseas and hearing loss was not diagnosed there or follow up not provided

Table 20: Most common reasons listed for diagnostic delay (2020-2022)

For the 2020-2022 period, those tamariki with the longest delays to diagnosis had the following reasons for delay listed:

- difficulty getting a referral to audiology (e.g. VHT referral not accepted by district, GP or other health professional dismissed parent concern and no referral was made) had an average delay of 50 months;
- 'being born overseas/lived overseas and hearing loss not identified there' had an average delay of 27 months;
- 'follow up lost in the system' had an average delay of 25 months.

Recent analyses of audiology data by the former Waikato DHB as part of their Equity Project were included in last year's report. Māori with bilateral moderate or greater hearing losses were diagnosed later than non-Māori. Factors contributing to delays among Māori were middle ear issues[i], delayed referrals from screening and, in one case, a DNA for an audiology appointment[139].

A recent paper in the *New Zealand Medical Journal* reminds us that not all efforts to increase attendance at appointments for audiology clinics are successful and that longer wait times are significantly associated with decreased attendance rates. It notes that non-attendance rates of 21-38% have been reported in audiology and ORL services in Aotearoa New Zealand[140]. The paper describes a retrospective audit at Counties Manukau and found that there were no differences in attendance rates between those who had participated in telephone consultation and those who had not.

"Pacific and Māori children were 68% and 64% less likely to attend appointments after adjusting for socio-economic deprivation level, waiting time and telephone consultation compared to NZ European children. Longer waiting times were significantly associated with decreased attendance rates."

The analysis found that attendance was found to be associated with ethnicity and waiting times, with those families waiting the longest time being less likely to attend, as the authors note had been previously reported. Telephone consultation did not improve attendance rates overall, nor for ethnicity subgroups.

The authors of this study noted that, while the catchment area for their clinic contains high proportions of Māori and Pāsifika whānau, these groups are generally not well represented in the audiology workforce. They suggest approaches to improve cultural safety could assist, as could

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 Pasifika cohort.

finding ways to introduce the clinician when making 'cold' calls to whānau.

Staffing and delays

Broader contextual issues such as availability of ear and hearing-care professionals influence delays in diagnosis as well as issues with intervention and follow-up.

Internationally there is a health workforce shortage, and a shortage of allied healthcare workers and hearing professionals[141]. There is also a growing concern that like many countries our aging population will require greater hearing care, exacerbating these shortages.

The initial emergence of COVID-19 was thought to have reduced recruitment challenges for the public sector, as the private sector, which traditionally has paid higher salaries, hired fewer staff. As the pandemic progressed, and the private sector began hiring again, some observers believe the number of audiologists moving into and remaining in the public sector declined and there has been a return to typical pre-pandemic vacancy levels, meaning there is more limited capacity to provide diagnostic, intervention and monitoring services to tamariki and rangatahi.

For the period covered by this report (2022), hearing care for children and young people in Aotearoa New Zealand was generally provided by the public health system, through district services, following the establishment of Te Whatu Ora. At times districts, particularly those outside the main centres, struggled to fill vacancies for audiologists. This resulted in long waiting times, which are thought to be associated with lower attendance levels[142].

Attendance rates

Thirteen children and young people had their diagnosis delayed because of non-attendance at appointments. COVID-19 has contributed to the number of whānau delaying non-urgent hearing care appointments in recent years, including because they could not or did not feel comfortable engaging through telehealth options[143].

Cases where the whānau or young person did not attend the appointment have typically been referred to as DNAs (Did Not Attend). More recently, it is 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". This puts the onus on the service to do what's needed so whānau/patients can attend appointments, to reduce delays in diagnosis and the start of intervention. This work also has implications for service efficiency.

> *"Nelson Marlborough Health general manager of Māori health and vulnerable populations Ditre Tamatea said it was time for the health sector to take responsibility for the attendance rates and change "did not attend" to "did not attract"."*[144]

As mentioned in previous reports, reducing rates of non-attendance has at times been an area of focus in some areas, not always in a sustained way, as resources, support and ongoing funding for continued efforts are not always prioritised. Significant improvements have however been achieved for periods of time as a result of increased focus on reducing DNA rates.

Successful processes have been implemented in Capital and Coast, which saw a drop of almost 50% in DNA rates for specialist appointments among Pāsifika patients over a five-year period, and Come Hear, in Taranaki, saw a reduction of 100%.

Common factors successful in reducing barriers to health service access include removing cost barriers, addressing transport and childcare issues[145], knowing the client population, personal engagement, a non-judgemental approach[146], strengthening cultural safety, and flexibility in service arrangements[147].

Marewa Glover from the Massey University School of Public Health said in 2017 that it *"cost money and time to go to appointments…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."*[148]

Māori and Pāsifika whānau have higher rates of non-attendance and are also more likely to live in areas of high deprivation than New Zealand European whānau.

It has also been suggested that higher rates of middle ear issues among Māori (and Pāsifika) children may require multiple appointments when

there is an underlying SNHL and that this can result in delays in diagnosis[149]. 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.

This year's cases

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 2022 of 1.6 months, an increase on 2021's 1.2 months, but a fall from 2020's 2.8 months.

"Audiologist had difficulties getting a confirmed diagnosis" was the most commonly mentioned cause of a delay in children's diagnoses for 2022, with 15 cases noted as being affected by this type of delay. (This reason for delay was also most commonly mentioned in 2019, the year immediately preceding the start of the pandemic.)

This was followed by "parents did not attend appointments/delayed or rescheduled these, for any reason" in 13 cases, and "Waiting time to see hearing professional or accessing services in their area", also with 11 diagnoses delayed for this reason.

Comments provided by audiologists shed further light on diagnostic delays and are included below.

Other causes

Audiologist had difficulties getting a confirmed diagnosis:

"ABR testing done on three occasions after left ear NBHS fail indicated bilateral middle ear issues but normal bone conduction thresholds in both ears. It is unclear at this stage as to whether or not Meli's hearing loss in the left is progressive. She has been referred to ORL about this today."

"Baby would not sleep well for ABR- required 2 appts."

"Delay due to snow 1st appt and did not sleep well for further appts."

"Pass level ABR but absent DPOAE's. Booked for f/u VRA at age 7 months."

"Otitis externa affecting reliability of results."

Parents did not attend appointments/delayed or rescheduled these, for any reason:

"Parents did not follow up and seek a hearing test as suggested by the Ear, Nose and Throat specialist."

"The family DNA'd their hearing screening follow up."

Waiting time to see a hearing professional featured in several comments:

"Babies prioritised in service, but severe staff shortages."

"Waiting time to see audiology was somewhat affected by COVID lockdowns."

"Difficulties for the audiologist in getting a diagnosis included two cases where three ABR sessions were required."

"Triaged as urgent, to be seen within 6 weeks. Patient not seen for 4 months - secondary to audiology service severely understaffed, affecting patient wait times."

Child or young person had other medical issue(s) which took precedent (e.g. feeding issues, medically fragile):

"Prem baby in NICU and on oxygen."

"Delay in diagnostic ABR as the baby was unwell and needed to be at NICU for an extended period of time. Very Prem – 24 weeker."

"Initial screen delayed until at corrected newborn age. Parents did not suspect hearing loss as baby observed to startle to loud sounds, settle with music and respond to siblings. She wore earmuffs in NICU as easily disturbed by noise. Variable responses noted but seem to be less now."

Difficulty getting a referral to audiology:

"Seen at the ENT Dept. Audiologist recommended follow-up but was Flynn was discharged from ENT due to resolving middle ear issues despite questionable hearing results."

"Under ENT management, conservative approach and only seen by Audiology via ENT clinic."

Parents/child/carers or educators (not health professionals) suspected something other than hearing loss or had no concern (e.g. speech delay,

developmental delay, selective hearing, passed screening test):

"Child mentioned hearing loss at age 5 but parents didn't think there was a problem because child appeared to be hearing well."

"Was referred to us in Feb 2018 post meningitis but assessment was not completed due to family's poor attendance. Was referred back to us in June 2022 and DNA'd 2x. Finally attended on 17.08.2022 when HT was done."

COVID-19 delays

In 2022, four cases where one or more reasons for a delayed diagnosis was provided specifically mentioned COVID-19. This related to delays due to children or families having COVID-19 or service delays due to lockdowns. This is fewer than the seven cases mentioning COVID-19 2021 and the nine mentioned for 2020 cases, but is perhaps surprising given that there were no lockdowns in 2022.

Comments provided elaborated on this cause, which delayed screening and diagnostic appointments:

"Covid lockdowns likely delayed diagnostic appointment, first appointment in November was rescheduled (unsure why)"

"Waiting time to see audiology was somewhat affected by COVID lockdowns. The family DNAed their hearing screening follow up."

"Baby got COVID."

"Mum reports that she started having concerns after the child had COVID in March."

Screening related delays

UNHS incident:

"Irregularities in NBHS - child passed NBHS and was offered rescreen due to incident however was not rescreened."

UNHS 2022:

"Hearing loss in right ear was unexpected as Alaia passed NBHS in her right ear.(hearing loss suspected to have been present at birth)."

"Reportedly passed NBHS & B4SC still acquiring records as child was born out of DHB."

"Family did not attend the screening follow up."

"Incomplete screening."

"Mum doesn't remember newborn hearing screening taking place."

"Known irregularities in NBHS - child was not rescreened."

"Irregularities in NBHS - child passed NBHS and was offered rescreen due to incident however was not rescreened."

"Reportedly passed NBHS & B4SC still acquiring records as child was born out of DHB."

UNHS under threshold:

"Child with mild SNHL, likely to have been present at birth, and passed newborn aABR given mild degree. Significant paternal [family history of] hearing loss. Refer from B4SC hearing screen, but parental concern prior to this. Connexin 26 and 30 testing negative, but likely unknown (to date) hereditary/genetic cause."

B4SC possible error:

"Child had previously passed hearing screening with Vision Hearing Technician in 2018 and 2019. Speech pronunciation would suggest to me that this loss has been present pre-lingually. Possible that previous screening no accurate (behavioural assessment) – good case for implementation of objective screening at 4 years such as DPOAEs. Uncertain of place of birth re if aABR or DPOAEs/ newborn hearing screening completed – will follow this up."

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.**
- **Many different frameworks categorise severity of hearing loss around the world. Here in Aotearoa New Zealand, the Clark (ASHA) framework is most commonly used by hearing professionals.**
- **Aotearoa New Zealand DND data show 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 we have examined. Several factors are likely to contribute to this, including the higher numbers of milder degrees of hearing loss found among Māori and Pāsifika children and young people.**
- **Asian and MELAA children and young people have the greatest proportion of severe and profound bilateral hearing losses when compared with other ethnic groups.**

Audiometric data

Audiometric data 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. In cases where the young age of the child meant the audiologist was unable to obtain audiometric data from pure tone audiometry, audiologists were asked to estimate thresholds from the ABR using correction factors from the National Screening Unit's (NSU) policy and quality standards[i, ii].

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 and less likely to be reported for 4.0 kHz and 1.0 kHz frequencies[iii].

As shown in Figure 11 below, the proportion of cases for which the thresholds were determined through ABR has been rising, from 21% in 2010 to 66% in 2022, with a high of 75% in 2021. This change is due to reducing numbers of tamariki being old enough to have their hearing assessed behaviourally, a result of the UNHSEIP.

i Correction factors: 5, 5, 0, and -5 dB for 0.5, 1.0, 2.0 and 4.0 kHz respectively as contained in 2016's Diagnostic and amplification protocols, which can be found on the National Screening Unit website and which used to be referred to as Appendix F.

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.

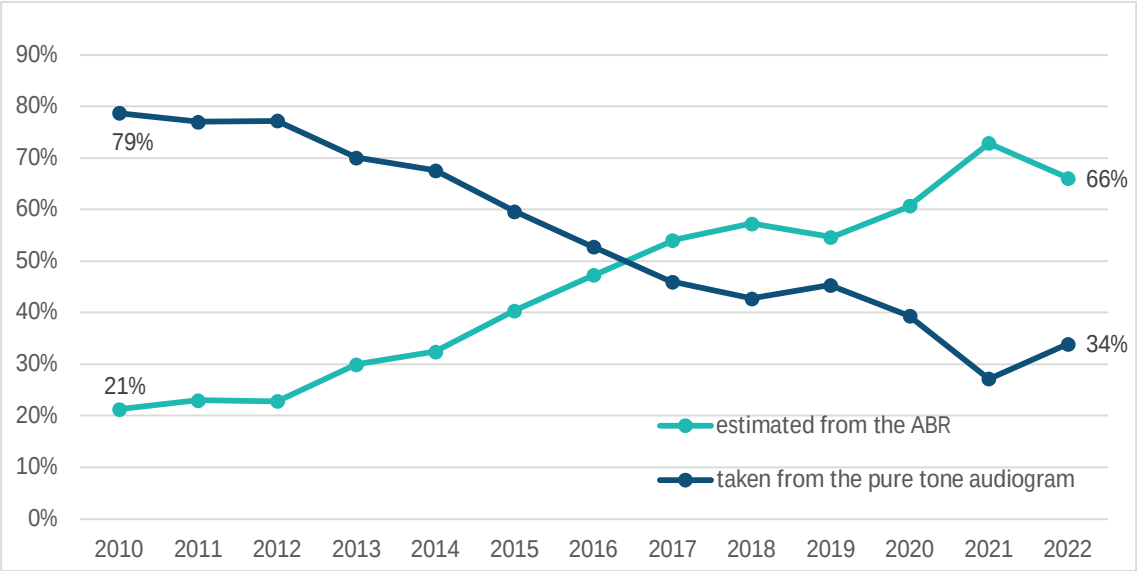

Figure 11: Proportion of cases containing thresholds from ABR and the Pure Tone Audiogram, by year, 2010-2022

Classifications

In Aotearoa New Zealand, the Clark (ASHA) codeframe is most used clinically. Therefore, this is the codeframe chosen for the majority of analyses in this report.

Further information about severity classifications can be found in Appendix H: Severity codeframes *on page 79.*

Degree of loss	Clark 1981 (ASHA)[150]
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

Table 21: Clark's 1981 ASHA severity codeframe

Calculating severity for notifications

From 2010, the re-launched DND form has requested full audiometric data for each case[i]. *Information about interpolation and its use in this report can be found in* Appendix I: Use of interpolation *which begins on page 79.*

Of the 2556 cases in the main dataset (2010-2022), 81% contain enough data to calculate severity. This means for those children and young people with bilateral hearing loss, all eight datapoints were provided, while for unilateral cases four were recorded.

Table 22 shows the proportion of cases in unilateral and bilateral categories in each severity (degree) grouping.

Degree of loss using ASHA severity codeframe	Unilateral 2010-2022	Bilateral 2010-2022
Mild	46%	52%
Moderate	17%	29%
Moderately severe	12%	8%
Severe	9%	4%
Profound	17%	7%

Table 22: Comparison of severity distributions for children with bilateral and unilateral hearing losses, 2010-2022

i While the DND collected some audiometric data for a number of 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.

By categorising notifications using the DND severity codeframe (1996-2005) and applying exclusion criteria from the original database[i], a longitudinal comparison of the proportion of rangatahi in each group was included in the 2019 report, using data reported between 2001 and 2004 and more recent data. We noted that the severity profile of cases had changed with a greater proportion of mild losses in the more recent data.

Mild hearing losses

Mild hearing losses are the most diagnosed among children and young people[ii, 151]. Definitions of what constitutes a mild hearing loss vary, as does prevalence, though the implications of these hearing losses are not always 'mild' as implied by the term. As with bilateral hearing losses, the implications of mild hearing losses have been re-evaluated in recent years and are often associated with persistent educational and communication difficulties[33, 152] though much of the data in this area focuses on children with hearing losses in the upper end of the mild range[151].

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 identified later and receive less support[153]. In some cases, mild hearing losses may not be identified at all.

Here in Aotearoa New Zealand, those with less severe hearing losses are less likely to receive technology and are more likely to be Māori and Pāsifika. Funding for those with more severe hearing losses is available to assist with cochlear implants, hearing aids and other devices, and to support speech and language development. Those with mild hearing losses often receive less support.

The policy and quality standards for the UNHSEIP note that, while children with mild hearing losses below this 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'115. It is worth noting that Māori tamariki are more likely to have mild or moderate hearing losses and as a result may benefit less than their New Zealand European counterparts from the UNHSEIP.

Ethnicity and severity profiles

Bilateral hearing losses

Within 2010-2022 cases for children and young people with *bilateral hearing losses*, severity profiles are somewhat different between ethnic groups as can be seen in Figure 12.

Numbers for the MELAA group are very small and change from year to year so should be treated with caution.

Māori tamariki

Both historically and in recent years, DND reports have shown that New Zealand European and Māori children have the greatest number of diagnoses, and that milder degrees of hearing loss are more commonly reported among Māori[154].

These findings have been confirmed by separate analyses of 1982-2005 data[iii] and 2010-2016 data[iv]. Māori tamariki also have higher rates of unilateral hearing loss than their New Zealand European counterparts as described previously.

Later analyses of cases that were listed only as Māori or New Zealand European (rather than both) was also completed for those with bilateral hearing losses, showing the proportion of cases of 'severe'[v] or greater severity was lower among Māori children and young people. This difference for the 2010-2022 period is 14% for European children, 6% for Māori and 13% for those both Māori and European.

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

ii Children with minimal hearing loss are not included within the DND.

iii Young Māori in the Database are more likely to have mild or moderate hearing losses when compared with their European peers.

iv A 2016 analysis showed the proportion of cases in each of the severity categories, split by ethnicity grouping, and found Māori had a higher proportion of mild and moderate cases than their European peers.

v Incorrectly listed as 'moderately severe' as listed in the 2021 report.

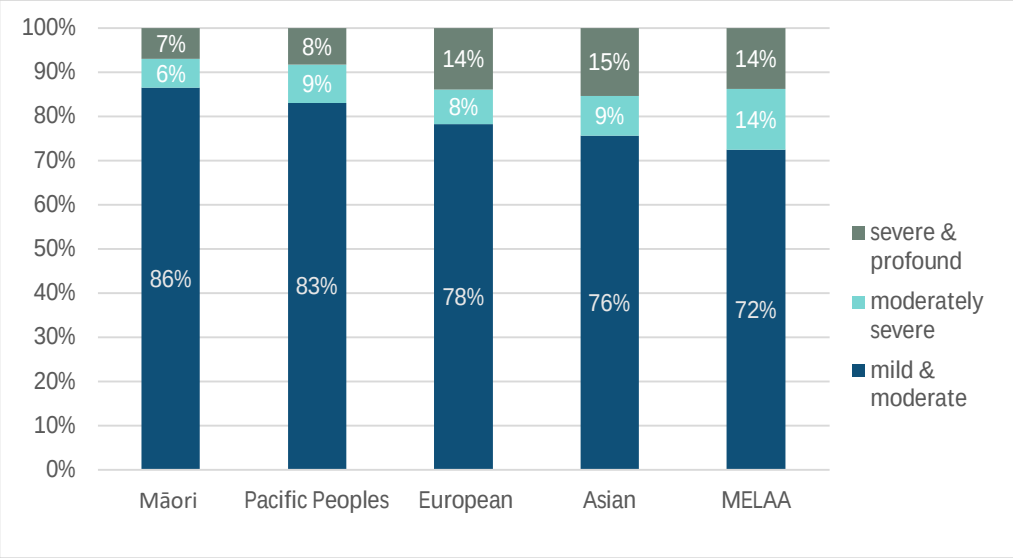

Figure 12: Degree of hearing loss by tamariki by ethnicity for bilateral hearing losses (better ear, 2010-2022)

Other ethnic groups

Pāsifika children and young people, like their Māori counterparts in the Database, also have a higher likelihood of mild or moderate bilateral hearing losses than their New Zealand European counterparts.

Children and young people from the Asian and MELAA ethnic groups are least likely to mild or moderate bilateral hearing losses at 76% and 72% respectively. Seventy eight percent of New Zealand European children and young people have these less severe bilateral hearing losses. Asian, New Zealand European and MELAA children are most likely to have severe and profound bilateral hearing losses at 14%-15% of their totals.

Unilateral hearing losses

Within 2010-2022 cases for children and young people with *unilateral hearing losses*, severity profiles are somewhat different between ethnic groups as can be seen in Figure 13. Numbers for the MELAA group are very small and change from year to year so should be treated with caution.

Pāsifika children and young people with a unilateral hearing loss have a lower likelihood of mild or moderate hearing losses (44%) than their New Zealand European counterparts (67%), as shown in Figure 13. MELAA tamariki are even less likely to have mild and moderate unilateral hearing losses, at 26% of the total.

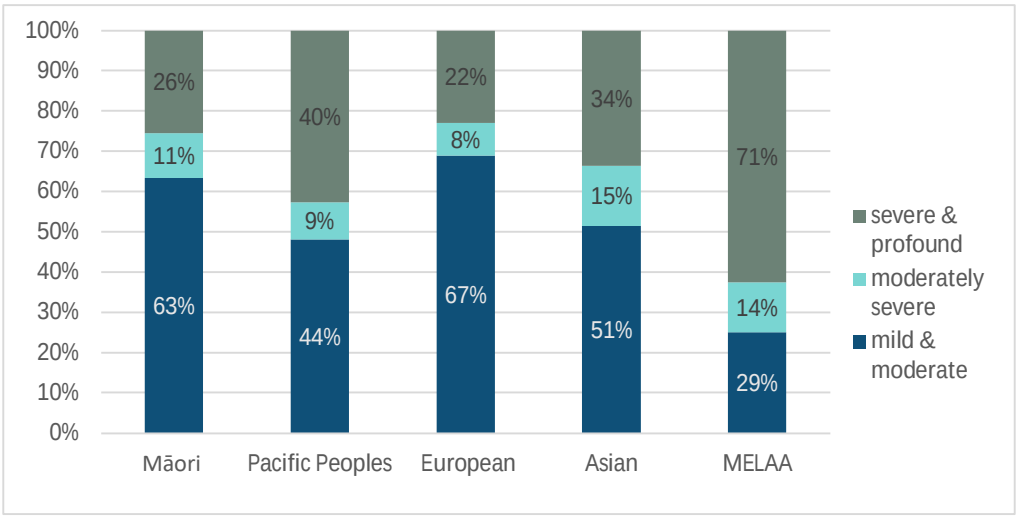

Figure 13: Degree of hearing loss by tamariki by ethnicity for unilateral hearing losses (better ear, 2010-2022)

Comparisons with international data

Several analyses have been conducted for previous DND reports to compare the notifications to the DND and their severity distribution with those from other countries and jurisdictions.

Despite differences in cohort, these analyses show a consistent pattern, with DND data showing a relatively higher number of cases with mild and/or moderate hearing loss, 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 hearing loss found among Māori and Pāsifika children and young people.

See Appendix J: International severity comparisons *on page 82 for further information.*

Intervention and support

Wawaotanga me te tautoko

- **The Ministry of Education provides services to students who are deaf and hard-of-hearing through groups such as Advisors on Deaf Children and other specialist educators. In 2022, they provided services to approximately 1,930 children under the age of eight, including 757 babies and young children identified as a result of the UNHSEIP.**
- **In the 2022 year, the Ministry of Education 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, habilitation support, and Ko Taku Reo – Deaf Education NZ**
- **At the time of diagnosis, professionals notifying cases expected half of the children and young people diagnosed in 2022 would receive two hearing aids. In total, 1,859 children and young people received hearing aids provided through MOH funding during the year.**
- **Thirty-one children and young people around the country received publicly funded cochlear implants during the 2022 calendar year.**

Ministry of Education

In the 2022 calendar year, the *Ministry of Education, Learning Support* provided service to approximately 1,930 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[155]. 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 Universal Newborn Hearing Screening programme (UNHSEIP) and their families and whānau – **number supported 757.**
- 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 229.**
- 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 849.**
- For the calendar year 2022 the Ministry of Education, Learning Support received 189 new requests for support for children identified with hearing loss through the Universal Newborn Hearing Screening and Early Intervention Programme:
  - 75% of children and their whānau were contacted within 10 working days of receipt of a request for support;
  - 92% of children and their whānau began receiving support by one month following receipt of request for support;
  - 100% of requests for support for children under six months of age began receiving support by six months of age.

The Ministry also funds support for children and young people who are deaf and hard-of-hearing 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.

Ko Taku Reo Deaf Education New Zealand

Ko Taku Reo | Deaf Education New Zealand is New Zealand's provider of education services for Deaf and Hard-of-Hearing (DHH) children[i]. They have a large team of over three hundred specialist staff across New Zealand with specialist school provisions in Auckland, Wellington and Christchurch.

Ko Taku Reo is a tri-lingual, tri-cultural organisation. With both Deaf and hearing staff, New Zealand Sign Language (NZSL) and English are used on a communication continuum throughout, from administration to the classroom.

Ko Taku Reo also reflects the importance of Māori culture and Te Reo Māori by adopting culturally sustaining pedagogy in celebrating diversity and respecting the preferred learning styles of the diverse range of DHH students nationwide.

The strategic focus of the Board is on working together with families/whānau and the Deaf community to provide equitable and coordinated deaf education, so that Deaf and Hard-of-Hearing students:

- contribute meaningfully to their communities;
- are socially included; and
- are able to determine their future and fulfil their dreams.

Services provided through Ko Taku Reo include:

1. Enrolled school

Ko Taku Reo currently have thirteen sites across Auckland, Christchurch and Wellington, with 120, students enrolled in total during 2022. Auckland has the greatest number (n=80), followed by Christchurch (n=36) and then Wellington (n=4). Students can access residential accommodation between 11 and 21 years of age at Kelston (Auckland) and Sumner (Christchurch).

Outreach School Resource Teachers Deaf

Ko Taku Reo Outreach currently has 3,226 students receiving varying tiers of graduated educational direct and indirect support services. The Ko Taku Reo Outreach service provides specialist teaching, advice and guidance, assistive technology and NZSL support to Deaf and Hard-of-Hearing students usually enrolled in their local mainstream school. This category includes children over the age of three years, although most children receiving this support are between the ages of four and half and 21 years old on the condition of being enrolled in a school or ECE.

Children in this category are not always Ongoing Resourcing Scheme (ORS) verified as this verification does not commence until children transition to school. ORS verified children make up approximately 10% of the DHH population receiving services nationally from Outreach.

Funding for this service comes from ORS funding (0.1 and 0.2 FTEs) and Ko Taku Reo also has an allocation of RTDs under the moderate needs contract.

2. Specialist support: funded, and teacher supplied by student's school

ORS verified children are school-aged children in mainstream schools and children in other specialist schools. These students have funding that is split, with the ORS DHH specialist teacher time allocated to Ko Taku Reo, while teacher aide and other specialist support is funded from the MOE to the child's school of enrolment.

For example, this funding can be used for teacher aides and other specialist support occupational support, physical therapy, speech language therapy, Kaitakawaenga, etc.)

i New Zealand has seen enormous changes in Deaf Education since its inception in 1880 with the Sumner School for the Deaf in Christchurch (later named van Asch College then Van Asch Deaf Education Centre); from a strictly oral approach that endured for almost a century, to now, when programmes and services are provided in a wide range of ways with all languages utilised (English, NZSL and Te Reo Māori). In 2019, the Kelston Deaf Education Centre in Auckland and the Van Asch Deaf Education Centre in Christchurch merged to become one national organisation: Ko Taku Reo Deaf Education New Zealand.

3. **NZSL@School**

The purpose of the NZSL@School is to provide access to the curriculum so that Deaf or Hard-of-Hearing children whose primary face-to-face language is New Zealand Sign Language (NZSL), achieve educationally and are confident and secure in who they are as a Deaf or Hard-of-Hearing person.

As a result, NZSL@School provides a range of support to schools, Deaf students and parents/whānau, in addition to any other special education support Deaf students receive, to help schools understand and provide learning environments that meet the learning, communication and cultural needs of Deaf students who use NZSL. In 2022, NZSL@School funding was provided to 121 students nationwide as top-up funding to increase the hours of their Communication/Education Support Workers (C/ESWs). A further eighty-nine students received support from an NZSL Tutor.

Continuing change

NZSL Day Schools (Hubs, Outreach) and Beacon School Projects (Outreach) are new services established by Ko Taku Reo and have been designed to meet the needs of students through extensive consultation with communities and whānau.

In 2022, there were 54 students enrolled at NZSL Immersion Day Schools across three locations. One location is currently on hold while the programme is reset. There are at least three other Outreach areas that are running a NZSL Immersion Hub on a regular basis based on the local needs of the students. This varies from once a month to weekly and may include half days only.

The NZSL Immersion Suite of Services also include NZSL Playgroups in Wellington and Dunedin. These serve as a pathway for students into the NZSL Day School. There is also a Virtual Deaf Space offered for High School students where there have been 18 students engaged in a virtual learning journey about Deafhood and identity in the last 18 months.

In 2022, the Beacon School Projects (Outreach) established a co-enrolment partnership model in Christchurch with KidsFirst Kindergartens. Two Kindergartens have been working closely with Ko Taku Reo to set up the successful conditions for co-enrolment. This has started in 2023, with local AoDC supporting this initiative through referrals.

For more information on the outreach programme or other services, you can visit the Ko Taku Reo website.

Ngā mihi nui ki a koutou to staff from Ko Taku Reo for providing data for this section of the report.

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. We have no data on what hearing aids, if any, were subsequently provided. 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).

Of the 165 cases notified to the Database in 2021, 159 contained information about whether hearing aids were to be fitted.

As has been the case with data since 2010, children and young people whose cases were diagnosed in 2021, are most likely to be fitted with two hearing aids (50%), though this is down on last year's 66%. This reflects the preponderance of bilateral losses notified to the Database.

Figure 14 shows a changing pattern in recent data when compared with 2010-2013 levels, with a reduction in the proportion of cases where the plan is to prescribe one or two hearing aids; and a rise in the proportion of cases in which the professional notifying the case is unsure whether hearing aids will be provided.

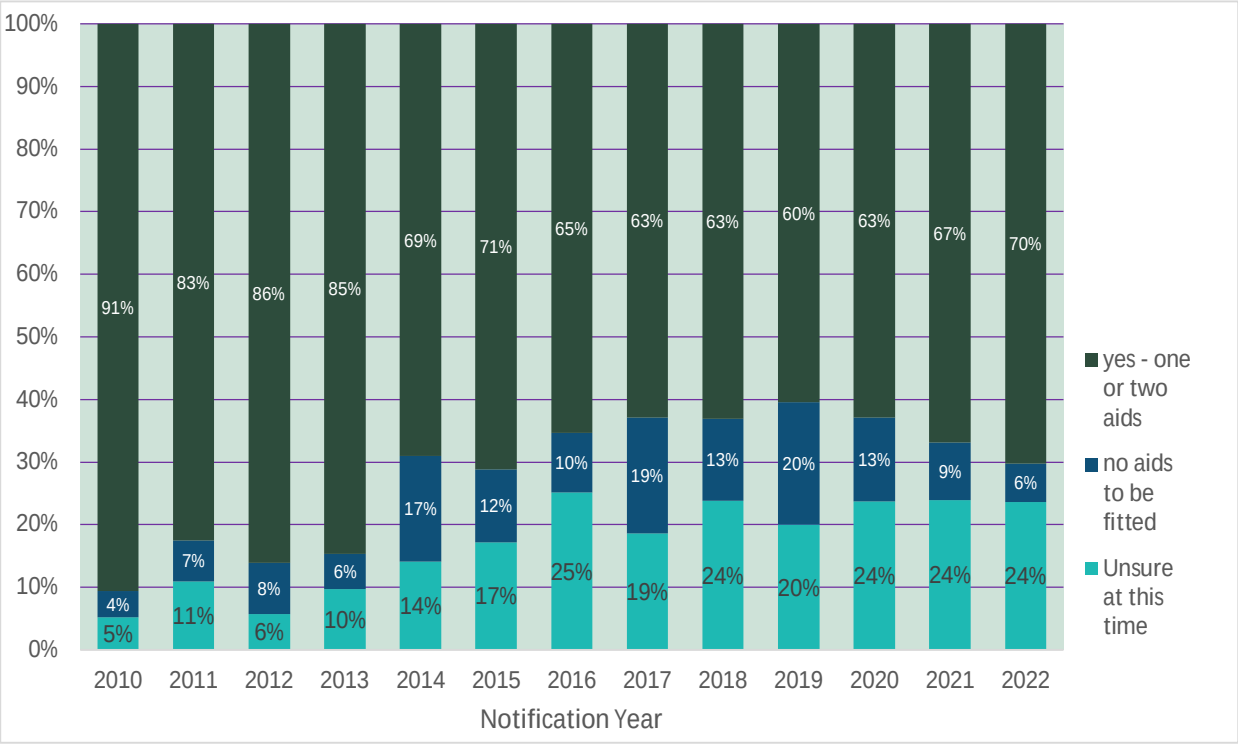

Figure 14: Hearing aids to be fitted by notifications (2010-2022)

When data for all children and young people notified from 2010 to 2022 were considered, the audiologist's intention was to:

- fit 73% of bilateral losses with one or two hearing aids, while 10% were not expected to receive any aids and the notifying clinician was unsure in 17% of cases; and
- fit 39% of unilateral hearing losses with one hearing aid, 26% two hearing aids[i], while 19% were not expected to receive any aids and the notifying clinician was unsure in 16% of cases[ii].

Intention to fit, ethnicity and deprivation

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

Chi squared analyses completed and described in the 2016 report, which held severity constant, showed more European and less Māori children with zero or one hearing aid to be fitted, reflecting the proportion of bilateral hearing losses in these groups. *[See the 2016 report for more information.]*

An analysis was also conducted in 2016 to establish whether there was a relationship between the level of deprivation and whether hearing aids were to be prescribed. This analysis found no significant differences (ANOVA: p=.8935).

Public funding for hearing aids

To provide some context for these figures, data from the Ministry of Health's provider for Hearing Aid Services during the period covered by this report, are shown in Table 23[iii].

i The child or young person's second 'normal' hearing ear presumably had some hearing loss present though it didn't meet the criterion for the DND because it was lower than a 26dB HL average over .5,1.0,2.0 and 4kHz.

ii It is worth noting that some children with unilateral hearing losses were reported to be receiving more than one hearing aid. In these cases, we can confirm that is because, although the average threshold for the better ear does not meet the 26 dB HL average required for inclusion in the Database, one or more hearing thresholds, including potentially one or more which are at higher frequencies than those collected for the DND, are sufficiently poor to warrant amplification in the better ear. This is indicative of one of the limitations related to classification systems that average hearing thresholds across four frequencies and categorise children into broad severity groups.

iii Please note that "Hearing loss is defined as a permanent sensorineural or conductive hearing loss described by Clark 1981 Scale of Hearing Impairment, as used by ASHA and the New Zealand Audiological Society Best Practice Guidelines July 2016." according to the Ministry of Health's Hearing Aid Services Manual, September 2017.

Ethnicity	0-3 years	4-5 years	6-15 years	16-18 years	Grand total
Māori	92	65	407	36	600
European	119	69	424	82	694
Pacific	33	32	111	14	190
Other	76	47	209	43	375
Total	320	213	1151	175	1859

Table 23: Whaikaha funding of Children's Hearing Aids, Calendar Year ending 31 December 2022, EnableNZ[i, 156]

These data show MOH funded hearing aids for tamariki under the age of nineteen, and those in fulltime education and under the age of 21 during the 2022 calendar year[ii, iii].

A total of 1,859 unique service users (tamariki and rangatahi) received hearing aid(s) during this period, slightly down on the 1,913 reported in 2021.

International research

A 2015 study from the United States examined language outcomes for 290 children between two and seven years of age with mild to severe hearing loss. Those fitted after 18 months of age improved in their language abilities as a function of the amount of hearing aid use[157]. Risks of oral language development delays were found to be moderated by early and consistent access to well-fitted hearing aids which provided optimised audibility.

Earlier device fitting (hearing aids and cochlear implants) is associated with higher global language scores (summarising language ability, speech production and speech perception evaluated using a range of measures). For those in the LOCHI study (Australia) with hearing aids, the impact of later fitting increased with the degree of hearing loss[158]. Also from the LOCHI study, the earlier children receive their first fitting with a hearing aid or are provided with a cochlear implant, the better their speech, language and functional performance outcomes[159].

Cupples *et al.* (2018) studied a population-based Australian cohort of 146 five-year-old children with hearing loss and additional disabilities. Earlier device fitting, higher cognitive abilities, milder hearing loss and higher levels of maternal education were significantly associated with better language outcomes within this study[160].

Cowan *et al*. (2018) found early fitting of hearing aids and cochlear implants was found to be a key influence on outcomes among 470 Australian children in the LOCHI study[161].

Munoz *et al*. (2019) surveyed parents with children under six on their experiences, from around the world. Hearing aid use was generally considered low by the authors, compared with the number of hours an infant is awake. Caregivers had positive views on information provided at the time of hearing aid fitting but had ongoing challenges in hearing aid management. Issues included a significant drop in the average number of hours the device was in use over time, a lack of loaner devices when theirs were in for repair, and lack of confidence and adherence to carrying out sound checks[162].

Visram *et al*. (2020) found that caregivers of eighty-one infants with a hearing loss in the United Kingdom revealed significant challenges in hearing aid management among very young children, with the authors suggesting that what is needed is specific behaviour change techniques to ensure intentions can be realised[163].

The latest Demographics report from Australian Hearing (for the 2021 year) shows that fitting rates (for both hearing aids and cochlear implants) have remained stable for those with moderate and greater degrees of hearing loss but have

i The current provider (EnableNZ) does not include repair or replacement requests, bone-anchored hearing aids, remote microphone (RM) systems, or funding for parts, molds or accessories in its data.

ii Domes and tubes, ear molds, remotes, FM (remote microphone hearing aid) systems, dry kits, and insurance excesses are excluded from these data.

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

increased for those who have less severe degrees of hearing loss[i]. This is thought to be the result of improved technologies, increasing options for those with unilateral hearing losses, more fitting of hearing aids for those who have long term conductive hearing losses and an increasing focus on possible adverse impacts of mild and unilateral hearing losses on development[4].

Also from that report, 2,918 children and young people under 26 were first fitted with hearing aids in 2021. Significant geographic differences by state are described among that group. They report that Aboriginal and Torres Strait Islander children are now more likely to be first fitted with hearing aids and that they are fitted, on average, much later than their non-indigenous Australian counterparts. This is thought at least in part to be due to the large proportion of hearing losses present and identified in non-indigenous children at birth and the high rates of persistent middle ear infections within the first year of life in indigenous children[4].

Prescribing and usage in Aotearoa New Zealand

A 2021 analysis by Waikato DHB 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 higher at 19 weeks, compared with 14 weeks for non-Māori[139].

A New Zealand study followed up 163 of the 189 children and young people, notified to the DND in 2010, seven-eight years later. Only 40% had been wearing their device(s) consistently since they were fitted.

Forty six percent of children who were recorded as Māori had inconsistent, seldom or no device use, compared with 23% of Europeans. Please note that Māori are more likely to have milder hearing losses compared with their counterparts; in adult studies hearing aid use time correlates with severity of hearing loss.

Readers should also be aware that while we have information from the UNHSEIP on the proportion of children who are screened by one month and who have diagnosis by three months, we do not have information on the proportion who receive hearing aids by six months of age, or on the average age at first hearing aid fitting. This information would be useful to help us understand whether screening is resulting in appropriately early intervention for those tamariki and rangatahi who receive hearing aids.

Cochlear implants

As the DND notification form does not request specific information about cochlear implant referrals, the authors of this report thought it was useful to provide information about 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 the Ministry of is administered by two cochlear implant trusts. 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.

These implants are provided based on Ministry of candidacy criteria for children and young people who are assessed by the cochlear implant teams[ii].

Most children receiving cochlear implants have severe or profound hearing losses, or progressive hearing losses that are becoming more severe. Some children have high frequency losses that are severe to profound in the higher frequencies and normal or near normal in the lower frequencies.

During the 2022 calendar year there were 38 publicly funded cochlear implant devices provided in the Northern Region and 14 in the Southern Region, to children and young people under the

i Please note that Australian Hearing use different severity categories to the ones used in Aotearoa New Zealand.

ii Since 1 July 2014, the Ministry of Health has funded bilateral cochlear implants (where this is clinically appropriate) for Aotearoa New Zealand children who are newly implanted. Children under the age of six at that time qualified for a retrospective second public implant.

age of 19. Please note, this differs from figures in the first table below, which relate to the number of children receiving implants, rather than the number of devices.

Readers of these reports will notice figures are lower than in recent previous years for the Southern programme. This programme noticed a smaller number of referrals in the 2022 year and question whether COVID-19 may have had any bearing on this reduction.

A summary table showing this change can be seen in Table 24.

Number of children implanted by year	Southern region	Northern region
2016	33	38
2017	28	31
2018	33	32
2019	30	32
2020	29	26
2021	18	22
2022	8	23

Table 24: Number of *children* receiving cochlear implants by year, split by cochlear implant programme (2016-2022)

Children receiving cochlear implants	Southern Cochlear Implant Programme[164]		Northern Cochlear Implant Programme[165]	
	Ears	Children	Ears	Children
ACC cases	0	0	1	1
Public Funding - (1 Jan to 31 December)	14	8	34	19
Private procedures	0	0	1	1
Re-implants – recalled devices, failed integrity tests, or soft failures	4	4	2	2
Sequential or retrospective second cochlear implants (second ear for those under six already with one publicly funded ear - 1 January to 30 June)	0	0	0	0
	14	**8**	**38**	**23**

Table 25: Publicly funded cochlear implants provided in Aotearoa New Zealand during (2022)[i]

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 a number of 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.

Appendices

Ngā āpitihanga

Appendix A: 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.

Audiometrists are warmly encouraged to make notifications for cases of hearing loss where they were the first to diagnose among those who are over the age of sixteen-years.

Notes for those completing notifications

1. **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.

   This ensures these reports contain accurate information about those children and young people diagnosed during each calendar year.

   Resources for clinicians making notifications can be found here – these include a PDF version of the notification form, background information about the Database and previous Database reports.

2. **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 where a consent has been signed by the parent or caregiver, or for older rangatahi, by the young person diagnosed. This form should be kept on file by the diagnosing clinic.

To maximise the number of notifications to the Database, ongoing efforts have been made to publicise this mahi (work) through emails distributed by the New Zealand Audiological Society (NZAS) to reach its members.

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

Appendix B: History of the Database

History of the DND

The original Deafness Notification Database (DND) was New Zealand's annual reporting system for new cases of hearing loss among tamariki from 1982 to 2005. This system included data on the number and ages of tamariki diagnosed with permanent hearing loss and annual reports describing collected notifications were released.

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 the Database, which applied to notifications until the end of 2005, required the hearing loss to meet the audiometric criteria in both ears and for the child or young person to have been born in New Zealand. When the Database was restarted in 2010, the criteria were broadened to include children with hearing loss in one or both ears and those born outside New Zealand.

The data presented in reports before 2006 contained notifications provided to the Database within a specific year; that is, they pertained to cases *notified to the Database in a particular calendar year*, rather than those who were diagnosed in that year.

During most of the period in which this Database was operating, it was managed by the National Audiology Centre on behalf of the Ministry of Health, and later by the Auckland District Health Board.

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

In 2006, the Auckland District Health Board discontinued its contract to provide services associated with this Database. No new provider was sought by the Ministry of Health. Between 2006 and 2009, several groups expressed concern that information on the number and nature of new hearing loss diagnoses among tamariki in Aotearoa New Zealand was no longer being collected.

The DND was seen to have even greater importance from 2007, at which time implementation of the national Universal newborn hearing screening and early intervention programme began.

Information from 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.

In 2010, the DND was re-launched, with audiologists around the country encouraged to notify diagnosed hearing losses through a new online form. This re-launched Database was initiated by Janet Digby with support from Dr Andrea Kelly and Professor Suzanne Purdy and was part-funded and supported by the New Zealand Audiological Society, which also allowed communication with its members to call for notifications.

The authors of this report are 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* and builds on the original relaunch work done by Janet Digby, Andrea Kelly and Professor Suzanne Purdy, with support from the New Zealand Audiological Society.

This history has implications for the longitudinal data we can include in these DND reports:

- the period from 1982 to 2005 contains notifications to the original 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;
- notifications have been reported for each calendar year throughout 1982-2005 and since the Database's relaunch, for 2010 to the current year.

Inclusion criteria

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, and included only children and young people born in Aotearoa New Zealand:

"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)[166]."

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

focused' and didn't adequately acknowledge or include hearing losses, particularly mild, acquired and unilateral losses, and where the family might not want hearing aids fitted or where hearing aids may not be appropriate.
The criteria for inclusion were modified for the 2010 re-launch of the Database, based on feedback from a small working group[i]. *The current criteria includes children and young people 18 years or younger[ii]:*

- 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[iii],
- regardless of their place of birth.

Specific additional guidance has been provided to hearing professionals to clarify the type of cases that are included in the Database, to try to increase consistency in the types of losses notified:

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

For several years after the relaunch of the Database, cases of high frequency hearing loss were being collected. Because only a small number, and likely a small proportion of cases were being notified, we have not described this group in recent years, and we will not be seeking these notifications in future.

Changes to the way cases were notified

Notifications to the re-launched Database, previously made on paper forms, have been collected through an online form to reduce data entry errors (which can occur when transferring data from the paper forms to electronic formats), and to try to make it as easy as possible for hearing professionals to notify cases.

A revised consent process was also implemented on re-launch to ensure all information is collected with the consent of the family; later this was added to through amendments to the newborn hearing screening consent, which also includes consent from whānau to have their child's data included in the Database. Data is backed up regularly and forms are submitted through a secure link.

Potential renaming of the Database

During 2012, 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 provide a clear path for renaming the Database.

Some individuals and groups felt that changing the name to a broader title, such as the Hearing Loss Notification Database, would have merit, as it would acknowledge the range of types and severity 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.

The name of the Database (Deafness Notification Database) remains open for consideration. A new name may better reflect the purpose and nature of the Database, particularly as changes to the inclusion criteria mean cases of unilateral hearing loss are now included in the Database.

If any reader of this report has any ideas for a new name for the Database, this will be gratefully received by Janet Digby.

i This group comprised: 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 in the development of the re-launched Database unanimously believed this group should be included in the Database, at least in part as there is strong evidence that they are at increased risk for poorer educational and speech/language outcomes compared to children and young people with normal hearing in both ears.

Appendix C: Completeness of notifications

While every reasonable effort has been made to ensure the newly re-launched Database improves our understanding of permanent hearing losses among Aotearoa New Zealand children and young people, 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 should be taken as indicative unless stated otherwise.

The authors believe it is now likely that the Database has been receiving notifications for between 70% and 85% of all new cases diagnosed each year.

As time passes, we will continue to work in an effort maintain or increase the proportion of notifications received, improving the ability of the Database to inform stakeholders (including the Ministry of Health, Ministry of Education, clinicians, educators and other service providers) about newly diagnosed hearing losses among Aotearoa New Zealand children and young people.

Appendix D: Māori, hearing and health

Unequal health access and outcomes 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, and further marginalisation through cultural oppression and the introduction of new social systems based on European norms and values[167, 168, 169, 170, i].

Disparities documented in many areas of health demonstrate Māori have poorer access 'to, and through' the health system[82, 171, 172], that they receive a poorer and slower service, and are less likely to receive appropriate levels of care[173], resulting in poorer health outcomes.

Despite relatively strong national policy frameworks recognising Māori health needs and engagement in health, these frameworks have not been successfully implemented and there is some indication that engagement with and recognition of Māori has actually been dismantled in some areas[174, 175, 176].

Both the Waitangi Tribunal 2575 inquiry (Stage One)[177] and the New Zealand Health and Disability System interim report[178] 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/the Treaty of Waitangi[ii]. The Treaty guaranteed Māori their full rights and benefits as citizens.

The Tribunal's Stage One report acknowledged that while the health sector is not able to influence all the social determinants of health, persistent inequalities constitute health sector Treaty breaches. It recommended that the principles derived from te Tiriti by the Royal Commission on Social Policy *(partnership*, *participation* and *protection)* be extended to include *equity* and *options*. It also asserted DHBs and other health agencies were not doing enough to reduce inequalities.

A number of district health boards (now districts within Te Whatu Ora) have in recent years re-asserted their commitment to achieving equity for Māori, including Northland [179] and Auckland[180], and reference the important role of eliminating institutional racism in achieving equity.

To better understand these issues, see Penney *et al*.[135] for Constructions of Māori medical compliance (2011) and Graham and Masters-

i An introduction to this topic can be found in King *et al.*'s 2009 paper in *The Lancet*.

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), which can be found in the references of this report.

Awatere (2020)[181] for a review of 14 qualitative studies, to understand Māori experiences of Aotearoa's public health system.

A recent ear and hearing care scoping review focused on First Nations children[182] suggests sustainable programmes within a connected system of care, and that future planning should involve First Nations communities at every stage of development, implementation and evaluation.

Prevalence of hearing loss

Several sources demonstrate the higher prevalence of hearing loss among Māori:

- Whakarongo Mai (1989) concluded that while the full extent of hearing impairment among Māori was not known because of information gaps, "a number of local and detailed studies demonstrate convincingly that hearing loss occurs excessively among Māori people" [183].
- A 1991 survey of hearing among schoolchildren in the North Island found high prevalence of hearing impairment, with more than 29% having 20dB or greater at three thresholds; 2% or more of the children tested had a bilateral sensorineural hearing impairment[184].
- Greville (2001) found higher prevalence of temporary and permanent hearing loss among Māori children[185].
- Diagnoses from the newborn hearing screening programme show that Māori infants who are screened, and for whom diagnostic information is available, have higher rates of hearing loss[186].
- Household Disability Surveys:
  - *1991-2006 Surveys[187] 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[188]. (For information about the limitations of these data please see the 2011 DND Report[189].)*
  - *The 2013 Survey continued to suggest Māori had higher unmet need for technology and equipment when compared with non-Māori[190] but also that they now have lower rates of hearing disability compared with their European counterparts[191], although this seems to relate to the lower age profile for Māori (younger people have fewer disabilities).*
  - *No Disability Survey was completed in 2018, with the Māori Social Survey being completed following the 2018 Census and alternating with the Disability Surveys after subsequent Censuses[192].*
- Findings from Digby *et al*. (2014) indicated young Māori have higher rates of permanent hearing loss than their New Zealand European peers, based on the previous and post re-launch DND datasets, which included notifications from 1982-2005 and 2009-2013[193].
- B4 School Check data:
  - *Data from the B4 School Check[i] analysed by Searchfield et al. (2011), show higher rates of referral from hearing screening for Māori tamariki (9%) compared with non-Māori (5%)[194] and this pattern still holds with 2020-2021 B4SC data showing 4% referral rates for Māori, compared with 3% for New Zealand European children and young people as shown on page 50[ii].*

Appendix E: Notifications and ethnicity

The method used in this report to classify ethnicity is the total response method, in which every person identifying with a specific ethnicity is included in that specific grouping[195]. This method uses all ethnicity codes a person or their parent/caregiver chooses for them.

For example, if someone considers their child to be of Samoan and Māori ethnicities, they are

i For more information on the B4 School Check, please click here or view the glossary on page 75.

ii It 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.

recorded under both these groups. This means the total number of ethnicity codes selected by respondents is generally greater than the number of respondents.

Using this method provides a more detailed and accurate measure of the relative size of the groups identifying with each ethnicity when compared with older methods, including those that required respondents to select only one ethnicity, the one with which they mostly identified, or where ethnicities are prioritised to include only one ethnic group per child using a predetermined hierarchy.

Using the total response method also aligns the Database with The New Zealand Census, which began explicitly instructing respondents that they could select more than one category for their ethnicity in 1996.

A recent study utilising large-scale data of multi-ethnic Aotearoa New Zealand children, adolescents, and adults examined individual and contextual demographic characteristics associated with discrepancies between administratively prioritised and self-prioritised ethnicity. It found administrative prioritisation via a predetermined algorithm were more than 50% different from those which were self-prioritised[196].

Previous coding in the DND

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

Categories used

The New Zealand Census (2006 and 2013) categorises respondents into five 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 may not be available for all cases and we don't want to have any deterrents in place 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 too much to the time taken to complete the form.

Appendix F: 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.

Appendix G: Key screening goals and history

Aotearoa New Zealand's UNHSEIP was implemented to reduce the length of time between birth and the start of intervention for children born with hearing loss, as this approach had been successful overseas in improving outcomes.

Such programmes achieve this by significantly reducing the age at diagnosis for hearing losses present at birth, compared with previously common identification approaches reliant on risk factors or subjective testing.
Key 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.

These are known as the 1-3-6 goals and are commonly used in newborn hearing screening programmes internationally.

All district health boards have been screening babies for the full notification period (calendar years) since 2011[i]. Data contained in this section of the report relate only to those children born in Aotearoa New Zealand.

This national screening programme was the result of long-term advocacy from groups like Project HIEDI and the work of clinicians and managers in a number of district health boards, who worked to introduce local screening programmes.

Appendix H: Severity codeframes

Differences between classification systems make it difficult for meaningful direct longitudinal and geographical comparisons of the proportion of tamariki in each severity category[ii]. 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.

Table 26 shows some of the differences between local and overseas severity classifications (these systems use an average of the pure-tone thresholds at 0.5 kHz, 1.0 kHz, 2.0 kHz and 4.0 kHz)[iii].

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

Category	1996-2005 NZ DND	1982-1996 NZ DND	Clark 1981 (ASHA)	Jerger and Jerger (ASHA)[197]	World Health Organisation[198]	CDC[199]	Proposed code from Davis and Davis[2]
Normal			-10-15dB HL		≤25dB HL		
Slight			16-25dB HL	0-20dB HL	26-40dB HL		
Mild	26-40dB HL	30-55dB HL	26-40dB HL	20-40dB HL		21-40dB HL	30-39 dB HL
Moderate	41-65dB HL		41-55dB HL	40-60dB HL	41-60dB HL	41-70dB HL	40-69 dB HL
Moderately Severe		56-85dB HL	56-70dB HL				
Severe	66-95dB HL		71-90dB HL	60-80dB HL	61-80dB HL	71-90dB HL	70-94 dB HL
Profound	>95dB HL	≥86dB HL	≥91dB HL	≥81dB HL	≥81dB HL	≥91dB HL	95+ dB HL

Table 26: Comparison of audiometric severity classification systems

Appendix I: Use of interpolation

Table 22 on page 62 shows the severity of hearing losses notified between 2010 and 2020.

While the Database contains estimates for those children and young people for whom all eight data-points are available, we generally 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[iv].

i Implementation of Aotearoa New Zealand's UNHSEIP began in 2007, and the last eight district health boards to be included in the roll-out began screening between July 2009 and July 2010. It is worth noting that the large Auckland DHBs (Counties Manukau, Waitematā and Auckland) had all begun screening by April 2010.

ii 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.

iii Australian Hearing uses the following codeframe (0-40dBHL, 41-60 dB HL, 61-90dB HL, 91dB HL+), but don't name the categories so these are not included in Table 26.

iv Please note that, while the label in last year's report indicated that the data in this table covered 2010-2017, it actually included only 2016 data.

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 means the points that may be interpolated are 1.0kHz and 2.0kHz. This technique is becoming increasingly useful as more tamariki are being diagnosed earlier, meaning they cannot have their hearing assessed behaviourally.

Please note that the severity analyses include either unilateral or bilateral losses and are based on the hearing-impaired ear in the case of unilateral losses, and on the better ear in the case of bilateral losses.

Key points regarding interpolation:

- the number of bilateral hearing losses for which severity can be calculated rises when interpolation is used;
- the proportion of cases with less severe hearing loss is higher among bilateral cases;
- the proportion of mild bilateral losses drops when interpolated cases are removed, increasing the proportion of moderate and greater hearing losses; and
- the proportion of moderate and moderately severe losses rises for unilateral cases.

Appendix J: International severity comparisons

Details can be found in the reports noted, comparing:

- United Kingdom, Finland and United States data with New Zealand data 2010-2012 (2012 report);
- Colorado data with New Zealand data 2010-2013 (2013 report);
- Australian data with New Zealand data from 2010 to 2015 (2014 report);
- Colorado data with New Zealand data 2010-2015 (2015 report);

With the mounting evidence described above, it seems clear that Aotearoa New Zealand may have higher hearing loss prevalence overall, and there is a smaller proportion of severe and profound hearing losses than other similar countries.

Factors that may be contributing to the generally small proportion of more severe hearing losses are listed below:

- This may be, at least in part, due to the fact that Māori have a different severity profile from other ethnic groups.
- Information about individual tamariki are included in the dataset at the time of first diagnoses. 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.
- Some cases with audiometric data points in the severe and profound range did not contain complete audiometric data and these have not been included in this table, meaning severe losses (and other degrees too) may be under-represented[i].
- Often children diagnosed with hearing loss have a sloping hearing loss and the better thresholds reduce the average degree of hearing loss.
- As noted previously, 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[200]. However, more recently, coverage rates have fallen. Regardless, any reduction in the number of more severe cases due to meningitis is likely to be small.

A number of viral infections can cause hearing loss, which can be congenital or acquired,

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

unilateral or bilateral and is typically sensori-neural[201], although mumps, for example, almost always causes single-sided deafness.

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[202], although research focusing on mild hearing losses remains limited.

As a result of this apparent difference, 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[203, 204], and that those families with children who have cochlear implants are managing and promoting device use more than those with hearing aids[205].

Glossary

Kuputaka

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 the two Deaf Education Centres[206]. Implementation of changes proposed in the Wilson Report (2011) were completed in 2015, meaning AODCs now work with an 'Early Years' focus, on 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.

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, audio-logical 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 Ministry of Health-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.

BLENNZ: Blind and Low Vision Education Network New Zealand is a school that comprises a national network of educational services for children and young people who are blind, deafblind or have low vision in New Zealand.

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. Those receiving cochlear implants usually have a hearing loss that is severe or profound in terms of its severity classification.

District health board (DHB) and Districts: These were organisations established to provide health and disability services to populations within a defined geographical area. DHBs were disestablished in 2022 under the (Pae Ora Healthy Futures) Act 2022 and replaced with 19 districts in four Regions within Te Whatu Ora Health New Zealand.

Data warehouse: A data warehouse is a type of database the integrates copies of transaction data from disparate source systems and provisions them for analytical use.

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.

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.

Full Time Equivalents or FTE: These are used to measure the number of full-time equivalent positions for audiologists and generally equate to approximately one full time equivalent for every 38 hours worked per week.

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 (Māori Dictionary). 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): Kelston Deaf Education Centre provided educational programmes and services to Deaf and hard-of-hearing students in the northern part of New Zealand, roughly from Taupō 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: Aotearoa 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 new name for what was previously termed 'Special Education' services provided by the Ministry of Education. The name change was in response to feedback that terms like special education and special needs create barriers for students.

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. Information is provided to the DND with the consent of the young person who has been diagnosed with a hearing loss, or their parent in the case of babies and children. This information has been provided to the Database manager via an online form since 2010.

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.'

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.

Special Education: Now referred to as Learning Support.

Suspicion age: For the purposes of this Database, this is the age at which the child or young person's hearing loss was first suspected.

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

Resource Teachers: Deaf (RTDs)[i]**:** 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 on the basis of 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.

An RTD is a trained specialist teacher who can:

- provide specialist 1:1 teaching;
- assist classroom teachers with curriculum adaptation and delivery;
- provide specialist advice, guidance and assistance for classroom environment and management;
- assist classroom teachers with the assessment of learning outcomes involving language and literacy achievement;
- liaise with all staff, support agencies, and caregivers;
- monitor and support the use of audiological equipment and respond to indirect service;
- referrals via audiology;
- provide improved access to the curriculum for deaf and hard-of-hearing students.

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

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

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

Unilateral hearing loss: Hearing loss affecting one ear. With regard to 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.

i This information was adapted from a helpful description found on the KDEC website, which no longer exists.

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): van Asch Deaf Education Centre 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 district health boards, 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 B4 School Check.

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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